ACCEPTING AN ASSISTED SLEEP

Addressing Barriers that Influence Engagement with
Continuous Positive Air Pressure
Therapy through Design.

A 90-point thesis submitted to the
Victoria University of Wellington in fulfilment of the
requirements for the degree of
Master of Design Innovation

By

Katie O'Brien

Supervised by
Edgar Rodríguez Ramírez,
Brian Robinson & Simon Fraser.

Victoria University of Wellington,
School of Design

2018

ACKNOWLEDGEMENTS

ABSTRACT

This paper aims to answer the question 'What are the initial experiences of people who use Continuous Positive Air Pressure (CPAP) therapy, and how can design address barriers that influence engagement within the first week of therapy?'

Obstructive Sleep Apnoea (OSA) is a respiratory sleep condition that is characterised by a repetitive collapse of the upper airway during sleep, causing a lack of oxygen and build up on carbon dioxide within the body. Left untreated, OSA can lead to serious medical conditions that may significantly reduce one's quality of life and risk early death. The primary treatment for OSA is Continuous Positive Air Pressure (CPAP) therapy. This is a machine that pumps pressurised air through a facial mask to keep the airway open during sleep. Even though CPAP is the most effective treatment for OSA, it is known to be burdensome and adherence is problematic.

This thesis identifies the barriers that influence CPAP engagement through literature reviews, online surveys, cultural probes, and interviews with manufacturers, clinicians and CPAP users. The barriers identified include first impressions, product-related and social stigma, the ability to troubleshoot issues and the level of support, education and feedback present in the initial stages of therapy.

The outputs from this research focus on improving the user experience through design-based interventions. First, packaging solutions that focus on the interaction, the user's first impressions, display of product information, and ease of assembly of the equipment. Second, a website that addresses education, support, customisation and ability to troubleshoot issues. Third, customisable aspects that focus on personalisation of the CPAP equipment through 3D knitting processes that develop customised fabric hose covers. Lastly an application that addresses feedback, support and troubleshooting issues. Concepts are assessed against their relevance to the design criteria.

TABLE OF CONTENTS

Acknowledgements
Abstract

01

INTRODUCTION

1.1
ETHICS

The research topic covered is new to Victoria University's School of Design, and thus required an extensive ethics application process. This research is in the high-risk category, since the primary focus is on non-invasive air pressure therapy for respiratory conditions (Obstructive Sleep Apnoea or OSA, in particular). Due to the risks associated with this subject area, Health and Disability Ethics Committee (HDEC) standards directed that the research can commence as an intervention-based study, where the therapy equipment is not altered. There are strict requirements and procedures that needed to be followed, requiring extensive planning and organisation for this project to commence with the requisite Health and Disability Ethics Committee (HDEC), and Victoria Universities' Human Ethics Committee's (HEC) approval. Following this procedure, the HDEC response stated this research is "Out of Scope" for an HDEC Ethics application (Appendix A). This study was accepted by the Victoria University of Wellington's Human Ethics Committee on the 4th of December 2017, and the final amendment was accepted on the 22nd of February 2018. The Approved Ethics application number is 0000025272.

1.2
THESIS OVERVIEW

Chapter 1 (Introduction)

Introduces the topic of this thesis and sets the scene. It also addresses the ethics application process that this research required to commence.

Chapter 2 (Literature and Precedent Review)

Analyses and investigates Obstructive Sleep Apnoea and the issue of adherence with Continuous Positive Air Pressure (CPAP) Therapy. Factors associated with non-adherence were essential in structuring the research question, and direction of this research. This section explores the areas that have been addressed and identifies areas that can be investigated through methods of persuasive design.

Chapter 3 (Methodology)

Addresses the aims and objectives of this research through appropriate methods. This supports the development of research through design, based on design criteria. The identified barriers and themes in this phase help to structure and direct design criteria.

Chapter 4 (Data Collection Results)

Develops the first aim of this research. This is the data collection phase, where themes are generated through analysis. This section identifies the different experiences, perspectives and insights into CPAP therapy management from focus groups involved.

Chapter 5 (Design Results)

Develops the second aim of this research through the development of criteria generated from the previous chapter. It identifies criteria that drive design directions addressing the touchpoints and themes found in the data collection phase. This section also addresses the different criteria through design development and prototyping to come to a final design system.

Chapter 6 (Discussion)

The final proposed user experience is compared to the current user journey and reports on the difference in the systems. With reflection on the limitations, this section summarises a proposed user journey for new CPAP users to improve their experience through the addition of design concepts.

Chapter 7 (Conclusion)

Concludes the research and reflects on the thesis as a whole and reflects on where methods of design used in this research can be applied in other areas of design.

0 2

LITERATURE REVIEW

The literature reviewed in the following pages identifies:

a) The barriers that influence engagement with new CPAP users,
b) Touch points where methods of design can intervene to improve the overall user experience of new CPAP users.

2.1
INTRODUCTION

The following section of this review (Section 2.2) describes the user journey to diagnosis and prescription of CPAP therapy, and the issue of adherence with this therapy. The next section, (Section 2.3), expands on the internal and external barriers that influence people's engagement with CPAP therapy including support, education and product-related stigma. This section also emphasises the importance of the first week of therapy in the development of positive behaviour patterns, and user's ability to troubleshoot common problems. Section 2.4 discusses persuasive design techniques, introducing some of the key factors that need to be integrated into the design process to create an engaging product. Section 2.5, 'Precedent Review', investigates current design strategies, such as inclusive and persuasive design techniques, in the design of medical technologies. These strategies were used by designers to reduce stigma and create a positive user experience in a range of products. Literature reviews have supported an in-depth investigation into the potential of design practices, as a process to increase user engagement during their first week of therapy.

2.2
OBSTRUCTIVE SLEEP APNOEA AND CONTINUOUS POSITIVE AIR PRESSURE THERAPY

2.2.1 What is OSA?

Obstructive Sleep Apnoea (OSA) is a respiratory sleep condition that affects approximately 4% of the world's male population and 2% of the female population (Shapiro & Shapiro, 2010 p.322). OSA is characterised by a repetitive partial or complete collapse of the upper airway dilator muscles during sleep, causing a lack of oxygen and a build-up of carbon dioxide within the body (Jordan et al., 2014 p.737). Obesity, neural injury, fatigue, lung volume, fluid-retention and dysfunctional upper airway dilator muscles all contribute to the severity, and the number of occurrences per hour, of the apnoea. The cycle of sleep apnoea in Figure 1 shows the constant system that people go through, depending on the severity, these instances can occur over 30 times per hour.

People with OSA experience sleep related symptoms such as snoring, waking with a choking sensation, non-restorative sleep, difficulty maintaining or initiating sleep, excessive fatigue or tiredness, and morning headaches (Jordan et. al. 2014. p.736). Performance related symptoms include daytime sleepiness (which can decrease productivity), a higher risk of motor vehicle or work place accidents, and other health related implications such as a disturbance in mood, depression and cognitive impairments (Shapiro & Shapiro, 2010, p.321).

Onset of
sleep

Partial or complete
airway collapse

Sleep is
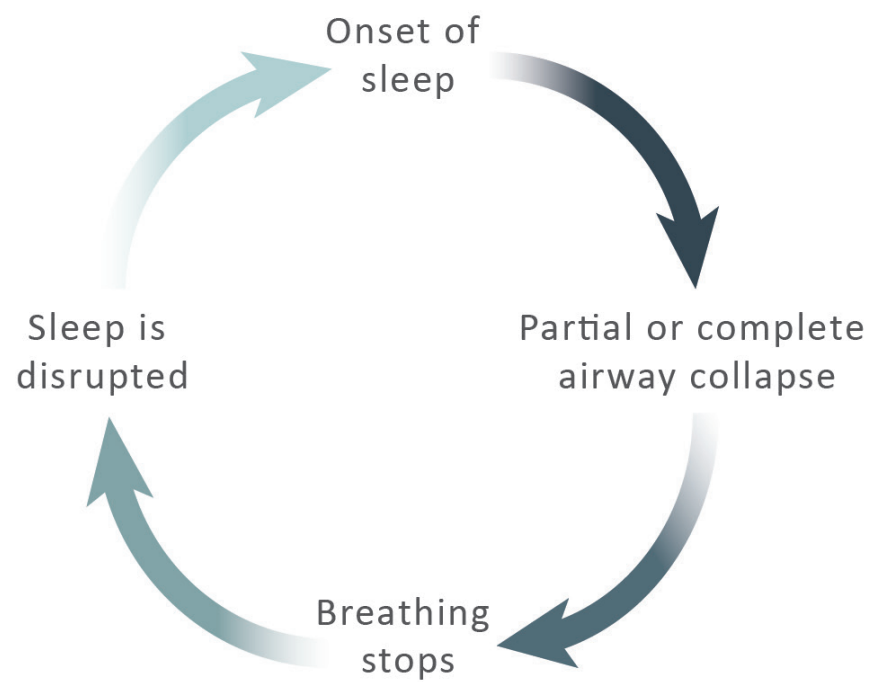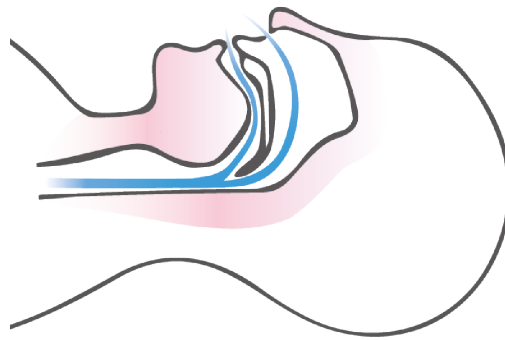disrupted

Breathing
stops

Figure 1 The cycle of Sleep Apnoea

Normal Breathing
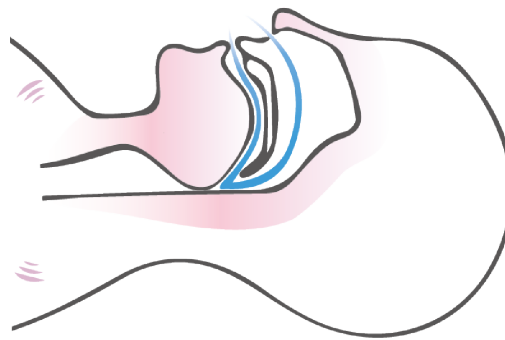
Obstructive Sleep Apnoea
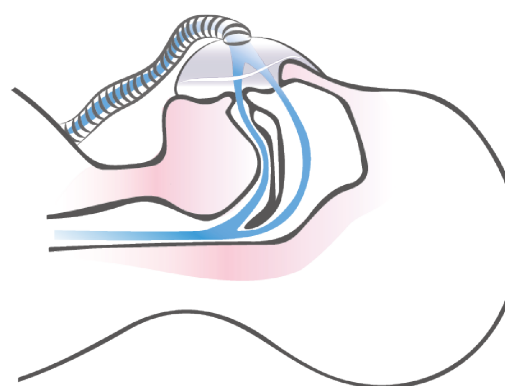
Air flow with CPAP use

Figure 2 Diagram showing normal breathing, Obstructive Apnoea, and CPAP therapy use

2.2.2 Seeking diagnosis

There are many factors that influence people to seek a diagnosis, as discussed in Chapter 4 of this research. The diagnosis scenario varies between each person. For this research, the following New Zealand centric model will be used. Initially, patients describe their experiences, including snoring, fatigue or witnessed respiratory arrest during sleep, to their general practitioners (Sleep Apnoea Association of NZ Inc., n.d.). If there is suspicion of Sleep Apnoea, a patient is given a wearable diagnostic device to take home, allowing the individual to test their sleeping pattern, pulse and oxygen levels (Penzel et al., 2018, p.3). If there is evidence of reoccurring apnoea, the patient must take an overnight sleep study – completed in a sleep clinic – to confirm the sleep apnoea diagnosis.

2.2.3 Sleep study

During the sleep study, patients undergo a full sleep examination, also called a polysomnography (Penzel et al., 2018, p.4), which tests patients' sleep patterns, blood deoxygenation, and the occurrences of apnoea per hour (Jordan et. al 2014). This involves monitoring the patients for the first 3 hours of the night to see if any apnoea occur (Malhotra & White 2002, p.241). In adults, less than 5 per hour is considered normal, between 5 and 15 events per hour is considered mild. Moderate OSA is considered 15-30 events per hour and anything above that is classed as severe OSA (Lee, 2008).

If regular apnoea is observed in the sleep study, the patient takes a nasal CPAP titration under the direction of a sleep physician to calibrate the pressure needed to prevent the apnoea (Malhotra & White 2002, p241, Van Zeller et al. 2013). This is generally where patients are exposed to CPAP equipment for the first time. Once diagnosed, patients follow up with their sleep physician and discuss the options for OSA treatment depending on the severity of their condition. CPAP is well established as the most efficacious domestic therapy option for OSA (Billings, & Kapur, 2013, p.207) due to its low risk and comparative ease of use (Shapiro & Shapiro, 2010, p.324).

2.2.4 What is CPAP?

Continuous Positive Air Pressure (CPAP) is an assistive machine that supplies continuous pressurised air, through either a facial or nasal mask (Figure 2, 3 & 4), maintaining airway patency and prevent airway obstruction. This provides the user with sufficient inhalation of oxygen and exhalation of carbon dioxide during sleep, significantly reducing respiratory disturbances (Giles et al., 2006, p.3).

2.2.5 What is the issue?

Even though CPAP therapy is the most effective treatment for OSA, the treatment is known to be burdensome, and adherence is problematic (Phillips & Dhaon, 2013 p.995). One in five people diagnosed with OSA refuse to initiate CPAP treatment completely (Billings & Kapur, 2013 p.207). Of those who do, half do not use it enough to gain the symptom relief and cardiovascular benefits; one year on, half of the patients abandon CPAP completely (Billings & Kapur, 2013 p.207). Those who are non-adherent to CPAP are at risk of more serious medical issues such as cardiovascular, metabolic and neurocognitive conditions, all of which can significantly reduce their quality of life or increase the risk of early death (Jordan, McSharry & Malhotra, 2014).

2.2.6 Adherence

Adherence is a clearly defined term used by health professionals to monitor patients, and for insurance companies to fund the equipment. Adherence is defined as proper use of the CPAP equipment for four or more hours per night. By this definition, 60-70% of active CPAP users are non-adherent (Jordan et al., 2014, p.742). Adherence is a requirement for patients, so that they comply fully with standards and legislation. These standards include maintaining a valid driver's licence (NZ Transport Agency, n.d.), and work-related safety standards (WorkSafe New Zealand, n.d.), among others.

Treatment adherence is recognised to influence engagement levels of both short and long-term therapy use (Weaver & Sawyer, 2010, p.251). Patients who become non-adherent within days of using CPAP therapy tend to remain non-adherent and refuse to persist with therapy (Weaver & Grunstein, 2008. p.173).

Figure 3 an example of CPAP therapy equipment

Figure 4 Eson 2™ Nasal CPAP Mask © 2012 Fisher and Paykel Healthcare Limited

2.2.7 The importance of the first week of use

It is essential to identify and engage those most at risk of abandoning therapy in the early stage. Identification of these patients aids the implementing of positive behavioural patterns (and education about the risk of non-adherence). There is a need to optimise adherence before or immediately after starting treatment (Jordan et al., 2014, p.742) because early usage patterns are developed within the first week of treatment (Weaver et. al., 2008, p.173). Long term adherence is significantly influenced by the initial short-term CPAP use patterns in the first two weeks of at home use (Somiah et al., 2012, p.497). The Australasian Sleep Association states that monitoring adherence and risk of abandoning the therapy is a "shared responsibility between the patients, the sleep physician, the sleep clinic and a third party such as a business or organisation which provides CPAP equipment" (2009, p.2). Immediate adherence and early perceived benefits are predictors of long term engagement to CPAP therapy (Jordan et al.,, 2014, p.742).

2.2.8 Engagement

This study focuses on "engagement" the person's self-directed choice to undergo therapy, not because they are told, or have to meet these particular standards, but because they want to. The therapy may be the exact same, but the motivation to properly adhere to the therapy is different depending on the experience and support system.

2.3
BARRIERS THAT INFLUENCE ENGAGEMENT

The barriers that influence engagement, and the factors associated with these, are explained in Table 1. This table expands on the points in the user journey where these issues may arise. The table is a summary of information provided by health professionals, user manuals and online sources.

Table 1 Barriers that influence engagement with CPAP therapy

Barriers	Factors associated with...	Explanation
First impressions	Treatment method.	Impressions and perceived value, initial experience using and when they receive equipment for the first time
Self-Efficacy	Patient, partner support and clinician support.	Cognitive and personality factors, health belief, intrinsic and extrinsic motivations to use the therapy.
Stigma	From diagnosis, and treatment method, product and social factors	The cumbersome lifestyle change. Product and social related stigma.
Support	Partner, family, clinician online and support groups.	From health professionals, partner, family, support groups and spousal acceptance.
Feedback	From the treatment method, physical and cognitive, clinical, applications and online support	Physical and cognitive adverse side effects, statistics, applications, reassurance, health professionals, partner and family.
Education	From online sources, clinician and packaging.	Provided from health professionals, equipment and packaging, online forums and websites.
Ability to trouble-shoot issues	Delivery of information, physician, packaging,	Provided from health professionals, equipment user manuals and packaging, online forums

2.3.1 First impressions

A patient's initial experience with CPAP, and improvement in sleep efficiency in the early stages of therapy, is a significant predictor of CPAP adherence (Somiah et al., 2012, p.497). Those with an initial negative perception of CPAP from their sleep laboratory titration are less likely to be enthusiastic about using the device at home, and less motivated to troubleshoot or address other issues (Billings & Kapur. 2013 p.207). CPAP therapy is intrusive due to the facial mask being difficult for some individuals to tolerate (Shapiro & Shapiro, 2010, p.325). The most obvious interventions are to remedy the physical factors that lead to poor tolerance in the first place. These physical factors include mask discomfort, mask leaks, oral leaks and pressure intolerance. Even though these factors have not been explicitly correlated with the improvement of adherence, it is still of great importance to eliminate factors that may discourage the user to continue using this therapy (Billings & Kapur 2013 p.208).

Dooley (2014) emphasises the importance of first impressions and unboxing experiences when expectations of the product are formed from the user's impression of the packaging; "first impressions form in milliseconds, before cognitive processing … impressions can persist even when contradicted by factual information later" (Dooley, 2014). It is important to provide a positive impression when users receive their CPAP for the first time. Good packaging can have a positive influence on the user's perception of the product. User testing for impressions can be found in Chapter 4 of this research.
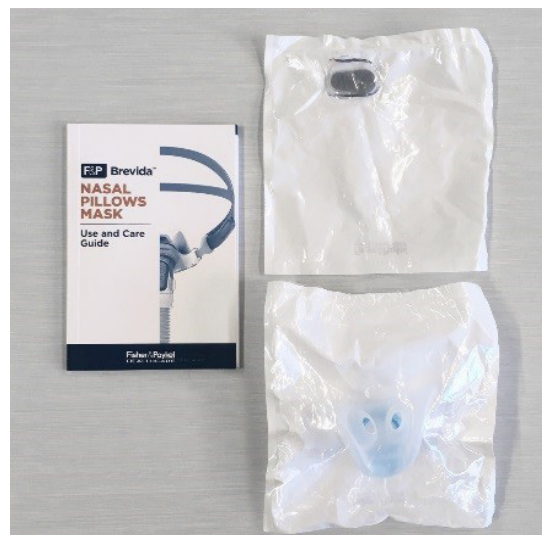
Figure 5 an example of how Nasal and facial masks are packaged and delivered to users.

2.3.2 Self-Efficacy

When delivering CPAP therapy to a new user, the role cognitive factors in the forming of first impressions need to be considered. Primarily, the patient is required to make adverse lifestyle changes, a task that is driven by their self-efficacy. This relates to the patient's belief in their own ability to use CPAP therapy to treat their OSA, and their understanding of the benefits of the therapy (Billings & Kapur. 2013 p.207). As the first week is an essential time for the development of use patterns, it is essential to make the development of these patterns as simple as possible to use. Other influential factors related to self-efficacy include the patient's readiness to change, health values, spousal or partner involvement, and attitudes toward the change in lifestyle (Olsen et al., 2008). These factors have been shown to predict short and longer-term engagement when assessed within the first week after CPAP exposure (Billings & Kapur, 2013 p.207).

2.3.3 Product related stigma

The consequences of product-related stigma are always dependent on the immediate context and the influence of that context on the user. Stigma can be defined as the connection between an attribute and a stereotype that links a person to an undesirable characteristic (Goffman, 1963 p.4). Medical products that are worn or used in proximity to the human body can have an emotional impact on users within their shared environments (Vaes, et al, 2012 p.1). For example, facial masks used for CPAP therapy (Figure 2, 4 & 6) are associated with a high degree of stigmatisation, as they tend to have a strong medical aesthetic, associated with a hospital or clinical environment. This stigma is referred to as an existential stigma, where the person has little control over their condition, or the therapy that they need to use (Vaes, et al, 2012, p.2). Patients cannot control the social stigma related to their condition. However, they can control whether they accept or reject the stigma associated with the therapy equipment.

Figure 6 Simplus™ Full Face CPAP Mask © 2015 Fisher and Paykel Healthcare Limited

Stigma in context

The bedroom is traditionally seen as a place of rest, intimacy and relaxation. However, people who use CPAP therapy see their bedroom as a place where therapy is imposed. Normal habits within this context need to be broken in order to successfully adopt this therapy. The association with medical devices in the home environment needs to be overcome (Vaes, 2014). It is essential to design for the cultural significance by neutralising the medical aesthetic of these devices to make them more suited to the home environment. This can be addressed through a better consideration of the context the devices will be used in. The precedent review (Section 2.6) addresses different types of assistive care that aims to reduce stigma, to make it more desirable for the end user (whether it is for long term assistive care, or for periodic therapy).

Overcoming stigma

It has been suggested that humans respond less to the physical properties of products, to their form and function, than they do to the individual and cultural meanings associated with them (Krippendorff, 2005). A user's resistance to using products due to product-related stigma is a continuous challenge for designers. Often, due to product stigma, patients establish negative usage patterns. This may be due to fear — of feeling like they will be perceived as having a serious disease – or due to the unappealing appearance of the therapy equipment. CPAP technology needs to respect and account for such individuals' resistance to engage. Patients are more likely to resist engagement with therapy if they struggle with cumbersome lifestyle changes, adverse side effects and if they are influenced by the stigma associated with this therapy (Shapiro & Shapiro, 2005, p.325).

2.3.4 Support, education and feedback

One of the greatest causes of non-adherence is poor communication between patient and clinician (Shapiro & Shapiro, 2010, p.329). It is thus essential to cohesively deliver information to the patient about their disorder, treatment options, therapy management, and what they should expect. Weaver states that patients' positive perceptions of the treatment – in terms of health value and benefit in symptoms following CPAP – have a positive impact of adherence (2008, p.325). A positive perception can be achieved by educating the patient – through both the physician and manufacturer, providing feedback and establishing a lifestyle that incorporates CPAP use (Shapiro & Shapiro, 2010, p.325).

Self-efficacy, patient expectation, spousal or partner involvement, encouragement, participation in support groups, intensive support programmes and education, are all associated with improvement of CPAP engagement, particularly with patients who already struggle to adhere (Balachandran et al., 2013 p.199; Jordan et al., 2014, p.742). The support from the patient's bed partner is also crucial in the adoption of CPAP therapy, as the disturbance of the CPAP equipment can be disruptive for those using it. Factors such as noise, the heated hose and air from the mask can all negatively impact the partner's comfort (Shapiro & Shapiro, 2010, p.328).

2.3.5 Ability to troubleshoot issues

Point of contact with sleep physicians is an invaluable time to deliver key information to the user on how to use their devices, and how to manage the therapy. Shapiro & Shapiro state that physicians should "take great care in explaining CPAP treatment (repeating instructions, writing down instructions, and clarifying unclear information), because patients are more compliant depending on their level of understanding about OSA and its treatments" (2010, p.329). When patients are at home, the therapy should be easy to use. It is also the responsibility of the manufacturer to provide sufficient instruction to the user, to be referred to if the clinic is not available to provide it.

2.4
STRATEGIES TO IMPROVE ENGAGEMENT

2.4.1 Identifying barriers

The barriers that contribute to nonadherence in the early stages of therapy can be reduced, by creating mechanisms that aim to improve long-term engagement. Studies suggest that monitoring early treatment use is of help to identify personality types, or experiences, which may discourage engagement (Van Zeller et al., 2013). Methods of design can be incorporated in the initiation and early treatment of CPAP therapy, with the aim to elicit positive usage habits in new patients. By identifying touch points, a designed system that provides education, support, feedback and encouragement, will benefit CPAP users to improve their impression, motivation and engagement with therapy in the home. The following pages expand on strategies to improve user engagement. Improving engagement is explored by looking at precedents in design that have successfully addressed comparable problems in this and similar fields.

2.4.2 Past intervention studies

Shapiro et. al. states that all the perceived problems associated with CPAP adherence can be dealt with by a "combination of physical, pharmacological and psychological remedies" (2010, p.325). Past intervention studies to promote CPAP adherence have ranged from a variety of methods such as education, cognitive behavioural approaches, mixed strategies and support (Weaver & Sawyer, 2010. p.245). However, these social responses lack design-oriented approaches that focus on the design of user experience, empathy and reduction of product-related stigma. CPAP adherence is a multifactorial clinical problem that requires similarly designed approaches, to effectively address barriers that influence engagement and adoption of CPAP therapy (Weaver & Sawyer, 2010. p.245). This is achieved through the understanding of user experience, and by considering the psychological impact of adopting a new lifestyle.

Initial follow-ups and intensive educational programmes have had limited success in improving adherence. However, cognitive behavioural approaches have had greater success improving CPAP usage by 1.5-3 hours per night – a substantial clinical impact (Billings & Kapur. 2013 p.208). Cognitive behavioural therapy approaches include the Patient Belief model. This psychological model attempts to explain and predict health behaviours of individuals diagnosed with certain health conditions. It focusses on using the attitudes and beliefs of individuals to predict future adherence and acceptability of these conditions (Rosenstock, 1974). Literature states that education has an important role in long term engagement – informed patients tend to be more motivated with CPAP therapy use (van Zeller et al., 2013). Patients that are aware of what the therapy entails, as well as the health benefits and troubleshooting approaches, are more likely to adhere to the therapy than those who are not (Jordan et al., 2014, p.742). Shapiro states that early learning can have a substantial long-term effect, however, due to the inconsistency of practices and the delivery of information, there are issues in relation to education about therapy management. Some proposed solutions are to design educational programs (Shapiro & Shapiro, 2010, p.325) to troubleshoot problems within the early stages of therapy, by providing consistent instruction to the user to assist in therapy management, and also to reiterate their belief in their health domains.

2.5
DESIGN FOR BEHAVIOUR CHANGE

The negative stigma associated with CPAP therapy is a challenge that requires more attention than personal and intervention-based encouragement. Persuasive design techniques aim to enhance the overall user experience by targeting small behaviour changes.

2.5.1 Persuasive Design

persuasive behaviour models such as the "Behaviour Model for Persuasive Design" (Fogg, a, 2009) and the "Hook Model for Habit Building Products" (Eyal & Hoover, 2014). Users can be subconsciously influenced to complete certain tasks related to their CPAP therapy. It is important to break down target behaviours into smaller tasks, performed subconsciously through the implementation of education and skill building in the early stages of CPAP therapy, so that simple tasks are performed habitually. The aim is to create and encourage habitual and routine behaviours in the early stages of the therapy, as the user's adoption of smaller target behaviours can naturally lead to the adoption of more ambitious behaviours later on (Fogg, b, 2009, p.2). For users to achieve a target behaviour, sufficient motivation, the ability to complete the action, and a trigger must be present at the same moment in time (Fogg, 2009. a).

A key difficulty with altering behaviour is the struggle between rational and irrational (or natural) behaviours. Individuals tend to make irrational choices more than usual if they do not receive immediate feedback about the consequence of their decisions. This is an important part of therapy compliance; patients may struggle to adhere if they do not receive the immediate and obvious feedback of symptom reduction. As a result, they may find that the reward of symptom reduction is not worth the discomfort of the therapy. Design can encourage the user to complete a target behaviour by making the desired behaviour the easiest option. Enabling a product to be used with little or no conscious thought is key to the successful creation of a habit-forming product (Eyal & Hoover, 2014).

2.5.2 Reduction techniques

Other methods of behaviour change often focus on the slow feeding of information to the user. This reduces a larger, more complex task into smaller, more manageable steps. Each piece of information can then be presented at a suitable time and in a suitable context. This technique changes the user's perceived utility of the tasks involved (Kraft et al., 2008, p.178), making it less overwhelming, and reducing information overload in the prescription process and the first week of therapy. According to Vicente, when technologies are well tailored to an individual's physical and cognitive ability, the user is more likely to accept and engage with them (2003, p.90). Products that pose too much of an immediate burden on our cognitive faculties, or violate expectations about cause-effect relationships, are more likely to be rejected by the user (Vicente, 2003, p.89). Products that require too much learning, or prove difficult to use, routinely fail (Eyal, 2014).

2.6
PRECEDENT REVIEW

Following are some examples of designs that analyse the product's ability to provide support, feedback and education to users. Following similar goals to therapy management, these precedents support the importance of self-management of devices in the home. Precedents are analysed for their ability to provide the user with sufficient motivation, trigger and ability.

