

Discourse and Design of CPAP Therapy Masks for OSA

Applying Foucault to Product Design Research

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Abstract

Current approaches to personal medical product design address complex governance, technical and functional issues. However, little attention has been given to broader perceptions of the social and interpersonal issues related to medical products despite community attitudes playing an important role in supporting or inhibiting treatment uptake. Rethinking personal medical product design in light of the complex social contexts that they inhabit is needed to improve their desirability and subsequent uptake.

Using the Continuous Positive Airway Pressure (CPAP) therapy mask when used to treat Obstructive Sleep Apnoea (OSA) as one example of a personal medical product, this study explored the social construction of breathing interfaces, by taking a critical approach to the design process. The purpose was to investigate how identification of the social and, relational understandings that are integrated into the design process and the product itself could be used as a tool to rethink and develop new possibilities for breathing interfaces and people with OSA.

This study explores the application of a post-structural philosophical approach to a live design project based on the work of the French philosopher Michel Foucault. Data is in the form of discursive texts¹. These texts are analysed using adapted Foucauldian discourse tools in combination with design tools and approaches. Texts for analysis include: 1) Existing literature on OSA, breathing masks (including the CPAP therapy mask) and patient experiences of them; 2) a CPAP therapy mask and packaging; 3) a total of 11 semi-structured interviews with clinicians and community advisors; 4) community market-based exhibitions of critical probes, involving culturally probing interactions with 50 passers-by; and 5) notes and reflections from design explorations, scoping conversations and clinic visits.

Findings show that the design of the mask is constrained by discourses associated with Western situated cultural aesthetics, masculine occupations and scientific legitimacy. While ‘successful’ users are almost evangelical about the CPAP therapy mask for treatment of OSA, the analysis shows how the subject position of the ‘successful’ user is shaped by the CPAP therapy mask design, and that there are multiple tensions for those who do not achieve this subject position. Indeed, data from the community markets reveals the diversity of subject

¹ Texts, in Foucault’s conception of discourse, are anything that makes a statement and includes material items, e.g., images, recordings, written material, spoken statements, practices and artefacts (see section 4.2).

positions that exist in relation to the mask and who participate in its social construction. The market-based interactions highlight subject positions that have been previously overlooked in human-centred design and the discursive tensions that affect device perceptions and potential uptake.

The findings of this study have highlighted design factors and effects (relating to uptake of a product) that have not been considered previously, and would not be accessible using current human-centred design approaches. The findings have highlighted important considerations specific to the CPAP therapy mask design, and the approach itself offers valuable material for the study of medical devices more generally. Indeed this may have even broader applicability in product design by presenting a method of appealing to a range of actual and potential future users, whose needs remain currently unmet.

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Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature:

Co-authored works

Two chapters of this thesis have been revised into journal articles for submission. The paper titles and authorship are as follows:

Cunningham, Helen. J., Fadyl, Joanna K., Reay, Stephen. D., White, David E. "Discourse and Co-design: exploring a critical approach to community engagement in design for health" (unpublished).

Cunningham, Helen. J., White, David E., Reay, Stephen. D., Fadyl, Joanna K., "Breathing interfaces and Obstructive Sleep Apnoea: Is there a need for a new approach to breathing support interface design?" (unpublished).

The papers are a revised version of chapters four and five respectively. In each case the intellectual contribution and writing was led by HC, supported by SR, DW and JF. HC wrote the first draft of each manuscript and revised them in light of suggestions from SR, DW and JF.

Work from these thesis has also been presented at the following conferences:

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The presentations are a revised version of chapters four and five respectively. In each case the intellectual contribution and presentation was by HC supported by and revised in light of suggestions from SR, DW and JF.

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Chapter 1 Introducing the thesis

The question to be asked of a face is not ‘what does a face represent?’ but rather, ‘what can a face do?’ (Rushton, 2002, p. 225)².

It reshapes the world so that we think or feel the world differently. When confronted by a face, whether reflective or intensive, we must re-coordinate [sic] our view of the world and subsequently our actions in that world. ... The face, more than anything, makes us approach the world anew. (Rushton, 2002, p. 234)².

Engaging with clinicians, researchers and community members as part of this inquiry has led to a profound reshaping of my understanding of the nature of design and the role of design practitioners in the development of medical products. In exploring not what a device, product, material, research tool or practice represents, but rather what it ‘does’ (i.e., how it reshapes the world or operates as a social construction), unchallenged assumptions are made visible. In this study, an investigation into the social construction of a device and how its many configurations and elements operate historically, materially, socially and culturally was made possible through an analysis of the situation, language, physical expression and interaction. The inquiry highlighted complex interconnections that make aspects of design seem self-evident – so sensible as to be almost inevitable. However, making these interconnections explicit enabled the possibility of becoming free to challenge this apparent inevitability and consider under what circumstances it might be otherwise.

1.1 Study origins

This study developed from research that is situated within the clinical and engineering disciplines of AUT’s School of Engineering. The engineers involved in that research developed a new Continuous Positive Airway Pressure (CPAP) breathing therapy technology. This novel technology aimed to improve treatment usability for those with breathing concerns (White, Makinson, & Bartley, 2014). The research team however had not yet developed an appropriate face mask interface for this technology. One critical application and potential market for the

² These quotes are in response to a contemporary of Michel Foucault, Gilles Deleuze, who is known, in some part, for his philosophical explorations that broadened previous conceptualisations of the face. Deleuze and Félix Guattari engaged with the concept of the face, broadening it to mean a recognizable assemblage that humans respond to in ‘Faciality’, chapter 7 of their popular book: *A Thousand Plateaus* (Deleuze, G., & Guattari, F. (1987). *A thousand plateaus: Capitalism and schizophrenia*. Minneapolis, Minnesota: University of Minnesota Press.). This is the work primarily responded to by (Rushton, R. (2002). What can a face do? On Deleuze and faces. *Cultural Critique*, 51(Spring 2002), 219-237.). Discussed on page 121.

new technology was as a treatment for Obstructive Sleep Apnoea (OSA). OSA is a condition that occurs during sleep. For people with this condition, the upper airway collapses and blocks or obstructs airflow to the lungs resulting in reduced oxygen flow to the brain. The brain rouses the nervous system, disrupting the sleep cycle and waking the sleeper as frequently as every two minutes which results in sleep deprivation.

It is worth noting that there are two important types of sleep apnoea. The second type is Central Sleep Apnoea (CSA), which is caused by a failure of the nervous system to trigger the breathing impulse successfully. Unless otherwise specified, the use of 'sleep apnoea' in this document refers to OSA and unless otherwise specified, CPAP therapy refers to CPAP therapy delivered through a mask on the face worn specifically for the treatment of OSA. CPAP therapy mask refers to face-worn CPAP therapy interfaces with physical forms such as the nasal, mouth or full face masks as detailed in section 5.3 but with a particular focus on nasal and full face masks due to their prevalence in publicly funded CPAP therapy treatment for OSA in New Zealand.

Within clinical, population health and economic discourses, untreated OSA is important due to its relatively high prevalence. A US study found that an estimated 2% of women and 4% of men in the middle-aged workforce met the threshold for diagnosis of OSA (Young et al., 1993, p. 1230) (see also section 5.1). This high prevalence amplifies the associated burden of the potential for severe health impacts, personal incapacitation, premature death and other associated family and social effects (American Sleep Disorders Association, 1997; Phillips, 2005; Shapiro & Shapiro, 2010). OSA is associated with hypertension, and almost every adverse cardiovascular condition has been associated with this condition (Phillips, 2005, p. 131). Myriad other disorders may become more problematic if OSA is not controlled (Shapiro & Shapiro, 2010, p. 324). The condition also presents an ongoing cost to society through the subsequent cost of healthcare complications and accidents (Sassani et al., 2004, p. 543) and reduced worker productivity (Mulgrew et al., 2007, p. 42).

Within clinical discourses, CPAP treatment is the clinical 'gold standard' for treatment for OSA (McNicholas & Bonsignore, 2007). Evidence for clinical success of the treatment is also robust (Shapiro & Shapiro, 2010, p. 324). However, studies into CPAP effectiveness have found low rates of treatment use. The majority (75%) of patients use their devices for less than the minimum prescribed average four hours per night (Arfoosh & Rowley, 2008). Furthermore, around 50% of patients will discontinue using CPAP in the long term (Worsnop, Miseski, & Rochford, 2010, p. 650). Uptake and continuation of treatment rates have also not changed despite solving many of the physical comfort issues reported by users. In other words, the low

rate of overall use persists despite the discourses of clinical success of the therapy. Steady low use rates highlight the ongoing failure of patients to effectively maintain the ongoing use of CPAP therapy within the broader social context of their own lives. As a result, the inability to effectively use CPAP therapy outside of clinical settings remains a significant barrier to the well-documented benefits of the treatment (Shapiro & Shapiro, 2010, p. 335).

My search of the CPAP therapy literature found an acknowledgement of the multifactorial nature of problematic CPAP therapy adherence (see section 5.2). However, I did not find any studies that explicitly used a design process such as co-design, human-centred design (HCD) or design thinking to address this issue. The absence of HCD as an approach was in spite of its demonstrated strength in dealing with other complex and multifaceted problems, particularly those associated with long term and chronic illness (Das, Bøthun, Reitan, & Dahl, 2015; Hendriks, Slegers, & Duysburgh, 2015; Kanstrup, 2014; van Rijn, van Hoof, & Stappers, 2009).

The work of philosopher Michel Foucault (1926-1984) provided tools particularly well suited to recognising the roles of discourse, power and the subject (McHoul & Grace, 1998). Foucauldian discourse analysis is an approach that asks: what are the effects of underlying attitudes about what is considered true or so evident as not to be sensibly questioned within a discipline or broader society? Many similar assumptions are richly embedded in the treatment space of CPAP therapy for OSA, particularly when considering this space outside of clinical settings. Despite an extensive literature search, I did not find post-structural discourse analysis that has been used as an approach to HCD and design thinking with the primary objective of creating a design intervention.

This study contributes to knowledge by developing and modelling the use of post-structural discourse analysis as a design research tool in two forms:

1. Post-structural discourse analysis as a philosophical framework for re-envisaging a design approach that addresses issues of philosophical consistency in the generation of new insights.
2. Using post-structural discourse analysis as a design tool for mapping the discourses that shape existing design embodiments. Applying discourse analysis as a design tool focuses on making visible the unchallenged assumptions that can be inherent in common design processes. Questioning unchallenged assumptions can be used as a trigger for identifying new possibilities.

Applying discourse analysis as a design tool is a new approach, used in the exploratory phase when developing a product design intervention. This new approach is of significance to design

research as a discipline and also in the context of design for healthcare and specifically, chronic illness.

In this study, I worked from the theoretical perspective that bodies (as conceived of in Foucauldian terms), technologies, and their meanings are always socially and culturally embedded. The Foucauldian theoretical perspective I used is a significant departure from clinical and engineering approaches where bodies and technologies are understood to exist independently from their social and cultural contexts.

This study is designed to focus on three main questions:

1. How might Foucauldian concepts of discourse analysis be used to explore the social construction of the CPAP therapy mask?
2. How might exploring the social construction of the CPAP therapy mask (and its design process) assist designers in identifying and challenging 'truths' that are current and held to be 'self-evident'?
3. How might knowledge of these 'self-evident' truths (or assumptions) be used to explore new possibilities for breathing interfaces generally, and with a focus on CPAP therapy face masks and people on the spectrum of living with OSA specifically?

Within a post-structural framework, value is understood to be contingent (i.e., valuing things in a certain way occurs only in the broader context of everything else that co-exists or is happening at the time without taking the extra step of determining causation). The same things could be expected to be valued entirely differently in another time or culture, or in the current time and culture but from a different frame of reference. Thus aiming to 'improve' a situation in absolute terms is problematic. Instead of aiming for an absolute improvement, targeting the 'exploration of possibilities' allows for the various and differing discourses of value that may co-exist in any situation. It is also likely that some of these possibilities will result in an improved valuation of some perspectives.

This study took the form of a front-end design process incorporating Foucauldian discourse analysis. The purpose was understanding and mapping the current discourses that have constructed CPAP therapy masks for OSA treatment. Developing this contextual understanding required identifying the interactions between the dominant discourses involved in the design process. For example, engineering and clinical knowledges and practices tend to value functionality and economic viability, whereas HCD knowledges and practices highly value personal emotional experience and meaning. The way these two potentially different value sets are weighed and negotiated in relation to each other is likely to impact considerably on

the outcome of the design process. However, these decisions and the dominant discourses underlying and influencing them are unlikely to be made explicit or examined using a systematic approach with existing HCD tools.

1.2 Situating the study

The CPAP therapy literature I reviewed distinctly acknowledged the multifactorial nature of CPAP therapy adherence (Shapiro & Shapiro, 2010). Many studies address CPAP therapy for OSA with a view to understanding the patient experience, using approaches familiar and well suited to scientific and clinically robust processes (Aloia, Arnedt, Stanchina, & Millman, 2007; Ayow, Paquet, Dallaire, Purden, & Champagne, 2009; Broström et al., 2008; Broström et al., 2010; Broström et al., 2007; Broström et al., 2009; Dickerson & Kennedy, 2006; Engleman et al., 1996; Galetke, Puzzo, Priegnitz, Anduleit, & Randerath, 2011; Holmdahl, Schöllin, Alton, & Nilsson, 2009; Meslier et al., 1998; Moroni, Neri, Lucioni, Filipponi, & Bertolotti, 2011; Pépin et al., 1995; Sage, Southcott, & Brown, 2001; Smith et al., 1998; Tyrrell, Poulet, Pépin, & Veale, 2006; Veale, Poussin, Benes, Pepin, & Levy, 2002; Wang, Gao, Sun, & Chen, 2012; Ward, Gott, & Hoare, 2017; Zampogna et al., 2019). While enabling reliable insights and powerful interventions based on sound forms of knowledge, these processes also limit what can be recognised and included for study. As Veale et al. (2002) acknowledge, “[i]n a non-directed conversation, ... [OSA] patients express concerns not revealed in the standard medical paradigm, and such concerns should be addressed in assessing treatment or evaluating the quality of life” (p. 389).

Similarly, the framing of research approaches has been found to cast CPAP therapy as negative and problematic, potentially influencing the information obtained and the approaches deemed worthy of pursuit (Ward, Hoare, & Gott, 2014). As mentioned earlier, I did not find any studies that explicitly used a design process such as co-design or human-centred design to help define or address the problems associated with CPAP therapy (although user-centred design focussed on the device has been proposed as an alternative to that of engineering design by Bitterman, Klimovich, and Pillar (2019)). The lack of co-design or generative design approaches with OSA was apparent despite their demonstrated strength in dealing with other complex and multifaceted problems associated with long-term and chronic illness. For example, generative design for progressive lung disease (Das et al., 2015), living lab and digital design for diabetes (Kanstrup, 2014), co-design for people living with impairment (Hendriks et al., 2015) and co-design for elderly and dementia (van Rijn et al., 2009). Mullaney, Pettersson, Nyholm, and Stolterman (2012) also completed a study of mask restraint for radiation therapy. In this study, they found the bulk of patient-based interventions aimed at improving the patient’s capacity

to cope with the mask and device (Mullaney et al., 2012, p. 29). The study did not address design assumptions that may act as triggers for negative patient experiences (Mullaney et al., 2012, p. 29). Findings that targeted building patients' capacity to cope and not changes to device design were also common in approaches to CPAP therapy interventions.

Some studies demonstrated the potential to improve CPAP therapy usability through a range of clinically based interventions. These interventions included: an educational video, follow up phone calls and additional appointments (Lewis, Bartle, Watkins, Seale, & Ebdon, 2006, p. 242), an audiotape with soft music and instructions for deep breathing and relaxation at bedtime combined with a diary to record their intervention related experiences (Smith, Dauz, Clements, Werkowitch, & Whitman, 2009, p. 184), and motivational strategies (Dantas, Winck, & Figueiredo-Braga, 2015). A systematic review of CPAP therapy adherence looked at clinical and empirical insights for developing adherence interventions (Sawyer, Gooneratne, et al., 2011). Sawyer, Gooneratne, et al. (2011) concluded that "significant opportunities exist to develop and test interventions that are clinically applicable, specific to subgroups of patients likely to demonstrate poor adherence, and address the multifactorial nature of CPAP therapy adherence" (p. 343).

Mass produced items, including medical devices, are typically designed by engineers or industrial designers. Design occurs in a team setting based on advice from the scientific literature and clinician input. Thus the industrial model of design involves an expert designer who gathers information from users and then creates a response separately from them (Sanders & Stappers, 2012). Designers have created many successful treatment technologies by adhering to this dominant design regime. However, this technological determinism falls short when it is too focussed on achieving an efficient design for a predetermined usage pattern. This is particularly so, when the design embodiment becomes limited in interactivity, exploration and learning (Giacomin, 2014). Suchman (2007, p. 178) highlighted this constraint, whereby interactions and meanings are the results of a difficulty in defining the communication process. Giacomin (2014) articulated this as "a process of communication and learning which cannot be fully anticipated within the original physical, perceptual and cognitive objectives of the design" (p. 609). The use of empathetic ethnographic-based techniques that specifically target emotional engagement during the design process, as proposed earlier by Norman and others, lead to more involved interactions and better usage outcomes (Norman, 2005).

Collaborative design or co-design was a further development in human-centred design based on the idea of partnership and equal participation in the design process (Sanders & Stappers,

2012, p. 15). Design roles in collaborative design approaches differ from the role of a more traditional designer who would lead the process as the expert. Collaborative design works on the premise that people are the experts through their own experience and are inherently creative (Sanders & Stappers, 2012, p. 15). This sharing of the expert role changes the experience not only for the designer but also for other stakeholders.

This image has been removed by the author of this thesis for copyright reasons.

<https://i.pinimg.com/originals/19/73/a0/1973a095b77a02d09c196e78e4f8b1b3.jpg>

Figure 1. The roles of researcher, user and designer in classical user-centred design and co-design models.

Source: Sanders and Stappers (2008, p. 11).

As Figure 1 shows, changing these fundamental differences in underlying assumptions about the design process changed the flow of information and resulted in more equal levels of power between participants within the design process (Sanders & Stappers, 2012). However, assessing the management of power relations often occurred after the fact rather than as an integral part of the process (Iivari, Kinnula, & Kuure, 2015; Jensen, 2008). Some designers and researchers considered HCD in terms of developing experiences rather than being primarily focussed on technical function, as was often the primary focus when designing medical devices. A co-design approach offered tools to assist in the process of managing power relations within a design framework. More active management of power relations resulted in a more significant weighting towards input from the broader community, including users and patients (Sanders & Stappers, 2012).

Krippendorff (2006, p. 48) put forward the concept of design as a way of making sense of things. He described HCD as being concerned less with assuring artefacts work as intended than with enabling many individual or cultural conceptions to unfold (Krippendorff, 2006, p. 48). He also states that these uninterrupted interfaces with technology attain user-centeredness only when attention shifts from objects to the processes of human involvement (Krippendorff, 2006, p. 48). In defining HCD, Giacomini (2014, p. 607) positions design as an intention as well as a physical process that includes drawings and sketches and further

describes it as “the driving force of creative thought itself” (Giacomin, 2014, p. 607). Giacomin (2014, p. 607) further likened usage of the word design to that of discourse as defined by Foucault (2002) and Butler (2002). He restated their position:

In this usage the ‘design’ assumes a role similar to that of postmodern discourse as defined by Foucault and others [Butler (2002); Foucault (2002)], thus it refers to language which is absorbed and exchanged between people, providing the basic units of meaning. (Giacomin, 2014, p. 607).

Hook (2001) contested and has thoroughly critiqued this view of Foucault’s definition of discourse as referring only to language and the application of a Foucauldian methodology with an emphasis on language and meaning (see chapters 2 and 3). Within his critique, Hook (2001) presents a reading of Foucault that includes materiality, within Foucault’s definition of discourse. He further promoted Foucault’s emphasis on the effects of discourse. Emphasising language and the meaning of discourse was dominant in some of the psychology based-applications of Foucault, and in other language-focussed forms of discourse analysis (Hook, 2001). Foucault advised understanding discourse not as signs or text but in terms of ‘practices that systematically form the objects of which they speak’ (Foucault, 1972, p. 49). He formulated discourse as being constituted through power, knowledge and truth (Foucault, 1980). (Giacomin, 2014) characterised Foucault’s discourse as language and meaning in a way that limits the breadth of application and opportunities that set Foucauldian discourse apart from its linguistic counterparts. Favouring a language-focussed view of discourse also seems to limit its use in a discipline focussed on the creation of material objects, systems, images and sensory experiences.

In the literature I reviewed, Faust (2015) provided one of the few Foucauldian discourse analyses that addressed design and discourse directly. In it, Faust analysed his approach to Foucault by referring to Krippendorff (2006) in *The Semantic Turn*. However, within this critique, he also characterised Foucault’s approach to discourse as “primarily focussed on language” (Faust, 2015, p. 85).

Krippendorff referred to Foucault only twice in *The Semantic Turn*³ (2006). In one case, he critiqued the validity of semiotic theories and used Foucault’s terminology of “regimes of power” (Krippendorff, 2006, p. 276). Krippendorff (2006, p. 276) explained Foucault’s “regimes

³ *The Semantic Turn* was a seminal text for the emerging trend toward human-centred design, defining an approach to design that focuses on product semantics, analogous to language semantics - through which meaning is produced.

of power” as being essential to keep meanings stable and describable propositionally. The second reference relates to Chernyshevsky’s political economy of aesthetics where Krippendorff (2006, p. 308) groups Foucault with Roland Barthes, Jean Baudrillard and Antonio Gramsci concerning the power of institutions.

Webster (2006) used Foucauldian discourse analysis and related Actor-Network Theory⁴ (ANT) to analyse relationships of power and the social process within design processes retrospectively. In studies, ANT has generally been used to analyse social processes retrospectively rather than as a design tool, or by a designer to understand the context in which they design. Other examples of using ANT and Foucault include a study assessing children’s participation in co-design for Information and Communications Technology (ICT) (Iivari et al., 2015), and as an after-the-fact analysis of a hospital telephone system (Jensen, 2008).

As the preceding discussion has outlined, there are particular design based approaches to any inquiry, namely human-centred design thinking and co-design that have been under-utilised in designing OSA treatment systems. These approaches, combined and augmented using a post-structural philosophical lens, are well suited to a design project focussed on the design possibilities for CPAP therapy masks. Using this approach to inquiry is appropriate due to the multi-factorial nature of the problem and its contextual location within treatment for chronic illness. I will discuss in more detail the form of the inquiry and issues associated with it on a philosophical basis in the methodology and design of study chapters (chapters 2, 3, 4). Figure 2 shows a visual representation of the approach taken in this study.

⁴ “Actor-Network Theory is a framework and systematic way to consider the infrastructure surrounding technological achievements. It assigns agency to both human and non-human actors (e.g., artifacts)”. Source: David L. (March 23, 2007). Actor-Network Theory (ANT). *In Learning Theories*. Retrieved from <https://www.learning-theories.com/actor-network-theory-ant.html>.

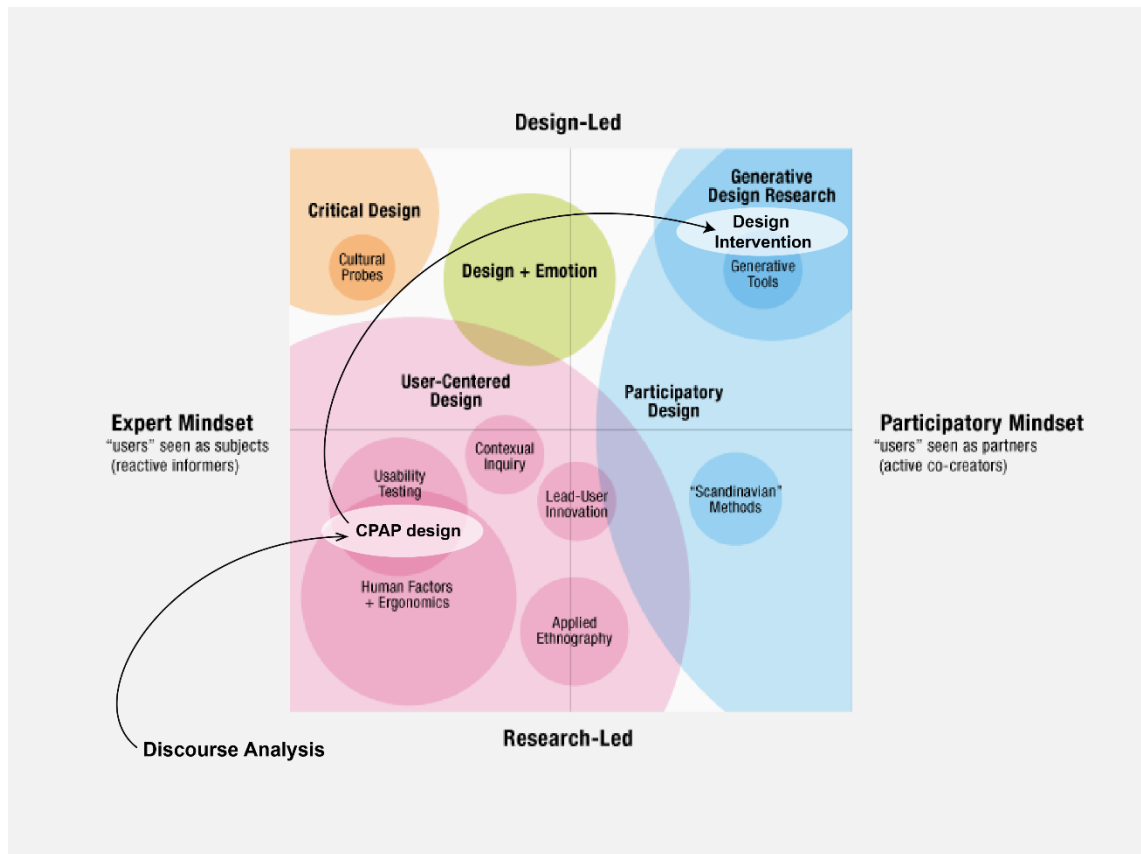


Figure 2. The current landscape of human-centred design research.

Image shows current CPAP design and the change in perspective proposed, showing the development of an explorative, collaborative, generative approach. It shows a shift from bottom left to top right in the development of new design possibilities. Source: Author's annotation of image from Sanders (2008, p. 3).

1.3 My background and interest in this study

My background and initial training was as a professional mechanical engineer. I completed a Bachelor of Engineering with honours motivated in part by an early interest in motor vehicle design. I subsequently completed a Master of Engineering Science research degree at the University of Tasmania, Australia. My Master's thesis focussed on the use of artificial neural networks in the prediction of vehicle roll-over parameters in a race car to improve vehicle safety. I worked for a number of years in Australia as an engineer in heavy industry, including mining, before returning to university to study undergraduate product design.

I am subject to my social positioning through discourses of gender and ethnicity as an Anglo-Australian woman. I can further situate my experience as the relative of a pedestrian that died in a motor vehicle accident. The role of driver fatigue in vehicle accidents emerged as a critical discourse during my time in industry. Extensive training about fatigue management was standard for the site where I worked and was generally well internalised by employees. My perception of these experiences framed my interest in the research approach I have taken.

Returning to university to study product design was also partly motivated by an interest in finding ways that my (then engineering) design practice could better deal with the social complexity of design processes. These aspects included the need for tools that would help to seek input, build consensus and generally improve the acceptance of design embodiments amongst users once implemented. These socially-focussed design aspects were all areas that received little attention in my previous studies but were essential factors in the success of many projects in the workplace. Having now trained as a designer, I have deliberately focussed on considering the limits of traditional scientific, clinical and engineering research approaches to the design of a CPAP therapy mask.

My early scoping work focussed on clinicians and users. This focus produced results that aligned with what was available at that time in the clinical literature (see section 1.2). Using a CPAP therapy mask for 4 nights over a long weekend demonstrated to me the intense focus on adapting to and mitigating the physical factors that emerge when using a CPAP therapy mask. Perhaps based on my background, the drive to ensure the CPAP therapy mask continued to operate physically as well as it did overshadowed any new possibilities for me when working from this perspective. The human centred design approaches and methods that I used in early exploration provided limited new insights beyond those already reflected in the literature.

Interestingly, I did not enthusiastically dive into using role play as a design tool by wearing the CPAP therapy mask product as I would normally do in a design process. Instead thoughts of wearing the mask reminded me of serious family illness, and the distress and fears I felt at that time. I strongly associated it with transparent breathing support masks in hospital wards and intensive care units. I found very little written about my associations and their effect on willingness to use a mask. My own association with the mask led me to consider whether experiences of other breathing support masks can play a role in the social construction of the CPAP therapy mask⁵. I became interested in the plight of those faced with the possibility of needing CPAP therapy more broadly and how this operates in the community.

Previously working at Fisher and Paykel Healthcare for several months over a summer had made me aware that product design and engineering approaches were also well known within manufacturing contexts. My interest in seeking new insights and a contribution niche for the research led me to seek out a Foucauldian methodological perspective.

⁵ The association between broader forms of mask use was also apparent in community based data collection with people referencing other masks and medical conditions treated with mask therapies.

Moving the focus away from CPAP therapy users was also in response to other research being undertaken concurrently in the Auckland context. Dr Kim Ward was completing a PhD on perspectives and strategies of successfully use CPAP therapy in the longer term. At the time of writing only some of the study results were published and investigation in this area appears to be ongoing (Ward et al., 2017; Ward, Gott, & Hoare, 2018; Ward et al., 2014). These findings further reflect and complement perspectives I found in my own research (see sections 9.3 and 10.2). My particular interest in this study was in using design and creative processes to identify potential 'missing demographics' from CPAP therapy mask users.

Consequently, my research aimed to seek opportunities to increase diagnosis, treatment uptake and use. I was also interested in how to better understand the factors that might make masks more appealing to people who may not yet have a formal diagnosis of OSA, rather than a particular focus on improving the comfort of existing users. As with any researcher, my background and subjectivities sensitise me to privilege particular situations and viewpoints. I have endeavoured to acknowledge this where I have recognised it, and have sought to present contrasting and counter-arguments to provide a balanced perspective. I address the role of my subjectivity as a designer further in chapter eight.

1.4 Structure of the thesis

This thesis consists of twelve chapters. Following this introduction, I have arranged the remaining chapters into three parts: 1. Developing the study methodology, 2. Exploration of the social construction of the CPAP therapy mask artefact and the successful user, and 3. Community attitudes.

The first three chapters focus on the philosophical background and methodological development of the data collection and analysis tools that I developed specifically for this study:

Chapter 2 (Foucauldian philosophical position and key theoretical concepts), introduces the philosophical and theoretical basis upon which I have built this study and the methodology I devised. In order to draw on discipline-diverse knowledges and practices, I used a post-structural approach. This approach uses the tools of French philosopher Michel Foucault (1926-1984).

Chapter 3 (From methodology to methods) outlines the methodological approach used in the study. I have provided explanations of how existing documents have been read and

interpreted in the context of this thesis. I also state my approach and justification, in which I have taken a specific position on concepts of materialism, or in other cases where more than one interpretation may be present in the literature.

Chapter 4 (Study design) addresses the design of the study and specific methodological applications of Foucault's tools in the context of re-envisioning a co-design process for improved philosophical consistency.

The next group of three chapters focuses in on how the CPAP therapy mask is shaped in the peer-reviewed literature, by manufacturers, and in legislation and history, and how it, in turn, shapes the kinds of people who can use it with success.

Chapter 5 (Contextual review findings) reviews clinical literature and supports the selection of the CPAP therapy mask for OSA treatment. I identify the gaps in previous research and articulate the research questions that form the basis for the remaining investigation.

Chapter 6 (Legitimacy and normativity in discourses of mass manufacture) presents the findings from the first stage of the inquiry and is focussed on a typical CPAP therapy face mask product. This chapter explores the constraints evident in the current design against a material 'history of the present' and constructions of legitimacy and normativity in discourses of mass manufacture.

Chapter 7 (The 'successful CPAP therapy user' - legitimised mask shapes the user) explores the birth of legitimised CPAP therapy, demonstrating how the 'successful user' and their treatment were co-created and legitimised together. Analysis of the 'successful user' subject positions from community market data constructs how users and their families have embraced dominant discourses in order to become 'successful users'.

The next four chapters shift focus from the CPAP therapy mask outwards to the community. These chapters explore the role of resistance in the study. I examine the limits of the design embodiment of the CPAP therapy mask in terms of dominant discourses that do not fit within the design limits of the mask and the tensions between different discourses.

Chapter 8 (Exploration of resistance through exhibition and analysis of artefacts), presents the study as a resistance to standard HCD tools and processes. I explore findings from the second stage of the inquiry and focus on markets, subject position and critical probe development. This chapter analyses the responses specific to the method of philosophically-driven post-structural community engagement. It covers the analysis of critical probe artefacts that render

visible the medical discourses of the mask to a general audience, then discusses their specific responses to them.

Chapter 9 (Subject positions outside of those assumed by mask designers) analyses the market data in terms of subject positions constructed in ways outside those assumed in the design of the CPAP therapy mask. In particular, I consider assumptions around privacy, sleep patterns and patient and household roles in terms of the mask artefact analysed in chapter six and data collected in community market sessions.

Chapter 10 (Conflicting discourses for dominant subject positions and design strategies) analyses market data relative to constructions of subject positions that relate to traditional forms of masculinities. I identify a number of marginalised subject positions along with specific strategies, desires and fears that appear to be specific to these positions. I argue for various discourses in the community that conflict with ‘successful user’ discourses in ways that generate complex tensions for designers and potential users to navigate.

Chapter 11 (Mass production and healthcare - an individualising and totalising power), explores constructions of and tensions between the individual and the community. I unpack the process of individualisation as one way of thinking about the data presented. I give examples of how participants have expressed discourses of illness as a challenge to their identity as part of a community, and their social standing. I discuss practices of resistance to these individuating discourses that are present in the data.

The final chapter reviews the process that has been developed and evaluates the experiment of using a post-structural approach to design exploration.

Chapter 12 (Why does this matter for design? Combining post-structural approaches with design), provides a summary and discussion of the study undertaken and explores how the study has addressed the question of *what a post-structural approach can offer design*. I summarise the critical contributions of the study and highlight useful focal points for future research.

1.5 Ethical Approval

An ethics application for expert interviews and re-envisioned co-design sessions was approved by Auckland University of Technology Ethics Committee (AUTC) under application 16/167 Design for sleep apnoea therapy interfaces (see Appendix A:).

1.6 Reference conventions

I have presented references in APA 6th format. Due to the interdisciplinary nature of the study, I have included page numbers where possible. This approach aims to assist the reader who may be dealing with material not usually included in their specialist field to quickly and accurately identify source material. The referencing process used is consistent with recommendations for design discipline research studies (Friedman, 2015, p. 27).

1.7 Summary

In this chapter, I have situated my interest in and approach to the research topic. I have introduced the background, aims and organisation of the inquiry detailed in this thesis. Chapter eight discusses further the role of resistance, not only in developing the approach I have taken in this study, but also in enabling the research methods I have developed and the responses from research participants. The next chapter, will explore the philosophical position and critical concepts driving the research and how these informed and shaped the project and the review of published literature in chapter five. Addressing these concepts in the second chapter of this thesis, rather than in a separate literature review, is a deliberate departure from a more traditional thesis structure. However, this provides a more appropriate flow of logic, given the philosophically-driven nature of the exploration.

Chapter 2 Foucauldian philosophical position and key theoretical concepts

The body of this thesis begins by situating the work of Foucault within broader social constructionist attitudes to reality, and then more specifically within post-modern and post-structural approaches. I have taken this path because the philosophical conceptualisations of knowledges defines the form and limits of this study and the ‘gap in knowledge’ that this study seeks to fill. As mentioned earlier, this thesis diverges from a traditional format that would see a literature review located in the second chapter. Instead, this foundation chapter focuses on articulating the philosophical position and the critical theoretical concepts upon which the rest of the study relies. A detailed discussion of the published literature about CPAP therapy masks for OSA appears later in the thesis in chapter five, as I treat this literature itself as data. In the current chapter, I draw selectively on Foucault’s work to focus in on the ideas and approaches most relevant to the study as I do not attempt to summarise or define the limits of Foucault’s wide-ranging works. Instead, this chapter addresses the principles of inquiry and critical Foucauldian concepts that were important to the study, as well as being a valuable background for a more generalist design audience. The concepts are central in the construction of this thesis, and therefore crucial to detail at the outset. The current chapter provides a foundation for chapter three, where I apply my specific interpretation and reading of particular approaches to the development of the method from the methodology.

2.1 Social constructionist views of reality

The range of approaches and perspectives that may be labelled as social constructionist is broad. Berger and Luckmann (2011) popularised the term *social construction* when presenting a symbolic interactionist⁶ account of reality in their book, *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, initially published in 1967. Far from having an accepted definition, social constructionist perspectives may be broadly categorised as meeting one or more of the following key assumptions, in line with Gergen (1985): a critical stance toward

⁶ Constructionism is a form of the sociology of knowledge that attempts to move beyond empiricist and rationalist schools of thought to emphasise the social practices that lead to knowledge. Source: Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266. A particular form of this symbolic interactionism emphasises communication whereby the child is formed into a social being through “learning the common meaning attached to symbols by his or her group”. Source: Symbolic interaction. (2017). *Oxford English Dictionary*. Oxford, England: Oxford University Press. Retrieved from <http://www.oed.com.ezproxy.aut.ac.nz/view/Entry/196202?redirectedFrom=symbolic+interactionism#eid19329448> .

taken-for-granted knowledge, historical and cultural specificity, and the idea that knowledge is sustained through social processes and the idea that knowledge and action go together (Burr, 2015, pp. 3-5). This approach differed from previous psychological understandings of knowledge with its use of anti-essentialism⁷, questioning of realism⁸ and the focus on language as a precursor to thought (Burr, 2015, pp. 9-11). The approach also differed through its focus on social action along with interaction, social practices and processes, rather than entities such as personality or social structures (Burr, 2015, pp. 9-11).

Social constructionists build arguments by recognising that the item in question was 'not determined by the nature of things' or is in a form that is in some way inevitable. Instead, a series of forces, events and history brought into existence or shaped, the item in question, in a way that could have been different (Hacking, 1999, p. 7)⁹. This perspective was vital to Foucault's approach. For example in his 'histories of the present' and his archaeology of knowledge, Foucault traced the history of thought by comparing what can be said and thought on particular topics in the present, as well as in selected points in the past (Foucault, 1972).

Foucault was not the only scholar of his time invested in social construction approaches. Other thinkers with work published after the peak dominance of structural¹⁰ approaches were also often grouped with Foucault. These groupings were not without controversy, as discussed below.

2.2 Post-structural critique of knowledge and truth

The terms post-structural and post-modern are often used interchangeably for a particular group of thinkers, despite essential differences between them, and often the thinker's personal aversion to these and other labels (Aylesworth, 2015). To acknowledge these

⁷ Essentialism is the assumption that people are "pre-existing, self-contained individuals who impact upon each other with particular social effects". Source: Burr, V. (2015). *Social Constructionism*. Retrieved from <http://ebookcentral.proquest.com/lib/aut/detail.action?docID=2011179> .

⁸ Social constructionism denies that knowledge is a direct perception of reality; rather as a culture we construct our own versions of reality between us. The implication of this is a form of cultural relativism that makes 'truth' problematic. Source: *ibid*.

⁹ A common corollary of this thesis is that the item in question is very bad in its current form and things would be better if it was done away with or changed significantly, although this is not always invoked. Source: Hacking, I. (1999). *The social construction of what?* Cambridge, MA: Harvard University Press.

¹⁰ Structuralism was an intellectual movement popular in 1960s France. Many positions in this purview include the notion that phenomena are intelligible only through their interrelations. Such interrelations constitute a structure where local variations can be explained through constant laws of this abstract ordering. Source: Blackburn, S. Structuralism. (2008). *The Oxford Dictionary of Philosophy*. Oxford University Press. Retrieved from <http://www.oxfordreference.com/10.1093/acref/9780199541430.001.0001/acref-9780199541430-e-2975>

differences and sympathies between approaches, post-structuralism was, at times, associated explicitly with American-based research that focussed on French thinkers such as Foucault and Deleuze (Schrift, 2009, p. 55). The term *postmodern* was associated with the work of Jean-François Lyotard, who defined it as “incredulity toward meta-narratives¹¹” (Lyotard, 1984, p. xxiv). Jacques Derrida¹² introduced deconstruction (Schrift, 2009, p. 54). His thinking has been drawn on extensively in and is associated with architecture, from which Foucault distanced himself (Schrift, 2009, p. 54). Schrift (2009) further identified the period ‘after structuralism’ with four dominant themes: “...the return to thinking *historically*, ...the return to thinking about the *subject*, ...the emphasis on *difference* and ... the return to thinking *philosophically* about religion and ethics” (p. 56, original emphasis preserved). This influence was visible in Foucault’s work. At any given point in time, there exists a social order that makes the social functioning of the time possible, and making knowledge and theory possible (Schrift, 2009, p. 57).

The death of the subject is a critical component of the scientific anti-humanism¹³; post-structuralism moves away from this. This return to thinking about the subject does not correlate to privileging the subject as the final word on experience and knowledge, as was the case in phenomenology. instead it relates to situating the subject historically (Schrift, 2009, p. 61). For Derrida,

the subject is absolutely indispensable. I don’t destroy the subject; I situate it. I believe that at a certain level of both experience and of philosophical and scientific discourse, one cannot get along with the notion of the subject. It is a question of knowing where it comes from and how it functions. (Derrida, 2007, p. 271).

¹¹ Meta-narrative is “any narrative which is concerned with the idea of storytelling, spec. one which alludes to other narratives, or refers to itself and to its own artifice. Also: a piece of narrative, esp. a classic text or other archetypal story, which provides a schematic world view upon which an individual’s experiences and perceptions may be ordered”. Source: Metanarrative. (2001). *Oxford English Dictionary*. Oxford, England: Oxford University Press. Retrieved from <http://www.oed.com/view/Entry/245263?redirectedFrom=meta-narrative> .

¹² *Of Grammatology* (in English 1974), *Writing and Difference* (in English 1978), and *Speech and Phenomena* (in English 1973).

¹³ In broad terms, anti-humanism “encompasses a range of different perspectives that all share a critique of humanism and an effort to displace the human subject as the centre of philosophical and social inquiry.” This can take the forms of “(1) a travel from the self-containing subject towards subjectivities as relational effects of arrangements or assemblages, and (2) an emphasis on materiality or more broadly the ‘non-human’ or ‘more-than-human’”. Source: Anti-humanism (2015). In S. Mayhew (Ed.), *A Dictionary of Geography*. Oxford University Press. Retrieved from <http://www.oxfordreference.com/view/10.1093/acref/9780199680856.001.0001/acref-9780199680856-e-3724>

Similarly, Foucault asks “how, under what conditions and in what forms can something like a subject appear in the order of discourse? What place can it occupy in each type of discourse, what functions can it assume, and by obeying what rules?” (Foucault, 1984e, p. 118).

New Materialist approaches have been used in design and they critique the focus on ‘human’, both in regard to design practice and Foucauldian theory (Barad, 2003; Haraway, 1991; Latour, 1990; Matthewman, 2017). While this critique is both valid and important, I considered that my study had a different purpose. Barad (2003) suggests that Foucault failed to offer an account in which the material played “an *active* role in the workings of power” (p. 809), with the effect of “forestalling an understanding of precisely how discursive practices produce material bodies” (p. 808). However, I would argue that the role of material is illustrated by Foucault as an important element in the operation of power through discourse particularly in his discussions on disciplinary practices and the *panopticon* (see 2.4.3). As such, I decided to focus this research using the methodological principles presented by Foucault, while drawing on additional applications of the principles of his work by Nicholls (2008a), Fadyl (2013), Dean (1994) and Rose (1996). Additionally in this thesis, I have drawn on the insights of other thinkers as and where appropriate (as described throughout the text).

Having situated Foucault and his contemporaries broadly, the following section will examine specific concepts and tools pertinent to this study. Given the wide-ranging scope of Foucault’s intellectual endeavours, I will limit the scope of this discussion and not attempt to describe or summarise the whole body of work with which he is associated.

2.3 Foucault’s philosophical position as it relates to this study

Foucault developed his methodological principles through analytic research (Fadyl, Nicholls, & McPherson, 2013, pp. 478-479). He wrote ‘histories of the present’, and archaeologies and genealogies of our present knowledge. However, he never presented guidelines (as such) to the use of his work (Fadyl et al., 2013, pp. 478-479). Instead, he indicated that readers should think of his work as

“little tool boxes” and if the reader wants “to open them, to use this sentence or that idea as a screwdriver or spanner to short-circuit, discredit or smash systems of power, including eventually those from which my books have emerged...so much the better!” (Foucault, 1979, p. 115).

I developed this study using selected elements of Foucault’s work that are best suited to the research question; they are used as guiding principles rather than a strict method or formula.

As discussed in more detail later in this chapter, the key texts on which this study rests are: *Orders of Discourse*, *Archaeology of Knowledge*, *Discipline and Punish*, *Birth of the Clinic* and *History of Sexuality Volume 1* (Foucault, 1971, 1972, 1977, 1978, 2003a). The focus of these texts is on the archaeological and genealogical tools used in relation to governmentality, particularly relating to bio-politics, bio-power and disciplinary technologies.

In building up a basis to discuss these approaches in more detail, the following section will address Foucault's conception of the subject, power-knowledge and the significance of materiality and the body as it relates to this study. Finally, the historical placing of this study will be related to Foucault's approach to critical histories. To this end, I will broadly introduce Foucault's concept of discourse and show how it differs from other forms of discourse.

2.3.1 Discourse

Foucault conceptualised discourse quite differently from the more traditional language orientated approaches to discourse. In particular, his discourse differs from those that emphasise signification and language as systems of representation. As such, language-based discourse may refer to more extended written or spoken texts, although the term has many "conflicting and overlapping definitions formulated from various theoretical and disciplinary standpoints" (Fairclough, 1992, p. 3). Language-based forms can include analysis approaches such as semantics, narrative, argumentation, semiotics and pragmatics, to name a few (van Dijk, 2011, p. 6).

To provide a point of comparison, the study of artefacts and designed products has also adopted semiotics, a *doctrine of signs*, as a theory, methodology and discipline that extends beyond words to cultural artefacts and media (Boradkar, 2010, p. 211). These studies focus on asking questions such as "what does something mean? How does it mean what it means? Why does it mean what it means?" (Danesi & Mazzuca, 2007, p. 24). In such approaches, "design is sign making" and the Latin origin of the word design, which is *designare*, is defined as "making something, distinguishing it by a sign, giving it significance, designating its relation to other things, owners, users, or goods" (Krippendorff, 1989, p. 9). More than other design disciplines, product design has taken to semiotics. Krippendorff defined product semantics as "the study of the symbolic qualities of man-made forms in the cognitive and social contexts of their use and the application of the knowledge gained to objects of industrial design" (Krippendorff, 1989, p. 10; Krippendorff & Butter, 1984, p. 4). In doing this, Krippendorff was further building on the work of de Saussure (1974) and Barthes (1973) (although Krippendorff argued against tying semantics to this origin (Boradkar, 2010)). The fundamental goal of this approach was to

“explain the mechanism by which objects acquire” or are assigned “meaning and to generate a better comprehension of the role that design plays in this process” (Boradkar, 2010, p. 226).

The purpose of this very brief overview is to highlight that product design-based understandings of discourse, much like language based on an understanding of discourse have been based on theories of signification and signs. Where French sociologist Jean Baudrillard locates objects simultaneously within semiotics and the political economy, he overlays Marx’s “commodity system of use-value (utility) and exchange-value (tradability), with structural semiotics by adding symbolic and sign value” (Boradkar, 2010, p. 242). Against this backdrop, where discourse-type analysis sought the meaning and the mechanisms of meaning in products, I will now discuss Foucault’s very different definition and purpose for analysing discourse. Notably, it is not a matter of denying the operation and existence of these meanings and the networks between them in this definition; rather, it is that they frame the purpose of analysis and conceptions of knowledge underlying them in different ways.

In social theory, and particularly Foucault’s work, discourse was a term that described the different ways of structuring areas of knowledge and social practice (Fairclough, 1992, p. 3). For Foucault (1972), discourse and its analysis was a “task that consists of ... no longer... treating discourse as signs... but as practices that systematically form the objects of which they speak” (p. 49). Foucault’s “discursive practices”, as he termed them, “work in both inhibiting and productive ways, implying a play of prescriptions that designate both exclusions and choices” (Foucault, 1971; Hook, 2001b, p. 43). In this way, discourse made current reality possible, but to attempt to do, say or think outside the current discourse was to present as mad or unreasonable or be doomed to be a failure in the endeavour.

Foucault’s view of discourse was that it operated as a rarefaction or thinning out of possibilities. While his view of discourse implied that what people experienced as reality was constructed rather than existing in an essentialist and enduring way, this did not imply that ‘anything is possible’. Rather than presenting a world that was arbitrary and open to manipulation, the various projects dedicated to mapping pieces of Foucault’s discourse elucidated whole systems of constraints (Foucault, 1971). Examples of these systems will be examined in more detail later in this chapter. Instead of a gateway to truth, in this study I used discourse itself as a tool for questioning the effects of knowledge and its role in shaping the world. The construction and role of discourse in this analysis will be addressed further in chapter three.

2.3.2 The Subject

Building on the concept of discourse, this study drew on Foucault's position that the delineation of the individual as a unit within society was socially constructed and historically contingent (Foucault, 1980). Similarly, the subject positions that people identified with, such as a patient, clinician, student, designer, author and so forth, were all constituted through discourse. A fundamental tenet of Foucault's position on the subject was that it moved substantially away from phenomenological perspectives that state the individual was unified and pre-existed any discourses that might have emerged in relation to them. Rather than privileging the experience of the individual as a source of meaning, the subject must instead be viewed as historically situated, constrained and enabled by discourse, and as a function through which discourse spreads and repeats (Foucault, 1984e, pp. 101-120). The individual as a discrete unit is essential to the underlying philosophy of human-centred design (HCD) (Giacomin, 2014). HCD focuses on understanding the experience of the individual, which in post-structural terms was what Foucault might consider a constituted subject. Other forms of design also used this kind of subject formulation, for example, co-design, participatory design, action research and design and emotion studies (Sanders & Stappers, 2012, pp. 21, 28, 29). Given the importance of the subject to medical device design, a key theme for this study explored the interactions between subject positions and in particular, those that are "gradually, progressively, really and materially constituted..." (Foucault, 1980, p. 99), and that emerged in relation to breathing support masks for OSA. Of similar importance was addressing the effects of the privileging, or otherwise, of particular discursive constructions within a design process.

[Viewing this subject in this way] means overturning the traditional problem, no longer raising the questions: How can a free subject penetrate the density of things and give it meaning? How can it articulate the rules of a language from within and thus give rise to the designs that are properly its own? Instead, these questions will be raised: How, under what conditions, and in what forms can something like a subject appear in the order of discourse? What place can it occupy in each type of discourse, what functions can it assume, and by obeying what rules? In short, it is a matter of depriving the subject (or its substitute) of its role as originator, and of analyzing the subject as a variable and complex function of discourse. (Foucault, 1984e, p. 118).

Foucault (1982) identified "two meanings of the word 'subject': subject to someone else by control and dependence; and [the] subject tied to his own identity by a conscience or self-

knowledge” (p. 781). Foucault acknowledged the main focus on his work as the Subject, which he saw as an effect of his particular notions of power.

For example, a person may exhibit symptoms of OSA, but until a clinician formally diagnoses them as having the condition and they become a ‘patient’, they are not eligible for treatment support. On the flip side, once they become an ‘OSA patient’, particularly if they also hold the subject position of ‘professional driver’, such as a taxi or truck driver, by law they must demonstrate adequate use of treatment or risk having their license suspended. Once an OSA patient is ‘successfully’ using CPAP therapy, they may in actuality have fewer OSA related symptoms than the person who was marginally below the diagnosis threshold, but who was still subject to the requirements of an OSA patient. The person with similar experiences but marginally below the threshold of diagnosis did not have access to treatment, but neither did legislation subject them to the risk of license suspension.

Adherents to Foucault’s view of the non-essential subject saw agency and selves as effects of discourse rather than facts of existence as per modern psychology. For feminist scholars, this was a point for critique as feminists took it as denying oppression, or the possibility of progress against oppression, on the understanding that subjects entirely constituted through discourse do not have the agency to change their situation (Alcoff, 1988; McNay, 1991). Scholars of Foucault’s may argue that he rejected the existence of agency in his early work, called the anti-subjective hypothesis by Allen (2000). Others argue that he later revised his position addressing the self and ethics in the later volumes of the *History of Sexuality* as outlined in Dews (1989).

This study takes the position that contrary to these interpretations, the discursive subject does not equate to an invalidating illusion (Fadyl, 2013, p. 17). Rather, the phenomena of the individual can be shown to be historically and culturally located in the current reality, rather than existing separately as an absolute truth (Fadyl, 2013, p. 17). This property of situated-ness calls into question the idea of a stable and enduring self, which is to say an *essential self*. Foucault (1984c) does not deny the existence of the body but argues that “...[n]othing in man – not even his body – is sufficiently stable to serve as the basis for self-recognition or for understanding other men” (pp. 87-88).

The centrality of the essential ‘female’ subject prevalent in feminist studies made a Foucauldian approach to feminism problematic, leading to misinterpretations of Foucault’s position (McHoul & Grace, 1998, p. 119). McHoul and Grace (1998) argued that this was due to

insufficient bracketing¹⁴ of philosophical positions, and importantly noting the Foucault's distinctive choice of the term 'sexuality' over an "*essentially* gendered subject" (pp. 119-120).

In line with Foucault, I have not privileged particular constructions such as 'male' and 'female' in this study. Feminist studies may advocate for privileging constructions such as 'male' and 'female' as an approach to ongoing gender inequalities (Jagose, 2002). A consequence of this is that different issues are highlighted using this approach than might be if I had chosen to use a specifically feminist approach to the study.

A final effect of the constituted subject, and one that has played an important role in the study design of this work, is that of the non-essential individual. Deleuze argues that we have already become 'dividuals', organised around aspects of ourselves rather than being ourselves as a whole person (Deleuze, 1992). Arbitrarily emphasising the separation of the individual from the community in which they are enmeshed is interpreted as a form of privileging the individual. This idea was influential in the development of a method for community engagement in the context of this study, as will be discussed further in chapter four. I have argued that the subject is an effect of discourse and power-knowledge constructs, so power-knowledge will be the focus for discussion in the next section.

2.3.3 Power-knowledge

Foucault's conception of power differs significantly from the Marxist philosophies of power that were prevalent during his writing years (Rummel, 1977). Foucault took care to differentiate power from violence, which he characterised as an instrument or result of power:

A relationship of violence acts upon a body or upon things; it forces, it bends, it breaks... Its opposite pole can only be passivity, and if it comes up against any resistance, it has no other option but to try to minimize it. (Foucault, 1982, p. 789).

Conversely,

a power relationship can only be articulated on the basis... that "the other" (the one over whom power is exercised) can be thoroughly recognized and maintained to the very end as a person who acts; and that, faced with a relationship of power, a whole field of responses,

¹⁴ Bracketing is the act of suspending judgement about the natural world in order to examine an aspect of experience.

reactions, results, and possible interventions may open up. (Foucault, 1982, p. 789).

In Foucauldian terms, power is not “negative and repressive but as the condition of production of all speech and if power is conceived as polar rather than monolithic, as an asymmetrical dispersion, then all utterances will be potentially splintered, formally open to contradictory uses” (Frow, 1985, p. 206). Foucault addresses power in three primary forms that will be covered in more detail in following sections on governmentality. Broadly speaking, in Foucault’s conception of power, discourses were not the slave of power or pitted against it, rather:

We must make allowances for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it. (Foucault, 1978, p. 101) .

Foucault offered guidance to using an ascending analysis of power, starting from the tiniest of mechanisms to seeing how these mechanisms shaped and continue to be moulded and changed by more general mechanisms of power (Foucault, 1980, p. 99).

What defines a relationship of power is that it is a mode of action which does not act directly and immediately on others. Instead it acts upon their actions: an action upon an action, on existing actions or on those which may arise in the present or the future. (Foucault, 1982, p. 789).

For Foucault, knowledge and power were always intertwined (Foucault, 1980, p. ix). He did not recognise knowledge as such if it was independent of legitimating techniques of power (Foucault, 1996, p. 394; Ransom, 1997). In the case of mask design, appropriately qualified people must design the mask to meet existing manufacturing standards. Accredited suppliers must supply the mask materials, by using techniques and procedures that reflect currently acceptable knowledge (i.e., scientific testing, and institution and government-sanctioned inspections). This entwinement was the power of legitimacy through knowledge, or the ‘knowledge-power complex’ as Hook termed it (Hook, 2001b, p. 66 note 65). Foucault was quick to emphasise that the purpose of defining power-knowledge was to use it as a tool, not in a search for truth (Foucault, 1996, p. 394). He postulated that

it is not a matter of describing what knowledge is and what power is and how the one would repress the other, ... rather it is a matter of describing the nexus of knowledge-power that allows one to grasp what constitutes a system's acceptability. (Foucault, 1996, p. 394).

Similarly, there was not "*a* knowledge or *a* power, still worse *the* knowledge or *the* power that would be in themselves operative. Knowledge, power, this is only a grid of analysis" (Foucault, 1996, p. 394). This study focussed on the microstrategies and highly localised situations encountered in relation to OSA breathing support interfaces. However, broader issues and strategies emerged and became relevant within this research framework.

2.3.4 Resistance

As discussed above, the idea of resistance is inherent to Foucault's concept of power. Foucault has variously conceived of resistance in terms of the 'transgression of limits' (Pickett, 1996, p. 448), the disruption or subversion of norms to destabilise forms of domination (Pickett, 1996, p. 452), and as that which eludes or threatens power (Pickett, 1996, p. 458). The different conceptualisations of resistance are reflective of Foucault's own changing ideas as his methodological approaches developed over time. The first two specifically require listening to the marginalised and excluded as an impetus to initiate resistive struggle (Pickett, 1996, p. 457). Interpreting resistance in Foucauldian terms remains indeterminate. For Foucault, a totalising theory supporting struggle would quickly provide another potential source of domination, leaving the argument for resistance under-resourced in various ways. For a critical discussion of resistance see Pickett (1996). However, it seems clear that Foucault supported resistance, and deemed it worthwhile. Far from resistance being impossible or pointless, Foucault's view is "that everything is dangerous means that there are multiple opportunities for resistance" (Pickett, 1996, p. 461). Resistance, in practice, is "linked to self-creation" and to "refusing what we are" (Pickett, 1996, p. 464) (see chapter 8).

One set of practices that emerged in this study (and may be associated with rendering fragile the power produced by discourse), was the practice of laughter. Foucault himself appeared to have written very little about the role of humour in discourse. However, Douglas (2015, p. 142) argues that laughter practices are significant within a Foucauldian framework and casts its nature as transgressive.

To all those who still wish to talk about man, about his reign or liberation, to all those who still ask themselves questions about what man is in his essence [...] we can answer only with a philosophical laugh—which means, to a certain extent, a silent one. (Foucault, 2002, p. 373).

The role of laughter and teasing has been discussed in terms of its disciplining role, particularly concerning constructions of masculinity (Franzén & Aronsson, 2013, p. 168) (see 10.2). In chapter eight, I consider laughter primarily for its involvement in the construction of resistance. I also note that a tendency to conversationally laugh and joke is also customary and cultural to various groups in Aotearoa/New Zealand. Emily Douglas takes a position that may well apply in this case also:

Laughing is not exactly discursive, but neither is it wholly divergent; in these examples, discourses provoke laughter. Furthermore, the fact that they provoke laughter is not an accidental correlation but an indication of something about the discourse itself. (Douglas, 2015, p. 143).

Chloë Taylor considered that Foucault's own work further suggested that the laughter of the reader or observer of a discourse is significant:

the work of discipline also works at the level of the body and thus can be undone only through the body, through shifts in its pleasures and affects and practices, and not merely through the acceptance or examination of philosophical ideas. (Douglas, 2015, p. 143).

In this construction, laughter may be a physical expression of the shifting ideas and bodily constructions of thought, understanding and subjectivity. An interpretation of laughter practices inevitably addresses a space of ambiguity, and as such, may present an exploration of possibility rather than a definitive explanation (see 8.2).

2.3.5 Materialism and the body

One of Foucault's key innovations was his sophisticated methodological approach and a specific emphasis on the body "as the place in which the most minute and local social practices are linked up with the large scale organization of power" (Dreyfus & Rabinow, 1983, p. xxvi). Rather than as the underpinning feature of an enduring self, Foucault situated the body as a specific site peculiar to the exercise of power. This focus of Foucault's work was one that made it pertinent to a study focussed on a personal medical device that is arguably also defined in relation to its physical interaction with the body.

The materialism of Foucault's conception of discourse was of key importance to its application in a product design process, as it differs from many conceptions of discourse that relate solely to language (Kendall & Wickham, 1998). Hook (2001) argues for "a methodology that d[oes] not prioritize textual forms of data at the cost of material forms ... and in one that favours a latitude of diverse data forms" (p. 526). Foucault also differentiated his conception of

discourse from the linguistic conceptions of discourse when he said that “the history which determines us has the form of war rather than that of language: relations of power, not relations of meaning.” (Foucault, 1980, p. 114). Accordingly, in this study, I considered forms of materiality, contingent with particular knowledges and practices, to both enable and constrain possibility in a similar manner to other discursive constructions. In line with this reading of Foucault, data included, for example, considerations such as materiality and physical forms, products, images, prototypes and physical design tools. People and materiality were both treated in this study as equally active in the construction of OSA, CPAP therapy and the design practices associated with breathing support interfaces.

2.3.6 Critical histories

Commentary on Foucault’s works has characterised them as critical histories, but his approach was quite different from common presentations of history. Rather than a linear story of progress and change on various fronts, his work was characterised by discontinuity and rupture. He was known for his ‘histories of the present’, in which the context of the past was used to make visible the discourses of the present (or the very recent past) (Dreyfus & Rabinow, 1983, p. xxvi). In other words, to “locate the conditions that allow us to think, speak and act as we do now” (Fadyl, 2013, p. 20). Rather than seeking the causes of today’s situations in the past, Foucault’s work demonstrated a situating approach where seeking causation was not required, and contingency was sufficient (see section 1.1).

It is worth noting the pervasiveness of Foucault’s conception of historical contingency. Similarly, “once one sees the pervasive, dispersion, intricacy, contingency, and layering of our social practice, one also sees that any attempt to sum up what is going on is bound to be a potentially dangerous distortion” (Dreyfus & Rabinow, 1983, p. xxvi). For this reason, Foucault was not in the business of creating generalisable solutions to current ills, as that would be empty or risk promoting his ideas, both poles that Foucault resisted (Dreyfus & Rabinow, 1983, p. xxvi).