2.6.1 Ami – Assistive Medical Device

Successful user-centred design methods simplify the product design so that all relevant information and features are focussed on enhancing the user experience. Ami (Figure 7) is an assistive medical device designed by Olivia Chandler (2017) that focusses on aged care management. The system is focused on home care and understands the importance of independence for users - but provides a connection to family through the application as a method of informal care giving. The system reminds patients of upcoming events, including appointments and when to take their medication, through a mobile application (Figure 8). Weinreich emphasises that the success of the product, and the behaviour reflected by its users in relation to it, is dependent on what the user finds desirable and if it supports their physical and cognitive needs. A product will be effective if the user believes that it will prevent or reduce the problem at hand, and if the choice to adopt and engage with therapy will be sustainable in the long term (2010, p.137).

Figure 7 (Above) Ami Assistive medical device Designed by Olivia Chandler 2017
Figure 8 (Below) Ami Mobile Application designed by Olivia Chandler 2017

Figure 9 (Above): Aer asthma inhaler and application designed by Abidur Chowdhury (2017)
Figure 10 (Below): Aer information display system designed by Abidur Chowdhury (2017)

2.6.2 Aer – Asthma Management system

Aer is an asthma management system designed by Abidur Chowdhury (Figure 9 & 10) that encourages people to be more compliant with self-management of their medication. It aids users with understanding their condition and notifies them of their progress through an application (Figure 10). The inhalers have a Bluetooth sensor that connects to an app which monitors use. The base also senses the humidity, air quality and the level of particles that may trigger asthma. The system encourages users to participate in managing their therapy by providing helpful feedback at the moment of use (and ongoing education), initiating the use of the inhaler when necessary. This effectively alters the behaviour of the user – motivation, ability and a trigger are all present at a single moment. To "distance" the device from stigma, the base was designed (Figure 10) to ensure the display of the system felt less "medical" and less prone to product stigma, providing similar aesthetics to domestic consumer products. The system provides audio-visual information to the user, so that the user is aware of medication doses through graphics and cognitive feedback.

2.6.3 Out of the box design for Samsung

One successful method of information delivery is the out of the box packaging designed for Samsung (Figure 11) by Special Projects Studio (2009). The project aimed to determine why some elderly users did not make use of their mobile phones. Results found that the main issue for these users were the supplied instruction manuals, which were difficult to understand. To encourage staggered learning, reduction techniques simplified the set up and use of the mobile devices through the books, to improve their technological understanding. There are two books in the packaging (Figure 11) that focus on setting up and using the mobile phone. This reduction of information simplified the process and made learning more motivating to users, creating a behaviour change.
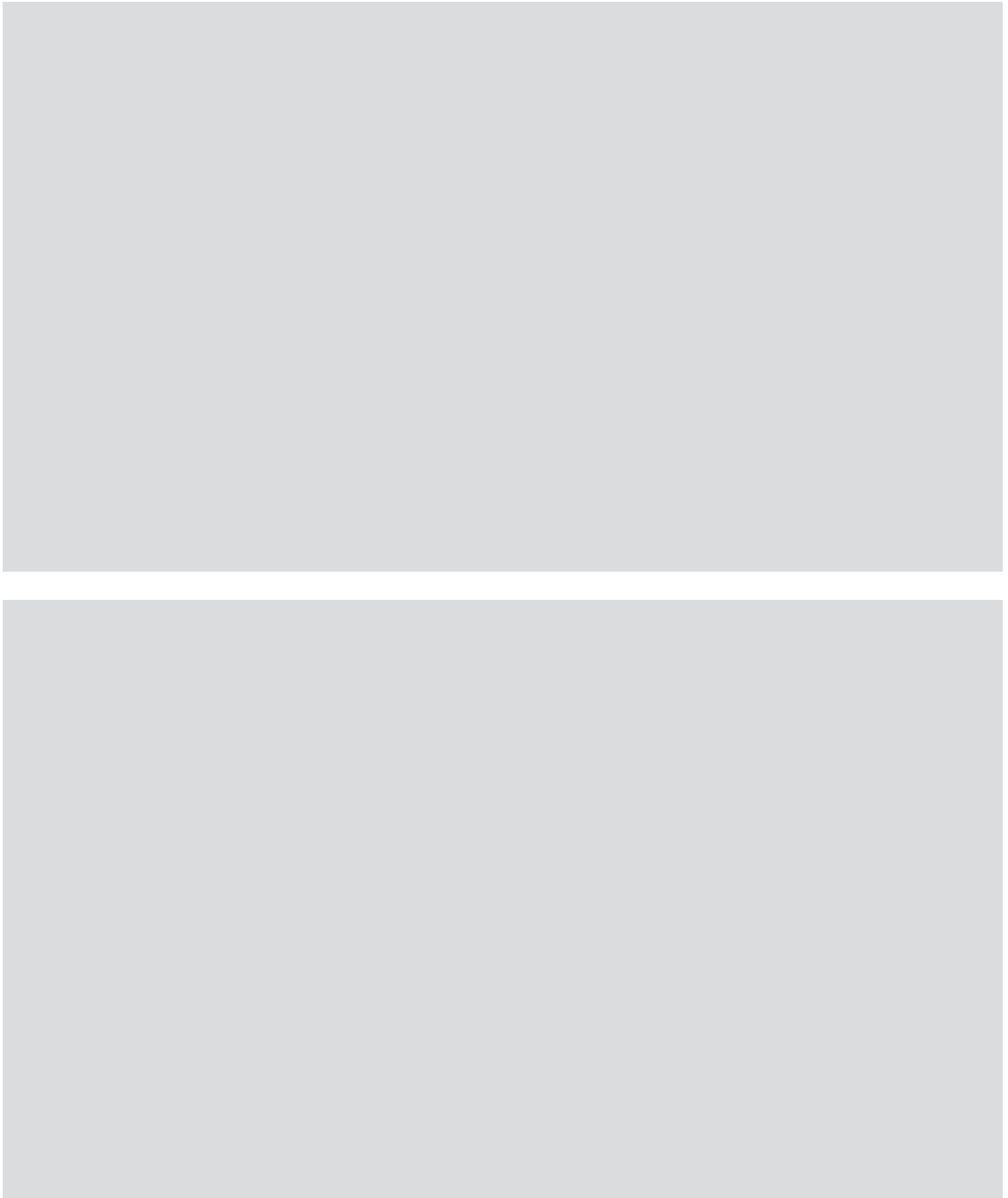
Figure 11 Out of the Box for Samsung packaging design by
Special Projects Design Studio (2009)

2.7
CONCLUSION

After reviewing the importance of CPAP therapy engagement and adherence for people with Obstructive Sleep Apnoea, this review concludes the necessity of design input to encourage the self-management of the therapy. Suggestions include addressing the delivery of information, first impressions, self-efficacy, stigma, the ability to troubleshoot issues, and the level of support, education and feedback provided in the early stages of therapy. This can be achieved through effective approaches such as reducing stigma, simplifying the delivery information and providing of constant support and feedback for longer term therapy management (applied by the precedents identified). This research identifies the gaps in the delivery of therapy to patients where the user experience does not cater for barriers that may influence engagement within the first week of therapy. These barriers include perceived value, education, support, feedback and reduce the product-related stigma associated with this therapy in the home. Methods such as inclusive design, persuasive design, user centred design considerations and implementation of the patient health belief into these processes of design, will bridge the gap between manufacturers and clinician processes, improving engagement through positive user experiences for patients using CPAP therapy at home.

03

METHODOLOGY

The methodologies applied in this research were chosen based on their ability to support the overall aims and objectives of this research. These aims are to;

1. Identify the barriers that influence people's engagement with CPAP therapy in the first week.

2. Design a response that encourages engagement with therapy through design concepts based on criteria.

3.1
THEORETICAL FRAMEWORK

The literature on past intervention studies highlights the absence of a user-centred design approach in addressing the initiation and experience of CPAP therapy to new users in the first week (De Vito Dabbs et al., 2009). This thesis aims to address this gap by identifying the barriers that influence engagement using Research through Design based on Design Criteria (Rodríguez Ramírez, 2017). This approach acknowledges that methods of data collection can drive potential design responses, through the development of criteria that aim to address the touch points and barriers identified.

Table 2 Research aims, objectives and methods table for phase one

Aim	Objective	Method
Research Phase To Identify barriers that influence engagement in the first week of Continuous Positive Air Pressure (CPAP) Therapy as treatment for Obstructive Sleep Apnea (OSA)	Conduct literature and design precedent reviews to develop a body of knowledge for thesis chapters	Postgraduate thesis model for Research through Design based on Design Criteria (Rodríguez Ramírez, 2017, p.25), Literature and Precedent Reviews
	Identify the experiences of people that use CPAP therapy through online surveys	Web based Reviews, Semi-Structured interviews, open ended interviews, surveys, Thematic Analysis (Alhojailan, 2012, p.40-45), Deductive Thematic analysis, Data visualisations (Few, n.d.)
	Interview Clinicians for their perspective of the barriers that influence patient engagement	Semi Structured Interviews, BRUSO Method (Zimmerman et al., 2007b) (Price et al., n.d.), Thematic Analysis (Alhojailan, 2012, p.40-45)
	Interview people that use CPAP to understand their experience in the first week of therapy	Semi-Structured Interviews Thematic Analysis (Alhojailan, 2012, p.40-45) Cultural Probes (Starkman & Chow, n.d.) (Mattelmäki, 2008, p.42)
	Interview Manufacturer representatives to understand their input in the product development phase	Semi-Structured Interviews, Thematic Analysis (Alhojailan, 2012, p.40-45)
	Identify and map an in depth journey to OSA diagnosis and CPAP device and mask prescription processes	Thematic Analysis (Alhojailan, 2012, p.40-45) of all data collected and identify key themes. Semi structured interviews, Literature reviews

3.1.1 The first phase

Table 2 and 3 structures the aims, objectives and methods of this research, separated this into two phases. Aims to understand and map the process that new CPAP users experience when first diagnosed with OSA, to the first week of CPAP therapy. The intention of this is to identify touch points that may cause difficulty in engaging with the therapy. The identification of these barriers supports the second phase of this research, where applications of design aim to intervene to improve the overall user experience through the development of design criteria (Rodríguez Ramírez, 2017, p.17).

Table 3 Research aims, objectives and methods table for phase two

Aim	Objective	Method
Design Phase Design a system that encourages engagement with CPAP therapy by addressing the barriers identified in the first phase following intervention based principles.	Identify where design can be implemented in the user journey	Mapping User Journey (Komninos, n.d.), Customer touch points (The Interaction Design Foundation, 2018)
	Develop design criteria	Criteria-based design research model (Rodríguez Ramírez, 2017, p.13)
	Iterate and prototype designs based on criteria and thematic analysis findings	Experimental discovery through making Iterative design, Prototyping through 3D modelling, 3D printing, Sketching (Rodríguez Ramírez, 2017, p.14)
	Produce a final design/s based on criteria and research findWings that may improve the experience of people in the first week of using CPAP Therapy	Research through Design (Zimmerman et al., 2007b), User centred Design (Greenhouse, 2012)
	To report on how the final design/s addresses the criteria developed through clinician, participant feedback	Usability Evaluation and testing using the System Usability Scale, Thematic analysis of semi structured interviews (Alhojailan, 2012, p.40-45), Assessing designs based on criteria (Rodríguez Ramírez, 2017, p.17)

3.1.2 The second phase

The second phase of this research recognises design criteria that structure the development of design concepts that is expanded in Table 3. Criteria are identified through analysis of literature reviews, semi-structured interviews, online surveys, and user diaries in the form of cultural probes. The design development phase utilises general design techniques and develops concepts relevant to criteria. Concepts are then tested against the relevance to the criteria. Chosen concepts are then developed into a final design output that addresses the barriers identified in the initial research phase.

3.2
DATA COLLECTION METHODS

3.2.1 Literature Review

Literature reviews situate the barriers that influence engagement with CPAP therapy and examine existing knowledge of CPAP adherence. This identifies the gap where design can intervene with an intervention-based experience for new CPAP users, guided by the research question. This review structures field research aims and design criteria (Rodríguez Ramírez, 2017, p.14).

3.2.2 User Testing

The aims of the user testing are to understand the relevance to the barriers identified in the previous chapter. The testing focusses on the initial unboxing experience and delivery of information to understand the perceived value of the equipment, cohesion of the delivery of information, and initial impressions of the equipment. Each phase tests certain aspects of the delivery of CPAP equipment using the thinking out loud method (Charters, 2003, p.69) and the system usability scale (Brooke, 2011, p.4).

3.2.3 Online Surveys

Online surveys are conducted. In order to achieve effective data collection, the link to the survey was posted in a popular online OSA/CPAP support group. Participants remained anonymous and provided key information about their experiences using CPAP in a little amount of time.

Because this research fundamentally focuses on the experience of people in the first week on CPAP therapy use, questions asked (Appendix B) focus on the following. First, people's past experience using CPAP. Second, reflection on their first week of therapy. Third, how they overcame certain barriers faced during their initial period using CPAP. Fourth (and final), how they currently manage their therapy. Results from the survey and an analysis of the findings, identifying the common themes found from responses, are coded using methods of qualitative and quantitative research methods, and are expanded on in Chapter 4 of this research.

3.2.4 Semi Structured Interviews

Given the breadth necessary to define the experience of new users, it is more relevant to gather the data relevant to users, clinicians and stakeholders from a larger perspective.

There are three main focus groups involved in the process of CPAP prescription and the journey of a new user. The experiences vary in the levels of support, education and feedback, dependent on the process they go through from diagnosis, prescription, and the first week's experience using CPAP. This study interviewed people from each focus group to understand the touch points, and to understand any biases that are involved. Development insights to the user experience in both the manufacturer, clinical and home environments are of immense value in learning and gathering insights from a real focus group's point of view (Wiklund, & Wilcox, 2005, p.59). This can bring rise to insights that the user experiences such as cleaning habits, sleeping routines, therapy management recommendations, and what features are used and ignored. This feedback is essential to remove the misinterpretation of the point of view of the users (Wiklund, & Wilcox, 2005, p.59).

3.2.5 Cultural Probes / Design Activity

Cultural probes or "Design Activities" are given to participants to gather insightful information about their experiences using CPAP therapy, without interfering or intruding into the home of the participant. CPAP therapy is used during sleep, and in the bedroom. This intimate context is difficult to investigate without discomforting the participants involved. Design probes require participation of the user by a means of self-documentation and reflection, using a set of tools that encourage them to document their experiences and express their thoughts (Starkman & Chow, n.d; Mattelmäki, 2008).

The design package contained several activities derived from pervious successful cultural probe examples (McCarthy, 2018) (Mattelmäki, 2008). The use of design probes opens an opportunity to gather key insights from the participant's outlook and experience of their own therapy, without intruding on their home environment. Researchers presence may have caused embarrassment or discomfort as the context of where the therapy is used is very personal and intimate. The cultural probes focussed on a personal relationship of the user with his/her equipment.
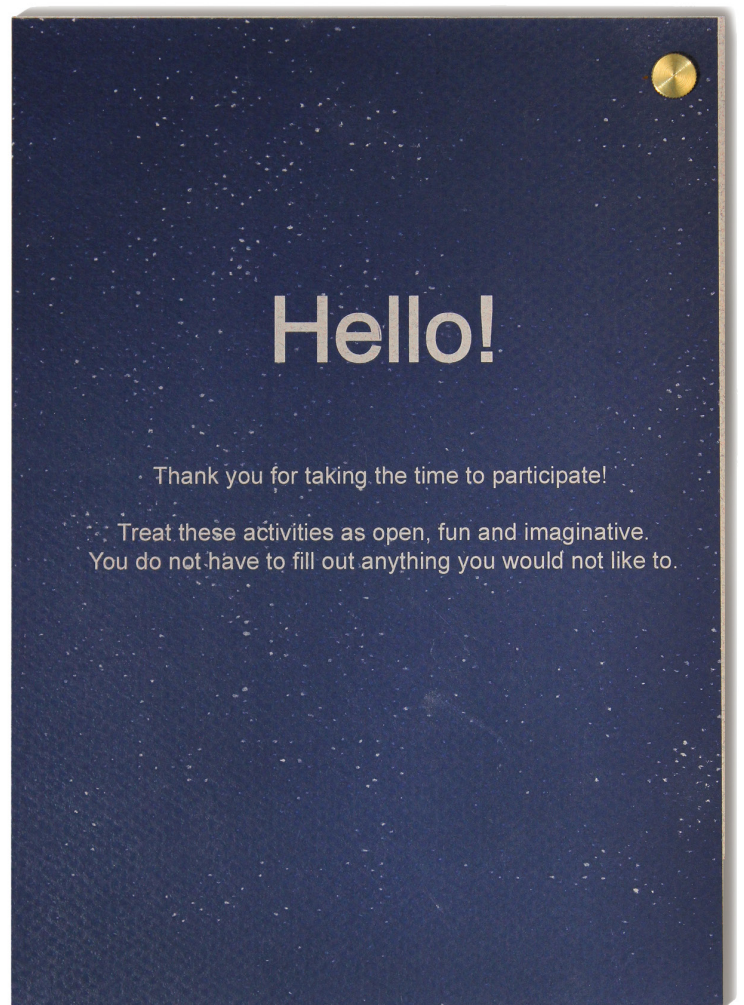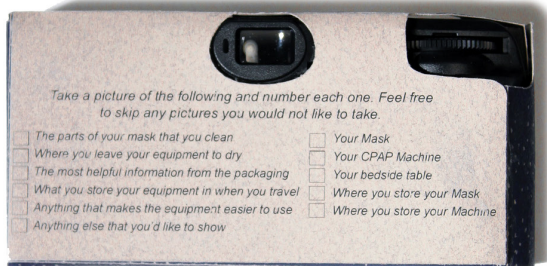
Figure 12: Physical design activity package

Activities

Tasks focus the user's attention to reflect on certain aspects of their lives, and how CPAP therapy has changed this (Mattelmäki, 2008). The intention is to find insights from the activities though analysis to identify key, and reoccurring themes (Mattelmäki, 2008) using qualitative thematic analysis (Braun & Clarke, 2006).

The activities in Figure 12 and 13 included; Capture the following, Finish the sentence, Bedroom Rules, Write a love letter and Write a break up letter. These activities aimed to identify the following: how their life has changed from when they started CPAP, the impact on their bedroom, their feelings, values and attitudes toward therapy, and their need to maintain and persevere.

Hello!

Thank you for taking the time to participate!

Treat these activities as open, fun and imaginative.
You do not have to fill out anything you would not like to.

CAPTURE THE FOLLOWING...

_____ Your Mask

_____ Your CPAP Machine

_____ Your bedside table

_____ Where you store your Mask

_____ Where you store your Machine

_____ The parts of your mask that you clean

_____ Where you leave your equipment to dry

_____ The most helpful information from the packaging

_____ What you store your equipment in when you travel

_____ Anything that makes the equipment easier to use

_____ Anything else that you'd like to show

FINISH THE SENTENCE...

1. When I use this therapy regularly I feel _____

2. CPAP therapy has changed the way I feel about _____
   _____

3. I am motivated to use the therapy when_____

4. I use my CPAP _____ times a week.

5. If I could change anything about the therapy it would be _____
   _____ Because _____

6. I get frustrated when_____

7. When I recieved the therapy for the first time I,felt _____
   _____

8. When I used the therapy for the first time I,felt _____
   _____

9. The advise that I would give to someone starting the therapy would be
   _____

BEDROOM RULES...

1. _____

2. _____

3. _____

4. _____

5. _____

WRITE A LOVE LETTER...

WRITE A BREAK-UP LETTER...

Figure 13: Design Activities in the booklet

3.2.6 Thematic analysis

This research uses methods of thematic analysis to analyse key themes that arise in the different phases of data collection (Alhojailan, 2012, p. 40-45; Braun & Clarke, 2006). This method focusses on qualitative research where repetitive occurrences of themes in the data collected are coded and discussed in the upcoming chapters. Thematic analysis is used to identify the barriers in summaries from interviews, cultural probe results and survey responses, in order to identify real experiences and touch points that direct design responses using the phases of thematic analysis in Figure 14. Deductive thematic analysis is used in open ended questions to identify key themes from the survey responses.

3.2.7 Deductive Thematic analysis

Deductive thematic analysis is a form of analysis where data is sorted in a qualitative way to form final conclusions or themes about the data collected (Guest, et al., 2012). It is used in open-ended questions to identify key themes in interview and survey responses. Particular themes are generated from the responses and collated into motivations to engage with therapy, influenced by health belief, physical, psychological and other considerations. Even though the output of the visualisations is quantitative, it is based on qualitative coding and analysis (Guest et al., 2012).

Transcribe data

Generate initial codes

Collate codes into potential themes

Review, define and name themes

Final analysis of themes relevant to the research aims
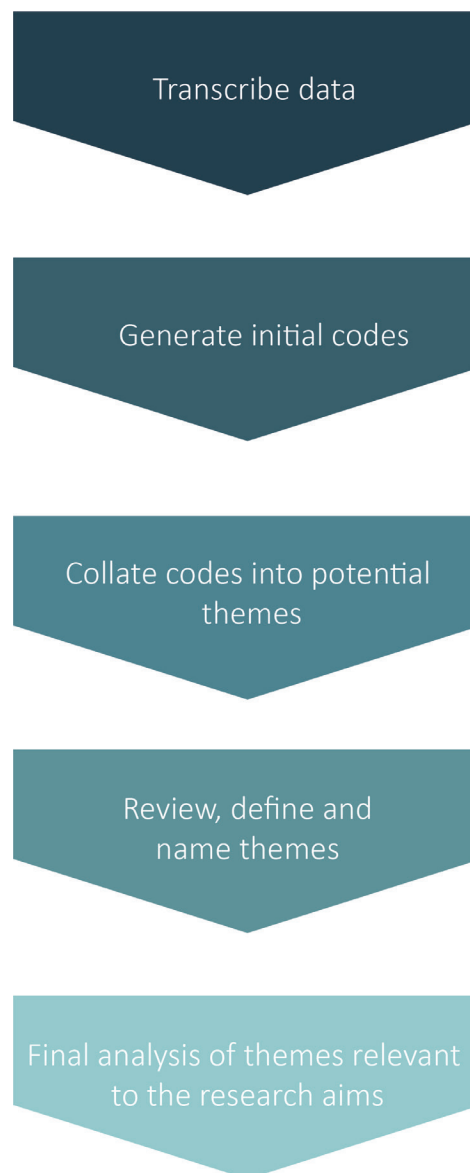
Figure 14 Phases of Thematic Analysis (Braun & Clarke, 2006 p.36).

3.3
DESIGN DEVELOPMENT METHODS

3.3.1 Development of Design Criteria

Design criteria establishes goals for the design phase of this research by stating goals where 'the design should…" (Rodriguez-Ramirez, 2017). This creates a structure or brief for the design phase, so that the refined design concepts can be reflected against the criteria in later user testing and discussion, particularly regarding the final designs and their relevance to the criteria.

3.3.2 Prototyping / Design Development

Rapid prototyping is used for physical production of design concepts, helping the understanding of the processes involved in each phase to come to a refined output. Different mediums such as physical model making and digital wireframes are used as part of the design development phase that are expanded on in Chapter 5 of this research.

3.3.3 Reflection of design against criteria

Aims to evaluate successful and unsuccessful aspects of the design output and assesses the designs to against the criteria. The criteria provide a structure for the design, with creative freedom to venture into different areas where design may impact in and out of scope. Exploration of these different areas may prove some to have a positive impact, and others may prove why these areas do not need to be explored in future research with similar goals.

3.3.4 Participant Feedback

As the data collection mainly focuses on the experience of individuals, the design is focussed on the experience users are likely to go through when they first encounter the system, investigating avenues with potential to improve this experience. This research uses assessment with a user (Participant 6) as a case study to model this first experience, and to receive feedback on the system.

04

DATA COLLECTION

RESULTS
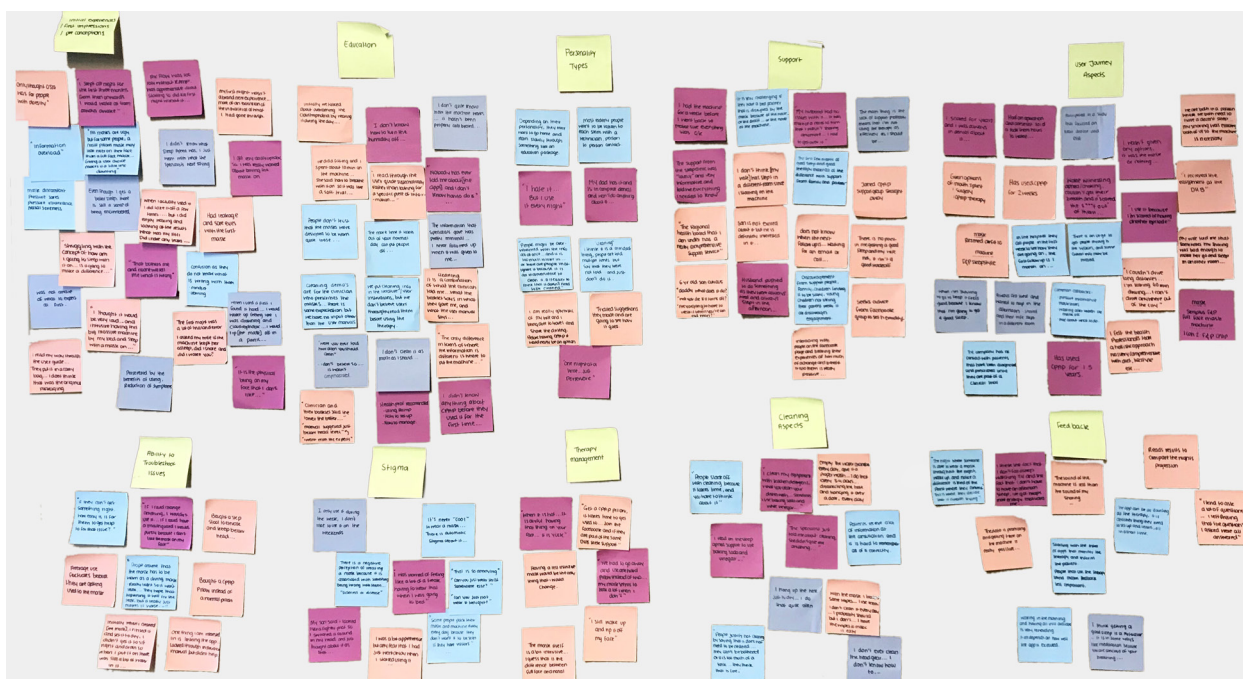
Figure 15: Example of coding for thematic analysis of Interviews

4.1
PARTICIPANTS AND CODING

The main goal of this research is to define the experience of new users in the first week of CPAP therapy. To examine this experience, interviews with clinicians, manufacturer representatives and users of CPAP therapy were held. Cultural probes were given to CPAP users, to gather more personal information about the individuals' outlook on their therapy. To gather information from a wider scope of CPAP users, online surveys were used to identify the variation of experiences.

The results from the data collected in these methods are collated into themes using thematic analysis (Figure 14 & 15). These findings generate the design criteria in the following chapter of this research.

As the data collection phase focussed on the experience of users, there were many reoccurring themes from each method. The results are coded using thematic analysis (Braun& Clarke, 2006), and participant references in the following chapter are coded in Table 4. Participants were invited to take part in the cultural probe activity after the interview. Some participants did not agree to an interview but were willing to take part in the cultural probes. Others took part in the interview and cultural probes. Participants have been coded with a corresponding number i.e. P1 = CP1.

Table 4 Participant coding for data collection methods

Data Collection Method	Participant	Code
Sleep Physiologist Interview	Sleep Physiologist	SP1
Manufacturer representative Interviews	Interface Development Engineer Clinical Research Associate	M1 M2
CPAP User Interviews	Participant 1 Participant 2 Participant 3 Participant 4 Participant 6	P1 P2 P3 P4 P6
Cultural Probe Responses	Participant 1 Participant 3 Participant 5 Participant 6	CP1 CP3 CP5 CP6
Online Survey Responses	77 Respondents	SR 1-77
User testing Session	Testing Participant 1 Testing Participant 2 Testing Participant 3	TP1 TP2 TP3
Online Support Group	Anonymous Support Group Member	SGM

4.1.1 Sleep Physiologist (SP1)

An interview was conducted with an experienced Sleep Physiologist (SP1). The Sleep Psychologist in question had over 23 years as a Sleep Technologist diagnosing sleep conditions, and specialising in prescribing CPAP equipment. SP1 stated that clinics in the public system's adherence rates tend to be between 50-60%. SP1 also stated that their clinic sits at 90% adherence. The high level of adherence meant that the clinic could set an example for good practice and could serve as a model for what works (and what does not), with CPAP users. Information sheets and consent forms are provided (Appendix C).

The aims of this interview were to understand:
1. The user journey of a new CPAP user from a Sleep Physiologist's point of view
2. The different focus groups involved in this process
3. The barriers that influence engagement with CPAP therapy
4. The services that the clinic provides

4.1.2 Manufacturer Representatives

An interview with two manufacturer representatives was held at Fisher and Paykel Healthcare, Auckland, New Zealand and lasted for 40 minutes. The first interviewee was an Interface Development Engineer (M1), involved in mask-interface development with a focus on comfort, usability and performance. The second interviewee was a Clinical Research Associate (M2), part of a team conducting clinical trials of in-development CPAP masks and post-market studies on masks that have already been released. Information sheets and consent forms are provided (Appendix D).