While Foucault’s approach was predominantly historical, he did not preclude alternative approaches that used his methods. In this study, I have explored design-based approaches as a way of destabilising ideas around current mask design to make visible the knowledges and practices that legitimise them.

2.4 Foucauldian theoretical discussion central to this inquiry

When examining the network enmeshing CPAP therapy masks for OSA, several theoretical notions were useful. While these notions are by no means unique to the broader functioning

of the CPAP therapy masks, their particular configuration in the current historical contingency provided insight into the design and functioning of the CPAP therapy mask in its current form. The following sections provide an outline of Foucault's theoretical ideas, which I used during analysis in this study. The following discussion and Foucault's ideas relate to the political trajectory of many Westernised, industrialised societies. It is likely that the ideas explored will be less useful if applied to societies with less emphasis on Westernised thinking and approaches.

2.4.1 Neoliberalism

Liberal approaches to government were situated historically at the end of the nineteenth century. It was at this point that Western government rationalities began to take an interest in health and economic wealth in population terms. This government rationality, known as Liberalism, marked a shift of influence away from government towards 'experts'.

Liberalism, in this respect, marks the moment when the dystopian dream of a totally administered society was abandoned, and government was confronted with a domain that had its own naturalness, its own rules and processes, and its own internal form of self regulation. (Rose & Miller, 1992, p. 179).

Similarly,

liberalism, as Foucault presented it, was precisely that kind of power within which the center comes to recognize that it cannot control all of the nodes, and that, in fact, the life of the nation is made up of a number of processes that are not only independent of the central authority, but which augment the force of the nation only to the extent that they are left alone to run their course. (Paras, 2006, p. 106).

In this period, expertise became intrinsically linked to the formal political apparatus and was tasked with offsetting the disadvantages of industrialisation, wage-based labour and urban existence (Rose, 1993, p. 285). In short, expert authorities operated on behalf of governments. In the process, a range of disciplinary technologies was used to modify conduct and maximise the efficient use of time and labour for the "the good of society as a whole" (Burchell, 1993, p. 272). Welfarism provided a counter-movement in the 1940s and 1950s that addressed issues with the explosion of expertise. In Foucault's opinion

the years 1940-1950 should be chosen as dates of reference marking the birth of this new system of rights, this new morality, this new politics and this new economy of the body in the modern western world. Since then, the body of the individual has become one of the

chief objectives of State intervention, one of the major objects of which the State must take charge. (Foucault, 2004, p. 7).

However, the constraining bureaucracy and requirements placed on individuals within the welfarism governmentality (such as requiring all decisions to be linked to institutional and governmental policies and mechanisms) became seen as stifling. A new shift to market-driven government replaced it by the end of the twentieth century. Government became the question of how “legal, institutional and cultural conditions” can be constructed “that will enable an artificial competitive game of entrepreneurial conduct to be played” (Burchell, 1993, p. 274). This form of government was known as neo-liberalism or advanced liberalism¹⁵. In this mode of government:

Government must work *for* the game of market competition and *as* a kind of enterprise itself, and a new quasi-entrepreneurial and market models of action or practical systems must be invented for the conduct of individuals, groups and institution within those areas of life hitherto seen as being either outside of or even antagonistic to the economy. (Burchell, 1993, p. 274).

In this scenario, citizens are cast as consumers. Consumer rights created a system or culture of enterprise and an entrepreneurship of the self (Rose, 1996, p. 151). This system came to replace the welfarist relationship between the state, expert practitioners and consumers (Larner, 2000, p. 13). Key aspects of this notion of government included personal responsibility, self-fulfilment and individual meaning: in short, in neoliberal strategies of rule (Larner, 2000, p. 13). Within this framework, people were encouraged to “see themselves as individualised and active subjects, responsible for enhancing their own wellbeing” (Larner, 2000, p. 13). This aspect of government was reflected in institutions such as education, hospitals, workplaces and other health and welfare agencies (Larner, 2000, p. 13). Unsurprisingly, given the neoliberal prevalence, these strategies also extended to design practice. The prevalence of neoliberal discourse became evident in the discourses associated with the ‘cost’ of OSA and ‘cost-benefit’ of CPAP therapy as a whole (see section 5.2). As will be explicated in later chapters, the market focus, risk management and population-based health concerns had a strong influence on artefact form and the design process of CPAP

¹⁵ Advanced liberalism is associated with Burchell, G. (1993). Liberal government and techniques of the self. *Economy and Society*, 22(3), 267-282. doi: 10.1080/03085149300000018, but the terms are used interchangeably in this thesis.

therapy masks. A clear example was the impact of health insurance reimbursement policies (see section 11.5, also section 7.3).

Compared to regular consumer products, the dominant market for CPAP therapy masks operated to satisfy the government about aspects of the design requirements (i.e., safety, risk management, medical practitioner approval), leaving little room for products to address possibilities of personal fulfilment for patients. For further discussion, see the analysis of a typical CPAP therapy mask in chapter six.

2.4.2 Governmentality and resistance

Government is any more or less calculated and rational activity, undertaken by a multiplicity of authorities and agencies, employing a variety of techniques and forms of knowledge, that seeks to shape conduct by working through our desires, aspirations, interests and beliefs, for definite but shifting ends and with a diverse set of relatively unpredictable consequences, effects and outcomes. (Dean, 2010, p. 18).

As discussed broadly in the section on power, for Foucault power and resistance were both creative forces. Hindess (1996, p. 97) outlines three forms of power that were mentioned by Foucault at different times: power in general, domination and government. Domination is power as used in everyday speech and refers to conditions “under which the subordinated have relatively little room for manoeuvre” (Hindess, 1996, p. 97). Government refers to power relations that are relatively stable and hierarchical, rather than situational power that may be unstable and quickly reversible (Hindess, 1996, p. 97). As such, government is the “conduct of conduct, aiming to affect the actions of the individual by working ... on the ways in which they regulate their own behaviour” (Hindess, 1996, p. 97)¹⁶. Foucault defined his conception of power as separate from situations of violence or slavery where resistance was not possible, arguing that “where there is no possibility of resistance there can be no relation of power” (Hindess, 1996, p. 101). For Foucault “resistance is more effective when it is directed at a ‘technique’ of power rather than at ‘power’ in general” (McHoul & Grace, 1998, p. 86). As power operated through techniques and interactions, it was through the explicit refusal of these techniques that power was most effectively resisted (McHoul & Grace, 1998, p. 86).

¹⁶ For a more detailed discussion of the forms of power and the different ways it has been conceptualised over time, including a discussions of legitimacy of the sovereign and consent, see Hindess, B. (1996). *Discourses of power from Hobbes to Foucault*. Oxford, UK: Blackwell Publishers.

Similarly, inventing tactics was not the sole domain of ‘oppressive forces’. In order to invent new tactics, those that were currently in use were first required to be recognised (McHoul & Grace, 1998, p. 87). Thus, as a first step to exploring resistance, the “ethical relationship of the protagonist to the ‘power’ being opposed and the historical relationship must be made explicit” (McHoul & Grace, 1998, p. 87). Addressing resistance in this study was twofold – first, the role of power in the construction of OSA and CPAP therapy masks was made explicit (see Chapters 5, 6 and 7). An exploration of opportunities that resist the tactics identified is discussed explicitly in chapter eight and touched on again in later chapters. Foucault presented governmentality in several forms, two categories of which are particularly relevant to this study. These categories are disciplinary technologies, and the relationships between biopolitics and power, which I will discuss next.

2.4.3 Biopolitics, biopower and disciplinary technologies

In *The History of Sexuality*, Foucault traced the origin of a “power over life” that began in the seventeenth century (Foucault, 1978, p. 139). Over time, this power over life came to take two forms. The first, centred on conceptualising the body as a machine, had the aims of addressing: “its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls”, through the “procedures of power that characterized the *disciplines*” (Foucault, 1978, p. 139). This form focussed on the mechanics of the body, which Foucault (1978, p. 139) termed an anatomo-politics of the human body. The second form emerged later and focussed on the collective human body as a population. For this power, the focus was on the body “imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary” (Foucault, 1978, p. 139). Foucault (1978) termed these regulatory controls and interventions a “*bio-politics of the population*” (p. 139, original italics).

Disciplining of the body as occurred through the army, schools, apprenticeships and education and heralded the era of bio-power (Foucault, 1978, p. 140). Foucault (1978) framed this bio-power as “an indispensable element in the development of capitalism; the latter would not be possible without the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes” (pp. 140-141). Dreyfus and Rabinow (1983) described bio-power as “the increasing ordering in all realms under the guise of improving the welfare of the individual and the population” (p. xxvi). They went on to recognise it in genealogical terms (see chapter 3) as a strategy “with no one directing it and

everyone increasingly enmeshed in it, whose only end is the increase of power and order itself” (Dreyfus & Rabinow, 1983, p. xxvi).

Bio-power was important in the operation of mass production. The increasing production gains through the training of bodies also resulted in changing the way designers shape products for mass production. More than ever, design is aimed at more efficient production, particularly in terms of streamlining products to minimise variation and simplifying manufacturing processes for automation. As Foucault (1978, p. 144) argued, the development of bio-power had the consequence of “growing [the] importance assumed by the action of the norm” (p. 144).

For a long time ordinary individuality – the everyday individuality of everybody – remained below the threshold of description. To be looked at, observed, described in detail, followed from day to day by an uninterrupted writing was a privilege.... The disciplinary methods reversed this relation, lowered the threshold of describable individuality and made of this description a means of control and a method of domination... This turning of real lives into writing is no longer a procedure of heroization; it functions as a procedure of objectification and subjection. (Foucault, 1977, pp. 191-192).

The body emerged as an object and the site of power in the classical age (Foucault, 1984a, p. 180). The docile body was one that was “subjected, used, transformed and improved” (Foucault, 1984a, p. 180). The shift that Foucault detailed was from initially from one of scale, of directing of the body *en masse*, to the micro-strategies of treating it at the level of a mechanism, as an individual (Foucault, 1984a, p. 181). The shift to micro-strategy was through the process of obtaining “holds upon [the body] at the level of... movements, gestures, attitudes, rapidity: an infinitesimal power over the active body” (Foucault, 1984a, p. 181). The second shift was away from significations of behaviour or the language of the body to efficiency and effectiveness, as both force constraints with an emphasis on exercise (Foucault, 1984a, p. 181). Finally, the modality shifted to constant coercion and the supervision of activity processes rather than their results – a discipline. The dual effect of these processes was a “docility-utility” (Foucault, 1984a, p. 181). Monasteries, armies and workshops were previously the sole arbiters of this disciplinary effect, which then proliferated as a general formula of domination (Foucault, 1984a, p. 181). Discipline in this sense would “increase the forces of the body” in terms of usefulness and effectiveness, but would diminish the same forces in political terms through obedience (Foucault, 1984a, p. 182).

For Foucault, the success of disciplinary technologies resulted from the simplicity of the instruments that elicited a docile or trained response (Foucault, 1984b, p. 188). The following

sections will discuss three such instruments associated with Foucault's work: hierarchical observation, normalising judgement and the combination of the two into the procedure of examinations (Foucault, 1984b, p. 188).

Hierarchical observation, as the first of these procedures, underpins the exercise of discipline as a mechanism that "coerces by means of observation" (Foucault, 1984b, p. 189). The 'gaze' is a common term for such a disciplinary mechanism. In this construction "the techniques that make it possible to see, induce effects of power and in which, conversely, the means of coercion make those on whom they are applied clearly visible" (Foucault, 1984b, p. 189). This principle was employed in schools, military camps and hospitals to create a situation where the individual could be seen by those in the hierarchy, but could not necessarily see those in control. An imagined physical embodiment of this technology was Bentham's *Panopticon* (Foucault, 1975), a prison design with a darkened central guard tower and a line of sight into brightly lit cells so the guard could see the prisoners, but the prisoners could not see if a guard was present. Foucault (1984d) discussed the guard tower just described as close to "the perfect disciplinary apparatus", making it "possible for a single gaze to see everything constantly" (p. 191). Similarly, the arrangement of the cells in this prison concept was such that individuals were separated from one another by walls or the like so they could not see each other. So the gaze has a dual effect. Power operates by this visibility, but the process also has an individualising effect. Through this kind of surveillance, disciplinary power becomes an 'integrated' system that links the activity "from the inside to the economy and to the aims of the mechanism in which it was practised" (Foucault, 1984b, p. 192). Foucault (1984b) characterised disciplinary power as functioning as a "piece of machinery", despite having a "head", the power itself is produced by the apparatus rather than wielded by that head (p. 192). The disciplinary powers operate by physics through "the laws of optics and mechanics, according to a whole play of spaces, lines, screens, beams, degrees, and without recourse, in principle at least, to excess, force or violence" (Foucault, 1984b, p. 193).

Next, I will discuss normalising judgement, which is the second of Foucault's instruments. Normalising judgement is a disciplinary technology that is made up of a series of operations. These operations form a process that compares an individual to others in terms of a desirable norm. Normalising judgement can be broken down into five distinct operations, as follows (Foucault, 1984b, p. 195):

1. It refers individual actions to a field of comparison, differentiation, and the principle of a rule to be followed.

2. It differentiates individuals in terms of minimum thresholds, averages or optimums to move towards in relation to the rule to be followed.
3. It measures in quantitative terms and places individuals in hierarchies that exist in terms of ability, level or the nature of individuals.
4. This measure produces a constraint of conformity that is a target to be aimed at or achieved by those who are subject to the normalising judgement technology.
5. It defines a limit that determines difference relative to all other differences, i.e., the frontier of the abnormal.

Exposing these differences creates a penalty that “traverse all points and supervises every instant in the disciplinary institutions compares, differentiates, hierarchizes, homogenizes, excludes. In short, it *normalizes*” (Foucault, 1984b, p. 195). Hoy (2004) argued that “individuals are complicit in the process of their self-formation and they learn to normalize themselves ... normalization does not suppress individualization but produces it” (p. 65). Thus rather than being a necessarily negative process, normalisation had positive consequences for people who subject themselves to it. Normalisation was in keeping with Foucault’s view of a positive rather than a negative form of power. Based on this, normalisation was an important construct to consider in the context of this study. It was important to explore how it lead to the construction of subjectivities and the institutions that define norms for various professions. Similarly, important constructions were norms related to perceptions of the body, professional practice and legitimacy both currently and historically, and in the context of OSA and CPAP therapy masks.

Finally, the combination of the two preceding instruments forms the third and final instrument. The examination or normalising gaze, often referred to as ‘the gaze’, is the combination of normalising judgement and the observing hierarchy (Foucault, 1984b, p. 197). The gaze is characterised through highly ritualised procedures, methods, characters and roles that proliferate through a whole domain of knowledge, and a whole type of power (Foucault, 1984b, p. 197). Foucault (1984b, p. 198) detailed the exercise of this power through school systems and pedagogy, disease diagnosis and medicine, inspections in the army and tactical knowledge. More recent investigations have demonstrated the gaze at work in the politics of women’s bodies, as revealed in women’s magazines (Duncan, 1994). It is particularly relevant when recognising the impact of the aesthetic aspects of mask design and the role played by community attitudes in the construction of the CPAP therapy mask (see section 9.1 for a more detailed discussion).

2.5 Summary

In this chapter I have provided an outline of the key theoretical ideas and concepts that were drawn on in the main part of this study. I situated the work of Foucault within broader social constructionist approaches to reality and then more specifically within post-modern and post-structural approaches. I then positioned the study in relation to Foucault's philosophical principles of inquiry. Finally, I introduced key theoretical concepts developed by Foucault that were pertinent to this study. The following chapter will provide a detailed account of the methodological principles I used to develop the study and examples of how I have applied each in this context.

Chapter 3 From methodology to methods

Over and above every opportunity for saying something there stands a regularizing collectivity that Foucault has called a discourse, itself governed by the archive. (Said, 1983, p. 186).

Paraphrasing this for the designer: over and above every opportunity for *designing or making* something there stands a regularizing collectivity also called a discourse, and this too is governed by the archive.

This thesis is an exploration of applying post-structural thinking in the context of a design project that sought to analyse a product with a view to its ongoing change and potential redesign. This chapter draws on Foucault's works on inquiry, and outlines my methodological exploration when articulating Foucault's ideas through the lens of product design practice. There are as many ways of applying Foucault's work as there are different ways of reading his work. This chapter presents one way of 'doing Foucault', by considering the interests and focuses that are important to product designers. This chapter (in addition to chapter 4), serves to ask *how a designer might use Foucauldian concepts of discourse analysis when exploring the social construction of the CPAP therapy mask*. The context I chose and the way I approached this question is a specific example, and necessarily employed a limited selection of concepts from periods in Foucault's work that I found particularly useful during my inquiry. Indeed there is potential for any number of Foucault's ideas to be applied in new and interesting ways in similar contexts.

3.1 Assessing Foucault's discourse analysis

Foucault argued against the idea of a final methodology to serve his analysis; he was instead a proponent of creating tools suited to the question and then applying them:

I do not have a methodology that I apply in the same way to different domains. On the contrary, I would say that I try to isolate a single field of objects, a domain of objects, by using the instruments I can find or that I forge as I am actually doing my research, but without privileging the problem of methodology in any way. (Foucault, 2003b, pp. 287-288).

Hook (2001), Nicholls (2008b) and Fadyl et al. (2013) argued to include two important elements in constructing research using Foucault's ideas and approaches. Firstly, the researcher should apply the work in a way that is suited to answering the research question, and secondly, the application, however novel, should demonstrate a degree of congruence

with Foucault's philosophical principles and methodological approaches. Thus rigour in research may also be evaluated and critiqued by considering the degree of alignment between Foucault's philosophical and methodological aims and how well the approach answers the research questions (Fadyl et al., 2013). In presenting this study, I intend to add to the discussion of applying a Foucauldian approach in the context of design for health inquiries. In doing so, I make no claim to this study being a 'true' or 'correct' application of Foucault's approach (if such a thing could even exist).

The focus of the inquiry and of the research questions are as follows:

1. How might Foucauldian concepts of discourse analysis be used in exploring the social construction of the CPAP therapy mask for OSA treatment?
2. How might exploring the social construction of the CPAP therapy mask (and its design process) assist designers in identifying and challenging 'truths' that are current and held to be 'self-evident'?
3. How might knowledge of these 'self-evident' truths be used to explore new possibilities for breathing interfaces more generally, and with a focus on CPAP therapy face masks and on people on a spectrum who live with OSA specifically?

3.2 Archaeology and genealogy

Foucault was well known for two particular methods, with the cut-off point between these two methods identified by Hook as occurring with his lecture "the Order of Discourse" (Hook, 2001b, p. 41). Foucault's archaeological method was the "analysis of local discursivities and possibilities of knowledge", whereas his genealogical method was the "*political* study of material arrangements of power and their strategic and critical uses" (Hook, 2001b, pp. 41-42). Genealogy was, to a large extent, dependent on the method of archaeology, and making a clear distinction between the two was difficult. From 'the culture of the self' lecture, Foucault was cited as addressing the confusion thus:

No, no, no... no, no, I never stopped doing archaeology. I never stopped doing genealogy. Genealogy defines the target and the finality of the work and archaeology indicates the field with which I deal to make a genealogy. (Foucault as cited in Mahon, 1992, p. 212 note 293).

For Foucault, archaeology, genealogy and ethics represented dimensions of analysis in which the aim was to feed the questioning of what may otherwise appear to be inevitable truths (Foucault, 1971).

Many influential thinkers have conceived of discourse analysis and the notion of discourse itself in terms related solely to language, like Coyle, who presented discourse analysis as follows:

Discourse analysis sees language not simply as reflecting psychological and social life but as constructing it. It rejects the idea that there are objective truths existing 'out there' that can be accessed if the appropriate scientific methods are employed. Instead, language in the form of discourse is seen as constituting the building blocks of 'social reality', the analysis of discourse emphasises how social reality is linguistically constructed.¹⁷ (Coyle as cited in Hook, 2001b, p. 42).

This presentation of discourse analysis was by no means universal. Alternative forms also included the need for a study of language to address the "tensions and contradictions which attend to political matters" (Parker 1992 as cited in Hook, 2001b, p. 42). This presentation of discourse analysis inferred that the dynamic "which structure[s] texts has to be located in an account of the way discourses reproduce and transform the material world"¹⁸ (Parker 1992 as cited in Hook, 2001b, p. 42).

3.3 Definition of Foucauldian discourse

The focus of Foucault's paper "The order of discourse", which detailed many aspects of Foucault's conception of discourse, was on the "rules, systems and procedures which constitute and are constituted by, our 'will to knowledge'" (Young 1981 as cited in Hook, 2001b, p. 42). In this sense, the focus of what Foucault aimed to analyse was not on what was thought or said as such, but on "all the discursive rules and categories that were a priori, assumed as a constituent part of discourse and therefore of knowledge" (Young 1981 as cited in Hook, 2001b, p. 42). The effects of discursive practices were to make thinking outside of them near on impossible, because "to be outside of them, by definition, is to be mad, to be beyond comprehension and therefore reason" (Hook, 2001b, p. 42). Thus, discursive rules and the exercise of power operated together with a discourse constituted by, but also necessary for, the reproduction of the social system, using forms of selection, exclusion and domination (Hook, 2001b, pp. 42-43).

¹⁷ Cited source: Coyle, A. 1998. 'Discourse Analysis', in G.M. Breakwell, S. Hammond & C. Fife-Shaw (Eds), *Research Methods in Psychology*. London: Sage, pp.243-258.

¹⁸ Cited source: Parker, I. 1992. *Discourse Dynamics: Critical Analysis for Social and Individual Psychology*. London: Routledge. p.2.

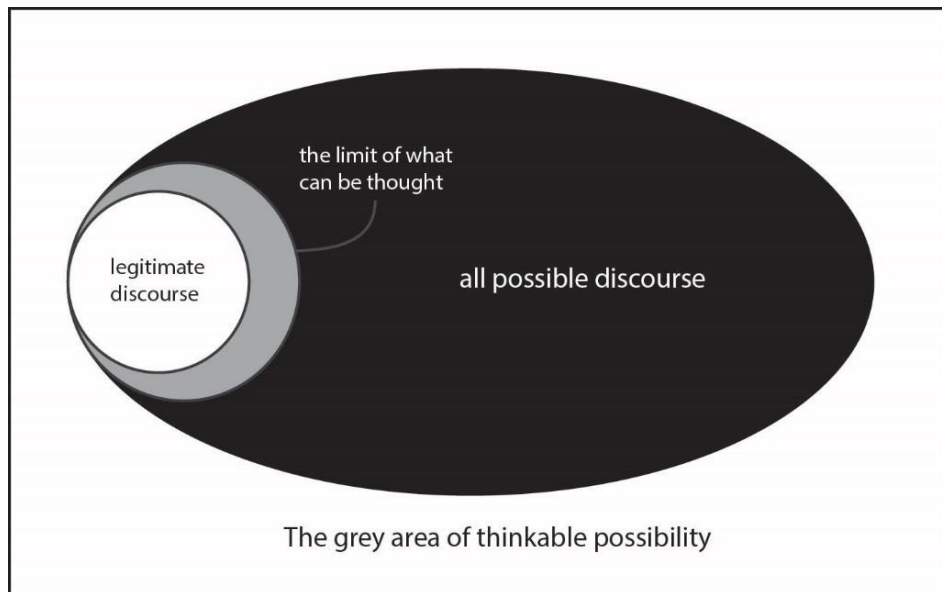


Figure 3. Visualisation of the limits of legitimate discourse and the grey area of possibility that Foucault endeavoured to open up.

Source: Author's image.

Hook (2001b, p. 43) argued that in contrast to the Anglo-American tradition, Foucault's approaches were an attempt to restore both materiality and power to the idea, at a time, when discourse was mostly seen as linguistic. Foucault's concerns also focussed on the role of discourse as both that which constrained, but also that which enabled writing, thinking and speaking, thereby situating it within the field of political action (Hook, 2001b, p. 43). His label of "discursive practices" implied a "play of prescriptions" that marked both exclusions and choices that worked productively but also to inhibit (Hook, 2001b, p. 43). For example, consider the powerful discourses around safety and science, and medical and professional legitimacy around medical devices, including their engineers and manufacturers. These discourses function to discredit or shut down the speaking possibilities of those uninitiated in these fields, such as new CPAP therapy users and members of the general community. These discourses also actively constructed authority and speaking opportunities for those in power. In this example, neither could exist without the other; their processes were complementary. They formed and constrained, produced and excluded, inseparably.

3.3.1 Statements

Statements for Foucault, were elemental to discourse. He conceived of them as a "function that cuts across a domain of structures and possible unities, and which reveals them, with concrete contents, in time and space" (Foucault, 1972, p. 87). Foucault took great care to differentiate the statement from the sentence and to place it in a position of materiality, although he was careful to acknowledge that it was not "the same kind of unit as a material object, with its limits and independence" (Foucault, 1972, p. 86). Within Foucault's

functionality of the statement, a key feature of existence was that it belonged to signs and “on the basis of which one may then decide through analysis or intuition, whether they ‘make sense’” (Foucault, 1972, p. 86). Such sense-making was according to what rules they followed, “of what they are a sign and what sort of act is carried out by their formulation...” (Foucault, 1972, p. 86). In short, statements “do things, bring about effects rather than merely ‘represent’ states of affairs” and must form part of knowledge (McHoul & Grace, 1998, p. 38).

Statements were always “endowed with a certain materiality, and can always be situated in accordance with spatio-temporal coordinates” (Foucault, 1972, p. 86). The materiality aspect of a statement also applied to spoken and written statements. For example, statements constructed from words passed through the physical world as vibrations, movements on a keyboard, imprints on a physical page or light on a screen. In each of these cases of materiality a linguistic sentence is present, but locating those words in time and space will change the statement made. For example, the words ‘I ride a motorcycle’ stated in a vehicle registry office make a particular statement. The same words ‘I ride a motorcycle’ stated in a hospital emergency room make quite a different statement. The words are the same, but the statement is different. Foucault further explicitly extended his concept of discourse beyond the linguistic, citing examples such as botanical classification tables, algebraic equations, a graph, a growth curve, an age pyramid and a distribution cloud (Foucault, 1972, p. 82).

While Foucault argued for a separation between the statement and the physical object, this does not mean that a physical object cannot make a statement. Instead a physical object *alone* cannot make a statement. It too must be located in time and space within systems of knowledge, including aspects that one can ‘make sense’ of with those knowledges and the activities carried out by their formulation. For designers and engineers, many material objects hold this kind of relationship to knowledge and are reflective of acts of formulation. This formulation is often through form, material selection, and visual, mental and emotional association. These formulations may be different from, but not completely foreign to oral or written formulations. In this study, where a material item was considered separately from its context (i.e., is considered only in its physical or material sense), I will refer to the physical form as an artefact. For example, the CPAP therapy mask is an object of analysis, whereas the CPAP therapy mask artefact refers only to the physical embodiment of the CPAP therapy mask.

3.3.2 Texts

A text is the data source for discourse analysis. In linguistic forms, this work was the written word such as books, transcribed conversations, and so on. In conducting an analysis, Foucault rejected solely focussing on written documents. In particular, he cautioned against accepting

unexamined constructions such as an author's. He instead argued for including "all statements out of which these categories are constituted – all the statements that have chosen the subject of discourse... as their 'object' and have undertaken to deploy it as their field of knowledge" (Foucault, 1972, p. 30). Thus a text was anything that made a statement. A text of interest for analysis was anything that made a statement about the 'object' of the investigation. For Foucault, images, material objects and arrangements of spaces all communicated statements within a field of relations and were thus considered texts (Foucault, 1972).

When considering the diversity of Foucault's texts, which range from a famous work of art such as *Las Meninas* to theatrical plays, literary works and even a smoking pipe. This became a challenge to future scholars of his ilk. The challenge was "that of going on 'inventing' new sources and areas of research not yet thought of by the so-called humanist sciences, so as continually to rethink and call into question the given truths of our world" (Tamboukou, 1999, p. 208).

3.4 The archive

In other forms of discourse analysis, the collection of texts assembled for analysis may be termed an archive (McHoul & Grace, 1998, p. 31). However, for Foucault, the term refers to the discursive formations revealed by the texts rather than the body of texts considered.

By the word ['archive'], I do not mean the mass of texts which have been collected at a given period, or chanced to have survived oblivion from this period. I mean the set of rules which at a given period and for a definite society defined:

- 1) the limits and the forms of expressibility...
- 2) the limits and the forms of conservation...
- 3) the limits and the forms of memory...
- 4) the limits and the forms of reactivation.

(Foucault, 1992, pp. 59-60).

In other words, the rules can be shown to define the body of texts required for a study. The self-referencing definition of useful texts makes their selection an iterative process, much like using a numerical solution method to solve an indeterminate mathematical equation. The analyst must select various texts, then analyse, evaluate and replace them until a collection is amassed that will demonstrate the rules governing the limits and historical forms inherent to a particular society. The following sections outline aspects of discourse that Foucault proffered as a starting point for analysing the practices that form them and their associated discursive formations.

3.4.1 Object

An object was “[o]riginally: something placed before or presented to the eyes or other senses. Now (more generally): a material thing that can be seen and touched” (Object, 2019 definition 1a). In this thesis, I have designated an artefact as such an item of material constitution that is encountered through sensory perceptions considered alone, and thus devoid of its various discursive connections (see section 3.3.1). The philosophical definition of an object includes both material and immaterial aspects and is much closer to the Foucauldian use of the term. “*Philos.* A thing which is perceived, thought of, known... a thing which is external to or distinct from the apprehending mind, subject, or self” (Object, 2019 definition 5). For Foucault, the practices that formed objects of discourse are of much greater interest than the objects themselves. An analysis of the formation of objects was a “task that consists of not - of no longer - treating discourses as groups of signs (signifying elements referring to contents or representations) but as practices that systematically form the objects of which they speak” (Foucault, 1972, p. 49). Figure 4 visualises an example of this idea.

This study will focus on two objects, which will be shown to be mutually constitutive. These objects are OSA and the device associated with its treatment, the CPAP therapy mask. These two objects, considered in the Foucauldian sense as constitutive of the practices that form them, will be discussed together in the following sections.

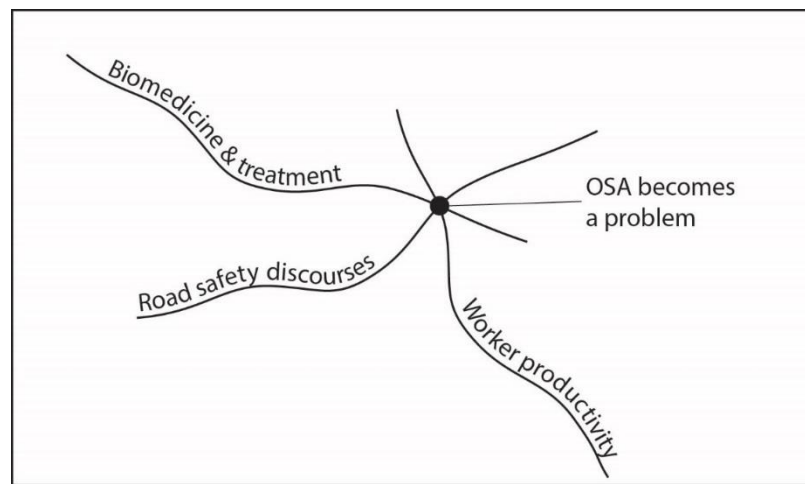


Figure 4. Example of the object forming at the intersection of discourse formations.
Source: Author's image.

In the task of identifying objects, there are three main places to look: surfaces of emergence, authorities of delimitation and grids of specification as will be discussed in the following sections.

The first place to consider when identifying objects, according to Foucault, was by looking at surfaces of emergence. For Foucault, objects emerged in different ways in different societies,

and at different times. Understanding the contingencies (which he refers to as a surface sliced through the three-dimensional volume that is reality) in which these objects emerged was important to understand and recognise (Foucault, 1972, p. 41).

Foucault's *surfaces of emergence* are "spaces and situations where objects emerge as 'manifest, nameable and describable' – visible, differentiated and describable in terms of what it is and is not" (Fadyl, 2013, p. 483; Foucault, 1972, p. 41). An example from this study was the emergence of OSA and CPAP therapy masks as objects of interest through, for example, studies on its effects on worker productivity (Mulgrew et al., 2007), road safety (Horne & Reyner, 1995) and population health studies (Sigurdson & Ayas, 2007), workplace medical examination (Philip, Taillard, Niedhammer, Guilleminault, & Bioulac, 2001).

The second place to identify objects is in the area of authorities of delimitation. Authorities of delimitation for an object are the major authorities in a society that designates, names or establishes an object (Foucault, 1972, pp. 41-42). Such authorities might include institutions with their own rules; such as professions involving a group of individuals, particularly those associated with bodies of knowledge and practice who may be recognised in public opinion, and by law and government (Foucault, 1972, p. 42). All of these authorities within a society established and gave importance to the objects of interest (Foucault, 1972, p. 42).

In the case of OSA and CPAP therapy mask objects, some examples were judicial and legislative authorities, medical and vehicle insurers and health schemes and government service delivery departments. In New Zealand, OSA patients must be reported to the motor vehicle authority to have their drivers' license suspended if they do not demonstrate 'successful CPAP therapy use' (New Zealand Transport Agency, July 2014, pp. 113-115). Thus the 'excessive sleepiness' associated with OSA was constructed by the legislative authorities as a risk to public safety that the New Zealand Transport Agency (NZTA) countered through license suspension. The law required hospital clinicians, nurses and doctors to enforce this countering of risk by notifying the motor vehicle licensing system. CPAP therapy (a component of which is the CPAP therapy mask) can monitor OSA or sleep without breathing disturbance and provide 'testimony' on behalf of the OSA patient to prevent license removal. Due to the sheer volume of OSA patients, potential offenders were only identified through a failure to use the CPAP therapy, as to manage all OSA patients exceeded the government resources allocated.

The third and final place to look for objects, according to Foucault, was in the grids of specification. Grids of specification are systems through which the object is "divided, contrasted, related, regrouped, classified" or otherwise organised (Foucault, 1972, p. 42). In

the case of OSA, the severity was broken down subjectively by the Epworth sleepiness scale, and objectively by the number of apnoea and hypopnea events per hour of measurement (see section 5.1). Clinicians compared these measurements to an agreed standard that designates mild, moderate or severe sleep apnoea, which then determines whether the OSA patient requires treatment or not. If there were less than five apnoea or hypopnea events per hour, the patient was considered not to have OSA. As such, OSA was organised by this specification (see Table 4 p.107).

Similarly, CPAP therapy masks are specified based on measurements of air pressure that also relate to treatment levels of this specification. Thus the grids of specification for OSA and CPAP therapy masks include manufacturers' catalogues and websites, the Epworth sleepiness scale, the Sleep disorders diagnostic manual and healthcare coverage documents. However, it is the relationships between these specifications that are the most important and that need to be mapped and examined. The question is, why this system of formation rather than another, and why now? (Foucault, 1972, p. 43).

3.4.2 Enunciative modalities

Enunciative modalities refers to questions of who is qualified to speak of a particular object or on a particular topic, and to be afforded the presumption that what they said was true (Foucault, 1972, p. 50). For Foucault, discourse operated to construct these modalities through the criteria of "competence and knowledge; institutions, systems, pedagogic norms; legal conditions that give the right – though not without laying down certain limitations – to practise and to extend one's knowledge" (Foucault, 1972, p. 50). In the case of OSA, an enunciative modality was evident in the diagnosis process. In this process, a potential patient consulted with a General Practitioner (GP doctor) whose medical degree, ongoing training, medical institute membership and legal registration marked them as qualified to speak on the symptoms presented. The result was a referral to a sleep laboratory. In the sleep laboratory, tests were completed by other medical staff and clinicians with varying levels of sleep science training or registration from similar institutions. In the case of OSA, a common referral modality was a bed partner relaying observed symptoms to the potential patient.

In some cases, the bed partner also suggested that the potential patient may have OSA based on their general knowledge of the condition or information search. The potential patient was not, however, considered to have this illness from the bed partner's statement, as the bed partner was not a qualified medical practitioner. The kinds of qualified professionals able to speak 'truthfully' on this topic included respiratory doctors, ward doctors, GPs, sleep

physiologists, sleep technologists and respiratory nurses. Importantly, the right of diagnosis was possible only within a very narrow range of data sets for all but the respiratory doctor.

A second key factor was that the sites from which legitimised subject positions made these statements contributed to the legitimacy of the discourses (Foucault, 1972, p. 50). In other words, the spaces and positions in which the statements were made lend legitimacy to the particular discourses of a particular author. For example, a community member speaking to their doctor at the supermarket or on the golf course would not constitute a diagnosis in the same way as if the two met and conversed at the GP's office or the hospital. In these institutionalised settings, the GP's advice takes on professional, legal and institutional significance.

This modality also exists for the object of the CPAP treatment mask, and for medical devices more generally, where specific qualifications are required for a device to be considered a legitimate treatment. This argument also drew on Foucault's notion of the 'author', which he outlined in his essay *What is an Author?* (Foucault, 1984e, pp. 101-120). To qualify as a treatment, a CPAP therapy mask must be produced by a manufacturer who can demonstrate to legislators that they have met relevant production standards. In general, regulatory authorities and health insurers must also approve treatments, and they must meet risk guidelines and manufacturing process standards (see chapter 6). In *Archaeology of Knowledge*, Foucault placed subjects as an enunciative modality, created through the rights of the legitimate speaker and supporting institutions and spaces. Within situational interactions, subjects can occupy a limited domain of such positions which are then defined "in relation to the various domains or groups of objects" (Foucault, 1972, p. 52).

3.5 Archaeological methodological principles

Foucault outlined his Archaeological principles in *The Order of Discourse* (Foucault, 1971). The following discussion provides an overview of some of the principles that were most relevant to the research questions and examples of how I applied them.

3.5.1 Principle of reversal

When we think we recognise the source of the discourse, the principles behind its flourishing and continuity, in those factors which seem to play a positive role such as the author discipline, will to truth, we must rather recognise the negative activity of cutting-out and rarefaction of discourse. (Foucault, 1971, p. 22).

One approach to addressing reversal was to recognise the role of silence as playing a positive role in the formation of discourse. Foucault differentiated it as a function, rather than a limit of discourse, when he said:

Silence itself-the things one declines to say, or is forbidden to name, the discretion that is required between different speakers-is less the absolute limit of discourse, the other side from which it is separated by a strict boundary, than an element that functions alongside the things said, with them and in relation to them within over-all strategies. (Foucault, 1978, p. 27).

The rarefaction, or thinning out, of discourse shaped and ordered how it functions. In architecture and design, far from practitioners considering 'empty space' as outside of the design, it was instead cast as 'negative space', the shapes and bodies formed not from matter or colour, but the apparent lack of it. Rather than focusing on that which is missing, it was important to recognise the process through which this occurs. Foucault argued for thinking of discourse as event rather than creation (Hook, 2001b, p. 52)

In this study, I used the critical principle of 'reversal' as a methodological strategy to make discourse more visible, - disrupting the usual (clinical) relationship with discourse that the CPAP therapy mask 'naturally' occupies by situating a discussion of the mask into a community market. Much of the clinical research used by product designers takes place in hospital environments (see section 5.2), or involves recruitment processes that approach patients and clinicians. Seeking input on the design of CPAP therapy masks from a broad community rather than using contacts through the hospital and district health board to recruit possible participants operated as a reversal. Using the reversal strategy highlighted people and perspectives that may be missing from research generated in a hospital environment. This in turn made visible the discourses that operated to exclude them. The data collection approach changed the usual relationship with discourse by changing the location of the interaction, thereby removing institutional markers from the interaction. Rather than CPAP users being cast primarily as patients and confronted with a one-on-one interview style and pronounced subjectivity, input was sought from private citizens in the course of their day and surrounded by people they had chosen to be with at that time and place.

This approach highlighted differences between those who were currently authorised to speak about OSA and CPAP therapy masks and other subjectivities with which they might not interact. Examples of those authorised to speak included: mask users, clinical staff and manufacturing staff. Examples of people not usually authorised to speak about OSA and CPAP therapy included those who know someone with OSA, those who have no particular

connection to OSA and those who have connections to other kinds of non-CPAP or non-medical masks.

3.5.2 External exclusion

In 'Orders of discourse', Foucault outlined the rules of exclusion, the purpose of which is to avert the 'powers and dangers' of discourse (Foucault, 1971, p. 8). He began with the 'most obvious' form of exclusion, that of prohibition.

Foucault organised prohibition into three types: prohibitions that cover objects; those that cover ritual and the circumstances that surround it, and the privilege of a restricted right to speak on a particular subject (Foucault, 1971, p. 8). Foucault identified these prohibitions as forming a complex web that interrelates with, reinforces and complements the other strands (Foucault, 1971, p. 8). So while the speech itself may not be of great importance, the prohibitions around it were revealing of the networks of power and desire (Foucault, 1971, p. 8). From an application perspective, the questions to be asked of the data collected may include (Fadyl et al., 2013, p. 485):

- Objects: what do we not have the right to say?
- Ritual and circumstance: within what we can say, what are the limited set of circumstances in which we can say it?
- The privilege of the restricted speaker: who has the right to speak on a subject and who does not?

For example, within current medical discourses doctors, nurses and clinicians have the right to speak on the adherence of patients to a CPAP therapy, that includes a mask, within the context of the hospital environment or academic publications. Friends and family of CPAP therapy mask users appeared not to have the right to speak about the appearance of the mask or its effect – but people otherwise personally unconnected to CPAP therapy users were free to comment on mask appearance (7.5).

In addition to prohibition, Foucault detailed the second principle of exclusion not so much as a prohibition but more as a division and rejection – in this case between reason and foolishness (Foucault, 1971, p. 9). In the Middle Ages, a man was considered mad if his speech did not fit the common discourse (Foucault, 1971, p. 9). While his words were neither remembered nor often accorded value, it was through his words that he was understood as mad (Foucault, 1971, p. 9).

In applying this opposition, one might ask of the data, what was considered mad or unreasonable? In the case of CPAP therapy, the idea of not using a treatment for life-threatening illness because of the way it looks was considered unreasonable or foolish. An effect of this discourse appeared to be that rather than refusing treatment and appearing unreasonable or foolish, people would accept the treatment but then not use it, or avoid or delay seeking treatment at all.

As a working definition, the 'will to truth' was the "way in which knowledge is put to work, valorised, distributed" (Hook, 2001b, p. 524). An important starting point was to investigate knowledge that is marked as legitimate and to identify what knowledges and 'truths' these statements rely on; what might cast them as false or invalid. It was important to ask what authorities or institutions operate to maintain these knowledges or truths. For example, in this study, knowledge of the object of OSA was cast as true or valid through reference to scientific and clinical discourses. These truths were maintained through adherence to scientific procedures and approved practices associated with peer-reviewed studies, as found in academic and scientific journals. These same systems applied to the knowledge of particular CPAP therapy mask types, which were also tested and validated in studies of this kind. This work was associated with manufacturers' researchers and current or largely successful CPAP therapy users. Flaws in the studies could render the knowledge invalid. Although it did not emerge as central to this research, an example I found was a study proposing a gas level-related panic response to wearing a mask (Klein, 1993). The study was subsequently discredited by a series of further publications (Ley, 1994; McNally, Hornig, & Donnell, 1995; Vickers & McNally, 2005).

3.6 Principles of genealogy

Foucault's genealogy (1971, pp. 21-22) was his reflection on the nature and development of modern power (Tamboukou, 1999, p. 202). Drawing on Nietzsche, Foucault built on the insight that "the truth cannot be separated from the procedures of its production" (Tamboukou, 1999, p. 202). The user of this approach was then tasked to "criticise, diagnose and demythologise 'true phenomena'" (Tamboukou, 1999, p. 202). Rather than seeking the truth, Foucault's genealogies sought to investigate "which kinds of practices tied to which kinds of external conditions determine the different knowledges in which we ourselves figure" (Tamboukou, 1999, p. 202). Using several principles (the principles of discontinuity, specificity and exteriority, as will be discussed subsequently), genealogy revealed disjoints in what has previously been viewed as a continuous historical development (Tamboukou, 1999, p. 202). Discontinuities in the past in turn, imply that similar discontinuities exist in present formations.

The aim was “to go further by tracing ways of thinking differently, instead of accepting and legitimating what are already the ‘truths’ of our world” (Tamboukou, 1999, p. 202).

Genealogies aimed to separate from “the contingency that has made us what we are, the possibility of no longer being, doing or thinking what we are, do and think” (Foucault, 1984f, p. 46). Genealogy was “history oriented toward the future” (Mahon, 1992, pp. 82, (122 similar))¹⁹.

3.6.1 Principle of discontinuity

While I have not applied the principle of discontinuity in the way it was used by Foucault, it provided an important conceptual inspiration and guidance when developing my methods. This section will briefly explore the principle of discontinuity in the form used by Foucault, before addressing how I adapted the principles to serve the purposes of this study (see also sections 4.4, and 8.2).

Foucault warned against imagining an ‘unsaid or unthought’ floating in the void awaiting rescue and restoration to speech (Foucault, 1971, p. 22). Instead, he argued that the appropriate response was a recognition of the discontinuous nature of the field of discourse; neither a coherent whole nor consistent even with itself. Here Foucault emphasised a distrust of the cause-effect style of historical explanations (Hook, 2001b, p. 54). Foucault upended the usual relationship with history by writing ‘the history of the present’. In this approach the historian begins by locating in a contemporary setting an example of a specific “ritual of power” or “political technology of the body” and then traces it back to see where it began, when it became prominent, how it took shape and so on (Dreyfus & Rabinow, 1983, p. 119)²⁰. Nietzsche’s “effective histories” cast historical material as a resource for upending traditional foundations and continuities (Foucault, 1984c, p. 88). Hook critiqued the linguistic form of narrowly focussed deep dive in discourse analysis that “reifies the text, recuperates the author-principle (in the figure of the interpreter), and restores a central anchoring point, not this time in truth but in the authoritative interpretation, which performs much of the same function” (Hook, 2001b, p. 63). He proposed instead, that “one needs... to map discourse, to trace its outline and its relations of force across a variety of discursive forms and objects”

¹⁹ “Critical philosophy is a philosophy of the present, but one which conceives of the present as a radical future.” Source: Mahon, M. (1992). *Foucault's Nietzschean genealogy: Truth, power, and the subject*. Albany, NY: State University of New York Press.

²⁰ This is in contrast to histories of the past, which re-interpret the past in terms of the discourses and values of the present, thereby alienating it. Source: Dreyfus, H. L., & Rabinow, P. (1983). *Michel Foucault: Beyond structuralism and hermeneutics*. Chigaco, IL: University of Chicago Press, Hook, D. (2001b). The 'disorders of discourse'. *Theoria: A Journal of Social and Political Theory*(97), 41-68.

(Hook, 2001b, p. 63). Thus a diversity of textual forms, including historical text and those from multiple spaces, were important for discourse analysis. Historical texts can give clues as to how this particular iteration of the present came about, while simultaneously highlighting the dangers of casting 'now' as the peak of knowledge (Foucault, 1984c, p. 88)²¹.

My approach to this study was inspired by Foucault's principle of discontinuity and the history of the present approach. In Foucault's application of the tools, he compares a later version of an object with one that is very different in a different historical context. In adapting my approach and drawing on the principle of discontinuity, my aim was to make what was considered commonplace seem strange in a similar manner. In practice, this meant juxtaposing the product of medical and manufacturing discourses with a similar shaped product that drew on familiar artefacts and material palettes from completely different environments and material sensibilities. These objects, when located in proximity to the 'true' CPAP therapy mask, provided a counterpoint that was able to challenge the self-evidence of the embodiment of the medical mask design. The value of adapting the tool of discontinuity in this way was that it opened complex theoretical ideas very quickly to external input, which would have been difficult or impossible using purely written or spoken methods. Importantly, the artefacts created for the purpose of this study, while also located within discursive formations, primarily functioned to make the 'true' CPAP therapy mask discourses visible and relevant to commenters.

3.6.2 Principle of specificity

For Foucault, the principle of specificity implied that "a particular discourse cannot be resolved by a prior system of significations; that we should not imagine that the world presents us with a legible face, leaving us merely to decipher it; it does not work hand in glove with what we already know" (Foucault, 1971, p. 22). Instead, discourse should be viewed as a practice or violence imposed upon things and through which the events of the discourse find their principle of regularity (Foucault, 1971, p. 22). In other terms, discourse is a human practice, not always open to interpretation. Discourse produces everything, and it must be shown for how it operates, in order to make space for things to be produced in a different way (Fadyl et

²¹ "'Effective' history deprives the self of the reassuring stability of life and nature, and it will not permit itself to be transported by a voiceless obstinacy toward a millennial ending. It will uproot its traditional foundations and relentlessly disrupt its pretended continuity." Source: Foucault, M. (1984c). Nietzsche, genealogy, history. In P. Rabinow (Ed.), *The Foucault reader* (pp. 76-100). New York, NY: Pantheon Books.

al., 2013, p. 488). A focus on texts detailing actual practices that show the right way to do things or purport to truth can help to address this principle (Fadyl et al., 2013, p. 488).

In this study, I focussed the first stage on academic texts that purported to be a source of 'true' knowledge about CPAP therapy, design and sleep. The second approach was to consult with clinicians and others associated with the hospital environment. Finally, as the CPAP therapy mask artefact was in wide usage, its form both reflects and shapes current practices of manufacture, prescription, distribution and usage. As such, I chose the CPAP therapy mask as the third point of detailed investigation for the surrounding links and passages of power.

3.6.3 Principle of exteriority

The principle of exteriority required taking the discourse itself to focus on its appearance and regularity (Foucault, 1971, p. 22), rather than seeking a hidden core or manifest meaning. The task then is to seek the "external conditions of existence" that gives rise to this discourse as a "chance series of events and fixes its limits" (Foucault, 1971, p. 22). In other words, do not look for hidden meaning in the discourse, instead "ask what it opens up and makes possible, and what it excludes or renders impossible or unreasonable" (Fadyl et al., 2013, p. 488; Foucault, 1971). Rather than going deep and narrow for an interpretive analysis, "one needs, by contrast, to map discourse, to trace its outline and its relations of force across a variety of discursive forms and objects" (Hook, 2001b, p. 63). In this way, Foucault placed genealogy as an overview or interpretation that "projects out over... depth, raised more and more above... leaving the depth below, exposed to an ever greater visibility. Depth is now restored as an absolutely superficial secret" (Foucault, 1990, p. 62)

I applied this principle by using a wide variety of texts and by seeking links between artefacts of interest and any associated knowledges and practices, as broadly as possible (see section 4.3 and chapter 6).

3.7 Summary

Chapter three provided an overview of Foucault's forms of discourse and the principles upon which he based his analysis. The discussion began by addressing some considerations in applying Foucault's methods and how a reader may assess them for rigour. The discussion of rigour was followed by contrasting linguistic concepts of discourse with Foucault's concept of discourse, statements and texts. I then examined discursive formations and their constituent elements before addressing the methodological principles used in the study from Foucault's Archaeology and Genealogy methods. Of key importance in this discussion was the role of the physical and particularly the artefact in this process, and the opportunities this presented for

applying the methodological principles in new ways. For each of the principles examined, I presented examples of how I have interpreted the principle and applied it in the context of this study. Chapter four will detail the design of the study that emerged from the process outlined in chapter three.

Chapter 4 Study design

Chapter four builds on chapters two and three to articulate the study design that I used to explore the current design embodiment of and the new possibilities for the CPAP therapy mask for OSA. In this chapter, I draw primarily on product design and discourse analysis principles to articulate a method of collecting and generating texts suited to answering the research questions, articulated in chapter one. Using Foucault's methodological principles, which were outlined in chapters two and three, this chapter outlines the development of a study design appropriate to collecting and generating data for a discourse analysis based on Foucault's principles of discourse and inquiry. In addition, I show how creative methods can be re-envisaged with Foucauldian concepts and his philosophical approach to generate an example of data collection and text generation. This would be useful for and relevant to addressing social construction in the context of product design for CPAP therapy masks.

Chapter four concludes the methodological development chapters. This chapter presents one response to the question of how Foucauldian concepts of discourse analysis and how a researcher might combine this inquiry with creative methods when exploring the social construction of a CPAP therapy mask for OSA. In chapter eight I further develop the discussion on this approach as a form of design inquiry, with an analysis of how it can be a resistance to existing design practice.

4.1 Approach to selection and generation of texts

Foucault's methodological guidance emphasised the importance of attending to local material practices, a wide range of textual sources and to the subjects, objects, and concepts that addressed the 'conduct of conduct', as they related to the topic at hand (Nicholls, 2008a, p. 58). The following sections will discuss how I used Foucault's guidance and methods as a guide to sampling, generating and analysing the localised texts in this study.

4.1.1 Criteria according to topic related emphasis

In his study of pleasure, Foucault sought to write a history of the experience of sexuality, "where experience is understood as the correlation between fields of knowledge, types of normativity, and forms of subjectivity in a particular culture" (Foucault, 1985, p. 4). Texts that focus on the 'experience' of using masks for breathing support are based on this definition. For this study, a breathing support mask is defined as any face-worn device that interacts with breathing, including devices that use additional air or oxygen, whether under pressure or not. Face-worn devices that provided passive filtration of air (for example surgical and dust masks

or industrial respirators) were initially considered to be peripheral to the research question, but later appeared in texts generated from engagement with the community.

The text selection process involved mapping texts associated with the object of the CPAP therapy mask and the perceived experience of wearing one. This process developed intuitively and iteratively.

4.1.2 Methodologically based emphasis criteria

In line with principles of specificity and exteriority, the texts sought focussed on the conditions of possibility that enable and limit CPAP therapy mask design. Thus texts about ‘good design’, ‘patient treatment adherence’ (which I have also considered as a form of ‘good patient conduct’), and ideas about ‘what is really going on’, were important focal points. The principle of exteriority led to the inclusion of texts that relate to material practice and the experience of interacting in material environments (i.e., the clinician’s office or a sleep lab) and with material items (i.e., the mask, head strap, tube and packaging). These physical elements constructed the actions, gestures and physical tolerance (or discipline) that must be mastered to use a CPAP treatment successfully.

The *principle of discontinuity* was used to guide the study when seeking out areas where discourses did not agree, or where alternative explanations were found to be available. These areas were given particular attention as they were productive areas for investigation.

The *principle of reversal* drove the focus on the present, in particular, the procedures of exclusion and limitation. Rules and restrictions on the speaking subject (Foucault, 1984e) or, in the case of this study, the rules and restrictions associated with making or manufacturing, drove the product mapping discussed later. The *principle of reversal* and restriction of the speaking subject also drove the data collection approach of going to a community market to seek new inputs. Similarly, using design probes to stretch the boundaries of what might be considered legitimate, reasonable or sensible, helped reverse the usual relationship with the artefact. For example, there was a clear, logical argument for seeking design input from people who need or use a particular medical device, and their families. However, I found it was much harder to make an argument for seeking input from people who have had no contact with a particular device whatsoever. This approach did not have the same markings of legitimacy in clinical and design practices as approaching ‘successful users’. Despite this, early findings show that this group also includes people who exhibited symptoms of disordered sleep. In Foucauldian terms, this approach used a form of resistance as a starting point to collect texts.

On a related principle, collecting texts in this way is also “an approach whereby discourses are made more visible, through interrogation of their limits” (Fadyl, 2013, p. 44).

In line with Hook (2001, pp. 542-543), care was taken to treat a collection of texts with the following methodological considerations at the forefront:

1. Texts must be historically contextualised.
2. Texts must focus on discourse as “a matter of the social, historical and political conditions under which... statements come to count as true or false” (McHoul & Grace, 1998, p. 29).
3. Text consideration must include their material effects, such as their dual role as the effects of power but also as the instruments of power.
4. Use texts in such a way as to “drive the analysis of the discursive *through the extra-discursive*” (Hook, 2001, pp. 543, original emphasis).

Under a post-structural and Foucauldian analysis approach the selection and analysis of texts results in findings that are socio-historically specific to the context in which they were created. It is a limitation of this research approach that findings cannot be extrapolated or applied beyond the context in which they were collected. The approach to engaging with CPAP therapy user’s own experience relative to the broader social construction of CPAP therapy is discussed in section 1.3.

4.2 Data collection

4.2.1 Consultation and ongoing design notes

The initial consultation and scoping period took place from May to August 2015. This preliminary consultation included site visits to a publicly run sleep lab and respiratory clinic, discussions with sleep and respiratory clinicians, mask design experts, patient advocates and local community members from different cultural groups in New Zealand. During this consultation period, texts generated or collected included design notes, journal articles, mask manufacturer information and website texts. I later used the texts generated through this process as data for various parts of the analysis. Figure 5 shows an overview of this initial consultation period, including topics, leads and the texts generated.

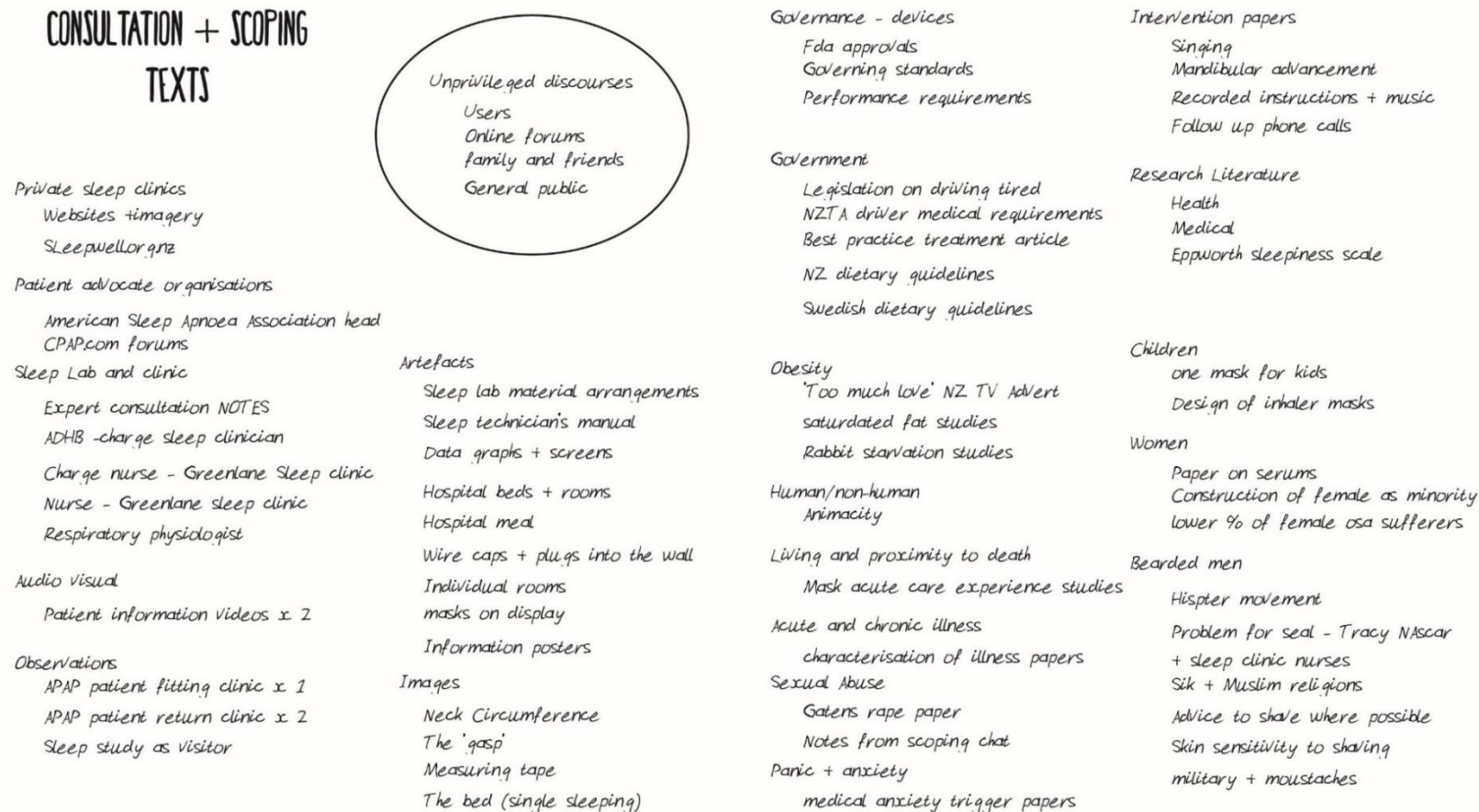


Figure 5. Overview of consultation and scoping texts, discourses and missing perspectives.
Texts collected in the period from May to August 2015. Source: Author's image.

Concurrent with and following this initial scoping, I collected and generated data for the study in four forms, as follows:

1. Contextual review of existing documents, in the forms of a scoping and a systematic literature review (see section 4.2.2 and chapter 5).
2. Eleven semi-structured interviews conducted with OSA and CPAP therapy experts (see section 4.2.4).
3. Analysis of an existing CPAP therapy product examining the knowledges and practices that have shaped the physical artefact (see section 4.3 and chapter 6).
4. Use of the preliminary findings to develop design probes to assist in generating data through a community engagement method (see section 4.4 and chapter 8).

The following sections will discuss each of these approaches. Sections 4.3 and 4.4 discuss the product analysis and community engagement in greater detail, as I developed these approaches specifically for this study.

4.2.2 Scoping, and contextual literature review

The literature review process focuses on texts available through the online databases that can be accessed through Auckland University of Technology library subscriptions (see section 4.2.3 for a detailed discussion of search terms and keywords). The search developed heuristically, following inter-disciplinary pathways. I collected relevant references in each article as texts, notably where they helped to unpack more dominant discourses. For example, Charmaz (1990) explains the term ‘chronic illness’ in the original grounded theory study that coined the phrase. Likewise, her precursor article discussing the ‘suffering of the chronically ill’ helped to build the foundation for the idea of ‘chronic illness’ (Charmaz, 1983).

Dominant clinical practices organised knowledge by illness (e.g., OSA or Chronic Obstructive Pulmonary Disease (an umbrella term for progressive lung disease)) rather than by physical device (i.e., breathing support mask) or treatment modality (i.e., gas delivery to an interface). Recognising the common mask functionality across clinical disciplines and illness definitions presented an opportunity to reorganise the available knowledge. Grouping together knowledge that relates to mask function, rather than the illness it treats, considerably broadens the user experience-specific material available for the literature review.

4.2.3 Systematic literature review

For the systematic review, the question was ‘what are the dominant themes identified in studies that investigate patient experiences of breathing support interfaces?’ The body of literature searched was largely that related to clinical sciences, health and medicine. See Table 1 for a summary of the search approach.