The aims of theses interviews were to understand:
1. The manufacturer's view of the user journey of individual CPAP users
2. The barriers that influence engagement of new users
3. Current methods of support that the company provides to users of their products
4. The areas where design can intervene in the user journey
4. Identify areas that design can intervene in the user journey

Table 5 CPAP user's completion of Interviews and design activities

Participant	Gender	CPAP Experience	Location	Recruitment	Interview	Design Activity
Participant 1	Male	5+ Years	Wellington, NZ	Word of mouth	✓	✓
Participant 2	Male	2 Weeks	Auckland, NZ	Support Group	✓	
Participant 3	Female	1.5 Years	Christchurch, NZ	Support Group	✓	✓
Participant 4	Male	< 1 Week	Wellington, NZ	Word of mouth	✓	✓
Participant 5	Female	4 Months	Gold Coast, AUS	Support Group		✓
Participant 6	Female	2 Years	Wellington, NZ	Support Group	✓	✓

4.1.3 CPAP users

Recruitment of participants was achieved through both a message post in the online support group, and direct contact. Respondents were invited to contact the primary researcher through a verified Victoria University email address to organise an interview. One of the participants did not want to be interviewed, but still completed the activity. All other participants completed the design activities after an interview. Activities required reflection on different aspects of their therapy.

The interviews were with four CPAP users varying in experience with CPAP therapy (Table 5). The interviews took place either in a quiet café, over skype, or over the phone, and provided information sheets and consent forms prior to the interview (Appendix E) were approximately 40 minutes. Afterwards, the interview participants were invited to participate in a design activity.

The aims of these interviews were to understand:
1. Personal experiences when going through initial prescription process
2. Barriers faced in the first week, and throughout
3. How individuals managed their therapy
4. The personal outlook of individuals on their therapy

The initial recruitment was dependent on clinicians providing contact with patients. However, this was not sufficient due to confidentiality issues. Participant recruitment for this study was difficult due to the need to adhere to existing ethics constraints. To overcome this, an ethics amendment enabled recruitment and data collection through online surveys and allowed recruitment through direct contact.

How long have you used CPAP for?

37.7%
More than 2 Years

35%
Less than 6 months

14.3%
1 to 2 years

13%
6 Months to 1 year
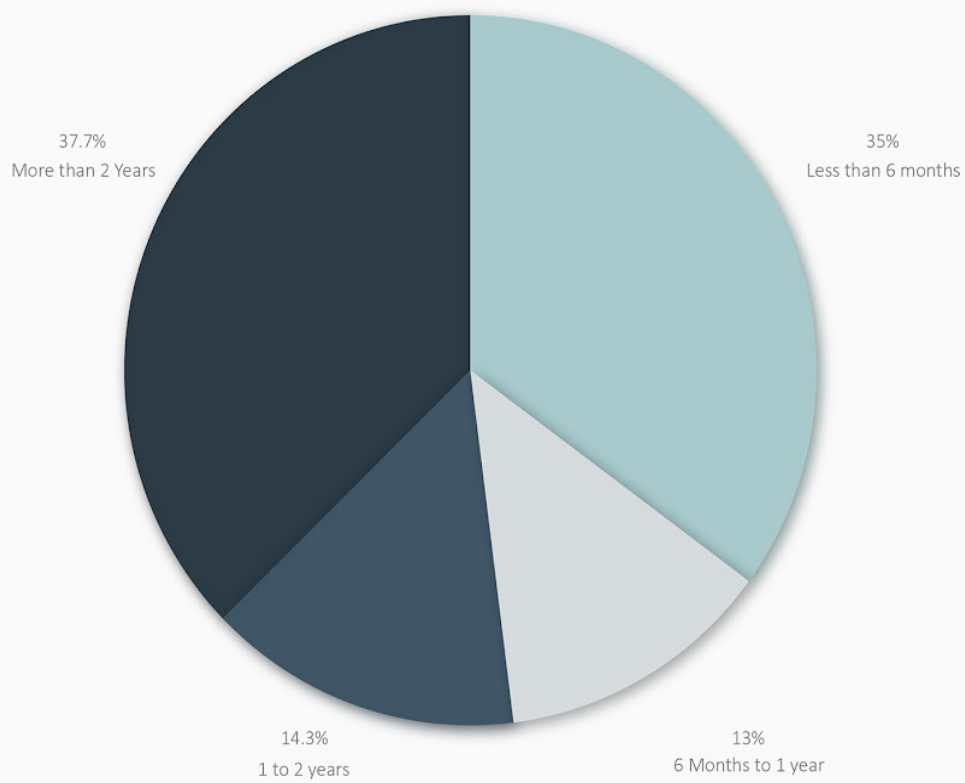
Figure 16 CPAP experience of survey respondents

4.1.4 Survey respondents (SR 1-77)

An online sleep apnoea support group (with 2200 members from Australia and New Zealand) provided key insights and information about the experience of CPAP users. With permission from the administrator, a link to the survey was posted. This link included a description of the research aims, and an invitation for members to take the survey. Survey participants were informed that of two points. First, all of information they provided was anonymised. Second, they did not have to answer all of the questions. The survey was accessible by members for 7 days and received 77 responses. 7 people contacted the primary researcher for a further interview and for participation in cultural probes, with 4 proceeding to a full interview. '

98.2% of survey respondents used CPAP to treat Obstructive Sleep Apnoea. Figure 16 and 17 show the age, and experience of respondents. There is a noticeable drop off in the respondents, mirroring the previously observed trend of patient drop-off (particularly after the 6-month mark). 35% of respondents have been using CPAP for less than six months, (Figure 17) and 37.7% have used it more than 2 years. The survey relies on reflection on past experiences to understand why people may have discontinued use at this time. Questions asked provided authenticity from real users, with examples of the experiences they have with ongoing CPAP therapy use proving that not every experience is the same. This allows variation in the experiences of CPAP users to be identified.

How old are you?

5% 65+

11% 25-34

28% 55-64

26% 35-44

30% 45-54
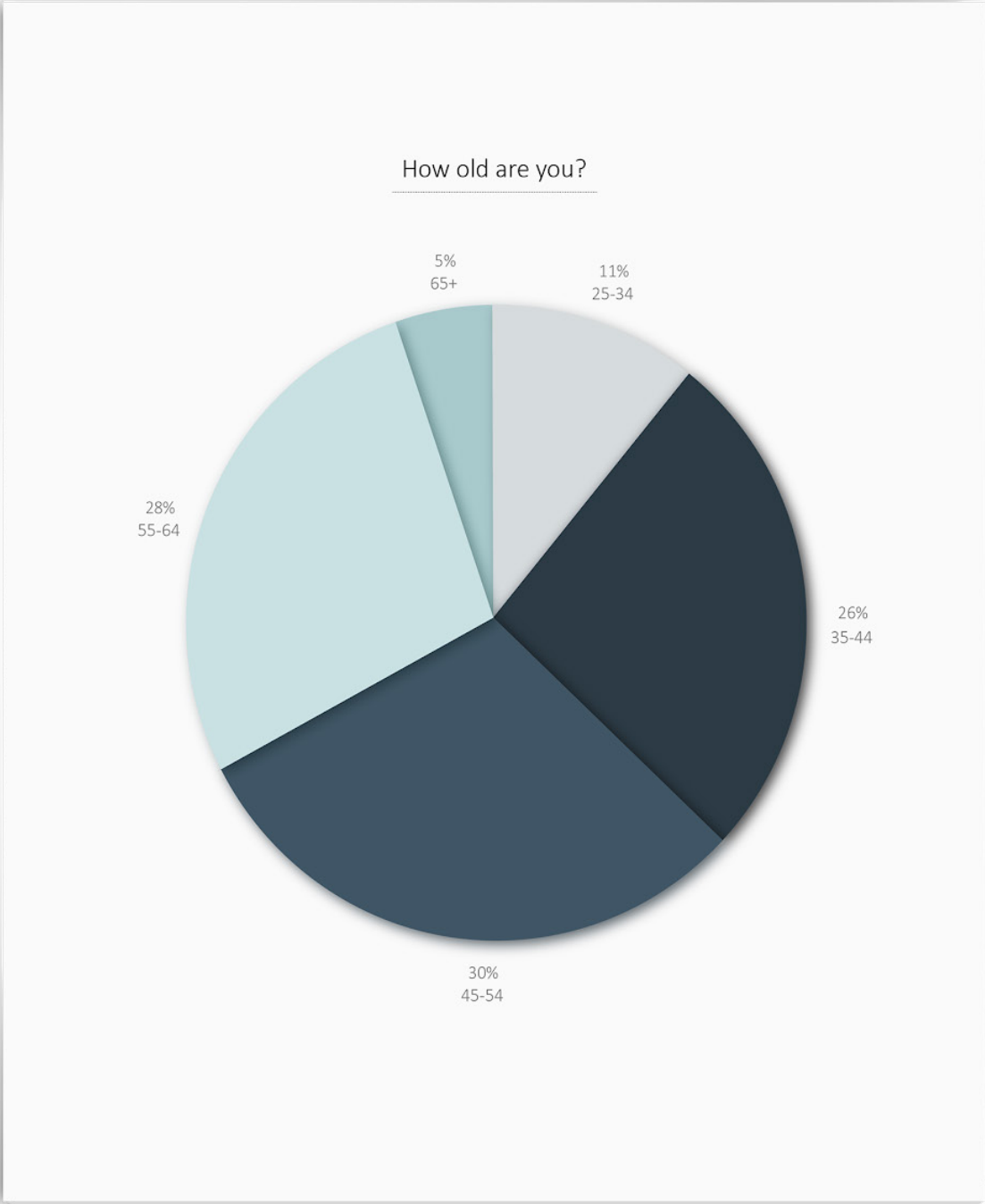
Figure 17 Age of survey respondents

4.1.5 User Testing Participants

The individual testing sessions are set up in the studio environment and three participants (TP1, TP2, and TP3) were individually recruited at Victoria University of Wellington. They have no relation with an OSA diagnosis.

The aims of the user testing is to understand:
1. The first impressions of the equipment
2. The perceived value of the equipment
3. The effectiveness of the information in the packaging

A lack of education provided in the packaging will make users follow strictly their instincts to disassemble the mask, where to put the CPAP device and what to clean it with. The therapy equipment will seem foreign to some and there will be hesitation toward accepting that this needs to be put in their home.

Figure 18 User testing

Procedure

The individual testing sessions are set up in the studio environment and three participants (TP1, TP2, and TP3) are individually asked to take part in the testing. They are given an information sheet and consent form to read through and sign. Participants are aware that the testing is recorded and they are unidentifiable in the filming process.

Participants are given an overview of the condition, and what people go through to get a diagnosis and the function of the equipment. The participant is given the equipment as if it was delivered to them. The CPAP device, hose, and power cord are packed in the travel bag. Inside the bag is also a mask that is packaged in the original packaging with the spare parts (including the spare filter and seal).

The participant is asked to talk about their first impressions of the equipment when they received it, using the thinking out loud method, they are asked to assemble and disassemble the equipment. Afterward they are asked questions about their experience receiving and unpacking the equipment.

The participant is then asked to fill out a sheet with questions using the system usability scale (Appendix E). When this is completed they were thanked for their time and for their assistance in the research.

4.2
THE USER JOURNEY

The user journey varies from patient to patient. To dissect the process that new users go through, allowing for variation, and to identify the areas where people may discontinue use, it is useful to break down the differences into two different categories. These categories include the prescription process (Figure 19) (the system health professionals use to diagnose OSA and prescribe CPAP), and the initial experience using CPAP therapy.

4.2.1 Motivation to seek diagnosis

Every patient who goes through the prescription process usually has a motivating trigger that leads them to seek professional advice. Similar to the findings in Chapter 2, many cases involve an intervention, key milestone or event that influences the person's decision to seek professional advice. The online survey asked 'can you identify any key milestones that made you seek a diagnosis?' This question is open ended and is representative of the variation in experience; the number of responses (77), was high. The responses are characterised in the following section, generalising the motivations patients had when seeking treatment.

What they did

The most common responses include themselves and other people noticing their snoring, consciously waking up at night gasping for air, and not being sufficiently well rested to be able to perform daily tasks safely. SR62 could "wake the world with [their] snores and [they] could fall asleep while even talking to someone 1:1." Some patients found that their driving was significantly impaired. SR28 "started falling asleep while driving and sitting at traffic lights" and SR23 "fell asleep at the wheel while [their] wife was in the car. SR60 had "a realisation that memory and lack of sleep affecting [their] job. And SR34 had "constant fatigue so [they] used to have afternoon naps everyday".

How they felt

Most respondents experienced noticeable symptoms, such as snoring, fatigue, lack of concentration and memory issues. The most common feeling was tiredness. SR53 "Wasn't feeling rested even when I had had 8+ hours of sleep", SR28 "was more exhausted after going to bed to sleep than when [they] just stayed awake. SR42 stated that they were always "extremely tired and had a lot of brain fog in the mornings".

Other people's influence

As part of support systems, individuals were generally influenced by their partner and family. Most responses had concerns that their partner was being negatively affected by their snoring and apnoea; SR45 sought a diagnosis when their "husband stopped sleeping in the same bed". SR14's "husband started waking [them] because [they were] not breathing. SR33 "Went on holiday with [their] sister and she noticed [that they] stopped breathing during sleep".

People without the support of a partner, reported health professionals witnessing or suspecting sleep apnoea; during a hospital admission SR31 was told they "snored loudly and stopped breathing many times. [they were] advised to speak to [their] doctor". SR68 experienced similar where they were "in the hospital for surgery and the nurses witnessed the apnoea." Some patients did not have any key milestones or events that made them seek diagnosis, experiencing the symptoms of OSA without realising it. SR47 only realised that they had symptoms of OSA when it was explained to them – they realised they had experienced this for "their whole life".

4.2.2 Prescription process

The experience of the diagnosis process varies with location, facility, insurance policy, and public funding availability. This study predominantly focusses on the New Zealand system, where public District Health Boards (DHB) fund CPAP equipment for people with OSA. Figure 19 shows a generic prescription process from the point of view of a new user.

Notice that there is an issue ·········· Partner witnessed snoring / apnea ·········· Physical symptoms of OSA ·········· Can refuse to take an overnight sleep study

Seek professional advice ·········· Doctor or nurse recommended a sleep study ·········· Referred to a sleep specialist ·········· X Discomfort taking a home monitoring sleep study

Referred for a home monitoring study ·········· Complete home monitoring sleep study ·········· Witnessed apnea ··········

Follow up with specialist ·········· Discuss results from home monitoring study ·········· Referred for an overnight sleep study ·········· May refuse to take the sleep study

Results and diagnosis ·········· OSA diagnosis ·········· Drivers license restriction depending on OSA severity ·········· May refuse to use the therapy

Discuss treatment options ·········· Prescribed with CPAP therapy ·········· Demonstration and Establish goals ·········· X Can have difficulty purchasing the equipment (Public or private system)

Receive equipment ·········· Wait for the equipment to be delivered ·········· Receive it at home

Figure 19 Prescription process for OSA

District Health Boards in New Zealand supply people with CPAP equipment through the public health system and the Accident Compensation Corporation (ACC). Some DHBs do not provide the equipment for free and patients must pay for this themselves (by insurer, or out of pocket) through a private clinic. Once referred, the clinic helps people with issues that they have with their sleep, such as snoring or disturbances (SP1). They are then tested with a sleep study and the diagnosis leads to the prescription of the CPAP device (and mask if it is necessary). If there is a suspicion of severe sleep apnoea, clinicians are required by law to inform the transport agency who may impose driving restrictions, applied until the patient uses the therapy (SP1). However, the DHB system delivery in information varies from varies from a private clinic.

After the results are analysed, patients have a follow up appointment with doctors who examine the test results and discuss ways to deal with the problem areas. These can be noise, tiredness and associated health risks. They establish the goals the patient would like to achieve and ship the equipment to them. The point of delivery is another point that can be difficult for users to accept the therapy; it is important to carefully control the information that they are given.

The common association of OSA with obesity, has resulted in mask designs that do not cater for smaller builds (or for non-weight-related causes of OSA). Participant 6 was referred by ACC to a clinic in another city, despite a clinic being available in their own city. The participant reported that they were "continuously given masks that were far too big because they hadn't had a face to face consultation" (Figure 19).

Due to the lack of direct patient to clinician contact, this same participant characterised the process as being a difficult one; they never met the specialist, never had a fitting and only communicated by email. As a result, they "went through many masks trying to find one that didn't leak".

The participant stated that the clinic kept trying with different masks, without directly addressing the issue that they did not fit the standard mask, or head gear. After a year the participant contacted a Wellington based clinician and was fitted with a juvenile mask. M2 states that giving the user choice to what mask they would like, makes the process much less intimidating, rather than being prescribed one. By providing a sense of choice, it makes the process less daunting. Participants in the support group stated that finding the right mask is a process, and you are generally not fitted with the right mask straight away. Without the education that this is generally the case, people can be disheartened by not having the correct mask the first time.

Figure 20 P6 - Masks trialled to get the right fit in the early stages of therapy

4.3
EDUCATION AND SUPPORT

Education has an important role in long-term engagement, where Van Zeller et al. states that informed patients tend to be more motivated with CPAP therapy use (2013 p.2050). There is a need for education that addresses different mediums so the information delivered is manageable, and consistent. It is important to minimise the impact of what new users actually need to know to manage their therapy effectively and with confidence.

4.3.1 Delivery of information

Because many parties are involved in the delivery of information, lines can be crossed with patients feeling misinformed. M1 states that "because time is so important for the therapists and doctors and DME's, the more time that they are spending with a patient to set them up and get going, that's something that turns into a higher cost." Because there is an urge to get people through the system quickly, critical information can be missed. In addition, the patients may be overloaded with information or misunderstand what is provided.

Across all respondents there is a clear pattern of inconsistency in information provided to or understood by them. There are inconsistencies around the amount of information provided to or understood by them. Participant 1 found that there was not enough information given to them from the professionals. P3 didn't know what CPAP was before starting treatment. P6 felt like there was an overwhelming amount of information given to them and were told by their clinician only "read a certain part of the instructions, and not to read the whole book because it is too complicated" and P2 read the user guide systematically.

Figure 21 (above) How a support group member received their equipment
Figure 22 (below) CP6's collection of masks and packaging over 2 years

SP1 expresses that "there are very few places that talk about the positives [of CPAP therapy] in lay language…instead using medical language that straight always alienates a component of your readership". By using medical terms, the therapy can seem overly complicated to the user, which can be overwhelming. SP1 generally simplifies it to a "fan in a box" to their patients. P6 stated that they only read the first page of the instruction manual when they received their equipment, solely because of all of the information they were given "was too much".

After the consultation with the specialists and people revive the equipment it depends on the mind-set of the person at the time, whether the information that has delivered to them by their clinician has been taken on board. When people receive the equipment, the information available directly to them in the user instructions in the mask and CPAP packaging. The information can be missed if the user finds this intimidating or if it is not in lay language, or they miss it completely.

Table 6: Survey Results from how helpful people felt the information in the packaging was before starting therapy

How helpful was the information in the packaging of your CPAP equipment in regards to...						
	Not helpful at all	Not so helpful	Somewhat helpful	Very helpful	Extremely Helpful	Total
Fitting your mask	9	7	37	19	3	75
Disassembling and assembling your mask	5	9	29	26	5	74
Assembling the mask, hose and machine	2	8	33	25	6	74
Cleaning instructions for your equipment	9	17	26	16	6	74
Where to store your equipment	15	20	25	10	4	74
Support groups	35	17	7	8	6	73
How to troubleshoot any issues	13	20	28	3	9	73
What to expect in your first week	31	18	17	6	2	74

4.3.2 Who is responsible?

Table 6 shows results from the survey (SR1-77) demonstrating the responses about how helpful the information on the packaging was. The main aspects of the packaging that were stated as not helpful at all are support group, and what to expect in the first week of therapy.

Manufacturer

The inconsistency of information from clinicians can be either not enough, or too much to take on board and become overwhelming. This can overwhelm the user when they receive the equipment for the first time.

Clinician

The support begins with health professionals where as part of the service they should provide the user with sufficient information regarding what to expect, therapy management and assistance in troubleshooting issues.

The Ministry of Health, New Zealand (2004) states that at a district and regional level it is essential to have clearly identified support staff (respiratory nurse or physiotherapist or physiology technician) trained in mask fitting, machine maintenance etc. These personnel are crucial to achieving patient confidence and compliance. Clinician support varies in the delivery and the experience through the practise can significantly influence people's engagement.

Table 7: Survey Results from the delivery of information from health professionals before starting therapy

How well was the following information delivered to you by a health professional before starting the therapy?						
	Very poor	Poor	Average	Good	Very Good	Total
What to expect on your first night	13	8	24	20	13	77
Where to put your CPAP machine	13	15	14	20	16	77
How to fit your mask	8	6	25	18	21	77
How to identify a leak	16	16	19	18	2	77
How often you should clean your equipment	12	11	13	23	18	76
What to clean your equipment with	18	7	21	16	16	77

Table 7 shows results from the survey (SR1-77) responses that show how people viewed the delivery of information from their health professional before starting the therapy. As stated in the support section, support from medical professionals is an important factor in the experience of the first weeks use and they have expect, how to identify and troubleshoot any issues, and therapy management.

This means that there is a wide variation in the delivery of information to CPAP users. Respondents found that their clinician provided better support fitting the mask were only 10% stated that the information was below average, in contrast to what to clean the responsibility of talking new users through the process, and provide them with information about what to you equipment with where 23.4% stated that the information about how to identify a leak was "very poor".

4.3.3 Ability to troubleshoot Issues

The accessibility of information is important for users to understand how to independently troubleshoot any issues that they may have in their first week of therapy. This all comes down to education, and the accessibility of information to the user from health professionals and manufacturers. There is a necessity for consistency with the delivery of this information as M1 states that they have "no input on the information given to the user, other than what is in the user manual". Clinicians, depending on the practise, often talk through common issues that rise. M1 states that "Clinicians often provide their own information to the patients, so there is a variety of information that is being delivered that is not always consistent". SP1's practise tells their patients not to use the mask fitting guides as they are "so complicated". By simplifying it the person becomes comfortable with it and they know that comfort is the most important thing.

4.3.4 Support groups

P6 believes that the reason for thier activity in support groups is because there is a need for clarification for any issues that they have. Addtionally they can see other members share experiences of how they may individually manage their therapy. The issue is, new users feel that they are failing if they go back to their clinician with simple or small problem. This may be a result of the clinician-patient relationship that is common in healthcare. Support groups are the opposite of that as there would be more empathic responses but the risk of seeking advice on these forums is unverified or incorrect information being provided

4.3.5 User personality types

Personality differences can influence the effectiveness of clinician and manufacturer information. Some users may want to be taken through the system with a technician (M1) to ask, one-on-one, questions to address their issues. Participant 2 "read through the user guide systematically" to understand each component of their therapy and how to manage it, and felt that the information given by their clinician was good, as they asked many questions, in contrast to Participant 1 who stated that the information they were given by the specialist was "pretty minimal" and they believe that they do not use the therapy effectively.

Other people "may want to go home and learn slowly through something like an education package (M1). P6 felt that "having clear understanding of "this is my mask" and "this is how it works" is important as questions can rise further down the track and people may be unsure. Sometimes, having more information later, is better, rather than having too much too soon.

4.4
WHAT TO EXPECT

Expectations are a reflection for users when they begin the therapy. All users need to understand the process. There are different aspects that need to be addressed such as the time element, the apparatus in the bedroom, and the fact that CPAP therapy is not an overnight cure, it is an ongoing iterative process that needs adjusting.

"Take a leave of absence from life for a month. No work, no kids, no nothing. CPAP does work. But the transition is savage. It's really hard. But it works. Be prepared for many early failures. And that is OK" SR30

4.4.1 The time element

There is an element of time required to adjust to the therapy, it is an iterative process to get everything right. SP1 states that "people that think that it will work in a single night are doomed to failure". Adopting CPAP therapy is a lifestyle change so providing the appropriate therapy for individuals is a process that involves trial and error. If people understand the process, it helps them to get started knowing that it does not need to right all at once.

SP1 states that when people receive the equipment without the understanding of the process then panic will set in because they have the preconception that it will work in a single night (SP1). For some users, they get it right the first time, but this is generally not the case. SP1 emphasises that a mistake that a lot of clinics make is to present the treatment as a 'this is going to work tonight and if it hasn't, you haven't tried hard enough, that leads low adoption rates'.

P6 experienced the trial and error of the first year using the CPAP without any notice that this was going to happen. This created a strain on the relationship with P6's husband "that is probably why I despise it".

P6 dealt with a clinician that had a "give this a go and see that happens" approach that did not help with their confidence with the therapy where they made a lot of phone calls asking "is it supposed to do this...is it supposed to do that". In other instances people may not have the motivation to call the clinic if they are having any issues or doubts.

Survey responses reiterate the importance of being informed of the process and that it does take time. When asked what they would give to a new user, the responses were to persevere, and take time to adjust to the therapy, and get the right mask.

4.4.2 The first night

SP1 states the one enemy for a clinician is the patient "freaking out". They encourage their patients to interact and play with the mask, take it off and put it on, take the hose off and put it back on, talk and laigh with it, watch television or read with it on. This encourages the user to do everything that they might do during the evening or during sleep, to reduce the chance of them panicking out during the night.

4.4.3 The Initial experience

The initial experience can be physically and emotionally draining for new users. There tends to be a negative perception of CPAP therapy because of the intrusive nature of the masks. Some people are more effected by intolerance to the air pressure, or they do not trust that the masks are made to be worn quite loose, instead they wear them like a diving mask (M1). SP1 states that the biggest problem is people adjusting to the air pressure. People are used to breathing in atmospheric pressure so when the therapy is introduced, the assistance in the inhalation and resistance in the exhalation brings discomfort as it is not natural.

When asked to reflect on their first night experience, survey respondents reiterated the importance of information and realistic expectations when starting the therapy. All of the following respondents currently use CPAP therapy and have persevered through these experiences with variations.

Some people adopt the therapy straight away and do not have any issues with adjusting to the therapy.. Some people experience drastic change in how they feel, because they had continually experienced poor sleep. SR46 states that in "the first night only got 2 or so hours before ripping the head piece off. But for some strange reason I was smiling stupidly the next day while driving". In contrast to CP1's first experience with they felt "A little claustrophobic". SP15 kept "having panic attacks. [They] had to take mask off frequently and try to calm [themselves]".

Unbox the equipment

Packaged separately Find a place for it to go .... Assemble the full system .... Could have issues, postponing the first night

Prepare for the first nights use

Evening routine to get ready for bed .... Fit the mask and turn on the machine .... Try to tolerate the air pressure and fall asleep

First nights use

First experience using CPAP in the home .... Did they use the bathroom during the night? .... May not tolerate air pressure, or take the mask off during sleep

Feedback during the day

Reflect on their sleep in the morning .... Did their symptoms reduce? .... Discomfort is not worth the reward

Follow up call with specialist

Troubleshoot any issues .... Talk about what to expect .... Lack of support if clinic does not call

Prepare for the second night

Troubleshoot any issues .... Evening routine to get ready for bed .... Fit the mask and turn on the machine

Figure 23 User journey showing the intial experience

Some respondents experienced no noticeable change, where SR42 stated that they "didn't notice anything initially.... This can be due to not having the right mask, or correct pressure where SR26 I didn't feel an immediate change. They found that "Finding a mask that worked for me took a very long time".

Some experiences were positive, where they experienced a reduction in their symptoms. SR73 felt "Tired, normal person tired. This was a huge improvement over the usual zombie tired." SR40 stated that it took a cloud off [their] tired brain. SR27 expressed that they felt "As strong as a Bull - When I woke up the first time couldn't believe how fantastic I felt".

In contrast to the previous experiences did not counter for devastation. SR28 states that they felt devastated when the next day they didn't feel any better. They thought it would be a miracle cure on the first go. They were concerned about the impact that their OSA had on their marriage such as the closeness to their partner, and their sex life. Because the therapy did not work instantly they thought their husband would leave them.

4.5
APPARATUS IN THE BEDROOM

The association of stigma and CPAP therapy is both product related and social due to the medical aesthetic and the intrusive nature of the equipment. People cannot control the social stigma related to their condition. However, they can control whether they accept or reject the product related stigma associated with the therapy.

4.5.1 Product Related Stigma

Product Appraisal model for stigma reveals the factors that contribute to the product related stigma process. This model aims to reduce product related stigma within new concepts surrounding assistive, protective and medical product design as these products carry with them a long history of rejection, while others become stigma sensitive when they are used out of their intended context, for example hospital equipment in the home environment or bedroom.

The association of stigma and CPAP therapy is both product related and social due to the medical aesthetic and the intrusive nature of the equipment. People cannot control the social stigma related to their condition. However, they can control whether they accept or reject the product related stigma associated with the therapy.

Not every user is influenced by stigma, however it is a factor that influences the way people celebrate, or hide their therapy. Some people pack their mask and machine away every day because they do not want it to be seen if they have visitors (M1). The design activity "write a list of house rules" gave insight to this as CP1 stated that the CPAP must "Hide when somebody else comes". During the interview the same participant stated that "if the cleaner comes I usually put the mask away as it doesn't particularly look that attractive, but I'd keep the machine in place". CP4 ruled the CPAP equipment to "Keep out of the way ESPECIALLY if I manage to find somebody who wants to join me despite me being so unattractive with my mask and hose" (Figure 25).

When Participant 6 received their equipment for the first time they were not willing to showcase it to their family. They "took it away to the bedroom to try it because [they] didn't want people to see it". The same participant puts "the machine down the side of the bed, because [they] hate it, if it is not in the way then [they] don't care for it. [They] try to minimise displaying it as much as [they] can" As opposed to embracing it (Figure 24). All user testing participants had a similar outlook and stated that said they would store it on the floor beside their beds or underneath, because they would "want" to hide it (TP2) or they did not have the right furniture to store it with (TP3).

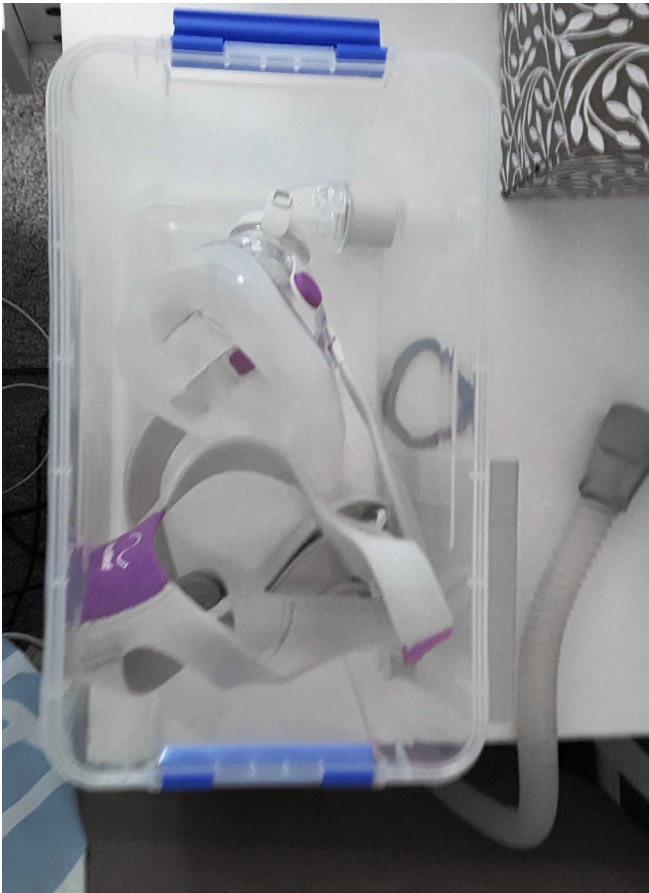Figure 24 CP5 - CPAP and mask location
Figure 25 CP5 - CPAP and mask location

Figure 26 CP6 Mask location

#3 A head strap makes the equipment more effective. keeps jaw closed

Figure 27 CP1 Chin strap

4.5.2 Social Stigma

The social psychology of stigma is something that is attributed to one person within a specific social context (Vaes 2014). People can attribute multiple meanings to a product whether it is through their perception, impression, intended use of the product, context and environment, or social normality, it is important for the meaning of the product to be limited to the context it is meant for, to reduce stigma. M1 states that "there is a negative perception of having to wear a mask because it is always associated with something being wrong with them or they're sick or they need support, so there is automatically this stigma about it". On their first impression TP1 stated that "I know it is a medical device, but it seems like a lot to take in. I can understand why there is a lot of stigma around it".

4.5.3 The mask

Issues with the mask is a reoccurring theme across all methods of data collection, where the factors are related to stigma, comfort, and discomfort, where Participant 1 states "even though I get a better sleep, there is still a sense of being encumbered" the same participant uses a nasal mask and a head strap to keep their jaw closed (Figure 27). CP5 has the desire to have a smaller mask because "it feels too big" (Figure 26). This is similar to P2's outlook where in their first week of therapy they stated that "Having a less intrusive mask would be the only thing that I would change…I still wake and rip it off my face". As a house rule CP5 stated that the CPAP equipment must "Make my treatment as comfortable and as unobtrusive as possible".

4.5.4 Partner Acceptance

SP1 states that patient acceptance can be highly influenced by their partner's SP1 states that patient acceptance can be highly influenced by their partner's acceptance the impact of how the therapy equipment impacts the partner is influential to patient acceptance. Often noise from the machine, and mask can cause discomfort for the bed partner. Initially partners are used to waking to their partner having an apnoea, but when the apparatus of machine that makes unfamiliar noises comes into the bedroom it is hard to know what is ok and what is not. P6 expressed that there is nothing that prepared them for the sound of the mask and machine…" The same participant's partner says the therapy is "…like sleeping next to a partially open dive tank…" SP1 states that If the partner doesn't like [the therapy], the chances of the person continuing with long term therapy drop enormously. If the partner is accepting, the change of the person adopting the therapy increases enormously". M1 reiterates the fact that "the first few nights of good sleep and good therapy make all of the difference with support from their family and partner".

4.5.5 Self consiousness

One of the factors for the person using the therapy is self-consciousness, but that is not the main concern for the partner. SP1 states that patients are prescribed with an 'ugly' mask that is really silent, partners will like it, but the patient will may not. If you have got a really cosmetic looking mask, that is really attractive, but that makes more noise, patients love it because it makes them less self-conscious, but the partners hate it because you have introduced a constant noise when the lights are out." This is also the case with user's children, as they have little education about the condition. Where P3's perception of the therapy changed when "My son said that I looked like a fighter pilot…I switched it around in my head and just thought about it as that".

Participant 6 stated that the look of the machine, and how it works and all those problems, are all outweighed by the desire to sleep.

Figure 28 SGM Mask location   Figure 29 SGM hangs their mask on their bed frame

Figure 30 SGM CPAP machine location

Figure 31 CP1 CPAP machine location

4.5.6 Placement of the machine

Even though manufacturers and sleep physiologists do recommend to have the CPAP on the floor, or below head height, the primary location of the CPAP is on the bedside (Figure 30 & 31). SP1 states that the most important reason is because there is real value in having the hose inside of the bed with the patient. If it is in their personal space they are more inclined to move it more instinctively, like moving a sheet. If it is hooked up behind their pillows or above the headboard or on a bedside hook unit, the likeliness of the mask being pulled away from the face when they move is much greater.

Figure 32 CP4- CPAP location on the bedside

Figure 33 SGM Mask holder and CPAP machine location   Figure 34 SGM coils their mask around their bedframe
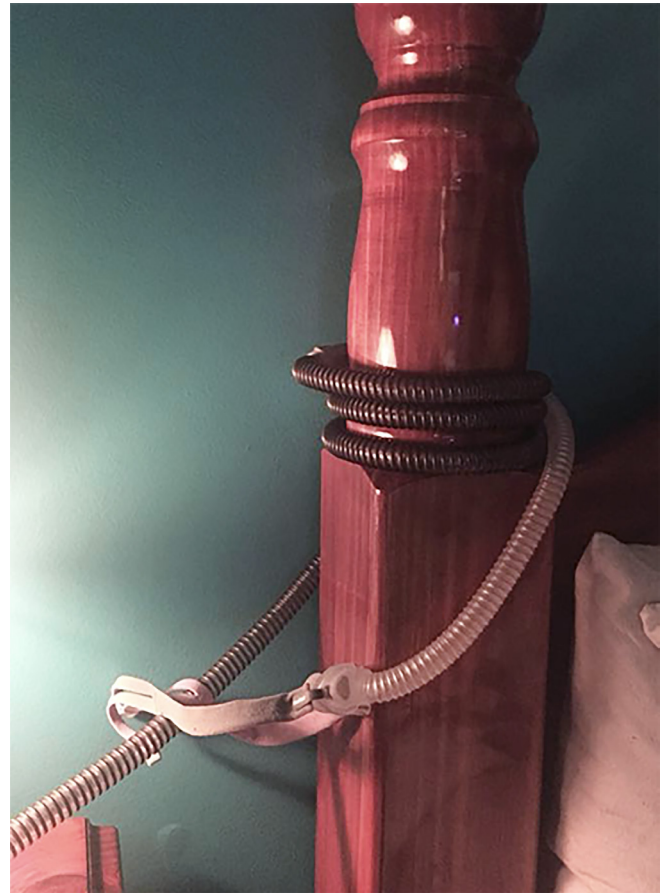
4.5.7 Overcoming Stigma

Some people on the online support groups have gone through efforts to reduce the impact of their CPAP apparatus in their own bedroom. P6 sates that "there is nothing about the therapy that states that it is for wellness, it is just medical. It is a piece of medical equipment". The efforts to customise, and reduce the stigma are shown in Figure 35, 36 , 37 and 38. These show a personal expression and customisation of their equipment.

Figure 35 SGM customised their CPAP device using stickers

Figure 36 SGM uses a scarf to cover the hose to reduce condensation   Figure 37 SGM made a fabric hose cover

Figure 38 SGM - CPAP and mask location with a hose cover

4.6
FEEDBACK

4.6.1 Feedback in the first week

There are differences in how people receive feedback from their equipment. M1 states that "We are getting better now with the introduction of mobile applications that monitor the therapy and start to give this feedback". This, however is only for a certain type of machine that the manufacturer produces where some of the older versions of the CPAP machines do not have the ability to show the necessary feedback.

Some machines have applications connected to them that provide immediate feedback from thenights sleep, and others fully rely on the statistics sent to the clinician via the machine, that the user is unable to see unless they get a report. Before the development of the mobile applicaions people used the therapy intuitively, relying on feedback from their therapist at followed up appointments.

Figure 39 shows the identified changes in their sleep during the first week of therapy from answers to a multiple choice question, where the responses mainly found the reduction of apnoea symptoms to be the main aspect that they noticed.

Identified changes in sleep during the first week of CPAP therapy (SR1-SR77)

Had a better sleep	16.1%
Had more energy	14%
Used the bathroom less during the night	12.8%
Woke less during the night	10.7%
Napped less during the day	10.3%
Used an application that tracks their sleep	8%
Partner noticed that they woke less	8%
Did not have any morning headaches	7.5%
Did not notice anything different	4.7%
Sleep was worse and woke more than before	3.9%
No more noticeable snoring	3.9%

4.6.2 Feedback from reports

Participant 1, 3 and 6 are essentially using the "therapy blind" due to their CPAP machine's inability to connect to these applications. The only feedback that they receive is either through how they feel, or from monthly reports from their clinician. P6 states that it is "hard without visual data to know initially if it is making any difference" the data does not get updated until mid-day. They only see how they did the previous night if they remember to check. They have an idea of how they felt, but getting the data confirms that they had a good night, and you can then take it on board. Because the only way to get a full report is to go through the clinic P6 felt that their statistics and results "belong" to the clinician. It is their machine, and they are managing it. So the data is not stored. It is only available from mid-day until they next use the machine. So trends are not provided and there is no information that they can respond to.

Figure 39 Graph from survey results showing noticeable changes in sleep during the first week of therapy

4.7
MOTIVATION TO USE THE THERAPY

The following section is a visual display of what motivates survey respondents to use their CPAP therapy (SR 1-77). These responses are coded to 'Physical Factors', 'Psychological factors', 'Health Belief' and 'Other'.

Other factors that motivate people to engage with therapy

Specialist scared them into engagement — 4.75%

Not disturbing their family — 4.75%

Parent influence — 9.5%

Intrinsic
14.25%

Want to perform well at work — 19.1%

Partner getting a better sleep — 38.1%

Responsibility to care for child/grandchild — 19.1%

Extrinsic
85.75%

Insurance — 4.75%
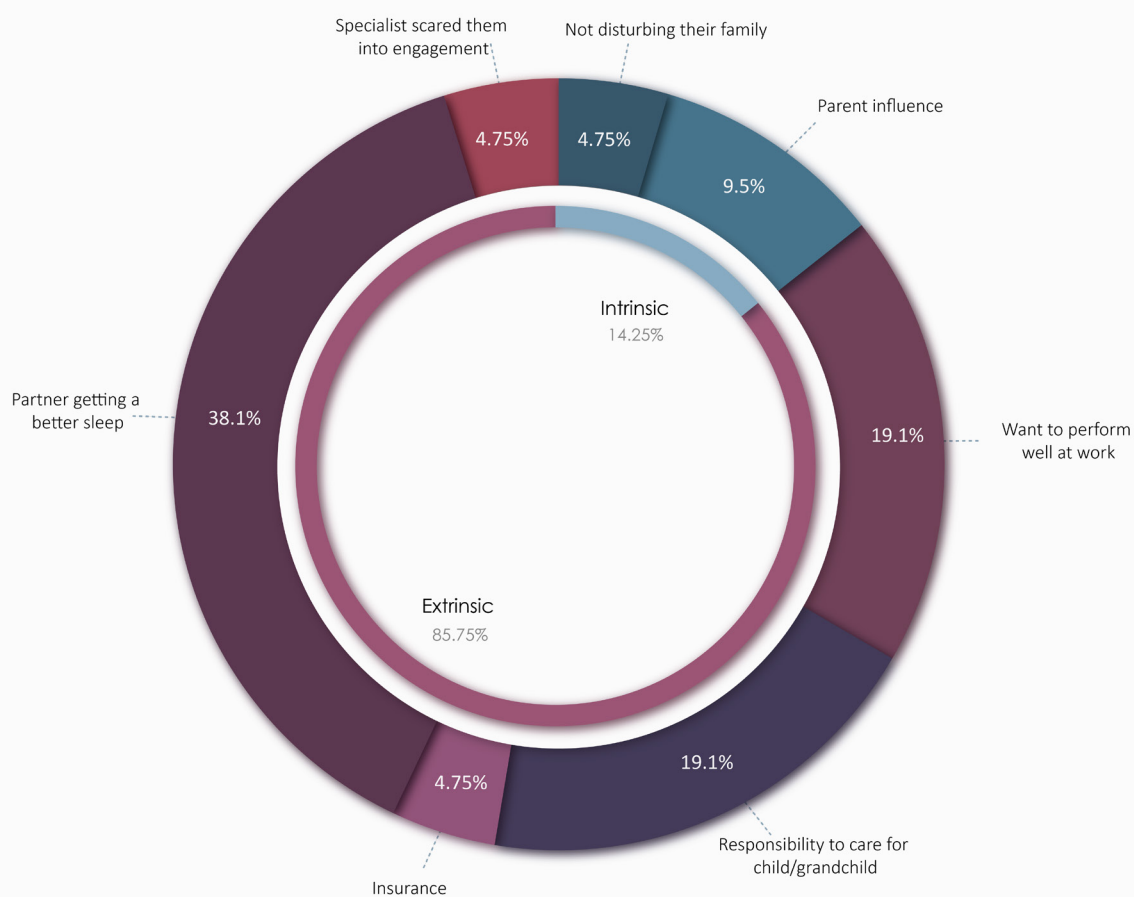
Figure 40: Graph showing other factors that motivate survey respondents to engage with CPAP therapy

4.7.1 Physical Factors

Figure 41 shows the ongoing physical factors that motivate survey respondents to engage with the therapy. The physical and cognitive feedback is a factor in long term engagement. These factors are driven by intrinsic and extrinsic motivation.

"Dear CPAP...you give me the gift of energy, and a restful night, you help me stay warm in the winter because I can stay submerged under the sheets" (CP1)

"I can't sleep without waking in 20 mins gasping for air with my heart pounding. It is now as automatic as putting on my P.J's." (SR15)

"CPAP therapy has changed the way I feel about: everything because I'm not so tired anymore and because of that I'm not so overwhelmed by even the smallest of things" (P3)

Physical factors that motivate people to engage with therapy

Feedback from data each day — 1.6%
Threat to drivers license — 4.7%
Non-disrupted sleep — 12.5%
Desire to have a better sleep — 17.2%
Do not want to feel constant tiredness, fatigue and exhaustion — 17.2%
Feel better with it — 15.6%
More productive, concentrated, better memory — 3.1%
Have more energy — 7.8%
Feel rested and wake up refreshed — 14%
Get through the day without having a nap — 3.1%
Less toilet trips during the night — 1.6%
Headaches if it is not used — 1.6%

Extrinsic 48.7%
Intrinsic 51.3%

Figure 41: Graph showing physical factors that motivate survey respondents to engage with CPAP therapy

4.7.2 Psychological factors

Motivation driven by psychological influences such as fear and desire tend to be more emotion based responses. SR64 stated that after using CPAP for less than 6 months it gives them "the will to live". This is a psychological attachment where they are emotionally dependent on their therapy as they suffered from 150 Apnoea events per 6 hours.

> SR39 "I can't cope with life if I don't. One night is ok....more than that, I am so tired and exhausted I can barely get through the day."

Psychological factors that motivate people to engage with therapy

Fear of snoring or choking during sleep

Improvement with treatment resistant depressions / anxiety

Hope for improvement weight management

Fear of dying in their sleep

Want to be able to drive safely

Cannot 'cope' without it

Mental clarity/feel better emotionally — 14.6%

"I want to live longer" 'It gives me the will to live" "I don't want to die" — 19.5%

Want to feel normal — 4.9%

Tolerate stress better, 'less grumpy', maintaining a positive attitude — 7.3%

4.9%

7.3%

4.9%

4.9%
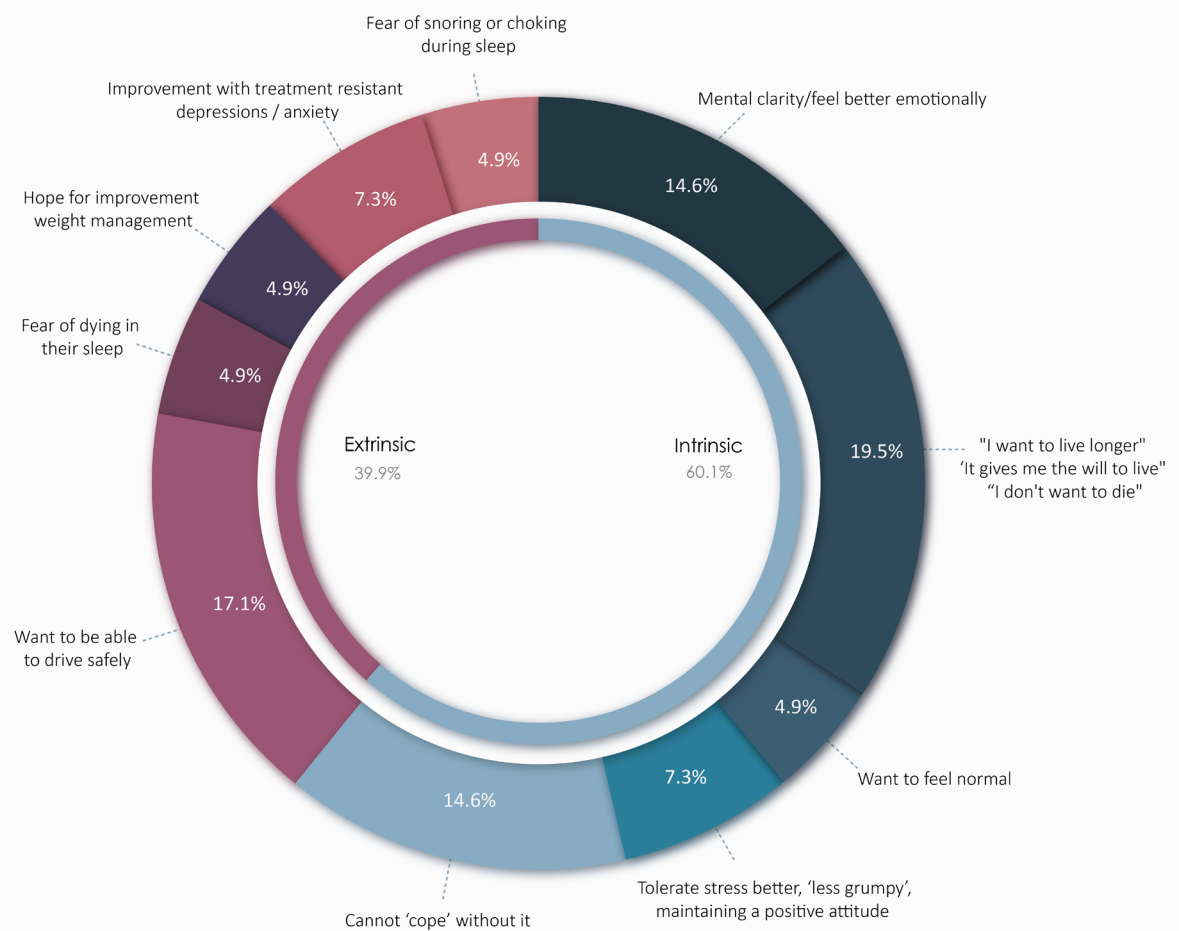
17.1%

14.6%

Extrinsic
39.9%

Intrinsic
60.1%

Figure 42 Graph showing psychological factors that motivate survey respondents to engage with CPAP therapy

4.7.3 Health Belief

Motivation to engage with CPAP can be influenced by the 'Health Belief M'odel where participant's motivation is due to their health and wellbeing such as preventing the decline in pre-existing health conditions. P1 in particular has not seen their clinician in over 4 years, so the motivation that to use the therapy is solely driven by health belief, despite explaining that they "are probably not using their CPAP as much as they should" (P1).

(SR37) My specialist scared the hell out of me...said if I didn't use it I would have either or both ...stroke or heart attack or both in the next 5 years
(SR4) I don't want to have a heart attack and die.

Health Factors that motivate people to engage with therapy

Improvement in their
blood pressure

6.7%

Pre existing health conditions

10%

Extrinsic
16.7%

Desire to have a better sleep

33%

Aware of health concerns
and the risk of not using it

33%

Intrinsic
83.3%

10%

Fear of a stroke or heart attack
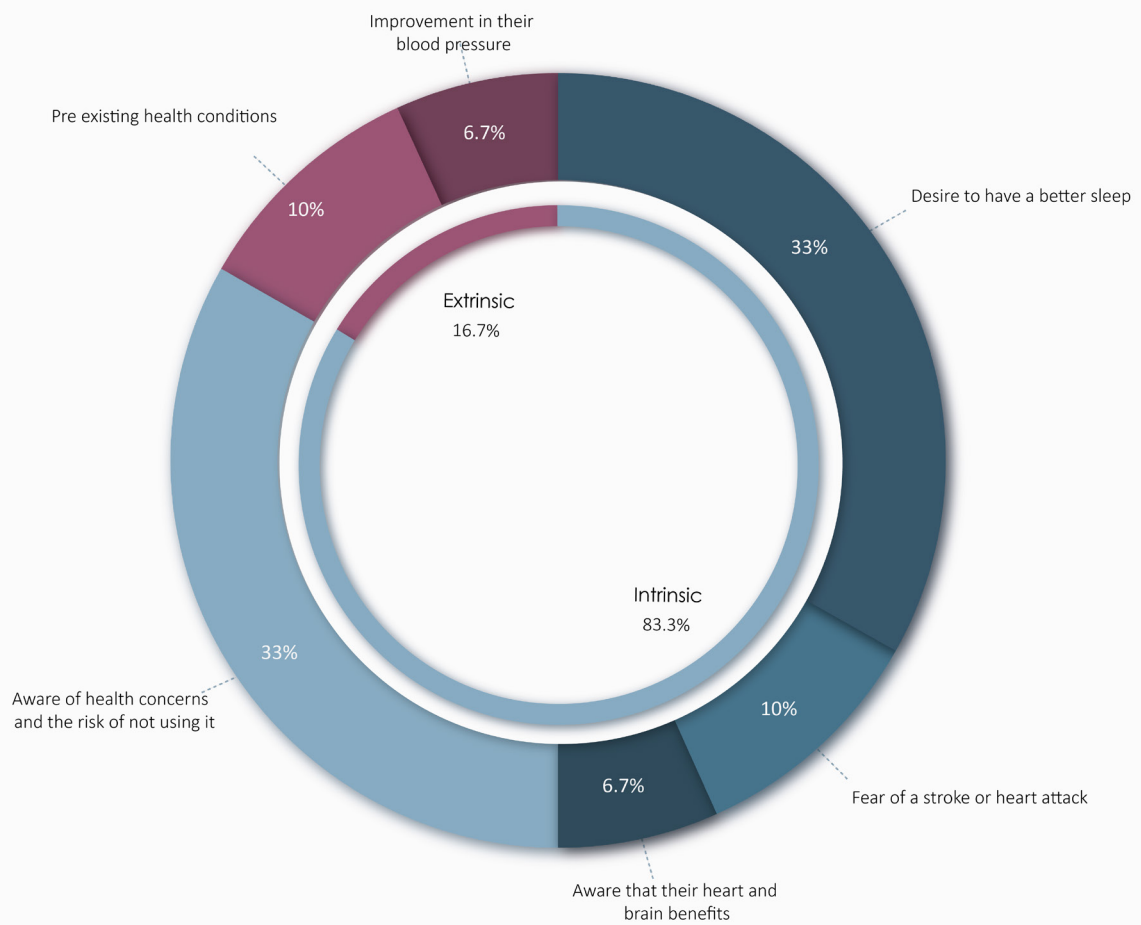
6.7%

Aware that their heart and
brain benefits

Figure 43 Graph showing Health Belief factors that motivate survey respondents to engage with
CPAP therapy

4.8
CLEANING

Cleaning equipment is a recognised ongoing maintenance aspect to CPAP therapy. The delivery of information is inconsistent due to the different parties involved. Consistent information such as how often the equipment should be cleaned and cleaning products used varies and are decisional factors that can influence the effectiveness of the therapy. During the user testing sessions, no participant looked for information about what to clean the devices with in the user manual as it was perceived as "a bit excessive". When participants were asked what they would clean the equipment with, the answers varied from "I would clean the outside [of the CPAP] with cleaning product and wipe every surface, but I wouldn't want any chemicals near my face, so I would clean [the mask] with water (TP1). TP2 states that they would clean it with boiling water, as using cold water is "probably not the cleanest way".

The information that people go to the support group for is generally in the user manual, for example there is a lot of discussion about what to clean your mask with on online support groups. M1 states that "We expect people to see it in the user instructions, but I don't really believe that people read the instructions that thoroughly…". SP1 recommends to clean the mask with what people are comfortable cleaning your face with. "You wouldn't clean your face with Dettol then don't clean your mask with it" (SP1). However, people on the online support group have recommended to clean the equipment with different combinations, such as vinegar and baking soda, white vinegar, or Dettol. P1 states that they only clean the mask with a tissue, and hang up the hose to dry, where P2 uses CPAP cleaning wipes given to them. P3 cleans their equipment with kitchen detergent, and sometimes uses baking soda and white vinegar. And one participant from the support group 'only cleaned it when they noticed black mould on the inside of the mask" (SGM).

Sometimes people justify not cleaning by saying that is does not need to be cleaned, they can't be bothered or it is too much of a task. M2 states that people might be overwhelmed with the information all at once and it is too much to take on, or there are some people that do also ignore it because it is an inconvenience to clean it. So if they think that they do not have to then it is easier. CP5 stated that they get frustrated when they clean their headgear as it is a pain trying to dry it for the next night. CP1 wrote bedroom rule 4: The equipment must "self-clean" identifying that it is a task that some users need to make time for.

SP1 advises not to wash the hose at all. "If there is condensation then by all means give it a wash and then make sure you dry it by connecting it to the machine and turning it on, blow it dry then turn it off" Figure 44, 45 and 46 show that this is not the case. There is balance between what is recommended by the health professionals, and the understanding of what real users do.

Figure 44 SGM "It's Cleaning Day!"

#6 Where I leave it to dry

Figure 45 CP1 Hanging the hose to dry   Figure 46 CP3 Hanging the hose to dry

4.9
REFLECTION

4.9.1 Findings

As stated in the earlier phases, issues with the mask and initiation of use, pressure intolerances and understanding of user needs is an area that can be addressed with the appropriate ethics and clinical trials of mask development and prototypes to suit the initial trial period for new users to get the right fit and comfort level. This is out of the scope of this research, however there is opportunity to investigate intervention based incouragement and expand the scope to how users experience the first week.

After the discussion with P6 the conclusion is that there is a necessity to make the therapy less of a tool, and more of an experience where the CPAP device and mask is only part of the therapy. There is a note to "celebrate the therapy" rather than being just being a task.

4.9.2 Similarities

Similarities in the interviews with participants and the cultural probes were due to the consistencies in which topics were discussed and questions asked. Participants that undertook the design activities were more creative with explanations in their interviews. The use of the design activities also makes them recognise and report the situation rather than the interviews that require recall. The images proved useful in explaining the context of their bedroom without intrusion.

Table 8 Themes found through methods

	Initial experience	First impressions	Self-Efficacy	Feedback	Support	Education	Troubleshooting	Stigma
Sleep Physiologist Interview	✓	✓		✓	✓	✓	✓	✓
Manufacturer Interviews		✓		✓	✓	✓	✓	✓
CPAP User Interviews	✓	✓	✓	✓	✓	✓	✓	✓
Cultural Probes	✓	✓	✓					✓
Online Survey	✓	✓	✓		✓	✓		✓
User testing	✓	✓						✓

4.9.3 Differences

User testing was relevant to understanding the perspective of a naive user, however the participants recruited do not have an OSA diagnosis, or are going through the prescription process so the data collected was not representative of a real user experience. Interviews and surveys with participants with the demographics of CPAP user CPAP users proved more valuable in understanding their experiences and impressions of the system as there is the psychological impact of the adoption of the therapy that can influence the perspective of the user.

05

DESIGN RESULTS

As stated in the previous chapter, to improve the experience of new users, the barriers need to be addressed. The identification of these barriers have developed the criteria for the design phase of this research in the upcoming sections. The following section investigates where applications of design address these barriers to encourage use through iterative design processes and exploration. A series of designs are expanded up on and reflected against the criteria and assessed through participant feedback.