Table 1. Key search terms and databases

Search type	Database	Search terms	Date
Exploratory	Various combinations of terms searched in Google Scholar, and, AUT's Summon, which searches databases including: CINAHL, EBSCO, ProQuest, science direct, Web of Science, Cochrane via OVID, MEDLINE and SCOPUS.	Patients, positive airway pressure, sleep apnea, continuous positive airway pressure, quality of life, sleep apnea, obstructive - therapy, apnea, sleep apnea syndromes, patient outcomes, sleep apnea, obstructive - ethnology, impact, characteristics, apnea/hypopnea syndrome, nocturnal positive pressure ventilatory assistance, CPAP, stigma, compliance, social comparison stigma, appearance, aesthetic. Factors affecting CPAP compliance, Sleep Quality, Short-Term and Long-Term CPAP Adherence; medical AND "design research" AND "product design" 2010-2015; Factors that influence CPAP adherence an overview, 2010-2015; medical AND culture AND "applied psychology" AND "sleep apnea"; medical AND culture AND "sleep apnea" AND mask experience; medical AND culture AND "applied psychology" AND CPAP; "mask design" AND art, dissertation/2010-2015; "history of masks" , (journal article and book); "face masks" design (refinements: books, 2015, included topics: therapy, technology & engineering, psychology, fine arts, performing arts, medical/evidence-based medicine, life sciences, literature, medical care).	May-June 2015
Exploratory	Additional journal hand search	HERD, arts and health, Sleep Breath, Sleep Medicine, Sleep and breathing	June 2015
Refinement	CINAHL via EBSCO, ProQuest, Science Direct, Web of Science, Cochrane via OVID, MEDLINE, SCOPUS	Mask, OSA, CPAP, nPAP, *PAP, positive pressure, mechanical ventilation, breathing, patient*, experience, phenomenology, grounded theory, 1990-2016.	June 2015-July 2019
Refinement	Google Scholar	Qualitative study, face mask, facemask, "patient experience", breathing, anxiety, "lived experience", NIV, non-invasive ventilation, New Zealand.	June 2015-July 2019
Refinement	Reference list searches	Key review and reference articles and journals.	June 2015-July 2019

I assessed articles for their contribution to answering the research question and whether they met the inclusion criteria as listed in Table 2. A summary of articles, data extracted and methodological quality assessment outcomes is available in Appendix E. Methodological quality was appraised using the JBI Critical Appraisal Checklist for Qualitative Research (Aromataris & Munn, 2017), CASP checklists for Systematic Reviews (Critical Appraisal Skills Programme, 2018d), Randomised Controlled Trials (Critical Appraisal Skills Programme, 2018c), Case-Controlled Studies (Critical Appraisal Skills Programme, 2018a) and Cohort Studies (Critical Appraisal Skills Programme, 2018b). I included in the review articles that I assessed to be high quality for the study type (defined as losing less than 4 points on any checklist).

Table 2. Inclusion and exclusion criteria

Inclusion	Exclusion
Papers focussed on any aspect of personal experiences using a form of breathing support for illness.	Not including any aspect of personal experiences using a form of breathing support for illness.
English language.	Not English language.
Papers from Jan 1990 to Jun 2015 from the main search.	Papers before 1990 and after Jun 2016 for the main search.
Papers before Jan 1990 where referenced by key papers.	Papers not published in peer-reviewed journals or academic theses.
Papers that were empirical, non-empirical studies, theoretical, systematic review, clinical review, intervention studies, letters published in peer review journals, academic theses.	

Thirty-eight articles were assessed to be of sufficient quality and relevance. They used an appropriate methodology to address the research question (refer to Appendix E) for key article assessment). Findings from the systematic review were analysed in thematic categories in section 5.3 to help conceptualise the range of personal, social and cultural aspects of breathing interface use and adherence.

4.2.4 Interviews

This study includes interview style interactions in two forms: expert interviews and design probe responses. The two stages of the research were approved by the Auckland University of Technology Ethics Committee (AUTC) with approval number 16/167 (see Appendix A:). Design probe responses are covered separately in section 4.4. The ‘Expert interview’ approach will be outlined next.

Interviews in various formats are a common form of data collection for both clinical sciences (DiCicco-Bloom & Crabtree, 2006) and human-centred design (Laurel, 2003, pp. 24-25). They provide access to otherwise excluded or subjugated discourses, which are critical to the exploration of new possibilities and forms of resistance (Nicholls, Giles, & Sethna, 2011). The format of interviewing is ubiquitous in Western societies, making it a broadly accessible option for the generation of texts (Mann, 2016a, p. 30).

In this study the use of the semi-structured interview, endeavours to provide flexibility and allow participants to express their views in their own way, while also maintaining some consistency and focus for comparative purposes (Mann, 2016b, p. 91). The semi-structured nature of the interviews meant that participants were also free to choose the information they saw as most relevant to the topic of the interview (Mann, 2016b, p. 91). Semi-structured interviews have the benefit that questions can be modified 'on the fly' and avenues of interest followed up directly with participants (Mann, 2016b, p. 91). These factors contributed to broadening an exploratory study, a decisive factor when contrasting the semi-structured interview with alternative interview formats.

Clinical staff and OSA clinical specialists associated with Auckland City Hospital Sleep Lab, Greenlane Respiratory Clinic and Manukau Super Clinic participated in a total of eleven semi-structured interviews. The experts interviewed initially were hospital professionals identified through the Design for Health and Wellbeing Lab²² (DHW Lab). Interviewees were invited using a snowball sampling approach where each interviewee was asked to suggest further potential participants. A DHW Lab contact or previous participant invited each potential participant by sending them a participant information sheet and consent form by email. With the participant's agreement, I arranged an interview time with them, and the participant signed the consent forms before starting the interview. The interviews were conducted based on the set of guiding questions that are included in the Appendix C: Expert Interview Protocol.

These questions focussed on the diagnostic process and aspects relating to the use and fitting of the CPAP therapy masks, and to clinician's perceptions of patient responses. All interviews were conducted in person at the participant's choice of location, usually their workplace. I made notes during the interview, audio recorded and personally transcribed all interviews. Findings from the interviews were initially analysed using a general inductive process (Thomas, 2006). Notes taken during interviews were printed on paper and cut into individual

²² The DHW Lab was a design research and 'living lab' collaboration between Auckland University of Technology and Auckland District Health Board, located in Auckland City Hospital.

statements. These were grouped together and pinned into categories related to processes and observations, insights, point of view and mask design opportunity statements (see Appendix G). This preliminary analysis was important in shaping the direction of the study (see 1.3 for discussion of user focussed data emphasis and use). This data was also included in the analysis of the market data where interviews were treated as ‘texts’ in the Foucauldian sense. The analysis method used to analyse texts is described using the example of the CPAP therapy mask artefact in section 4.3. The same analysis method is applied to interview and market data texts although these have not been described separately. The interview analysis acted as a sensitisation process that fed into the development of design research methods for text collection and generation, as will be discussed next.

4.2.5 Development of design research methods for text collection and generation

The final approach merged data generation/collection with analysis, and involved novel approaches that I have elected to outline in much greater detail. Thus, the subsequent section (4.3), is dedicated to a discussion of two new methods of text analysis and generation. These were both developed from a theoretical basis and informed by design theory and Foucauldian scholarship.

I will provide a brief overview here and use the next section to discuss the detail and the theoretical basis. The first method analysed the effect of knowledges and practices on the form of a designed artefact. This involved directly examining the artefact, and then tracing the markings of various discourse formations to collect related texts. This created a collection of texts, which I analyse in chapter six.

The second method used design probes to destabilise and make visible the knowledges and practices that shape a CPAP mask artefact. These probes were exhibited in community market environments to seek engagement from community members. Used in this way, these probes sought to generate texts from discourses that may be subjugated or missing from legitimated forms of knowledges and practices. Collecting community responses to the design probes generated new texts for analysis. The two methods are illustrated in Figure 6.

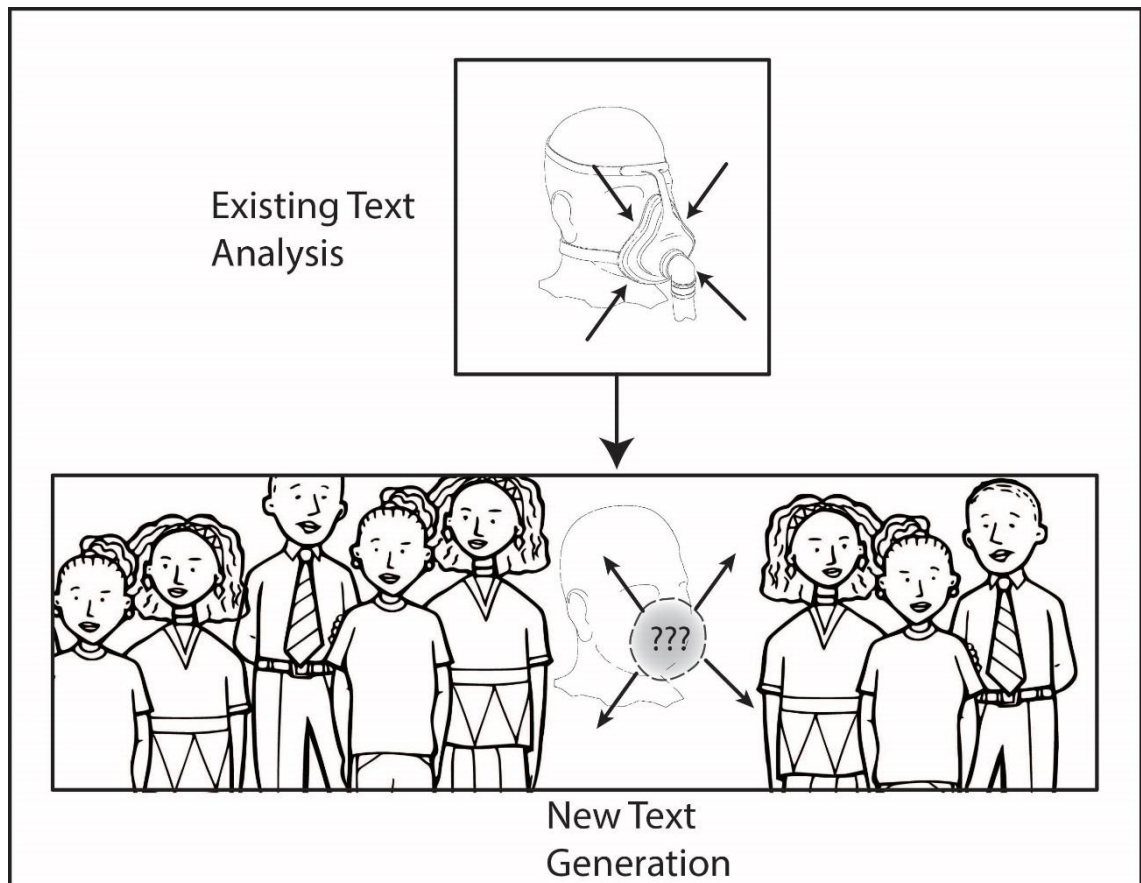


Figure 6. Diagram showing mask focus and community focus used in the two methods
Source: Author's collage including public domain line drawings.²³

4.3 An existing product analysis method

As discussed in section 2.3.1, Foucault (1972) conceptualised discourse not “...as signs... but as practices that systematically form the objects of which they speak” (p. 49). The following section brings this idea into a design process through an analysis of a CPAP therapy mask artefact.

4.3.1 Artefact selection for analysis

Given that the starting point for the discourse analysis was the problematisation of an existing product, the first text assemblage chosen for analysis was a physical face mask along with its box and documentation. The analysis focussed on a specific and localised product example,

²³ Family image source: family-mother-father-daughter by Clker-Free-Vector-Images from Pixabay: <https://pixabay.com/vectors/family-father-mother-daughter-28725/> used under Pixabay license (Free for commercial use, no attribution required) see <https://pixabay.com/service/license/>
Mask image source: Patent CPAP outlet vent gas diffuser, US8353293B1, Public domain, <http://patentimages.storage.googleapis.com/US8353293B1/US08353293-20130115-D00000.png>

which I used to expose broader discourses and to pose analytic questions, enabling consideration of other texts. Thus, the specific brand of the product was not crucial in choosing where to start.

I began the analysis with a readily available example of the product under consideration for a redesign. The mask chosen was a convenience sample and was borrowed at no cost. It was a Zest TM Fisher & Paykel Healthcare Ltd Standard nasal mask (Fisher & Paykel Healthcare Limited, 2019). The Zest TM nasal mask is common in the New Zealand public health system. Clinicians interviewed advised that it is the first choice for most patients working with a sleep clinician or technician as it tended to be cheaper for patients (Clinical Specialist 1, Clinical Staff 6, Clinical Staff 8 – see Appendix D).

Initially, I considered the mask, seal and head strap as a text assemblage separate from the box and accompanying instructions. The manufacturer supplied these component/elemental parts already assembled, and patients use them in the assembled form. I also considered the elements separately for a further focus and analysis on specific discourses.

4.3.2 Analysis questions

The analysis began in a spreadsheet format where I tabulated written answers to the questions against each item of the box-mask-instructions assemblage (see Figure 7). The triggering questions were paraphrased from Nicholls (2008a, pp. 85-86) as follows and used as an initial guide when writing a commentary on my first impressions of the text (naïve reading):

1. What statements were evident?
2. What was said and not said?
3. What was being conveyed?
4. What was in the text?
5. What was the context surrounding the text?
6. What subject positions were evident?
7. What objects were available for analysis?
8. What strategies and systems were at play?
9. Why have I chosen it?
10. What was the date and time of the reading?

I arranged my responses to the questions above in a spreadsheet format.



Figure 7. Images of the items physically examined during this stage. Images include mask assembly, box and instructions. Source: Author's photographs.

While useful for quickly collecting responses, the overall layout of the document did not readily lend itself to making links between items for the later stages of analysis. In design discourses, the way information is constructed or laid out is essential for and reflective of developing thought and understanding. Many design tools incorporate this facet of knowledge through making. This construction of knowledge in an image-based format also supported communication within a design research environment.

Discourse mapping

In the next stage of this methodological approach, I have laid out written notes about the texts and linked them to a series of images. I chose these images because they provided a sufficient degree of repetition²⁴ of the original text to allow the linking of ideas, without using the specific text itself.

In line with my training as a product designer and mechanical engineer (see section 1.3), these linking texts tended to be documentary style images of the physical items I photographed. In these images, I focussed on showing the physical elements that stood out to me after examining the physical items (refer Figure 8). I acknowledge that these images are separate texts (Foucault, 1972, p. 193). I used the repetition of images to highlight the process and findings from the physical examination in a diagram format. Using a visual format enabled a

²⁴ In seeking a positive form of difference, Foucault argued for a concept of repetition which rather than comparison and negative difference between two similarities, each are considered in their own right as part of a multiplicity. "Let us pervert good sense, and allow thought to play outside the ordered table of resemblances". Source: Foucault, M. (1970). *Theatrum philosophicum. Critique*(282), 885-908. This concept of repetition is part of the change from the philosophical mind/matter duality common in Western thought to an approach that does not include this division, which is known as a monist ontology.

holistic view and avoided some of the constraints of written language (which would have required a strict succession of one idea after another to be intelligible²⁵).

The image-based analysis proceeded as follows:

1. Select a digital image repetition of the physical text.
2. Place this image in the centre of an A3 page using Adobe Illustrator²⁶
3. Using words and arrows annotate the image to illustrate the initial naïve reading of the object and physical features.

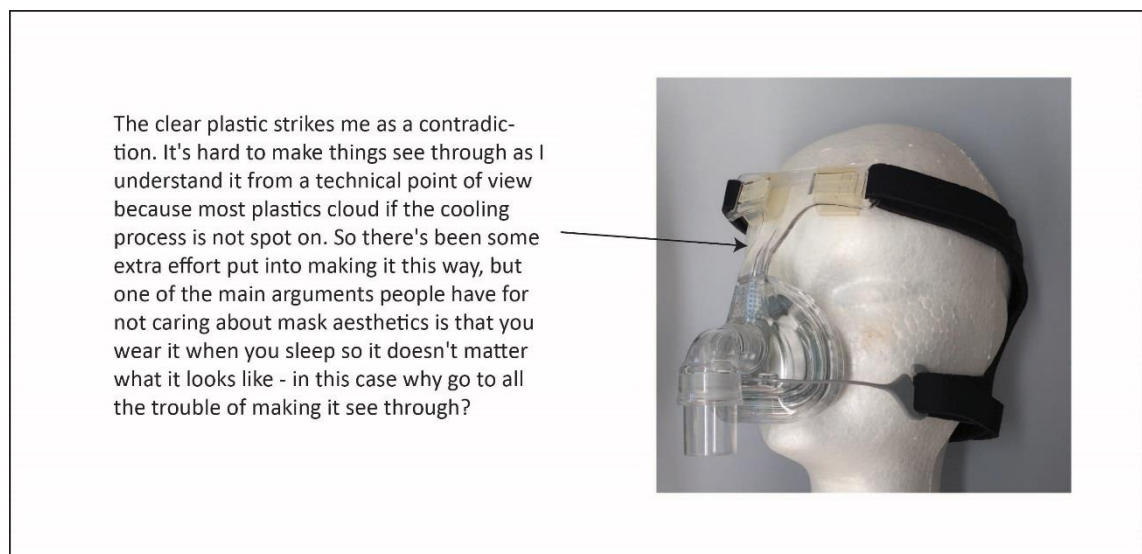


Figure 8. Initial observations visualised – example of annotated image.

Source: Author's photograph and image

The visual link analysis was a step towards building a gestalt sense of the object through the geographic location of ideas around the artefact. The volume of written language embedded in the image obscured a cohesive view of the discourses. In the next phase, I replaced the written language with additional images selected by making associations based on specific statements that link one image to another. These links were then further expanded for different statements, including what is communicated by materials, graphics, manufacturing and

²⁵ Similarly, circular references can be shown very simply in a diagram but are very complex and lengthy to clearly articulate in written or spoken language forms.

²⁶ Various programs could be used, however the specific limits and discourses of the software chosen will have an impact on how the ideas can be constructed within it, so acknowledgement of the software and page sizes used is of interest. This will be discussed further in the section on design tools and manufacturing discourses).

2. Symbol association (e.g., the size symbols are also symbols used for masculine gender in public signage)
3. Construction (e.g., the box net shows one way of making the box but where there may be several different ways of doing this)
4. Pattern (e.g., light and dark patterns in the colour blue is also typical of water)
5. Image construction (e.g., the net effect image is familiar to flow modelling technical program imagery²⁷)

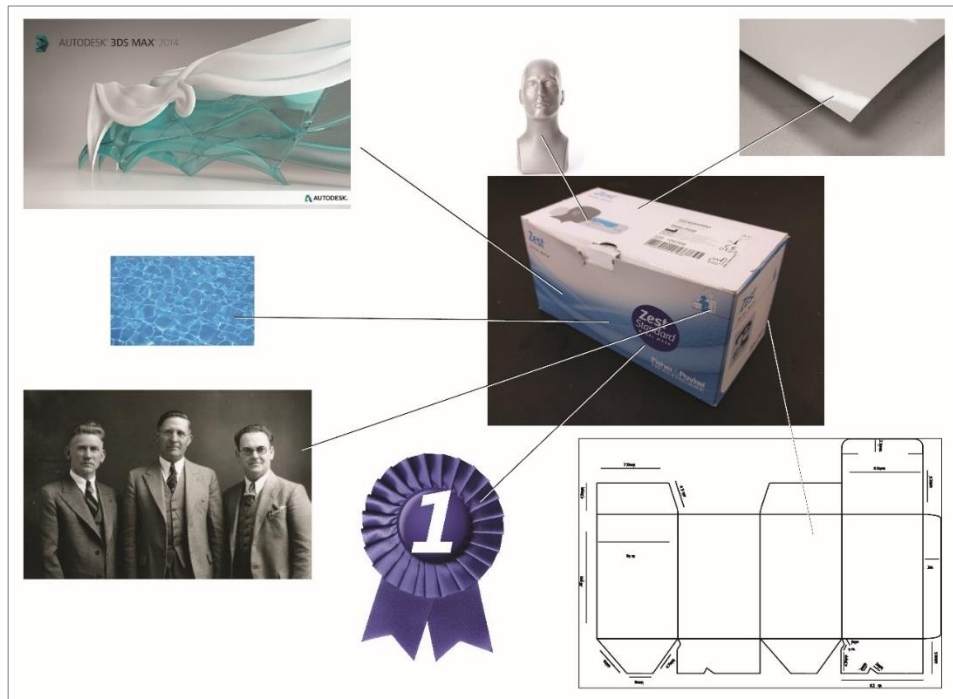


Figure 10. Fisher and Paykel Zest Nasal mask box image initial based associations.
Source: Author's collage of images.

Design tools and manufacturing discourses

The next stage of analysis involved following up references in the items examined that linked to other processes, other documentation or texts. For example, the material and moulding marks on the hard mask shell point to an injection moulding process. I identified the material and manufacturing process indicators in this way:

1. Mould split lines, push-pin circles, sprue break off points, material thicknesses, material type, possible mould tool complexity and part numbers

²⁷ A second image of this type is added to provide a repetition of this idea thus highlighting the repetition.

2. Cutting processes (e.g., unfinished edges for die cutting of headgear²⁸)
3. Assembly processes (e.g., where manufacturers made items from different processes requiring different machinery but assembled them before delivery)
4. Product lifecycle (e.g., design process to the production of product from sourcing raw materials through to manufacture including the development of tools, sales, distribution, use and disposal)

In the case of numerically controlled tooling, the input designs are typically produced using parametric three dimensional (3D) or two dimensional (2D) design software that may be further expanded to consider the technology discourses evident in its development. For example, SolidWorks from Dassault Systems is a standard Computer Aided Drawing (CAD) and engineering design tool that uses parametric modelling²⁹. The product feature tools were designed around existing manufacturing processes and were named to varying degrees because of these. Some example tools are: revolve (lathe work), extrude (material extrusion), shell (slip casting), cut (saw or router), deform (bend, twist) and so on. Other functions are based on mathematical concepts such as combine, scale and subtract, which have parallels in drawing and mathematics more than to physical processes. The software is designed to encourage the user to create designs that can be made using conventional manufacturing processes. Developers created the software based on their understanding of common 'making' equipment available at the time. What designers can produce is both enabled and limited, based on these inputs.

Symbols and institutional discourses

The next level of mapping teases out any markings and documents related to the items, particularly symbols and codes listed on the retail box. Symbols and institutional discourses relate to items such as:

1. Symbols (e.g., the variety of symbols on the box sticker related to medical standard symbols)
2. Standards (e.g., the symbols that are shown related to a standard; this standard also references other standards)

²⁸ Rather than, say, burnt edges, which may indicate laser cutting.

²⁹ Parametric modelling programs keep data in the form of equations or relations between design elements. This differs from non-parametric modellers, more common in game or CGI design, where information is kept as a cloud of spatial points with very little history of the relationships that formed them.

3. Patent numbers (e.g., the patent numbers listed were looked up in a patent search system, and then any entities were mapped based on these numbers)
4. Patent inventors (e.g., I searched for people listed on patents and for any of their other patent numbers, and also for any online resumes and associations)
5. Phone numbers (e.g., these were mapped concerning location and company registration information)
6. Manufacturer (e.g., I investigated Fisher & Paykel Healthcare Ltd as an entity, including shareholder reports for values, drivers and sales figures)
7. Barcodes (e.g., these were used to identify information about the product, using the manufacturer's codes, shipping and product transport information)
8. Legal entities and legislation indicators (e.g., patent courts and patent offices)

4.3.3 Identifying elements of discourse

The initial mapping was analysed as part of learning about and understanding how the process might work, which was then modified further to suit the application. In this case, the reasonably light initial discourse map was taken as a starting point to identify the elements of discourse. Figure 11 shows the initial attempts at analysing the discourse 'on the wall' using brightly coloured sticky notes to identify the different elements of a discourse.

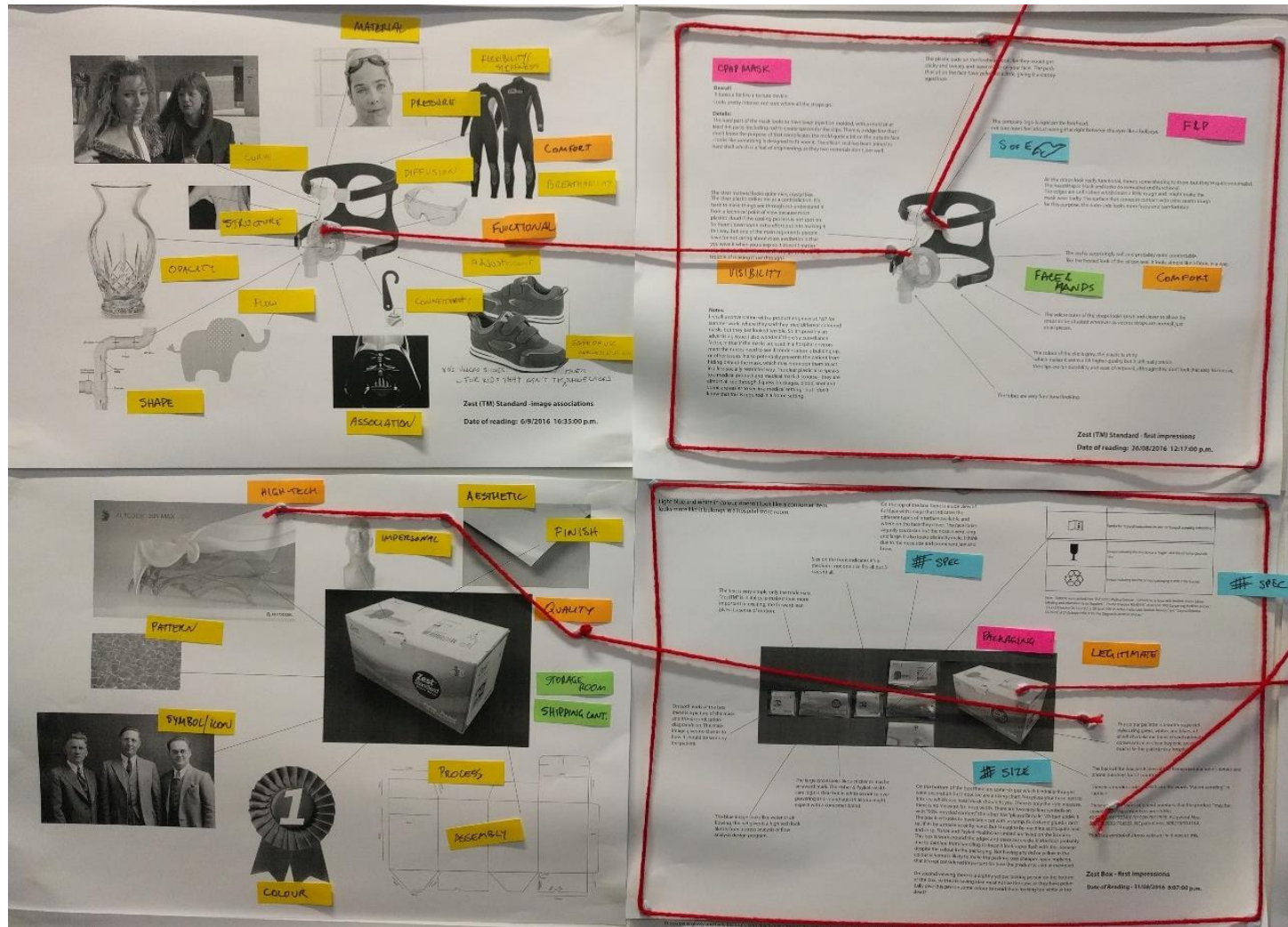


Figure 11. Initial discourse identification using coloured sticker notes Pink – object, Yellow – strategy, green – enunciative modality, blue – surfaces of emergence (Foucault, 1972). The red string is to highlight links and separations that were not clear. For a full explanation of these concepts, see Foucault (1972). Source: Author's photograph.

4.3.4 Existing text discussion

This map produced a series of discourses for further examination and discussion. During the process it became apparent that the product had been shaped and influenced by the dominant discourses around it, including legal issues, risk, educational institutions, manufacturing techniques and material properties. What was not evident from focusing on the product itself was the user, the human element. For example, if one were to consider removing the mask from the centre of the discourse map in which it sits, it is difficult to imagine any other form of mask that could operate in that space and be significantly different. It seemed apparent from this exercise that challenging the form of the mask would require finding a way to resituate it.

An additional method was required to focus on and collect data that might illuminate the influences on the other side of the mask. The focus of the final data generation method was people, including those who may or may not ever wear a CPAP therapy mask, their communities and their social attitudes. In Foucault's view, the individual is not a pre-existing entity but instead is constituted historically (Foucault, 1982). Thus actions of the power-knowledge complex result in subject positions that are also constituted discursively (Foucault, 1982, p. 781), both in the way people are acted upon by others and how they come to understand themselves. Which 'subject positions' are sought for involvement or partnership in currently accepted formulations of human-centred design can also be challenged by taking a critical approach to design research. The following section describes the way I have incorporated this position into a design research method for community engagement.

4.4 New text generative method and considerations

Design research is an emerging discipline. Questions of what constitutes knowledge and ways of knowing are far from resolved. Feast (2010) classified several prominent designers' work with regard to dominant paradigms defined in disciplines outside of design. Cross and Frayling also proposed different forms of knowledge specific to designers as well as to modes of research that relate to and use design in different ways (Cross, 1984; Frayling, 1993). While some design researchers are explicit in their epistemological outlook, such as Friedman (2003), many others are less explicit about their epistemological positioning, for example, Norman and Verganti (2014). Unlike long-established disciplines such as architecture or clinical sciences, product designers rarely engage with the philosophies of knowledge to the extent that studies can be grouped or assessed on this basis. The difficulty of this grouping approach is the challenge it presents to situating and assessing new methods in the design research field. The purpose of this study was not to attempt to classify others' work epistemologically or to find a way of situating new research approaches epistemologically in the design research field. The

the approach I took, in line with Mazé and Redström (2009), was to situate a new research method relationally to an existing design method, without attempting to discern a consistent basis of knowledge. The method had elements in common with the existing method and so could be assessed in relation to it in practical terms. It was also consistent with the chosen philosophical approach to the current study. As such, the 'new method' can also be critiqued independently in philosophical or epistemological terms. The following section describes how I implemented this approach in my study.

4.4.1 Problematising co-design

I identified co-design as a generative approach that would be appropriate for mask design as it may provide new insights and understandings around how the mask might be changed. An awareness of the web of dominant discourses in which the mask sits indicated that it might be difficult to encourage people to see what else might be possible as the problem seemed so constrained by the dominant discourses.

In the context of a post-structural methodology, this method was also problematic. Co-design approaches typically involve regular meetings with a group of individuals. The identities and the particular set of lived experiences that make up this group are likely to become privileged in the final analysis. Privileging any particular texts rather than situating them as part of a broader discursive analysis is inconsistent with the principles of Foucauldian analysis (Fadyl & Nicholls, 2013). I needed a way to re-envision co-design to draw on the benefits of a broader range of subjective experiences, but also to be more consistent with the discourse analysis approach under exploration. In this study, I addressed co-design as a method. However, it can also be termed a mindset or a tool (Sanders & Stappers, 2012, p. 30).

In my original research proposal I planned to conduct co-design sessions at the city hospital or the university. As well as my analysis rendering the method itself in its current form problematic (as outlined above), Foucault's conceptions of the role of the built environment in power and subjectification problematised these environments. Foucault's analyses of power are particularly significant concerning the patient-clinician power relationships and the intimidating nature of medical and educational environments. The setting and context of data collection, therefore, had to be re-thought also. The following section describes a critical approach to the notion of co-design. It aims to balance the post-structural underpinnings of Foucault's discourse analysis with the practical need to collect data about the social context of a medical device in the community.

4.4.2 Re-envisioning co-design methods for a post-structural methodology

Table 3 maps the two forms of co-design against an underlying set of principles, providing a comparison between co-design and how a post-structural re-envisioning of the approach might look.

Table 3. Co-design vs post-structural re-envisioning

Principle	Co-design from Sanders and Stappers (2012)	Post-structural re-envisioning
Creativity	All people are inherently creative to varying levels (pp. 39,40).	The concept of creativity is socially and historically situated. At different points in time ideas around creativity have varied. For example, at one point creativity was a muse or spirit that visited artists. Currently, society commonly views creativity as an inherent talent limited to a select few – but for co-design approaches, all people are inherently creative to different degrees.
Design stage and value	All stages – pre-design to marketing. Value accrued is societal, user, monetary (p. 27).	‘Pre-design’ on an existing product. Value is a discursive construct.
Source of knowledge	Individuals are the experts of their experience (p. 24). Knowledge exists in four layers: explicit, observable, tacit and latent that require different techniques to access and guide participants through (pp. 52-53, 67).	The meaning of a product is socially constructed. Knowledge is an effect of power and subjectification. Different subject positions provide different perspectives on knowledge, but these subject positions are also socially and historically situated.
Design authority	Design partners are potential beneficiaries of design outputs and as such are experts of their own experience. Co-design is a collaboration between experts of equal footing in a design process, where the design is improved through the combined skills and knowledges of each (p. 24).	Decisions are made based on discursive analysis that privileges neither designer nor design partner and positions these subject positions alongside other discursive constructions including artefacts, knowledges and practices.

Principle	Co-design from Sanders and Stappers (2012)	Post-structural re-envisioning
Design objective	The objective of co-design is to bring those served by design into the process to meet their needs and dreams for the future (p. 12). Using do, say and make techniques to “reveal deeper levels of understanding... moreover, [to] access both tacit and latent knowledge” for prospective design beneficiaries (p. 75).	To develop a rich understanding of the discourses and historical conditions that shape current artefacts and individuals; how these affect the way existing artefacts function within society. To map the alternative discourses that might be available to reimagine or radically rethink the role and function of artefacts and their users within the limits of the current historical situation. To test these alternative constructs with individuals to see how effectively they tie into and function within the targeted discourses and whether any unexpected results occur that will further clarify the design objective.
Group make up	The designer/researcher sets up a series of group sessions with one or more interested parties, using opportunistic, representative or purposive sampling (p. 155). The group goes through a series of activities, including making, along the path of expression from immersion in current experiences, activating feelings and memories from the past, dreaming about possible futures, generating and expressing new ideas relating to future experiences (p. 156).	The designers/researchers set up a series of group sessions where the members in each session may or may not be the same as in previous sessions. Discourses and situation construct the subject positions associated with individuals. Individual meaning contributes to but is not privileged in the analysis. The individuals at each different session are part of a broader discursively constructed group. The changing of group members at each activity also acts to reduce the tendency to privilege individual voices over other discursive constructions, (all of which influence the social construction of the artefact and the possibilities and constraints it produces).
Session structure	Example student project – participants recruited through informal networks, two sessions, three families – grandparent, child and grandchild. The first session with three grandparents, the second session with additional family members (i.e., 3-9 participants in 2 sessions – duration is not explicit but likely to be 2-3 hours) (pp. 102-105). Many group members may be common across the sessions.	One or more people in multiple making sessions until the kinds of information collected for each session approaches the limit of the range of things that can be said or thought in the particular social and historical situation, and resulting in no new information. Workshop sessions can be any length or involve casual passers-by, adding to the makings of previous participants. Identifying group members for different sessions is not of great importance. They may be the same but are likely to be different.

Principle	Co-design from Sanders and Stappers (2012)	Post-structural re-envisioning
Tools	<p>“[C]onvivial tools are those which give each person who uses them the greatest opportunity to enrich the environment with the fruits of his or her vision. Industrial tools deny this possibility to those who use them, and they allow their design to determine the meaning and expectations of others. Most tools today cannot be used in a convivial fashion” (Illich, 1973, p. 21).</p>	<p>Using a convivial toolset within a post-structural framework provides a set of tools that allow for the input from the constructed individual, but with an added layer that can assess actioning this input in the current historical climate. It also provides an opportunity to take a step back and examine how the needs expressed are constructed and to look at alternative possibilities for meeting them within existing and emerging discursive structures.</p>
Fitting the design to the user	<p>Actively involve users in the design process to ensure the design output meets their needs (p. 14).</p>	<p>Actively involve interested parties in highlighting the discourses in which they and their needs are constructed to challenge their problem’s processes of formulation.</p>

4.4.3 Choosing a research location

I chose community markets as a research site after taking the various aspects of re-visioning discussed in Table 3 into consideration. Community markets were found to offer the following advantages over more traditional co-design locations such as universities, hospital or business premises:

- They consist of diverse populations in a semi-anonymous community atmosphere with minimal overt presence from the government or other large institutions
- People dress casually; there are few uniforms or other markers of profession or other social structures that may encourage privileging some subject more than others. In a hospital environment markers of authority are ubiquitous.
- Community markets provide cultural norms and expectations, which fit with the ethical considerations of the study. For example, at a market, it is customary and expected that a market-goer can talk to stall holders for as long as they like and can leave anytime, knowing they will be safe and not harassed.
- People are there to see interesting and unusual artefacts and food and to talk together and encounter new things.
- Many markets also promote themselves as places to develop and test products and business ideas and to get feedback.
- Security staff were available to assist with any potential safety or security issues.

4.4.4 Market selection

I selected the three market locations based on practical considerations specific to the purposes of the research. I aimed for:

- Openly accessible locations that are free for attendees and minimal cost for stall holders.
- Markets that reflect diverse populations or additional different markets with less diverse populations
- All-weather markets that do not require advanced booking
- Clear site purchase and allocation, and support by security personnel.

I chose the two largest and most culturally diverse markets in Auckland for two sessions each, and a third 'bric-a-brac' market in a less diverse and more affluent area for a single session.

4.4.5 Design probe development

Polanyi (2009, p. 12) likened the idea of a “probe” in design research to the interpretive understanding that may come from prodding something with a stick. The understanding of the subject comes from both the response of the subject to the prodding, and also an interpretation of the sensation of the instrument in the hands of the investigator (Polanyi, 2009, p. 12)³⁰. The decision to use probes stemmed from the difficulty of communicating many of the ideas made visible through the initial product discourse analysis, and specifically, around communicating these ideas to a broad non-specialist audience. I considered a range of communication approaches, such as posters or collections of images, similar to the analysis itself, with a short, written statement or discussion. These ideas drew on written academic formats that have been used to present Foucauldian scholarship. However, developing these materials or even explaining the process or background in a written or spoken form proved extremely difficult to do in a simple and engaging way, appropriate for trying to connect with diverse groups of people. Instead, I settled on 3D making and design synthesis to create a series of artefacts and images as a response to the analysis (see Figure 12, Figure 13 and Figure 14). I then used these responses as design probes. In this study, I used two types of probes, the first of which drew on ideas from critical design. I created a design that was intended to critique, rather than to be practical or functional.

In many cases, creators of critical artefacts and creative probes intend probes to be used to help ask questions rather than to answer them (Bowen, 2007). Provotypes [sic] are another example of this kind of probe (Boer, Donovan, & Buur, 2013). I developed three probe artefacts, each based on a familiar location in the average household that often holds tubes, cones and fabrics in different forms. These areas were linked to the existing mask through discourses around fabric, ‘hose’, ‘tube’ and ‘pipe’, but also ‘plunger’, ‘vacuum’ and ‘pot’. Changing these materials in concert with one another made an explicit statement. This statement rendered the medicalised discourses that were produced by the current masks visible, instead of them being taken for granted. The common element creating these links was a very loose interpretation of the shapes of the three elements that make up the current CPAP therapy masks (i.e., the facepiece, the hose and the head strap). Each of these elements was recognisable due to its situation on a display head adjacent to a CPAP mask product.

³⁰ Polanyi argues for a form of tacit knowledge based on the idea that “one can know more than one can tell”. Source: Polanyi, M. (2009). *The tacit dimension*. Gloucester, MA: University of Chicago press.. This idea is further drawn on in Schön, D. A. (1983). *The Reflective Practitioner: How Professionals Think in Action*. New York, NY: Basic books.



Figure 12. CPAP therapy mask showing differences in material discourses between two common settings of use, the hospital and the home.

Images shown are similar to those used in field research. Source: Images counter-clockwise from top: a hospital (c)Tomasz G. Sienicki

(https://upload.wikimedia.org/wikipedia/commons/5/57/Hospital_room_ubt.jpeg), Public domain; A hotel suite bedroom in the Doubletree Hotel in downtown Columbus, Ohio (c) Derek Jensen

(<https://pt.wikipedia.org/wiki/Cama#/media/File:Hotel-suite-bedroom.jpg>), Public domain); A

comfortable mask at CPAP central (c) Rachel Tayse

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Figure 13. Mask probe drawing on bathroom elements.
Images shown are similar to those used in field research. Source: Author's photographs.



Figure 14. Mask probe drawing on garden elements.
Images shown are similar to those used in field research. Source: Author's photographs.

Cultural probes

The second type of probe used in this study was a cultural probe, which served a different purpose to the critical/creative probe (Mattelmäki, 2006). I used a simple set of cultural probes to allow a physical construction of participant responses. They were made up of a series of emotion icons (also known as emoji or emoticons), images of the critical probes and their source environments and a series of statements or possible responses to the idea of wearing a standard CPAP therapy mask (refer Figure 15). Each tile had a magnet attached, I used two small magnetic whiteboards as a surface for community members to arrange their chosen ideas. I asked market attendees who stopped to talk about what they would think of wearing the standard CPAP therapy mask. I asked them to select the tiles they associated with the CPAP therapy mask. If any emotions or statements did not have tiles, I wrote them on sticky notes and included them in the arrangement. I also asked market attendees to review the concepts and select the ones they either preferred or disliked the most. Some market attendees also proposed the things they thought were most important to consider in designing a new mask. The Auckland University of Technology Ethics Committee (AUTEC) approved the process of public engagement under the second stage application 16/167 Design for sleep apnoea therapy interfaces (see Appendix A:).



Figure 15. Cultural probes, including magnetic concept images, environments, emotion icons and short phrases.

Source: Author's photograph.

4.4.6 Exhibition development

I ensured the stall displaying the probe artefacts, which consisted of a fold-up table covered in paper, fitted in the back of an available vehicle. I also kept a selection of rapid prototyping materials on hand in a box in case a participant wanted to explain their ideas through making models, drawings, or writing notes. The materials included felt tip coloured pens, tape, paper, plasticine, stickers, post-it notes and a small paper notepad. The main table included a clipboard with the research information sheets, a contact sheet for people interested in leaving their details, and a short survey. The first display included five sheets of concept images, an image association/concept map and the three environmental elements and mask images mounted on a cardboard display board with a “CPAP” and “what matters?” sign above it. The physical masks on display were a full face CPAP therapy mask attached to a non-functional CPAP therapy machine and a flower pot mask with a hosepipe. They were both displayed on Styrofoam display heads, that were selected for their neutral appearance, mounted on a small particle board base for stability. The table included a sign with the words: “Sleep Apnoea”, “CPAP”, “What matters?” and “Let’s talk” (refer Figure 16).



Figure 16. Stall set up test before market sessions.

This set up included material exploration models that I omitted from the arrangement before the first market session. Source: Author's photograph.

The stall and probe development continued during the data collection sessions. Initially, the tiles used were preliminary concepts on cards. In subsequent sessions, I included tiles with emotion icons on them. I also added magnets to the cards and used a small metal whiteboard to resist weather interference. Participants did not use the prototyping materials in the early sessions, so I omitted them in later sessions (see Figure 17).



Figure 17. Final streamlined market stall.

Image shows session in progress at an Auckland market in early 2017. Source: Author's photograph.

4.5 Discussion

The use of co-design tools in the market can be discussed in terms of the 'path of expression', which describes a method of directing attention through the stimulus 'now' to the past via associated memories and then through ideas projecting into an imagined view of future possibilities or 'dreams' (see Sanders & Stappers, 2012, p. 55). I addressed the first stage of the 'immersion into current experiences' part of the co-design session process by locating the research in a community market (see Sanders & Stappers, 2012, p. 156). The mask product, in many cases, had been seen previously by participants and by asking 'do you know what this is?' or 'do you know someone that needs a CPAP mask?' I helped trigger participant reflections from the past. The matching tiles exercise was used to access feelings and associations. The second interactive mask (flower pot or industrial pipe) acted to trigger possible or alternative

futures. The process was heavily condensed from a 1-2 hour session, which might be more common in a co-design setting, to short conversations of 2-20 minutes involving a (more) diverse community of people. The reduced session time may mean that there was limited time for the sensitisation, incubation and intimation phases which is Wallas' model of the creative process to occurring (Sanders & Stappers, 2012, p. 51). The generation of new ideas relating to future experiences was found to be somewhat limited in the data collection phase.

Conversations did, however, point to new lines of inquiry, with each line of inquiry associated with new possibilities for the mask. An essential benefit of this new method was that I was able to engage with the community as itself. Co-design sessions are typically made up of individuals, who may or may not know each other. With this method, individuals, pairs and small groups interacted with the display, but also altogether as a group. Responses were, therefore, more likely to reflect how community members might receive the mask in a home or community environment. For a further discussion on using exhibition in a community market as a resistance to established design approaches, see chapter eight.

It is worth noting at this point that based on the research methodology, the data collected is limited in its applicability to the socio-historical context in which it was collected. As such broader themes cannot be drawn out or viewed as representative of any situations outside of those sampled.

4.6 Summary

In this chapter, I detailed the study design generated from the theoretical and methodological basis outlined in the previous chapters. The methodological principles and criteria for the selection and generation of texts that I used as data were detailed, including the specific methods used for acquiring the various texts. These texts included design notes from consultation and early scoping to literature reviews of existing academic texts, semi-structured expert interviews, artefact analysis, and community-based input from a community market that utilised design probes. I have discussed the difficulties in situating new design research methods in an emerging discipline and described my approach to addressing this issue. The next chapter will present the findings from an analysis of published peer-reviewed literature that situated CPAP therapy as the dominant response to the specific instance of problematic sleep that is OSA.

Chapter 5 Contextual review findings

Chapter five presents the findings from the analysis of texts collected from contextual and systematic literature searches (as detailed in sections 4.2.2 and 4.2.3). Foucault articulated important features of discourse such as surfaces of emergence, authorities of delimitation and grids of specification that operate together in the construction of an ‘object’ (Foucault, 1972, p. 42) (see 3.4.1). This chapter explores the findings from applying these analytical concepts to the CPAP therapy mask for OSA. Foucault emphasised an understanding of *how power operates in constructing objects* as important above and beyond understanding the objects themselves. This study seeks to make visible how discourses of legitimacy, normativity and the restricted speaker positions have operated to thin out the possibilities for how the two interrelated objects of OSA and the CPAP therapy mask can be thought about and talked about, and both discursively and materially constructed. This chapter maps out the landscape of scientific and clinical legitimacy that defines and enables the shape and limits of possibility for objects constructing the CPAP therapy mask for OSA and OSA itself. It addresses the discourses, frameworks and regimes that legitimise the use of a mask, air flow and a pressure generating device as a legitimate and near unassailable response to a specific instance of problematic sleep. In doing so, the chapter articulates the role of discourse in shaping the clinical drivers for current CPAP therapy mask technologies.

From a designer’s perspective, this chapter explores how I used the process of problematising objects as a design thinking tool to expose and destabilise processes that may make their forms seem inevitable. This process explored the limits put on technical design approaches by legitimised knowledge and clinical research formats, particularly in terms of what remains unknown about patients’ experiences of living with breathing support devices and interfaces. The investigation began with identifying discourses and contradictions that construct normal versus problematic sleep in a socio-historical context, and challenging constructions of effectiveness.

5.1 Normal sleep vs problematic sleep

The Oxford Dictionary of English defines sleep as “a condition of body and mind which typically recurs for several hours every night, in which the nervous system is inactive³¹, the eyes closed, the postural muscles relaxed, and consciousness practically suspended” (Sleep, 2010). It is a

³¹ Interestingly, REM sleep is a sleep stage defined later within a sleep science discourse that features a high level of nervous system activity and dreaming (see Figure 18).

simple fact that humans require sleep to survive (Kroll-Smith & Gunter, 2005, p. 346). Sleep has also been described as a “non-social somatic state” (Kroll-Smith & Gunter, 2005, p. 346). Functionally, sleep is framed by Parsons in *The Social System*, as serving the social purpose of releasing tension and as an escape from the “frustrations and disciplines” of daily life (Kroll-Smith & Gunter, 2005, p. 346).

Thomas Cogan describes a historical, medical conception of the mechanism of sleep in *The Haven of Health* (Ekirch, 2001, p. 348). The Aristotelian view Cogan articulates is that sleep originated in the abdomen (Ekirch, 2001, p. 348). In this description, following digestion in the stomach, fumes rose to the head where “through coldnesse of the braine, they being congealed, doe stop the conduits and waies of the senses, and so procure sleepe [*sic*]” (Ekirch, 2001, p. 348). The “moisture, silence and darkness” of the night further assisted the process (Ekirch, 2001, p. 348). The amount of sleep thought to be required varied considerably in the texts examined by Ekirch, although 6-8 hours in bed was common (Ekirch, 2001). In one common saying of the time, “Nature requires five, Custom takes seven, Laziness nine, And wickedness eleven [*sic*]” (Ekirch, 2001, p. 349). The bedding available to the poorer classes meant that families routinely slept two, three, or more people in a bed, with overnight guests included (Ekirch, 2001, pp. 360-361). An Italian proverb highlighted the situation: “in a narrow bed, get thee in the middle” (Ekirch, 2001, p. 361).

Ekirch (2001) investigated pre-industrial sleep in early modern British society. In so doing, he uncovered a segmented form in which most Europeans experienced two significant intervals of sleep bridged by an hour or more of quiet wakefulness (Ekirch, 2001, p. 364). The initial slumber was referred to as “first sleep” or “dead sleep”, with the sleeper roused by “first waking” (Ekirch, 2001, p. 364). The subsequent period of sleep was known as the “second sleep” or “morning sleep” (Ekirch, 2001, p. 365). Ekirch described “Western Europeans of varying backgrounds” referring to these sleep patterns as if they are “utterly familiar to their contemporaries and thus require no further elaboration” (Ekirch, 2001, p. 365). For example, poet George Wither wrote, “[a]t mid-night when thou wak'st from sleepe [*sic*].” (Ekirch, 2001, p. 365).

Robert Luis Stevenson described his experience of the waking hour of segmented sleep as a more “perfect hour...[than any other]... free from the bastille of civilisation” (Ekirch, 2001, p. 343). Dr Thomas Wehr studied human sleep patterns when people were deprived of artificial light for several weeks (Ekirch, 2001, p. 367). He subsequently found sleepers reverted to a broken pattern of slumber almost identical to that described in pre-industrial households (Ekirch, 2001, p. 367). He found the very peaceful period of waking to have “an endocrinology

all of its own”, with significantly elevated levels of prolactin present (Ekirch, 2001, p. 368). Prolactin is a pituitary hormone best known for allowing brooding chickens to sit over their eggs for long periods (Ekirch, 2001, p. 368). Wehr likened the experience to an altered state of consciousness, not unlike meditation (Ekirch, 2001, p. 368).

This image has been removed by the author of this thesis for copyright reasons.

<https://www.reibel.io/content/images/2015/05/rem-sleep.jpg>

Figure 18. A plot of normal sleep cycles showing slower brain wave frequencies at deeper levels of sleep vs. accumulated hours of sleep.

Source: Normal Sleep (1974).

Sleep science emerged within scientific discourses following the invention of tools to detect and record brain activity of animals through the scalp in 1875 (Berry et al., 2012, p. 11; Caton, 1875). The detection and characterisation of wakeful activity in humans through external scalp measurements was first reported in 1929 (Berry et al., 2012, p. 11). Normal sleep was defined in recent medical discourse by using technical measurements and the form of brainwave characteristics over time (Berry et al., 2012, p. 11). Sleep researchers agreed and standardised the criteria for normal sleep in a standardised scoring manual developed by Rechtschaffen and Kales and published by the US department of Health, Education and Welfare in 1967 (Berry et al., 2012, p. 11). This standardised scoring manual was in response to early difficulties in consistently characterising sleep patterns (Berry et al., 2012, p. 11). At the time of writing, normal sleep was divided into periods of Rapid-Eye-Movement (REM) and Non-Rapid-Eye movement (NREM) (Stevens, 2015). These periods occur in a series of sleep cycles across eight hours, as Figure 18 shows (Stevens, 2015).

Social discourses have conceived of sleep quite differently, in line with Parson’s conceptualisation of sleep as entailing rest and repose (Kroll-Smith & Gunter, 2005, p. 346).

Poetry and literature echoed similar sentiments, in children's literature in particular (Kroll-Smith & Gunter, 2005). Sleepy, for example, was a lovable member of the seven dwarfs in *Snow White*, the fairy tale from the seventeenth century (Kroll-Smith & Gunter, 2005). More recent books have included *Sleepy Me*, a popular children's book from 2001 (McGee & Williams, 2001). In this book, McGee and Williams (2001) describe sleepy people as placid, unagitated and serene (Kroll-Smith & Gunter, 2005). Feeling sleepy in this genre of literature has been painted as a "routinely occurring bodily state" that is to be welcomed and encouraged (Kroll-Smith & Gunter, 2005, p. 355). The Barnes' and Noble book-selling site, referenced by Kroll-Smith and Gunter (2005), also lists children's books featuring stories about sleepy bears, owls, dogs, lambs, elephants, and crocodiles. Drowsy children, as well as drowsy animals, suggests the survival value of an episodic quieting of both physical and mental work (Kroll-Smith & Gunter, 2005, p. 355).

'Normal sleep' is also portrayed through image-based discourse. Searching the image database 'google images' for 'sleep' returned recognisable imagery (see Figure 19). Such imagery reflects promotional material and popular media discourses that typically depicted young, healthy, Caucasian individuals or heteronormative couples in a state of peaceful repose (Wolf-Meyer, 2015, p. 446). As can be seen in Figure 19, the image creators have chosen white, clean bedding, carefully arranged the models' hair, and applied natural makeup. The camera angle is from the perspective next to the sleeper, as if the observer was about to wake the subject, or above as if watching over the sleepers (see Figure 19 for examples).

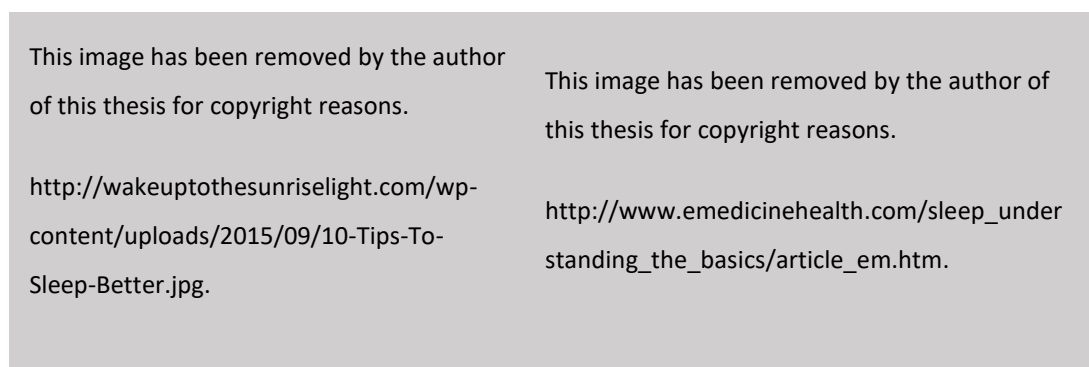


Figure 19. Images of people sleeping from google image search.

Sources: Left: 10 tips to help you sleep better. (2015). Retrieved from: <http://wakeuptothesunriselight.com/wp-content/uploads/2015/09/10-Tips-To-Sleep-Better.jpg>. Right: Sleep: Understanding the basics. (2016). Retrieved from: http://www.emedicinehealth.com/sleep_understanding_the_basics/article_em.htm.

In dominant Western (and specifically Anglo-American) discourses, I found sleep occurs in the 'private' bedroom spaces designed for this activity (and sleepers discipline themselves so that it occurs only there). Legitimised sleeping spaces are part of a cultural construct whereby

public sleeping is considered lazy and indolent and is largely discouraged. For example, it is not uncommon to see signs up in libraries and public places such as student workspaces that advise that sleeping in these spaces is prohibited. An alternative discourse exists in Japan where Japanese people consider *inemuri*, a form of daytime sleeping, as a sign of diligence and hard work rather than the laziness of poor planning. *Inemuri* is short spontaneous napping that occurs in public, including in meetings at work, on public transport and in a class. It is considered both normal and desirable (for further discussion see 9.2). So the level of public resistance to this forms of sleep is significantly lower than in many Western countries (Steger, 2006). In Western countries, talk of sleep is generally relegated to clinical environments, discussions about children, or the times close to bedtime or shortly after waking. Despite the prevalence of discourses around normative sleep, there have also been a number of critiques about the limitations of ‘normal sleep.’

In arguing a case for ‘the whiteness of sleep,’ Wolf-Meyer described patients’ at a sleep clinic (Wolf-Meyer, 2015). He illustrated the two stages of abstract data application for the determination of normal orderly sleeping (Wolf-Meyer, 2015). In the first stage, this data was generated from studies of predominantly Caucasian male populations that were then taken to be representative of ‘normal sleep’ (Wolf-Meyer, 2015, p. 451). In the second stage, the abstract data was applied to particular bodies in which “issues of race” appeared (Wolf-Meyer, 2015, p. 451). The mechanism that linked the appraisal of physical bodies with the abstract sleep data was termed a normalcy discourse (Wolf-Meyer, 2015, p. 451). Wolf-Meyer (2015, p. 447) found sleep patterns between individuals also varied widely, further questioning the concept of ‘normal sleep’. Following on from his investigation of historical sleep, Ekirch (2001, p. 344) argued that the experience of consolidated sleep was not only unnatural but also quite a recent phenomenon. His study showed the idea of consolidated sleep coincided with the introduction of artificial lighting and the wealth to use it (Ekirch, 2001, p. 344). The role of discourse and social norms was not limited to normative constructions of sleep but also extended to the construction of problematic sleep.

The American Sleep Disorders Association (1997) categorised problematic sleep into three forms: too much sleep (sleepiness), too little sleep (insomnia) or based on events that may happen during sleep (e.g., sleepwalking). Historically, the symptom of heavy snoring was noted in Ancient Egypt as far back as the Ptolemy dynasty, which was in power from 305BC to 30BC (Barnes & ResMed, 2007, p. 5). Historical accounts report many prominent historical figures as exhibiting symptoms associated with problematic sleep, including Napoleon Bonaparte, Queen Victoria, US President Taft; both US Presidents named Roosevelt and Johannes Brahms, a lullaby composer, to name a few (Barnes & ResMed, 2007, p. 5). Charles Dickens (1873, 1998)

first gained notoriety when he published a novel in serial form titled *The Posthumous Papers of the Pickwick Club*. In it, he presented a very influential description of problematic sleep (Kroll-Smith & Gunter, 2005). One of the more notable characters, Joe, was an “excessively sleepy, red-faced, loud snoring, cognitively dysfunctional, ‘wonderfully fat’ boy with peripheral edema” all symptoms associated with a particular form of problematic sleep (Barnes & ResMed, 2007, p. 5). Another character, “Mr Pickwick”, was also obese and would fall asleep and exhibit “perpetual snoring, with a partial choke occasionally” after drinking too much alcohol (Dickens, 1873, 1998, p. 37). Sir William Osler adopted the term Pickwickian Syndrome³² before it could even be adequately diagnosed as repeated airway blockages (Barnes & ResMed, 2007, p. 5). These recurrent blockages are now termed Obstructive Sleep Apnoea (OSA), based on the Greek ‘apnoea’, or ‘want of breath’ (Shiel Jr., 12/27/2018).

A specific form of problematic sleep, “excessive daytime sleepiness”, debuted as a term in popular print in 1982 (Kroll-Smith, 2003, p. 629). In their later study, Kroll-Smith and Gunter (2005) found two major themes in the discourse of popular print and digital texts: “(1) sleepiness as a measurable somatic condition that poses a risk to self and others and (2) maintaining alertness and lucidity is both a personal and moral responsibility” (p. 353). Clinicians and researchers heralded the invention of the machine to treat daytime sleepiness as a miracle for its demonstrated ability to remove the presence of associated airway blockages in test subjects (Barnes & ResMed, 2007, p. 2). Interestingly this event appeared in the scientific literature the year before the entrance of “excessive daytime sleepiness” into popular print (Sullivan, Berthon-Jones, Issa, & Eves, 1981).

Accordingly, the American Sleep Disorders Association (1997, p. 52) accepted OSA to be a specific instance of ‘problematic sleep’, classing it as an intrinsic dyssomnia. It is a chronic condition, identified by repeated occurrences of upper airway obstruction during sleep and associated with reduced oxygen saturation (American Sleep Disorders Association, 1997) (see Table 4 for diagnosis details).

³² Osler was Canadian and one of the most influential persons in medicine in the late 19th and early 20th centuries. Source: Barnes, C. S., & ResMed. (2007). *ResMed origins: A brief history of the establishment of a company manufacturing devices for the diagnosis and treatment of sleep disorder breathing*. Bella Vista, N.S.W: ResMed.

Table 4. AHI criteria and diagnosis for OSA

Apnoea	Hypopnea	AHI
The term 'apnoea' is defined as a complete cessation of airflow for at least 10 seconds (Rowley, Aboussouan, & Badr, 2000, p. 931).	'Hypopnea' refers to a reduction in the airflow of 50 % for at least 10 seconds and is associated with either arousal or a 3% drop in blood oxygen saturation (Rasmusson, Bidarian, Sennerby, & Scott, 2012, p. 476).	Apnoea-hypopnea index (AHI) is defined as the total number of apnoea and hypopnea events per hour of total sleep time (Rowley et al., 2000, p. 931).
Diagnosis	Recommended OSA diagnostic criteria include an AHI of five or more (as determined by overnight monitoring) and evidence of disturbed sleep, as measured by subjective measures of daytime sleepiness using the Epworth Sleepiness Scale (ESS) (Johns, 1991) or other daytime symptoms (Rasmusson et al., 2012, p. 476).	
Severity	The AHI classification has three levels of OSA severity; mild (AHI 5 - 14), moderate (AHI 15 - 30) and severe (AHI > 30) (Rasmusson et al., 2012).	

Figure 20 shows the mechanism of airway blockage. OSA results in sleep disturbance. People with severe OSA may be woken up by the condition as frequently as every two minutes, frequently resulting in excessive daytime sleepiness (McNicholas & Bonsignore, 2007, p. 156).

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<https://beautytohealth.com/wp-content/uploads/2015/09/Causes-Of-Snoring.jpg>.

Figure 20. Airway physiology during an episode of upper airway breathing obstruction (apnoea).

Source: Causes of snoring. Retrieved from: <https://beautytohealth.com/wp-content/uploads/2015/09/Causes-Of-Snoring.jpg>.

As with many sleep disorders, the daytime sleepiness associated with OSA can be incapacitating (American Sleep Disorders Association, 1997, p. 53). It may result in job loss, accidents, self-injury, marital and family problems and poor school performance (American Sleep Disorders Association, 1997, p. 53). “Secondary depression, irritability and even profound despair” are also commonly associated with problematic sleep (American Sleep Disorders Association, 1997, p. 57).

OSA is significant from both individual and population health perspectives, and is commonly associated with hypertension and cardiovascular conditions (Phillips, 2005, p. 131). Acute cardiovascular events in particular have a demonstrated close association with OSA, including stroke, myocardial infarction and nocturnal death (Phillips, 2005, p. 131). Myriad other disorders may be more problematic without OSA being controlled including Type 2 diabetes, glaucoma, depression, Parkinson’s disease, Down’s syndrome and impotence (Shapiro & Shapiro, 2010, p. 324). While obesity is often associated with OSA, a minority of patients with

the disorder were not overweight, and morbid obesity was also only present in a minority of cases (American Sleep Disorders Association, 1997, p. 55).

As touched on in chapter one, Young et al. (1993, p. 1230) in a US study found that an estimated 2% of women and 4% of men of in the middle-aged workforce met the sleep apnoea breathing obstruction threshold, having an apnoea-hypopnea score of 5 or more. Researchers established the Cleveland Family study to investigate causal factors and the natural history of sleep-disordered breathing. They have documented the increasing prevalence of OSA with age (Tishler, Larkin, Schluchter, & Redline, 2003, p. 2230). Other studies support this insight, finding that OSA occurs at much higher rates within the elderly population (Tarasiuk, Greenberg-Dotan, Simon-Tuval, Oksenberg, & Reuveni, 2008, p. 247).

Mulgrew et al. (2007, p. 42) demonstrated a clear relationship between daytime sleepiness and decreased worker productivity for a group suspected of experiencing sleep disordered breathing. Similarly, Philip et al. (2001, p. 111) demonstrated a link between subjective daytime sleepiness and sickness absenteeism in a French study of National Gas and Electricity Board workers. A 1995 survey of South West England drivers identified that sleep-related driving incidents accounted for 16-20% of all motor vehicle accidents (Horne & Reyner, 1995). In these survey findings, morbidity and mortality associated with sleep-related accidents were higher than for non-sleep related accidents (Horne & Reyner, 1995). A Medline Database meta-analysis scanned close to 10,000 peer-reviewed articles, targeting the relationship between vehicle collisions and OSA from 1980 to 2000 (Sassani et al., 2004, p. 543). This study estimated OSA-related collisions, their financial costs and fatalities, then estimated the potential cost savings if CPAP treatment of OSA drivers was used as an accident prevention method (Sassani et al., 2004, p. 543). Using a prevalence rate of 3% of all drivers being affected by OSA, and applying an attributable risk percentage calculations approach, this investigation estimated that over 800,000 vehicle collisions were related to OSA in the year 2000 (Sassani et al., 2004, p. 543). Sassani et al. (2004, p. 543) estimated OSA-related vehicle collisions cost US\$15.9 billion and 1,400 lives each year. In the United States, and it has been estimated that treating the number of drivers suffering from OSA (4.7 million) with standard treatment methods would cost US\$3.18 billion annually (Sassani et al., 2004). However, these treatments would save an estimated US\$11.1 billion in collision-related costs each year, and save 980 lives annually (based on a rate of CPAP effectiveness and patient compliance of 70%) (Sassani et al., 2004). Other studies have drawn similar conclusions about the prevalence of OSA and the risk reduction that happens when CPAP therapy is used, specifically for commercial drivers (Tregear, Reston, Schoelles, & Phillips, 2009, 2010). The savings calculated from the Medline Database meta-analysis demonstrates the potential for a direct benefit to public safety (and

related costs) from treating OSA with technologies that already exist (Shapiro & Shapiro, 2010, p. 324).

As the preceding discussion shows, neoliberal discourses that require an economic return on treatment at a societal level creates a clear case for using CPAP therapy for OSA, within clinical populations. These arguments are hinged on discourses of effectiveness to underpin how the devices deliver results and the argument further supported by an economic rationale. Discourses of reduced cost, improved productivity and reduction in death and injury all support a value system that allows for understanding the way individuals operate in terms of a system of economic behaviours (see Foucault, 2010, p. 252). This centring of economic thought does not imply that all individuals would behave in an economically rational way; rather it means that economic behaviour is the 'grid of intelligibility' through which individuals and their decisions would be understood (Foucault, 2010, p. 252). The following section will explore the construction and limits of these discourses which discuss CPAP therapy effectiveness as a response to a specific instance of problematic sleep.

5.2 Constructing treatment effectiveness

At the time of writing, Continuous Positive Airway Pressure therapy, or 'CPAP therapy' as it is commonly known, was the accepted clinical 'gold standard' or 'first-line' treatment for OSA (Burman, 2017; McNicholas & Bonsignore, 2007). Alternative treatments for OSA included surgical intervention, oral appliances, and weight loss (Marti et al., 2002, p. 1515). In some cases, these alternatives were reported to be as effective as CPAP in reducing mortality (Marti et al., 2002, p. 1515). However, factors such as the low risk, the wide-ranging effectiveness and ease of use made CPAP therapy the "treatment of choice" (Basner, 2007). CPAP therapy was more broadly effective at countering the different underlying causes of sleep apnoea than other more specific treatment approaches (Jordan, McSharry, & Malhotra, 2014, p. 740). CPAP therapy was demonstrably effective in keeping airways open and eliminating hypopneas and apnoeas associated with OSA (as defined in Table 4) (Giles et al., 2006). Other factors in the treatment of OSA as discussed in section 5.1, include estimates of the decreased healthcare utilisation on a benefit-cost basis (Albarrak et al., 2005, p. 1306) and the reduced number of traffic incidents (Sassani et al., 2004, p. 453) that have been delivered by this treatment.

The evidence for the effectiveness of CPAP treatment is robust (Shapiro & Shapiro, 2010, p. 324). CPAP treatment has been shown to reduce patient daytime sleepiness (Marshall et al., 2006, p. 430) and marital conflict (Baron, Smith, Czajkowski, Gunn, & Jones, 2009). The use of CPAP therapy has been shown to improve driver alertness (Marshall et al., 2006, p. 430),

sexual performance (Weaver, 2006, p. 727), blood vessel function (Ip, Tse, Lam, Tsang, & Lam, 2004, p. 348) and to lower blood pressure (Dhillon, Chung, Fargher, Huterer, & Shapiro, 2005). Studies have also suggested that CPAP therapy can improve the subjective quality of life for both the patient (Flemons, 2002, p. 500) and their bed partner (Parish & Lyng, 2003, p. 942).

Researchers have painstakingly assembled the evidence of CPAP therapy effectiveness from carefully controlled clinical testing published in legitimised clinical journals. These journals sought input and reviews from highly qualified clinicians. These clinicians provided peer reviewed studies that were primarily undertaken in the controlled conditions of sleep clinics and laboratories. The 'real world' measure of CPAP therapy use outside the clinic or laboratory did not detract from this 'robust effectiveness'. This measure will be discussed separately in discourses on CPAP therapy adherence rates.

The average nightly use of CPAP therapy among people the doctors have prescribed this therapy to was commonly termed adherence or compliance to treatment (Shapiro & Shapiro, 2010, p. 324). The difference in terminology reflects a shift from the medical model (in which patients "obey physician's instructions" (Lutfey & Wishner, 1999, p. 635) to a multifaceted social model (where patient adherence is dependent on various economic and social constraints (Lutfey & Wishner, 1999). While, the required nightly usage for the best effect is still unknown (Shapiro & Shapiro, 2010), the recommended rate varies between six and eight hours (Pruitt, 2009). In spite of this recommendation, regular use is commonly defined at well below this level, with a minimum of four hours of CPAP use on 70% of the days monitored (Kribbs et al., 1993, p. 887). Duration of use was often overestimated by patients when self-reporting adherence (Kribbs et al., 1993, p. 887). Differing definitions of adherence or compliance that used values other than four hours over five days was common, and meant that user adherence rates based on these differing definitions of adherence or compliance could vary from as low as 28% to as high as 83% (Shapiro & Shapiro, 2010, p. 324). As monitoring seemed to improve use, the lowest rates were likely to be amongst unmonitored patients and hidden from measurement reporting (Shapiro & Shapiro, 2010, p. 335).

The evidence of effectiveness and the benefits of CPAP therapy in treating OSA is substantial (Shapiro & Shapiro, 2010, p. 324). However, the percentage of patients who continue with the treatment at recommended levels of use is low (Shapiro & Shapiro, 2010, p. 324). When patients do not adhere to the treatment, the potential benefits diminish (Shapiro & Shapiro, 2010, p. 324). Given the low levels of use that tend to define adherence, as well as the poor adherence rates, it is clear that maintaining ongoing use of CPAP therapy was a significant

barrier to realising the apparent health benefits offered by this treatment (Shapiro & Shapiro, 2010, p. 335).

Somewhat unsurprisingly, given the ethnicity-based critique of normative sleep by Wolf-Meyer (2015), there have been studies linking ethnicity and CPAP therapy adherence rates.

Specifically, ethnicity and residential factors in relation to CPAP adherence were implicated as predictors of poor adherence (Billings et al., 2011). Several studies looked at comparable rates of adherence within select populations, although often with mixed results. In a US-based study, African Americans and Hispanic veterans recorded lower adherence rates when compared with to Caucasian Americans (Wallace, Vargas, Schwartz, Aloia, & Shafazand, 2013).

Conversely, other studies such as Scharf, Seiden, DeMore, and Carter-Pokras (2004, p. 173) found no difference in adherence that could be associated with ethnicity. A retrospective New Zealand pilot study found that patients' who self-identified as one of a group of non-European ethnicities and whose address was located in an area of high socioeconomic deprivation (using the New Zealand Deprivation Scale (NZDep06) adapted from the 2006 census data), were associated with a lower level of CPAP therapy use for patients with OSA (Campbell, Neill, & Lory, 2012, p. e95)³³. However, the same clinic in a follow up prospective study found that controlling for socioeconomic factors in part removed the variation in adherence rates previously observed. This implied that it was the high levels of socioeconomic deprivation, rather than ethnicity, that was associated with lower adherence rates (Bakker, O'Keeffe, Neill, & Campbell, 2011, p. 1595)³³. Subsequently, Bakker et al. (2011, p. 1595)³³ found ethnicity was not a significant independent variable within the limitations of the research. The improvement in adherence rates may have been due in part to the prospective nature of the second study, rather than the retrospective nature of the first study. During the second study, staff knew the results of the first study. This created the possibility that unconscious changes in staff support towards the groups identified in the first study may have affected the results of the second study (Bakker et al., 2011, p. 1595)³³. Despite ethnicity not being a significant variable for adherence to CPAP therapy, Māori were more likely to report prevalence and risk factors than non-Māori in New Zealand (Mihaere et al., 2009).

In these discourses of poor adherence, a discourse of deficit became focussed on people who were attempting to use CPAP therapy regularly in the home. Given the powerful and

³³ The authors advise that due to vagaries of the publishing process, the publication date of the preliminary study (2012) is later than the publication date of the follow up study (2011). The authors advise that the preliminary study was conducted in full prior to conducting the follow up study.

legitimated discourses of clinical effectiveness, the ability of the device to operate in a way that served those that attempted to use it was not in question for clinicians or researchers. The behaviour and situation of those for whom the treatment was prescribed was the focus of discussion. The literature constructed variable CPAP therapy use rates as a problem. The discourse framing this problem was such that the solutions proposed and trialled focussed on improving patient behaviour, aptitudes and attitudes.

Many studies investigated why specific people did not adhere to CPAP treatment and how clinicians might recognise these people and intervene to improve adherence (Shapiro & Shapiro, 2010). Individual adherence research primarily focuses on developing interventions, including educational, technological, psychosocial, pharmacological, and multi-dimensional approaches (Sawyer, Gooneratne, et al., 2011). The psycho-social factors explored include patients' perceptions of self-efficacy³⁴ (Stepnowsky, Marler, Palau, & Annette Brooks, 2006). Sawyer, Gooneratne, et al. (2011) found that patients' perceptions of self-efficacy, early success with treatment and close relatives who point out improvements in the patients' health were effective in improving treatment adherence. Sawyer, Canamucio, et al. (2011, p. 86) also found that cognitive perception domains (from social cognitive theory), including social structures as barriers to or facilitators for use, also influenced CPAP adherence. Intervention models include educational, behavioural and technological components, which have been proposed to provide a base-level of support for CPAP therapy users (Engleman & Wild, 2003, p. 81). Additionally, researchers have found that socio-cognitive factors, in particular higher self-efficacy, correlated with higher levels of CPAP therapy use for experienced users (Stepnowsky et al., 2006, p. 350).

Approaches to understanding CPAP therapy adherence have focussed on a broad range of possible factors, summarised by Shapiro and Shapiro (2010, p. 325), which includes treatment methods, the patient, the patient's partner and family, the physician, healthcare professionals, the healthcare facility and government policies. However, the personal experience of coming to terms with an OSA diagnosis and a CPAP therapy prescription, including the personal experience of wearing a CPAP therapy interface, has received little attention.

Previous research recognised that the patient's feelings were of embarrassment (Almeida et al., 2013, p. 659) and that their experience of the stigma associated with chronic illness or with

³⁴ Self-efficacy is "the extent to which a patient holds attitudes or beliefs that he or she is capable of attaining positive outcomes from treatment". Source: Bakker, J. P., O'Keeffe, K. M., Neill, A. M., & Campbell, A. J. (2011). Ethnic disparities in CPAP adherence in New Zealand: Effects of socioeconomic status, health literacy and self-efficacy. *Sleep*, 34(11), 1595. doi: 10.5665/sleep.1404.

wearing a mask were factors affecting their adherence to treatment (Shapiro & Shapiro, 2010). Patients also mentioned appearance, embarrassment and stigma as reasons for avoiding CPAP use (Almeida et al., 2013, p. 659). These effects receive less attention in the literature than the intrusive lifestyle changes and the physical discomfort associated with CPAP treatment use (Shapiro & Shapiro, 2010). Shapiro and Shapiro pondered the psychodynamic effects of “a ‘clumsy machine’ used nocturnally” (2010, p. 326). They questioned whether it is “a constant reminder of the patient’s chronic condition that may cause embarrassment, social stigma, and be ego-dystonic, leading to poor adherence rates in some patients” (Shapiro & Shapiro, 2010, p. 326).

Since the personal experience of the user of breathing support interfaces has previously received little attention in the CPAP therapy adherence literature, I reviewed the literature focussed on breathing support interfaces more generally. Of particular interest was patient experience, including personal, social and cultural considerations, which may influence uptake or continuation of use for breathing support interfaces. The rationale for this approach was the recognition that while a diverse range of illnesses lead to the use of breathing support interfaces, often the interfaces themselves are identical. Similarly, breathing support is thought of in much less specific terms by those who are not in regular contact with medical devices, unlike health professionals. Therefore the issues that people experience across the breathing support spectrum may be relevant to users of CPAP therapy devices. I will address this topic next.

5.3 Exploring broader patient experiences of breathing support interfaces

I have organised the following discussion into a series of four themes to improve readability. The first of these themes explores the potential significance of using the same masks for life-threatening illnesses and chronic conditions. Different breathing support technologies deliver positive air pressure to patient airways through an interface with the nose or mouth or both and sometimes directly into the throat (Mehta & Hill, 2001). These devices address a wide range of patient breathing support needs for conditions that may or may not be acute (rapid onset) (Mehta & Hill, 2001). In Non-Invasive Ventilation (NIV) the patient could be given both air and oxygen through a facial or nasal mask without the use of tracheostomy to alleviate the

effort required to breathe and support the associated muscles (Lightowler, Wedzicha, Elliott, & Ram, 2003, p. 1)³⁵. For examples of common interfaces refer to Figure 21.

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<https://ebookcentral.proquest.com/lib/aut/detail.action?docID=792785>.

Figure 21. Interfaces used to deliver mask-based breathing support.
From top left to bottom right: Nasal mask, orinasal mask, nasal pillows, helmet system, simple mouthpiece, mouthpiece with lip seal. Source: *Practical guide to mechanical ventilation* (2011, p. 9).

'BiPAP' is a pressure support therapy that is used to treat OSA (and for acute respiratory treatments). It provides two levels of positive airway pressure that may be synchronised with the patient's breathing – higher for inhalation and lower for exhalation (Hörmann, Baum, Putensen, Mutz, & Benzer, 1994, p. 37). Mask-based NIV and BiPAP, for treatment of acute conditions in hospital, utilise CPAP therapy breathing masks as breathing interfaces, rather than having their own variants and development (Mehta & Hill, 2001, p. 543). As such, I concluded that in some non-invasive ventilation and breathing support applications, the same masks and breathing interfaces were worn to treat different illnesses. Some of these illnesses were acute and life-threatening such as chronic obstructive pulmonary disease (COPD)³⁶, but others were chronic (not easily cured or prevented, do not go away by themselves and persist

³⁵ NIV is an umbrella term and these breathing support technologies differ in the pressure levels and degree of variability including continuous pressure (CPAP), Bi-Level Pressure (BiPAP), and Automatic Pressure (APAP); degree of invasiveness: non-invasive ventilation (NIV) for face mask or nasal mask, invasive for tracheostomy. The severity of illness and time of day the mask must be worn: nocturnal ventilation, 24hrs per day for ventilator support, several hours per day for oxygen therapy and when sleeping for Sleep Apnoea. For definitions of these technologies see Mehta, S., & Hill, N. S. (2001). Noninvasive ventilation. *American Journal of Respiratory and Critical Care Medicine*, 163(2), 540-577. doi: 10.1164/ajrcm.163.2.9906116.

³⁶ COPD is an umbrella term for degenerative lung disease.

beyond three months); for example asthma, emphysema and chronic bronchitis (Mehta & Hill, 2001). Because of this, the needs and situation of a person wearing a breathing support mask can differ significantly depending on their illness.

Charmaz (1990, p. 1161) detailed the concept of chronic illness and the common themes that cut across illnesses. In an earlier paper, interviewing a variety of individuals with different illnesses and differing outlooks, Charmaz (1983, p. 168) identified loss of self as a fundamental form of suffering in chronic illness. This form of suffering developed from four sources relating to the experience of chronic illness, including that it leads to a restricted life, the experience of social isolation, being discredited and being a burden on others (Charmaz, 1983, p. 168). Charmaz's (1983, p. 168) conceptualisation of chronic illness was distinct from traditional conceptions of illness that focussed on acute illness. These critical conceptual differences highlight that there was likely to be tangible differences between acute and chronic illness situations, particularly regarding the priorities, needs and expectations of both the patient and their family, their carers and supporters.

As the patient is an important subject position in subsequent chapters, the second theme looks at the effects of breathing interfaces on self and identity. In the broader context of wearing a mask for breathing support, the 'self', described in terms of autonomy and identity, came under threat (Ando et al., 2015, p. 341). This threat to identity emerged in a study that explored why people living with motor neurone disease chose to discontinue or refuse ventilation with a mask. In this study, participants considered several themes more important than prolonging life in its current form. These themes were: preservation of the self, maintenance of perceived self, autonomy, dignity and quality of life (Ando et al., 2015, p. 341).

Engleman and Wild (2003, p. 89) provided a model, visualised as an old-fashioned set of scales usually associated with the weighing of justice. On the left, personal patient costs weighed against personal patient benefits of using the treatment on the right (Engleman & Wild, 2003, p. 89). Table 5 shows the weighed issues in a tabular form. These were consistent with familiar themes of breathing interface use, and in particular, visualised the idea of the 'trade-off' for a person regularly wearing the mask (Engleman & Wild, 2003, p. 89).

Table 5. Cost-effectiveness from a patient perspective

Costs	Benefits
Financial costs, ongoing commitment to therapy, lifestyle restrictions, significant others, aesthetics, self-image, discomfort, side effects, dissonance in health beliefs.	Symptom improvement, functional improvement, risk reduction, significant others.

Data from Engleman and Wild (2003, p. 89).

Johnson (2004, p. 192) investigated the experiences of long-term ventilated patients in a critical care unit in Australia. The findings describe the participants engaged in a series of strategies in that were directed towards *reclaiming* a sense of self (Johnson, 2004, p. 192). In a recent literature review that addressed participants' perceptions of oxygen home therapy, Kelly and Maden (2014, p. 219) describe persistent themes of conflict between the participants' sense of 'self' (or identity) versus the delivery of oxygen. They found feelings of hopelessness in nine studies (Adams, 2008; Arnold et al., 2011; Borak, Sliwinski, Piasecki, & Zielinski, 1991; Currow, Agar, Smith, & Abernethy, 2009; Demirel, Demir, & Umut, 2003; Eaton, Grey, & Garrett, 2001; Kampelmacher et al., 1998; Lewis, Eaton, Young, & Kolbe, 2003; Neri et al., 2006; Robinson, 2004) and disappointment arose in six studies (Adams, 2008; Doi, 2003; Goldbart, Yohannes, Woolrych, & Caton, 2013; Kampelmacher et al., 1998; Robinson, 2004; Wrench, 2012).

The loss of self is a characteristic of long-term and degenerative illnesses (Charmaz, 1983). The relationship to illness implies that this sense of loss may have less to do with using a breathing support mask and more to do with the chronic illness. However, people who use face masks for breathing support suffered the loss of their sense of 'self' and personal identity, caused by either the illness or the mask. Consequently, there is evidence in the medical literature that there is a need for mask design embodiments that support or reinforce identity. In particular, Ando et al. (2015, p. 356) highlighted the need for identity support and called for breathing assistive equipment to be explicitly designed to support the identity of patients. Bakker et al. (2011, p. 1602) also called for any intervention package aimed at improving CPAP adherence to be culturally appropriate and developed with input from users and their supporters from a variety of backgrounds.

Briscoe and Woodgate (2010, p. 60) studied patients in intensive care who had been offered ventilation. These patients described a sense of diminished 'self' associated with accepting long-term mechanical ventilation (Briscoe & Woodgate, 2010, p. 60). In this case, symptoms engulfed the 'self' resulting in feeling disembodied (Briscoe & Woodgate, 2010, p. 60). However, a sub-theme of the 'self in peril' revealed the breathing technology's role in

characterising what it meant to recognise one's nearness to death (Briscoe & Woodgate, 2010, p. 60). In this study, the recognition was made up of (a) making a decision to accept ventilation or death, (b) being in the hospital intensive care unit, and, (c) being ventilated (Briscoe & Woodgate, 2010, p. 60). Patients associated a compromised ability to communicate with ventilation with a sense of frustration, dependence, vulnerability, isolation, and a diminished sense of self (Briscoe & Woodgate, 2010, p. 61). However, when offered ventilation, the intensive care participants described the choice between ventilation and death as 'having no choice' even with limited prognosis for recovery (Briscoe & Woodgate, 2010, p. 60). The finding of 'having no choice' was in contrast to the study by Ando et al. (2015, p. 341) where 9 out of 35 motor neurone study participants chose not to be ventilated to prolong their lives, or withdrew from treatment. These examples potentially highlight a key difference between chronic and acute illness. In acute illness, the intensity of a high dependence care environment and fear of imminent death may be interpreted to tip the scales away from the 'costs of treatment' side of the scale shown in Table 5.

The third theme of patient experiences addresses the fears that are engendered by the appearance of the mask or the requirements of use. A study of patients with post-traumatic stress related to experiences of hospital intensive care units demonstrated the significance of the breathing interface in affecting users' experiences (Glimelius Petersson, Ringdal, Apelqvist, & Bergbom, 2015). In this study, 39% of participants specifically remembered the breathing mask (Glimelius Petersson et al., 2015). Many of those patients described the breathing support mask as 'frightening' (Glimelius Petersson et al., 2015). Multiple authors described fear in relation to restraint by breathing support equipment, including the mask and headgear and the potential for entrapment (Dimech, 2012; Sørensen, Frederiksen, Groefte, & Lomborg, 2014). The second theme of fear related to the fear of complete dependence on others and the anxiety and panic associated with loss of control (Torheim & Gjengedal, 2010). Anxiety management techniques have often been used to treat fear of entrapment or restraint within a mask and headgear (Chasens, Pack, Maislin, Dinges, & Weaver, 2005). In all of the articles surveyed, there were no recommendations to change the design of the mask to assist patients with these fears. The popular media may add to the shock associated with the first encounter with sleep apnoea breathing interfaces through associating and portraying the use of breathing support with intense stress and end of life (Boone, 2014; Nyswaner, 1993). Consequently, CPAP therapy advocates advise clinicians not to refer to breathing devices 'as a mask' due to horror movie associations and are encourage them to allow the patient to hold the mask and get used to it for a few minutes before putting it on (Selecting the Right CPAP Mask Every Time, 2015).

The fourth and final theme was related to stigma, embarrassment and other social perception barriers. The physical side effects that occur when using CPAP treatment are well documented (Shapiro & Shapiro, 2010), and commonly included a dry, runny or blocked nose and nasal cavities (Worsnop et al., 2010, p. 650), skin irritation, redness and in some cases ulceration of the nasal bridge (Mehta & Hill, 2001, p. 543). Device discomfort was also a key theme prevalent in patient and nurse perspectives on oxygen therapy (Eastwood, O'Connell, Gardner, & Considine, 2009). Sørensen et al. (2014, p. 1726) studied how patients adjusted to ventilation in acute care. They found that controlling the discomfort associated with non-invasive ventilation, and the first sensations of ventilation or breathing of pressured air through a mask was an essential theme for improving the treatment experience for patients with degenerative lung disease (Sørensen et al., 2014, p. 1726).

Interestingly, patients often describe themes related to physical issues, such as mask constraint and discomfort, in relation to other factors, particularly concerning fear, control and social stigma. Sørensen et al. (2014) previously identified the sensation of being inflated by a positive airway pressure device as a source of discomfort. However, this was rarely mentioned elsewhere in the literature I reviewed. Possibly, this was because inflation discomfort was inherent to positive pressure breathing therapy and as such researchers saw it as unavoidable or outside the control of clinicians or designers. Although studies have shown that CPAP therapy discomfort may create physical problems, some studies have also demonstrated that these problems do not necessarily prevent CPAP therapy use (Chasens et al., 2005).

Stigma, embarrassment, and subsequent isolation emerged as common social themes across the breathing therapy groups. These themes were in tension with themes of physical enablement. While Eastwood et al. (2009) showed breathing support therapies were physically enabling of everyday activities, they conversely have also restricted social activities amongst those undergoing treatment with oxygen for degenerative lung disease (Kelly & Maden, 2014). Williams, Bruton, Ellis-Hill, and McPherson (2007) found the ability to maintain everyday activities was as an essential factor in a study of 'what really matters' to patients living with breathing therapy treatments. Stigma and embarrassment were recognised as difficulties for those undergoing oxygen therapy (Kelly & Maden, 2014) as well as CPAP treatment (Ayow et al., 2009) and home mechanical ventilation with children (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). While studies supporting the role of stigma and embarrassment focussed primarily on patients perceptions, I did not find the perceptions of third parties (i.e., those not directly involved in the treatment support) reported in the literature I reviewed.

5.4 Discussion

The studies presented in this chapter were predicated on discourses and paradigms of scientific and empirical research. While they explore reported experiences, they do little to explain the operations of power or the discursive structures that lead to these powerful conceptions of knowledge. In this thesis, I argue that the answers to questions asked in the legitimised literature may be outside the current research limits of legitimated clinical knowledges. As such, I argue that a new approach to understanding the variable rates of CPAP therapy use in the home is required. In order to highlight the limits, the following discussion outlines one underlying assumption about breathing therapy mask design that was not addressed in the literature reviewed.

Gilles Deleuze³⁷ considered the role of the face in his work on affect in film, *Cinema 1 – Movement-Image* (Deleuze, 1986), extending and applying ideas developed in *A Thousand Plateaus* (Deleuze & Guattari, 1987). In structural discourse terms, Deleuze attributed three key roles for the face beyond functional physiology:

Ordinarily, three roles of the face are recognisable: it is individuating (it distinguishes or characterizes each person); it is socialising (it manifests a social role); it is relational or communicating (it ensures not only communication between two people, but also in a single person, the internal agreement between his character and his role). (Deleuze, 1986, p. 99).

Discourses on OSA breathing technologies have typically constructed the face mask as an interface and described it as interfacing between the person and the technology (Mehta & Hill, 2001). Mehta and Hill (2001) described the way the CPAP therapy mask obscures the face as a side effect (see Figure 21). This obstruction of the face interferes with the face's non-physiological roles as described by Deleuze (1986, p. 99). However, this interpretation of a mask blocking the face is specific to medicalised discourse as the following example articulates.

³⁷ Gilles Deleuze is known for his philosophical exploration that broadens previous conceptualisations of the face, as developed in chapter 7 of the popular book he co-wrote with Félix Guattari: Deleuze, G., & Guattari, F. (1987). *A thousand plateaus: Capitalism and schizophrenia*. Minneapolis, Minnesota: University of Minnesota Press. In this work, Deleuze and Guattari engage with the concept of the face, broadening it to mean a recognizable assemblage that humans respond to, or 'faciality'. This is the work primarily responded to by Rushton, R. (2002). What can a face do? On Deleuze and faces. *Cultural Critique*, 51(Spring 2002), 219-237. The quotes are on page 13 of this study.

I shall compare CPAP therapy discourses about the mask's 'side effect of blocking the face', with performance mask discourse. Anthropologist M. C. Jedrij remarked that within performance mask discourse "a mask is a relationship rather than an entity" (as cited in Popenhagen, 1994, p. 31). Rather than blocking communication, "a mask initiates a dialogue" (Popenhagen, 1994, p. 1). Furthermore, within this discourse, "a mask is a face" (Popenhagen, 1994, p. 1). Deleuze also presented the idea of transformation as part of a broader philosophy, "a mask does not hide a face... it is a face" (Deleuze & Guattari, 1987, p. 115). The mask did not obscure the face benignly, rather it transformed it. In this discourse of the mask, the mask itself is an active participant in constructing the responses of the people that saw it along with the sense of self of the person who wore it. Clinical discourses, as such, depicted the CPAP therapy mask as a largely neutral entity, one that people respond to in various ways due to who they are and their own ability to regulate their behaviour, rather than how the mask was constructed socially and materially. This is a key limitation in legitimised scientific and clinical discourses. In constructing CPAP therapy as clinically effective and legitimate, a user who does not succeed in using the device is also constructed as personally liable for the failure to succeed. The interaction between the discourse of effectiveness and the problematic user also operated to construct the device itself as effectively invisible in the literature. This in turn made it difficult to imagine changing the form of the mask. This effect of discourse is important for designers to recognise, as it implies the design of the mask is of little importance beyond its clinically measurable functionality.

In the context of use, constructing a neutral mask that is proven to be effective in a clinical setting belies the differing experiences that came with different contexts of use. For example, in an acute illness situation, a very unwell patient in a hospital Intensive Care Unit (ICU) may wear a breathing support mask 'temporarily' for days, weeks or months and in the presence of highly trained medical staff. In a chronic illness situation, a patient who may have no other health limitations may be required to wear a mask every night, for their remaining lifespan (in some cases many decades). The chronic illness patient would likely sleep at home, either alone, with the same partner, or from time to time a new partner. They may be in a domestic situation where they may be required to assist children or grandchildren during the night, or be presentable on short notice in the morning for work, or even simply to answer the door. Home-based treatment is in contrast to the acute illness situation where such everyday demands on the patient are few. Patients will primarily encounter medical staff who are highly trained and accepting of medical devices and illness. Patients will use identical breathing support devices and interfaces in both acute and chronic situations.

Popular media discourses also consistently portrayed medical breathing support devices in constructions of weakness and severe illness. Breathing support devices are commonly shown as an imminent precursor to death, particularly in movies about terminal illness such as *Philadelphia* (1993), *The Bucket List* (2007), and *The Fault in Our Stars* (2014). However, the dominant clinically-informed understanding of CPAP therapy breathing technologies is that they are restorative and have the potential to significantly and positively affect the life of the wearer (Shapiro & Shapiro, 2010). The problematic nature of using identical breathing interfaces in vastly different treatment contexts has been overlooked by the clinical literature. The focus of clinical literature is, instead, on the deficits of the user, their qualities and ability to use the device, rather than including operations of power through discourse in the broader social context.

5.5 Summary

This chapter contrasts historical and recent constructions of historical sleep to highlight the ways in which discourses of normative sleep have been legitimised in very different forms. I considered problematic sleep in contrast to accepted forms of normative sleep with examples of socio-cultural differences that undermine the idea that problematic sleep is problematic universally. I contrasted legitimated discourses of clinical effectiveness discourses with patient adherence. Doing so has shown the effects of separating the clinical effectiveness from a real-life use situation. The separation of discourses casts the role of the mask as neutral, simply obscuring the face in a non-descript way.

I further explored patient experiences of wearing a broad range of breathing support interfaces as they were presented in the clinical literature. I found these experiences were framed in terms of how the patient reported their experience but they did little to uncover the role of the mask or the broader social context that generates those responses. Drawing on post-structural concepts of the face suggests that masks can play an active role in generating the experiences of the wearer. From this frame of reference, the mask itself may play a more direct role in the construction of broader patient experiences. Focussing on peer-reviewed and clinical literature demonstrates the thinning out of discourse restricted by the high levels of qualification and the institutional markings associated with peer-reviewed literature. The body of this review has also demonstrated that:

1. CPAP therapy is both invasive and uncomfortable to use, but that these factors appear not to entirely predicate or explain the lack of adherence that is so prevalent with CPAP therapy, and

2. there is a strong indication that social and cultural factors play a significant role in adherence. However,
3. there is not yet enough information about how social and cultural mechanisms operate in relation to breathing mask interfaces generally, or to CPAP therapy, in particular, to be able to design interventions or new devices that specifically address the issues.

The next chapter will examine a typical CPAP therapy mask that manufacturers have developed in partnership with researchers and clinicians in light of the literature just discussed.

Chapter 6 Legitimacy and normativity in discourses of mass manufacture

This chapter presents the findings of an analysis that draws inspiration from Foucault's critical histories or 'history of the present' approach, using an examination of the past to make visible the discourses of today (Dreyfus & Rabinow, 1983, p. xxvi) (see section 2.3.6). This chapter focuses on a typical mask artefact, presenting the results of the process of analysis outlined in chapter four (see section 4.3). From this analysis, I show the discourses that have shaped, normalised and legitimised the form, design and material choices in the typical CPAP therapy mask (i.e., why it has come to look and operate in the way that it has). This chapter seeks to challenge the taken-for-granted form of the typical CPAP therapy mask by showing its contingency with this socio-historical moment, analysing this contingency and presenting examples to indicate that it might not be universally considered the most obvious and most appropriate design embodiment.

Chapter six builds on the previous chapter, which established the space created for CPAP therapy masks for OSA within the peer-reviewed literature. In showing the socio-historical contingencies that shape and reinforce the current mask design, this analysis continues to destabilise the self-evidence of what is considered 'true' and the most reasonable approach to answering the question of this specific instance of problematic sleep.

6.1 Situating the discursive frame of analysis

In developing the analysis findings in this chapter, I focussed on one CPAP therapy mask manufacturer, Fisher and Paykel Healthcare (FPH), and a specific CPAP therapy mask product (Zest nasal mask). In situating this analysis, I must first draw attention to the *Fisher and Paykel Information Memorandum* (Fisher & Paykel Industries Limited, 2001, p. 21), which helped frame the domain of discourse that this analysis reflects. This memorandum document states the business case that shareholders voted on to split the Healthcare division, now known as FPH, from its parent company Fisher and Paykel Industries to create two companies, FPH and Fisher and Paykel Appliances in 2001. The change in business structure occurred at a time that was close to, but preceded, the production of the specific Zest Mask analysed in this section. According to the product markings, FPH first produced the Zest mask in 2008. Importantly, the memorandum document shows the jurisdictional legislation FPH recognised as necessary to its product developments. In 2001, FPH identified four main categories of governmental regulation applicable to its healthcare business (see Appendix F:). The focus of these categories was on "safety, effectiveness and adherence to Good Manufacturing Practice and

related manufacturing standards” (Fisher & Paykel Healthcare Limited, 2001, p. 21 original capitalisations preserved).

The US Food and Drug Administration (FDA) was highlighted as being particularly rigorous and was of specific concern for sales into the US. However, Fisher & Paykel Industries Limited (2001, p. 21) noted at the time, that “the trend in New Zealand, Australia, Europe and Japan is towards increasing surveillance and regulation of the design, manufacture and distribution of medical devices” (p. 21). In addressing the government regulations for Japan, Fisher & Paykel Industries Limited (2001, p. 23) noted that the regulatory approvals were more strict for Europe and the US, so Japan did not require additional regulatory consideration. Fisher & Paykel Industries Limited (2001) also presented increasing control through governmental mechanisms as a source of potential uncertainty that might apply to their business “practices and products” (p. 21). These government mechanisms acted as a risk mitigation incentive to design for the strictest regulatory condition – being the US and its regulatory body the Food and Drug Administration (FDA) (Fisher & Paykel Industries Limited, 2001, p. 21). Thus the design of devices FPH intended for international markets was governed by both the size of the market and the need to meet the requirements of the strictest regional regulatory conditions (potentially stricter than in New Zealand). Once such a device met the strictest regulatory requirements, FPH could readily sell it into more lenient regulatory markets. Encouraging practices to match the strictest and most dominant market regulatory approvals - in this case, US requirements - operated as a disciplinary mechanism and dominated the discourses of medical device manufacture for most manufacturers supplying Western and global markets.

In the method development I outlined in chapter four, I detail my analysis on consideration of a typical CPAP therapy mask product and packaging. Figure 22 is a documentary style photo of a typical CPAP therapy interface and the headgear I chose for analysis. One focus of this study is to consider the voyage of physical artefacts between different socio-technical environments. These artefacts can be read from a variety of points of view depending on ideas, approaches and constructions of knowledge. For example, as someone with training and experience working as a mechanical engineer, some factors stood out to me that highlighted the CPAP therapy mask as being a product of mass manufacturing discourses. An analyst with different background training and experiences may use other aspects as their route into the analysis (i.e., read it differently).



Figure 22. CPAP therapy interface with box and instructions.

Source: Author's photograph.

6.2 Historical constructions of legitimacy in medical devices

Having determined the worldwide dominance of the FDA in defining medical device legislation, I considered the origins of this legislation in the US. In particular, it was important to understand the practices and events that triggered legislative changes that affected discourses around medical device legitimacy. The following section problematises early medical treatments and medical devices that led to the establishment of legislation to regulate Food and Drug labelling in the US. Throughout the legislation history, difficulties in defining the differences between medical devices and drugs have meant that the two have often crossed over in legislation. For example, based on the 1906 Act that brought the FDA into being, a bandage met the definition of a drug, “because it was a substance intended to be used for the cure, mitigation, or prevention of disease in either man or other animals” (Munsey, 1995, p. 165). I will discuss the two concepts together in the following sections.

Early US legislation relating to medical devices began the construction of a discourses of legitimacy that targeted device effectiveness. The enactment of the Federal Food, Drug, and Cosmetic Act (FD&C Act) of 1938 redefined the medical device separately from drugs as “instruments, apparatus, and contrivances, including their components, parts and accessories,

intended: 1) for use in diagnosis, cure, mitigation, treatment, or prevention of diseases in man or other animals; or 2) to affect the structure or any function of the body of man or other animals” (Federal Food, Drug, and Cosmetic Act (FD&C Act) of 1938) (Munsey, 1995, p. 163). The push to legislate medical devices at this time was in response to a proliferation of fraudulent medical devices “such as nose straighteners, height-stretching machines, and heated rubber applicators (advertised as a cure for prostate gland disorders)” (Munsey, 1995, p. 163 brackets added for clarity). As such, discourses of legitimacy came to be constructed in terms of device effectiveness in response to discourses of fraudulence. Discourses constructing what constituted ‘proof of effectiveness’ entered into legislation as the FDA brought legal actions against statements, designs, or labelling that were ‘false’ or ‘misleading’ (US Food and Drug Administration, 1989, p. 3).

Prior to this act, devices that had already “tragically demonstrated their danger to people” were subject to enforcement actions, and the regulations designated medical devices as drugs (Rados, 2006, p. 61). In this sense, legislators were also responding to discourses of harm, including some influential cases relating to poor public understanding of the effects of radiation with products promoting it as beneficial to health rather than harmful (Walker, 2000, p. 4). The FDA took on a policing role and began testing devices as discourses of safety became central to device legitimacy.

The safety and legitimacy of medical devices initially focussed on biological risks through discourses of hygiene. Discourses of hygiene emerged in the legislation as the FDA began to also bring charges in court against products or materials on the market that were found to be “filthy, putrid, or decomposed substances or those prepared, packed, or held under unsanitary conditions” (Munsey, 1995, p. 163).

In more recent times, the discourses of safety that drove appeals for drug testing prior to approval intensified. This intensification followed a major crisis where extensive birth deformities appeared in babies born of mothers using the drug thalidomide during pregnancy (Vargesson, 2015, p. 140). Manufacturer’s initially marketed the drug as a pregnancy safe sleeping aid, but it became widely used as treatment for morning sickness (Sjöström & Nilsson, 1972; Vargesson, 2015, p. 140). As a consequence, institutional approval for the safety for drugs prior to public release soon became a legislated requirement for legitimacy. In 1970 Theodore Cooper as part of the Cooper Committee, the group tasked by the US congress to investigate and make recommendations, further extended these requirements into recommendations for medical device specific legislation (Link, 1972, p. 624). These were aimed at providing “practical and realistic” approaches to medical device control (Link, 1972, p. 624).

Discourses of risk assessment as a strategy of device control to ensure safety further extended into new legislation that recommended creating different classifications for medical devices based on the level of risk they presented (Link, 1972, p. 625). When a legislative agreement was not initially forthcoming from Congress, the FDA of its own accord created an inventory of all medical devices being used and classified them according to their potential risks (Maisel, 2004, p. 296). At this time, the FDA had recorded some 10,000 injuries related to medical devices (Maisel, 2004, p. 296).

In the Medical Device Amendments act of 1976, a medical device was defined as similar to but distinct from a drug, as per (Medical Device Amendments of 1976, p. 539):

an instrument... which is... intended for use in the diagnosis, ...the cure, ...treatment, or prevention of disease ... and which does not achieve any of its intended purposes through chemical action within or on the body. (Maisel, 2004, p. 296; Medical Device Amendments of 1976, 1976, p. 539).

Regulators chose the risk categorisation in relation to the specific device. For example, tongue depressors were covered by the general controls already in place at the time (Class I).

However, the legislation subjected devices such as wheelchairs, optical lenses and breathing support masks to performance standards. Regulators applied standards in cases where they considered the general controls insufficient to ensure the safety and effectiveness of the product (Johnson, 2012, pp. 5-6). Class III products (e.g., implants or artificial hearts) were required to undergo pre-market approval. If the devices were substantially equivalent to pre-1976 devices, they could be marketed immediately, subject to the requirements of the device type (Johnson, 2012, pp. 5-6).

The Bureau of Medical Devices merged with the Bureau of Radiological Health in 1982, when it was renamed the Center for Devices and Radiological Health (CDRH) (Munsey, 1995, p. 167; Rados, 2006, p. 64). Up to this point, regulation of medical devices was focussed on the production and testing of the device itself. However, a further shift came when CDRH Assistant Director Mark Bennett argued that “[t]he safety of most medical devices depends to a large degree on their[sic] being used properly” (Rados, 2006, p. 64). Stating the examples of surgeons implanting devices into people through to anaesthetics controlling complex machine gas delivery, or home use glucose monitors operated by patients, Bennet articulated that the FDA’s responsibility in all of these situations was to “educate health care practitioners and patients about safe use” (Rados, 2006, p. 64). This was a shift in the discourse from the FDA enforcing responsibility for device safety onto manufacturers to a situation where the way

patients and others who interact with and use medical devices could instead be indicated as the reason for device failure. The operation of these discourses constructs the device user as responsible for using a device consistently and flawlessly.

The remaining onus on manufacturers for constructing device legitimacy through safety focussed on the construction of good manufacturing practices and quality control. Legislators authorised the Good Manufacturing Practice (GMP) regulations in 1978 (Federal Register of July 21, 1978), which aimed to ensure that devices were manufactured to be safe and effective. Assurance was made through quality control processes focussed on design, manufacture, labelling, testing, storage and distribution (Federal Register of July 21, 1978). The onus was with manufacturers to demonstrate these systems, or if failing to do so, they could be audited by the FDA. This led to another key strategy for the construction of legitimacy through safety and control, which was to use the disciplinary procedures of surveillance and reporting to legitimise devices through the conduct of the manufacturing processes.

The key milestone with respect to legislating the role of surveillance and reporting in device regulation was the Safe Medical Devices Act (SMDA), which was passed in 1990 (Flannery, 1991). In this act, amendments to the 1976 bill were modified to provide further protection against dangerous medical equipment. The law took on a reporting form of surveillance by requiring nursing homes, hospitals and other health care facilities to report to the FDA when devices they used were likely to have caused or contributed to patient death or severe illness or injury (Flannery, 1991). Regulators also required post-market surveillance on implanted devices where serious harm or death was a possible consequence of failure. The SMDA (1990) provided the FDA with the legal authority to take a range of actions following reports of device failures, including recalls of faulty or unsafe products, particularly if there was a likelihood of death resulting (Flannery, 1991, p. 141). In the next section, I will explore how historical constructions of legitimacy shaped the CPAP therapy mask artefact.

6.3 Discourses of effectiveness and safety

Discourses of effectiveness were some of the earliest drivers of medical device legislation. In the CPAP therapy mask that was analysed, patent numbers were displayed prominently on the mask packaging and again in the instructions material (see Figure 23). The numbers serve to warn potential copiers of the design, but also indicate functionality and therefore, the effectiveness of the product. They also support the credentials of the manufacturer through the reference to the patent office and to the associated examination processes.

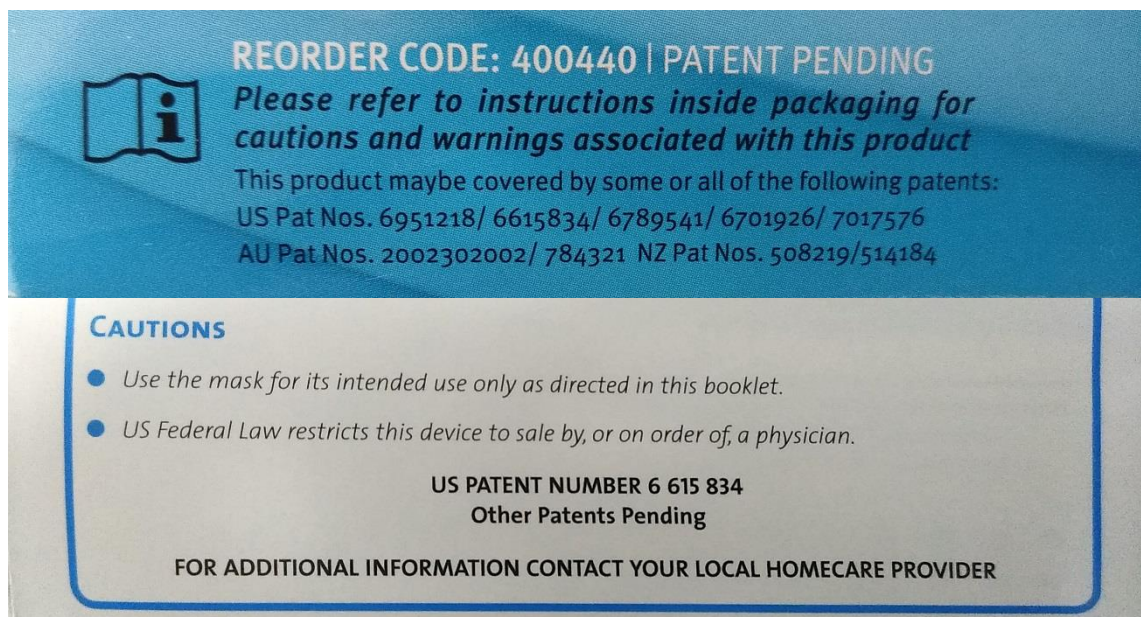


Figure 23. Patent numbers and advisories are displayed prominently on the box. Inside is also an instructions booklet with caution and warning headings. Source: Author's photograph.

A second indication of the effectiveness of the device that further builds its legitimacy is in the appeals and assumptions of clinical input. As Figure 24 shows, instructions addressed 'the patient', a clinical construction of a device user that would commonly be used by medical staff and professionals. The design of the mask for both "Single Patient Adult Use" in the home and "Multiple Patient Adult Use" in the hospital or other clinical setting was unique to and consistent with medical equipment and operates as a mark of device effectiveness. Consider, by way of contrast, the vast market for hobby level power and hand tools, designed specifically for the home user over the professional trade-level tools for the worksite, despite the main function being identical³⁸.

Medical devices for the treatment of diagnosable conditions differ significantly from retail products. The requirement in many countries that prescription medical devices are sold only by order or through a qualified physician enacts this difference. Effectively, the product choice, purchase decision and (for health insurance schemes) the payment for the product, is not in the hands of the person who eventually uses the device. Consequently, the design of the product responds to the needs and interests of the prescribing clinicians and physicians. Where retail products refer to the 'user' or the 'consumer', the instructions address the clinician's characterisation of the medical user, also known as 'the patient' (Figure 24).

³⁸ Wearable technology may be an emerging exception, where in some cases what is available domestically may be superior to what is available clinically.

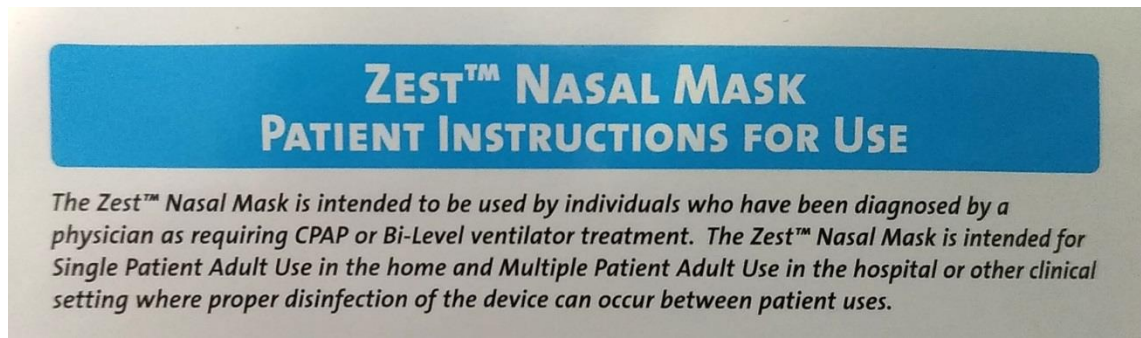


Figure 24. Instructions aimed at clinicians.

Clinicians will decide the need for and correct selection of the mask. Even the instructions refer to the clinical construction of the device-user as the “patient”. Source: Author’s photograph.

As a commercial business, FPH built on these discourses of effectiveness through corporate strategy. FPH valued and cultivated “close working associations with a number of hospitals and clinicians, particularly in New Zealand and the U.S.” (Fisher & Paykel Healthcare Limited, 2001, p. 17). Both locations offered the business “valuable opportunities to test emerging technologies and access to world-class medical expertise” (Fisher & Paykel Healthcare Limited, 2001, p. 17). These alliances and processes further legitimised the CPAP therapy mask by continually testing and reinforcing the notion of device effectiveness, as judged by the legitimated clinical disciplinary authorities.

This strategy extended to the mechanisms through which the market strategies operated including several interactions, particularly in legitimated situations and venues:

The sales and marketing strategy involves a variety of initiatives to increase the Company’s penetration of target markets, including participation in trade shows, attendance at scientific meetings, and developing and distributing educational and marketing materials describing the benefits of the healthcare business’s products and heated humidification. (Fisher & Paykel Healthcare Limited, 2001, p. 20).

The choice of trade shows for promotion, and marketing through materials and scientific meetings reflected the role of the clinicians in decision-making for CPAP therapy purchases. A key feature of the FPH effectiveness proposition was thus its sales, marketing and distribution channels. Two important sales streams used for the CPAP therapy mask were:

- “Direct. [FPH] sells directly to hospitals, long-term care facilities, and [importantly to the US market,] home healthcare dealers” as well as to other dealers who then on-sell to these same customers (Fisher & Paykel Healthcare Limited, 2001, p. 19).

- “Distributors. [FPH sells] to a network of approximately 100 distributors across 90 countries who in turn sell to hospitals, home healthcare dealers and other manufacturers of medical products” (Fisher & Paykel Healthcare Limited, 2001, p. 19).

The use of the term ‘educational material’ as opposed to ‘information’ was consistent with the terminology used in clinical interviews (Clinical Specialist 1, Clinical Staff 2, Clinical Staff 3, Clinical Staff 6, Clinical Staff 7, Clinical Staff 8 - see Appendix D). The implication was that of an educated decision, which had the expected outcome if the person making it was ‘educated’. An alternative to the expected outcome was a failure of education, or of the participant to become educated, rather than a rational decision based upon their circumstance. A similar term, ‘informed choice’, would seem to imply that an individual may reasonably decide in either direction on the balance of individual circumstances and the information available. The process of making a choice is what lends support to the decision (rather than the outcome) when making a judgement about a person or their decision-making process.

In addition to discourses that legitimate device effectiveness, discourses of safety include a prevailing faith that manufacturers know what they are doing. The constructions of a knowledgeable and legitimate therapy manufacturer are present in visits to the Auckland District Health Board (DHB) sleep clinic. The sleep lab visitors book features a great many entries related to visitors from FPH (Visit notes with Clinical Staff 3 - see Appendix D). Early scoping interview notes suggest mask manufacturers are highly knowledgeable sources of information (Scoping notes with Clinical Specialist 4 - see Appendix D). FPH produced two videos that are shown to Sleep lab attendees at Auckland DHB sleep lab (Visit notes with Clinical Staff 3 - see Appendix D). The videos feature employees at FPH talking about their personal experiences with OSA and FPH’s sleep lab, as well as giving explanations of the equipment, how to use it and examples of successful users of CPAP therapies (Visit notes with Clinical Staff 3 - see Appendix D). Clinicians mentioned meetings and training sessions with mask manufacturers where feedback on designs was sought (Clinical Specialist 1 – see Appendix D). Clinicians were unable to share any details of this work due to the signing of confidentiality agreements (Clinical Specialist 1 – see Appendix D). Through the process of signing a confidentiality agreement, the knowledge of clinicians employed by the public sector was constructed as property and controlled through legal entities. While clinicians were happy to comment on the process of diagnosis or their own opinions of particular mask designs, they were not able to talk about the process of relaying this same information to mask manufacturers.

In Foucauldian terms, these examples construct the mask manufacturer as possessing the ‘right to speak’, or in this case, the right to ‘make’ that was characteristic of enunciative modalities (see section 3.4.2). Such rights to ‘make’ are determined in relation to medical devices by meeting a variety of legislative requirements that are fundamentally focussed on constructions of safety.

The strategies and approaches through which FPH established discourses of manufactured legitimacy also shape the CPAP therapy mask product. Mask packaging includes references to manufacturing standards and product traceability, such as the lot number and an acceptable temperature range (particularly for storage and shipping). The box includes detailed and densely written instructions and these carefully direct how to correctly use the device. The box itself also includes a symbol and directions to refer to the instructions for “cautions and warnings associated with this product” (see Figure 25).



Figure 25. Photographs of the interface’s cardboard box.

Instructions also include references to standards, codes and patents with which the device complies. In this case, CE advises compliance with relevant European health and regulatory safety codes, with the number indicating the governing body. Source: Author’s photographs.

Safety was established in the CPAP therapy mask through clear processes of surveillance and an examination of product deficiencies. As shown in Figure 26, extensive contact details provided on the box construct surveillance. These may also work to divert complaints from

public databases by minimising the appearance of issues that could undermine subsequent constructions of safety and legitimacy.

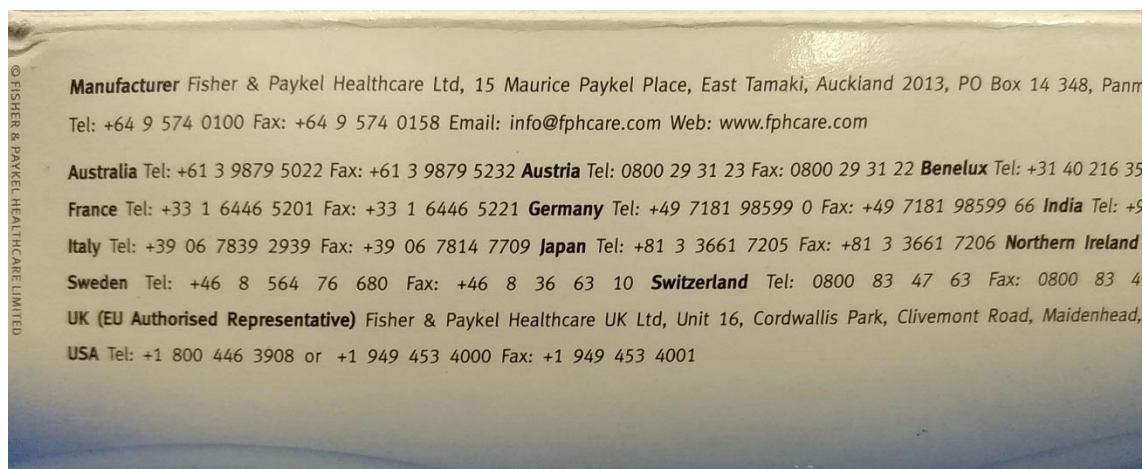


Figure 26. Extensive company contact details for multiple countries on the back of the therapy mask box.

Source: Author's photograph.

In legislative terms, disciplinary technologies of surveillance and examination to international standards constructed quality. Failure and complaint data received was made available by the FDA in the MAUDE database, which stands for Manufacturer and User Facility Device Experience (Food and Drug Administration, 2019). Through a brief search of this database, I found that CPAP therapy related entries mostly focuss on the CPAP therapy device itself rather than interfaces or masks. The information supplied to the MAUDE database was typically from patients, nurses and doctors, rather than manufacturers. The arrangement and accreditation of the material processes used in the manufacturing processes establishes the legitimacy of the company as a manufacturer in material terms.

6.4 Discourses that construct 'normal' production methods in CPAP therapy masks

Discourses of normativity in the CPAP therapy mask were made up of two key parts. The first was the operation of the discourses of mass manufacture that operate to deliver very high numbers of a particular design embodiment to a large population. The second was the underlying design assumptions, the material constructions, and the ways in which they may or may not reflect the situations of those in the population who would use them.

From a mass manufacture point of view, the mask is constructed through an approach of modular construction and assembly. As Figure 27 shows, the mask is made up of six or seven different parts and types of material.



Figure 27. Interface and headgear show discourses of modular design
Source: Author's photograph.

The manufacturer designed and fabricated the masks in such a way that almost anyone can easily and quickly assemble and disassemble them. This also makes for ease of cleaning by users. Ease of assembly and disassembly is also an important manufacturing principle (Boothroyd & Alting, 1992), that allows parts to be worked on and constructed separately. Parallel construction may be either by different people in the same workshop or by people in different countries around the globe. By way of contrast, in an artisan approach an item would be made from start to finish by one technician or craftsperson. With a more artisanal approach, there is likely to be less emphasis on the need to disassemble the different parts, as one person normally works on one component or aspect at a time.

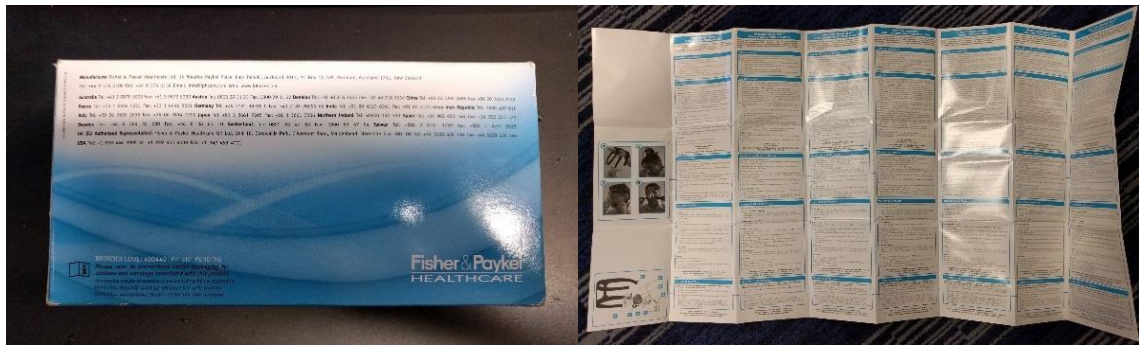


Figure 28. Images of the interface's cardboard box and instructions.

Images show a gloss finish that was invented to speed drying times, and a restricted colour palette often associated with lower printing costs. Source: Author's Photographs.

The gloss finish on the cardboard box and printed instructions indicate the fast drying times of the printing inks (Figure 28). Matt paper often absorbs inks, which can result in less efficient ink use, including poorer finishes and longer drying times. When printers print images in 'passes' (i.e., adding one colour at a time), the smaller variety of colours and tones (i.e., light and dark blues, grey and black) results in fewer passes of the printing machine, and a much quicker and more cost effective turn around for high volume production runs. The invention of gloss finish paper was originally intended to accelerate drying times (Cost, 1986). As will be discussed in later sections, the level of gloss or sheen on an item was also often associated with a discourse on 'high-tech' and 'precision machining'. The absence of factors such as bright colours constructed the instructions as functional and did not appear to have been chosen to draw specific attention. For example, unused colours include warning colours such as red, orange or yellow.

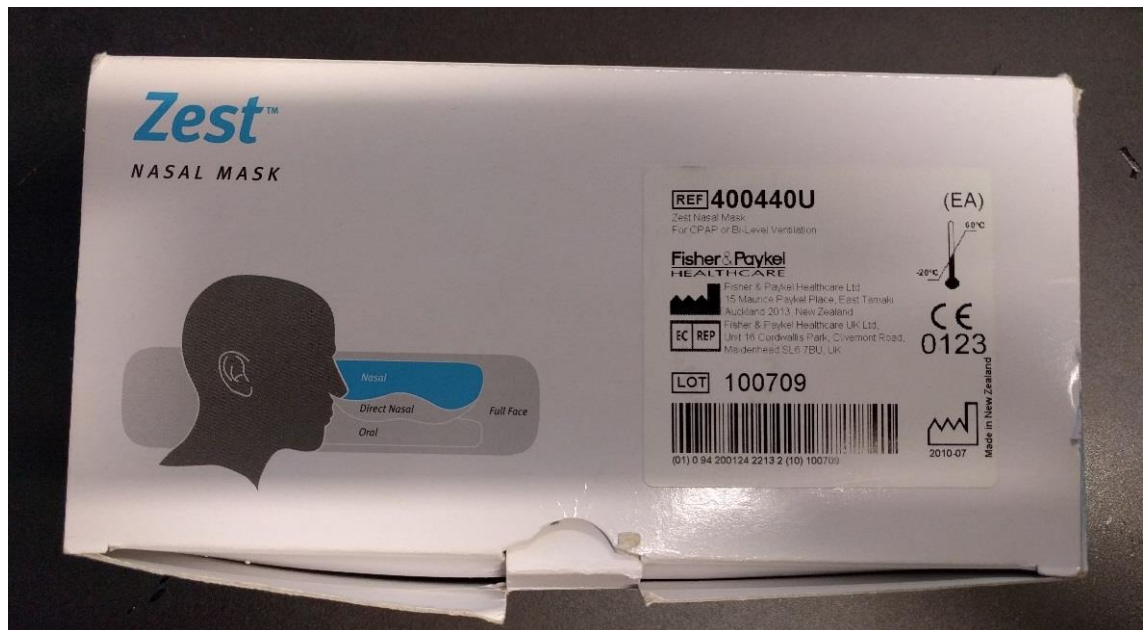


Figure 29. Box label includes manufacturing information, standards and lot numbers.
Source: Author's photograph.