5.1
THE DESIGN APPROACH

The design approach addresses the second aim of this research (outlined in Chapter 3) where methods of design prototyping are used with different mediums to enhance the scope of how the application of design can improve the experience for new users.

5.1.1 Criteria generation

After reviewing the importance of therapy management, and the focus of the user experience, the touchpoints have been generated into criteria to structure design directions and initial exploration. Initial sketches are used as part of the approach as a mind map to explore potential directions from the following criteria in Figure 47.

Criteria	The design should...	Barriers addressed
1 ——	Provide the user with adequate information about their initial experience and support them through the prescription process to prepare them for the first week of therapy	—— First Impression, Education, Feedback, Support, Social Stigma, Self-Efficacy
2 ——	Provide the user with the ability to customise aspects of their therapy equipment to suit their bedroom and personal preference	—— Product related stigma, Self-Efficacy, Partner acceptance, Support
3 ——	Provide the user with a positive first impression through interaction and the display of information	—— First Impressions, Display of Information Stigma, Education
4 ——	Provide the user immediate feedback of their nights sleep, showing their progress and accessibility to support and information about their therapy management	—— First Impressions, Education, Feedback, Support, Self-Efficacy

Figure 47 Initial criteria developed from research fingdings

Figure 48 Initial concept sketches

5.1.2 Initial Sketches and concepts

The initial concepts were devloped through a broad range, where there was no limitation with the scope of the design. This is to identify potential areas that can be addressed in the time fame, and in the ethics requirements.

Concepts are chosen on their ability to support and address the barriers that they are targeting, to insinuate that the experience can be improved with more than intervention based encouragement as stated in Chapter 2.

5.1.3 System Overview

Rather than having one final output, this research has addressed multiple areas in the user journey that can be addressed. Table 9 introduces the concepts within the overall system, the barriers targeted and the relevant design criteria associated with the concept identified.

Table 9 overview of the system

Concept	Barriers aiming to address	Design criteria
Website	First impressions Eduation Feedback Support	Provide the user with adequate information about their initial experience and support them through the prescription process to prepare them for the first week of therapy
3D Knitting	Stigma Investment	Provide the user with the ability to customise aspects of their therapy equipment to suit their bedroom and personal preference
Packaging	First impressions Education Stigma	Provide the user with a positive first impression through interaction and the display of information
Mobile application	Self efficacy Education Support Education Feedback	Provide the user with immediate feedback of their night's sleep, showing their progress and accessibility to support and information about their therapy management

5.2
WEBSITE DESIGN

5.2.1 Aim of the design

The aim of the website is to allow the user to gain access to information while they are in the prescription process. Figure 50 displays the website process flow, also showing the features that aim to make the process easier for new users.

WEBSITE

Welcome screen

Our mission

General information

Create account

Log in

Home page

Support group

Posts

What's new

Share

My Equipment

Management

Accessories

Customise

3D Knitting

Hose Covers

Headgear

My Account

My Journey

My Goals

My Statistics

Sync

Clinician

Sync clinical info

Contact

Connect

What to expect

The mask

The CPAP

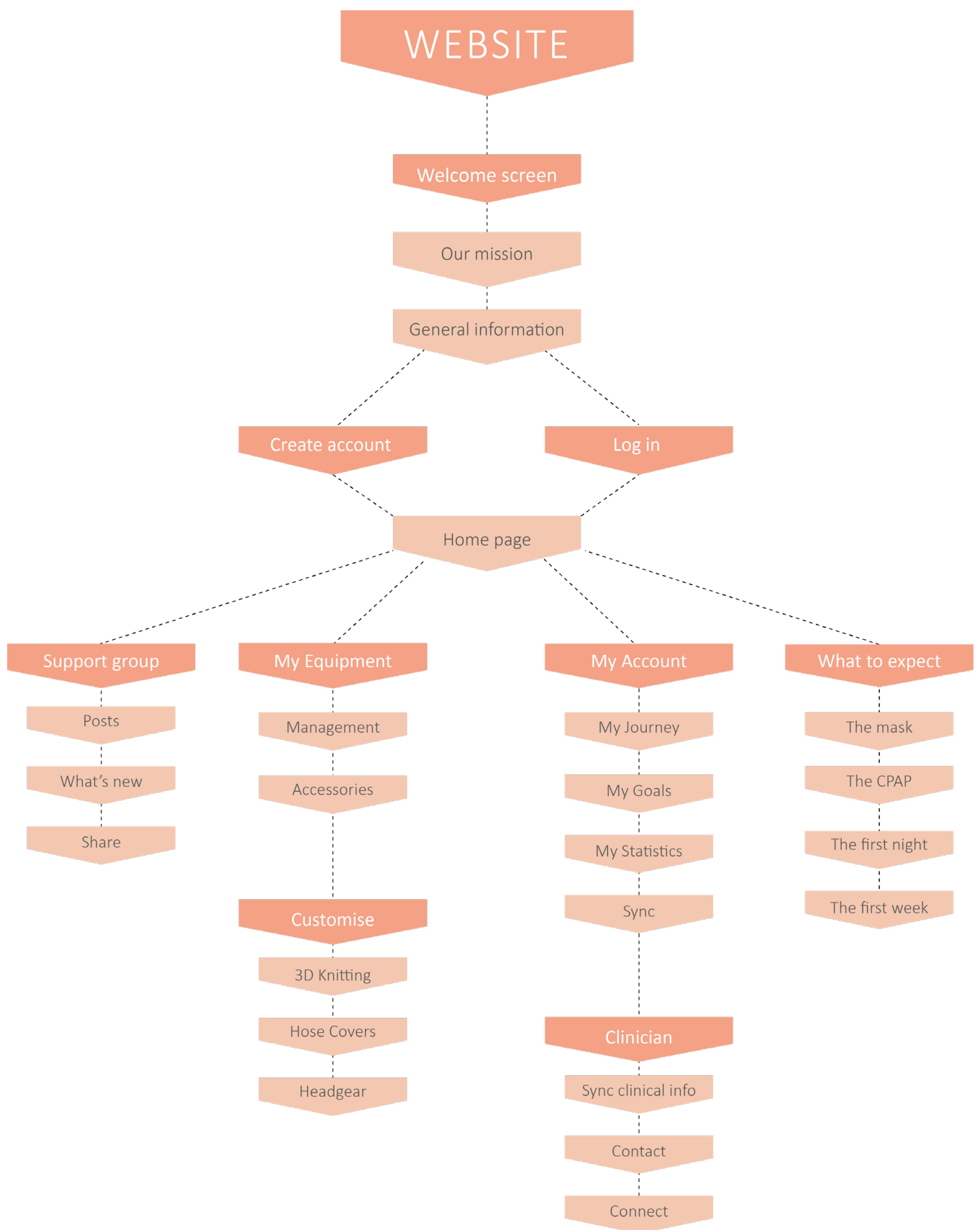The first night

The first week
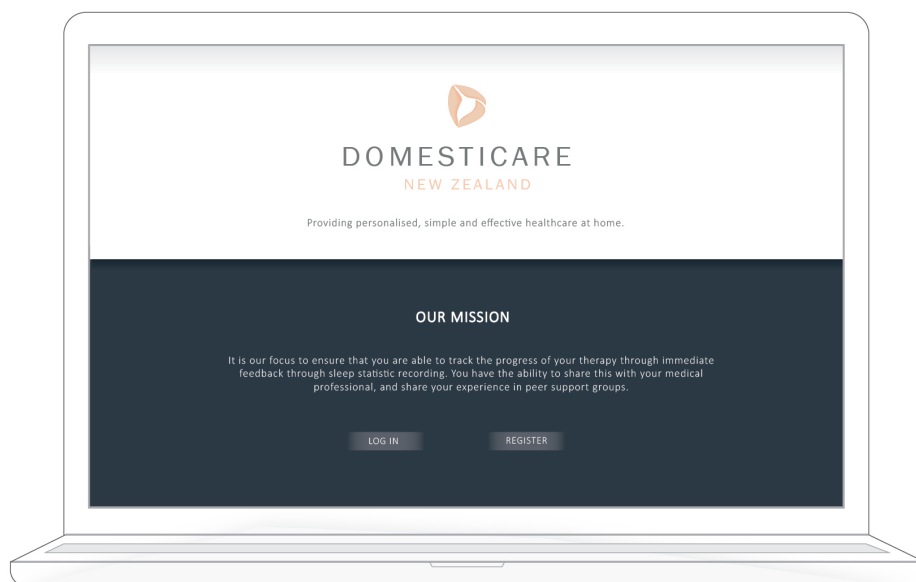
Figure 49 Website process flow

Figure 50 Website welcome screen

5.2.2 The design process

The website includes features that needed to be addressed in the early stages that were identified in chapter 4. The website acts as the first point of contact with the new user during the clinician contact. They have the ability to read information on what to expect, the process they will go through, and the ability to join verified support groups before they start treatment.

5.2.3 Reflection

The website can provide alignment with the information that people receive when they begin the prescription process. This can provide information in lay language where it is not in medical terms. It can also provide verification and a direct answer to questions that may rise in the first week. It enables users to set up appointments with their clinician. It provides education about the therapy and what to expect slow learning process a gradual input of information, with access to support group with verification from the clinicians. Customise certain aspects.

The focus of the different support groups is different, where clinicians are more interested in the factual "is it working?" rather than "how did you feel using it?" If the stats are correct then that is all that matters.

According to P6, "In the community of CPAP users it would be good to have an opportunity to share results with others". There is no connection on that level what so ever. There are things that can be shared for experience and results on the same platform, through verified support and verified answers. Clinicians can reach certain groups of people, and users can reach all. With a pool of users that can connect. This removes the misinformation that can occur. Table 10 expresses the design of the website and the aspects.

Table 10 The aspects of the website

Aspect	Description	Barriers addressed
Account	Allows the user to create a person-al account that stores their results from their therapy use and allows connection with their clinician	Self efficacy
Support group	Gives the user access to verified support gruops to seek support and share experiences	Support Education Self-efficacy
My Equipment	Allows users to add their mask and machine model access the specific information	Education Ability to Trouble-shoot issues
Sync	Allows the user to sync their results with the mobile applcation and machine for instant feedback	Feedback Self-efficacy
What to expect	Provides key information to the user in regard to what to expect in their first week before they recieve their equipment	Education Impressions Support Feedback

5.3
3D KNITTING

5.3.1 Aim of the design

3D knitting is an area that can provide customisation for therapy equipment. As seen in the previous chapter, people have made efforts to cover the hose. This is not only for aesthetics, it also serves a functional purpose as well. Having a hose cover keeps the air warm and reduces discomfort for the user. It also prevents condensation and rainout, where the moisture build up in the hose blows through into the mask. The hose covers also attempt to reduce the apparatus appearance in the bedroom as the plastic tube can be stigmatising. This also can act as a reward for users that feel more invested in their therapy, and can lead to excitement when receiving the equipment for the first time.

Figure 51 Yarns available to use for swatches

5.3.2 The design process

There are no CNC knitting facilities at Victoria University of Wellington so the Textile lab at Auckland University of Technology is used to develop the 3D knitting prototypes and develop the final form. There are limitations with the yarn colour and thickness as the yarn available for prototyping are left over from other projects, or donated.

Figure 51 shows the selection of yarn that the initial prototypes are selected from. To test the capabilities of the machine (Figure 52) patterns were developed using the software in Figure 53 to understand the capabilities of this system for customisation.
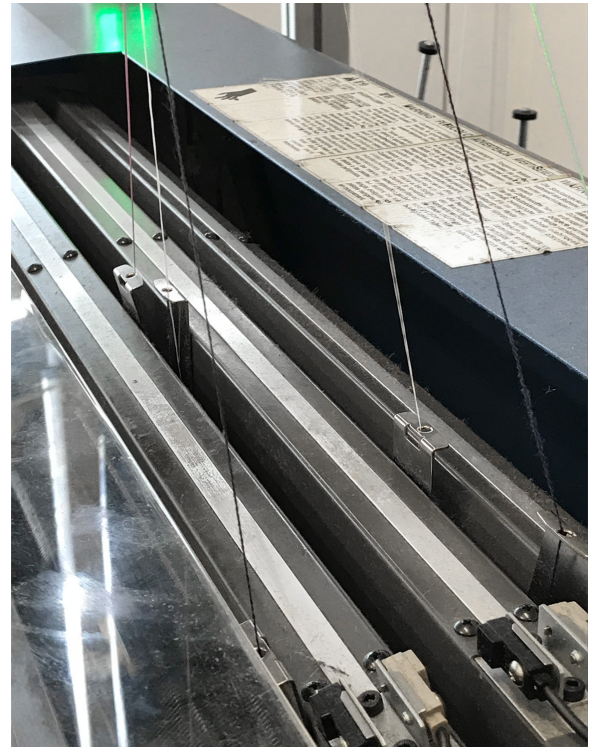
Figure 51 The CNC knitting machine
Figure 52 Range of yarn
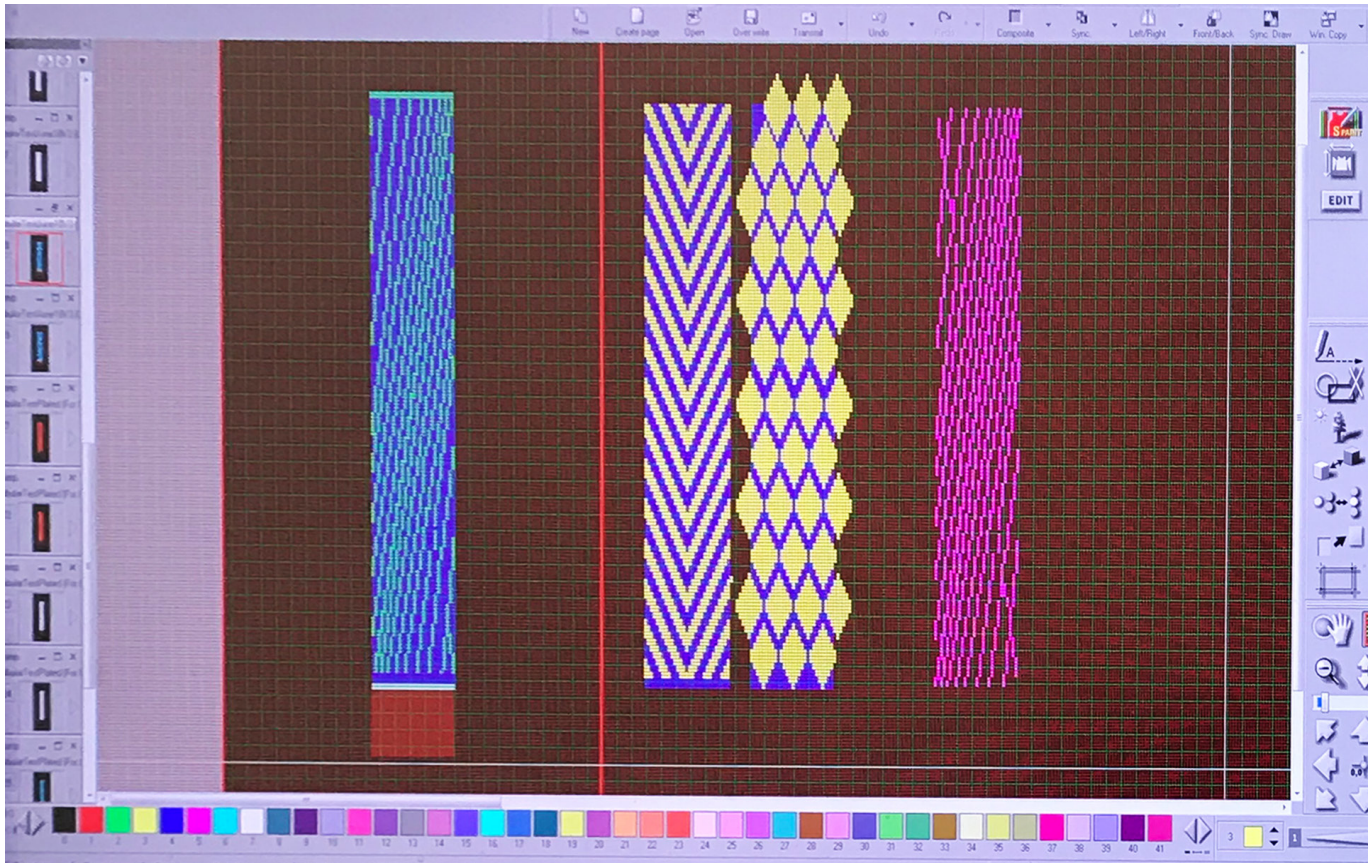
The software used to develop the 3D knitting prototypes became a precedent for
the customisation interface in the website.

Figure 53 Software used to develop patterns

Samples included 9 swatches (Figure 54) that varied in colour, thread count and pattern. These swatches are approximately 15cm each and took approximately 8 minutes to knit each.

Figure 54 CNC knitted swatches

Figure 55 Feedback session wih Participant 1

5.3.3 Participant feedback

A feedback session with Participant 1 is held to understand their impression and what their thoughts are on the samples. They are asked to order the samples from least favourite to most favourite and expand on their preferences in regard to colour, pattern, durability and texture. The aim of this is to understand where design constraints for the system can be made for future 3D knitting and customisation of the hose covers. The final selections reflected that the participant enjoyed the colour of the purple sleeve, but preferred the texture of the green sleeve on the bottom image of Figure 55.

There is responsibility to make decisions for the customising process where users do not necessarily have the option to choose the thickness of the yarn. This response has driven the development of the design interface where the colours available are the preferred thickness with specified patterns available.

CUSTOMISE

1. SELECT YOUR HOSE   2. PATTERN   **3. THREAD COLOUR**   4. PREVIEW   5. KNIT!

3. SELECT TWO THREAD COLOURS

PRIMARY COLOUR   SECONDARY COLOUR

CUSTOMISE

1. SELECT YOUR HOSE   2. PATTERN   3. THREAD COLOUR   **4. PREVIEW**   5. KNIT!
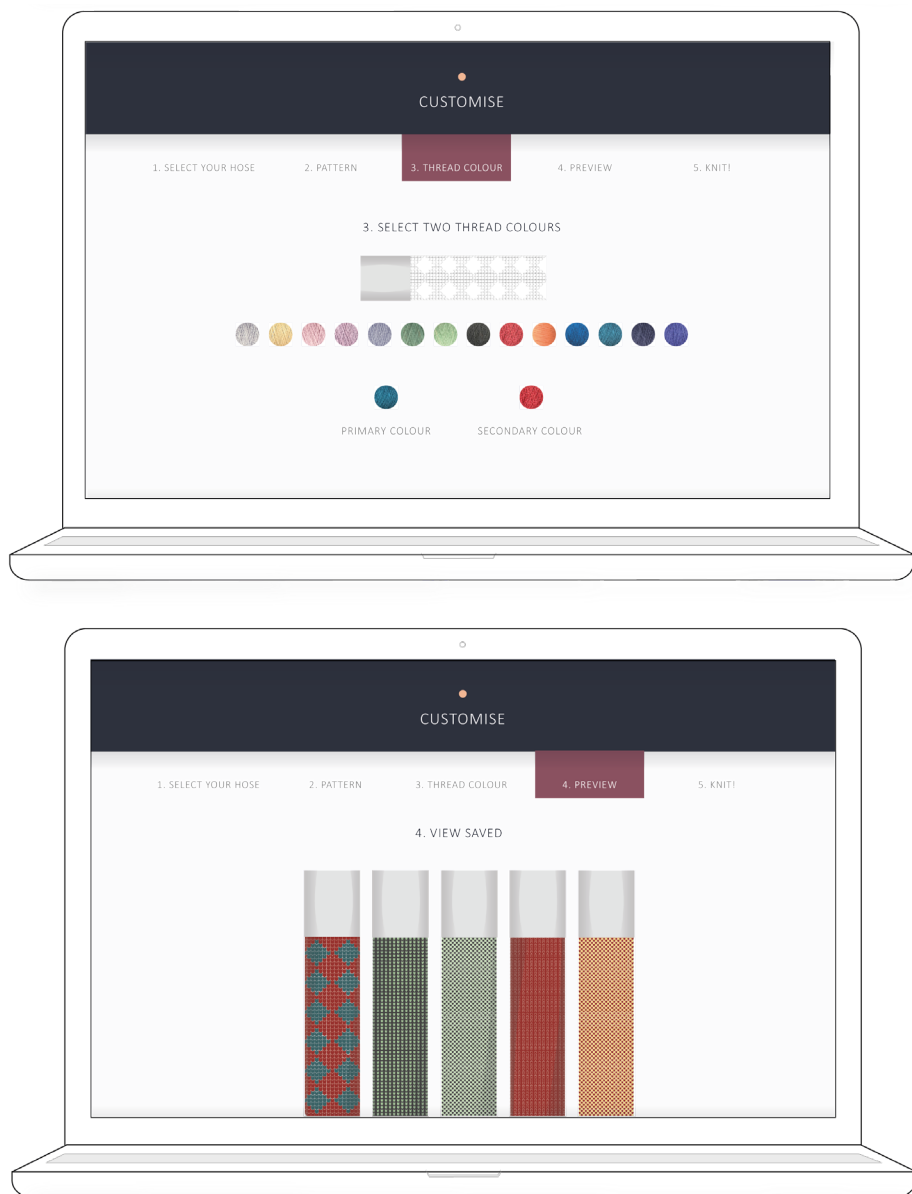
4. VIEW SAVED

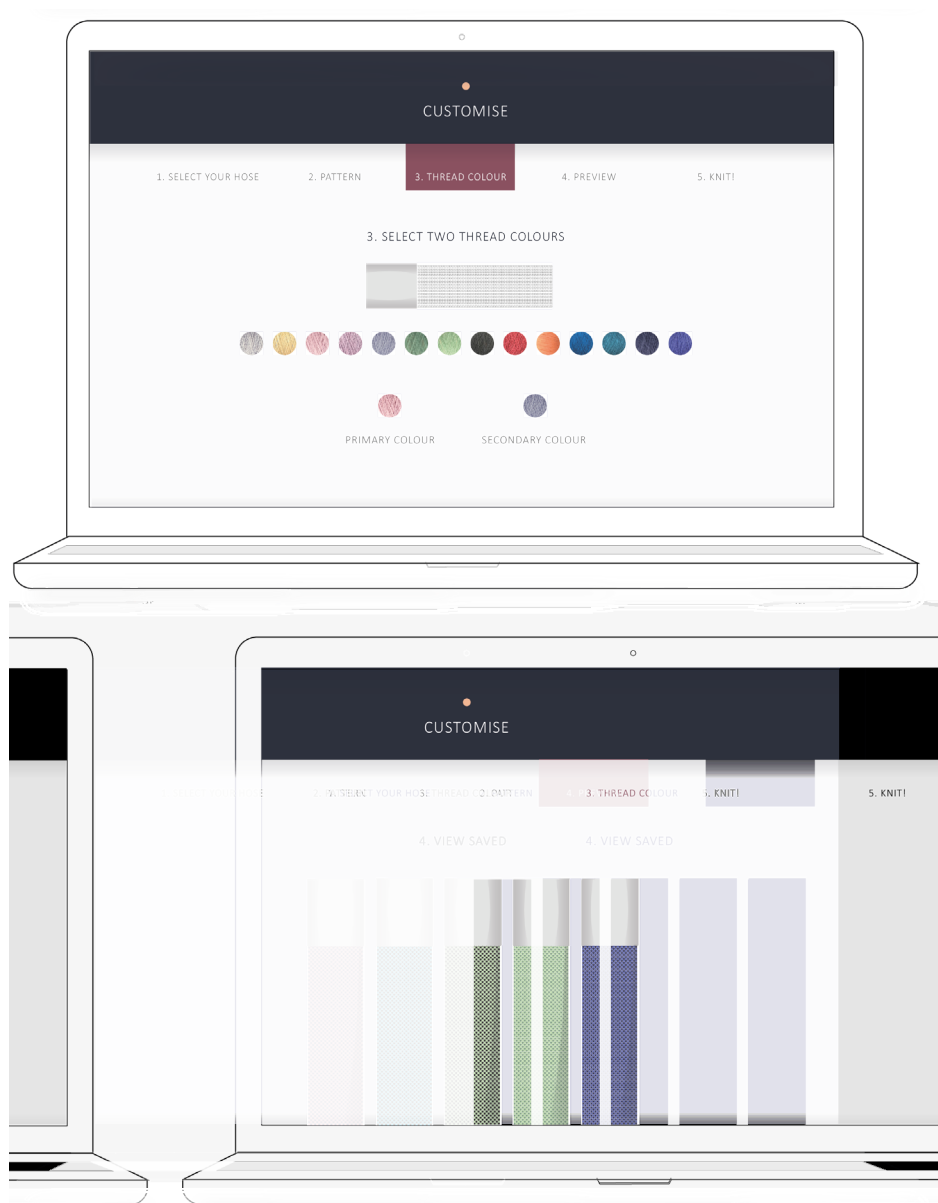Figure 56: Participant 4's series of knitted designs

Figure 57: Participant 3's series of knitted designs

5.3.4 Participant customisation

Participant 3 and 4 are invited to design their own knit to produce a full length prototype for their machines. The following images are the process they went through to get this. As the interface is not fully operational, so participants sent their top choices of pattern, and a primary and secondary yarn colour. These combinations are rendered manually, and sent to them Figure 59 and 59 are the result of the process.

Participant 4

Participant 4 is a new user. When they contacted the primary researcher they were still waiting for their equipment to arrive. The process of design and 3D knitting the prototypes was faster than the equipment delivery so the participant received the cover first. They stated that they were looking forward to putting it on their equipment and they really enjoyed the customisation as the parent and colour com-bination is similar to their families tartan.
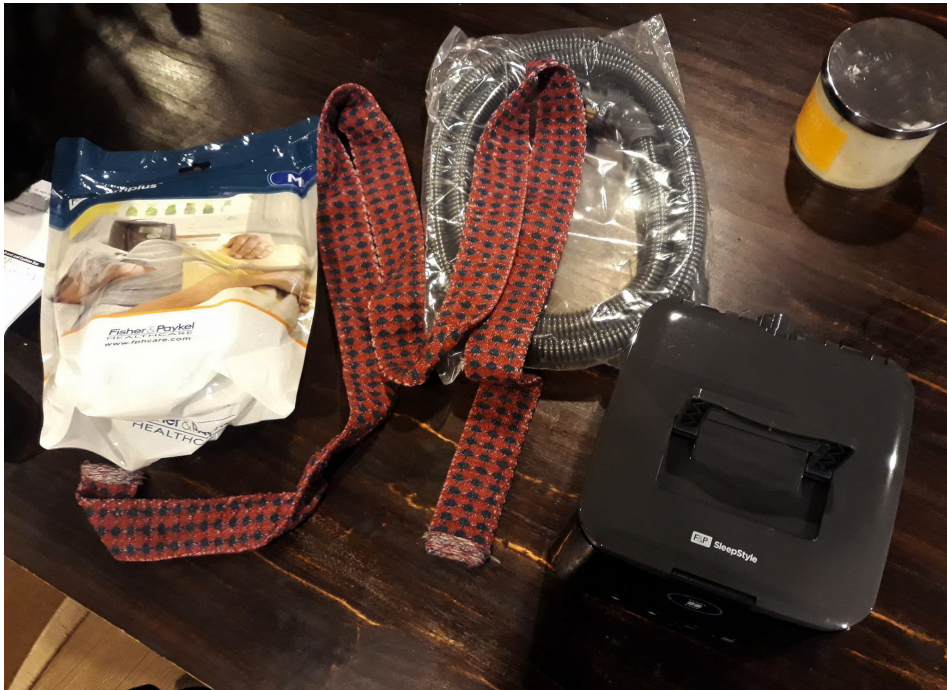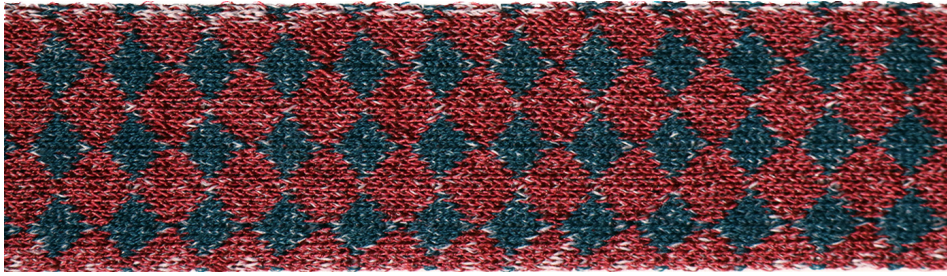
Figure 58 Images from P4 comparing before and after they received their hose cover
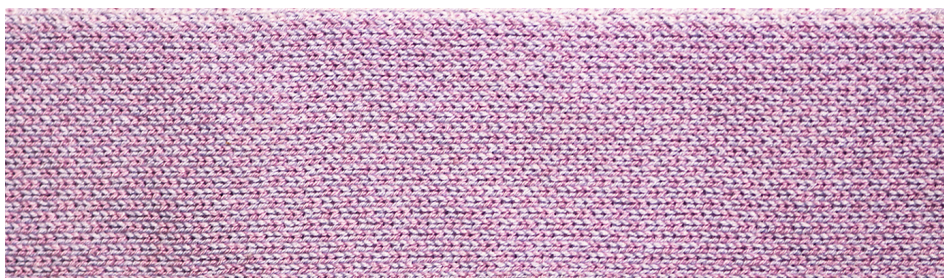
Figure 59 Images from P3 comparing before and after they received their hose cover

Table 11 3D knitting aspects and the barriers addressed

Aspect	Description	Barriers addressed
Website interface	Allows the user to create a personal account that stores their results from their therapy use	Self efficacy
Customisation	Gives the user access to verified support gruops to seek support and share experiences	Support Education Self-efficacy
Physical 3D knit	Allows users to add their mask and machine model access the specific information	Education Ability to Trouble-shoot issues

5.3.5 Reflection

The 3D knitting recieved positive feedback from the participants. Table 11 expresses the different aspects included in the 3D knitting system. Including the website, the system addresses different barriers identified in Chapter 3.

5.4
PACKAGING DESIGN

5.4.1 Aim of the design

People's initial reaction when they receive the equipment is to unpack it all at once, put on the mask and turn the machine on. The first instinct is to try it out, skipping the process of becoming familiar with the equipment and learning. P6 stated that "reducing the information overload in the initial stages of treatment would make it less overwhelming". The packaging aims to address the users first impression, improved perceived value, reduction of stigma and the gradual feed of information.
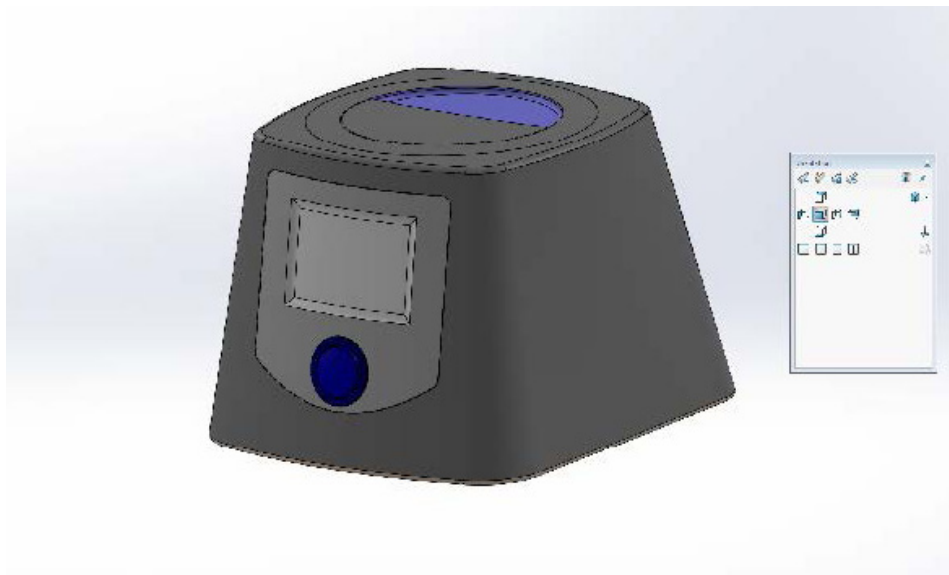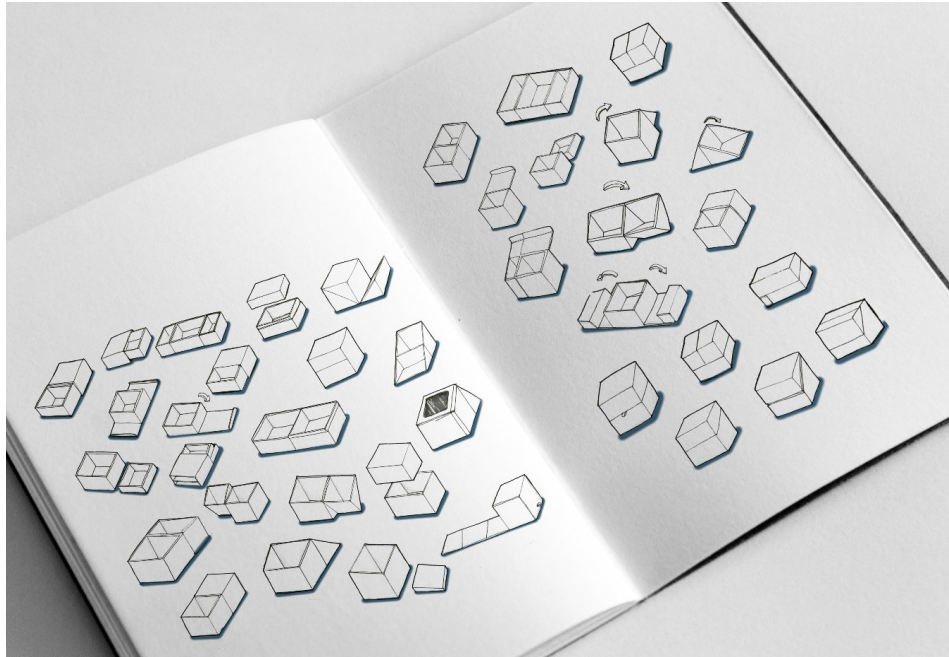
Figure 60 Initial Sketches
Figure 61 CAD Model of CPAP device

5.4.2 The design process

The following pages show the design process to develop the final packaging prototype. The intention is to reduce the waste experimenting with different interactions. A 3D model was developed (Figure 61) and 3D printed to build the packaging around. Figure 62 & 63 displays the exploration of the interaction of the box opening.
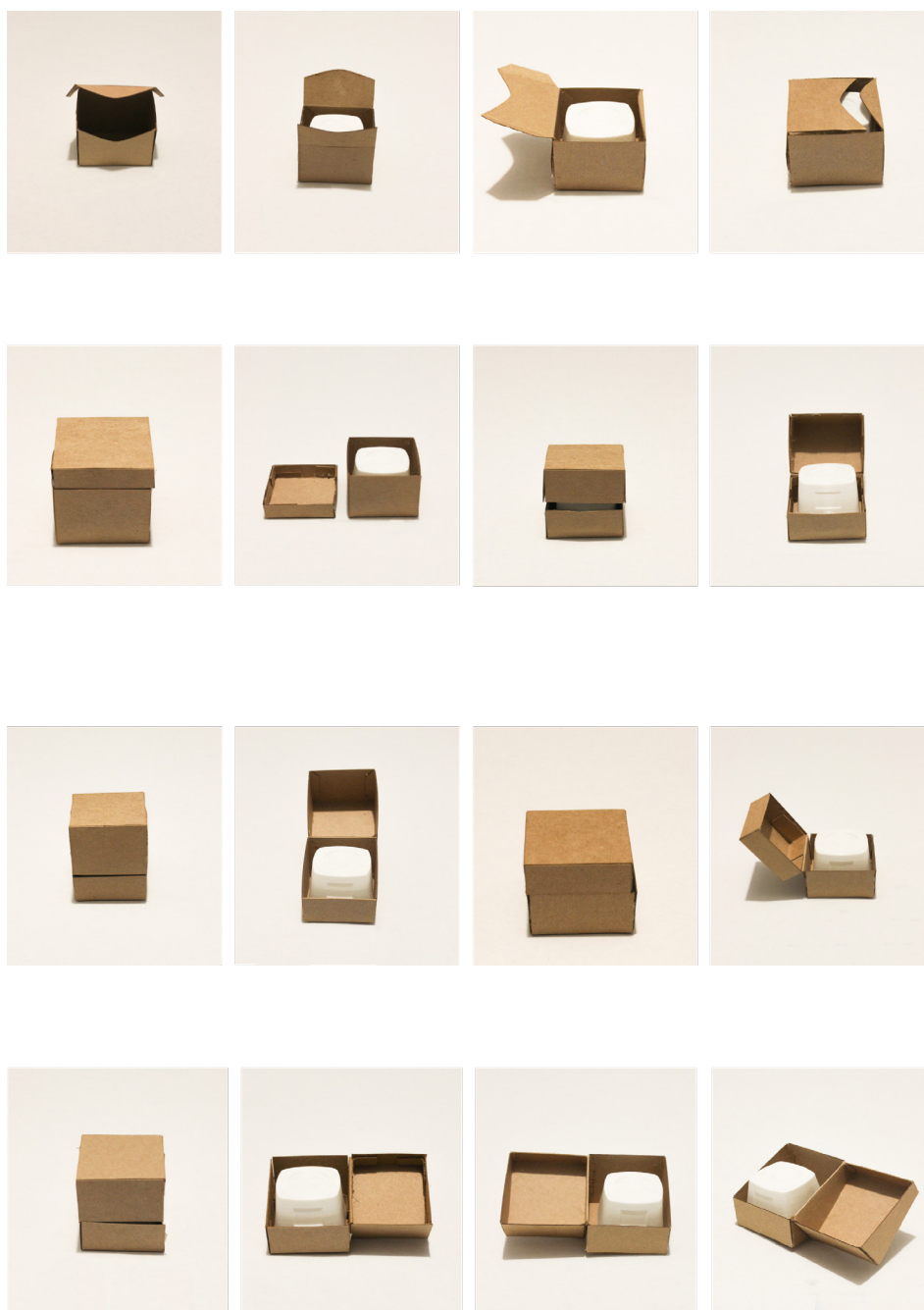
Figure 63 1:5 scale models
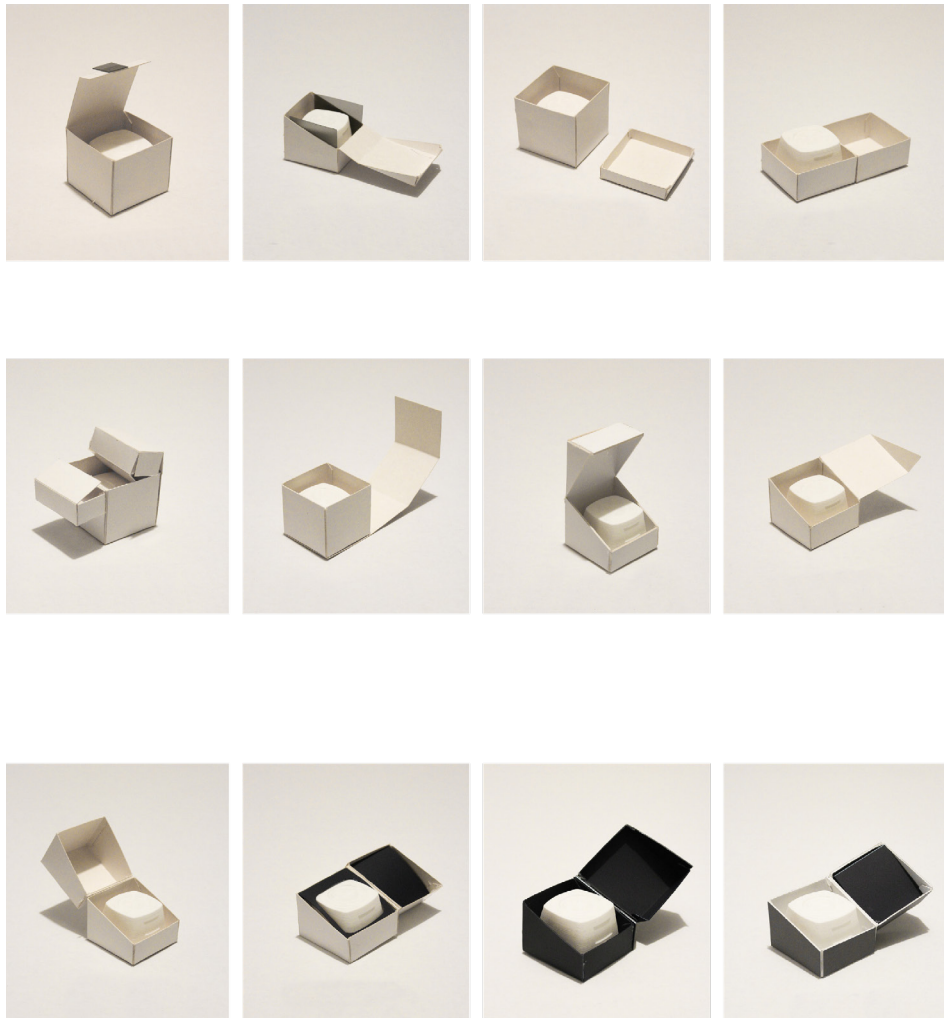
Figure 64 1:5 scale models
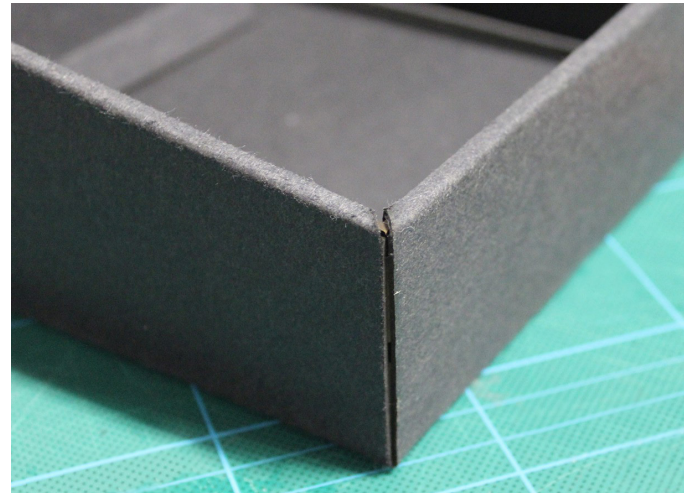
Figure 65 Group of process images using hand craft and laser cutting

1:1 models

After the design direction was decided, material experiments were made with different types of cardboard, and assembly techniques. Following the interaction of the CPAP box design, the mask packaging followed the same method of opening to create cohesion.

Figure 66: 1mm brown card

Figure 67 3mm white corregated card

Figure 68 2mm black card

Figure 69 2mm black card
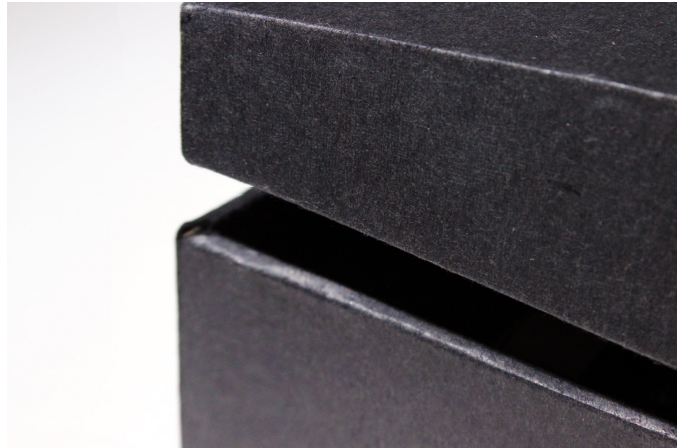
Figure 70 2mm black card   Figure 71 3mm card with paper cover

Table 12 displaying the different methods used in each prototype

Material	Feature							
	Hand Made	Laser Cut	Laser Engrave	Curved edge	Seamless edges	Glue	Magnets	Fabric Pull tabs
1mm Brown Card	✓	✓	✓			✓		
3mm White Corregated Card		✓	✓			✓		
2mm Black Card	✓		✓	✓		✓		
3mm card inner with 1mm Paper cover	✓		✓	✓	✓	✓	✓	✓
3mm Card inner with Fabric Cover	✓	✓			✓	✓	✓	✓
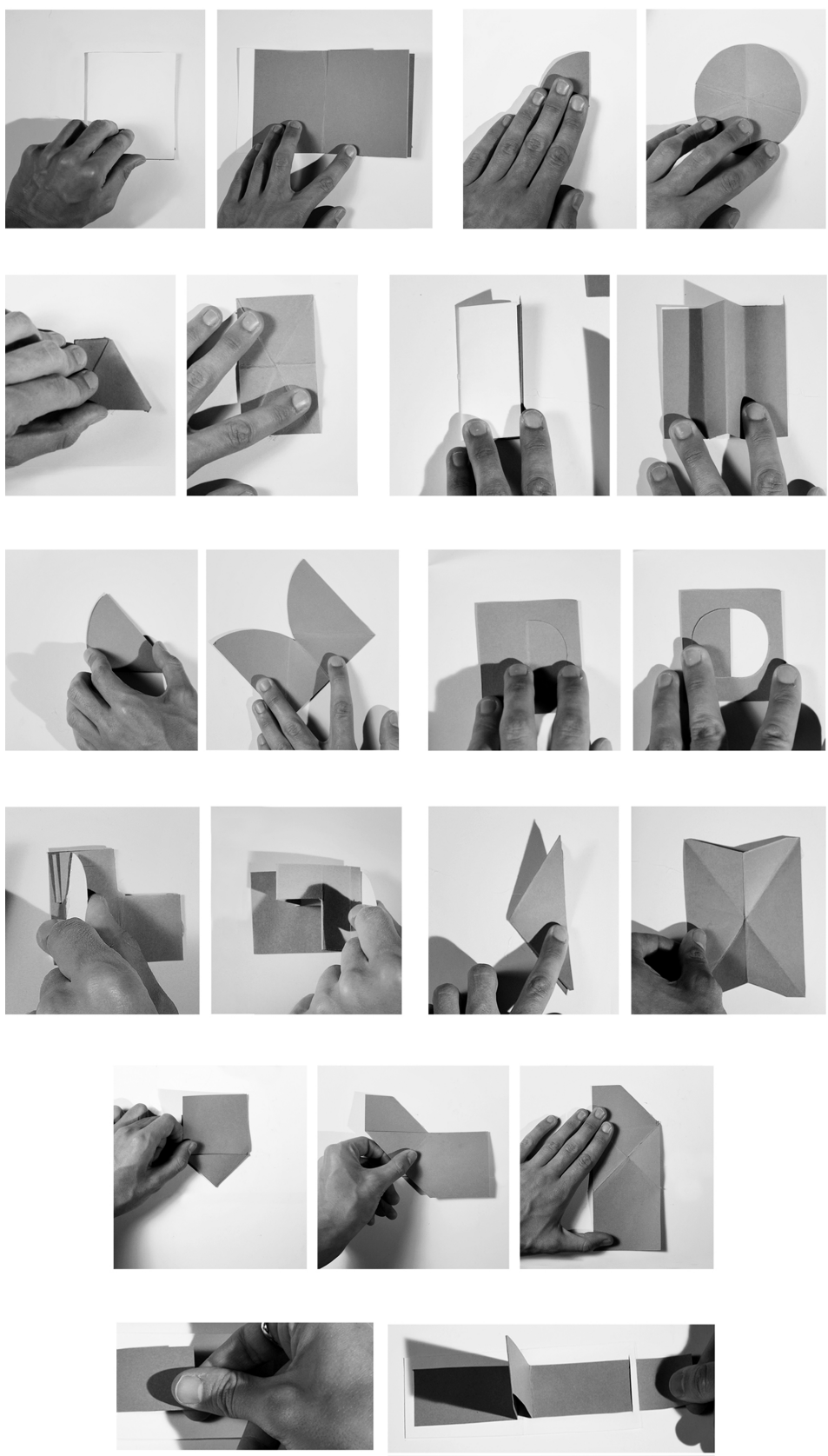
Figure 72 exploring interaction design through pop up

This packaging concept acts like a book in the way that it opens and displays the information and equipment to the user. Pop up books and similar precedents have driven the design to be a sophisticated interaction (Figure 72 & 73). Each phase of the interaction reveals key information specific to CPAP therapy management. The materials also encourage long term use for storage.

Figure 73 Develped packaging concept

5.4.3 The final concept

The final concept for the packaging has blue pull tabs for the user to interact with. These allow the user to open the packaging. Inside, the mask is held on a laser cut piece that is embossed with a graphic of a face to indicate where the mask sits.

Figure 74 Final mask packaging prototype

Figure 75 Final mask packaging prototype

Table 13 CPAP packaging aspects

Aspect	Description	Barriers addressed
The box	Like the mask box, the box is made with card and covered on fabric. There are fabric pull tabs encourage the user to open the box gradually	First impressions Percieved value
The hose holder	The hose can be overwhelming, the holder aims to provide information about where it connects to without overwhelming the user	First impressions Product Related Stigma Education
Display of the CPAP	The interactive aspect of the box focusses on the simplicity of the system and provides all of the key information about how to assemble the system. Displayed simply, this aims to reduce the visual impact of the CPAP device and hose.	First impressions perceived value education
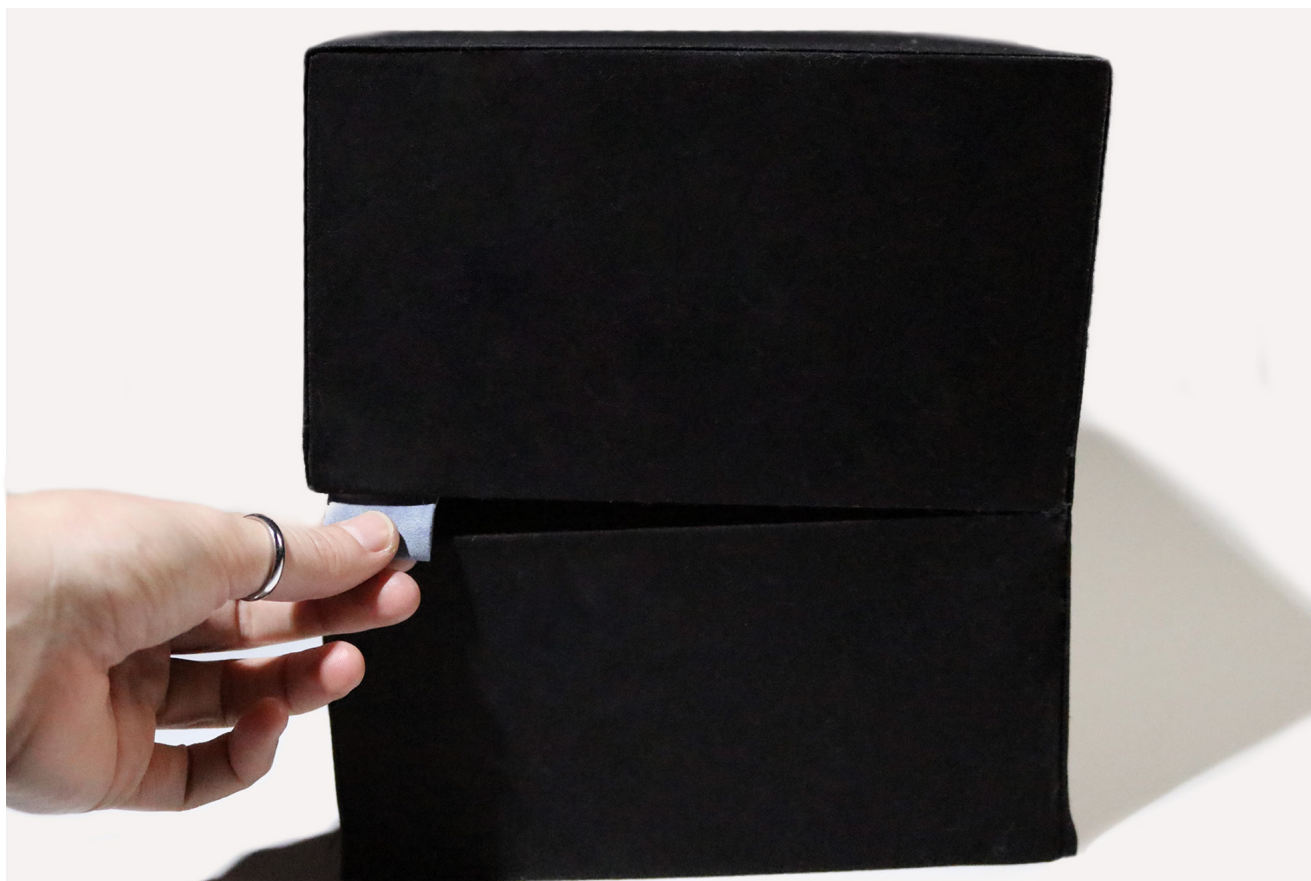
Figure 76 Final CPAP packaging prototype

Figure 77 Final CPAP packaging prototype

Table 14 Mask packaging aspects

Aspect	Description	Barriers addressed
The box	The box Is made with card and covered in fabric. The materiality of the design encourages the user to keep it for long term. And for storage if they need.	Self efficacy First impressions Percieved value
The mask holder	The mask holder on the inner indicates what the mask is for, in this instance it is for a nasal mask.	First impressions Education Stigma
Information display	The interactive aspect of the box focusses on the simplicity. It provides all of the key information on the card. Information includes cleaning aspects, how to fit the mask, assembly, and identifying a leak	Education Ability to Trouble-shoot issues

5.5
MOBILE APPLICATION

5.5.1 Aim of the design

The mobile application gives feedback to the user about their behaviour. By not only focussing on the recording of the sleep quality and apnoea disturbances, the application also enables the user to log their sleep routine and mood in the morning. This converts the focus from the result to the overall management of the therapy. By enabling this tracking of sleep hygiene and mood, the user is able to see not only their progress but their effort to optimise their sleep, outside of the therapy. It targets those that may not necessarily notice a change straight away. When they do not receive instant symptom reduction, they can see their progress through the application, and see what does work, and what might not in regard to their bedtime routine.

Figure 78 User logs for sleep hyigene and mood

5.5.2 Aim of the design

The application allows for the user to log their symptoms, and sleep hygiene. As stated previously, all apps currently focus on the result – a good night sleep, and not the ongoing therapy management and areas that may influence their sleep effectiveness. This includes aspects such as did they have a shower before bed, did they leave the electric blanket on all night, or did they have coffee or tea.
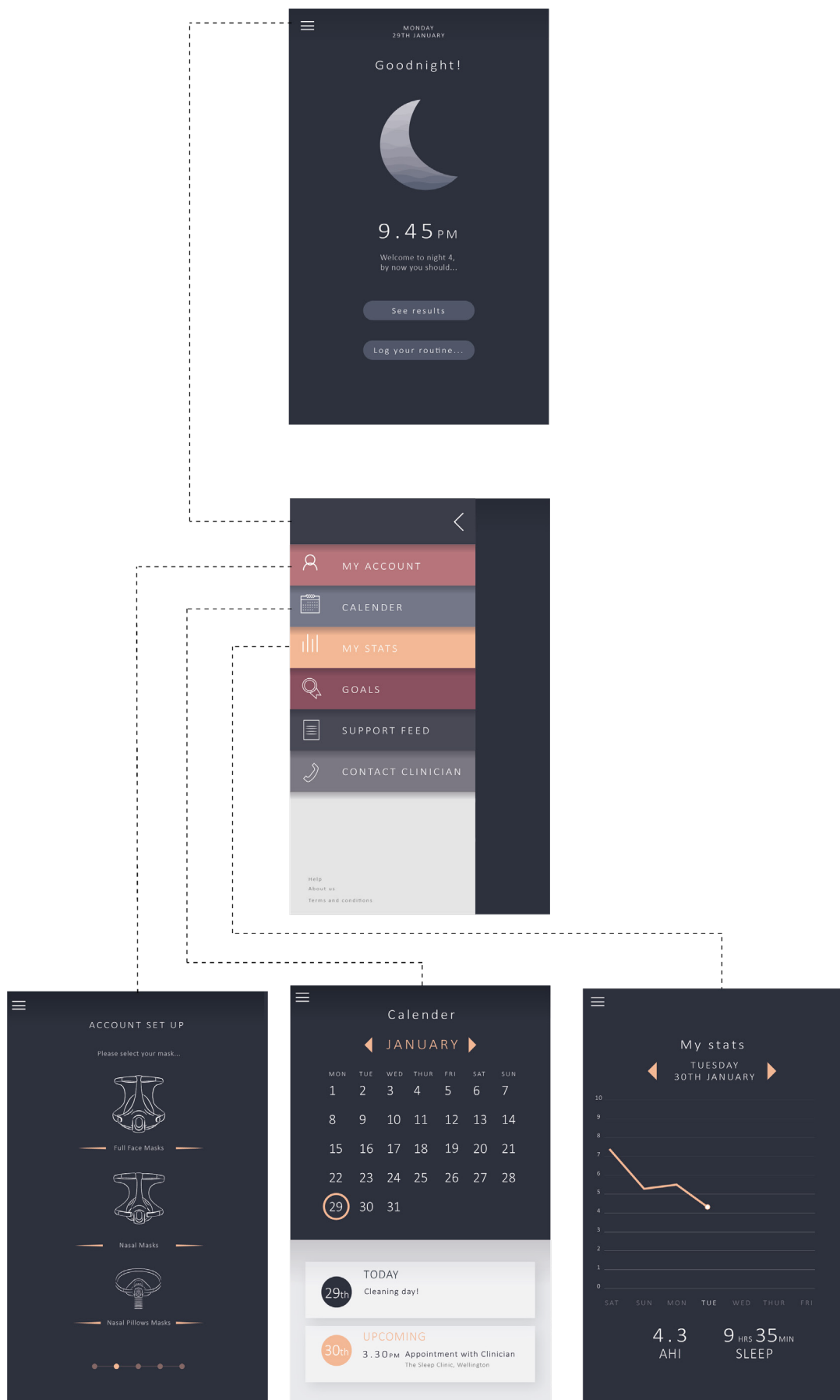
Figure 79 User account and results
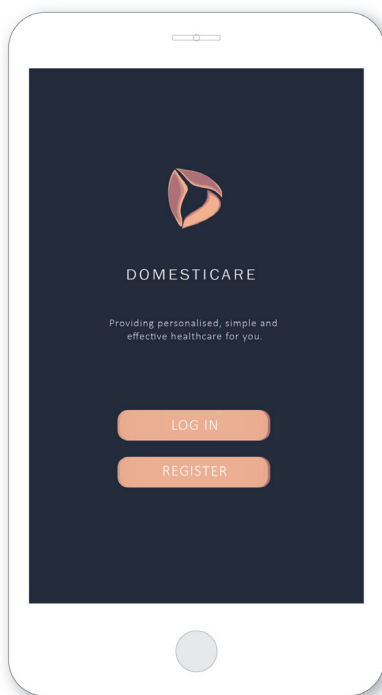
Figure 80 Mobile application interface

APPLICATION

Welcome screen

Our mission

Create account | Log in

Home page

Calendar
- Upcoming
- See results

Support
- Contact clinician
- Sync data

Support Group
- Posts
- What's new

My Account
- My Journey
- My Goals

My Equipment
- Set up
- Select mask
- Select machine

What to expect
- The mask
- The CPAP
- The first night
- The first week

Troubleshooting
- Cleaning
- Fill water chamber
- Fitting the mask
- Identifying a leak

My statistics
- See AHI
- See sleep stats

Log
- Sleep routine
- Mood

Figure 81 Mobile application process flow interface

5.5.3 Participant feedback

As a response Participant 6 stated that the feedback from the application will be valuable for them to manage their therapy effectively. "Sleep is part of health, so why can't it be tracked like lifestyle a fitness applications too? It is the same… it is what is going to keep me well". This can reduce the didactic relationship where the clinician has ownership of someone else's problem. Giving access to users will make it more equal. If it was an appointment where they had "here is my app and here is my data" there is a talking point between patients and clinicians P6. It also creates a sense of wellness to the user.