The barcodes on the box may have been part of a system used for worldwide distribution and the tracking of masks (Figure 29). Similarly, the box size (or dimensions) was likely adjusted to fit the maximum number of masks in a standard freight box and a maximum number of boxes inside a shipping container. Designing for shipping efficiency has increasingly become an important consideration for manufacturers in a globalised trade environment (Chaudhuri, 2015).

The materials in the mask artefact are associated with mass production. In particular, plastics suited to injection moulding tended to be part of high-volume and low-cost production processes. Polycarbonate, a clear plastic, is injection moulded to make the mask frame and cone parts (Figure 31). The pushpin marks³⁹ in the finish indicate an automated injection moulded manufacturing process (Figure 32) as do the imperfections from the injection sprue in the connecting swivel elbow (Figure 30). The headgear material is a neoprene laminate that appears to have been cut using a blade, potentially using a die cutting process. The fine tolerances and high gloss finish on the plastic indicate a carefully engineered and consistent process of manufacture. By comparison, a handmade product would be more likely to exhibit

³⁹ Push pins push injection moulded parts out of the injection mould tool usually before the part is fully cooled. This makes the process faster and means that the plastic is flexible and easier to remove. In this state the pins will also leave small indents.

small variations and imperfections in the form (often highly valued in objects where there is a revival of artisan approaches constructed as high-quality craft).



Figure 30. Circular opaque crystallisation structure typical of injection moulding sprue. Point of plastic injection into the mould. Source: Author's photograph.

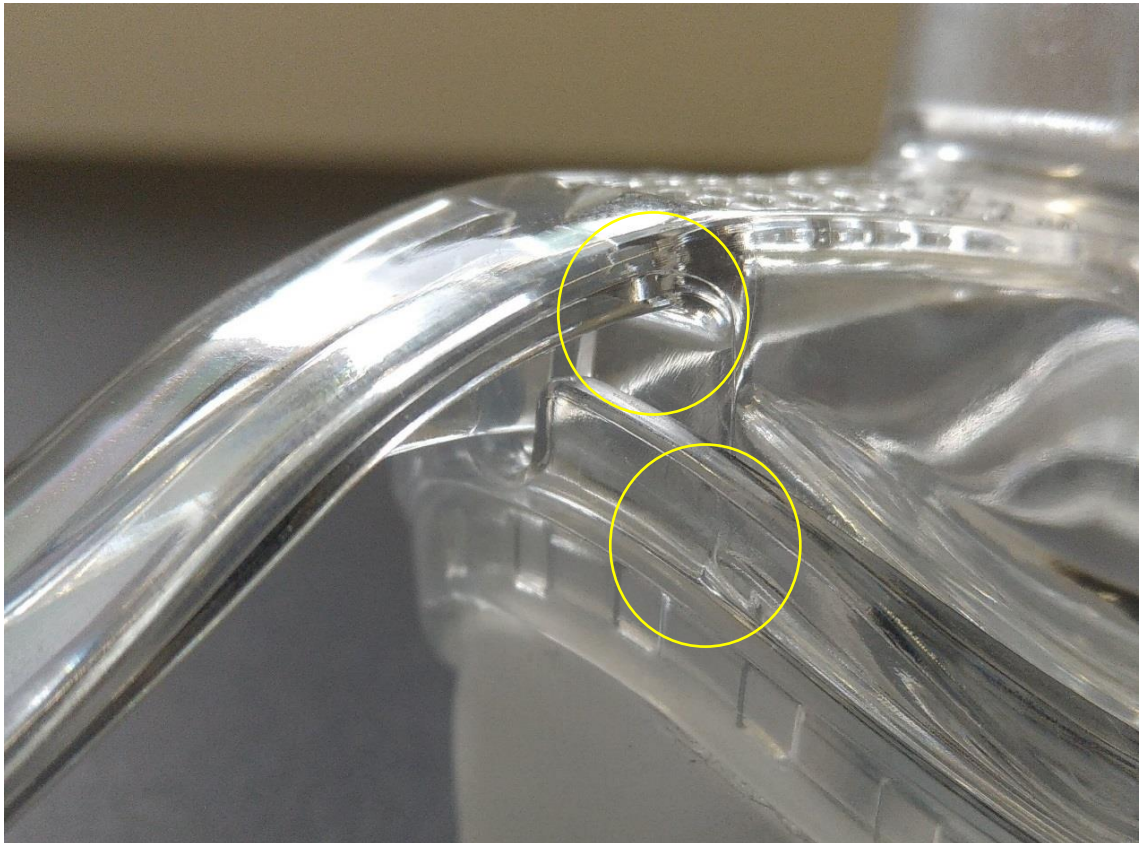


Figure 31. Parting lines. These are thin ridges or lines may occur at interfaces of different parts of a multipart mould tool. Source: Author's photograph.

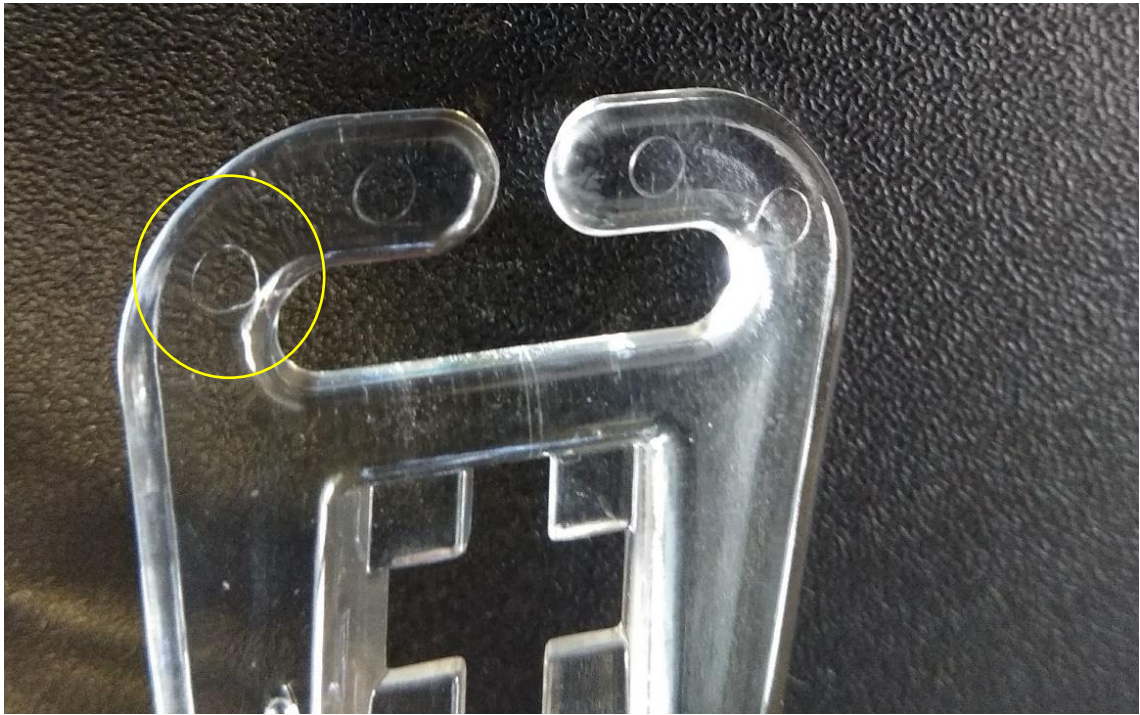


Figure 32. Small circular indents formed by 'push pins'.

Pushpins are used to push the moulded part from the mould tool while the material is still soft and are typical in fast, automated injection moulding processes. Source: Author's photograph.

Synthetic rubbers, or elastomers as they are more generically known, are present in two forms in the CPAP therapy mask. The first, more commonly known as silicone, is an elastomer that is well-known for its non-stick and heat resistant abilities in the kitchen. The second elastomer is a laminate in the headgear, made from neoprene with nylon and Lycra fabric attached on either surface through a flame heating process. This material is widely known as Breathe-O-Prene, a name first used in 1998 and later trademarked by ResMed (ResMed, 2002). The material was intended to be breathable, meaning that there was space for air and humidity to flow between the skin and the rubber laminate. The laminate performance is a unique combination of form holding and flexibility. The fabric weave attached to the neoprene provided particular characteristics that prevent it from curling up and becoming stretched and tight, but still allows a degree of form-fitting.

6.5 Discussion

In my early analysis of the artefact, I proposed that the dominance of blue in the box colouring, the markings of functional design style and the mask's transparency differentiated the mask as a medical device. From my Western-situated perspective (see 1.3), I viewed these aspects of the design embodiment as constructing medical product legitimacy. I read the device, based on these material cues, as neutral and rational and therefore trustworthy. In addition to the

scientific data that supported or confirmed their clinical effectiveness, medical device material choices can construct a trustworthy appearance due to the viewer's interpretation of features as further reflecting discourses that build legitimacy, as discussed in sections 6.2-6.4. For example, interpretations of a product being 'hygienic' imply safety, so it is seen as 'good quality' along with 'high-tech' implying effectiveness. The following discussion will unpack and culturally situate some of these object-based interpretations and show how they operate to construct legitimacy in a CPAP therapy mask embodiment within a Western cultural frame of reference. I will also consider the ways in which aspects of transparency, colour and opacity were situated differently in specific socio-historical cultures. By doing so I aim to demonstrate that these constructions are not universal. As a consequence, those outside the normative constructions of Western cultural groups may experience them as a disciplinary norm. Being 'othered' by the device in this way has the potential to impact the experience of the product in ways that may be difficult to articulate.

6.5.1 Western norms in the CPAP therapy mask embodiment

A physical example of Western norms being incorporated into the CPAP therapy mask is the three sizes the mask is offered in. This is reflected in the icon with three people reflecting size standardisation that was a feature of mass production (Figure 33). Nose length and outward protrusion formed the basis for the three-size size system. Sizing guides constructed a nose shape that was assumed to be in a 'normal' and therefore desirable range. This sizing chart ignored the width of the nose (and size of the face and head more generally). The mask sizing is such that noses that are wider than the narrow nose shapes typical of many European ethnicities may be outside of this normative range. Any person whose nose did not fit the scale for the mask may find themselves cast as an 'other' through the interpretation of these design elements. The design of the CPAP therapy mask constructed nose shapes and sizes outside the narrowly targeted fitting scale as being a minority case and not a member of the dominant group.

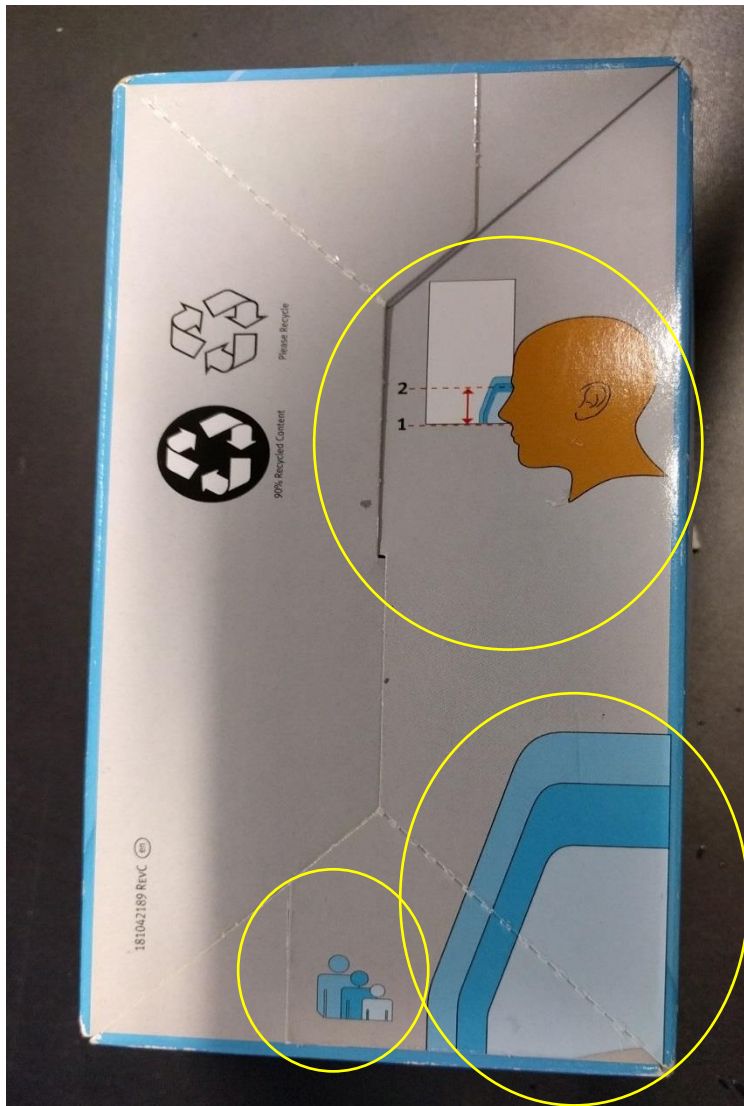


Figure 33. Box images showing nose and sizing system.

Three sizes based on nose protrusion and height, but nose width and head size were excluded. Source: Author's photograph.

Figure 34 shows design scoping notes from discussions with mask manufacturing professionals. The manufacturing professional described materials in terms of their functionality and desirable properties for the application. The notes show that polycarbonate's desirable qualities include tolerance of the high temperatures required for sterilisation – this is primarily for hospital use where a mask may be cleaned and used on a different patient. High-temperature sterilisation is unlikely to be used in the home.

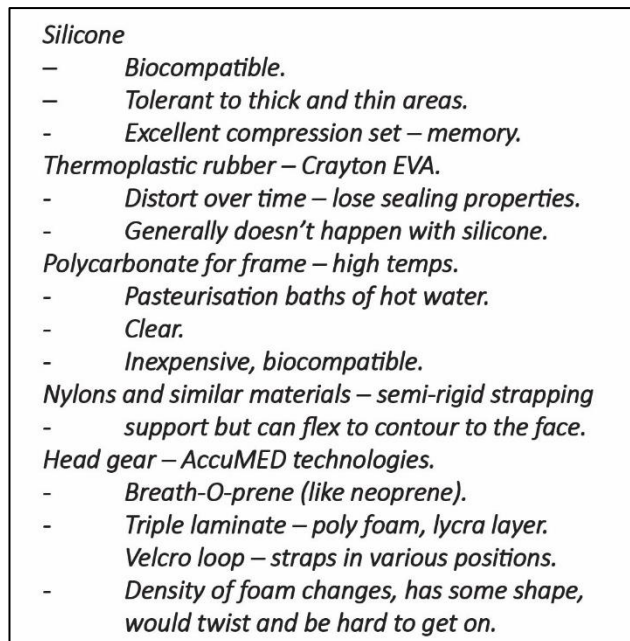


Figure 34. Notes from scoping conversation with technical specialist.

Source: Author's image.

The social discourses that link plastics and hygiene in public knowledge emerged as part of the move towards marketing plastic products to women, which occurred following the Second World War (WWII). Reconstruction efforts included government campaigns to take up the homemaker/housewife role with enthusiasm and *“as part of their patriotic duty in the battle for peace”* (Attfield J. and Kirkham P. 1989, as cited in Holdsworth, n.d.). Plastics had the advantage of being wipe-clean, so becoming *“a vital asset in the housewives’ daily battle against the dirt and grime they were constantly being warned about by such magazines”* (Holdsworth, n.d.). *Good Housekeeping*, *Woman’s Journal*, *Every Woman* and *Ideal Home* spread the word on domestic design principles and advances. These magazines featured articles on achieving spectacular levels of home cleanliness alongside a plethora of advertisements for home products in plastics. Discourses of hygiene have carried over into the application of plastics for medical products, thus constructing plastics as a logical choice for medical devices.

The use of plastics, however, can be at odds with a discourse of quality and effectiveness due to a Western association with (particularly cheap and poor quality) brightly coloured plastics marketed at children. Figure 34 also notes that polycarbonate was recognised as a cheap material. Plastics and toys are a feature of Christian Christmas traditions, from small plastic tokens in Christmas crackers through to the light fittings, decorative bulbs and in recent times the Christmas trees themselves. Cheaper toys are often characterised by being thin and flexible, with flashing remaining around the mould lines (see Figure 35).

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<https://www.indiamart.com/proddetail/kids-plastic-toy-nano-car-12401839112.html>.

Figure 35. Example of 'cheap' plastic toy car.

Showing thin walls and furry unfinished edges with flashing from the low tolerance moulding process or lack of finishing processes. Source: Retrieved from <https://www.indiamart.com/proddetail/kids-plastic-toy-nano-car-12401839112.html>.

Even well manufactured toys are often used as a contrast to 'real' things that should be taken seriously. A common phrase used to deride an object is to describe it as 'toy-like'. This description references the rounded edges and organic shapes often used in plastic toy design. These forms are particularly prevalent in early childhood toys where small replica objects are created, such as toy cars and trucks (see Figure 36).

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<https://auto.howstuffworks.com/under-the-hood/auto-manufacturing/automotive-plastics-manufactured.htm>

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[https://uk.wikipedia.org/wiki/Suzuki_Vitara#/media/File:1988-1990_Suzuki_Vitara_\(SE416V_Type1\)_JLX_hardtop_\(2015-06-03\)_02.jpg](https://uk.wikipedia.org/wiki/Suzuki_Vitara#/media/File:1988-1990_Suzuki_Vitara_(SE416V_Type1)_JLX_hardtop_(2015-06-03)_02.jpg)

Figure 36. Toy car with more refined plastic moulding details.

Bulbous features contrast with a full-sized production vehicle. Source: Left image retrieved from <https://auto.howstuffworks.com/under-the-hood/auto-manufacturing/automotive-plastics-manufactured.htm> and right image retrieved from [https://uk.wikipedia.org/wiki/Suzuki_Vitara#/media/File:1988-1990_Suzuki_Vitara_\(SE416V_Type1\)_JLX_hardtop_\(2015-06-03\)_02.jpg](https://uk.wikipedia.org/wiki/Suzuki_Vitara#/media/File:1988-1990_Suzuki_Vitara_(SE416V_Type1)_JLX_hardtop_(2015-06-03)_02.jpg)

One argument in the data from the community market discussions for why the CPAP therapy mask takes its current form was: "[woman speaking] so it's not like a toy ...stop people playing with it and not using it properly" (young couple, unfamiliar with CPAP (male and female)).

From this perspective, the use of toy-like material discourses such as bright colour and rounded edges would detract from the legitimacy of the CPAP therapy mask. The sense of the mask commanding respect, as required of a healthcare product, was constructed in part through the lack of bright colours and in part through the appearance of transparent, hard-edged plastic.

6.5.2 Historical constructions of transparency in Western culture

Figure 34 also notes the use of polycarbonate because it is 'clear' or transparent. Arguably this is what differentiates a medical CPAP therapy mask from any other type of breathing mask. For example, identifying a CPAP therapy mask relative to an emergency aeroplane oxygen mask, firefighter's respirator or diving equipment is largely through its material construction choices (see Figure 37). Specifically, the medicalised face mask is transparent where other types of masks are likely to be made from opaque plastics and rubbers, frequently black in colour. While there might be perceived clinical advantages of transparency in a clinical setting (e.g., seeing a hospital patient's nose and mouth for observation or recognising accumulation or the pooling of condensation in the mask should it occur), there are also cultural discourses relating to transparency that are valuable to discuss.



Figure 37. Images of aviation and gas masks.

Source: Left: US Air Force 1st Lt. Matthew Alexander, an F-16 Fighting Falcon aircraft pilot with the 555th Fighter Squadron, straps on an MBU-20/P oxygen mask at Lask Air Base, Poland, before taking off for a training mission March 18, 2014. Photo by A1C Ryan Conroy Public domain photograph from <http://www.defenseimagery.mil/imagery.html?&guid=bbc772f2cd4325d7beb113382d43dc5e4e741ac6>. Right: C3 M69 gas mask, view of the inside, Photo by Lklundin, 25 May 2015, Creative Commons Attribution-Share Alike 4.0 International, <https://creativecommons.org/licenses/by-sa/4.0/deed.en>.

While the history of polycarbonate only goes back to 1953 (Schnell, Bottenbruch, & Krimm, 1953), transparent materials, particularly in a Western context, have a much longer history,

beginning with ancient uses of rock crystal and the production of glass in antiquity. Glass was not naturally without colour. The sand from which it was originally made would generally contain black particles of iron oxides, which when fired would give it a natural aqua blue or light green tinge (Fleming & Shafer, n.d.). It was, however, discovered that a mineral rich in manganese, such as pyrolusite, would provide a purple glass in an oxidising atmosphere but could also be reduced to produce a colourless glass (Fleming & Shafer, n.d.).

Transparency played an important role in Western historical constructions of wealth; the earliest candle chandeliers appeared in the 15th century and used crystals to refract light.

Its history spans more than eight hundred years and as time progressed designs became ever more elaborate, reflecting the growing wealth and power of the highest echelons of society, as well as progress in terms of technological development and workmanship. Since its inception, the chandelier has been closely associated with royalty and the aristocracy which perpetuated its status as a symbol of wealth, luxury and grandeur. (Mallory, 2015).

Westernised constructions of morality and religion involved the use of stained glass windows in churches, in addition to chandeliers. The use of glass in windows is also a predominantly Western construction with glass particularly suited to temperate climates, and stained glass windows dominated various constructions of Christianity. Westernised use of glass was common for drinking vessels, where historically it constructed trust or distrust in one's host.

We drink from glasses, Ponticus, you from stone— so we can't see your wine's unlike our own. (Martial & McLean, 2014, p. 41).

While the use of transparent glass dates back to the 1700s in Britain and parts of Europe, the ubiquity of glass within cultures was far from universal. In Korea, China and Japan, people historically constructed windows from paper and bamboo rather than glass (see Figure 38). Traditional buildings in warmer climates such as the Pacific islands were also likely to focus on airflow where shade and shutters provided more protection from the heat than glass house elements were likely to. In China, the culture prized highly elaborate paper lanterns rather than glass chandeliers.



Figure 38. Glass windows are not universal.

Images from left: Woven bamboo window in Japan (Source: By Chris 73 / Wikimedia Commons, CC BY-SA 3.0, <https://commons.wikimedia.org/w/index.php?curid=26166>). Japanese room with sliding *shōji* doors and tatami flooring (Source: By Fg2, Public Domain, <https://commons.wikimedia.org/w/index.php?curid=4079310>)

The role of transparency in constructions of disciplinary technologies such as surveillance and observation extended further into the discourses of law enforcement. Particularly in popular media storytelling, law enforcement uses one-way glass to observe the interrogation of suspects. News media also use transparent materials to mediate the construction of subject positions through discourses of protection and vulnerability. For example, riot police gear includes transparent visors or shields that protect the officers using them, while at the same time the visor plays a role in mediating the person on the other side of the shield or as a more vulnerable subject position (Figure 39).

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<https://www.stuff.co.nz/world/americas/81982164/remarkable-photo-of-woman-facing-riot-police-that-may-define-black-lives-matter>

Figure 39. A demonstrator protesting the shooting death of Alton Sterling.

The demonstrator is detained by law enforcement near the headquarters of the Baton Rouge Police Department, US. Source: By Jonathan Bachman, Retrieved from <https://www.stuff.co.nz/world/americas/81982164/remarkable-photo-of-woman-facing-riot-police-that-may-define-black-lives-matter>)

Anonymity may be protective in some situations. In situations where anonymity is desired, people may become vulnerable when transparency leads to identification. For example, historical discourses of masquerade masks from the Carnival of Venice speak of anonymising masks as levellers of class and social role, lowering inhibitions and even perceptions of pain. It would seem that such effects would be valuable in an application such as CPAP therapy masks, which are often described as uncomfortable. However, the reverse of this is that removing transparency from the mask may also render the prescribing clinician vulnerable. In many situations, masked and anonymous faces are construed as unpredictable and unaccountable, constructing those that witness them as potentially at risk of harm. Images of crime and wrongdoing often feature an obscured face, through the use of a balaclava or other cloth over the nose and mouth.

6.5.3 Western historical constructions of colour

As I have mentioned already, my early analysis of the CPAP therapy mask and box highlighted the prominent use of blue as an important marker of a rational medical device from my situated perspective. Further investigation into historical constructions using blue highlighted the Westernised nature of this interpretation. Starting in the twelfth century AD, the white-red-black chromatic system that was common across all early human cultures, not only in Europe but also in Asia and Africa, reduced in prominence and lost its dominance in Europe *despite remaining so on other continents* (Pastoureau & Cruse, 2001, p. 42). The cultural constructions contingent with a shift from a red-white-black chromatic systems also goes some way to explaining the dominance and highly valued nature of colourless transparency in Western cultural constructions.

One such factor is the early Western church's view that opaque colour was made not of light, as science at the time constructed it, but from matter, making it "vile, useless and base" (Pastoureau & Cruse, 2001, p. 42). This separation of light and matter was potentially contingent on Plato's philosophy on subsequent Cartesian philosophies that separated mind and matter, popular when Western religions were developing (Calef, 2016). Pastoureau and Cruse (2001, p. 42) argued that the valorisation of blue in Western religious art was a result of a series of shifts that began around 1000 AD, when blues became "clearer and less heavy" in manuscripts, and they gradually become used to indicate light (Pastoureau & Cruse, 2001, p. 41). For example, the in Christian art, the image of the Virgin Mary was commonly depicted as wearing blue, though this was not always the case (Pastoureau & Cruse, 2001, p. 50). Prior to the twelfth century, this important religious icon was depicted in a range of different dark

shaded colours such as black, grey, brown, violet, blue or dark green (Pastoureau & Cruse, 2001, p. 50).

Sumptuary laws in the mid-fourteenth century AD required all members of society to dress according to their sex, estate, dignity and rank on pain of sacrilege to the God-given order. These laws aimed to redirect spending away from clothing and accessories and direct the economy into more productive activities. They also served to enforce Christian traditions of modesty and virtue and reflected widespread moralising throughout Europe at the time, which eventually resulted in the Protestant Reformation (Pastoureau & Cruse, 2001, p. 87). The Protestant aversion to colour, dominant in the sixteenth and seventeenth century, probably also fed into the valorisation of transparent and colourless glass.

The rise of blue was also linked to the rise of black, to the further detriment of red in Western art and society (Pastoureau & Cruse, 2001, p. 86). Pastoureau and Cruse (2001, p. 86) furthered this idea arguing that its influence extended to the early days of industrial mass manufacture:

The valorization of black for Western clothing in the late Middle Ages and early Renaissance had a considerable impact on society. Its legacy is still visible today in dark suits, tuxedos, mourning clothes, the famous “little black dress,” and perhaps even in jeans, blazers, and navy blue uniforms. Indeed Navy blue – the most common color in Western clothing today – has assumed in the twentieth century many of the values expressed by black in preceding centuries. (Pastoureau & Cruse, 2001, p. 86).

Leading industrialists of the time were intimately tied to the Protestant culture of the day, and mass production of daily use items was intricately tied into moral and social debates fuelled by the protestant ethic (Pastoureau & Cruse, 2001, pp. 112-113). A key example of this was Henry Ford, who, said to be pre-occupied with ethics, refused to sell cars in any colour other than black on the grounds of morality, despite public clamour for cars in different hues (Pastoureau & Cruse, 2001, p. 113). In this context, it is notable that many products were only available initially in black, grey, white, and blue, including fountain pens, typewriters and a great many household appliances. More than half of all adults surveyed in Western Europe and the US indicate blue as their favourite colour, followed by green at 20%, white and red 8% and other colours far behind. (Pastoureau & Cruse, 2001, p. 170).

The dominance of blue as constructive of authority extends into its common use in recent times in the uniforms of police and military personnel. Prior to a widespread but spontaneous shift in military uniform colours to various shades of blue, red, white, and other bright colours

were often used in Europe (Pastoureau & Cruse, 2001, p. 159). The use of red in military uniforms was held the longest by the French military, who adopted red trousers due to dye shortages between 1829 and 1859 (Pastoureau & Cruse, 2001, p. 159). The colour red was kept in use for military trousers due to their status as a national symbol of French spirit until as late as 1910 (Pastoureau & Cruse, 2001, p. 159). The bright, highly visible colour resulted in heavy losses in battles associated with the wide spread use of modern warfare's more accurate and longer range weapons (Pastoureau & Cruse, 2001, p. 160). The shift to blue was completed in 1915 when the French military changed their uniform from red trousers and navy blue jacket to navy blue trousers (Pastoureau & Cruse, 2001, p. 160). This shift soon passed through to sailors, guards, police, customs agents and even postmen and other social groups and institutions, drawing on the association with morality and trust built up through early Christian art traditions (Pastoureau & Cruse, 2001, p. 163). Blue became emblematic for positions of institutional trust and rational authority (Pastoureau & Cruse, 2001, p. 163).

The phenomenon of colour was also conceptualised and lived differently from culture to culture. For example, in Japan, knowing if a colour is dull or shiny that is of much greater importance than if it is red, blue or yellow. There are many words in Japanese for white, denoting shades from sombre to the most luminous. (Pastoureau & Cruse, 2001, p. 175). In Sub-Saharan African society, there is little importance placed on the variation between red, brown and yellow tones, or even distinguishing them from green. "It is much more important to know if a colour is dry or damp, soft or hard, smooth or rough, mute or sonorous, joyful or sad" (Pastoureau & Cruse, 2001, p. 175).

In contrast with alternative material discourses, my characterisation of the CPAP therapy mask as trustworthy, neutral and rational becomes visible for its situation in a Westernised material history. Furthermore, my analysis indicates that people from cultural situations less influenced by Western culture may be affected (or may 'read' the product) in an entirely different way – indeed they may perceive it as 'Western'.

6.6 Summary

This chapter presents the results from a desk study drawing on Foucault's history of the present approach. In this study, I explore the mechanism through which scientific and healthcare discourses operate to legitimise the CPAP therapy mask. I have outlined enunciative modalities (see chapter four) through which the legitimacy of the CPAP therapy invention emerges. This chapter further problematises the 'fraudulent medical device' implicated in legislated requirements to manufacture legitimacy. I have examined and problematised

manufacturer constructions of legitimacy in relation to the CPAP therapy mask discourses of safety and effectiveness. Finally, I have explored differences in manufacturing discourses and in the socio-historical construction of relevant aspects of transparency, colour and opacity, and how they might come to be experienced as a disciplinary norm. In the next chapter, I will take this analysis in a new direction, exploring how the CPAP therapy mask and the conditions of its legitimacy play into the construction of the 'successful CPAP therapy user'.

Chapter 7 The 'successful CPAP therapy user' - legitimised mask shapes the user

Power is exercised on the dominant as well as the dominated. (Dreyfus & Rabinow, 1983, p. 184).

Chapter seven outlines the findings from a power analysis using Foucault's concept of positive forms of power that operate through discourse and constructions of subject positions (see sections 2.3.2 and 2.3.3). The previous chapter was an analysis focussed on a history of the present that has enabled and limited the typical CPAP therapy mask artefact. The focus of chapter seven shifts to the other side of the interface, the people that use CPAP therapy masks. The data for this analysis was the texts collected from interactions with market attendees across the community market exhibitions, detailed in section 4.4. The first part of this chapter discusses how power operates in the design of CPAP therapy masks and in particular, how subject positions related to the successful use of CPAP therapy masks are constructed.

In *The Subject and the Power*, Foucault argued for the need to know the "historical conditions that motivate our conceptualization" (Foucault, 1982, p. 778). In line with Foucault's approach, the second part of this chapter explores the question of how this applies in relation to the continued legitimacy and use of a specifically designed artefact.

7.1 The significance of successful user subject positions

Collecting data in community markets brought a great many more subject positions into the research process than would normally occur using a more traditional approach (co-design or qualitative research), where participants are often recruited into research via a hospital or clinician. The vast majority of studies of CPAP therapy and OSA explored in chapter five were focussed on patients (and potential patients) who came into contact with healthcare systems. Researchers and clinicians recruit their participants during consultation sessions or from database lists based on clinical diagnosis process interactions. Clinical and research structures (implied in the studies from chapter 5) mean that the data generated through such approaches constructs successful users, current and past patients as being most available but also most in need of service. The structures constructing the data therefore include operational processes that include ethical approvals and recruitment processes, doctor-patient referral systems and patient contact lists, as well as physical structures such as waiting rooms, combined with clinician focussed scheduling of appointments. The combination of these elements limits who is constructed as available - namely patients who may be coming in for appointments as well

as former patients who are still ‘on the books’ and thus contactable by post, email or telephone.

Similarly, user centred product design and co-design approaches typically construct ‘the user’ as an independent, primary expert on the product in question. However, for many other CPAP therapy user-related constructions, such as potential and future users, circulating discourses play a very strong role in the perception of the CPAP therapy mask and treatment.

Figure 40 provides a list of examples showing the range of subject positions presented by the community market research participants.

CPAP therapy users Couple both use CPAP Couple one uses CPAP CPAP user – less than 2 years CPAP user – over 10 years Former CPAP user	OSA related symptoms Waiting for study/diagnosis Relative waiting for study Has not sought medical help Will not seek treatment	Non-CPAP familiar Sports - Tai chi etc Fashion Art & DIY Surgery related masks Asthma Snorkelling/diving Aviation Workplace respirators Workplace dust masks
Knows someone with CPAP Parent of CPAP user Brother in law is a cpap user Brother is a CPAP user Father is a CPAP user Daughter of a cpap user Sister is a CPAP user Brother of a CPAP user	In process of diagnosis Person who snores Friend who snores Person who can't sleep or wakes up repeatedly	
Roadtrip with CPAP user Works with CPAP user Deceased relative CPAP user	Professionals Doctors Nurses Engineer Social worker Teacher	

Figure 40. Range of subject positions in community market data.

Successful users are in the red box which includes participants who exhibited a range of very positive constructions concerning the mask. Source: Author's image.

There was an overlap in the subject positions found in the community market and those generally accessed for clinical research (CPAP therapy users).

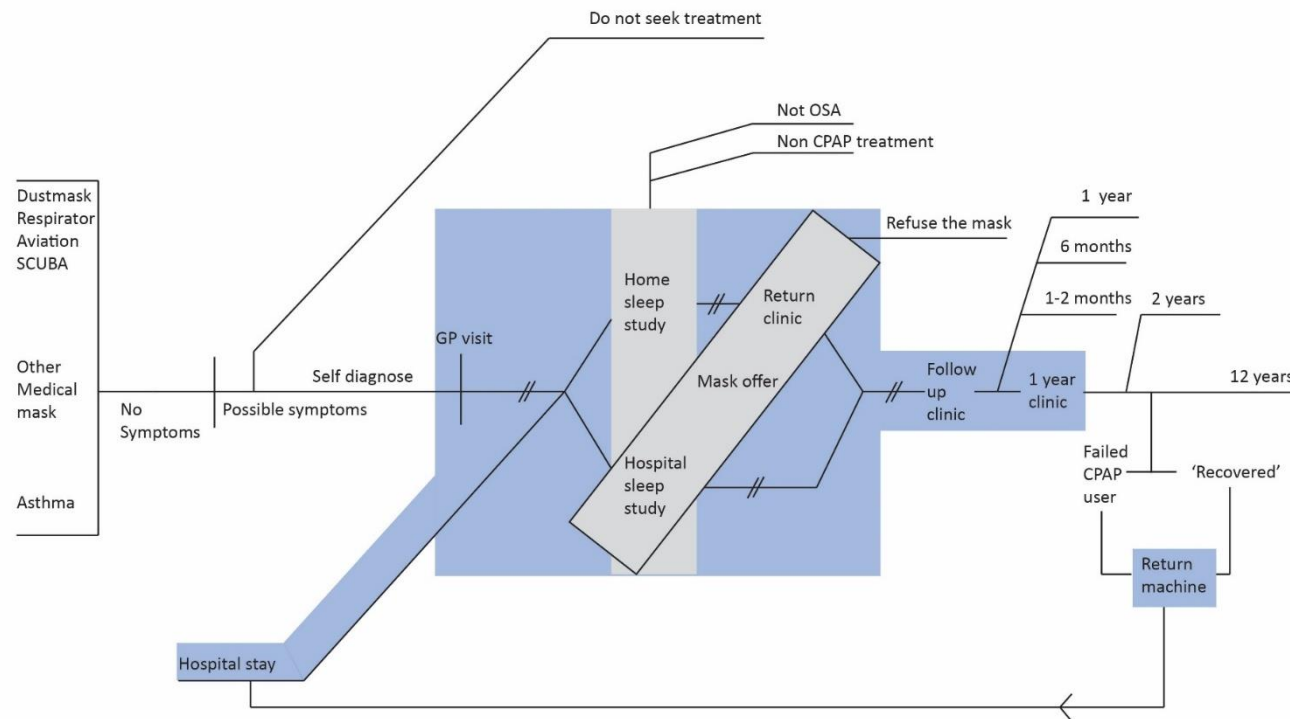


Figure 41. Data points diagram with situations of clinical/manufacturing contact with potential users highlighted in blue.

Grey sections show the locations where the mask was offered by staff to 'patients'. Some other subject positions from the community market data are shown outside of the blue to indicate that there is no formal clinical or manufacturing contact with these subject positions, despite them showing an interest and expressing an opinion on the topic. Source: Author's diagram generated from scoping notes and interviews with Clinical Staff and Specialists (see Appendix D).

Figure 41 shows the formal clinical and manufacturer contact points in The Auckland DHB diagnosis system, with potential users highlighted in blue, from information obtained through early scoping conversations and expert interviews (Clinical Staff 7 and 8, Scoping notes – see Appendix D). The legitimated diagnosis pathway begins with a visit to a GP. At this point, a person may have symptoms but the doctor has not formally diagnosed them with OSA. The visit generally involves discussion of symptoms, completing questionnaires and the potential need for the clinician to refer them for testing (sleep test). During a sleep test, either at home or in the sleep laboratory, the suspected symptoms may be confirmed. Clinicians or sleep study technicians then collate the results, and if the results meet the diagnostic criteria, the potential CPAP therapy user is constructed as a ‘patient’ and offered a mask and treatment. If the patient accepts the mask offer, the staff show them how to use it. Patients then attend a return clinic for pressure adjustments and then a one-year check-up before being removed from the patient follow up list. The ongoing care expectation is that patients will continue to use the treatment independently, and return to the clinic if they have any issues or need changes made. The follow-up may take place in the clinic with the patient’s partner, or support person if they prefer, such as another immediate family member (parent, child, carer or similar) (Clinical Staff 7 and 8, Interview and Scoping notes – see Appendix D).

The market data indicates that ‘successful’ CPAP therapy users are likely to express positive associations with the mask. Some people who have used types of masks other than a CPAP therapy mask before, also indicated positive associations as shown in Figure 42 (Interested passer-by, uses a mask for running (male)).

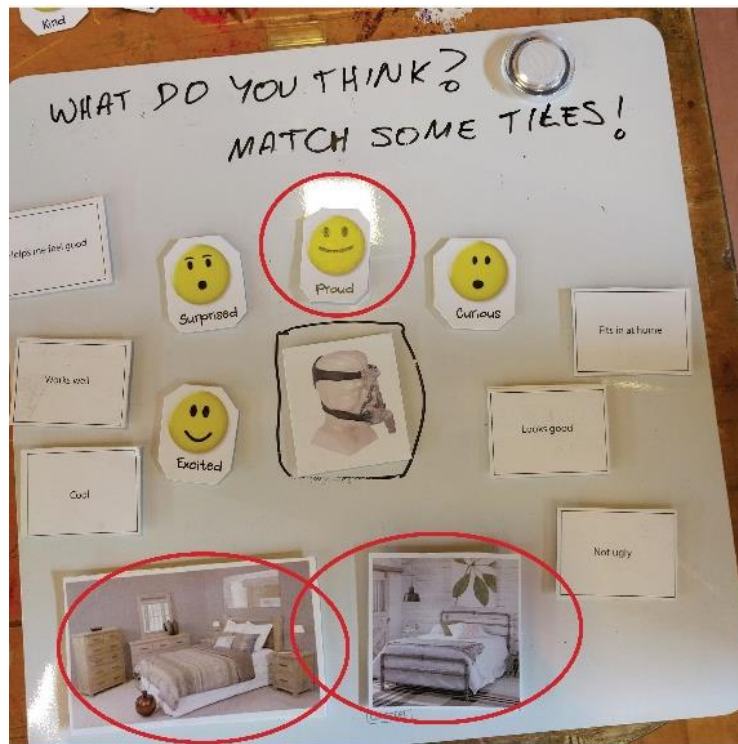


Figure 42. Example of cultural probe constructions showing positive mask associations. Some market participants demonstrated positive constructions concerning the mask. Source: Author's image of cultural probe constructions by study participant.

This effect was contrasted in several CPAP therapy and mask naïve subject positions where the mask had much more strongly medicalised and negative associations in the cultural probe constructions (see Figure 43).

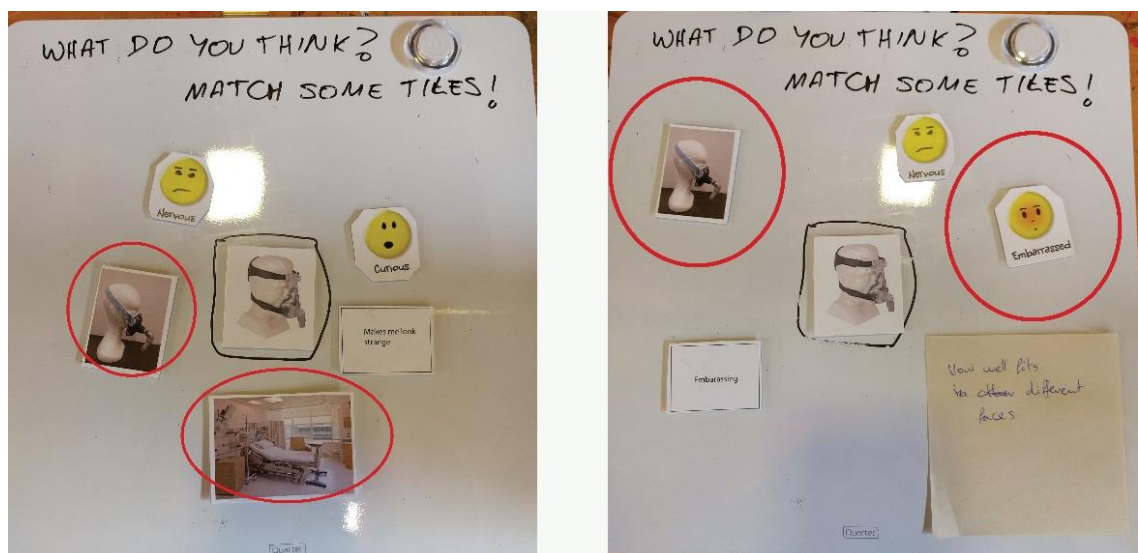


Figure 43. Example of cultural probe constructions from CPAP therapy naïve subject positions. Many CPAP therapy mask users expressed less positive constructions and emotions concerning the mask. Source: Author's image of participant cultural probe constructions.

These subject positions, who displayed more negative associations with the mask, will form the focus of later chapters. The following discussion will focus on constructions of successful CPAP therapy user subject positions.

7.2 'Successful user' subject positions

Discourses in the data have constructed an evangelical 'successful' CPAP user as successful through the embodiment of health discourses in their living practices. Constructions of this success in some cases included discourses of epiphany and having had one's life saved, with associated obligation or impetus to reproduce this effect in the service of others. A key feature of the evangelical user was their overwhelming enthusiasm for the treatment, their desire to tell others about this experience and the need to help others experience the same benefits.

For one user the therapy was constructed as a positive change to life, the experience of living with treatment like being in "a different world":

[man speaking] It's been like a godsend really, a lifesaver, I still struggle now without it, but if I'm wearing it, all night get a good night sleep you really get the benefit, it's a different world hey? ...it was much better. My life changed quite dramatically. - Couple, man uses CPAP therapy regularly (male and female).

Not having treatment was also framed as a risk or inviting risky consequences, both for themselves but also the recognition that it extends to bed partners. Discourses of risk and the links between driving accidents and sleep deprivation were evident.

[Man speaking] without it I'd probably fall asleep mid-afternoon, crash my vehicle, fall asleep in my office, I don't know, haha,

[Woman speaking] and I don't get any sleep if he doesn't wear it ... he snores like a train.

- Couple, man uses CPAP therapy regularly (male and female)

Successful CPAP therapy use was largely constructed in relation to a profound improvement in sleep. For some, using CPAP therapy well is described almost in terms of an epiphany. One successful user talked about a "holy cow moment" and the realisation of good sleep after a year of failed attempts at using CPAP therapy (Scoping notes with Advocate 2 – see Appendix D). For others, the mask was less of an issue to begin with; one user talked about the mask being "no problem seriously" (Long-term CPAP therapy user, partner also uses CPAP (female)). However, this was framed relative to high levels of desperation around ongoing sleep

deprivation: “I just needed to have a decent sleep so I would put up with anything... I had to” (Long-term CPAP therapy user, partner also uses CPAP (female)).

Evangelical CPAP therapy users talked about their desire and interest in ‘spreading the word’ about CPAP therapy, or saw it as a calling to help others as the therapy had helped them: “[I] thank the doctor [for] saving [my] life and now want to pay it forward⁴⁰” (Scoping notes with Advocate 2 – see Appendix D). Some were very comfortable about talking about CPAP: “I wouldn’t have a problem talking in a group environment about anything to do with a CPAP and that myself” (Advocate 1 – see Appendix D). Some were very comfortable using their devices in any situation and were unfazed by any difficulties they might have with the device in a group setting such as teasing or unwanted questions. They saw themselves as part of a distinct group, whose identity was growing in profile: “I think it’s more recognisable now. We’re more here” (Long-term CPAP therapy user, partner also uses CPAP (female)).

The above quoted user drew on discourses of identity, self-improvement and empowerment. As discussed in section 2.4.1, discourses of self-improvement and empowerment feature in neoliberal forms of governmentality. Discourses of personal responsibility include the desire and the belief that one can act in ways that prevent sleep-related traffic accidents. Discourses of self-fulfilment and individual meaning emerged through the discussion about helping others to find out about and receive the benefits of CPAP therapy use. Similarly, identifying oneself as a CPAP therapy user and delineating CPAP therapy users as an identifiable group makes it important enough to be recognised and accommodated in public, for example, as part of an airport screening process, which is a way in which people see themselves as neoliberal subjects. In other words, people can see themselves “as individualised and active subjects, responsible for enhancing their own wellbeing” (Larner, 2000, p. 13). Participants construct the device through a “confidence of knowing”, which gives the participant control over their condition in ways that far exceed any perceived drawbacks the therapy may have for them personally: “it’s that confidence of knowing... I definitely would not go without it [to a hotel] ...that’s just part of me” (Long-term CPAP therapy user, partner also uses CPAP (female)).

Long-term CPAP therapy users tended to focus on the functional aspects of CPAP therapy that they had trouble with, for example, parts that would break, and were expensive to replace or the mask being quite ‘sweaty’ in general (Long-term CPAP therapy user with walking frame (female)). This participant spoke of having used CPAP therapy for many years, agreed it was

⁴⁰ Pay it forward is a movie in which the protagonist gives freely then asks the next person to do the same to someone else rather than pay him back directly. This is termed paying it forward.

almost ‘forever’, and also explained “I wouldn’t be without mine” (Long-term CPAP therapy user with walking frame (female)):

They’re really sweaty! Really sweaty, yeah, yeah, do you wear one? Yeah, I use it, I’ve got a machine...parts break really, really, easily ... does yours cover the nose and mouth? No, just the nose ...yeah, no it’s good though... apart from being sweaty and it leaks, they need to find a better suction... so you know where about it leaks for you? Yeah, just the front, just above the lip... apart from that, it’s ...I wouldn’t be without mine - Long-term CPAP therapy user with walking frame (female).

The focus on functionality⁴¹, physical comfort and the de-emphasis of appearance was consistent with the literature discussed in chapter five. Long-term and ‘successful’ users constructed CPAP masks as being ugly in a very ‘low-key’ way, describing them as not making them ‘feel attractive’: “It doesn’t make me feel bad... but definitely doesn’t make me feel attractive... like I say it’s doing what I need it to do”, or alternatively, because: “they’re not the nicest things to look nice in” (Long-term CPAP therapy user, partner also uses CPAP (female)). However, this was always followed up with a caveat that emphasised the low importance of aesthetics, particularly in relation to the experience of the illness and the sleep deprivation that the therapy treats: “I don’t really mind what it looks like because for me it’s serving a purpose” (Long-term CPAP therapy user, partner also uses CPAP (female)). The view that it did not matter what a device looked like as long as it worked drew on a rational discourse of functionality, which extended further into long-term user’s opinions on the aspects of the mask that they would like to see improved.

The data generated by market-goers in part constructed successful male CPAP therapy users through the reported discourses of their female bed-partner. One market attendee, reporting on their knowledge of the wife of a male CPAP therapy user, noted: “[woman speaking] I know the wife of a man that uses it. She says ‘I love that he is [using the device] because I know he’s going to be around longer’” (Couple that know a CPAP therapy user (male and female)). In these constructions, health was produced through conducting oneself in a manner consistent with discourses of healthy behaviours, or in this case, using the mask to treat symptoms of a condition. Discourses in the data cast these practices as being both reassuring and a method to

⁴¹ For a critical discussion of design history, the focus on functionality and discourses of ‘good design’, see: Jackson, A. (n.d.). *Designing Britain 1930-1950. From solving problems to selling product: The changing role of designers in post-war Britain*. Retrieved 4/10/2018, 2018, from https://vads.ac.uk/learning/designingbritain/html/crd_desref.html

prolong life in a desirable way. In contrast to creating health through successful usage was the expression of risk that came with incomplete or less than successful use. This was expressed by a market attendee who identified as having a father who was a CPAP user. This participant noted that their father relied on the CPAP therapy mask and when it sometimes slid off their mother worried about him (Group of 3-4 young people, one has father with OSA (mixed gender)). This degree of concern existed within social discourses of elevated risk of morbidity or mortality associated with untreated or incompletely treated OSA (see section 5.2).

7.3 The work of becoming a ‘successful user’

Successful and regular CPAP therapy users were reluctant to identify with their former selves from the time when they had initial concerns about wearing the mask. They focussed instead on the period after this, “when you get past all the vain part, you realise how beneficial it is to you, and then you make sure it’s something you do, every night” (Former long-term CPAP therapy user (female)).

One participant explained it as ‘a life thing’, interpreted to mean the parts of life that one adapts to or deals with rather than seeks out, much like work or childcare.

[Woman speaking] You know it’s just a life thing that you get used to, but then because it was just weight around the neck, so over the years you’re able to reverse that and be a bit more healthy....

[HC] You must have been pretty pleased when you didn’t have to use that anymore...

[Woman speaking] yeah absolutely

- CPAP user of 14 years, no longer using it (female).

The data constructs the physical work of adapting to using CPAP therapy as a disciplining of the body to adapt to interfacing with the device itself, but also adapting the self to enacting use of the device: “over time... you just had to train yourself to always just close your mouth... but, it was just going to be a matter of time to get used to, so you just have to condition yourself to use it” (CPAP user of 14 years, no longer using it (female)). Framing the process as ‘just a matter of time’, implied that success was more or less inevitable. However, this included an assumption of ongoing and consistent effort that is the working on oneself that is required to produce good health.

The effect of time and the work involved with using CPAP therapy does not feature prominently in the literature around adherence. Notably, a recent study provides some specific details of kinds of equipment adaptations made by users of CPAP therapy (Miech et al., 2019). As illustrated in Figure 41, clinical contact for many publicly funded CPAP therapy users in New Zealand may end after the one-year review appointment (Clinical Staff 8 – see Appendix D). One market attendee, who had been using CPAP therapy for about 14 years, constructed the expertise that results from the ongoing work adjustment through many years of trial and error:

[Woman speaking] they just become quite bulky if you were turning...

[HC] so how did you manage that?

[Woman speaking] it was just trial and error, I tried to do the straps a little bit firmer and yeah ...I mean, gosh, I had ten years to do it...

[HC] wow, you must have been an expert by the end,

[Woman speaking] yeah well

- CPAP user of 14 years, no longer using it (female).

Rather than drawing on the inherent characteristics of those who happen to be successful at using CPAP therapy, the personal changes associated with learning to use CPAP therapy appear to be the result of a process of acceptance. Through this process of acceptance, one becomes the kind of person who can use CPAP therapy in response to the presence of the mask in one's life. In other words, the materiality of the mask may define a fairly narrow range of subject positions that can and will use it. The closer one's community and personal constructions are to fitting into this range of 'successful' subject positions, the less work and adjustment is required to become someone who can use CPAP therapy 'successfully'. Consequently, several market goers, rather than experiencing the "holy cow" moment, or just being profoundly desperate, related their experiences as more of a process of transition.

[HC] So you're a regular user of CPAP, how long have you had it for?

[Woman speaking] since last year... so about six months

[HC] Did you take a while to get used to it?

[Woman speaking] Yeah, and I didn't like it at first, but now, I really if I don't have it on I don't sleep

[HC] it's a real benefit?

[Woman speaking] yeah, really do [get the benefit]

- Regular CPAP therapy user for 6 months (female)

Others expressed similarly mixed sentiments: "I've got used to it now, yeah,... last night I took it off, it was so hot, yeah, but I love it" (Regular CPAP therapy user for 6 months (female)).

Some market attendees mentioned experiencing embarrassment about needing CPAP therapy early in their CPAP therapy journey, but the notion that it mattered what the mask looked like was not considered important:

[HC] When you first got shown the mask... how did you feel at that point?...

[Woman speaking] still just a bit embarrassed at first, yeah...

[HC] but you're really happy about how it works?

[Woman speaking] I'm really happy.

[HC] Do you think it matters how it looks when people first see it?

[Woman speaking] Not really, I mean who's going to see it, my husband sleeps in the other room

- Regular CPAP therapy user for 6 months (female).

The view that 'no one sees the mask when you sleep' was repeated throughout the data collected (chapter nine discusses this discourse in greater detail).

Some participants described the mask in terms of a barrier that people 'just have to get over'. Health discourses frame the practices of attaining health in terms of self-control, and sacrifice: "[woman speaking] I have no idea if they are [ok with the mask] but you get to a point where they need to have it, yeah and they have to get over it" (Couple that know a CPAP therapy user (male and female)). The data casts the behaviour of 'getting over' reticence to wear the mask for whatever reason as an imperative of 'good' or 'responsible' citizen behaviour. In neoliberal discourse, the self is constructed as an entrepreneurial asset which should be taken care of and managed to remit the maximum dividend in terms of earnings, longevity and health

(Foucault, 2010, p. 241; Oksala, 2013, p. 41). However, some acknowledged emotional complexity, or difficulty, in adhering to this advice or standard: “[woman speaking] I would really struggle to put that on in front of someone... if... you’ve got a partner. You want to feel good about yourself around them” (Couple that know a CPAP therapy user (male and female)). However, participants often tempered this type of construction with the view that “...if it’s going to help you to breathe, I think I’d wear it, ... regardless of how ridiculous it looks” (Interested passer-by works in early childhood, arts and crafts (female)).

Some CPAP therapy users talked in terms of discourses of growth, as they described the transition from reluctant to successful CPAP user. In response to managing the change in subjectivity that wearing the mask around a partner or husband brought, one female user, said they “just had to do [/wear] it” with the justification that “it was for my benefit” (Former long-term CPAP therapy user (female)).

Users extended the knowledge of OSA and CPAP back into a form of deficit before they ‘grew’ into their current identity:

[Woman speaking] my husband’s [OSA] was [quite serious] and I was ignorant enough to say to him before that, that, “you know we work together, why are you falling asleep on the couch, its morning tea time? I’m making you a coffee you had a decent sleep last night, why are you doing that? Wake up!” I was quite ignorant and arrogant and “get moving”

[HC] and people can’t help it...

[Woman speaking] exactly so when you are aware of it you actually you notice all these things

- Long-term CPAP therapy user, partner also uses CPAP (female).

Evangelical CPAP users also exhibited this argument which they further amplified into discourses of empowerment and personal growth. These discourses fall within the realm of Foucault’s technologies of the self (see section 2.4.3), which also prevail alongside neoliberal modes of government (see sections 2.4.1, 2.4.2 and 2.4.3).

Neoliberal discourses frame patients as responsible for creating their health outcomes (Roy, 2008). However, this study shows the way many users must work hard at becoming ‘successful users’ of CPAP therapy. Some users frame the work of becoming a ‘successful CPAP therapy

user' through discourses of personal growth (see section 7.1), making hard choices, and prioritising health.

Interestingly, participants also described the way a difficult or unattractive product could signal effectiveness or benefits to the users: "[woman speaking] I know the benefits must outweigh the negatives sort of thing to me when I see this sort of things it's a negative sort of thing, yeah, yeah, that's me, personally" (Couple that know a CPAP therapy user (male and female)). This view of the mask as something to 'get over' is likely to reinforce and even be significant in creating the evangelical user subject position. Because in so many cases there has been such a great effort in seeking treatment and learning to use it, some market goers concluded that it must somehow be worth it. Renowned design researcher Don Norman is known for his studies demonstrating that people perceive attractive products as working better than unattractive products (Norman, 2002). Interestingly, for medical products, an unattractive product, or one that suggests an aesthetic that presents social disadvantage or looks difficult or uncomfortable to use in some way is credited with a high level of benefit, as there must be enough of a benefit to the user to outweigh the perceived negatives.

Consumers show this effect in some product and marketing research, where contrary to market logic, products are valued by consumers more highly when they cost more. Consumers experience the products as more enjoyable and therefore rationalise that they must have been worth the cost (Plassmann, Doherty, Shiv, & Rangel, 2008; Shiv, Carmon, & Ariely, 2005). In this sense, the sheer difficulty that many people face when trying to use the CPAP therapy mask initially may well translate into constructing the treatment as even more valuable when they are eventually able to make it work.

Participants had a tendency, when expressing a view of the mask other than positive and functional, to frame the 'negative' perspective almost apologetically as a personal subjective opinion and not a claim to knowledge. Participants that emphasised the subjectivity of their views may have been responding to two dominant discourses, the first being the severity of the breathing condition and its life threatening nature (see section 5.1). The second discourse is made up of broad community discourses that prioritise health above all other concerns (e.g., reflected by the adage 'as long as you have your health') (Gana et al., 2013, p. 902).

Going against a 'universal truth', such as the importance of good health, by expressing a negative view of a difficult but potentially lifesaving treatment may be considered nonsensical, 'mad' (outside the 'true' in a Foucauldian sense) or not legitimate. Thus, such an opinion potentially only makes sense when expressed as an irrational personal preference or a matter

of taste (for a critical discussion of good taste see (Bourdieu, 1984; Ollivier & Fridman, 2001; Sandelowski, 2015; Woodward & Emmison, 2001)). I propose that an expression of personal opinion provides an avenue of resistance against the dominating discourse of neoliberal health requirements. An alternative reaction to the same issue, (if it is not legitimate to think that the treatment is a problem), is arguably also demonstrated in my data: where people faced with the prospect of using a difficult treatment may draw the conclusion that it must be worth the difficulty it implies.

The context of life or death attached to successful mask use means that seeking feedback on how someone feels about the mask can be easily and quickly dismissed as irrelevant. This perspective was expressed by one participant who identified as having travelled with a man who was “using ... [the mask] every night” (Went on a road trip with a CPAP therapy user (male)), so could be considered a ‘successful user’: “We were on a road trip... that’s interesting, did he feel ok? He wasn’t embarrassed? He felt great... he was just this is how it is... he felt good not dying... yeah, yeah, always positive” (Went on a road trip with a CPAP therapy user (male)).

That someone would feel good because they were “not dying” is constructed in a healthcare context of life at any cost. Extending this discourse into a broader social context, a death related to OSA is not considered an acceptable risk of possible death in current Western cultures. Indeed any ideas around what might constitute a “good death”, dying well or dying for a worthy cause remain concentrated in palliative care and debates about euthanasia (Emanuel & Emanuel, 1998; Payne, Langley-Evans, & Hillier, 1996; Steinhauser et al., 2000). By contrast, in cultural contexts (and earlier constructions of masculinities in Western cultures, particularly gentry masculinity), protection of one’s honour and risking death in, for example, a duel (or fight) to protect it was considered reasonable and appropriate (Gallant, 2000). New Zealand society (at the time of writing) relegates acceptable voluntary risk to life in the pursuit of enjoyment or adventure. When pursuing dangerous activities for fun, a death from misadventure is acceptable to some degree with the consolation of the dying performing a cherished activity as being as close to a good way to die as any (Breton, 2000). However, in the data generated in the community markets, OSA was not constructed as an adventure, so it would be considered ‘mad’ to refuse treatment and risk death.

7.4 Contextualising the first ‘successful user’

The market exhibition data constructed a present day ‘successful user’ subject position that was also reflective of that constructed in peer-reviewed and legitimated literature. Drawing on

a history of the present in my approach to analysis presented an opportunity to contextualise this subject position. Examining the emergence of the first legitimated ‘successful user’ of CPAP therapy provided an insight into the operation of power through the product-user subject position for a medical therapy device. In April 1981, CPAP therapy literature credits Colin Sullivan with the invention of CPAP therapy, largely due to his paper published in *The Lancet*, titled “Reversal of obstructive sleep apnoea by continuous positive airway pressure applied through the nares” (Sullivan et al., 1981). In this paper, he documented the successful treatment of OSA patients using his test equipment.

The set up for his test rig was rudimentary; the airflow source was from a vacuum cleaner motor. Air flowed through a flexible tube to a nasal mask improvised from a manifold made from a rigid wide-bore plastic tube held in place under the nose with headgear. Two soft silicone tubes entered the nostrils from the manifold, which were then glued in place using silicone adhesive to achieve an airtight seal (Figure 44 shows a slightly more advanced version of this approach) (Barnes & ResMed, 2007).

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<https://www.google.com/url?sa=t&rc=j&q=&esrc=s&source=web&cd=8&ved=2ahUKEwin1LqiicDmAhXF73MBHRWbAvAQFjAHegQIBRAC&url=https%3A%2F%2Fwww.resmed.com%2Fus%2Fdam%2Fdocuments%2Farticles%2Fresmed-origins.pdf&usg=AOvVaw0ThQ9ps0RqycDXB2uTsngW>

Figure 44. Glue-on nasal mask.