Table 15 Mobile application aspects

Aspect	Description	Barriers addressed
Account	Allows the user to sync their account from their website with all their account information connected to it.	Self efficacy
Log sleep routine	The aim of this is to log the users symptoms, in general terms this can collate information in the morning to see the physical and cognitive effects that the therapy is having	Support Education Self-efficacy
Log mood	Allows users to add their mask and machine model access the specific information	Education Ability to Trouble-shoot issues
Results	The results display the trends developed from the logs, and results from their sleep, and the CPAP	Feedback Self-efficacy
Calendar	Allows for the user to track their progress, and set specific events relative to their daily routine. It reminds the user of events such as when to clean, or appoint-ments with their clinician	Feedback Support Education Self Efficacy

5.6
REFLECTION

With reflection on the system described, the participant stated that "These additions make it so much more personal. Setting goals is a big part of it, at the moment I have no engagement with [the therapy]. If I can see how I am doing it will make a big difference". The feedback is useful to reflect on aspects that may not have necessarily worked so they can reflect on what they can improve on next time. Table 16 reflects on the barriers that each concept addresses, this concludes that the system cannot fully address all of the barriers with a single approach.

Table 16 Reflection of concepts against the barriers

Barrier	Website	Packaging	3D Knitted hose cover	Mobile Application
First Impressions		✓	✓	✓
Product related stigma		✓	✓	
Social stigma	✓		✓	✓
Delivery of information	✓			✓
Education	✓	✓		✓
Feedback	✓			✓
Support	✓			✓
Troubleshooting issues	✓	✓		✓
Apparatus in the home		✓	✓	
What to expect	✓			✓
Self-Management	✓	✓		✓

06

DISCUSSION

6.1
THE CURRENT SYSTEM

6.1.1 The disconnect

There is disconnect between the manufacturer, clinician, and user in regard to the design of the equipment, delivery of information, and the ability to self-manage from the user's perspective.

The manufacturer designs the therapy for the clinician to deliver; the clinician prescribes and delivers the therapy to the user. There is no connection between the manufacturer, clinician and user in regard to the design of the equipment, information provided, and self-management, the point of view varies from each party (Figure 81, 82 and 83). These are observations of the relationships after interviewing each group in the process. This is fairly typical of the system at present.

6.1.2 The design disconnection

The design of the therapy is for a single use system where the manufacturer dictates the design and functionality aspects of the equipment for clinicians to distribute. Figure 80 expresses this where the user is the one that needs to adhere. The design is solely for the device to function, and effectively reduce apnoea events, however there is no design element as to how the user adopts the therapy into their lifestyle.

MANUFACTURER
Designs the equipment for performance and usability

CLINICIAN
Responsible for diagnosis and prescription of CPAP equipment

USER
Adheres to the therapy and equipment

Clinicians retail equipment

Monitor adherence from results
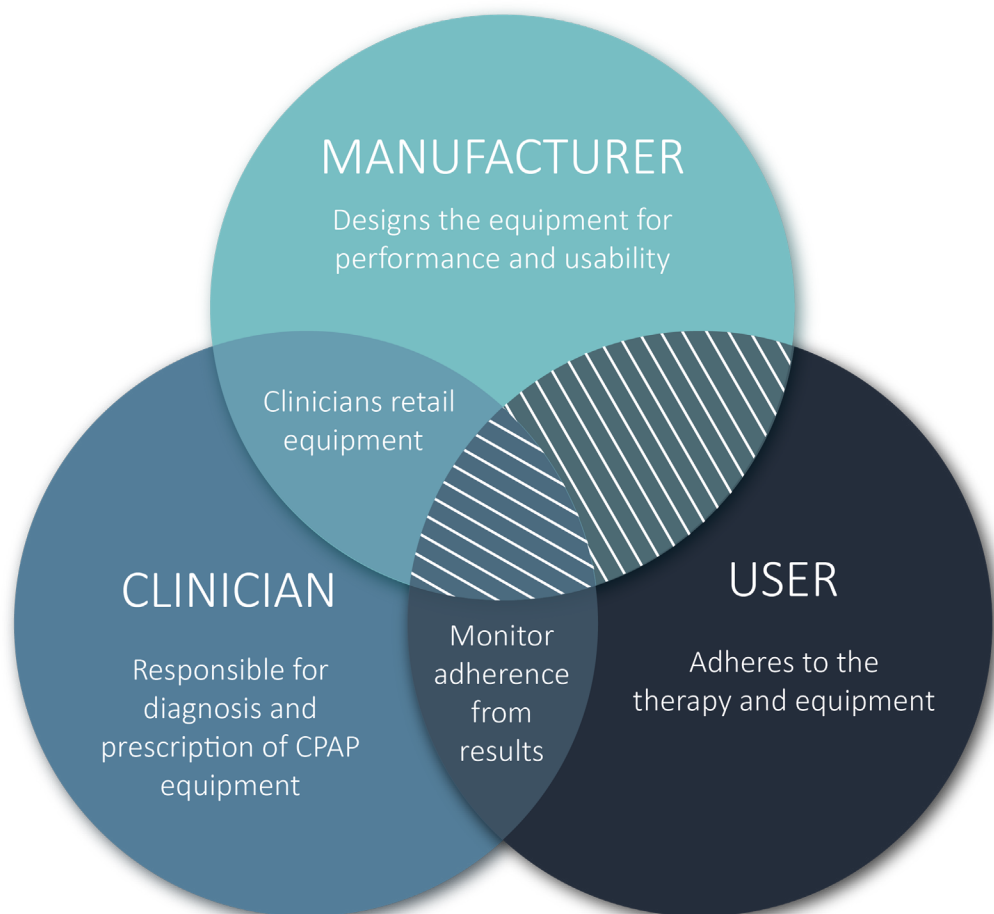
Figure 81 the design disconnection

6.1.3 Delivery of information

There is an overload of information delivered to the user from all of the parties. The manufacturer and clinicians need to communicate the content that is delivered to the end user through one cohesive strategy. Instead, in the current system, users are overloaded with information from the prescription process, the follow up appointments, and information from user manuals and manufacturer websites.

MANUFACTURER

Generating documentation that is part of a registration and compliance requirement

Use manuals and website details

CLINICIAN

Ignore information provided by the manufacturers

USER

Overloaded with information - seek support from other groups

Consultation and follow up
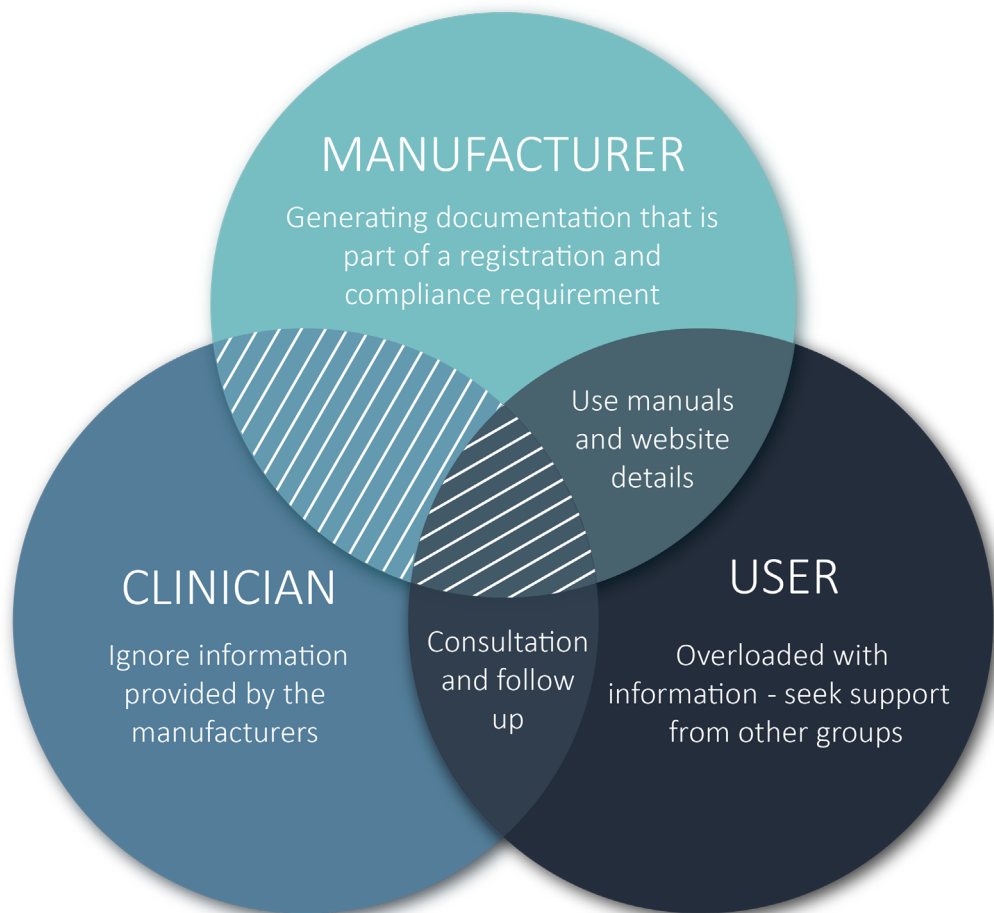
Figure 82: The information disconnection

6.1.4 Self-management

There is only one way to use the therapy that is dictated by the manufacturer and clinician. Clinicians are less interested in self-management; their main focus is the making sure patients are adherent. An important challenge for self-management is that patients are given therapy by the clinician who also diagnosed their condition. The conflict of interest creates is a didactic relationship where the clinician has ownership of someone else's problem. Participant 6 reiterates that "To manage your own therapy, you have to own it, but you are not actully given any skills to manage it". The main focus of the user is to adopt the therapy into their lifestyle. When they do not feel that they have any control over the therapy or have the ability to self-manage, they have less motivation to accept the therapy.

MANUFACTURER

Develop the therapy equipment that is automated with a pre-set interaction

CLINICIAN

Responsible for monitoring adherence through the results from patients

USER

Uses the therapy with little opportunity for personalisation or how they interact with it

Uses features to monitor patients
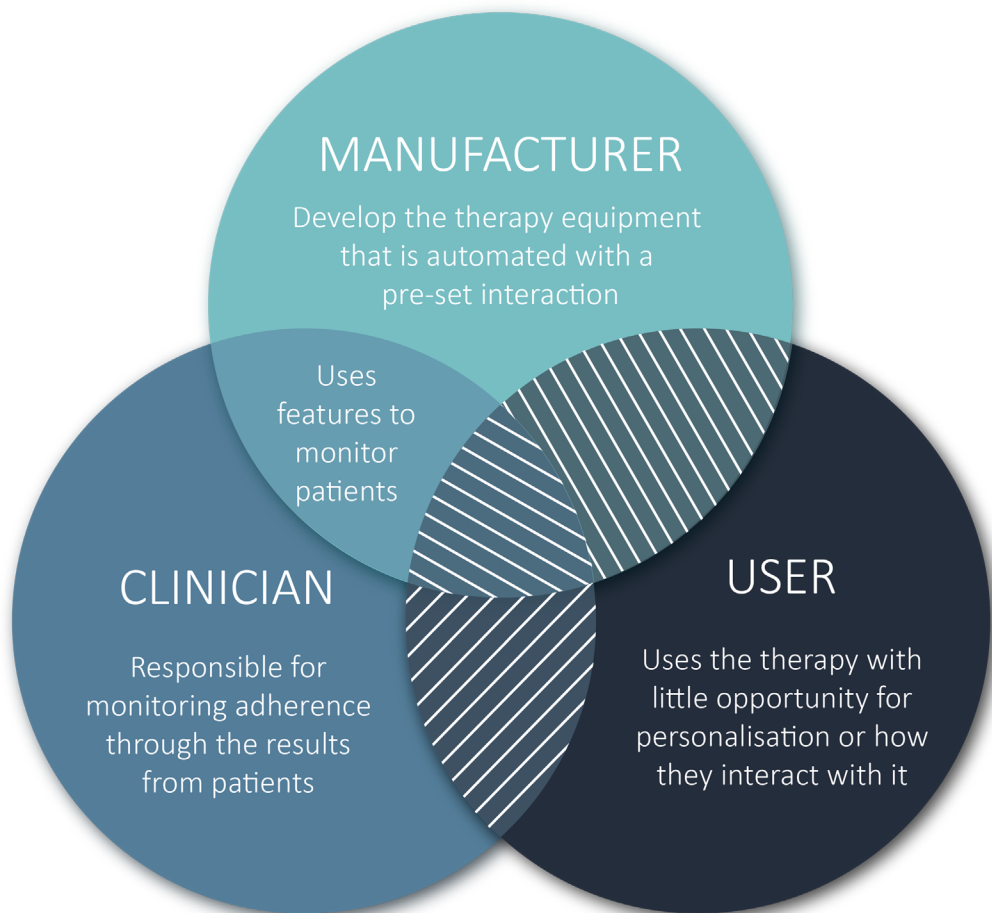
Figure 83: The self management disconnection

6.2
PROPOSED USER JOURNEY

The design system generated from the results focus on where therapy management can be improved, from the users' perspective, by creating cohesion in the information delivered, as well as an opportunity to personalise aspects of their equipment. The system also provides feedback through results and logging of sleep hygiene and symptom reduction. The system flow in Figure 84 -86 expresses the proposed user journey with these aspects integrated.

6.2.1 Pre Diagnosis

This system provides a gradual feed of information through the prescription process. The information provided is verified. If need be, users have the ability to contact the clinician, but there is also a support system where they can self-manage and access important information (particularly information missed in the consultation and follow up) through the application and website. If they come across any issues that they are unable to troubleshoot, they are able to call the clinic. The website allows for personalisation of the equipment. The system allows personalisation through the website, were users can design their own hose cover, and this gets delivered with the CPAP device. As noted in the research findings, there is real value in creating excitement to receive the equipment through investment and personalisation. For example, Participant 4 went through the customisation process in this study. When they received the hose cover before their equipment, they were excited to receive it to put the cover on their hose.

PRE DIAGNOSIS

User journey	Website	Packaging	Application
Notice that there is an issue			
Seek diagnosis			
Referred to a sleep clinic			
Suspicion of OSA			
Overnight sleep study			
Diagnosis	Connect to the website		Download mobile application
Consult with clinician	Information about the process		Account sync and set up
Discuss treatment options	Sync profile with clinician		Learn about the therapy
Prescribed with equipment	Customise equipment aspects		Log mood, sleep routine pre therapy
	Order equipment		Notification about mask shipping

Figure 84 User journey pre diagnosis

6.2.2 Day one and two

Day one and two (Figure 4) focus on the initiation and set up of the equipment in the home. The mask is delivered first so that the user does not miss any key interactions (if they receive the CPAP at the same time). As P6 emphasised, the initial reaction is to put it on and try it straight away. This slow delivery encourages the user to interact with the mask first, so they are not overwhelmed. The CPAP is delivered the next day. The application in the initial stages encourages the interaction, and provides information about what to expect, and gives them the opportunity to log their sleep routine and how they feel in the morning.

DAY 1

User journey	Website	Packaging	Application
Mask Delivered			
Unbox the mask		Unboxing experience	Step by step guide
Interact with it and try it on		Staged reveal	
Prepare space for CPAP		Information about the mask	
		Fitting, identifying a leak, cleaning	
		Assembly and disassembly	Complete activities
		Try on the mask, fitting test	Notification of CPAP shipping

DAY 2

User journey	Website	Packaging	Application
CPAP delivered		Unbox the CPAP	Step by step guide
		Staged reveal	
		Education about CPAP	
Fill the water chamber		Encourage to become familiar	
Connect system			Complete activities
Prepare for the first night	Browse support group		Log sleep routine
First nights use			What to expect overnight
			Breathing exercises

Figure 85 Day one and two

6.2.3 Day three to six

Day three to six are generally an iterative process, with the encouragement of the application and the accessibility to the clinician they are able to share their results with them and discuss if they have any issues. This allows the patient to gradually get used to the treatment. The application also helps to identify any leaks, their average number of apnoea events per hour, and the amount of time spent using the machine. Their key reward is the information in the morning, and by logging the information, they can see what worked for them and what did not. This phase is an iteration of lifestyle change, and for the therapy equipment and air pressure.

DAY 3-6

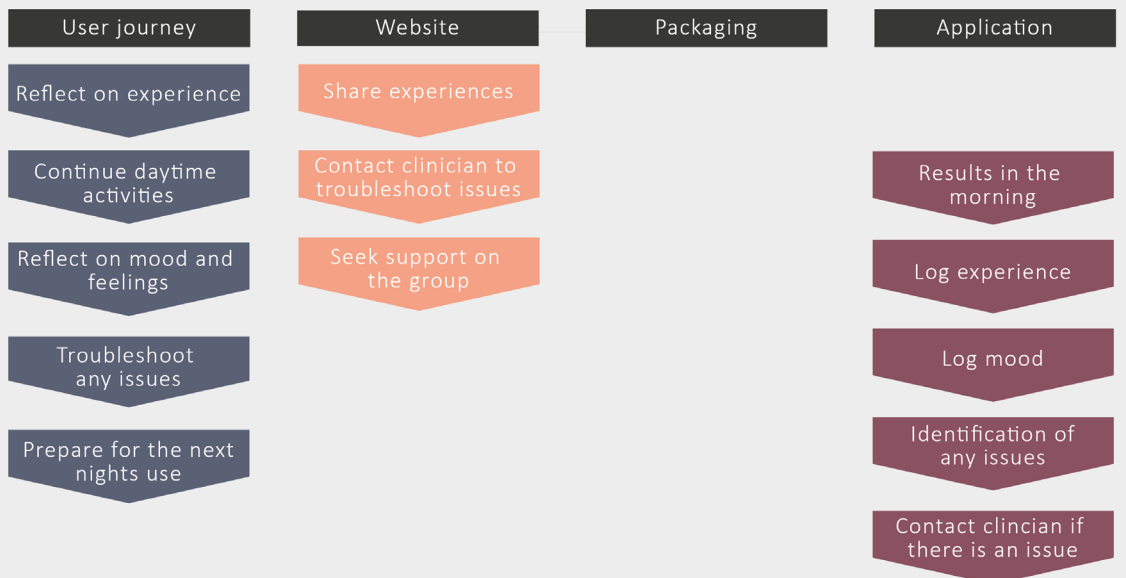| User journey	Website	Packaging	Application
Reflect on experience	Share experiences		
Continue daytime activities	Contact clinician to troubleshoot issues		Results in the morning
Reflect on mood and feelings	Seek support on the group		Log experience
Troubleshoot any issues			Log mood
Prepare for the next nights use			Identification of any issues
			Contact clincian if there is an issue

Figure 86 Day three to six is an iterative process

6.2.4 Day Seven

By day seven the user should have sufficient results on the application to motivate them to continue use, or to troubleshoot any issues that their clinician may notice. By logging the sleep routine, therapy use and how they are feeling, the results can be compared at this point. The user knows about their result before the consultation. With a follow up with the clinician, talking points can be about the result gathered. This creates more of an equitable relationship between patient and clinician. This type of self-management removes the view that the therapy management is under the sole control and responsibility of the clinician's, and not the responsibility of the user to self-manage. This encourages the user to develop self-efficacy and take more control of the direction of their own treatment.

DAY 7

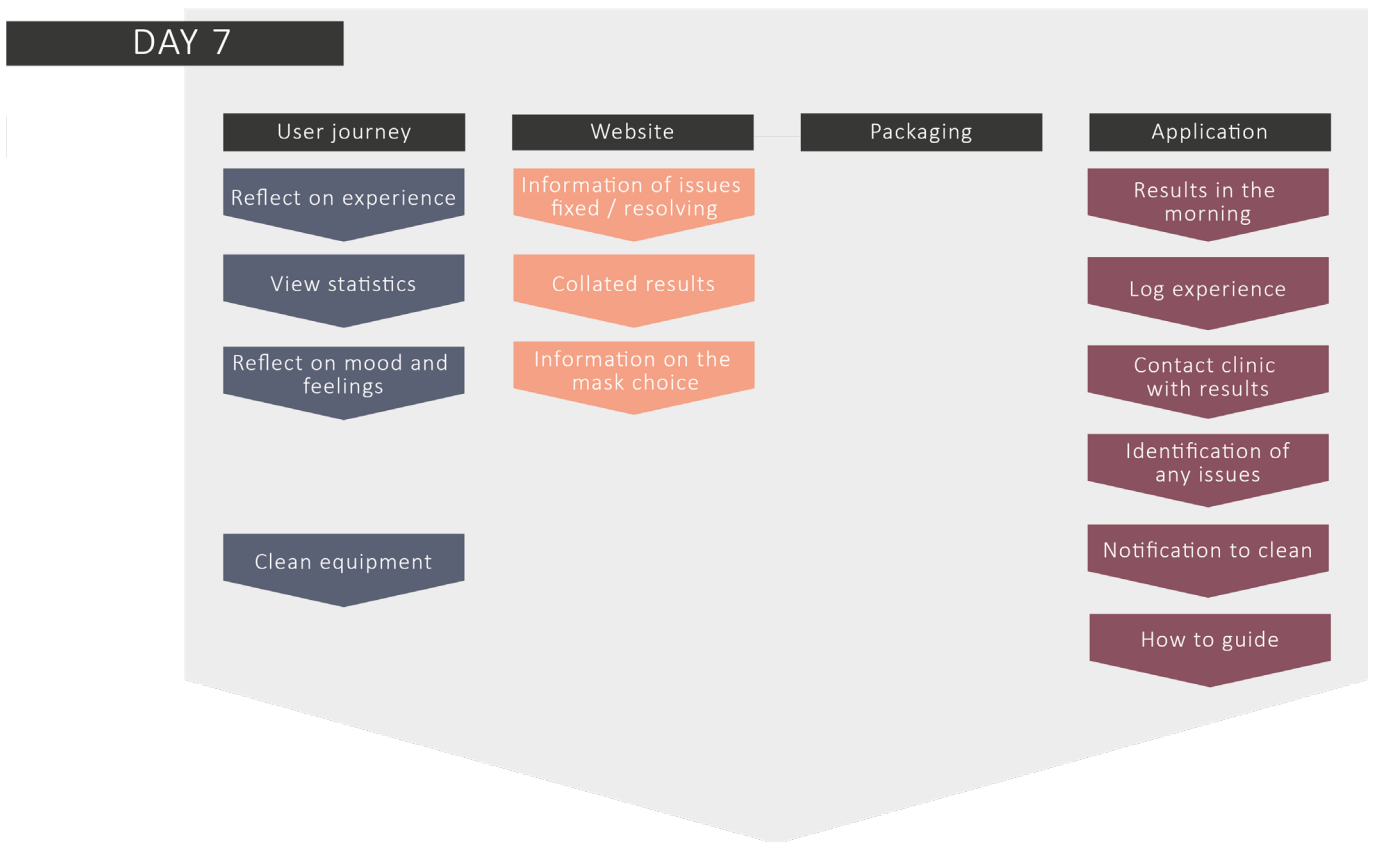| User journey	Website	Packaging	Application
Reflect on experience	Information of issues fixed / resolving		Results in the morning
View statistics	Collated results		Log experience
Reflect on mood and feelings	Information on the mask choice		Contact clinic with results
			Identification of any issues
Clean equipment			Notification to clean
			How to guide

Figure 87 Day seven is for reflection and cleaning

6.3
LIMIATIONS

The key limitation of this research is the time constraint of the master's thesis research, which requires Human Ethics approval to conduct research in the clinical environment and, recruitment and engagement of clinicians and patients as participants. This limited the recruitment of a larger group of participants. Results are based on a small number of participants.

User testing participants were students recruited at the university; they did not have an OSA diagnosis. As a result, there were limitations when it came to observing their cognitive behaviours and responses. The impressions may have been altered as participants have not experienced the prescription process, or have gone through the user journey, of a person just diagnosed with OSA. However, the therapy equipment should provide a universal understanding, not just a niche focus group.

Improvements methods or process of design can be developed through improvement in the sample size and the ability to develop concepts further. As the first week is an essential time for decisional processed for new users, it is highly important to conduct research at this time. During the first week, the participants are adjusting to significant changes in their health management. The designs developed do not directly influence the effectiveness of the therapy, as this is out of scope, they address the ability for users to self-manage by addressing the barriers identified.

The methods of research can be developed through other areas of design for medical devices and self-management where the methods applied in this research identify with attention to the real user's experience. This additionally follows a method of data collection that all focus groups are represented.

07

CONCLUSION

The primary focus of this research is to understand ways that design focused intervention can assist with non-invasive air pressure therapy for respiratory conditions and Obstructive Sleep Apnoea (OSA) in particular.

As the research was considered to be in the high-risk category, there were strict requirements and procedures that needed to be followed, requiring extensive planning and organisation for this project to commence with the requisite Health and Disability Ethics Committee (HDEC), and Victoria Universities' Human Ethics Committee's (HEC) approval. The resulting delays were eventually overcome but the process proved to be a lot more challenging than expected.

The research proceeded with the analysis and investigation of Obstructive Sleep Apnoea and the issue of adherence with Continuous Positive Air Pressure (CPAP) Therapy. Factors associated with non-adherence were essential in structuring the research question, and direction of this research. A number of areas were explored to identify those areas that could be potentially influenced through methods of persuasive design.

A methodology was formed to address the aims and objectives of the research through appropriate methods. The methodology supports the development of research through design, based on design criteria. The identified barriers and themes in this phase helped to structure and direct design criteria.

In the data collection phase, themes were generated through analysis. The different experiences, perspectives and insights into CPAP therapy management were identified from the focus groups involved.

The insights uncovered in the data collection phase were used to further develop the design criteria and address identified barriers in the design results phase. The criteria were used to drive design directions and address the touchpoints and themes uncovered in the data collection phase. The design developed through reflection, prototyping and participant feedback to come to a final design system containing a number of design aspects, including web site, custom hose sleeves, packaging, and mobile application.

In the final reflection and discussion phase, the final proposed user experience was compared to the current user journey and any differences in the systems was reported. With reflection on the limitations, a user journey was proposed for new CPAP users to improve their experience through the addition of design concepts.

In general people are more motivated to use medical devices when they can manage them confidently, ideally with the ability to personalise their use of that device. With CPAP therapy, there is typically only one way for patients to use it. In traditional therapy, there is not much attention paid to diverse use cases, or the patient's ability to personalise. The system proposed in this research will allow users to personalise, and will thus increase patient's personal attachment to their CPAP equipment, as well as their self-efficacy and motivation in treatment.

Design can influence people's engagement with therapy by not only focussing on the tool that provides the treatment, but by also expanding the focus to how people initially experience and manage the therapy. There is a need for control over the way CPAP therapy is delivered by developing an in depth understanding of the initial experience and understand ways in which barriers can be overcome. This allows the identification of important parts of the user experience, such as first impressions, the efficiency of support, education and feedback, stigma, and the ability for users to troubleshoot issues. The key finding is the necessity to self-manage so new users are able to own their therapy.

This thesis proposes that there needs to be more than technological and clinical advancements in the field of CPAP therapy. Design practises and understanding of real users can be of great value to identify barriers that influence people's experiences, thus creating better experiences for current, and future users.

Future studies should attempt to investigate those individuals who do not engage or stop using CPAP therapy. This would result in a better understanding of the barriers to continued therapy adherence. Other studies could further explore areas for personalisation and self-management, where design can allow people to have more control and improve motivation and self-efficacy, not just with the device but in the way that they use it.