Early nasal CPAP therapy mask – fibreglass nose casing glued in place each night with silicone adhesive, removed and cleaned the following morning and reused. 350 patients in total were treated with this mask. Source: Barnes and ResMed (2007, p. 13).

While the publication met the requirements for scientific publication, the response received demonstrates that individual article publication at that time, while necessary, was insufficient for a full claim to legitimacy. Similarly, the use of glue to improvise a mask falls well short of eliciting acknowledgement as a legitimate medical device.

As demonstrated by the published responses, the material implementation of CPAP therapy at that time was lacking in many of the markers of device legitimacy. While this mask was sufficient to demonstrate the physical treatment principle, the journal readership greeted it with scepticism. This is chronicled by ResMed as being because “the method was not simple to apply”, and very early reports were said to have failed to replicate the results (Barnes & ResMed, 2007). Wagner, Pollack, and Weitzmann (1983) attempted to mimic the treatment method in a group of four patients across three months. They outlined their experiences in a letter to the editor as follows: one patient (cognitively impaired) became “increasingly non-compliant and required constant nursing attendance at night, because he would remove the mask during sleep”, a second patient was “unable to go to sleep on either of two nights while wearing the mask” and a third had “134 apneas per hour despite up to 15 cm of continuous positive airway pressure” (Wagner et al., 1983, pp. 461-462). The fourth, “after sleeping fitfully for approximately three hours, he suddenly sat up screaming and tore off the mask. Once calmed down, he explained he had been dreaming that he was suffocating” (Wagner et al., 1983, pp. 461-462). The letter concluded that “these cases illustrate the complexity of the social, technical and physiological problems that we encountered with initial and long-term use of nasal continuous positive airway pressure... Our experience thus far suggests that nasal continuous positive airway pressure will often fail or be impractical” (Wagner et al., 1983, p. 462). This particularly graphic account of problems with initiating the treatment was likely to have dampened the interest amongst clinicians looking to extend the lives and improve the wellbeing of their patients. My own experience of using a CPAP therapy mask for 4 nights over a long weekend (as a part of a role-play approach to design research) echoed the personal complexities of sleeping with such a device (see Appendix G).

Interestingly, the above account also highlights the early construction of the ‘successful user’ through the exclusion of a number of unsuccessful users from the treatment’s target sample. These include the cognitively impaired, those non-cooperative with treatment, those with very high-pressure requirements and possibly anyone likely to experience a traumatic response to sensations of restricted breathing. In this early construction, before a fully constructed legitimacy, the treatment itself is criticised as much as the patients (as discussed further in chapter 9).

Sullivan, Berthon-Jones, and Issa (1983b, p. 462) replied to the criticism of their treatment by Wagner et al. (1983, p. 462) in a letter to the editor in the *New England Journal of Medicine*, where they put forward the first construction of the successful CPAP therapy user, stating: “We agree with Wagner et al. that non-invasive long-term management of the sleep apnoea syndrome by the use of nasal continuous positive airway pressure can be achieved only in the

cooperative well-motivated patient” (Sullivan et al., 1983b, p. 462). Notably this articulation of requirements references a “cooperative and a well-motivated patient” to “achieve” long-term management of OSA (Sullivan et al., 1983b, p. 462). Through careful re-definition of the target user, Sullivan et al. (1983b, p. 462) could define the treatment as successful. This re-definition was likely used to draw a line around the requirements of the future mask and device designs that consequently no longer needed to address the needs of, or appeal to the uncooperative or unmotivated patient.

Following this, Rapoport, Sorkin, Garay, and Goldring (1983) replicated Sullivan’s results, appearing to use the recommendation of Sullivan et al. (1983b) to use “a lightweight mask with a soft cuff that is well fitted to the nose” (p. 462). Figure 45 shows their experimental setup.

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<https://www.nejm.org/doi/full/10.1056/NEJM198302243080820>

Figure 45. CPAP system used by Rapoport, Sorkin, Garay, and Goldring.
Source: Rapoport, Sorkin, Garay, and Goldring (1982, p. 932).

Sullivan, Berthon-Jones, and Issa (1983a) in response to Wagner et al. (1983) further addressed the issue of treatment comfort by emphasising technical difficulties with ensuring sufficient peak airflow while citing their successes with long-term patients:

We can only conclude that Wagner et al. were unsuccessful for technical reasons. Indeed, the fact that three of their four subjects awoke with a “choking” sensation is a sure clue to the problem – that of a circuit with a high dynamic resistance. The key to successful treatment of obstructive sleep apnea with nasal CPAP is to maintain oropharyngeal airway pressure above a critical minimum level during inspiration; therefore, the dynamic resistance of the nasal CPAP circuit, as well as the mean pressure in the circuit, must be considered. The dynamic resistance must be kept low. We suspect that is Wagner et al. measured the pressure at the nostrils during normal breathing

they would find large pressure swings due to high apparatus resistance. (Sullivan et al., 1983b, p. 462).

The usability and psycho-social difficulties for patients of this treatment method are, even at this very early stage, addressed in technical and discipline-specific terms. Rapoport et al. (1983, p. 462) articulated what they saw as the limits of early CPAP therapy treatment as follows:

These cases illustrate the complexity of the social, technical, and physiological problems that we encountered with initial and long-term use of nasal continuous positive airway pressure. Any treatment of obstructive sleep apnea must provide reasonable continuity of sustained sleep, since the excessive daytime sleepiness of the patient with sleep apnea is probably related to arousals associated with apneas. Patients are unlikely to continue with a treatment that does not reduce the severe sleepiness. (Rapoport et al., 1983, p. 462).

Sullivan's response to the editor was appended to the article by Rapoport et al. (1983, p. 462):

To the Editor: We agree with Wagner et al. that noninvasive, long term management of the obstructive sleep apnea syndrome by the use of nasal continuous positive airway pressure can be achieved only in the cooperative, well-motivated patient. Patient comfort requires a selection of a lightweight mask with a soft cuff that is well fitted to the nose, and proper adjustment of the flow through the system so that the peak inspiratory demands of the patient are met. We have not encountered the complaint of suffocation; in our studies six patients and four sleep-deprived normal subjects were all able to fall asleep. Furthermore, Sullivan et al. have also reported the successful long-term use of nasal continuous positive airway pressure in 10 patients. (Rapoport et al., 1983, p. 462).

Similarly, the important role of the 'cooperative and well-motivated patient' was emphasised in treatment success over the 'complaint' of suffocation in Sullivan's response to Rapoport et al. (1983, p. 462).

Arguably, the discourse of patient compliance set up a situation where device success became measured against only those who were 'happy' to use it. The compliant patient assumption in effect excluded many of the psycho-social aspects from the criteria used to measure the success of the treatment. Further justification and legitimisation of this approach drew on a large relative improvement for the patient experience or 'better than the alternative' discourse, which will I will discuss in more detail in chapter nine.

7.5 Discussion

Evidence and discourses constructing successful users were consistent with those found in the clinical literature (Gibson, Campbell, Mather, & Neill, 2018; Luyster et al., 2016) (see chapter 5). The existence of similarities between ‘successful’ user attitudes and study results found in the clinical literature (and in many examples of perspectives that were not present in the clinical literature), highlight the dominant assumptions and limitations of those research methods most commonly used in relation to CPAP therapy evaluation. Importantly, the spread of discourses associated with successful use through the friends and families of successful CPAP therapy users may mean that including only friends and family of successful users (as may occur in hospital based research), and not seeking input more broadly may miss some insights into how or why some community members refuse or avoid CPAP therapy.

Also highlighted in this study, was the way contact with medicalised discourses shaped those people who became CPAP therapy users. In particular, when design researchers recommend ‘users’ as the focus for user-centred design improvement (Bitterman et al., 2019), or within practice for feedback on masks or other design-based processes these users were likely to have already exerted significant effort into coming to terms with the mask in its current form. To do this, they would likely have had to internalise discourses that cast appearance as shallow and trivial. To become successful, users must re-shape themselves and their identities in response to the mask they use. Success in this endeavour may then become a source of pride by drawing on discourses of self-efficacy, maturity and wisdom. They no longer associate themselves with the discourses of the new user or everyday person with possible OSA symptoms. Successful users may be highly invested in the mask maintaining its current form. The more difficult it is for them to come to terms with the therapy, the more they may be invested in its current form.

Successful users were shown to have adopted historical discourses of ‘good design’ and the ultimate importance of health when considering the CPAP therapy mask. These discourses included the importance of function, limited value of appearance, and internalisation of neoliberal and health discourses that accept the work of creating good health through practice and ongoing effort. The process of coming to terms with a diagnosis of OSA and learning to use CPAP therapy became a source of pride and identity for many of these subject positions. In cases of a long process of coming to terms with the mask, participants spoke of personal transformation and growth.

While successful users were likely to provide expert level information on functional improvements, they were unlikely to argue for the needs of the new or uninitiated users, despite having occupied this position at some point previously. Consequently, the needs of less successful users may remain inaccessible to designers if they focus on existing user-centred design processes, where design teams invite users (who by definition have become 'successful users') into the design process. Also, mask designers and engineers themselves are likely to have absorbed the medicalised discourses and views of the successful CPAP therapy mask and users. This study suggests that even the families of mask designers who may not have any other involvement with CPAP therapy are likely to have become culturalised into these discourses.

From a design perspective, the effect of this is twofold:

1. Successful users may be less likely to still identify with the subject position they occupied before coming in contact with biomedical discourses, particularly in relation to the appearance of the mask or the relative importance of any perceived mask flaws.
2. Successful users may be less supportive of making changes to a mask that through its difficulties and form has become a source of identity and personal pride.

These findings draw into question the unquestioned centrality of an expert 'user' subject position in product design research and development processes, particularly when applied to medical devices.

7.6 Summary

As the literature and some of the participants in this study show, many people use CPAP therapy with great success and value the improvements to their lived experience. The success of those that use the CPAP therapy mask regularly reinforces the legitimacy of the product and its form and function. This legitimacy of the CPAP therapy mask further reproduces the subject position of the 'adherent' or 'successful' user. The presence of a successful user subject position is then constructive of other attempted users as 'failed' users. If there were no 'successful users', clinicians would deem the device itself as faulty, as it was before the first 'successful user' emerged. If this first successful user had not emerged, it is likely that the design would have been abandoned or at least changed. Because some users were in this landmark study (with many subsequent successful users) the data cast the device as successful and consequently framed those 'unsuccessful users' as being at fault in various ways.

The next chapter will examine the role resistance has played in the development and execution of this research inquiry. The discussion builds on the findings of the 'successful user' and legitimated CPAP therapy mask as covered in chapters five, six and seven. Chapter eight begins by exploring the constraints emerging from a commonly used design process that has led to seeking to upend the dominance of the 'successful user', for the reasons stated above.

Chapter 8 Exploration of resistance through exhibition and analysis of artefacts

Maybe the target now is not to discover what we are, but to refuse what we are. We have to imagine and build up what we could be to get rid of this kind of political “double bind,” which is the simultaneous individualisation and totalisation of modern power structures. (Foucault, 1982, p. 785).

The following chapter continues the power analysis undertaken with the data collected in the community markets, but draws the focus into a particular aspect – ‘resistance’. Foucault (1982) argued for using “resistance as a chemical catalyst so as to bring to light power relations, locate their position, find their point of application and the methods used” (p. 780). Using objects or artefacts as a starting point is common in critical design approaches, as it creates a kind of “enigma for the interpretive mind” (Gentès & Mollon, 2015, p. 82), wherein the physicality of form acts “as a sociocultural intervention at personal, community, or political levels” (Gaver & Dunne, May 15 - 20, 1999, p. 9). This chapter explores the sites and forms of resistance that emerged in this inquiry through the development of the exhibition, the probes as resistance to the mask, and finally the combination of exhibition and probes in creating a space for participants to resist dominant ideas about the masks. This chapter further provides analysis and direct community feedback on a creative method that has been used to make a range of complex power operations visible and able to be spoken about.

8.1 Exhibition as resistance to technical product design practice

In understanding the ways exhibition operates as resistance in this research project, it is perhaps useful to explore my specific design approaches that resist disciplinary norms. This section draws on texts from the early stages of my PhD journey where I had intended to apply a variant on the product design process and tools that I had learned during my product design degree to design a new mask artefact. In the case of this research project, I did not originally set out to explore the role of discourse as it operates in product design; my focus was initially on developing a new breathing support mask for CPAP therapy. The first working title of the study was *Evidence-Based Design and Engineering Innovation of Face-Worn Medical*

*Products*⁴². As described in chapter one, I first became interested in the design of CPAP therapy masks in order to design a new one for a new form of CPAP therapy.

The application for doctoral study explains the original study objectives:

The practice-based PhD will comprise evidence-based design of a novel medical device and thesis. The design will focus on the balance and integration of three key product design themes:

- Patient emotional needs focussed on potential impacts on the lived experience of using breathing masks
- Patient physical needs as a driver for product usability
- Engineering functionality optimising device efficiency and effectiveness.⁴³

I approached the design investigation and early exploration of the research area in line with the design skills I had learned during my undergraduate product design studies, which were commonly used in practice-based design research at doctoral level and below. This process included a range of activities aimed at developing empathy with the CPAP therapy user and understanding their 'needs', as well as scoping interviews with clinical staff who work with patients and fit masks to them. The following quote shows the evidence-based design approach from the original thesis proposal:

Evidence Based Design (adapted from (Kitchenham, Dyba, & Jorgensen, 2004, p. 2)) steps :

1. Converting the need for information (about patient needs, lived experience etc.) into an answerable question.
2. Identifying the best evidence with which to answer that question.
3. Critically appraising evidence for its validity (closeness to the truth), impact (size of the effect), and applicability (usefulness in product design practice).
4. Integrating the critical appraisal with product design expertise and with user and stakeholders' values and circumstances.
5. Evaluating effectiveness and efficiency in executing Steps 1-4, and seeking ways to improve them.⁴⁴

⁴² Cunningham, H. (2014). Evidence based design and engineering innovation of face-worn medical products *Form PGR2 - Admission to a Doctoral Programme* (pp. 1-7): AUT University.

⁴³ Ibid.

⁴⁴ Ibid. - Steps adapted from Kitchenham, B. A., Dyba, T., & Jorgensen, M. (2004, May 23–28, 2004). Evidence-based software engineering, May 23–28, 2004, Edinburgh International Conference Centre, Edinburgh, Scotland, pp.273-281.

As the details above show, the user, or in this case the patient, was central to my understanding of what constituted a design process. Strong discourses of scientific and engineering legitimacy pervaded my early ideas about where this study might lead. I used a series of human-centred design tools to explore possible mask ideas. These included consultation interviews with clinician sleep experts; visits to sleep labs and clinics and roleplay by attempting to sleep with a CPAP therapy mask for four days over a long weekend⁴⁵ (see Appendix G). In parallel, I also began developing design approaches to the problems through 2D sketching and 3D design using SolidWorks. I scanned my face using a 3D laser scanner and imported the model into SolidWorks to enable specific detailed modelling. I experimented with different materials and prototyping techniques, including using 3D printing face moulds for wax casting, rotational moulding, injection moulding a home-made elastomer, and material experiments with fabric, plasticine, wax, inflatable thin plastic sheets and PLA plastics (for a selection of process images see Appendix G).

Through making and experimenting with mask designs, I became aware of the tendency of software tools to 'push' designs in a particular direction (see section 4.3). I also became more aware of the many highly skilled engineers and scientists who have been working for many years in mask manufacturing. Given the commercial effort already directed towards improving CPAP therapy mask use, I had to consider the question of what new perspectives or insights could I as an independent individual researcher bring that might be less accessible to the many other professionals already working in the space? The approach I eventually pursued was the result of seeking new ways of thinking about CPAP therapy mask issues that might add to or complement, rather than inadvertently replicate, commercially sensitive research that may already exist outside of the public domain.

I was also stuck in terms of trying to develop co-design sessions. I came to the realisation that the approach I had intended to take did not align with the methodological basis I was subsequently working from (i.e., post-structural). I had started consulting with potential participants and was finding it difficult to articulate my ideas (following the preliminary analysis of the CPAP therapy mask artefact detailed in chapter six). I was effectively stuck on

⁴⁵ Source: Cunningham, H. (2016). Design notes - role play entry 22/4/2016. *Design research notebook March 2016 -August 2016*.

two fronts, 1. Developing the methodology for the co-design sessions and 2. Identifying how to communicate my ideas to gather a diverse range of inputs.

Discussing the problems with my supervisors I commented that despite these issues seeming quite intractable to me at the time, I seemed to have no trouble in finding people to talk to about CPAP therapy in everyday life. For example, borrowing a book at the library and mentioning my study the librarian she exclaimed that her husband had OSA and gave me a quick summary of his challenges with using CPAP therapy. Similar conversations came up socially and at any time I was seeking help from a research perspective on courses where we were asked to explain our research topics.

One of my supervisors had a similar experience through showing his CPAP therapy technologies at trade shows, and with many people wanting to tell him about their experiences. From these collisions of ideas, and an observation that community markets attract a broad range of people, the idea of seeking input in the same kinds of ways emerged – i.e., by creating a different space where people could have a ‘low-pressure’ opportunity to share their knowledge and tell the stories they wanted to tell.

This new direction left me with the problem of explaining my quite complex analysis of the CPAP therapy mask and seeking input on it. Despite having spent a substantial amount of time in design experimentation, I was still finding it difficult to articulate my understanding of the factors shaping the mask, and how to make it more usable or desirable to those faced with it based on the empathy exercises I had conducted (see Appendix G). At this point I reframed my focus from trying to solve the problems I had observed and instead tried to design embodiments that would show the problems more clearly. Approaching design in this way was a resistance to the more technically focussed aspects of my product design and engineering training, where solving the problem was the primary focus. Making a device to ‘show’ a problem or express it in a different way was a way to use design to further post-structural thinking. It was also an experiment. At this time, it was not clear whether the mask probes I had created would be taken seriously, or would trigger any new inputs or engage people’s interest.

Showing the mask products in a casual public setting was in itself a resistance to established precedents in critical design practice. These precedents recommended that critical design artefacts be displayed primarily in highly legitimised and intellectualised environments (i.e., art galleries) as a method to construct legitimacy (Dunne & Raby, 2001). Holding discussions outside and early in the morning presented a degree of resistance to Western norms

associated with appropriate times and places to talk about sleep (see section 5.1). Furthermore, the exhibition created space for market attendees to articulate resistance through their responses. In effect, the community market exhibition made space for resistance to be both thinkable and able to be spoken about in the ways outlined in this chapter.

Overall, the group of market attendees engaging with the research was quite broad in terms of knowledge and interest in CPAP therapy, OSA and breathing masks in general, and included hospital staff including doctors and nurses, as well as a range of people with knowledge outside traditional clinical environments and practices. Discussion length was limited and in most cases was around two to twenty minutes for each person. Discussions would only reach a certain depth and some remained entirely superficial, potentially due to the public setting, possible interruptions and people going about their lives. In many respects this was similar to the way many people would engage with the mask in society, reacting rather than giving it much thought or making concerted efforts to understand it.

8.2 Design probes as resistance to the mask 'as is'

The design of these artefact probes fell into a critical design approach, similar to that described by Dunne and Raby where the aim “... is not to present the dreams of industry [but to] stimulate discussion and debate amongst designers, industry and the public” (Dunne & Raby, 2001, p. 58). Rather than problem-solving, the focus was on ‘problem finding’ or exploration (Mazé & Redström, 2009, p. 32). Dunne and Raby’s concern is for critical approaches to help to make visible mainstream conventions in design that “at its worst” may “simply reinforce[e] global capitalist values” (Dunne & Raby, 2001, p. 59). In post-structural terms, the purpose was to make discourses visible, and in turn, make visible the operations of power through the subject positions these discourses construct.

As detailed in chapter four, I created the mask probes from familiar and non-medical materials and items that I obtained from a home hardware supply store (see Figure 14 and Figure 13 in section 4.4.5). As such these elements are mass-produced and readily available so recreating the mask artefact form is likely to be repeatable. Part of what appealed to participants appeared to be the level finish on the mask probe. The finished headgear seams, clean fit and lines and no unfinished edges, of the approximate shape of a mask, meant that the mask could be considered for its ideas rather than dismissed as childish. In this way, a degree of making skill and to some extent power-knowledge legitimised the probe enough for people to be curious, and to interact with it. Mass-manufactured products that were re-purposed in the probes displayed fine tolerances, even finishes and regularity of form that constructed a

surprising discourse of legitimacy that conflicts with the unexpected and seemingly nonsensical choice of items to construct a mask and tube in the form of a probe.

The lack of functionality of the mask probes used for the community market exhibition resists the notion of the functional but provocative provotype *[sic]* articulated by Boer et al. (2013) (see section 4.4.5). Far from hiding its non-functionality, the mask probes openly communicate their under-functioning status through material choices and lack of form-fitting to the face. By deliberately shunning function, the probes resist classification as fraudulent, and do not fully construct a discourse of legitimacy, thus allowing them to remain ambiguous.

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<http://www.fundairing.com/#liberate-sleep-apnea-sufferers-everywhere>

Figure 46. Airing micro-CPAP – how the technology works.

Source: Airing. (2015-2017). Airing: The world's first maskless, hoseless, cordless micro-CPAP device. Retrieved 5/2/2018, from <http://www.fundairing.com/#liberate-sleep-apnea-sufferers-everywhere>.

The probes differed in this respect to the “Airing™: the world's first maskless, hoseless, cordless micro-CPAP device” shown in Figure 46 (Airing, 2015-2017). The Airing™ was a CPAP therapy concept device launched on crowdfunding website www.indiegogo.com in 2015 that very quickly raised two million dollars for its development (Airing, 2015). Progress since the launch appears to have stalled due to technical difficulties encountered with executing the concept. The concept documentation includes what appears to be a theoretical explanation of how the device ‘will work’. The developers of the Airing™ concept further legitimised their concept by referring to scientific-sounding logic and similar devices and technology such as semiconductor microchips. The functionality of these chips may be widely appreciated but not well understood in the specific detail of how they function or in the limitations of these mechanisms. Where the Airing™ has been accused of being fraudulent or a rip-off (Airing, 2018), the mask probes designed for this study were never really read as fraudulent devices as they did not make a claim to be working prototypes. Instead, they seemed to purvey a humorous character or some degree of irreverence: “well, this is interesting because it's a

hosepipe in a pot plant! Hahaha!” (Interested passer-by who has trouble going to sleep (female)).

The mask probes were often described as ridiculous and triggered outright laughter in many cases:

[Group member 1] it is ridiculous!

[Group member 2] I think it kind of looks like a gas mask like it's got that shape of it,... it kind of reminds me of you know the old ... world war two sort of gas mask... looks a bit like the modern soldiers one but slightly taller

- Group of 2-3 young people (female).

While the lack of functionality seemed to enable broader thinking, it seems likely to have constrained the discussion for several subject positions. Successful users, in particular, preferred to comment on the CPAP therapy mask relative to the mask probes rather than the mask probes themselves. Successful users seemed to find the mask probes, when situated next to the CPAP therapy mask product, to be coercive towards a particular view of the CPAP therapy mask product. Some people commented that the CPAP therapy mask was ugly, but they did not think that the CPAP therapy mask appearance was important: “Ah it is ugly, but I don't mind, it's doing what I need it to do” (long-term CPAP therapy user, partner also uses CPAP (female)).

The ridiculous nature of the mask probes meant that participants might have been subject to social requirements to discipline themselves to be polite about them, so they chose to comment on the CPAP therapy mask instead. On reviewing my notes and recordings to develop the arguments from the research undertaken, I was struck by the volume and regularity of laughter and joking around that came through in the market sessions. The prevalence of laughter had me both pleased that people seemed to enjoy the process so much, but I also found I was perplexed as to how to deal with comments that were clearly, or to some degree, said in jest (see section 2.3.4).

8.3 Responses from participants resisting dominant discourses

Mask probes and the ‘lightness’ that they afforded to the conversation also appeared to prompt discussion about frustrations and possible resistance practices due to the constraints of the ‘legitimate’ mask. One such discussion focussed on the cost of the mask and consumable or spare parts. During interviews, it was noted by clinicians that there were

rumours of CPAP therapy products manufactured in New Zealand being available for sale in the US at a lower cost than with the registered New Zealand sellers (Clinical Specialist 1, Visit notes, Observation notes – see Appendix D). I noted buying online as resistance to the regulated distribution networks. Discussions with people at the markets looking for parts reflected similar interest in alternative methods of purchase: “It’s good but one of these parts... yeah it’s broken...they’re quite expensive aren’t they? Oh yeah, they are so I was wondering if you’re selling parts... I thought oh good I can get one for him [husband]” (Husband has OSA seeking replacement for broken parts (female)).

People also talked about having bought New Zealand manufactured CPAP therapy products overseas and having them shipped to New Zealand for less than the cost of buying them in New Zealand:

[Woman speaking] he’s looking for parts... they’re quite expensive as well... I bought this one, [the production mask] from an American website,

[HC] ok you bought that online, was it cheaper online?

[Woman speaking] Yeah, yeah, the same one but cheaper

[HC] cheaper to buy online and send all the way to New Zealand?

[Woman speaking] Yeah, they’re quite expensive locally, you don’t sell the parts?

[HC] No I don’t

- Wife of CPAP therapy user, buys parts online for husband (female).

Products being more expensive closer to their manufacturing location conflicts with the product valuation discourse that a product sells for its manufacturing and transport cost, plus some margin for profit (Boztepe, 2007). The price differential was likely made possible by the market distortion wherein prices are reduced in the US to match insurance reimbursement scheme rates, which act as local market restrictions. However, the difference produces a mismatch between community discourses of cost where a product costs a certain amount to manufacture and then transport, with a local product travelling a shorter distance expected to be cheaper. The price difference may also reflect the low cost of shipping globally and the high cost locally. The mismatch triggered a sense of unfairness amongst market attendees that was then resisted by seeking other channels to acquire masks and parts, such as buying online or at

a community market to save money. It may also reflect a cultural symptom of a relatively small and isolated country with higher prices, which results in a culture of bargain hunting. Searching for mask parts in a community market may also be seen as a form of resistance to the dominant distribution discourses. As discussed in chapter six, medical distribution chains are highly regulated and carefully legitimised. Similarly, it may also reflect a rejection of the premium placed on risk management when it comes to less critical components such as consumables, head straps and other breakable components.

A set of responses to the discourse of high cost was resistance through a discourse of “Do-it-yourself” as giving freedom from the high cost of medical products through practices of self-sufficiency such as making things for yourself. Do-it-yourself (DIY) is the practice of doing particularly home repair and maintenance without the assistance of professional tradespeople (Do-it-yourself). DIY is also associated with resistance to many of the product form drivers discussed in chapter six. One self-identified ‘DIY enthusiast’ commented on the mask product that “if any parts break you’d have to pay heaps” (Interested passer-by works in early childhood, arts and crafts (female)). The participant compared the mask probe favourably to the CPAP therapy mask product in this respect: “this one you’ve just got to get mum’s pot plant, haha, cut some more hose, hook it up... so you could kind of fix it yourself, it’d be more cost efficient... people laugh, but it’s got so many advantages” (Interested passer-by works in early childhood, arts and crafts (female)).

A number of people stopped by looking to buy cheaper replacement parts for themselves or people they know (Husband has OSA seeking replacement for broken parts (female)). The high cost of CPAP parts was reiterated by one CPAP user, who explained that parts break easily and a simple T shaped part made from hard plastic cost \$120NZD (Long-term CPAP therapy user with walking frame (female)). The participant considered that this was a high cost for someone on the NZ Government living support payment known as ‘the benefit’ (Long-term CPAP therapy user with walking frame (female)). The cost of material for these parts would likely be a few cents for the few grams of plastic. Participants viewed DIY as instrumental in framing freedom from the tyranny of excessive and unexpected expense from breakage (as well as the breakability of) medical equipment. The expression of freedom from cost highlights the domination that healthcare suppliers enact over patients via their reliance on a medical device.

Participants also invoked DIY to express frustration and exert a form of resistance to the slow work of diagnosis. For some, the mask probes were appealing for their DIY manufacturability. For a parent, whose son was in the process of what may have eventuated as an OSA diagnosis, a homemade mask, while acknowledged as unexpected by the attendant laughter, offered the

possibility of regaining personal control over the diagnosis system: “I just want him to get better ... I just thought when I saw that, maybe I could jig something like that up at home! Haha... get him to try that on” (Man whose high school aged son has possible symptoms waiting for diagnosis (male)). In this sense, the mask probe presented a possibility of making one’s own mask and resisting the discourses of subservience to a medical system that runs to the convenience of staff rather than patients.

These attitudes would seem to resist ideas of the passive consumer and instead suggest desire from some community members to disengage from the market based neoliberal system by literally ‘taking things into their own hands’. While it seems unlikely that they seriously intended to go home and make a mask for themselves or their loved ones, the presence of a potentially home-made mask provided an avenue to express their frustration. The mask probes created a space where it was possible to think of a situation where they could take control of their loved one’s illness and take action to remedy the situation quickly.

In effect, the probe changed what was thinkable and able to be spoken of in relation to CPAP therapy masks, and in so doing brought to light a hidden desire for control over a situation. Without the mask probes being present it is much less likely that the conversation about cost and resistance to the discourses of manufacturing product legitimacy would have come to light. When faced with a precision manufactured medical facemask product alone, suggesting a desire to make one yourself and no longer be at the mercy of the medical system is much less likely. The mask probe presented resistance to current discourses that see remote production and manufacture of everyday items as desirable. Product mass manufacturers are becoming increasingly remote from the users of those products, particularly in Western countries.

I will now return to the discourse of displaced agency in mass manufacture that two participants mentioned in relation to DIY making. Participants also touched on the role of mass manufacturing in displacing agency, and to resistance through re-emerging discourses of making and repair. The problem of technology is often framed as a lack of control, as if the issue is with “the objectification of everything by a subject who is intoxicated with power, leading to a triumph of ‘instrumental rationality’” (Crawford, 2009, p. 70). Heidegger argued that “the nearest kind of association is not mere perceptual cognition, but, rather a handling, using and taking care of things which has its own kind of knowledge” (Crawford, 2009, p. 69). Such notions of separated forms of knowledge may remain contested, but they are also of great interest to the design research and art practice research communities who continue to explore forms of *tacit* knowledge (Polanyi, 2009).

Crawford (2009) argues that a number of people may experience themselves as inherently instrumental or pragmatically orientated (Crawford, 2009, p. 69). Considering this interaction as a necessary and fundamental facet of the human condition reverses the arguments present in mass manufacture discourse. In discourses of mass production, hiding complexity from view (for example behind generic boxes as in computers or toasters) is presented as freedom *from* knowing the workings. However, for some “the problem is not ‘instrumental rationality,’ it is rather that we have come to live in a world that precisely does *not* elicit our instrumentality” (Crawford, 2009, p. 69). Crawford (2009) argues that “the growing dependence of individuals, in fact, is accompanied by the ever more shrill invocations of freedom in *theory*, that is, in the ideology of consumerism” (pp. 70-71).

In many cases, the social processes limit the shaping of the making process to the extent that: “The act of giving form to things seems to be increasingly the business of a collectivised mind, and from the standpoint of any particular individual, it feels like this forming has already taken place, somewhere else” (Crawford, 2009, p. 70). Interacting with artefacts and the built environment has been disciplined and limited to predetermined, sanctioned processes that substitute consumer choice in place of making agency and autonomy. While Marx famously argued against the alienation of the worker from the product of their labour (Marx & Engels, 2009), the data presented show a degree of alienation of the product user from the means of production. This alienation through discourses of medical legitimacy limits the opportunities for self-actualisation through modification, personalising and other activities.

For non-medical products, manufacturers constrain such activities into a pre-approved range of ‘choices’ (Crawford, 2009). Medical products are even more constrained, along with others that sit outside the classically consumer-driven model – such as medical products paid for through communalised or government health insurance schemes, including in New Zealand. The medicalised end user is in this system, liberated from needing the skills to make a mask for themselves or their family. However, at the same time, their freedom to modify, make, create and personalise is effectively illegal or subversive at best.

While repairing parts is now considered quaint, early automobiles, for example, were designed to be maintained with readily available materials. By 1949 evidence was mounting that this had shifted (Fisher, Griliches, & Kaysen, 1962). The discourse of the repairable product business became supplanted by discourses and theories of planned obsolescence from the 1950s onward (Galbraith, 1967; Galbraith & Crook, 1958; Jeremy, 1986). The CPAP therapy mask frame in many cases is highly durable – more than one participant explained that they had used the same mask for 10-12 years or more. However, the main manufacturing profit for

companies selling CPAP therapy systems is in the ‘consumables’ - mask seals and other parts that break or wear out, and which have a large profit margin. Resistance to such discourses is becoming increasingly visible with some eighteen states across the US recently passing legislation in terms of ‘the right to repair’ and the EU preparing to do the same (The right to repair consumer goods, 2019).

8.4 Discussion

The combination of the market exhibition and the mask probes created a space that enabled people to think differently about the typical CPAP therapy mask on display next to the probes. The discussions covered topics that were different from those that participants might have discussed in a clinical setting, or in a more traditional one-on-one research interview without mask probes present.

I made the mask probes in response to a preliminary analysis, but before completion of the detailed analysis of material legitimacy outlined in chapter six. How the form of the mask constructed legitimacy, successful users and subject positions through discourses of mass manufacture emerged in the analysis of the market sessions. The idea of DIY and ‘agency of making’ or production was an unexpected outcome of the research approach. It was, however, very relevant and made visible an important part of the socio-historical context that played a role in shaping the CPAP therapy mask.

The mask probes presented resistance to discourses of patient responsibility and risk because they presented as a DIY artefact and thus appeared to be modifiable. Foucault characterises this form of resistance as an “opposition to the effects of power which are linked with knowledge, competence, and qualification: struggles against the privileges of knowledge. But they are also an opposition against secrecy, deformation, and mystifying representations imposed on people” (Foucault, 1982, p. 781).

The exhibition of mask probes resisted dominant healthcare discourses. These discourses included the importance of cleaning, preventing infection and bacterial growth. The probes also resisted the role of reduced agency associated with the powerful clinical discourses that shape the CPAP therapy mask. The data highlighted the disconnect and barriers to access between the people who live with the mask and those who make and design it. This finding will be explored further in the discussion on institutionalised individualisation (see chapter 11).

As outlined in chapter six, without changes to the complex legislative, manufacturing, healthcare and social web that dominates the shaping of the mask, it is difficult to imagine

how design changes would effectively address issues around the agency of making. The methods used resulted in an engaging exhibition construction that encouraged and generated interesting and relevant discussion. It also allowed for insights to emerge in a way that appeared to be fun and enjoyable for the community. Further, taking the exhibition out into community markets was significant in that it generated the opportunity for the community to engage with these ideas as a community, in small groups of friends, families, partners or spouses and individuals by and large on their own terms.

This approach of using artefacts, developed in response to a discourse analysis in a community market setting, was significant because of the focus on the operation of power through the material, as well as written and spoken discourse. The making of physical artefacts in response to a power analysis and to communicate different ideas is a new approach to post-structural discourse text generation. Furthermore, the approach analysed in this chapter contributed to the overall analysis through generating the possibility of engagement with subject positions beyond the 'successful user' and making possible the exploration of discourses that resist those of clinicians and manufacturers. This approach resists common discourses of design thinking, co-design and HCD approaches that focus data gathering for design insight firmly on experienced users of a device or product. Such approaches in some cases acknowledge the limitations associated with their design tools (Jones, 2013). For example, a persona is an excellent tool for summarising data into a form that designers can work with, but it does not provide any functionality with regard to who should be included or omitted from the process (Jones, 2013, p. 39).

8.5 Summary

This chapter articulated forms of resistance to the traditional CPAP therapy mask and community discourses about these artefacts (see probe development in chapter 4). The situated effects of mass manufacture were made visible through the contrast of a mask probe artefact made from materials sourced from a home hardware store. The juxtaposition of this materially diverse product with a typical CPAP therapy mask was both intriguing and quizzical for participants. Through the analysis, I have argued that this exploration of resistance resulted in the emergence of DIY as a source of agency and resistance, challenged sleep as a private matter and explored the dominance of medical distribution systems. I found that the mask probe challenged and resisted discourses of legitimacy and distribution systems, and brought out or made visible discourses of agency and loss of power in relation to dealing with the medical system and aspects of diagnosis.

Building on the idea of resistance, and in contrast to chapter seven, the next section chapter nine now explores how the data generated during the market exhibitions constructs subject positions outside of those assumed by the design of the CPAP therapy. Chapter nine presents an exploration of the subject positions articulated during the market sessions that the narrowly constructed 'successful CPAP therapy user' operates to marginalise.

Chapter 9 Subject positions outside of those assumed by mask designers

Chapter nine explores the findings of a power analysis primarily using texts generated during the community market sessions described in section 4.4. These findings are also supported by data collected in the form of design reflections, exploratory prototypes and sketches, notes or transcripts made as part of scoping, and consultation or interviews with health professionals (see section 4.2). Chapter nine builds on the exploration, in chapter seven, of the ‘successful user’ subject position that is destabilised by the context and practices of resistance discussed in chapter eight. In this analysis I drew on the work of Foucault and other Foucauldian scholars who explore his disciplinary technologies, such as hierarchical observation, normalising judgement and the normalising gaze illustrated through the example of the *panopticon* (see 2.4.3). The analysis presented in chapter nine also draws on Foucault’s *principles of exclusion* and *reversal* (see section 3.5.2 and 3.5.1). In this chapter I ask who is marginalised in the construction of the ‘successful user’ subject position (as articulated in chapter 7). I explore who else is present in the community that this construction appears to miss or ignore, and the discourses that shape the subject positions that appear to be outside of those assumed in the design of the mask. I then consider important discourses present in data that construct the CPAP therapy mask embodiment and system as socially problematic for these subject positions. The chapter concludes by asking what designers can learn about the operations of power in design through considering the range of subject positions that may not currently be the focus of a design process (i.e., those participating in a community who are not ‘successful users’ or formally employed in relation to CPAP therapy related work).

9.1 Problematising discourses of privacy and changing intimacies

As discussed in chapter eight, the community market exhibitions resisted culturally specific discourses of sleep as a private matter. A common comment by participants both in clinical interviews and in the community market was that it does not matter what the mask looks like because people wear it at home in private and nobody sees them when they sleep: “if it helps the person breathe they won’t care what it looks like, they are asleep, and you are at home” (Interested passer-by, likes technology (male)).

Although the assumption of privacy was the first response, some group discussions included the possibility of the reaction of a new bed partner:

[Group member 1] You’re wearing it because you can’t breathe, you wouldn’t run around telling people though would you?

[Group member 2] No, but if you just wear it at home when you sleep who's going to see it?

[Group member 1] What if you come home with someone, they're like what are you wearing!

[Group member 2] Oh my god

- Group of 2-3 young people (female).

Clinicians also cited a new bed partner as one reason cited by patients that prevented or led to the disruption of CPAP therapy use (Clinical Specialist 2, Scoping note with Advocate 2 – see Appendix D). Similarly, going away with friends for a weekend and not wanting to be seen bringing an unwieldy device, particularly for younger people, was viewed as a possible reason for disrupting CPAP therapy (Clinical Specialist 2 – see Appendix D).

Some users expressed concerns about using the device in any situation that was outside of the privacy of their own home, or even at home when they might be seen by those with whom they live. Some successful users expressed reservations, but suggested that the perceived personal benefits usually outweighed these: “Well I do feel a bit uncomfortable using it [on a marae] only because people didn't sort of know what it was and because it's made so much blimming noise, that was the main point because of the noise” (Advocate 1 – see Appendix D).

While it seems clear that using CPAP reduces snoring to the point where the bed-partner can also sleep, this consideration does not necessarily take priority in a community sleeping setting like a *marae*⁴⁶. Where the tolerant private space is no longer fully private, the disciplining of, for example, masculinity through teasing, jokes, and other forms of social policing are likely to take place. While some participants mentioned concerns about noise from the CPAP therapy device and mask, it seems possible that the social penalty for this kind of noise may be more costly to the individual in terms of social status than the penalty for the more socially acceptable or at least common condition of loud snoring: for instance being compelled to sleep outside.

⁴⁶ “The marae (meeting ground) is the focal point of Māori communities throughout Aotearoa/New Zealand. Marae are used for meetings, celebrations, funerals, educational workshops and other important tribal events. The people who belong to a marae do not live there full time, but will come and stay during important occasions. Marae life is very communal – everyone sleeps in the same room (usually the main meeting house) on mattresses lined against the walls.” Source: The marae (meeting grounds) is the focal point of Māori communities throughout New Zealand. (2019). from <https://www.newzealand.com/int/feature/marae-maori-meeting-grounds/>

Participants constructed smaller and less obtrusive devices as being more attractive and better for camping, or in some cases use on the marae:

[man speaking] they'd be good but if you're travelling, you know if you don't have power, yeah camping, any of those sorts of you know and its subtle instead of having to pull out a whole mask if you're sleeping at a marae...

[HC] How would you feel about doing that on a marae?

[Man speaking] Oh no I wouldn't

[Woman speaking] he hasn't, but he's been lifted up, his mattress has been lifted up, and he's been chucked out... that's what happens when you snore a bit loud!

- Couple, man uses CPAP therapy regularly (male and female).

The noise from the device or the mask, particularly when the mask becomes dislodged during sleep was considered particularly concerning for CPAP users, even for some highly successful users. Another other example from the data included the subject position of someone who had been on a road trip with a 'successful user' and shared a room with him (Went on a road trip with a CPAP therapy user (male)) (see section 7.3).

However, discourses⁴⁷ shaped tolerance for sleeping related noise in community sleeping situations such as camping (Scoping notes with Clinical Staff 3 – see Appendix D), a road trip (see section 7.3) or on a marae (see section 7.3). By not using their CPAP therapy in public spaces, otherwise successful user subject positions may be interpreted as defending themselves from the operation of power. Various discourses enable the operation of power through social interactions that may include teasing, aversion or other negative responses. Notable in common and powerful discourses that constructs particular behaviours are discourses of gender and illness. The complex interaction of competing discourses will be discussed further in chapter ten. So while the situation of use does not preclude everyone from using the CPAP therapy device, there are subject positions for whom the presumption of privacy or confidence when wearing the device in public was problematic.

⁴⁷ From this study, examples of discourses that may operate in this way included discourses of gender (see section 9.1), illness (see chapter 11) and the many other social constructions through which power operates such as design and mass manufacture (see section 8.3), or through which power is resisted (see chapter 8).

Duncan (1994, p. 49), argued that the term 'privacy' rather than being an absolute term is a Western ideological construct that is of key importance to related economic and political systems. The term 'private' assumes in an unquestioned way that all people are individuated selves, with particular qualities unique to themselves and that differentiate us from others (Duncan, 1994, p. 49). Furthermore, the ideological construct of 'private' that works to separate us from others indicates isolation from the construct of 'public', with its inherent social and cultural influences (Duncan, 1994, p. 49).

The idea that the appearance of the CPAP therapy mask is less important "when you are at home" (Interested passer-by, likes technology (male)), relies on this individualising assumption, associated with the 'private' bedroom space that culturally legitimises sleep in a Western context. The individuating effects of the mask are made visible through the act of displaying it in public. The exhibition of the CPAP therapy equipment resisted the assumptions of legitimised sleep and the individualising assumption of privacy by occurring in a public, non-clinical setting where it was open to comment and critique from the community. It resisted assumptions by allowing for group commentary on what may usually be considered a "private matter".

Duncan describes the *gaze* as an important example of how public and private can become conflated (Duncan, 1994, p. 49). She refers in this instance to the body practices of women, although arguably similar mechanisms also apply to other subject positions in society such as racialised subjectivities, illness status, age groups or particular groups of men that culturally produce and propagate dominant ideals. The 'gaze' is an economy of surveillance rather than an act of visual recognition (Duncan, 1994, p. 49). In Western culture, women, in particular, are trained through social processes to view themselves as others would see them (typically male others) (Berger, 1972; Sptizack, 1990 as cited in Duncan, 1994, p. 50). This conception of themselves as both spectator and spectacle, in comparison to a social ideal of femininity, becomes so ingrained as to seem that it stems from one's own desires rather than being culturally and socially prescribed (Duncan, 1994, p. 49) (see also section 2.4.3 for a brief overview of the work of Foucault (1977, pp. 191-228) on the disciplinary technology of the *panopticon* that forms the basis for Duncan (1994, p. 49)).

Where potential CPAP therapy users conflate public and private through self-surveillance, the effects of public attitudes on CPAP therapy masks are likely to have a greater impact on how a potential user may feel about wearing one. The view that 'no one sees you when you sleep at home' is problematised by how social conditioning may discipline a CPAP therapy user to see and judge themselves as if through the eyes of others.

9.2 Problematising discourses of normative time-based sleep patterns

Discourses of time division when applied to sleep also construct non-normative discourses of sleep. A researcher of Japanese culture, Steger, purports that eight hours bedroom relegated sleep is highly characteristic of Western mono-chronic clock-orientated societies, where the balance between work, leisure, family, rest and sleep is negotiated through the separation of times for each activity (as cited in Steger, 2006, p. 198). By contrast, polychronic societies may allow more than one thing to happen at a time, for example, Japanese *inemuri*, which are socially acceptable forms of day time napping (see section 5.1). The following subject positions problematise assumptions of Westernised divisions of time and activity in terms of CPAP therapy use.

As will be discussed further in chapter ten, normative constructions of sleep also tend to reflect masculine constructions of sleep. Masculine constructions refer to those constructions that reflect a manner of living that public discourse has historically associated with dominant constructions of what it is to be a man. There is no one way to construct masculinity, or as gender theorists such as Judith Butler (1988) would describe it, there is no one way to 'perform' masculinity. Particular forms of this construction play a greater role in shaping social norms than others. In terms of this discussion, I argue that traditionally powerful forms of Western masculinity have shaped discourses of sleep. Such dominant forms of masculinity have been typically assertive, independent, able-bodied, Anglo-European, professional, managerial and white-collar worker styles of masculinity. Dominant discourse constructs such a form of sleep as being part of a theoretical eight hour working day, a total of eight hours of 'leisure'⁴⁸ and eight hours of continuous peaceful, private and uninterrupted sleep. The following sections will discuss a number of ways of living and sleeping that do not adhere to this structure. Such forms of sleep also present problems with using the CPAP therapy mask for OSA, thereby making visible the underlying assumptions in discourse that frame this way of living in normative terms.

Clinicians presented shift workers as an example of people that may have problems adhering to CPAP therapy prescription and who might need extra help. As one clinician described, the difficulties for shift workers are in fitting in with family life and adjusting their sleep so that:

⁴⁸ Leisure in this sense was constructed as time away from paid employment but differentiated from sleep, rather than necessarily the pursuit of what might now be considered leisure activities. As such, it might also occur around other activities, rather than in a continuous eight hour block.

they're available times when family are on normal waking sleep cycles and often [its] that kind of falling asleep in the chair instead of even making it to the other room to where the equipment is in the bedroom. So if there's some kind of way of seamlessly, how, I don't know ... I guess it's hard if you're not consciously going to sleep... and you don't have that preparation (Clinical Specialist 2 – see Appendix D)

Some clinicians described shift workers with difficulties using CPAP therapy as experiencing emotions of shame about their struggles to adhere to CPAP therapy. Users often critiqued the CPAP therapy mask and device in this study for its lack of portability and travel related concerns. This lack of support for the need to nap further constructed Westernised discourses of sleep. The association between age and additional periods of sleep is reflected in the popular culture term 'nana nap', meaning "to sleep for 1-2 hours in the afternoon when one is not a grandparent" (Aussieandy, 2011). Similarly, the 'power nap' is defined in the Oxford English Dictionary as "a brief but refreshing nap, esp. one taken during a long working day to restore alertness", indicating there is some degree of tolerance for napping behaviour within Westernised cultural contexts (Powernap, 2019). The dictionary example phrases for power nap were all examples of powerful males taking a nap, indicating a masculine construction of the behaviour (Powernap 2019).

One particular group of potential CPAP users stood out for being largely absent or appearing only briefly during data collection activities but declining to participate. These were younger adult women with possible OSA symptoms (and young mothers in particular). During the market sessions, young mothers often declined to participate in the research fully. However, on two separate occasions, a woman with a pram and infant acknowledged that they 'need a mask' before moving on. A couple of young women who were not pushing prams also volunteered to participate, but pulled out part way through because they were 'too shy'. At least one clinician mentioned that they did not see many young mothers with children for mask fitting (Clinical Staff 8 – see Appendix D).

Given the documented presence of weight gain, poor sleep and snoring associated with pregnancy, it is perhaps surprising that more cases of OSA amongst young mothers did not emerge through this inquiry. Correlations are emerging between sleep problems associated with caring for infants and depressive symptoms (Koyanagi & Stickley, 2015). Such problems are further contingent with post-natal depression and other mental illnesses in new mothers for whom some degree of sleep deprivation is so common as to be considered normal (Dennis & Ross, 2005). The legitimised explanation is likely that young women do not experience OSA symptoms at anything like the rate of men. However, as clinicians and researchers have based

the definition of the condition largely on studies of the visible experiences and symptoms of older, working male patients, it can be speculated that alternative discursive effects may also be operating. The invisibility of women with young children extends further through their likely absence from the working world and the structures that fail to recognise anyone outside of paid employment (Jansen, 1989).

As discussed in section 3.5, Foucault conceived of silence as a functioning element of discourse (Foucault, 1978, p. 27). Consistent with this, Rosiek argues that interpreting socially produced silences requires the “use of theories that explain both the source and effects of those silences” (Rosiek & Heffernan, 2014, p. 726). The risk of ignoring what is not said is a privileging of “presence over absence and voice over silence” (Rosiek & Heffernan, 2014, p. 726). Traditionally conceived power imbalances can result in social silences, or as they will be constructed here, as the result of subject position constructions that enable the operation of power.

Although, as I have indicated, it was notable that women shied away from discussion at the community market, and the feminine experience was marginalised in the expert interviews due to this ‘silence’, there were also instances of feminine-situated responses in my data. The following example from the data presents a particularly feminine situated response:

even when you come home from work, and you're feeling a little bit tired, you hop on it for half an hour and that's amazing, what it does, I don't only go on it when I go to sleep when I'm tired or I'm feeling a bit down I jump on it for half an hour like I said, then I get up and I do my cooking and whatever I have to do as a mother and a bloody wife! - Former long-term CPAP therapy user (female).

I read the use of the device not only ‘when I go to sleep’ by contrast to the normative pattern of eight hours of sleep as an act of resistance. It is a very much feminine-situated resistance when contrasted to the dominant discourses of eight hours sleep arguably situated around a Western male paid working day⁴⁹. Young women with babies have been advised to “sleep when your baby sleeps” (Royal New Zealand Plunket Trust, 2019). This division of time is very different to the contemporary or post-industrial revolution trade-off of eight hours work, eight hours sleep, eight hours recreation (as cited in Tully, 2011, p. 160). Western discourse back to

⁴⁹ This may vary in a country with a cooler daytime climate than say Spain or Mexico where the afternoon siesta is more common.

the antiquities has valorised an early rising sleep pattern as particularly desirable: “Early to bed, early to rise, makes a man healthy, wealthy and wise” (Franklin, 1887-1888, p. 447).

Interestingly, more recent sleep studies have shown that the sleep/alert timetable varies through the life course and the 9 am to 5 pm work schedule is particularly suitable to small children and for adults aged in their fifties (Saner, 2015). Typically, bosses are likely to be in this age range, while teenagers are most likely to be disadvantaged by being required to rise some three to four hours earlier than their circadian rhythms might dictate. While the saying above may attribute success to early rising attributes, a plausible alternative is that subject positions likely to have their view recorded and repeated are also likely to be prosperous, healthy and of an age where early rising is very much in tune with their circadian rhythm. The effect of such discourses is that popular discourse may portray sleepy people, those who are operating outside of this prized rhythm, as unhealthy, lazy and foolish. These discourses persist despite the need to sleep in different formats for a variety of other legitimate reasons (e.g., nocturnal childcare, shift work). Perhaps not surprisingly, women have been found to exhibit higher rates of sleep disturbance than men in other countries adhering to similar ideas about sleep patterns such as Australia (Hillman & Lack, 2013). The rise in driving legislation aimed at fatigue further underpins arguments that the family ‘breadwinner’ must have a good and undisturbed night’s sleep or risk losing their driving license and therefore livelihood (New Zealand Transport Agency, July 2014).

The apparent difference between male and female sleeping patterns may be further contingent with changes that occurred during the industrial revolution. Farm work, particularly with animals, would likely have involved many people in a 24-hour operation. Before the industrial revolution, there may have been a greater similarity in sleep patterns between the genders (Ekirch, 2001).

9.3 Negotiating intimacy with a mask

The mask was constructed as a barrier to intimacy in a bed partner relationship through added complexity and by creating a fixed endpoint to intimacy behaviours within the confines of the bed space. The need to put the mask on physically implies a conscious decision not only to sleep, but to extricate oneself from any other activity in a defined and conscious way. As one participant noted, this potentially interferes with intimacy and has an individuating effect on the CPAP user within the bed partnership. Participants reflected on how the mask experience might create a hard separation between sex or other forms of intimacy, and sleep: “[Woman speaking] Forget trying to be intimate, hey! ...I think it kind of like puts an extra process, so you

have to kind of decide, ok done with that now, we put [it] on, yeah” (Couple that know a CPAP therapy user (male and female)). Similar concerns were also reflected in study of the experiences of CPAP therapy couples by Ye et al. (2017).

In some instances, perceptions of the noise involved in the snoring associated with OSA meant that rather than destroying intimacy, participants constructed the mask as a possible opportunity for re-entry into a bedroom from which their partner may have previously banished them.

[Man speaking]...and he doesn't snore anywhere? Where before he'd fall asleep and he would like just rip the house down kind of yeah and now he goes to sleep, and no one can hear him,

[Woman speaking] quietly,

[HC] it must make a big difference for other people's quality of sleep as well,

[Man speaking] haha, yeah, ...

[Woman speaking] they're allowed to sleep in the bedroom now, haha

- Couple that know a CPAP therapy user (male and female)

Clinician interviews suggest that the hoped-for results do not always eventuate, despite patients often seeing the mask and therapy as a single and complete solution to a wide range of complex problems. For example, the difficulties around fatigue, anger, and sleep deprivation related personality changes mean that fixing sleep issues is only one of the many issues that must be addressed to mend a difficult bed partnership.

Comments from another community member highlighted the possibility of longer-lasting damage to a partner's attractiveness: “...what about your partner? Haha, there's no more kissing for you after that, ever, ever, for life, for life!” (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)). While probably said in jest, this statement points to a discourse of a fleeting spark of attraction that drives what might be termed “passionate love” (Huston & Altman, 1974, p. 357). Until relatively recently, long-term partnerships were largely defined in terms of marriage and may have been discussed in legal terms as involving ‘duty’ and ‘service’ (Perry, 2003). More recently, popular discourse constructs romantic relationships of all kinds in terms of neoliberal discourse that seeks ‘fulfilment of potential’, excitement, comradeship and status from long-term domestic

partnering (Gershon, 2011). In this case, the discourse feeds into popular discourses that require a sexual partner to work at their desirability when seeking a partner, and traditionally for women but commonly now for men too, also to maintain their desirability within the long term relationship.

Discourses of vanity in relation to feminine constructions are interpreted to mean physical rather than achievement vanity. In this context, physical vanity can be defined as “excessive concern for, and/or a positive (and perhaps inflated) view of, one's physical appearance” (Netemeyer, Burton, & Lichtenstein, 1995, p. 612). The construction of vanity in relation to the CPAP therapy mask operates in the context of discourses that position the construction of health as more important than anything else. The threshold for what might be considered vain in this context is therefore extremely low. The notion of an experience of physical vanity is itself gendered. Studies have shown that the importance placed on appearance has historically been much higher for women than for men (Durvasula & Lysonski, 2008). Similarly, social status is historically much more dependent on appearance for women than for men, for whom financial achievement is more likely to correlate to social status (Durvasula & Lysonski, 2008).

Admissions of reluctance by women to wear a mask was also present in responses from women who did not identify themselves as having OSA or being CPAP therapy users. One participant related her reluctance instead to her subject position as a woman or “female”: “[woman speaking] as a female, I wouldn't want to wear something like that” (Couple, woman's friend's partner uses a CPAP therapy (male and female)). Statements such as these make sense or are unsurprising in light of discourses of femininity and the construction of women in popular media as desirable and valuable only when seen and validated through the mechanism of the male gaze (Duncan, 1994). If this statement is contrasted with an analogous statement when spoken by a man: “as a male I would not want to wear something like that”, the kind of product that comes to mind might be very different (e.g., feminine clothing that is pink and may involve lace). As such, I propose that the mask lends little assistance to the construction of desirable femininity and is likely to actively detract from it in ways that are different from (although potentially as socially painful as) the ways the presence of a mask may undermine desirable masculinity. Recent studies have considered the role of the bed partnership from the perspective of long term CPAP therapy users in terms of ‘becoming a team’ for ‘successful’ treatment (Ward et al., 2018; Ye et al., 2017). Ward et al. (2018, p. 85) also detailed the level of cooperation involved and also noted a sense of reluctance to use CPAP therapy in a new bed partnership, even amongst long term and ‘successful’ users.

9.4 Discourses of users excluded through differing ability

The data constructed some healthcare related subject positions as advocating for the wellbeing of those in their care. Social workers, in particular, emphasised the needs of those who have disabilities, brain injury, are elderly, or have mental illness (including bipolar and schizophrenia). In particular, one respondent referring to the CPAP therapy mask suggested: “how are you going to stick that on someone with dementia?” (Social worker, disabled clients and those with mental illness and impairment (female)). Another participant identified as a nurse who had seen many long-term users who were also older having difficulties with the mask:

usually you'll have patients that have reduced vision and can't move around very much so yeah, they do struggle with putting it on, it's just quite a complicated mechanism [even] for people who know how to use it... it's definitely tricky... something that's a bit easier for people with arthritis or could have eye problems, .. I guess you underestimate the dexterity that you need to actually be kind of pulling stuff and touch, and the thumbs and bits and pieces, and the little clips and things, it's a lot... fiddly and even putting water in - Nurse that sees people using CPAP in post-op surgical ward (female)

These discourses highlight the normative assumption of mental competence and basic dexterity associated with the mask design. The assumption of baseline dexterity and range of motion does not necessarily reflect the ability of the full range of people who need to use the mask. For example, the dexterity levels required to otherwise live independently without OSA may be much lower than the dexterity and limb mobility required to operate a CPAP therapy mask and to attach headgear. People who need a CPAP therapy device but who are physically unable to put it on without help may be excluded from the possibility of independent living, based on the CPAP therapy mask. Those needing care might then be expected to have someone on hand to assist them with putting a mask on every night. It seems that the mask may be the factor that tips the balance of care to requiring greater levels of assistance, which might not otherwise be required for everyday living tasks (e.g., if arm range of motion, finger and hand dexterity is sufficient to prepare meals, eat, wash and use the bathroom but not put the mask on).

9.5 Contextualising acceptable psycho-social impacts of CPAP therapy

The discussion above indicates that there are a great many people in need of CPAP therapy who have varying degrees of ability and mental capacity, which is in contrast to the advertising material from manufacturers. In the advertising and educational material, many

representations are of average weight middle-aged men and women, with few if any markers of disability (Visit Notes with Clinical Staff 3 see Appendix D). Similarly, reconsidering the historical data in section 7.4, a range of subject positions were excluded in defining the characteristics of potential successful users. Further investigation into this historical situation of CPAP therapy exposes relative improvement discourses that have been used to set the criteria for functionality. In response to questions of usability, Sullivan et al. (1983b) presented data to show a patient preference for CPAP therapy over tracheostomy⁵⁰, the only alternative for severe OSA at the time. In this discourse, the focus was on the patient's experience of CPAP therapy's ease of use, relative to the highly invasive alternative tracheostomy:

We now have 25 patients receiving home therapy; the longest duration of such therapy is two years. All these patients were given the choice of tracheostomy but chose nasal-CPAP therapy instead. One patient, a non-obese man, requested a change in therapy from tracheostomy to nasal CPAP. After experiencing approximately one year of each form of therapy he has repeatedly informed us in no uncertain terms that nasal CPAP is by far preferable to a long-term tracheostomy. He has found use of the nasal mask easier than managing his tracheal stoma. (Sullivan et al., 1983a, p. 112).

What this data demonstrates is that early CPAP therapy was only given to patients with very severe OSA. Clinicians considered that these patients were in close enough proximity to death to otherwise be prescribed a tracheostomy (Conway et al., 1981). Tracheostomy also raised demonstrable psycho-social concerns amongst clinicians at the time (Conway et al., 1981; Guilleminault et al., 1981) (see Table 6).

⁵⁰ Tracheostomy (also tracheotomy) is a procedure wherein an incision is made in the trachea (the airway to the lungs) and a curved hollow tube inserted, thereby providing an alternative airway that bypasses the vocal chords, upper airway, mouth and nasal cavities. See: Tracheotomy. (2018). In P. Lagasse & Columbia University (Eds.), *The Columbia Encyclopedia* (8th ed.). New York, NY: Columbia University Press. Retrieved from <https://networkservices.aut.ac.nz/ezproxy.cgi?url=https://search.credoreference.com/content/entry/columency/tracheotomy/0?institutionId=5349> .

Table 6. Psychosocial problems encountered in treating sleep apnoea with tracheostomy

	No. of Patients	
	Before Tracheostomy	After Tracheostomy
Disability	2	7
Depression	3	0
Adjustment reactions	0	6
Marital discord	0	2
Alcohol or drug abuse	3	3
Dependency	4	4

Source: Conway et al. (1981, p. 349)

In a memo, the US public medical insurance coverage decision body, the Centers for Medicare and Medical Services (CMS) (2008) advised that “[w]e are deleting the distinct requirements that an individual have moderate to severe OSA and that surgery is a likely alternative” (p. 1). In this way, CPAP therapy became available to many people for whom clinicians may not otherwise have prescribed it. Subsequently, clinicians can prescribe CPAP therapy treatment for significantly milder cases of OSA than those addressed in the original therapy development. In the past, clinicians would have been unlikely to prescribe tracheostomy in the absence of CPAP therapy as an option for these much milder cases, due to the severe psycho-social impacts of the treatment. Clinicians determined CPAP therapy as being preferable to tracheostomy due to its severe psycho-social impacts but, despite tracheostomy no longer being the alternative for many patients, the form of the treatment mask itself remains largely unchanged from early experiments. Clinicians now apply it to cases where it is likely they would not consider tracheostomy as a reasonable alternative.

9.6 Discussion

As may be seen from the data presented in this chapter, the data generation approach reached a number of subject positions that appear to be poorly served by the embodiment of the CPAP therapy mask. Definitions of ‘normal sleep’ can be shown to include both assumptions of a Western cultural frame of reference in terms of time and sleep patterns. The data also constructs ‘normal sleep’ as being based on an assumption of a masculine subject position within a Western context of women as the majority of primary care givers.

This construction of women as primary caregivers was further constructed by clinicians. In many cases “the wife” is seen as the first line of recognition of OSA as they are likely to be the first person identifying the problem and pushing their male partners to seek a diagnosis. Similarly, the strategy of getting the family on board during the diagnostic process is seen as helpful, and potentially ensures a transfer of techniques of surveillance in the family home as the wife is traditionally held responsible for the wellbeing of her children and a male partner.

Such findings were also reflected in a more recent study of the experience of OSA among older people in the New Zealand context (Gibson et al., 2018). In addition to issues of intimacy that are not helped by the presence of a CPAP therapy mask, clinical discourses around the bed partnership presented a tension between ideas of the bed partnership and individuating practices inherent in clinical practices. This finding is also reflected in what appears to be a growing recognition of the combined bed partnership experience in treatment of OSA (Luyster et al., 2016).

On the one hand, in clinical settings, the partnership was recognised, and its support enlisted to benefit the treatment process: “both partners need to be educated” (Clinical Staff 8 – see Appendix D), and, “It’s a good idea for wives to come into the clinic” (Clinical Staff 8 – see Appendix D). However, wives are also painted as possible barriers to successful treatment: “Some wives’ can’t stand the noise and complain” (Clinical Specialist 1 – see Appendix D). This contradiction between wives that help and wives that hinder highlights the ambiguity associated with mask design that focuses on the individual at the expense of their broader family assemblage. The underlying assumptions in the application of a mask as a solution to the ‘problem’ of disordered sleep are those of individualised independence, fixed working patterns and freedom from care responsibilities constructed through discourses of masculinities. Such forms were reflected in ideas around the privacy of sleep, physical abilities and the mental toughness required to withstand the psycho-social impacts of using a treatment that emerged as better than tracheostomy, a very severe alternative. Studying the data for constructions of excluded users was a process that made visible the assumptions about the CPAP therapy mask that were not visible to me through just considering the mask through the lens of the dominant discourses of ‘normal sleep’.

9.7 Summary

Chapter nine problematised the operation of discourses of privacy in relation to sleep and the use of CPAP therapy masks in terms of Western assumptions around sleep and stable intimacies. Examining discourses that construct the subject positions associated with non-normative sleep patterns made visible the differences in sleep patterns associated with nocturnal childcare and home duties historically associated with women. I found that power also operated on some participants through the discourses of labour division in relation to the CPAP therapy mask. Finally, the chapter addressed groups of excluded users, such as those who have dementia or reduced dexterity from age-related changes to dexterity. Such users could be addressed by the mask design but currently are not. This highlighted assumptions of independence and self-sufficiency inherent to mask design. Such values are also commonly

associated with historical conceptions of masculinities. As this chapter has highlighted, some dominant discourses shape mask design and the social construction of mask use. One such set of discourses that I have identified in both the 'successful user' subject positions (see chapter 7) and through my analysis of the subject positions outside those considered by mask designers (see chapter 9) is a discourse of masculinities. Chapter ten will consider the role of discourses of masculinities and the complexity emerging from the interactions of different and conflicting discourses as they were explored in the community market setting.

Chapter 10 Conflicting discourses for dominant subject positions and design strategies

If one tries to erect a theory of power one will always be obliged to view it as emerging at a given place and time and hence to deduce it, to reconstruct its genesis. But if power is, in reality, an open, more-or-less coordinated (in the event, no doubt, ill-coordinated) cluster of relations, then the only problem is to provide oneself with a grid of analysis which makes possible an analytic of relations of power. (Foucault, 1980, p. 199).

Chapter ten again addresses the findings from a power analysis of data collected at the community market exhibition. In this chapter, the data analysis builds on themes that emerged in chapter nine and chapter seven and is presented using the framework of a socially constructed theory of gender. Applying Foucault's approach of analysing the micro-operations of power in terms of a grid (Foucault, 1980, p. 199), I chose gender over a range of other possible social markers and frameworks such as wealth, class and ethnicity, due to its prevalence in the data collected and its identifiable role in constructions of breathing support for sleep. As the bulk of data included clear references to a gender binary and indicators of broadly heterosexual relationships, I analysed the data on this basis. This chapter considers the role of humour and teasing as a disciplinary technology (see section 2.4.3), the role of the subject in power hegemony (see section 2.3.2) and strategies to subvert marginalised subject positions. In this chapter I consider, *what is the role of masculine subject positions in constructions of appreciation, fear and aversion to CPAP therapy devices*.

Chapter six outlined how powerful norms and discourses of legitimacy have shaped the CPAP therapy mask. Some of these powerful norms also reflect dominant constructions of masculinity. Chapter nine outlined a range of subject positions outside of those assumed by the mask design which was also shown to subvert aspects of dominant masculine norms. In chapter ten, I ask, what is the combined effect of these powerful discourses, how do they interact, what are examples of the tensions produced and what are the discourses and subject positions drawn on to negotiate them. As a designer, I ask what I can learn from considering the complex interactions of dominant discourses on particular subject positions, and how might they be used to inform my design approach.

10.1 Situating gender as a frame of analysis

In this analysis I draw on post-modern and socially constructed ideas of what constitutes gender. For Judith Butler, gender is performative, meaning "that it is real only to the extent

that it is performed” (Butler, 1988, p. 522). Rather than being a fact in and of itself, the acts of gender generate the idea of gender, which could not exist without those acts (Butler, 1988, p. 522). Butler argues that “that certain kinds of acts are usually interpreted as expressive of a gender core or identity, and that these acts either conform to an expected gender identity or contest that expectation in some way” (Butler, 1988, p. 522). In this way, gender may appear to exist as a kind of core to identity that popular opinion may consider “the spiritual or psychological correlate of biological sex”, a concept generally based on the basic facts of primary bodily characteristics (Butler, 1988, p. 522). In line with Butler, this analysis questions the idea that an individual exists independently of their context. Instead, this analysis views data from the perspective that conventions, taboos and constructions of norms and others shape acts (Butler, 1988, p. 522). In this frame of analysis, rather than an enduring fact, gender is a construction performed or enacted in time, through which individuals stabilise personhood and become intelligible as people (Butler, 2011)

In this study, I have analysed masculinities as inherently historically located within ongoing processes of making and remaking in contingent political, social, personal and communal processes (Connell, 1995, p. 44). As Connell (1995) explains: “[g]ender is not fixed in advance of social interaction, but is constructed in interaction” (p. 35). However, rethinking the discursive construction of the body does not need to ignore the embodied experience of gender. The physical sense of gender has been central to gender, broadly and historically in Western culture (Connell, 1995, p. 52):

Masculine gender is (among other things) a certain feel to the skin, certain muscular shapes and tensions, certain postures and ways of moving, certain possibilities in sex. Bodily experience is often central in memories in our own lives and in our understanding of who and what we are. (Connell, 1995, pp. 52-53).

In constructing the analysis that follows I have avoided assuming a bodily basis of gender, while still acknowledging the role of the material in discourse in line with previous philosophical positioning (see 2.3.4). What power ‘does’ in relation to the material body is the metaphorical or discursive construction of the body. For example, in scientific and clinical discourse, the body may be articulated as a machine wherein it ‘functions’ and ‘operates’, and behaviour ‘mechanisms’ mean that brains are considered ‘hardwired’ to produce masculinity (Connell, 1995, p. 48). Such discursive constructions pre-empt discussion and shape the way evidence is read and interpreted (Connell, 1995, p. 48).

Using a primarily performative interpretation of gender means that there is a difference between 'being a man' and 'masculinity' as such. In this study, I work from the perspective that the social-historical construction of 'being a man' may be generated through a range, repetition and 'performance' of particular sets of material and discursive constructions of masculinities. However, masculinities may also be considered such through constructions historically associated with male behaviour. Such behaviours may also be exhibited by any subject position regardless of gender and indeed in support of aims other than producing gender. For example, adjusting one's sleep patterns to fit a 9 am to 5 pm working schedule is associated with discourses of 'masculinity', due to the historically and socially constructed role of an adult male as the 'standard' full-time worker subject position. The construction of the 'standard' full-time worker is in opposition to historically 'feminine' roles that have required combining work and caring, or working in care roles that are typically not limited to 9 am to 5 pm. In practice, women may work 9 am to 5 pm hours exclusively and men may work in care roles and as primary care givers in addition to working. However, these practices can still be described discursively as 'masculine' and 'feminine', regardless of the gender of the person performing them because of their socio-historical construction. While there are many ways to 'be a man' or any other configuration of gendered subject position, power operates through different discourses of masculinity (or other gendered discourses) to shape and regulate these different forms.

10.2 Hegemonic masculinities in relation to CPAP masks

The data presents forms of masculinity through references to physicality in the form of physically demanding work (e.g., Brother-in-law is a fireman, has OSA and CPAP therapy device (male); Concrete cutter, stops breathing in sleep (male)), sport (e.g., Interested passer-by, uses a mask for running (male); Man with possible symptoms, friend with CPAP mask) or active hobbies (e.g., Interested passer-by associates CPAP therapy with a diving mask (male)). In this study I understood these as references to a hegemonic form of masculinity. Hegemonic masculinity as a term embodies the most honoured way of being a man in a particular locality and at that point in history (Connell, 2005, p. 832) Hegemonic masculinity is not 'normal' in the statistical sense, as in the most common way of constructing 'being a man' as only a minority of men might enact it (Connell, 2005, p. 832). However, it may be considered normative in that all other masculinities are positioned in relation to it (Connell, 2005, p. 832). As Connell (2005, p. 832) puts it:

hegemonic masculinities can be constructed that do not correspond closely to the lives of any actual men. Yet these models do, in various ways, express widespread ideals, fantasies, and desires... At a society-

wide level... there is a circulation of models of admired masculine conduct, which may be exalted by churches, narrated by mass media, or celebrated by the state. (Connell, 2005, p. 838).

Hegemonic masculinities, like other discourses of gender in this study, are performative. Despite men on average being stronger than women, wide variance across tasks mean that this does not always hold in individual cases or for all tasks (Pheasant, 1983). Hegemonic masculinity, particularly as it proliferates through advertising has been constructed in terms of rugged individualism (Hirschman, 2003, p. 11). Rugged individualism in advertising features imagery of competition against self and others, solo performance, technology and machines, instrumentalism, nature and individual freedom (Hirschman, 2003, p. 11).

One participant, in speaking about his brother-in-law who had a CPAP therapy mask, explained he could not comment on his brother-in-law's experience: "I don't know... it's just sitting at home in a box now... but he used to have it when he was younger...he was a lot worse for it...it's not too bad now..." (Brother-in-law is a fireman, has OSA and CPAP therapy device (male)). This participant described himself as a scuba diver, which meant he had no problems with using a mask, but his brother-in-law was a fireman so "he's completely used to having a mask on his face," but he had trouble "when he was younger... I think it's because you know if you're claustrophobic that would be the worst thing for you" (Brother-in-law is a fireman, has OSA and CPAP therapy device (male)). People who constructed subject positions in terms of socio-historically masculine pursuits such as 'scuba diver' or 'fireman', articulated that masks were normal to wear in the context of those pursuits. As such they were comfortable and familiar with wearing masks in the context of these roles. They constructed a preference for non-use as being caused by other factors. In this case the construction of non-use was linked to claustrophobia.

Another participant with possible OSA symptoms identified his work as requiring a respirator to cut concrete (Concrete cutter, stops breathing in sleep (male)). He also presented using a respirator as part of, and appropriate to this role, and presumably while not necessarily physically comfortable, wearing a mask was considered normal in the context of his work. Conversely, in these cases the preference for non use of a CPAP therapy mask was constructed as being due to the restriction of physical positioning for sleep: "I need to sleep on my side... and open my airway" (Concrete cutter, stops breathing in sleep (male)). This is despite the pressure from the CPAP therapy device doing the work of opening the airway.

Many jobs involving the use of protective facemasks are male-dominated. Mask-using work includes the bulk of industrial site work, heavy industry, chemical manufacture and oil refining.

These jobs often involve shift work (see chapter 9), and may require a high level of on the job training (not least for adherence to safety legislation). They are often very well paid (in-part owing to a history of unionised activity and the societal discourses of the male breadwinner). Similarly, many of these jobs involve hard physical labour and require physical strength, which has been typically framed in terms of hegemonic masculinity. The solution to OSA being a device and a facemask (rather than a more discursively feminine solution such as a dietary or behavioural intervention for example), aligned it discursively with discourses of masculinities. This alignment was through the association of masks with forms of work and professions that are socio-historically constructed as masculine.

The mentioning of hobbies, in particular, the use of diving masks or snorkelling, was commonly related to male participants in the study. One participant spoke about how they felt comfortable around masks because they had used a diving mask (Interested passer-by associates CPAP therapy with a diving mask (male)). Familiarity with wearing masks was associated with masculine discourses of work and hobbies, which may extend to an improved tolerance for using prescribed medical mask products.

A number of participants made mention of rugby⁵¹ in relation to the CPAP therapy mask. Interestingly, the few other competitive sports mentioned in relation to masks were individual sports or hobbies, including cycling or running training (Interested passer-by, uses a mask for running (male)). The significance of a team sport (such as rugby) in this study, is its community-based nature. The effect of this was that there were more people involved in the sport and each other's lives in a way that was open to observation and comment.

In early scoping meetings with clinicians, clinical constructions of problematic or common OSA patients situated rugby players as a specific problematic subject position in relation to OSA. Rugby players⁵² were singled out and constructed as problematic, in part due to larger than average neck circumference being common in this sport and being a predisposing factor for OSA (Scoping Notes with Clinical Specialist 4 – see Appendix D). Similarly, particular ethnicities associated with rugby players and body hipetus was also noted in relation to OSA (Scoping Notes with Clinical Specialist 4 – see Appendix D). During market sessions, some participants

⁵¹ Rugby refers to the sport of rugby league and rugby union, both of which are forms of football involving two teams, traditionally played only by men. Rugby is of particular cultural significance in Aotearoa/New Zealand, see: Calabrò, D. G. (2016). Once were Warriors, now are Rugby Players? Control and Agency in the Historical Trajectory of the Māori Formulations of Masculinity in Rugby. *The Asia Pacific Journal of Anthropology*, 17(3-4), 231-249. doi: 10.1080/14442213.2016.1191530

⁵² Weight lifters were also mentioned in this respect; however, the focus is on rugby players in this discussion as they featured in the generated data.

identified themselves as rugby players. Their teammates or other players in their communities were also mentioned in relation to claustrophobia (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)), teasing about wearing a mask and reluctance to seek diagnosis or treatment in light of identifying possible OSA symptoms (Man with possible symptoms, friend with CPAP mask).

While clinicians presented rugby players as an identifiable group in clinical interviews, they did not mention rugby players in relation to problems with claustrophobia specifically. However, in the market setting, there was one specific reference to claustrophobia tendencies amongst rugby players. The participant identified the CPAP therapy mask headgear as presenting a similar experience to the protective headgear worn by rugby players during training and games: “I’ve played [rugby] league all my life, so I know what headgear does to a lot of people” (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)). In clinical settings, clinicians instead identified OSA patients that struggled with claustrophobia as more likely to be female. The combination of sporting culture, discourses of masculinity and the stigmatisation of help-seeking behaviours (as has been identified in college football players (Steinfeldt & Steinfeldt, 2012)), may have obscured this discourse in the context of male users.

In discussing the design of the mask, the medicalisation of the mask in the context of a masculine sporting identity presented a barrier to seeking treatment. One participant spoke of a friend who had struggled to come to terms with OSA and the need for using a CPAP mask in the context of enacting a ‘rugby player’ subject position (Man with possible symptoms, friend with CPAP mask). This participant’s friend had been teased in the change room of his rugby club, as other members had found out about his use of the mask. The participant’s friend had spoken about delaying seeking diagnosis or treatment for over a year and then the difficulty withstanding teasing when teammates found out about it. The young man recounting the situation spoke of his own possible symptoms and reluctance to get them checked out. He further added that despite this, it had helped him to hear of another’s troubles in this respect (Man with possible symptoms, friend with CPAP mask).

Data collected in the market highlighted the prevalence of responding to the mask appearance with jokes and teasing, which is the possibility that concerned the participant above. Several participants spoke of male users of CPAP they knew of that were teased for the appearance of the device:

[Man interjecting] ...kids call him elephant man!

[HC] You know someone that gets called elephant man?

[Man interjecting] Yes, and um,

[Woman speaks] geez more negative stuff hey! Haha!

- Another man interjects into conversation with Couple that know a CPAP therapy user (male and female)

[Man speaking] I don't know how your sleep with it, but it's like a Darth Vader mask, cause he's got one of those ones that's like a helmet

- Couple that know a CPAP therapy user (male and female)

I do have a good friend whose husband has sleep apnoea ... and he certainly doesn't like wearing and he has been the butt of jokes

[HC] just for what it looks like?

[Woman speaking] Like the whole Darth Vader, that... haha!

- Woman with good friend whose husband has sleep apnoea (female)

Even where teasing was not the focus, the associations of the mask with Darth Vader⁵³ from Star Wars were relatively common and demonstrated the pervasive nature of broader culture within communities: “they’d make fantastic, foundation pieces for star wars masks, haha! ...the evolution of Darth Vader... this is probably Lucas films, prototyping shots hey, you know!” (Knew a short-term CPAP therapy user who then had an operation (male)). Participants generally saw this kind of discussion as light-hearted and amusing. However, as discussed, the effect of even hearing about other men’s experience of teasing for at least one participant resulted in a reluctance to seek treatment and the demonstration of deep embarrassment about the possibility of needing to use a CPAP therapy mask. Darth Vader and other masked entities were also mentioned in clinical interviews but have received minimal coverage in peer-reviewed academic literature, particularly scientific and engineering literature related to CPAP therapy. The study by Ward et al. (2017) that also includes references to Darth Vader was a notable exception.

⁵³ “Darth Vader was a fictional character in the *Star Wars* franchise. He was a primary antagonist in the original trilogy.” Darth Vader’s breathing apparatus is iconic as is the sound of his machine ventilated breathing throughout important dialogue and scenes in this iconic film. See: Darth Vader. (2019). *Wikipedia*. Retrieved from https://en.wikipedia.org/wiki/Darth_Vader

Franzén and Aronsson (2013) explain the role of humour and teasing as an “important feature of (male) identity construction” wherein a male is expected “to be able to take a joke and ‘fight back’” (p. 168). In this way “the team” acts as a community standard, disciplining and enforcing the masculinity on men in ways that may be limiting constructions of health-promoting behaviours. This standard both creates and maintains the privilege and status of the group and its associated members, but constrains members’ freedom to seek help through the operation of teasing and stigma. Steinfeldt and Steinfeldt (2012) identified this mechanism as limiting help-seeking behaviours for mental health issues in studies of college men or in football or rugby related team sports.

The market data constructed the action of using a CPAP therapy mask as being in tension with maintaining a hegemonic masculinity in ways that wearing other masks was not. This was articulated by those familiar with CPAP therapy and also with those who did not identify a relationship to CPAP therapy masks. Some participants proposed strategies to try to address this tension by making masks more attractive to potential users. These suggestions were in some cases ideas to make the mask more ‘cool’. The ideas proposed referred to making the mask more evocative of other objects, particularly those that embodied values associated with masculine status, these included superhero masks, cars, aircraft, and sporting equipment such as for running training or diving. Notably, one participant suggested creating a mask that could be removed by tilting it up like a welding mask, or flicked up or unhooked like a fighter jet pilot mask (Interested passer-by, likes technology (male)):

[Man speaking] also if you can get a mask that’s moveable, so you can like pop it on,

[HC] like a welding mask or something...

[Man speaking] like a welding mask or like those fighter jet ones where you just clip it on ... but the welding mask is much better because you can just like, ... and just flip it down, and that’s it kind of thing... or you can design a mask which can like overlap each other... so it can go down directly, yeah so when you pull it up it’s just like a convertible

[HC] so it’s got the cool factor,

[Man speaking] yeah, yeah, sure or like that iron man mask, yeah, haha, see I am really into the technology

- Interested passer-by, likes technology (male).

Technical and masculine materials were used as a way to construct a 'cool factor' to make the mask more desirable for possible wearers. While there were a number of mentions of this strategy, taking one example, that of making a mask that lifts up 'like a convertible' (Interested passer-by, likes technology (male)), provides the opportunity to explore in more detail the way particular objects may embody values associated with masculine status. This exploration may also open the possibility of using such an approach in a design strategy aimed at resisting or easing the tensions that exist between using CPAP therapy masks and hegemonic forms of masculinities.

Making a mask that lifts up 'like a convertible' is evocative of a particular type of car. In an article for *Men's health*, car commentator Dan Neil (2010) explains the link between the desire for masculine cars and masculinity. In it he explains the attraction in terms of the way cars articulate and enable the expression of hegemonic masculine ideals. For example, Ellaway, Macintyre, Hiscock, and Kearns (2003) found that driving a car embodied feelings of "autonomy, protection, and prestige" for both genders, but the type of car was found to increase self-esteem only in men (p. 217). Car ownership is strongly correlated with access to resources and power and is seen to contribute to status (Jensen, 1999). Similarly, Neil (2010) argues that cars provide access to autonomy, express individuality, and allow a socially sanctioned form of solitude as well as acting to attract women. Cars and specific types of cars act to construct desirable characteristics of masculinity, such as the ability to provide for a partner or offspring, power, status and wealth. In the proposed approaches to making CPAP therapy masks more desirable or 'cool', the appeal was to these same values, with reference to the convertible as an expensive high-status car that projects the values of sought-after prestige. Similarly, the welding mask appeals to risk, skill and control of dangerous work processes. Firefighters and jet pilots also speak to the discourses of heroism, featuring the individuality, skill risk, danger, speed and accomplishment that exemplify powerful masculinities.

As has been discussed, the CPAP therapy evokes a range of complex responses in subject positions that have mentioned traits related to the formation of hegemonic masculinities, such as active and physically demanding work and culturally and historically masculine forms of sports such as rugby. Several participants spoke of wearing a mask as a normal part of doing work reflective of hegemonic masculine norms such as cutting concrete, firefighting or an active hobby such as diving or wearing a mask for running training. While these examples situated wearing other forms of masks as being a normal aspect of these activities and so wearing a mask should be 'no problem', participants also noted that this did not necessarily result in consistent use of a CPAP therapy mask for those in these positions. There was,

however, one set of discourses used in constructions of masculine subject positions that reacted more positively to the mask. In this group, participant perspectives on the CPAP therapy mask were characterised by discourses that are commonly grouped together as Science, Engineering, Technology and Mathematics (STEM). These discourses will be considered in the following section.

10.3 Masculinities drawing on discourses of Science Technology Engineering and Mathematics (STEM)

For participants drawing on Science, Engineering, Technology and Mathematics or STEM discourses of masculinities, descriptions and responses to the mask focussed on the high-quality engineering, markings of functionality, and the sense of the mask as being high-tech, practical and professional. This was also reflected in the findings from the existing product analysis outlined in chapter 6, where the CPAP therapy mask artefact was shown to respond to rational economic and safety discourses. Such characterisations exhibit a high degree of trust in the process and a rational focus of the mask manufacturers, and these constructions included identifying with a profession. The reference to a technical role was seen as significant to construction of particular forms of masculinity in light of the study by Connell (1995).

Connell (1995) argued that the last two centuries have seen a split in hegemonic masculinity from evolutions of the gentry⁵⁴ forms of masculinity, through the growing expertise in military techniques and their spread to other parts of the economy. Practices around physical dominance now exist in tension with practices related to expertise in technical knowledge. Connell (1995, p. 165) argued, as such, there is a tension not only between masculine and non-masculine discourses (such as feminine discourses), but also between forms of masculinity organised around direct domination (e.g. corporate management, military command) and forms organised around technical knowledge (e.g. professions and science). Connell (1995, p. 165) suggested that at the time of his writing, “the latter have challenged the former for hegemony in the gender order of advanced capitalist societies without complete success” and that they “currently coexist as inflections or alternative emphases within hegemonic masculinity” (Connell, 1995, p. 165).

In exploring masculinities that draw on STEM discourses, the concept of ‘a mask’ as ‘a normal part of life for some’ further emerged as gendered. Masculine subject positions cited work and activities related to the wearing of other masks or professions related to design (Machinery

⁵⁴ ‘Gentry’ masculinities refers to the practices of masculinity in England in the 18th century involving wealthy landowners, who took part in fighting duels to protect masculine forms of honour.

designer, wife stops breathing in sleep (male)). One male participant also self-identified as a university researcher (Passerby interested in research, University researcher (male)). Specifically, another participant stopped to explain the use of oxygen masks, as he was an airline pilot and to describe a particular type of quickly donned headgear associated with this type of equipment airline pilot (Airline pilot, uses oxygen masks for work (male)) (see also section 11.5).

[HC] what your initial impressions of that might be? ...

[Man speaking] that uh, ...at my age, I think practical, I'm not worried ... what it looks like it's how practical it is ... and ... I know, I think it would be a reasonable time...I think it's practical... if that makes sense?

- Airline pilot, uses oxygen masks for work (male)

The need for practicality and pragmatism combined with the previous mention of a skilled profession, such as one that might be included in construction of STEM discourses, typified a form of technically focussed masculinity. The use of 'at my age' as a qualifier (Airline pilot, uses oxygen masks for work (male)), combined with the professional technical competence associated with identifying oneself with a profession, pointed to a strategy of masculinities constructed through technical skill rather than physical prowess. Due to the reduced need for physical work in technically skilled and knowledge labour, the physical prowess associated with other hegemonic forms of masculinities may be de-emphasised. In this case, qualifying the comment with 'at my age' may indicate a construction of masculinity through technical mastery that does not require the ongoing exhibition of physical prowess.

Such characterisations of technical professionals are also communicative of masculinities long embedded in biomedical discourse, and typified, in the words of Shildrick (2015b), by the "rational, reflective, detached figure of the male philosopher", posited as "the ideal of masculinity" (p. 44). By way of contrast, the mask probe that resists this discourse of rationality and efficiency may be seen as reflective discourses of femininity. In such discourses (and commonly in the history of biomedical discourse), women were understood as essentially irrational, "rooted in a determinate bodyliness, unable to maintain a proper distance between subject and object, and not fully agents of their own will" (Shildrick, 2015b, p. 44). The framing of the CPAP therapy mask as desirable due to its careful engineering and clear scientific and technical development are reflect discourses of hegemonic masculinities that are likely to also be found amongst those working in medicalised product design and development teams.

Participants who were pleased or impressed with the current design of the CPAP therapy mask product cited the brand and general competence of manufacturers in their assessment and their trust of the CPAP therapy mask. A participant identified as a professional designer, but was not related to masks (see also Figure 47):

[Man speaking] I think that one is pretty cool actually if someone has to use it, as you say, that they're really suffering from that thing [OSA], that is pretty cool actually,

[HC] you think it's like pretty professional and that side of things,

[Man speaking] it's Resmed is alright... yeah the company and the brand you know, you know it's going to be pretty good if it's got a pretty strong kind of [brand/company] yeah.

- Machinery designer, wife stops breathing in sleep (male).

The appeal of the mask was through its professional appearance and trust built up in the brand. This reading of legitimated mask reflects a technical appreciation for the form as detailed in chapter six. While only a few examples emerged in the data collected, technical professionals are a group of particular interest in a design context due to the importance of STEM knowledge in medical product design, as well as product manufacturing more generally. Many design and manufacturing operations remain male dominated. Even for those that have employed women in increasing numbers, complicating factors including that women do not necessarily embody feminine discourses, limited changes to STEM education and slow rates of cultural shifts may mean that masculine forms of STEM discourses could still dominate internal perspectives and decision making. Such preferences may also extend beyond design and manufacturing, as one self-identified research professional also attested to liking the mask aesthetic for reasons of its professionalism, in particular citing its clean, clear appearance.

[HC] like that one better?

[Man speaking] Yes, I do, cause it's clear...

[HC] the medical one?...

[Man speaking] yes I do cause it's clear... because it looks more clear and professional and again this is subjective and aesthetic...

[HC] so you think it's quite important it looks professional?

[Man speaking] yep, yep

– *Passer-by interested in research, University researcher (male) (see Figure 47).*

Despite the mixed images in Figure 48, the presence of a bed other than a hospital bed appeared to indicate a degree of comfort with the idea of the mask in the home. Where many subject positions who expressed negative associations with the mask associated it only with the hospital bed, subject positions drawing on STEM discourses included images of beds and rooms more like those found in a home.

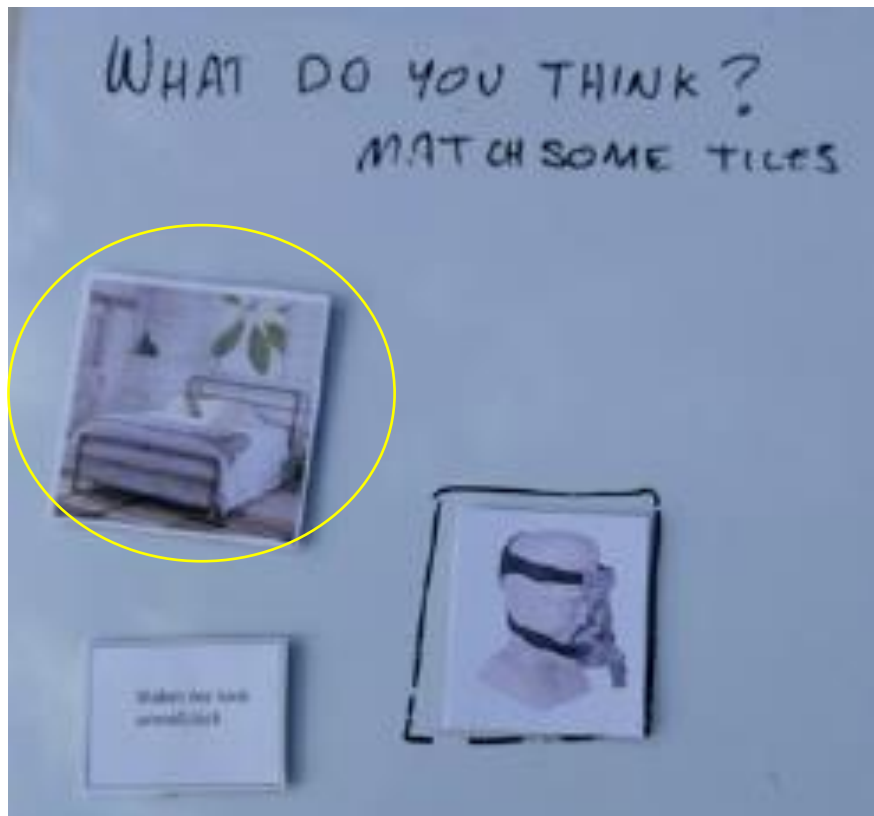


Figure 47. Market session design notes showing mixed mask associations.

Source: Author's photograph of cultural probe construction by market participant (Machinery designer, wife stops breathing in sleep (male)).

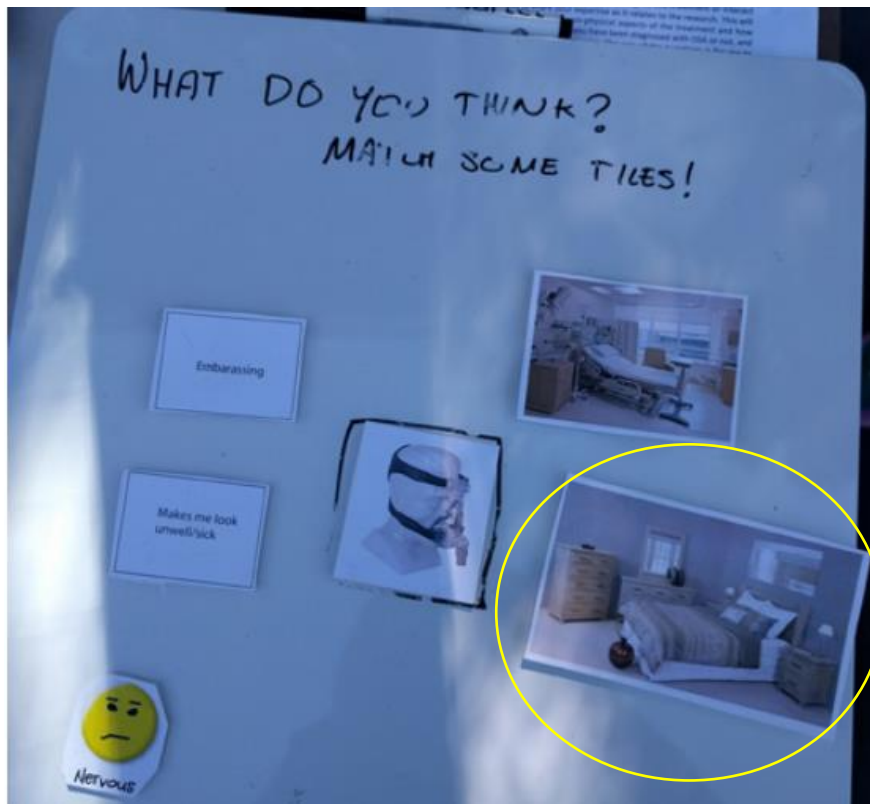


Figure 48. Images accompanying quote from market session design notes.

Source: Author's photograph of cultural probe construction by participant (Passer-by interested in research, University researcher (male)).

Participants' identification of a profession also acted as a type of social currency. As Connell (1995) further identified, the technical professional forms of masculinity may not experience the effects of community opinion and censure in the same way as other hegemonic masculinities. As will be discussed further in chapter eleven, the education system, which in many cases creates technical professional masculinities, is presupposed on the ability to travel and attend class as an individual. The result of this is a presupposed individualism that is likely to be reflected in technical masculinities.

As the previous sections have outlined, the market data has constructed hegemonic masculinities through discourses of physicality, but also through appeals to professionalism and STEM discourses. Hegemonic masculinities also present possible strategies for making the CPAP therapy mask more attractive to users by drawing on the values embodied in objects commonly associated with constructions of masculine status, such as particular types of cars or work related equipment. The following section explores the tension between these powerful discourses of masculinities embodied in the CPAP therapy mask and the discourses of illness also constructed in the design embodiment of the CPAP therapy mask.

10.4 Masculinities and the social construction of illness

As the preceding section has outlined, the CPAP therapy mask embodies discourses of masculinities that valorise physical prowess, individuality and STEM discourses. In contrast, the discursive construction of illness is constructed in terms of physical weakening, dependence and uncertainty that can threaten masculine identities. For a masculine hegemonic subject position a discursive construction of vulnerability (such as that associated with illness made visible through wearing a CPAP therapy mask), risks constructing the user in a marginalised subject position. In a similar vein, the very visible construction of illness embodied by the mask can mean these concerns become constructed as fear inducing or horrific. A male participant mentioned horror movie discourses in response to the mask appearance, because he preferred the mask probes to the CPAP therapy mask product: “[man speaking] looks more like the medical one [you get operated on], [or]... doctor death” (Couple that know a CPAP therapy user (male and female)), another spoke of the subject position the CPAP therapy mask would construct as “if it’s Batman then I think you look like a person that’s a baddy in it!” (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)). This sentiment was further reiterated in this same participant’s selection of tiles for the cultural probe construction shown in Figure 49.

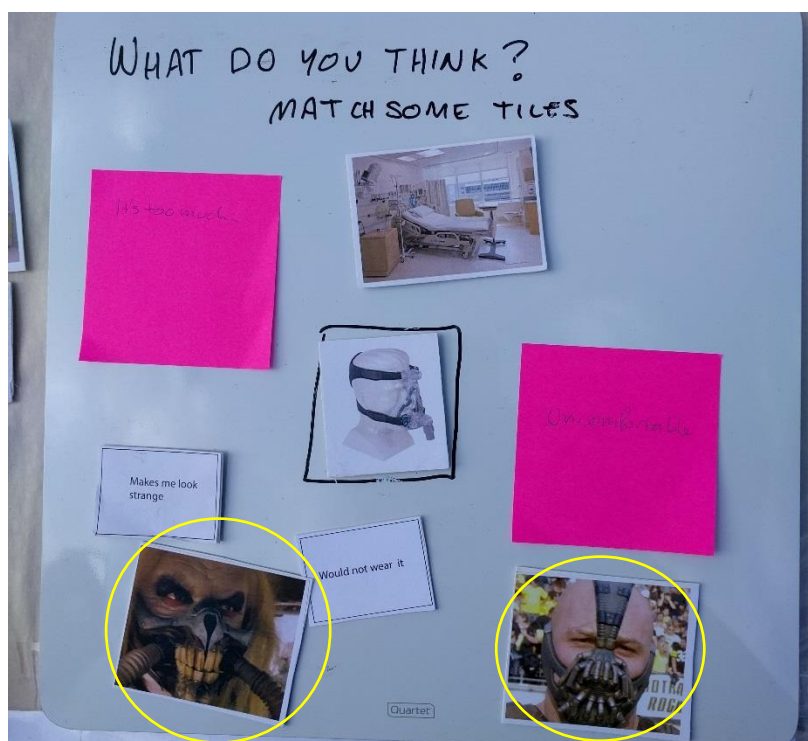


Figure 49. Participant cultural probe construction showing negative associations.

Source: Author’s photograph of participant’s cultural probe construction (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)).

Additionally, this participant perceived the CPAP therapy mask to be particularly medicalised, and also noted the crossing of boundaries associated with the mask that often accompanies constructions of horror: “but it’s on your face! Yeah, yeah, it’s breaking the personal barrier, or what do you call it? [like, personal space?] that sort of thing” (Interested passer-by, plays rugby and dives, saw someone use CPAP therapy (male)).

Margaret Shildrick (2015b, pp. 21-24) argues that perceiving such a threat as horrific, operates in a biomedical context through constructions of gender. The underlying construction of horror and the crossing of boundaries emerged in discourses of early medicine and is built upon assumptions of an individual, neutral, male embodied subject that has been considered the ‘normal body’ for much of biomedical history (Shildrick, 2015b, pp. 21-24). The body was considered as an “essentially socially isolated, self-contained mechanism” (Shildrick, 2015b, p. 20). This ‘normal’ (male) body is cast as a “stable, unchanging given, differentiated by its variable manifestation of the signs and symptoms of health or disease, ability or disability, normality or abnormality” (Shildrick, 2015b, p. 20). For Shildrick (2015b, pp. 21-24), through the history of biomedicine and even in phenomenology where the ‘whole body’ is considered, that body is still intrinsically masculine. The result of this is an ordering of knowledge in which women, by means of their positioning, are “never in full existential health” (Shildrick, 2001, p. 19). Against the backdrop of this essentially unchanging and discrete (masculine) ‘self’, “at the very simplest level, the monster is something beyond the normative, and stands against the values associated with what we choose to call normality and that is a focus of normative anxiety” (Shildrick, 2001, p. 37). This in turn frames a situation in which illness and deviation from discourses of normal health conflict with discourses of masculinities, resulting in a possible threat to masculine status. The response to this is horror (much like the perceived transgression of boundaries that occur in normal processes associated with women’s bodies (for a discussion see Shildrick (2001, p. 37)). In the context of normative hegemonic masculinities, women were seen as a corrupting threat, creating situations where constructions of masculinities come to operate in tension with their own vulnerabilities (Shildrick, 2015b, p. 45).

The powerful discourses shaping dominant subject positions were constructed to some degree by the marginalised form of the other, who may fall short of the masculine ideal in any number of ways. The idea of the ‘the other’ is explained by Cherry (2009) as follows:

The concept of Othering is related to identity, both in terms of the self and of society. The Other is central to definitions of identity since it is anything that is outside of or different from the self or the society... In

very simple terms, the Other is that which is separated off from ourselves by subjectivity. (Cherry, 2009, p. 107).

A dominant subject position at any time may be at risk of becoming ‘othered’ and losing whatever degree of privilege and standing their current position affords them. Given the risk to dominant forms of masculinity, it is perhaps not surprising that discourses of horror may emerge in relation to the CPAP therapy mask.

I just think the actuality of the mask sitting on their face, like young men especially, it's just not very sexy, and they can see, you tell them, that it's not going to fix it, but they have to use it for the rest of their life ... it just stretches out ahead of them I think (Clinical Staff 3 – see Appendix D).

As this clinician alluded to in their observation, and as Margaret Gibson (2010) argues, artefacts can be a conduit for such experiences, as they “mediate and produce death discourse just as death mediates and produces value and meaning” (p. 54). In this discursive frame, a relationship with a particular item associated with severe illness (see section 5.4) that is expected to persist throughout the remainder of one’s life may also be associated with an increased awareness of existential vulnerability, or one’s own mortality.

The market data constructed tensions between stable unchanging hegemonic masculinities and the vulnerability and uncontrollable shifts associated with possible illness and death. In addition to constructing these tensions, the data also constructed discourses relating to a desire to approach the mask in ways that reaffirm masculinity in the face of physical disability. These discourses were constructed in terms much like those described by Gershinck and Miller (as cited in Connell, 1995, p. 55), that included a preference for a treatment strategy that would allow redoubling efforts toward meeting the hegemonic standard, building on discourses of overcoming the physical difficulty.

[man speaking] I guess it's a bit like braces in a way you know,... you can go get braces, and you can wear them for two years, and it's done, or you can get that one where you have that strap on there,

[HC] oh the retainer,

[Man speaking] the retainer type, and you wear that for 3-4 hours, you know, but its 5-6 years before you're done with it. I think I'd just rather deal with the two years and be done with it and get it over

- Couple that know a CPAP therapy user (male and female)

However, with the mask as an ongoing treatment rather than building towards a cure, this illustrates an important difficulty in making peace between the CPAP therapy treatment and the ideals and strategies present in masculine discourses. Recovery discourses speak to processes that return the body to a pristine or original condition. Such discourses allude to returning to constructions of the masculine 'stable' body. Such discourses are in contrast with constructions of the embodied feminine which is marked by its ability to change shape through pregnancy and childbirth (Shildrick, 2001, p. 37). As Braidotti (2011) argues, the embodied feminine "is therefore capable of defeating the notion of fixed bodily form, of visible, recognizable, clear and distinct shape as that which marks the contour of the body" (pp. 225-226). In discourses where embodied masculinity is the norm, the feminine body and through discursive association other bodies operating in tension with masculine norms, become "morphologically dubious" (Braidotti, 2011, pp. 225-226). Similarly, empowerment and self-help discourses present a case for a short-term sacrifice that leads to ongoing change or improvement in terms of seeking a return to the masculine 'stable' body. While the CPAP treatment and support methods deal in both of these discourses, unlike the scenario with braces, the result of hard work to adjust to the mask, was also ongoing work that continued to use the mask and therapy. In many cases, with little hope of full recovery, chronic illness discourses developed similarities with negative discourses of ageing and associations with long-term decline.

In the case of the clinical interviews in this study, clinicians mentioned young men regarding this concern, but this may be due to the lower rates of presentation among women for CPAP therapy treatments in the literature (Young et al., 1993, p. 1230). For young men, discourses of illness and decline were strongly at odds with society's accepted ideal of the young, virile, masculine subject positions, required as they are to be invulnerable to weakness in any form. As discussed in the sections on rugby subjectivities, other young men, teammates or the broader society may address the appearance of any such vulnerabilities through the disciplining effects of 'good natured' teasing. The aim and effect of this teasing is to reinforce both the status and privilege of the masculine subject position while separating it from a feminine or childish 'other' (see section 10.4).

In another conversation, the participant puts the perspective that the appearance of the mask might discourage someone from seeking treatment, and that a fearsome mask such as the

Bane⁵⁵ mask would be preferable (see Figure 50, Figure 51 and Figure 52)⁵⁶. This participant had some possible symptoms of sleep apnoea and was wrestling with the idea of seeking treatment.



Figure 51. Negative mask association market probe construction.

Source: Author's photograph of cultural probe construction by participant (Man with possible symptoms, friend with CPAP mask).

This image has been removed by the author of this thesis for copyright reasons.

https://vignette.wikia.nocookie.net/batman/images/f/f0/Bane_TDKR3.jpg/revision/latest?cb=20120511112335

Figure 50. The Bane mask.⁵⁷

- Young guy 20s-30s – recording fail
- Appearance of the mask would put off people from seeking help
 - Likes Bane mask
 - Scary
 - Friend avoided doing it for ages, worried about what the wife might think
 - Confronting in a very intimate and personal space
 - Lots of people worry about snoring and sleep & embarrassed

Figure 52. Market notes describe the Bane mask as desirable.

Source: Author's photograph of own notes from interactions with participant (Man with possible symptoms, friend with CPAP mask).

With regard to the Bane mask, I have interpreted this as consistent with protest strategies such as violence and rebellious display in the face of disempowerment through an illness inferring mask. Interestingly, in this case, there was not the same appeal to or enjoyment of the technology embodied in the mask. It was seen instead as threatening and dehumanising. The participant saw the mask as potentially becoming a point of teasing amongst the participant's rugby team, an outcome that had anecdotally befallen others in the data (see

⁵⁵ The Bane mask was worn by a character in from Batman movie, *The Dark Knight Rises*.

⁵⁶ A data recording failure during this conversation meant that direct quotes are not available and notes made at the time and recollections recorded after the failure was discovered were used as texts.

⁵⁷ Source: Bane mask. Retrieved from <https://www.complex.com/pop-culture/2012/05/new-image-of-bane-from-the-dark-knight-rises-explains-the-origins-of-his-mask>.

section 10.2). He spoke of preferring the idea of a fiercer or deliberately grotesque design like that of the Bane mask (Man with possible symptoms, friend with CPAP mask).

On the surface, seeking a mask that is scary looking could be a personal preference. However, the idea of a fierce looking mask, or one that might seem to threaten the potential for violence, when considered discursively speaks instead of adjusting the mask to assist in the discursive construction of masculinity. The Bane mask, draws on depictions of masculine heroes in movies and in popular culture representations. Such heroes are depicted in a number of categories but are overwhelmingly men (Sparks, 1996). In children's media, men's power is glorified, with male characters shown as aggressive or assertive and more likely to work outside of the home (Schrock & Schwalbe, 2009, p. 283). Video games depict male characters as heroes and violent perpetrators, but depict female characters in video games as victims, sex objects or not contributing as much as men (Dietz, 1998, p. 438). The lesson portrayed through this construction of masculinity in media is that men "naturally command the attention and deference of others by virtue of their greater strength, daring, and capacity for violence" (Schrock & Schwalbe, 2009, p. 283). Similarly, in films aimed at adults, the "theme of the peaceful, gentle male who turns into a death-dealing warrior after suffering an unbearable outrage has been recycled often in Hollywood films" (Schrock & Schwalbe, 2009, p. 283).

Adler and Ansbacher (1964) described a concept or pattern of behaviour as 'the masculine protest', wherein a series of motives arise from "childhood experience of powerlessness and result in an exaggerated claim to the potency that European culture attaches to masculinity" (pp. 46-47). Connell's (1995) work sees constructions of masculinities with much in common with Alders' masculine protest. In these constructions "the difference is that it is a collective practice and not something inside that person" (as cited in Connell, 1995, p. 111). In these collectives, there is a response to powerlessness, a claim to a gendered position of power and a pressured exaggeration (i.e., gay bashing, particular forms of motorbike riding) of "masculine conventions" (as cited in Connell, 1995, p. 111). As such, "the effect is to construct a claim for power where there are no real resources for power" (Connell, 1995, p. 111). Interestingly, in Connell's (1995) sketch of protest masculinity, there also exists respect and attention to women, egalitarian views about the sexes, affection for children and "a sense of display which in conventional role terms is decidedly feminine" (p. 111). Connell (1995) describes one of his participants as: "bejewelled with tattoos, which he has planned and financed over the years with as much care as any vogue wardrobe" (p. 111).

I would argue that this sense of display extends to some sports motorcycle riding attire and the colourful, flashy nature of sports bikes. In a social system where the display is overtly feminised, masculine forms can flourish under the protection of a hyper masculinised mantra of 'live fast, die young' (Connell, 1991). A desire to construct a claim to power through overt display of a protest masculinity aesthetic appeared to be reflected in some instances in the market data (e.g., participants suggesting fearsome masks from superhero movies such as the Bane mask from *The Dark Knight Rises*).

The market data constructed complex interactions relevant to the design of CPAP therapy masks through a lens of gender and specifically through a focus on constructions of hegemonic masculinities. The masculinities constructed in the data were those associated with physical prowess and those constructed in terms of STEM discourses of technical and professional proficiency. The CPAP therapy mask has been shown to embody precision engineering and design to construct discourses of legitimacy. While this is desirable and appreciated in masculinities constructed using STEM discourses, the association with illness and potential weakness presents a threat to other hegemonic masculinities in the data. Specifically, masculine situated responses to the threat posed by the 'weakness' associated with illness was to suggest the design invoke a 'cool factor'. This approach involved drawing on masculine values embodied in objects commonly used in the construction of masculine status, for example, the mechanism that might lift and fold like the roof of a convertible car.

10.5 Discussion

In the data, discourses of scientific and technical appearance, as discussed in chapter 7 operate to both reassure but also to medicalise the mask. This creates associations with the mask that are desirable for some subject positions, but are fear and horror inducing for other subject positions. The form of the CPAP therapy mask is strongly evocative of medicalised discourses. For those familiar and comfortable with STEM discourses, this is seen as reassuring and professional. Within hegemonic masculinities, the obviousness of the relationship of the mask to discourses of illness, and consequently weakness or feminisation, presents a potential for loss of masculine hegemony, or a process of othering. Design possibilities that move away from STEM orientated discourses to reduce the obvious construction of medical-ness in the CPAP therapy mask will be faced with this tension. CPAP therapy masks that do not look medical may risk being read as untrustworthy or subversive in some respect. As it stands, discourses in the market data construct the mask embodiment as a threat to hegemonic forms of masculinity, to the point where some participants acknowledged that they would refuse to wear it, no matter how badly they needed to.

Building on the strategy of changing the heavily medicalised discourse in the mask embodiment, the data also raised the prospect of using technical and 'cool' factor design possibilities. These design possibilities contrasted with more feminine situated responses to the improving the mask design (e.g., seeking to make the mask more 'sexy', or less artificial and more 'natural') and offered particularly masculine situated approaches to resisting the tensions associated with the current 'medicalised CPAP therapy mask design embodiment. Drawing on values embodied in products already constructed in ways that are sought after or used to construct masculine status suggest new possibilities for mask design. For example, design references to particular kinds of cars, tools, and trade technologies and equipment can evoke discourses of masculinity. Similarly, possibilities may emerge from drawing on physical elements that are used in constructions of fictional heroes such as superhero masks, or equipment used by those in real-life roles that may include acts of heroism or masculine forms of prestige. For example, such roles and activities might include jet fighter or other pilots, divers (recreational, naval or special operations) or professional sporting equipment.

Subsequently, the masculine protest aesthetic presented one of the more interesting insights into the possibilities for design embodiments that may resist biomedical discourses. The 'live fast, die young' mentality identified by Connell (1991) would seem to be at odds with attending to any inconvenient medical treatment. Such subject positions create themselves as contrary and rebellious when successful patient-hood requires compliance, obedience and adherence to trusted and legitimated medical advice and a respect for authority. In the literature, this mentality constructs a marginalised subject position that in terms of a customer or patient for treatment would not only be difficult to serve, but potentially prone to treatment failure, so possibly not worth addressing specifically. However, as constructed in the data from the markets, protest masculinity discourses may also be desirable for those who identify with hegemonic sporting masculinities but find themselves marginalised through illness or injury. While these subject positions may have an interest in drawing on masculine discourses that allude to control of the means to violence, they may also be highly disciplined and socially well situated, with much to gain and maintain from enacting successful treatment.

Finally, by exploring the data in terms of gender, differences between masculine subjectivities likely to be approached for input into the design process were evident. Masculinities constructed in part through STEM discourses were likely to appreciate the mask in its current form. Importantly, this form of masculinity is likely to be involved in design and manufacturing decisions for making the masks or future masks. Hegemonic masculinities associated with physical prowess tended to construct the mask as potentially fearful or horrific. The data constructed these subject positions as members of communities, gaining community situated

masculine status through membership in sporting teams, making them more prone to disciplining practices such as teasing or ridicule. By contrast, masculinities subject positions constructed in terms of STEM discourses drew on their professional status or job title rather than community standing. By not situating themselves within a community they were protected from the dominance of masculine prowess discourses that might expose them to disciplining behaviours. Likewise, having the technical masculinity available to maintain their status, it was unlikely that such disciplinary teasing would have the same impact, as their masculine status could not be undermined in this way. Hegemonic masculinities, prior to seeking diagnosis for possible symptoms, may be under-represented in design discourses that focus on regular users, or manufacturing employees, family and friends for input to mask design and testing. As with the silence potentially constructed around the participation of young women (see chapter 8), these examples point to further 'blind spots' created by the heavily individualised and risk-based requirements that are definitive of current discourses of design for medical devices.

10.6 Summary

The findings of this chapter provide examples of the tensions that exist across discourses of masculinity as they relate to the CPAP therapy mask. Initially, the mask seemed well suited to masculine subject positions in terms of the 'successful users' and powerful masculine worker subject positions constructed through discourses of STEM. However, the marginalisation of particular sleep and work patterns for some masculine subject positions did not fit this bill. While, the CPAP therapy mask appeared to meet the specification and gained the approval of subject positions who value the rational, technical and crisp professional styling of the CPAP therapy mask considered in this study, these details also mark it out as a device that signals illness. For male users in particular, there is an interplay between the tensions and operations of discourse that cross over and subvert each other. The complexity of these interactions presents a real problem for designers of CPAP therapy masks, although (as has been hinted at by some participants) the complexity may also present some possible approaches and new insights that could help move the problems forward. A clear design consideration is understanding that discourses and the subject positions they construct do interact and subvert each other. Understanding that discourses situate experiences of devices and design embodiments with a range of subject positions is an important indicator of the limitations of seeking input only amongst successful users. The next chapter will consider in more detail how the data constructs illness and risk in relation to CPAP therapy diagnosis and use against underlying discourses of individualisation and risk.

Chapter 11 Mass production and healthcare - an individualising and totalising power

They are struggles which question the status of the individual: on the one hand they assert the right to be different and they underline everything that makes individual truly individual. On the other hand, they attack everything which separate the individual, breaks his links with others, splits up community life, forces the individual back on himself and ties him to his own identity in a constraining way. (Foucault, 1982, p. 781).

Chapter eleven is the final chapter discussing findings from a power analysis of data collected from the community markets. As well as the market data, this chapter draws on texts and the discourse analysis from preceding chapters that explored a broad range of discourses in relation to the construction of OSA and CPAP therapy masks. Chapter eleven explores one way of thinking about these discourses and how they operate. This discussion draws on Foucault's conceptualisation of discourses of individualisation and security/danger as necessary underpinnings of capitalist forms of government (Foucault, 2010).

The following sections address two key concepts: the individualisation and risk that were engaged with by Foucault and further expanded upon or refocussed by others who have followed. Combined with additional data, they further illustrate the issues facing CPAP therapy users, people who are facing possible OSA symptoms, and their communities.

11.1 Constructions of Individualisation

Beck and Beck-Gernsheim (2002, p. 2) describe individualisation as the process through which social forms and categories such as gender roles, family, class and social status become increasingly fragile and can disintegrate. Rather than being born into a particular station in life, as may have occurred in a traditional society built around religious structures, feudal or social estates, one must instead know how to be deliberately active in making an effort to do something to reach this life purpose and role (Beck & Beck-Gernsheim, 2002, p. 3). For people living in an individualised society, this effort must continue to be applied, day after day (Beck & Beck-Gernsheim, 2002, p. 3). Much of this thinking, planning and action must take place within a specified horizon in which new social arrangements place new demands on individuals. From the job market to the welfare state and institutions, requirements are applied to individuals as a network of regulations, conditions and provisos (Beck & Beck-Gernsheim, 2002, p. 2).

There are a number of features of individualisation that provide a helpful way of thinking about the operation of CPAP therapy discourses. As Beck and Beck-Gernsheim (2002, pp. 3-4) outline, the process of individualisation constructs features around individuals rather than families. For example, employment often presupposes education, which in turn both presupposes mobility or willingness to move.

By all these requirements individuals are not so much compelled as peremptorily invited to constitute themselves as individuals: to plan, understand, design themselves and act as individuals -- or, should they 'fail', to lie as individuals on the bed they have made for themselves. (Beck & Beck-Gernsheim, 2002, pp. 3-4).

A whole range of opportunities, risks and uncertainties that previously would have been pre-determined by family or local community station or rules must now be considered and acted on by individuals who each bear the consequences, both opportunities and burdens alone: "individuals who, naturally, in face of the complexity of social interconnections, are often unable to take the necessary decisions in a properly founded way, by considering interests, morality and consequences" (Beck & Beck-Gernsheim, 2002, p. 4). According to Beck's conceptualisation, individualisation is "imposed on the individual by modern institutions", because they take individuals as a starting point rather than families or communities (Beck, 2007, p. 681).

In one respect, Beck (1992, p. 132) argued that the individualisation process might be considered democratic in that everyone is individualised in the same way whether they want to be or not, without regard for gender, age, race, religion or other demographic consideration. This process is contingent with mass manufacture, market, and consumption systems, which then necessarily feature generically designed products, housing and lifestyles: "individualization delivers people over to an *external control* and *standardization* that was unknown in the enclaves of familial and feudal subcultures" (Beck, 1992, p. 132). Market dependency is a result of individualisation across the dimensions of living (Beck, 1992, p. 132). The new possibilities bring with them a massive demand for individual reliability and responsibility. Sørensen and Christiansen (2013) articulate Beck's conceptualisation as "an 'all-risk' individualization... which forces each individual to bear the weight of the global and collective risks and uncertainties on his or her own shoulders. Life becomes quite a risky affair indeed, filled with 'risky freedoms'" (p. 49). The following section explores examples of how constructions of individualised responsibility operate within discourses associated with CPAP therapy.

11.2 Illness as a challenge to identity, family and social standing

The health system addresses and tests the individual by making a note of all individual variation and unique differences. At the same time, the provision of the CPAP therapy mask may interfere with aspects of identity important to an individual's place as part of a community. They may become constructed in terms associated with negative stereotypes of a 'sick person', someone who is 'obese', or in poor control of their health. Furthermore, such an individual may become a target for the disciplining of masculine discourses through humour and teasing. The aims of such practices is to bring them back into a normative state. Similarly, the diagnosis process includes the normalising forces of comparison to a 'healthy, normal sleeper', the OSA sufferer becomes constructed as 'other' lacking in 'health', vitality and self-efficacy (Dickerson & Kennedy, 2006; Stepnowsky et al., 2006), .

Participants discussed a concern with looking sick, what it felt like to be on the receiving end of the perception, or connotations of 'being sick' in relation to the CPAP therapy mask or associated morbidities,

cause when you're feeling sick you have all those negative emotions coming up, ...people say 'oh poor you' they don't say, 'oh you look good and hopefully you'll be well soon'. Yeah uplifting them they tend to go oh poor you, what happened, and then you've got to relive, that empathy and that

- Social worker, disabled clients and those with mental illness and impairment (female).

In this description of other people's reaction to the appearance of illness, the participant describes sickness in social constructionist terms. Her prior self-identification as a social worker (Social worker, disabled clients and those with mental illness and impairment (female)), indicates the possible shaping of her interpretation by her exposure to social studies conceptualisations of illness. The power effects of knowledge act to frame the way she constructs this experience of illness. It further suggests the construction of illness as being a social process rather than purely physical (Conrad & Barker, 2010). In addition to negative stereotypes, some forms of sympathy can also be a difficult and challenging experience.

Some clinical approaches to supporting new CPAP therapy users identified getting additional support from family members. However, where patients advocate for solutions to CPAP therapy problems for both bed partners, this becomes problematic when dealing with an individuating framework of clinical (and manufacturing) discourses. For example:

I've had this guy go I think there's a problem with my machine making a noise and it's annoying her, and I think we need to do something with the machine...and it's like am I treating her or am I treating you? You're being treated properly, and there's nothing I can do about the machine (Clinical Specialist 1 – see Appendix D).

The device and its instructions target clinicians, users' and carers for the support and wellbeing of the patient. Troubleshooting, or adjusting the mask or air flow to benefit a bed partner is difficult to justify in the context of optimum individuated treatment approaches. However, it may be that an unhappy bed partner would be motivation enough to stop the CPAP therapy user receiving a treatment that is already hard to tolerate. In an individuated approach such as this, adjusting the mask to help the bed partner, potentially providing a sub-optimum treatment setting, is ethically risky for the clinician. It does not appear that there is a framework through which a clinician can weigh the potentially increased likelihood of continued use (if the bed partner is happy) against the risk of eliminating fewer apnoea events if the settings are changed.

Anecdotally, there was evidence that some male patients expect that their wives will do the cleaning of the mask and machine ("that's the wife's department") (Clinical Staff 7 – see Appendix D). Other female CPAP therapy users constructed the mask as enabling them to get enough rest to then complete the cleaning and cooking tasks required of them after getting home from work (Former long-term CPAP therapy user (female)) (see also section 9.2). The handouts describing device use do not depict cleaning the mask as integrated with any other personal cleaning activities (e.g., brushing teeth) or general cleaning activities (e.g., washing dishes).

In examples where cleaning is not done by the CPAP therapy mask user, discourses of individuated healthcare treatment were in tension with discourses of family roles and some family assemblages. In particular, manufacturers and clinicians have primarily designed the healthcare device (as well as the diagnosis and treatment regime) with the individual in mind. However, in a home sphere or domestic family environment, the CPAP therapy treatment needs to exist within a family assemblage. The various responsibilities of the home might be borne by an individual living alone or distributed across the multiple bodies of family members or carers. For example, for a single person living alone, the tasks of cooking, cleaning, home maintenance and repair are likely to all be organised or carried out by that one person. In a multi-person home, these tasks would be distributed across several different bodies, and often in traditional family structures will be assigned along gender lines.

In this way, designers have included an assumption of individuation in the design and prescription of the CPAP therapy mask artefact assemblage (i.e., CPAP therapy product artefacts, including mask parts, consumables, packaging and instructions). The CPAP therapy mask artefact assemblage assumes that the person who wears the mask will also be responsible for cleaning, repair and use in fixed, consistent and stereotypical patterns. In current design discourses, a mask that was intended to be cleaned by a non-user may, for example, include a separate cleaning pack that could be removed and stored separately with other cleaning products within the home. The CPAP therapy artefact assemblage provided may even reflect the role of the person expected to undertake the cleaning and be (aesthetically and functionally) more in line with other domestic cleaning products (i.e., brightly coloured, with fish, star or dot patterns).

The data also constructed participants as seeking to resist the intrusion of the institutionalised form of the individual in illness treatment discourse and medicalisation. Participants articulated some of these resistance strategies in response to perceived medicalised discourses of the CPAP therapy mask and how designers might better navigate them outside of the clinical environment. When in a hospital visiting friends or relatives it is common to bring some items from home, such as pyjamas, pictures and other personal items to help make the person feel more comfortable. One participant highlighted that this process might also work in reverse with a highly medicalised mask design: “because you don’t want to put this, like you in hospital like that type of thing on your bed, haha... make your bedroom look like a hospital” (Interested passer-by (male)).