08

REFERENCES

Alhojailan, M. I. (2012). Thematic analysis: A critical review of its process and evaluation. West East Journal of Social Sciences, 1(1), 39–47. Retrieved from http://www.westeastinstitute.com/journals/wp-content/uploads/2013/02/4-Mohammed-Ibrahim-Alhojailan-Full-Paper-Thematic-Analysis-A-Critical-Review-Of-Its-Process-And-Evaluation.pdf

Australasian Sleep Association. (2009). Best Practice Guidelines for Provision of CPAP Therapy. Retrieved from https://www.sleep.org.au/documents/item/66

Balachandran, J. S., Yu, X., Wroblewski, K., & Mokhlesi, B. (2013). A Brief Survey of Patients' First Impression after CPAP Titration Predicts Future CPAP Adherence: A Pilot Study. Journal of Clinical Sleep Medicine : JCSM : Official Publication of the American Academy of Sleep Medicine, 9(3), 199–205. https://doi.org/10.5664/jcsm.2476

Billings, M. E., & Kapur, V. K. (2013). First impressions matter: transforming CPAP from Efficacious to Effective therapy for OSA. Journal of Clinical Sleep Medicine. https://doi.org/10.5664/jcsm.2478

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brooke, J. (1995). SUS: A quick and dirty usability scale (Vol. 189). Retrieved from https://www.researchgate.net/publication/228593520_SUS_A_quick_and_dirty_usability_scale

Charters, Elizabeth. (1 July 2003). 'The Use of Think-Aloud Methods in Qualitative Research An Introduction to Think-Aloud Methods'. Brock Education Journal 12, no. 2 https://doi.org/10.26522/brocked.v12i2.38.

Dooley, R. (2014, October 13). How Your Packaging Improves Customer Experience. Retrieved from https://www.forbes.com/sites/rogerdooley/2014/10/13/how-your-packaging-improves-customer-experience/

Esmond, G., & Mikelsons, C. (2009). Non-Invasive Respiratory Support Techniques: Oxygen Therapy, Non-Invasive Ventilation and CPAP. John Wiley & Sons.

Eyal, N., & Hoover, R. (2014). Hooked: How to Build Habit-Forming Products. Portfolio/Penguin.

Fogg, B. (2009a). A Behavior Model for Persuasive Design. In Proceedings of the 4th International Conference on Persuasive Technology (pp. 40:1–40:7). New York, NY, USA: ACM. https://doi.org/10.1145/1541948.1541999

Fogg, B. (2009b). Creating Persuasive Technologies: An Eight-step Design Process. In Proceedings of the 4th International Conference on Persuasive Technology (pp. 44:1–44:6). New York, NY, USA: ACM. https://doi.org/10.1145/1541948.1542005

Fogg, B. J. (2009). Creating persuasive technologies: an eight-step design process. In Persuasive (p. 44). Retrieved from http://www.bjfogg.com/design_files/page8_1.pdf

Giles, T., Lasserson, T., Smith, B., White, J., Wright, J., & Cates, C. (2006). Continuous positive airways pressure for obstructive sleep apnoea in adults. In The Cochrane Collaboration (Ed.), Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd. https://doi.org/10.1002/14651858.CD001106.pub3

Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. London: Penguin Books. Retrieved from https://www.freelists.org/archives/sig-dsu/11-2012/pdfKhTzvDIi8n.pdf

Guest, G., MacQueen, K., & Namey, E. (2012). Applied Thematic Analysis. 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. https://doi.org/10.4135/9781483384436

Jordan, A. S., McSharry, D. G., & Malhotra, A. (2014). Adult obstructive sleep apnoea. The Lancet; London, 383(9918), 736–747. http://dx.doi.org/10.1016/S0140-6736(13)60734-5

Krippendorff, K. (2005). The Semantic Turn: A New Foundation for Design. CRC Press. Lee, W., Nagubadi, S., Kryger, M. H., & Mokhlesi, B. (2008). Epidemiology of obstructive sleep apnea: a population-based perspective. Expert Review of Respiratory Medicine, 2(3), 349–364. https://doi.org/10.1586/17476348.2.3.349

Malhotra, A., & White, D., P. (2002). Obstructive Sleep Apnoea. The Lancet, 360, 237–245. Retrieved from http://forum.drbarryglassmanseminars.com/docs/advsleep/2010%20Sleep%20Lit/2010%20Sleep%20Lit/Malhotra%202002.pdf

Mattelmäki, T. (2008). Design probes. Helsinki: University of Art and Design Helsinki.

McCarthy, Gillian. 'Dear My Very Problematic Blood Glucose Meter: Adolescents' Experiences Self-Managing Type 1 Diabetes and Their Psychosocial User Requirements Of Medical Technologies', 2018. http://researcharchive.vuw.ac.nz/handle/10063/6975.

Ministry of Health NZ. (2004). 'Standards for Adult Respiratory and Sleep Services in New Zealand',. https://www.health.govt.nz/system/files/documents/publications/standardsforadultrespiratoryandsleepservices.pdf.

NZ Transport Agency. Medical aspects of fitness to drive – A guide for health practitioners
 (n.d.). Retrieved from https://www.nzta.govt.nz/resources/medical-aspects/10/

Kraft, P., Drozd, F., & Olsen, E. (2008). Digital Therapy: Addressing Willpower as Part of the Cognitive-Affective Processing System in the Service of Habit Change. In Persuasive Technology (pp. 177–188). Springer, Berlin, Heidelberg. https://doi.org/10.1007/978-3-540-68504-3_12

Penzel, T., Schöbel, C., & Fietze, I. (2018). New technology to assess sleep apnea: wearables, smartphones, and accessories. F1000Research, 7, 413. https://doi.org/10.12688/f1000research.13010.1

Phillips, B., & Dhaon, N. A. (2013). Weigh the Options before Starting CPAP. Journal of Clinical Sleep Medicine. https://doi.org/10.5664/jcsm.3066

Rodríguez Ramírez, E. (2017). A Postgraduate Thesis Model for Research through Design Based on Design Criteria. The International Journal of Designed Objects, 11(4), 11–27. https://doi.org/10.18848/2325-1379/CGP/v11i04/11-27

Rosenstock, I. M. (1974). Historical Origins of the Health Belief Model. Health Education Monographs, 2(4), 328–335. https://doi.org/10.1177/109019817400200403

Shapiro, G. K., & Shapiro, C. M. (2010). Factors that influence CPAP adherence: an overview. Sleep and Breathing; Heidelberg, 14(4), 323–335. http://dx.doi.org/10.1007/s11325-010-0391-y

Sleep Apnoea Association of NZ Inc. - Diagnosis. (n.d.). Retrieved from http://www.sleepapnoeanz.org.nz/osa_diagnosis.shtml

Somiah, M., Taxin, Z., Keating, J., Mooney, A. M., Norman, R. G., Rapoport, D. M., & Ayappa, I. (2012). Sleep Quality, Short-Term and Long-Term CPAP Adherence. Journal of Clinical Sleep Medicine. https://doi.org/10.5664/jcsm.2138

Starkman, A., & Chow, J. (n.d.). Cultural Probes | Design Research Techniques. Retrieved from http://designresearchtechniques.com/casestudies/cultural-probes/

Vaes, K. (2014). Product stigmaticity understanding, measuring and managing product-related stigma: proefschrift. Delft.

Vaes, K., Stappers, P. J., Standaert, A., & Desager, K. (2012). Contending stigma in product design: Using insights from social psychology as a stepping stone for design strategies. In Central Saint Martins College of Arts and Design (p. 11).

van Zeller, M., Severo, M., Santos, A. C., & Drummond, M. (2013). 5-Years APAP adherence in OSA patients – Do first impressions matter? Respiratory Medicine, 107(12), 2046–2052. https://doi.org/10.1016/j.rmed.2013.10.011

Vicente, K. (2004). The Human Factor: Revolutionizing the Way People Live with Technology. New York, NY, 10001: Routledge.

Weaver, T. E., & Grunstein, R. R. (2008). Adherence to Continuous Positive Airway Pressure Therapy: The Challenge to Effective Treatment. Proceedings of the American Thoracic Society, 5(2), 173–178. https://doi.org/10.1513/pats.200708-119MG

Weaver, Terri E., & Sawyer, A. M. (2010). Adherence to continuous positive airway pressure treatment for obstructive sleep apnoea: implications for future interventions. The Indian Journal of Medical Research, 131, 245–258.

Weinreich, N. K. (2010). Hands-On Social Marketing: A Step-by-Step Guide to Designing Change for Good. SAGE.

White, J., Cates, C., & Wright, J. (2001). Continuous positive airways pressure for obstructive sleep apnoea. In The Cochrane Collaboration (Ed.), The Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd. https://doi.org/10.1002/14651858.CD001106

WorkSafe New Zealand. (n.d.). Change in attitude key to tackling fatigue. Retrieved from https://worksafe.govt.nz/the-toolshed/case-studies/work-related-health-case-studies/change-in-attitude-key-to-tackling-fatigue/

LIST OF FIGURES

All images not listed below are developed by the primary researcher.

Figure 4. © 2012 Fisher and Paykel Healthcare Limited, Eson 2™ Nasal CPAP Mask, [photograph]
https://www.fphcare.com/nz/, Reprinted with permission.

Figure 6. © 2015 Fisher and Paykel Healthcare Limited, Simplus™ Full Face CPAP Maskm [photograph]
https://www.fphcare.com/nz/, Reprinted with permission

Figure 7. Olivia Chandler 2017, Ami Assistive Medical Device [photograph]
https://www.behance.net/gallery/54085611/Ami, Reprinted with permission

Figure 8. Olivia Chandler 201, Ami Assistive Medical Device [photograph]
https://www.behance.net/gallery/54154957/Ami-Medical-app-design, Reprinted with permission

Figure 9. Abidur Chowdhury 2017, Aer Asthma Management System [photograph]
http://www.abidurchowdhury.com/aera/   Reprinted with permission

Figure 10. Abidur Chowdhury 2017   Aer Asthma Management System [photograph]
http://www.abidurchowdhury.com/aera/   Reprinted with permission

Figure 11. Special Projects Design Studio, Out of the Box, Packaging Design [photograph]
http://specialprojects.studio/project/out-of-the-box/   Print permission pending

LIST OF TABLES

APPENDIX A

Approved Ethics Applications

Health and Disability Ethics Committees

Monday, 4 September 2017

Katie O'Brien
Victoria University of Wellington
obrienkati@myvuw.ac.nz

Dear Miss O'Brien,

Study title:	Influencing engagement with CPAP therapy for Obstructive Sleep Apnoea through design

Thank you for emailing HDEC a completed scope of review form on 28 August 2017. The Secretariat has assessed the information provided in your form and supporting documents against the Standard Operating Procedures.

Your study will not require submission to HDEC, as on the basis of the information you have submitted, it does not appear to be within the scope of HDEC review. This scope is described in section three of the Standard Operating Procedures for Health and Disability Ethics Committees.

Your study meets the student-led research exemption criteria described below. Your scope of review form described an observational research project for the attainment of a masters degree. Participants will share their experience of continuous positive air pressure therapy (CPAP) for obstructive sleep apnoea (OSA). By understanding design barriers associated with the use of CPAP then long-term engagement mechanisms can be established to help avoid patients abandoning CPAP.

For the avoidance of doubt a study conducted wholly or principally for the purposes of an educational qualification requires HDEC review only if it:

- is an intervention study, or
- is not conducted at or below a Master's level.

If you consider that our advice on your project being out of scope is in incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

Please note, your locality may have additional ethical review policies, please check with your locality. If your study involves a DHB, you must contact the DHB's research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.

Please don't hesitate to contact us for further information.

Yours sincerely,

Tom Kent
Advisor
Health and Disability Ethics Committees
hdecs@moh.govt.nz

APPENDIX B

Online Survey Questions

Online Survey Questions

1. How old are you?   <18   18-24   25-34   35-44   45-54   55-64   65<

2. What do you use CPAP to treat? ....

3. Can you recall and key milestones that made you seek diagnosis? ....
....

4. How long have you been using CPAP therapy?

   <6 Months   6 Months- 1 Year   1-2 Years   2+ Years

5. Can you recall how you felt after using CPAP for the first time? ....
....

6. How well was the following information delivered to you by a health professional before starting your CPAP therapy?

	Very poor	Poor	Average	Good	Very Good	Total
What to expect on your first night						
Where to put your CPAP machine						
How to fit your mask						
How to identify a leak						
How often you should clean your equipment						
What to clean your equipment with						

7. How helpful was the following information in the packaging of your CPAP equipment in regards to...

	Not helpful at all	Not so helpful	Somewhat helpful	Very helpful	Extremely Helpful	Total
Fitting your mask						
Disassembling and Assembling your mask						
Assembling the mask, hose and Machine						
Cleaning instructions for your equipment						
Where to store your equipment						
Support groups						
How to troubleshoot any issues						
What to expect in your first week						

8. What motivates you to use your CPAP therapy? ....
....

9. How did you identify any changes in your sleep during your first week of CPAP therapy?

   ○ I had a better sleep   ○ I had more energy in the morning
   ○ I used the bathroom less during the night   ○ I did not have any morning headaches
   ○ I use an app that tracks my sleep   ○ Nap less during the day
   ○ My partner noticed that I wake up less   ○ I did not notice anything different
   ○ I Woke less during the night   ○ Other (please specify)

10. What advice would you give to a person that has just started their therapy? ....
....

APPENDIX C

Sleep Physiologist interview information and consent forms

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI
VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.

INFORMATION SHEET FOR CLINICIAN/SLEEP PHYSIOLOGIST INTERVIEWS

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Who am I?

My name is Katie O'Brien and I am studying a Master's Thesis at Victoria University of Wellington's School of Design. I am interested in industrial and product design, with a specific focus on the user experience. This research is being conducted as a requirement for a Master's degree.

What is the aim of the project?

The aim of this research is to identify barriers that influence people's engagement with Continuous Positive Air Pressure (CPAP) therapy when they are exposed to it for the first time. The identification of these barriers will influence design decisions that aim to improve the user experience of using CPAP equipment within the first week of therapy.

This research has been approved by the Victoria University of Wellington Human Ethics Committee. Application Reference number: 0000025272

How can you help?

You have been invited to participate because you have expertise with the prescription of CPAP equipment to patients, and have contact with patients that use CPAP therapy. If you agree to take part I will interview either over skype or in person depending on your location. Interviews will either take place in a private place such as Victoria University's School of Design in Wellington, or the Sleep Clinic you are associated with. I will ask you questions about your understanding of patient behaviours when adopting this therapy, aspects that influence patient engagement, and the procedures that your practise use to overcome the resistance of patients using CPAP therapy. The interview will take approximately 1 hour. However, it may take longer if you have more information you would like to provide me with. I will audio record the interview with your permission and transcribe it later. I may video record any demonstrations that are valuable to this research with your permission. No content that is identifiable will be published without your permission. You can choose to not answer any question or stop the interview at any time, without giving a reason.

1

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the research data will be combined and your identity will not be revealed in any reports, presentations, or public documentation unless you wish to have your identity published.

Only my supervisors and I will read the notes or transcript of the interview, videos and photographs taken. The interview transcripts, summaries, any photographs, audio and video recordings will be kept securely and destroyed on 30th November 2018.

You will not be named in the final report but your organisation will be named (provided you have the authority to agree to this on behalf of the organisation).

What will the project produce?

The information from my research will be used in my Master's Thesis, academic publications and conferences.

This project may produce commercialisable property.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before 30th April 2018;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- receive a copy of any images, video that are taken
- approve all images that will be published in the thesis
- read over and comment on a written summary of your interview
- be able to read any reports of this research by emailing the researcher to request a copy.

2

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.
CONSENT TO INTERVIEW
This consent form will be held until the 30th November 2018.

Primary Researcher: Katie O'Brien, Victoria University of Wellington, School of Design.

• I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

• I may withdraw from this study at any point before 30th April 2018 and any information that I have provided will be returned to me or destroyed.

• The identifiable information I have provided will be destroyed on 30th November 2018

• Any identifiable information I provide will be kept confidential to the researcher and their supervisors.

• The interview will be audio recorded and video will be taken if I show any important demonstrations.

• I understand that the results will be used for a Master's Thesis.

• I understand that I have no right to any commercialisable property that may result from this research.

• I consent to information or opinions which I have given being attributed to me/my organisation in any reports on this research and have the authority to agree on this on behalf of the organisation

• I agree not to disclose to any third parties any description of the designs that may be shown to me during the interviews   Yes ☐   No ☐

• I would like to pre approve the images taken before they are published   Yes ☐   No ☐

• I agree to take part in an audio recorded interview.   Yes ☐   No ☐

• I would like a copy of the recording of my interview: Yes ☐   No ☐

• I would like a summary of my interview: Yes ☐   No ☐

• I would like to receive a copy of the final report and have added my email   Yes ☐   No ☐
address below.

Signature of participant:_____

Name of participant: _____Date:_____

Contact details: _____

APPENDIX D

Manufacturer interview Information and consent forms

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.

INFORMATION SHEET FOR MANUFACTURER REPRESENTATIVE INTERVIEW

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Who am I?

My name is Katie O'Brien and I am studying a Master's Thesis at Victoria University of Wellington's School of Design. I am interested in industrial and product design, with a specific focus on the user experience. This research is being conducted as a requirement for a Master's degree.

What is the aim of the project?

The aim of this research is to identify barriers that influence people's engagement with Continuous Positive Air Pressure (CPAP) therapy when they are exposed to it for the first time. The identification of these barriers will influence design decisions that aim to improve the user experience of using CPAP equipment within the first week of therapy.

This research has been approved by the Victoria University of Wellington Human Ethics Committee. Application Reference number: 0000025272

How can you help?

You have been invited to participate in this research because you have expertise in CPAP development and you have knowledge of the experience of people in the first week using CPAP therapy. If you agree to take part I will interview either over skype or in person depending on your location. Interviews will either take place in a private place such as the firm you are associated with or Victoria University's School of Design in Wellington. I will ask you questions about your understanding of patient behaviours when adopting this therapy, aspects that influence patient engagement, and the procedures that your practise use to overcome the resistance of patients using CPAP therapy. The interview will take approximately 45 minutes. However, it may take longer if you have more information you would like to provide me with. I will audio record the interview with your permission and transcribe it later. I may video record any demonstrations that are valuable to this research with your permission. No content that is identifiable will be published

without your permission. You can choose to not answer any question or stop the interview at any time, without giving a reason.

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the research data will be combined and your identity will not be revealed in any reports, presentations, or public documentation unless you wish to have your identity published.

Only my supervisors and I will read the notes or transcript of the interview, videos and photographs taken. The interview transcripts, summaries, any photographs, audio and video recordings will be kept securely and destroyed on 30th November 2018.

You will not be named in the final report but your organisation will be named (provided you have the authority to agree to this on behalf of the organisation).

What will the project produce?

The information from my research will be used in my Master's Thesis, academic publications and conferences.

This project may produce commercialisable property.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before 30th April 2018;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- receive a copy of any images, video that are taken
- approve all images that will be published in the thesis
- read over and comment on a written summary of your interview
- be able to read any reports of this research by emailing the researcher to request a copy.

2

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.
CONSENT TO INTERVIEW
This consent form will be held until the 30th November 2018.

Primary Researcher: Katie O'Brien, Victoria University of Wellington, School of Design.

- I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

- I may withdraw from this study at any point before 30th April 2018 and any information that I have provided will be returned to me or destroyed.

- The identifiable information I have provided will be destroyed on 30th November 2018

- Any identifiable information I provide will be kept confidential to the researcher and their supervisors.

- The interview will be audio recorded and video will be taken if I show any important demonstrations.

- I understand that the results will be used for a Master's Thesis.

- I understand that I have no right to any commercialisable property that may result from this research.

- I consent to information or opinions which I have given being attributed to me/my organisation in any reports on this research and have the authority to agree on this on behalf of the organisation

- I agree not to disclose to any third parties any description of the designs that may be shown to me during the interviews   Yes ☐   No ☐

- I would like to pre approve the images taken before they are published   Yes ☐   No ☐

- I agree to take part in an audio recorded interview.   Yes ☐   No ☐

- I would like a copy of the recording of my interview: Yes ☐   No ☐

- I would like a summary of my interview: Yes ☐   No ☐

- I would like to receive a copy of the final report and have added my email   Yes ☐   No ☐ address below.

Signature of participant:_____

Name of participant: _____Date:_____

Contact details: _____

APPENDIX E

Participant interview and design activity, Information and consent forms

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.

INFORMATION SHEET FOR PARTICIPANTS FOR AN INTERVIEW AND ACTIVITY

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Who am I?

My name is Katie O'Brien and I am studying a Master's Thesis at Victoria University of Wellington's School of Design. I am interested in industrial and product design, with a specific focus on the user experience. This research is being conducted as a requirement for a Master's degree.

What is the aim of the project?

This project aims to identify barriers that influence people's engagement with Continuous Positive Air Pressure (CPAP) therapy. The identification of these barriers will help me to design prototypes that may influence how well the experience can be for people using this therapy for the first time.

This research has been approved by the Victoria University of Wellington Human Ethics Committee. Application Reference number: 0000025272

How can you help?

You have been invited to participate because you currently use CPAP therapy. If you agree to take part I will interview either over skype or in person depending on your location. Interviews will either take place in a private place such as Victoria University's School of Design in Wellington, or over skype. All transport costs will be reimbursed to you. I will ask you questions about your experiences using CPAP Therapy. I anticipate that this interview will take no longer than 45 minutes, however it can last longer if you would like to provide more information to me. I will audio record the interview with your permission and write it up later. You can choose to not answer any question or stop the interview at any time, without giving a reason.

You will receive an activity package after the interview that I would like you to fill out in your own time. These activities relate to your management of your therapy. This includes where you store and how you use your equipment.

The activity package consists of a disposable camera with a booklet that has a list of things that I would like you to take photos of. If you do not want to take any of these photographs you are not required to. You can choose to not complete or answer any of the questions in the activity package,

1

without giving a reason. Please make sure any images that capture, do not contain any identifiable information such as names, or photographs. If they do I will remove this content with image adjustment and censoring. I will give you a copy of the images you have taken if you would like. After the package has been returned to me, all postage costs will be reimbursed to you. If I want to publish some of the images in this thesis, I will ask for your permission to use these.

Finally, I would like to share the result of the project, such as the prototype designs, with you through a password protected blog and would welcome any feedback.

You can withdraw from the study by contacting me or any of my supervisors at any time before 30th April 2018. If you withdraw, the information you provided will be destroyed or returned to you.

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the published research data will not contain your identity. It will not be revealed in any reports, presentations, or public documentation.

Only my supervisors and I will read the notes or transcript of the interview. The interview transcripts, summaries and any recordings will be kept securely and destroyed on 30th November 2018.

If specific information from the activity package needs to be published, such as written content and the images taken will be published with your permission.

If specific information you have completed in the activity package, such as the written content and the images taken in the activity package is beneficial to this thesis, I will ask you for your permission to publish this content.

What will the project produce?

The information from my research will be used in my Master's Thesis, academic publications and conferences.

This project may produce commercialisable property.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before 30th April 2018;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- receive a copy of the content created from the activity package;
- approve any images taken that will be published in the thesis;
- receive a copy of any images taken that will be published in the thesis;

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.
CONSENT TO INTERVIEW AND PARTICIPATE IN RESEARCH ACTIVITY
This consent form will be held until the 30th November 2018.

Primary Researcher: Katie O'Brien, Victoria University of Wellington, School of Design.

- I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

- I may withdraw from this study at any point before 30th April 2018 and any information that I have provided will be returned to me or destroyed.

- The identifiable information I have provided will be destroyed on 30th November 2018

- Any identifiable information I provide will be kept confidential to the researcher and their supervisors

- Content from the activity package may be published in the Master's Thesis with my permission.

- I understand that the results will be used for a Master's Thesis.

- I understand that I have no right to any commercialisable property that may result from this research.

- My name will not be used in reports, nor will any information that would identify me.

- I agree not to disclose to any third parties any description of the designs that may be shown to me during the interviews   Yes ☐   No ☐

- I agree to take part in an audio recorded interview.   Yes ☐   No ☐

- I would like a copy of the content of my activity package: Yes ☐   No ☐

- I would like a copy of the recording of my interview: Yes ☐   No ☐

- I would like a summary of my interview: Yes ☐   No ☐

- I would like to receive a copy of the final report and have added my email address below.   Yes ☐   No ☐

Signature of participant:_____

Name of participant: _____Date:_____

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.
CONSENT TO INTERVIEW
This consent form will be held until the 30th November 2018.

Primary Researcher: Katie O'Brien, Victoria University of Wellington, School of Design.

- I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

- I may withdraw from this study at any point before 30th April 2018 and any information that I have provided will be returned to me or destroyed.

- The identifiable information I have provided will be destroyed on 30th November 2018

- Any identifiable information I provide will be kept confidential to the researcher and their supervisors.

- The interview will be audio recorded and video will be taken if I show any important demonstrations.

- I understand that the results will be used for a Master's Thesis.

- I understand that I have no right to any commercialisable property that may result from this research.

- I consent to information or opinions which I have given being attributed to me/my organisation in any reports on this research and have the authority to agree on this on behalf of the organisation

- I agree not to disclose to any third parties any description of the designs that may be shown to me during the interviews   Yes ☐   No ☐

- I would like to pre approve the images taken before they are published   Yes ☐   No ☐

- I agree to take part in an audio recorded interview.   Yes ☐   No ☐

- I would like a copy of the recording of my interview: Yes ☐   No ☐

- I would like a summary of my interview: Yes ☐   No ☐

- I would like to receive a copy of the final report and have added my email Yes ☐   No ☐
  address below.

Signature of participant:_____

Name of participant: _____Date:_____

Contact details: _____

APPENDIX F

User testing participant Information, consent and questions

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.

INFORMATION SHEET FOR PARTICIPANT FOR PROTOTYPE ASSESSMENT AND INTERVIEW

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Who am I?

My name is Katie O'Brien and I am a Masters student in Industrial Design at Victoria University of Wellington. This research project is work towards my Thesis.

What is the aim of the project?

The aim of this research is to identify barriers that influence people's engagement with Continuous Positive Air Pressure (CPAP) therapy when they are exposed to it for the first time. This assessment and interview aims to simulate a first time user of CPAP equipment. Prototypes are related to unpacking, setup and cleaning of the equipment. You will not be turning the equipment on, or using the therapy equipment.

This research has been approved by the Victoria University of Wellington Human Ethics Committee. Application Reference number: 0000025272

How can you help?

You have been invited to participate because you have never interacted with Continuous Positive Air Pressure (CPAP) Therapy equipment before. If you agree to take part I will provide you with a variety of activities interacting with the CPAP equipment and interview you afterward. You will not be turning the equipment on or using the therapy itself. You will be assessing various prototypes as a new user scenario. I will observe your interaction with these prototypes. This will take place at Victoria University of Wellington's School of Design. I will ask you questions about your experiences using these prototypes and your perception of the designs. The assessment will take approximately 45 minutes. I will video record the session with your permission and transcribe it later. You can choose to not answer any question o participate in any activity. You may stop the assessment and interview at any time, without giving a reason. You can withdraw from the study by contacting me at any time before 30th June 2018. If you withdraw, the information you provided will be destroyed or returned to you.

1

What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity but the research data will be combined and your identity will not be revealed in any reports, presentations, or public documentation.

Only my supervisors and I will read the notes or transcript of the interview and view the video and any still images taken from the video. The interview transcripts, summaries and any video recordings will be kept securely and destroyed on 30th November 2018.

Some of the action that you have completed in the prototype assessment, such as video recordings and images of your interaction, answers to the interview questions will be published with your permission. No published material will identify you.

What will the project produce?

The information from my research will be used in my Master's Thesis, academic publications and conferences.

This project may produce commercialisable property.

If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the assessment;
- withdraw from the study before 30th April 2018;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- receive a copy of the content created from the user assessment activities;
- receive a copy of any images taken that will be published in the thesis;
- read over and comment on a written summary of your interview
- be able to read any reports of this research by emailing the researcher to request a copy.

VICTORIA
UNIVERSITY OF WELLINGTON

Influencing engagement with CPAP therapy through design.
CONSENT TO PARTICIPATE IN PROTOTYPE ASSESSMENTS AND INTERVIEW
This consent form will be held until the 30th November 2018.

Primary Researcher: Katie O'Brien, Victoria University of Wellington, School of Design.

• I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.

I understand that:

• I may withdraw from this study at any point before 30th April 2018 and any information that I have provided will be returned to me or destroyed.

• Any identifiable information I provide will be kept confidential to the researcher and their supervisors and will be destroyed on the 30th November 2018..

• The interview will be audio and video recorded.

• Results from the interview and assessment may be published in the Master's Thesis with my permission.

• My name will not be used in any reports, nor would any information that would identify me.

• I understand that the results will be used for a Master's Thesis.

• I understand that I have no right to any commercialisable property that may result from this research.

• I agree not to disclose to any third parties any description of the designs that may be shown to me during the interviews   Yes ☐   No ☐

• I would like to pre approve the images taken before they are published   Yes ☐   No ☐

• I agree to take part in an audio recorded interview.   Yes ☐   No ☐

• I would like a copy of the recording of my interview: Yes ☐   No ☐

• I would like a summary of my interview: Yes ☐   No ☐

• I would like to receive a copy of the final report and have added my email address below.   Yes ☐   No ☐

Signature of participant:_____

Name of participant: _____Date:_____

Contact details: _____

1.   This system is very easy to assemble.

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

2.   I could travel easily with this equipment.

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

3.   I easily understood how to clean this device

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

4.   I easily understood how to disassemble the mask to clean it

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

5.   I would keep all of the packaging

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

6.   This would suit my bedroom

       Strongly Agree   Somewhat Agree   Agree   Disagree   Strongly Disagree

Could you briefly explain your answer? _____

_____

7.   I think that the mask is worth...

            $1-100 $101-$200 $201-$300 $301-$400 $401- $500 $500<

Could you briefly explain your answer? _____

_____

8.   I think that the CPAP Machine is worth...

   $101-$300 $301-$500 $501-$700 $701- $900 $901<

Could you briefly explain your answer? _____

_____