Paul Chamberlain of Lab4Living explored this tension by creating works in an exhibition that melded medical devices with objects from home using techniques of critical design (Chamberlain & Craig, 2017). Particularly expressive of the eerie nature of this tension was the *Infusion lamp* a traditional floor standing lampshade combined with a stainless steel stem, a medical telephone cord and a medical drip bag (Chamberlain & Craig, 2017). The sense of horror that comes from subverting boundaries and norms around the body is not limited to imagery of the body itself. Constructions of equipment associated with crossing boundaries in the human body can also elicit this same response (see section 10.4 and Shildrick (2001, 2015a)). However, such articulation of the tensions in combining the home with boundary crossing medical devices does not appear to have clearly translated into the legitimised scientific and clinical discourses that drive the definition and design of medical products that target users in the home. The image of Chamberlain’s IV lamp (Chamberlain, 2018, p. 88) operates as a provocation that I suggest is paralleled very clearly by the CPAP therapy mask that is used in the home every day and in hospital ICUs.

A number of participants resisted the medicalised form of the CPAP therapy mask, with some seeking to moderate the medicalisation expressed through the design of the mask embodiment. These participants argued for a mask that was more personalised and playful rather than being related to sickness:

[Man speaking] you know sometimes when people wear this kind of stuff, they feel like very sick,

[HC] you mean they're quite unwell when they start to wear it?

[Man speaking] Yeah, yeah, so it should be more like personalised or something ... that's what really make[s] you feel comfortable wearing it, like more comfortable, yeah, if you're like playing with it, not feeling that it's like a sickness like this

- Interested passer-by, likes technology (male).

In this passage, it is not just other's perceptions of an individual illness that may make people feel worse than they would otherwise feel. The device also participates in the construction of illness. In this example, the participant has constructed personalisation as a form of comfort, along with avoiding traditional constructions of sickness and medicalisation.

In contrast to the technical masculinities previously discussed that believed the mask must be well-designed and based on the brand and appearance (see also section 9.2), some participants resisted the idea that the mask already presented the best possible balance of factors or the peak of knowledge in all areas:

[Man speaking] My opinion is that definitely needs to be more research done to make that more, you know if they're making everything else smaller, faster and better,... you know what I mean,

[HC] like they can change the phone size and computers,

[Man speaking] yeah everything like that you know ...surely there's something that's more like that, maybe even, smaller tube you know, like that's quite bulky

- Couple, woman's friend's partner uses a CPAP therapy (male and female).

In addition to recent discourses of miniaturising technology, participants picked up on the rising trend of mass customisation discourses:

[man speaking] Well you know there's options for everything, so I mean why not have an option to have something... customise[d] you know, like that's a big part of your life hey?

- Couple, woman's friend's partner uses a CPAP therapy (male and female).

This participant's suggestion resists the imposing of institutional norms on the individual through the design of the worn medical device in the home.

Discourses of the 'sick role' emerged in the 1950s, and were articulated by Talcott Parsons in *The Social System* (Parsons, 1951). Parsons defined the socially constructed 'sick role' in terms of institutional expectations with two main rights and two main obligations. The rights of the sick person was to be exempt from normal social roles, and they were not to be held responsible for their condition (Segall, 1976, p. 163). The two main obligations held that they were obliged to get well and they should seek help and cooperate with the medical profession to do so (Segall, 1976, p. 163). The 'sick role' has been modified and critiqued extensively by researchers who do not credit it with being based on any empirical evidence, but rather developed from an intuitional perspective (Segall, 1976, p. 163).

Critics of the 'sick role' concept argue that it was developed in relation to acute illness, so is not appropriate for chronic or psychiatric illness, for which ongoing social responsibilities are common and may be desirable (Segall, 1976, p. 163). In the case of chronic illness, striving to get well may be futile and adapting to live with the condition is likely to be more realistic. Segall also identified 'the sick role' as affected by social, cultural and personal factors with the only common perspective across groups being that "to be ill, is inherently undesirable" (Segall, 1976, p. 166).

In the CPAP therapy masks considered in this study, there was a strong sense from participants that the mask would construct the user as 'sick' or unwell due to its highly medicalised material choices and appearance. As this study shows, the 'rights' associated with constructions of the 'sick role' do not always apply. People who are overweight may be held responsible for their illness due to discourses of lifestyle induced obesity. The chronic nature of OSA means that many users of CPAP therapy are unlikely to recover in the short term, as may be the case with acute illness. It is perhaps understandable in this context that potential users would seek to reduce the association of the mask in their home to avoid the potential for being categorised as constructing what might be considered an 'illegitimate sick role'.

11.3 Constructions of risk and individualised responsibility

The word 'risk' covers a range of meanings in English, including from the dangers that people may encounter in different spheres of life (employment, health, legal) to the products that are sold by financial companies and other organisations. However, beyond the word itself, the abstract idea of 'risk' is even more complex:

the term designates neither an event nor a general kind of event occurring in reality (the unfortunate kind), but a specific mode of treatment of certain events capable of happening to a group of individuals – or, more exactly, to values and capitals possessed [...] by a collectivity of individuals: that is to say, a population. Nothing is a risk in itself; there is no risk in reality. But on the other hand anything can be a risk; it all depends on how one [...] considers the event. As Kant might have put it, the category of risk is a category of the understanding. (Ewald, 1991, p. 199).

Rather than being ever-existing and timeless, 'risk', like many other concepts and understandings, may be considered as a specifically and historically situated category. It exists and is produced in its current form by society in a particular context or "moment of emergence deeply linked to specific values, social groups and problems" (Burgess, Alemanno, & Zinn, 2016, p. 36). The experience of events as 'risks' does not occur spontaneously and rather requires a transformation linked through knowledges, practices, institutions, rules and authorities with which to govern these domains in terms of uncertainty (Burgess et al., 2016, p. 36).

Before the emergence of risk, theological certainties associated with determinist forms of fatalism dominated conceptions of the future. Specific conditions mean that the

experience of 'risk' emerged in the late twelfth century, within a particular context of negotiations between theology and mercantile practices. 'Risk' at this point implied the estimation of an uncertain gain/peril so that one could determine a price for it, exchange it or cover it in a legitimate contract. (Burgess et al., 2016, p. 37).

Risk in this period of emergence became a contractual concept legitimising the remuneration of those placing their capital or goods in what might eventuate as some temporal degree of peril (Burgess et al., 2016, p. 38). The potential for loss was what made the profit legitimate in the context of theological rulings that otherwise forbade the loaning of capital or taking of interest on such loans. In this sense, the taking of profits without the 'taking on' of risk, or clear elements of uncertainty or peril, meant that the merchant could be considered usurious.

Those attempting to manage risk and remuneration conceived of risk in terms of an agreement between parties with contractual arrangements.

While the seeds of current forms of population governance may be seen here, the application to broader population governance required further shifts in thinking. The idea of the individual as bearing their own risks, unless transferred to others through contracts for a determinate sum of money, was fundamental to the liberal model of responsibility (Burgess et al., 2016, p. 40; Levy, 2014). The liberal notion of responsibility was dominant through to the mid-nineteenth century in Western contexts (Burgess et al., 2016, p. 40; Levy, 2014).

The development of probabilities and statistical tools facilitated the possibility of articulating 'risk' based on the frequency of events when considered *en masse*. Risk became "integrated in various governmental practices that sought to govern events that may affect a population as a whole" (Burgess et al., 2016, p. 37). Such events might include morbidity, mortality or accidents. However, "the discovery that risks were actually potential events, whose probability was – at the level of population – almost as regular as astronomical laws, deeply modified this situation" (Burgess et al., 2016, p. 40; Ewald, 1991; Levy, 2014).

The newly enabled understanding was dissonant, holding the individual entirely responsible for themselves and their own categories of risk. Contingent with this conceptualisation of risk was the shift towards liberalism. The developing culture of risk soon became associated with a dramatic increase in disciplinary technologies inclined to manage this risk. Alternatively, as Foucault put it:

There is no liberalism without a culture of danger. The second consequence of this liberalism and liberal art of government is the considerable extension of procedures of control, constraint, and coercion which are something like the counterpart and counterweights of different freedoms. (Foucault, 2010, p. 67).

The role of constraint and personal responsibility for managing and avoiding risks is a key underpinning of liberal governmentality and a particular approach to making capitalism work (Foucault, 2010, p. 88). Next, I will explore these concepts further in relation to the CPAP therapy mask.

11.4 The risk of diagnosis and risk of use

Neoliberal constructions of individual responsibility mean that diagnosis becomes a risk for those with possible OSA symptoms. This risk is in part because upon diagnosis, through their ability to adhere to medical advice, people are at risk of becoming constructed as responsible

for causing their illness. The process that legitimises OSA diagnosis, combined with literature and community awareness, also constitutes the subject position of the neoliberal individual as being at fault. Thus, the potential CPAP therapy user is disciplined by their community to act on themselves in certain ways. In this situation, 'doing nothing' by, for example, not using CPAP therapy or even seeking treatment, may be seen as a position of unreasonable risk or of an irresponsible decision.

During the market exhibition data collection, several participants discussed their sleep in terms of potential OSA symptoms, but without seeking treatment:

[Man speaking] cause yeah, I just if I lay on my back, stop breathing and wake up with a mean headache and yeah, you know, fatigue yeah

[HC] sounds horrible

[Man speaking] and you're so tired all day

[HC] oh wow... did you get the test and everything?

[Man speaking] I didn't, no, but I don't need a test to tell me what's wrong! Yeah, yeah, I know! My wife wakes me up when I stop breathing, I definitely develop like very loud snoring

- Concrete cutter, stops breathing in sleep (male).

Participants framed reluctance to seek treatment as a reluctance to use CPAP therapy, due to a sense that it would not work or was not worth the effort. This view of the 'not being worth the effort' had the potential to obscure discourses of risk associated with using the CPAP therapy mask. For example, in the market sessions, I found discourses of risk and personal responsibility framed seeking a diagnosis and potentially failing to use it effectively as socially and personally risky to participants in several ways.

The market session data demonstrated how negative perceptions of what it means to need a CPAP therapy mask constructed discourses of individualised responsibility for health. In responding to how participants might feel if they were told they needed to use a CPAP therapy mask, discourses around disappointment were familiar. One group of participants explained:

[Woman speaking] You'd feel like kind of embarrassed and disappointed with yourself I think...because the only time that I've really heard of sleep apnoea is related to obesity and being heavily

overweight where you know it's all the pressure on your lungs... I mean essentially it's your own fault for letting it get to that point.

- Group of 2-3 young people (female).

Rather than attracting sympathy, patients were held responsible to themselves for their condition. The participants constructed obesity as being something people have actively created through their shortcomings as they have not maintained a healthy, able body. Consequently, those with OSA are essentially regarded as at fault for their illness (for critical discussion on the social construction of obesity see Cain, Donaghue, & Ditchburn, 2017; Dickins, Thomas, King, Lewis, & Holland, 2011).

Additionally, discourses in the data constructed CPAP therapy users who under-used the therapy as responsible for their death in ways that those undiagnosed with OSA would not be. Examples of discourses associated with OSA sufferers who have died after being provided with CPAP therapy equipment further illustrates the idea of personal responsibility for wellness that comes with being offered treatment.

[Man speaking] In my family, there's you know ...one of my cousins, she died and uh she didn't take her machine with her

[HC] so she didn't have it with her and then

[Man speaking] yeah, well her own fault ... still, you know, not good, but they get into a downward spiral, yeah it's pretty hard when it's getting harder to do stuff, ... it's hard on the body, and it's hard on the spirit and the mind as well hey?

- Wears a respirator for work, sister needed to use a mask (male).

Within neoliberal health discourses, society views personal behaviours as a key mechanism in creating good health. Not taking the CPAP device with her meant that her death might be considered a repercussion of her behaviour and choices (i.e., her fault), despite the complexities of the condition and treatment. The effects of the illness on the ability to exercise control over the body was acknowledged by the market participant but was not sufficient to override the powerful discourses of risk and personal responsibility associated with prescription and access to treatment.

At particular risk when seeking a diagnosis for OSA is the right to drive a vehicle. The New Zealand application of traffic laws are outlined in the *Medical Aspects of Fitness to Drive: A Guide for Health Practitioners* (New Zealand Transport Agency, July 2014, p. 112). This guide

advises that driving should be restricted or cease following a sleep study and if CPAP therapy is not or cannot be used to treat the symptoms as follows:

Driving should be restricted or cease for individuals who meet the high-risk driver profile, as follows:

- are suspected of having OSA where there is a high level of concern regarding the risk of excessive sleepiness while driving while the individual is waiting for the diagnosis to be confirmed by a sleep study
- complain of severe daytime sleepiness and have a history of sleep-related motor vehicle crashes or there is an equivalent level of concern
- have a sleep study that demonstrates severe OSA and either it is untreatable or the individual is unwilling or unable to accept treatment. (New Zealand Transport Agency, July 2014, p. 114).

For commercial drivers the New Zealand Transport Agency guide *Medical Aspects of Fitness to Drive: A Guide for Health Practitioners*, acknowledges that OSA symptoms may be underreported as detailed in the following quote:

Commercial drivers may spend long hours driving their vehicle, operate a heavy vehicle or carry many passengers. A crash involving such vehicles could place many people at risk. Suspected OSA should always be investigated by a sleep study. Symptoms maybe underreported, given the potential implications of driving restrictions. (New Zealand Transport Agency, July 2014, p. 114).

Commercial drivers, like non-commercial drivers, also risk having their license removed if they are found to have OSA that is untreatable or they are unable to tolerate the mask and accompanying treatment. Additionally, for commercial drivers, treatment and diagnosis may also result in restrictions to possible working hours or changes to shift work, both of which may be associated with loss of the higher remuneration associated with working non-standard hours. Possible restriction of work hours is a risk for commercial drivers with diagnosed OSA under New Zealand Government legislation. Guidance for when driving may occur or may resume is detailed as follows:

Individuals may resume driving or can drive if their OSA is adequately treated under specialist supervision, with satisfactory control of symptoms. Consideration should be given to the type of driving and hours of driving an individual undertakes. If there is any residual risk of daytime sleepiness, health practitioners should recommend a restriction in working hours or shift work. The Transport Agency may impose licence conditions for regular medical assessment. Medical follow-up may be delegated to the General Practitioner. (New Zealand Transport Agency, July 2014, p. 115).

Therefore the risk of diagnosis for commercial drivers is not only associated with a responsibility for one's health or death, but also potentially one's livelihood and ability to support a family or other dependents. As the quote above illustrates, once clinicians make the diagnosis via a sleep study, there is no way for a commercial driver to avoid driving restrictions without using CPAP therapy or otherwise proving the symptoms have subsided. Not adhering to treatment when it is a condition of a driving license would also void any insurance coverage in the event of a motor vehicle accident (in a similar way that driving over the permitted alcohol blood limit or without a vehicle warrant of fitness voids an insurance claim).

In addition to the risk of diagnosis, the data constructed risk of use as a facet of risk and individualisation. It is important to note that the treatments themselves are also not without risk, such as equipment fire from faults in electrical heating elements. While the medical equipment standard covers the risk of equipment failure, there does not appear to be a regulatory body that would attribute the risk of equipment that failed to prevent death to the manufacturer of that equipment. In all likelihood, where deaths occurs it would be attributed to the underlying condition requiring the treatment, rather than a failure of the treatment itself.

In some cases, it seems that using a CPAP therapy mask is not sufficient to construct the health outcomes desired. As discussed in section 11.4, where the death occurs through under-usage or poor discipline of the user's body to the equipment this is constructed as the responsibility of the user. Where the death is age-related, neither the device nor the illness appears implicated, nor is anyone else to blame. While the equipment manufacturers have carefully articulated the terms of use to avoid legal responsibility for the death of users that may occur while wearing the mask, community experiences may attribute responsibility differently, as this next example illustrates.

A participant explained that an uncle, for whom a clinician prescribed CPAP therapy using a mask, took the mask home, wore it once and died. The response of this group passing the exhibition was constructed through dismissive gestures, hand waving and head shaking, and bodily distancing themselves from the mask display. The impression from the group was that for them, the use of CPAP therapy masks could precipitate death, and they wanted nothing more to do with them. The risk of death from using CPAP therapy was not evident to me during the literature review and as such appeared to be quite low. However, deaths from OSA symptoms while using CPAP therapy with a mask (that should be removing symptoms) may not be well reflected in the literature. The death of the participant's uncle in the example from the market data could also have been unrelated to both CPAP therapy and OSA, but the

material coincidence was such that the social group attributed it to CPAP therapy or the underlying OSA.

The responsibility for one's death may not extend to the regular user of a CPAP therapy device who dies as an older person. In this case, it may be considered an age-related death. Considering the death as natural because it is due to age, is despite the potential for complications from OSA or other related co-morbidities. In this case:

[Woman speaking] a friend of ours had one, and they sort of used to have to carry it around if we went away or something... he'd have to carry it around and put it beside his bed, but he had a mask similar... well, he's passed away now but... yeah, he said he couldn't sleep without it, I mean I never saw it working or anything I wasn't really that close to him, but I know that he did use it

- Woman with possible symptoms and friend who used CPAP therapy.

Regular use of CPAP therapy coupled with advanced age could be considered to have absolved the user from responsibility for their death. Negative associations with the CPAP therapy device were not only limited to the potential for death, but also the negative effects that persisted through life. One participant talked about other people telling her not to use the CPAP therapy mask and treatment before she first encountered it, giving her a negative first impression of the CPAP therapy mask. The advice from people she knew drew on discourses of addiction. These discourses shaped long term mask usage as an unnecessary crutch or prop, that once used exerts unwanted control over the users' life.

[Woman speaking] Sometimes ... its other peoples are they telling you... not to use this...

[HC] why do they say that?

[Woman speaking] Oh I don't know, they said not to use it, and once you go on it then you get addicted to it

- CPAP user of 2 years (female).

The community member subsequently explained that they now understood this was misinformation, and that clinicians dispelled the myth of addiction during their first appointment.

Where those 'getting started' on CPAP therapy are addressed in legitimised scientific and clinical literature, those who have recovered from needing CPAP therapy have very little

presence in the literature. The few participants in this study who self-identified as having used CPAP therapy at one time for OSA expressed a degree of ambiguity around their health status. Former user subject positions cited lifestyle changes and losing weight as reasons for no longer needing CPAP therapy, or just using CPAP therapy occasionally. However, they stopped short of identifying themselves as cured or no longer suffering from OSA, focussing, instead on not needing or using the mask (CPAP user of 14 years, no longer using it (female); Former long-term CPAP therapy user (female)).

When asked if they no longer need CPAP therapy, one participant replied:

[Woman speaking] I should really [use it] but, I've lost a lot of weight, I lost a lot of weight I needed to lose, but, no, I did find the value in it, I did appreciate it when I finally came to terms with, you know.

- Former long-term CPAP therapy user (female).

The moral imperative implied by the use of 'should' in relation to continued use of prescribed treatment is constitutive of the neoliberal individual. This responsibility for producing and enacting one's health is not only a construction of academic and scientific literature (Dickins et al., 2011); it extends to discourses enacted within community settings as a form of community expectation. Clinical narratives addressing OSA focus on obesity as an associated or aggravating factor. Losing weight may reduce the dose of CPAP therapy required, but does not remove the need for CPAP therapy entirely (Shapiro & Shapiro, 2010, p. 326).

Clinicians also describe patient difficulties with CPAP therapy use as often focussed on difficulties with having anything on the face due to claustrophobia, memories and triggers from abuse, and related difficulties (Clinical Specialist 2 – see Appendix D). Clinicians and researchers traditionally may have classed potential CPAP therapy users who struggle with treatment for these reasons as non-adherent or non-compliant. This classification implies that the CPAP therapy user is choosing to adhere or comply with advice, or not to do so. This framing holds them responsible for the decision to use or not use CPAP therapy. Discourses associated with negative judgements about health also hold people responsible for the choices that lead to higher body weights. However, there are emerging discourses linking higher rates of weight gain to the experience of trauma. For example, in *Hunger: A Memoir of (My) Body*, Roxanne Gay frames weight gain as a strategic response to dealing with the aftermath of sexual trauma (Gay, 2017). Similarly, a recent Christchurch longitudinal study found severe childhood sexual abuse to be a predictor for obesity later in life (McLeod, Fergusson, Horwood, Boden, & Carter, 2018). Underlying such a strategy (expressed by Gay (2017) as a largely

unconscious behaviour) was the idea that gaining weight can make one less attractive physically and also less attractive as a candidate for further abuse. Increasing bodyweight in this way is in tension with individuated responsibility discourses that frame obesity as the result of laziness or lack of effort and solely the responsibility of the owner of the obese body. Such discourses align personal responsibility for health through control of bodyweight and appropriate exercise as explored by Dickins et al. (2011). I propose that discourses of individuated personal responsibility may operate to constrain approaches to addressing non-adherence, particularly where they are related to experiences outside the control of the CPAP therapy user.

Practice innovations in other medical areas (e.g., dentistry) that aim to manage the after-effects of abuse in patients have reported success in treating patients by addressing issues of power in clinical interactions (Truu, 2019). While this is significant from a practice perspective, as discussed in chapter six, power interactions are also shaped by material choices (e.g., the role of transparency in some power interactions and the strong association of blue with Western protestant culture (see section 6.5)), meaning that this is potentially also a strategy that designers and manufacturers could address through design decisions.

11.5 Discussion

In the market sessions, the mask probes presented resistance to discourses of patient responsibility and risk. Foucault characterises this form of resistance as:

Opposition to the effects of power which are linked with knowledge, competence, and qualification: struggles against the privileges of knowledge. But they are also an opposition against secrecy, deformation, and mystifying representations imposed on people. (Foucault, 1982, p. 781).

The market sessions exhibited mask probes that resisted dominant healthcare discourses such as the importance of cleaning, preventing infection and bacterial growth. It further acted as a trigger to bring out the discourses discussed. The following example illustrates the operation of power to reallocate risk and responsibility away from the mask manufacturer.

As discussed in section 7.4, the definition of the normative user can be traced to the first articles providing evidence of treatment, which included the requirements for a “cooperative and a well-motivated patient” to “achieve” long term management of OSA (Rapoport et al., 1983, p. 462). These requirements were against the backdrop of the early attempts to use CPAP therapy by Wagner et al. (1983, p. 462), which resulted in the definition of potential

‘successful users’ as excluding the cognitively impaired, those non-cooperative with treatment and those with very high-pressure requirements (see section 7.4). Those removed from the pool of potential users were also likely to be those who had a traumatic response to sensations of restricted breathing, a situation that might also indicate a prior experience of trauma (see chapter 7).

While designers appear to have continued to excuse these subject positions from the therapy design criteria, they have not been excused by clinicians from diagnosis of the condition. Neither have regulators excused these subject positions from legal restrictions such as those that require them to be treated in order to continue driving (New Zealand Transport Agency, July 2014). With the removal of OSA symptoms by CPAP therapy found by Sullivan et al. (1981) and confirmed by (Rapoport et al., 1982) for users that fit the normative ‘user’ categories that the mask design assumes, the publishing researchers and clinicians confirmed the condition not only for the normative ‘user’ categories embedded in the design of the CPAP therapy mask, but for all people exhibiting those symptoms. Clinical literature has since constructed non-normative users as failing to use the treatment, despite researchers and clinicians never proving the treatment as effective on those unable to use the mask.

Similarly, there appears to be no requirement for manufacturers to provide usable solutions beyond those appropriate for the most profitable subset of the diagnosable population. For example, difficulty in navigating the CPAP therapy mask was mentioned a number of times, particularly for older or cognitively impaired users (Social worker, disabled clients and those with mental illness and impairment (female); Nurse that sees people using CPAP in post-op surgical ward (female)). An aviation professional at the market suggested that the quick-donning headgear design used for oxygen masks in the event of cabin depressurisation in commercial airline jets might also be a useful approach to CPAP therapy mask design (see Figure 53).



Figure 53. Inflating head strap from quick-donning airline pilot oxygen mask.

The head strap inflated fully using one hand can be slipped over the head and then deflates into an elasticised fit. Source: Author's photographs.

The speed, ease and limited range of dexterity required to fit the jet pilot's oxygen mask would tend to imply that such a solution would assist those with limited dexterity or ability to solve complex clipping and twisting issues that would fit their CPAP therapy mask more easily.

However, this solution appears not to have been implemented in mask design thus far. One possibility for why a kind of quick-donning headgear like that used in commercial aeroplanes has not been implemented in a CPAP therapy mask to date may relate to discourses of value, which I will discuss next.

Discourses of value are prevalent in retail product development contexts. Business discourses of value are particularly dominant in the development of mass-produced products and reflect the idea that an integral part of the design function is to improve a company's financial standing. Raymond Loewy (1893-1986) was a pioneering US Industrial designer and was instrumental in the development of industrial design as a profession (Schönberger, 1990). He articulated a turning point for the role of Industrial design when he was able to demonstrate to retailer Sears Roebuck that the industrial design of a product could "improve its function, use new materials, lower its cost, make it better looking and increase sales and profits" (Loewy, 1981, p. 204).

In Foucauldian terms, the notion of value is historically situated and discursively constructed along with the subject positions of those that engage with it⁵⁸. As critical design theorist Boradkar (2010) explains, "value takes on different disciplinary meanings as it is discussed in

⁵⁸ For a genealogy of value about co-creation see: Lopdrup-Hjorth, T. (2013). *"Let's go outside": The value of co-creation*. (Doctor of Philosophy PhD), Copenhagen Business School, Frederiksberg, Denmark. Retrieved from <http://hdl.handle.net/10398/8701>

the social sciences, philosophy, business and design” (p. 53). Discourses of value for design traditionally focussed around form and function. However (in Western contexts as manufacturing has moved offshore), the purpose of design has more recently become reframed, particularly in the *Experience Economy* by Pine and Gilmore (2011), as the need now is to “stage truly engaging experiences” where once physical products were the focus (pp. 285, original emphasis). In turn, this is reflected in new discourses of value “since products enable an experience for the users, the better the experience, the greater the value of the product to the consumer” (Cagan & Vogel, 2002, p. 62). As Pine and Gilmore state:

no one repealed the laws of supply and demand. Companies that fail to provide consistently engaging experiences, overprice their experiences relative to the value received, or overbuild their capacity to stage them will, of course, see demand and/or pricing pressure. (Pine & Gilmore, 2011, p. 35).

In terms of healthcare and medical products, the key complicating factor is that the user of the product is very often not the person assessing or choosing the product. The remote purchasing system effectively removes that patient’s consumer purchase power from the business equation or model. In enhancing value for healthcare products, businesses will see the greatest improvement to their bottom line where the purchasers of the equipment are satisfied. This satisfaction will at best only indirectly relate to the satisfaction of the wearer or user of the equipment. The split roles and widely differing subject positions of the professional selector/purchaser/prescriber and the private user of CPAP therapy masks complicates the role of the consumer in prescribed and insured healthcare.

Because the person buying or choosing the prescribed product is not the one using it, many of the theoretical assumptions about how design can operate to create value are inappropriate in CPAP therapy design contexts. Processes of legitimising CPAP therapy and the organisation of prescriptions and the health and insurance systems mean that market forces of supply and demand will not operate in the same way for manufacturers and consumers. They will not act to reduce sales for hard to use masks, or drive innovation or personalisation. In fact for some, products, CPAP therapy devices in particular, many reimbursement schemes require that only medically necessary equipment will be covered. For example, US Medicare patients must pay extra or in total for devices with additional features and a waiver needs to be signed by the patient to agree to this additional payment (Medicare Rights Center, 2019, para. 1). This type of provision limits innovation, as patients themselves must purchase any device that exceeds the basic requirements. Without full insurance reimbursement, improved designs would usually be outside the reach of the majority of users. As such, there is reduced incentive for

companies to innovate beyond existing standards of care. Profits will not necessarily increase to reflect added value due to the limits on compensation imposed by healthcare insurance schemes.

Under some business discourses, a potentially higher manufacturing cost of a new mask solution that threatens the product's profitability may be taken to mean manufacturers and designers should not pursue the mask solution (McKenna, 2015). The financial rationalisation for not pursuing the product may hold even for a highly profitable company, both for an illness that was defined by their current treatment method, and for a solution that could make OSA treatable for a group that is currently untreatable.

Despite this, courts, clinicians and manufacturers do not bear any liability for the cost of lost income for those CPAP therapy users whose main income source comes from driving commercially and who cannot use the current treatments. Many commercial drivers may be unable to continue their livelihood due to not being able to show they are successfully controlling their OSA using CPAP therapy. This under-use of CPAP therapy may indicate that clinicians have diagnosed them, at least in part, by using masks that may not have been made to work for them as potential users. In a sense, these masks are technically not proven for such individuals as a treatment.

Where clinical discourses commonly hold the patient responsible for their health and weight, what they do not hold them responsible for is making their own devices. As such patients are kept in a double bind, as they are held responsible for the use of a device the design, manufacture and efficacy of which they have no control or influence over. However, the design, manufacture, fit, aesthetic and related encroachment on their sense of self or community standing are effects of the same device over which they have no control or influence. The knowledge of manufacturing skills and production processes is a closely guarded secret, protected by legal and technical mechanisms. The knowledge fields of medicine, engineering and sciences are fields that require many years of advanced study merely to comprehend the language in which it is written. Biomedical design discourses thus reflect operations of power and the forms of knowledge used to support it are carefully controlled and supported by scientific, legal, financial and clinical discourses. As such patients are responsible for making the device work for them; they bear the responsibility for its failure, but have no control over design, manufacture or modification.

11.6 Summary

Discourses of risk and individuated responsibility position a diagnosis of OSA as risky. I have argued that discourses of individualisation and mass manufacture construct CPAP therapy failure as a risk to the patient rather than the manufacturer. I have shown how the operation of obesity discourses serve to enforce this responsibility, despite emerging discourses that this construction is an oversimplification. Formidable medical discourses of risk arguably construct the manufacturers' success in outsourcing both risk and responsibility for successful treatment. In turn, these discourses may discourage CPAP therapy users from exercising traditional property rights and agency in constructing or modifying their masks to make them more suitable for themselves or their communities.

Finally, I have considered discourses of individualised responsibility in combination with the successful user subject position as one way of thinking about discourses that shape the CPAP therapy mask. For those with possible OSA symptoms, seeking diagnosis without knowing that they can use the mask successfully was risky. The data showed that diagnosis combined with sub-optimal use of CPAP therapy could construct an attempted user as responsible for or contributing to their death or declining health in a way that remaining undiagnosed does not.

This chapter concludes the analysis of data from the community markets and analysis of the role of discourse and power in the shaping of CPAP therapy masks. The following chapter will review the knowledge contributions to design for CPAP therapy that have emerged from this analysis. Chapter twelve will also review the outcome of this study as an experiment in applying Foucauldian ideas of discourse, power and subjectivity to a personal medical product used in the home.

Chapter 12 Why does this matter for design? Combining post-structural approaches with design

This study was carried out in two stages, the first of which involved expert interviews with a range of sleep clinicians through connections at Auckland District Health Board. Based on these interviews, the literature review and desk-based studies, a co-design process was re-envisaged to be consistent with a social constructionist and post-structural concept of knowledge (Sanders & Stappers, 2012) (see chapter 4). For the second stage of this study, critical mask design probes were created and exhibited at a range of different community markets, along with interactive cultural probes. Market attendee interactions with the cultural probes and discussions were recorded and analysed concerning ideas such as constructions of legitimacy, norms, and the operations of power and subjectivity.

In addition to being completed in two stages, the inquiry also had two purposes. Firstly, it was about exploring the operations of power and subjectivities in relation to the CPAP therapy device. Chapters two to four address the question of *how Foucauldian concepts of discourse analysis might be used to explore the social construction of the CPAP therapy mask* including the translation of a philosophical basis to a methodology and then developing specific novel methods for this study. Chapters five to eleven address each address an aspect of 1. *How exploring the social construction of the CPAP therapy mask (and its design process) might assist designers in identifying and challenging 'truths' that are current and held to be 'self-evident',* and 2. *How knowledge of these 'self-evident' truths (or assumptions) might be used to explore new possibilities for breathing interfaces generally, and with a focus on CPAP therapy face masks and people on the spectrum of living with OSA specifically.* I have included a summary and discussion of findings in relation to CPAP therapy masks, users, materials, gender and individualisation at the end of the relevant chapters. For a review of these specific findings, please refer to each of the relevant chapter discussions.

The second purpose of the study was about exploring the use of a post-structural and discourse analysis approach in conjunction with a design process to address the three research questions. This chapter reflects on and evaluates the work presented in the previous chapters. Specifically, the development, application, significance, opportunities and limitations of using this approach will be the primary topic of the current chapter. This chapter provides a summary and discussion of the study undertaken and explores how the study has addressed the overarching question of *what a post-structural approach can offer design.*

12.1 Knowledge contributions to design for CPAP therapy knowledge

Insights from the previous chapters have focussed mainly on the results in relation to attitudes and constructions attached to the CPAP therapy mask. The first key result focussed on making visible the complexity and limits of current approaches to the design of personal medical devices. Human-centred and user focussed design processes have proven valuable for development in many product and design categories (Boradkar, 2010). In the context of a formal healthcare system, a user does not normally directly choose or pay for the products they use. Prescribed healthcare products differ from retail products in this respect. As discussed in chapter eleven, there is also an expectation in countries with universal healthcare that quality care should be equally available and accessible to all. This is at odds with business discourses where seeking out and supplying a niche market is a lucrative strategy. Applying this approach in a healthcare market leaves many people potentially underserved and with diminished health outcomes.

As discussed in chapter six and chapter eleven, some products are required by law to be prescribed by clinicians. In many cases, these devices are then purchased not by the user but by a hospital or health insurer. A key assumption present in most theories of design is that the person responsible for choosing and buying a device will often be the person that uses it. For prescribed healthcare devices used in the home, this is most often not the case. Standard retail market theory would advocate that an improved product will result in higher sales or valuation by the customer and a greater profit for the company overall (Boztepe, 2007; Cagan & Vogel, 2002; Kim, 2005). However, where insurers reimburse the cost of a product from an insurer, often there are requirements that only the minimum functional unit will be covered (see section 11.5). Additional features or improvements may result in a device that is not covered by a particular insurance scheme or procurement system. Changes and improvements to the product then become a risk to the manufacturer, rather than an opportunity. In this way, insurance reimbursement schemes may stunt development until all manufacturers convince insurers to improve their base model functionality at the same time (Medicare Rights Center, 2019).

This study has highlighted the limitations of human-centred or co-design approaches specifically for the design of healthcare devices for use in the home. Current design models and approaches such as the double diamond process (UK Design Council, 2019), co-design (Sanders & Stappers, 2012) or other forms of human-centred design provide little help in navigating the legislative environment of design for health. Within these complex webs, the user perspective becomes one small voice amongst many and as such has very little purchase

power, with the consequence being that a user's voice has little or no influence in the final design. The process of using a discourse analysis approach to design allowed me, as a designer, to map out and explore this system. Furthermore, a discourse analysis approach has enabled me to a certain degree to expose the strategies and constructions that are currently driving the medical device and manufacturing system. Using a post-structural analysis process opened the possibilities of using or adapting existing strategies, discourses and approaches (or resisting them), as an approach to navigating such a complex system.

12.2 Value of combining creative methods with a post-structural approach

The approach developed, based on Foucauldian discourse analysis, went some way to addressing what I came to perceive as the shortcomings of current models of designing healthcare devices for use in the home. A particularly powerful effect of using a broadly community-based approach to design research was that it uncovered perspectives that are not always accessible in the current research and design approaches. In particular, it is difficult to imagine a purely interview-based, more institutionally situated study that would be able to access the broad range of subject positions that engaged with the research in a community market setting.

For example, in early discussions with clinicians, the issue of how to get input from users who were unhappy with the CPAP therapy mask seemed intractable. The initial strategy planned to recruit study participants by an invitation letter from a sleep lab patient database. This approach was problematic from a number of perspectives. One issue was how to get a range of perspectives from a broad diversity of people (gender, ethnicity, age groups) within a manageable sample size. The method I subsequently applied in this study accessed a broad range of subject positions. This broad range of subject positions highlights the range that escape inclusion if product designers and design researchers focus solely on successful users and clinicians. The difference in perceptions of the mask between some successful users (pride and happiness) and some people with possible symptoms (fear and embarrassment) came as a surprise, but highlighted the usefulness of broad-based exploratory research.

The use of design and of cultural probes appears to have generated a level of interest beyond what might have been obtained using more traditional interview or survey approaches without props. The use of ambiguous artefacts created a discursive space more conducive to reaching subject positions that may not normally engage with traditional forms of health research (including patient interviews or surveys). The high levels of laughter present in the data indicated a level of enjoyment amongst participants, suggesting a degree of ease in talking

about what might have otherwise been perceived by some participants as a dry or discouraging topic.

I was surprised by some results that emerged from the analysis of the design probes. While I was aware of the legislative constraints when making the probes, and felt that the probes in some way captured the overly constrained nature of design for health. I did not anticipate the contingency of historical constructions of powerful subject positions in relation to material applications (see chapter 6). Using creative methods that were intuitive and subjective drew out unexpected insights. Results from creative methods, in combination with the post-structural power analysis, made visible the cultural discourses dominant in medical design that were previously invisible to me as a researcher.

The use of creative methods and creating provocative artefacts in response to a discourse analysis was a new approach. This approach stimulated discussion and created a space for participants to think differently and resist dominant discourses in ways that might not occur in a research format that did not involve artefacts in this way. For example, the DIY nature of the creative probes in section 8.3 created space for participants to express a desire to make their own mask as a way of resisting the disempowerment that came from waiting for testing or diagnosis. The discussions around manufacturing and sales distribution were also unlikely to have emerged from a discussion that did not involve the creative probes, as these artefacts effectively gave form to a different system of making (i.e., DIY). In addition to new knowledge insights, this study has demonstrated the potential for creative methods to be used as a research tool by post-structural researchers (including through partnership with those who do not identify as designers).

This research approach may be particularly suited to reimagining existing products. The potential of this approach is for insights leading to radical shifts in thinking, rather than the incremental improvement that is more commonly associated with human-centred design approaches (Norman & Verganti, 2014). Rather than creating new products from scratch by identifying needs, the research approach may allow for the re-envisioning of an existing product in a way that potentially shifts the category of the product. Research approaches such as those explored in this study may prove useful to continually test and make visible the underlying assumptions and limits of design research and product design approaches. Doing this would allow these discourses to be questioned, challenged and resisted. The aim of challenging discourses is to open space to move away from their unconscious reconstruction and seek new opportunities.

12.3 Methodological contributions

This study explored and trialled some approaches and techniques that are new to design research, particularly for the discipline of product design. Typically, analysis of design input or feedback is limited to thematic analysis in order to generate insights, particularly in design thinking approaches (IDEO, 2012). Analysis of the context of input is limited to clarifying or understanding the intent of the person giving feedback. Conversely, the use of a discursive framework emphasises social construction and analysis of the operations of power. Using this analysis method has resulted in a number of tools that may be useful in other studies of or related to designed products.

The first set of tools that I will discuss involves the use of theoretical lenses through which to view and interpret collected data. By applying a theoretical lens to the data, I aimed to interpret and contextualise that data in terms of the ideas and worldviews associated with the chosen lens (for detailed discussion of applying strategic lenses in the context of design and innovation see Dawans, Alter, and Miller (2017)). Inevitably, the data in this project was complex, which is likely to be case in other projects using this kind of approach. While using one lens provided a degree of organisation for the data, considering and overlaying different lenses allowed for a richer analysis as different factors emerged as intertwined in the analysis. Three important lenses used in this study were history, materiality and gender.

The first important tool for this study was using history as a lens. As design is a future-focussed activity, the use of history as a lens may seem initially counter-intuitive. Historical and cultural constructions can provide a way of broadly highlighting areas for further investigation that current popular views of the world may have embedded in the collective consciousness so thoroughly that they are largely invisible. For example, there is an elevated status of transparent materials in European history relative to non-European histories of materials. Material histories in countries such China, do not show a preference for or use of transparent materials to the same elevated level. The sociocultural and historical differences in use potentially opened this material up to widely differing associations and impacts for the different people who view it. While participants often interpreted these different impressions as 'individual preference' or a form of self 'expression', this does not necessarily mean that they are free from the operations of power. Cech (2013) demonstrated that similar 'personal expressions' or preferences might propagate from discursively shaped subject positions (such as constructions of gender) that then shape these preferences through discourses of identity.

As a second important tool, I also used materiality as a lens. When I applied a lens of materiality in combination with historical constructions of powerful subject positions and marginalised subject positions, it made visible a range of cultural assumptions. Further, this approach provided another way of thinking about what designers might frame as an intuitive process of material selection - one that others cannot easily challenge. Designers' 'finely tuned' decisions may be based on a 'designer's sensitivity' as to what looks or feels 'right' that can be difficult to articulate. This study proposes, by using materiality as a lens, that this sense of 'rightness' is historical and culturally situated. Further, I argue that power operates through this process, with discourses of particular materials developing in some instances through targeted advertising campaigns and historical design and manufacturing decisions for particular product groups. These, in turn, were used by designers and manufacturers to valorise some subject positions.

This difficult to articulate process may then act in ways that reinforce the 'expertise' of the designer. The expert designer may mean that those coming in contact with the design process or products have few tools and discourses themselves to articulate their response to such products. In this way, the designed product operates as a mechanism through which power replicates itself. As identified in this study, various subject positions may view the same set of materials very differently and feel in turn empowered, alienated, dominated, trapped or otherwise operated on by power. Further exploration of these ideas may go some way to untangling the complex associations people have with material constructions such as the CPAP therapy mask.

Finally, the use of gender as a lens was particularly relevant for this product, principally for the way gender maps onto the subject positions and patterns assumed in the design of the mask. Different gendered subject positions expressed different fears related to the mask. In relation to masculinity specifically, this study showed the importance of considering more than just a hegemonic masculine subject position. The more complex interactions were between discourses of masculinity and discourses of illness and vulnerability. Subject positions in the data constructed the complexity of navigating these discourses in terms of navigating processes that construct masculinity and 'being a man' in the community (e.g., through teasing and team sports). The complexity of these discursive interactions creates a problem that may be difficult for designers to navigate.

The non-normative user also articulated many assumptions about gendered ways of living that were reflected in the design of the mask (see chapter 9). Arguably, gender could be replaced by any number of other social categories, examples of which might include: wealth, class, age

or ethnicity. I chose gender in light of the data collected, as it presented a way of arranging and making sense of the data that provided a reasonable degree of coverage and organisation concerning the other factors present. Based on the data collection location and regime, gender was one of the few factors present in the data that could be determined by listening to recordings of conversations. A more comprehensive collection process may have allowed analysis based on other socio-economic factors but this would likely have undermined one of the perceived strengths of the study. This strength involved seeking to limit the imposed individualisation by deliberately not collecting data on ethnicity, age or income levels, socio-economic status and so on, except where participants volunteered this information.

In using the lenses discussed above, I have developed the following questions as a tool to help frame discussions for designers or other researchers without requiring a full and in-depth analysis of post-structural theory from first principles.

- What is the body of knowledges and practices that form the basis on which our conception of materials is constructed?
- What are the dominant and marginalised subject positions that include these materials in their construction currently, historically, and for different cultural or class groups across time?
- How else might these materialities be categorised, other than in scientific and technical categories? (e.g., opacity, historically associated with masculinity, glossy, matt finish and so on).
- Who are the recognised stakeholders for the product being studied? What are the knowledges and practices that define them as stakeholders? What are the practices and knowledge that legitimise them as important? What are the institutions and practices that perpetuate and build this legitimacy?
- Who is missing from commonly held ideas about who is a stakeholder for the product being studied? Do they have a pathway to be involved in this design process? How are they constructed as already included, not relevant, unrelated, unimportant or not included through their own free choice? In what ways could there be a socially constructed silence around these groups? What elements do they have in common with groups or people that are addressed by the current design process?
- Who is the key beneficiary of the product being studied? How do they come to be included in the product design brief? In what ways do they differ from the broader possible community? In what ways are they constructed as more powerful or important than other community members or users? In what ways is the product tailored to their

social or cultural situation? Is there a history or storyline that is more positive for this group than might be the case for other groups (i.e., gender, ethnicity, language, culture)? Does this device draw on, or combat, historical constructions or events that may delegitimise it?

The power of post-structural thinking is in its ability to help researchers/designers extend beyond the data and explore the effects of particular discourses. The questions above are intended only as a starting point. I found that for any particular design question I had in this study, the inquiry would extend beyond these preliminary questions, and in ways specific to my design question. I developed these questions against the backdrop of human-centred design theory as being socio-culturally situated and the exploration covered in this study. These questions are intended to be used as tools, or as an entry point into a process of inquiry. One aim of such an inquiry might be to seek to develop and adapt these questions further, away from and beyond the paradigms to which they originally responded.

In this study I aimed to explore the construction of the successful user as a new way to approach the design persona⁵⁹ as a subject position. With the user in such a key role in human-centred design processes, I focussed on how the data constructed the 'successful user' and provided insight into what was included, excluded, privileged and marginalised in the design process. The notion that the user is always the most critical voice in a human-centred design process reinforces and replicates existing power-knowledge structures. How the successful-user subject position has been shaped, through using the product and contact with the medical system, was made visible by considering the voice of the user against a range of independent and non-user perspectives. In light of this mechanism of power, many of the issues faced by those who feared the mask, or who said they would not seek treatment also became visible. Constructing product use as a continuum through time, rather than as a fixed persona (common in HCD approaches), provides a very different view of the product and its design and manufacture. Such a 'user' continuum may extend from 'unrelated bystander' to 'possible symptoms', 'in-process-of-diagnosis', 'potential user', 'user', 'former user', 'deceased user' and so on. Across this spectrum, the operation of discourses and systems that affect diagnosis rates, as well as success in use, become evident.

⁵⁹ Personas are usually concise snapshots of composite data from design research participants described as a fictional people, see Jones, P. (2013). *Design for care: Innovating healthcare experience*. Brooklyn, NY: Rosenfeld Media.

Further to exploring the 'successful user' I also chose to explore discourses that construct legitimacy and normative existences as a design tool. Exploring how legitimacy and norms are constructed by, or around, an existing product provides a way of situating and challenging design and manufacturing choices. In Foucault's conception, power will always operate in ways that appear logical and appropriate, and that are difficult to challenge. Exploring the construction of legitimacy and normativity around and through a product can render unstable the inevitability of some existing product design choices. Destabilising the inevitability of the current form helps in situating the product form historically and socially in a way that makes space for new possibilities.

Finally, I also chose to explore the role situating the self could play if used as a design tool. Designers practice a form of situating themselves concerning an area of research through exercises that explore the advantages of the beginner's mindset (Stefik & Stefik, 2005). The tools and lenses associated with exploring the beginner's mindset can also be applied by designers to themselves to interrogate and challenge their own ideas and assumptions. As a designer, I found that considering how my experiences and various social subject positions have shaped my approach opened up what I considered as constructing a legitimate process. I was then able to locate new possibilities for experimentation and exploration.

By way of summary, in this inquiry I have developed and applied a range of methodological approaches that design research literature has not previously articulated in relation to the form of a breathing support interface or medical device. These approaches have yielded new and unexpected insights into the social construction of the CPAP therapy mask in community settings. I have successfully used the methodological approaches developed and applied in this study to identify a range of possible processes operating in the community in relation to CPAP therapy. Through the operation of the processes explored, diagnosis may be delayed or avoided, CPAP therapy may be abandoned, used less than recommended or avoided by those who may benefit from using it.

12.4 Limits and tensions in using post-structuralism and design

I combined co-design, product design and creative methods with a post-structural philosophical approach in this study. The results have provided a range of insights that appear on face value to be have been unlikely to emerge if I had applied any one of these knowledges and practices in isolation. That said, some methodological tensions emerged when using this approach. These tensions resulted from combining an applied discipline focussed on the material world (such as design) with a post-structural approach that tends to be language and

social interaction focussed. I explore some of the limits and tensions discovered through this study in the following sections.

The first tension I found was that post-structural inquiry is 'written', but a design embodiment is 'made'. Post-structural approaches developed from language-based analyses and in many cases remain focussed on written language texts. As such, there was a limited analysis of physical artefacts and manufacturing based work to draw on. Similarly, academic publications have a high-cost premium on the use of images, resulting in a privileging of the linear format of written words in post-structural scholarship. Design has a much more visual educational history. Design is also relatively new as an academic discipline, and emerged with a mass consumption culture. Apprenticeship practices in more historical design education and production mean that written records of innovations in design practice and thinking are limited. Such written records have emerged only very recently. The effect of this has been to make post-structural theory challenging to read, and to apply to design artefact constructions. It is hoped that the written record of this study may provide a useful example for researchers to draw upon in the future. Similarly, the work produced in the field of Science and Technology Studies may lend greater support to this kind of inquiry for design intervention.

The second tension is that post-structuralism explores complexity, but by its essence, 'Design' must simplify. The strength of post-structural approaches is through the exploration of complexity. This rich exploration of complexity is in tension with design practice, which fundamentally requires simplifying and distilling complexity down to an essential core idea (in order for a design to be produced). The difficulty with this tension is that combining the two approaches results in an excess of data to consider. This data must somehow be stripped down to a point where it can be used to make something, without losing the richness, detail and complexity of the original⁶⁰. The problem with attempting this is that the detail that makes for the elegant and sensitive solution becomes smoothed out as the complexity is averaged out⁶¹. Published academic studies exploring post-structural approaches do not seem to offer any new insights or guidance into this issue, possibly due to the difficulties inherent in combining both theoretical and applied research development in one project.

⁶⁰ While a post-structural approach amplifies this issue considerably, excess complexity is also a problem in design, particularly when dealing with 'wicked problems', see: Conklin, J. (2005). *Wicked Problems and Social Complexity Dialogue Mapping: Building Shared Understanding of Wicked Problems*: Wiley.

⁶¹ Reportedly from a talk by Jewellery artist, researcher and designer Jayne Wallace, <https://www.jaynewallace.com>

The third limitation is that post-structural analysis will help create possibilities, but it will not help with decision making. The nature of post-structural analysis is the tendency to generate ever more complex and divergent explorations. For design, at some point exploration and analysis must stop, and something tangible must be created. Divergent and complex exploration within a finite process is a tension that requires strict management, and even more so when using post-structural approaches to support design objectives. Imposing an endpoint rather than waiting for one to emerge was essential. As a designer, I found that just as there is no ‘one way’ to analyse in a post-structural approach (see section 2.1), there may be no apparent or logical endpoint for exploring and analysing post-structural considerations. While a number of interesting avenues for analysis remained in this study, resource and time constraints required limiting the exploration. Once I had enough insights from my analysis to provide a set of responses in adequate detail to the research questions, I imposed an endpoint.

12.5 The risk of nihilism and approaches to managing it

One of the effects of the preceding limitation is that post-structural approaches can devolve into nihilism and the generation of excess possibilities. Many arguments in Foucauldian work lead to the question of agency. Some readings of Foucault’s work tend towards a spiralling nihilism about whether anything other than critique is logically possible, if not, then what? The conclusion for many of these is that all tends toward domination (Latour, 2004).

The scepticism and resulting neutrality or suspension of judgement associated with post-structural approaches such as Foucault’s, creates problems for fields such as design where ultimately action is required. At its most extreme, academic scepticism results in a paradox where one must accept that one cannot know anything, including that “we cannot know that we cannot know” (Durant, 1944, pp. 494-495). One way of approaching this tension is through considerations of possibilities (see section 10.5). Variations, iterations and permutations are all in the realm of possibility and do not require a judgement about which is preferred or superior. The creative exploration, generative or ideation phase of many design processes (often including tools such as brainstorming) is perhaps the closest disciplinary parallel to this way of thinking (IDEO, 2012; Jones, 2013, p. 289; Sanders & Stappers, 2012). Based on this study, I suggest that possibilities may be explored and created through a process of selection and judgement executed separately and potentially under very different paradigms. From a post-structural theory perspective, recommendations for action or decision making based on the outcome of a post-structural study is inconsistent with philosophical scepticism, the theory that real or certain knowledge is impossible (Scepticism/skepticism, 2019). Philosophical

consistency would normally require that practice operates in line with philosophical reasoning and underpinnings. The requirement for some pervasive philosophical consistency is a key tension in using post-structural thinking as part of a design process. This is perhaps not inconsistent with aspects of Foucault's own work and thinking. Arguably his involvement in political action highlighted shortcomings in popular analysis approaches, prompting him to seek new approaches. In this sense, political action led him to topics to analyse and also to ways of analysis (Deleuze, 1988).

In practical terms, there are ways of choosing and testing that can help with decision making, (in terms of defining the focus of the design problem to be addressed, but also the material choices and form of the design embodiment). However, philosophical inconsistency is more difficult to assuage. Design operates across diverse paradigms and epistemological considerations have often been omitted from design research reporting (Feast, 2010). This is in part due to the difficulty in positioning design knowledges (that emerged from a master-apprentice guild tradition) within epistemological traditions developed in service of other disciplines (Feast, 2010). The work may even be classified by others after it is complete (Feast, 2010). For design research, pragmatic approaches are common and in the case of practice based research solutions are often unique, locally applied, and fundamentally material (Yee, 2010, pp. 8-9). Where the outcome of the research is a suitcase⁶² that embodies the entirety of the thesis resulting from the design research (Yee, 2010, pp. 8-9), the need to translate knowledge through or across epistemological boundaries is very different to other approaches to knowledge (such as scientific research as opposed to qualitative forms of research where the philosophical basis affects how such knowledge can be applied - see Scotland (2012)).

While the findings from this study suggest that the CPAP therapy mask design 'eco-system' seems highly constrained, it may be acted upon in ways and along discursive lines outside of those legitimised in current ways of thinking. For example, some constructions of an individual agency may see designers acting within manufacturing companies to improve designs to better accommodate all possible users. However, as I have shown there is a fundamental disconnect, both practical and philosophical, between the purchasers of the device and those individuals

⁶² Daria Loi presented an innovative practice-based research thesis titled: *Lavoretti Per Bimbi: Playful Triggers as Keys to Foster Collaborative Practices and Workspaces Where People Learn, Wonder and Play* (RMIT University, Australia, 2005). "The thesis was presented as a suitcase containing participatory devices to enable readers to engage with the thesis in more than one way, including experiencing how the concepts and tools presented in the thesis turn out in the context of use." Source: Yee, J. S. R. (2010). Methodological innovation in practice-based design doctorates. *Journal of Research Practice*, 6(2), 1-23.

who rely on the devices for treatment in their own homes. The device's funding through bulk negotiated healthcare insurance schemes constructs the role of individual designers relationally and in service of the business enterprise that employs them.

The situation of individual agency⁶³, in a post-structural framework and as a relational form of agency, does not preclude interventions that aim to reach the input loops of manufacturing design firms. For example, academic analyses in published journals may make visible how design structures and approaches may be impacting upon CPAP therapy uptake for some groups. Rather than aiming to create a new product, a strategic intervention to influence discursive constructions may instead be a more appropriate design research goal.

As discussed in section 6.4, a design based suite of skills generated a great deal of discourse that shapes community understandings of material properties (e.g., 1950s print-based advertising aimed at women that linked plastics to hygiene). Arguably these same skills can be used to influence discursive formations in new ways. For example advertising, imagery, critical design, art and conceptual product design as well as more traditional product design, and approaches all participate in building new and changing discourses. In the context of design for health, (and considering design for health as potentially a new discipline) design can give form to or make visible new ways of thinking about what is possible in health and in so doing, help to open up and challenge embedded dominant discourses (in both design and health). Design actions that target clinicians, patients and the general public may also broaden the possibilities for CPAP therapy mask design. Design actions of this kind might, for example, supply visual aids (such as concept masks, or guides on how to articulate complex socio-cultural design feedback). Design interactions such as these may assist in articulating the constructions that make the CPAP-OSA-user-life difficult for those in communities that may not easily fit within the current constructions of the 'successful CPAP therapy user' or patient .

While one can argue the philosophical position that exploring the socio-historical construction of a medical therapy does not result in philosophical determinism, my experience was that it still led to (and eventually through) a place of nihilism. The experience of attempting a design project that appeared to preclude enacting any change was challenging. Design in its essence is about change and creating change⁶⁴. Design is also future focussed. At some point, using an

⁶³ For a discussion of individual agency see section 2.3.2.

⁶⁴ To design is to devise "courses of action aimed at changing existing situations into preferred ones." Source: Simon, H. A. (1988). The science of design: Creating the artificial. *Design Issues*, 4(1/2), 67-82.

approach such as this, a design researcher is likely to find themselves facing nihilism. The question will then become, how will they respond to this?

I found several considerations were important in my process of working through and situating the experience of nihilism within a design context. Current research on the human brain points to a negative perceptions bias that has been useful across the evolutionary process (Rozin & Royzman, 2001). While this disposition has served the human race well in some contexts (particularly in relation to a heightened sensitivity and attention to possible physical danger) it does not always provide the structure to navigate problems or challenges. It can also be challenged. In short, vision and inventiveness come down to optimism. Design is about the choice for optimism⁶⁵ (Kolko, 2013, p. 80). A way forward through nihilism is to focus on the question of what does this (e.g., discourse, situation, subjectivity and so on) make possible, rather than focussing too heavily on the contrasting question of what it constrains.

Further to this, I would add an observation that technical constraints have always changed and will likely continue to change. Against this backdrop of constant change, unrecognised discursive constructions can limit actualisation of possibilities long after the original technical limits have shifted⁶⁶. As such, discursive shifts spotted early may present significant opportunities. Additionally, as evidenced by the use of historical material discourses in creating subject positions in chapter six, discourses can be shaped by various forms of promotion and advertising. If, as a designer, I can recognise the constructions of discourse for what they are, they can be consciously resisted using the same design techniques that promoted the original discourse⁶⁷. Finally, recognition of existing discourse opens the possibility for radical shifts, rather than just incremental improvements.

⁶⁵ "Learning to iterate and variate leads to an appreciation of multiple outcomes. And in those multiple outcomes lies an optimistic future" Source: Kolko, J. (2013). The optimism of design. *Interactions*, 20(4), 80-81. doi: 10.1145/2486227.2486245

⁶⁶ For example, early designs of steel bridges used techniques that were used for making wooden carriages. The materiality and constraints had changed, but the design knowledge and processes lagged in the discourses of design for wood. Another example is 3D design software which reflects constraints of manufacture using lathes, milling machines, and other traditional mass manufacture equipment. New designs are possible in light of 3D printing processes that are not constrained by traditional manufacturing processes. However these are still being developed, as the design discourse lags behind the technology that can produce it.

⁶⁷ Powerful examples of this include the reclaiming of racial slurs or minority slurs by various groups for whom these words have come to be empowering and reinforcing rather than derogatory.

12.6 Opportunity and possibility

The philosophical tensions associated with decision-making and change in a post-structural framework were touched on in sections 12.4 and 12.5. In the following section, I will explore opportunities for addressing and re-considering these tensions and the subsequent generation of possibilities.

One approach to generating new possibilities within the current frame of discourse is to capitalise on discourses that have become evident throughout the study. Rather than taking design feedback and suggestions at face value, they could be contextualised within a particular discourse and then addressed from the constructions associated with that. For example, I would like to consider the participant who spoke about preferring a mask similar to the fierce ‘Bane mask’ from the Warner Brothers movie *The Dark Knight Rises* (2012). In this case, the mask drew on discourses of protest masculinity, violence and anger. While the mask may not need to look exactly like the Bane mask to appeal to this participant, one that embodies a range of these discourses may provide tools to further explore the possibilities of a discourse-based approach to design.

Deleuze and Guattari’s (1987) concept of ‘lines of flight’ may also provide useful opportunities for exploring possibilities. Rather than strictly drawing on the discourse referenced, there may instead be other approaches that can be spun out of the data or tagged on to other discursive shifts to generate lines of flight. For example, the difficulty with implementing an inflatable headgear solution (see section 11.5) may be down to the expense of the headgear relative to the high-profit margins of the current design. The rise of self-funded retirement plans that involve the bulk of individuals managing small share portfolios online has given rise to a new group of ‘activist’ shareholders (Gillan & Starks, 2007; Perrault, 2015). Shareholders could advocate for changes to company policy that along lines other than maximising profits. If, for example, predominantly elderly CPAP therapy users with activist representatives come to hold a sizeable proportion of the mask manufacturers’ shares it is possible that the range of CPAP therapy users targeted by the designer may expand, with new lines of design approach being pursued.

Broadening the terms of engagement may offer opportunities to develop explanations and interventions on a wide range of healthcare issues. The use of physical constructions in this study demonstrates its capacity to engage, challenge, explore and investigate the role of living with illness and living well. The range of people who interacted with the exhibition, compared with the range of subject positions in the peer-reviewed literature, demonstrates the

possibilities associated with a broadened approach. Exploring the mechanisms through which power operates at the level of devices and within the community, home, and clinic may go a long way to constructing new possibilities for intervention and support.

Importantly in this study, the constrained nature of clinical research became apparent. Similarly, the possibilities for design research to bridge and support the links between medical device manufacturers and communities also presented as both possibility and opportunity. Current healthcare models and clinical engineering design professionals are extremely skilled at responding to acute healthcare needs within the hospital or clinic. However, design as a discipline is well placed to lead research on questions of home and a community-led integration of devices. An even partnership combination of Design and Health rather than Design for Health is an exciting possibility. Developing expertise in community embedded research and design presents a great opportunity for improvements to long-term treatments of chronic illness and the support of living well.

Possible interventions based on this study may include developing a range of concept masks that visualise the ideas explored. These might be used to further the discussion of new possibilities. Developing tools and examples may assist the public to consider and critique design in ways that engineers can understand, but that speaks to the community-based issues many potential users face.

12.7 Contributions and emerging questions and avenues for future research

This chapter has provided a summary and discussion of the study undertaken and explored how the study has addressed the question of *what a post-structural approach can offer design*. The key contributions of this study have been:

- To show the constraining and enabling factors that have made the current situation possible.
- To make visible the research ‘blind spots’ contingent with these factors as a way to destabilise understandings of the current situation.
- To outline the way knowledge structures and assumptions dictate and impinge on design processes: for example, problematising assumptions around who designers and manufacturers should ask for input when designing new products/solutions.
- To make visible the processes and analysis that legitimise not only the data supporting design decisions but also the people who generate or use the data.
- To explore the mechanisms through which design shapes users and their feedback.

- To problematise current categorisations of materials and reframe them discursively, highlighting the issues caused by a narrow envisaging of what constitutes a material, as well as those properties considered relevant to design.
- To articulate and make visible the mechanisms through which knowledges and practices are used in the design and manufacture of a medical product to reinforce and continually reconstruct dominant discourses and subject positions.

This inquiry has contributed to knowledge by:

1. Developing a new approach that applies discourse analysis (building on Foucault's concepts of discourse) as an approach to design.
2. Using this novel, broadly community based approach, combined with creative methods that are intuitive, thereby making visible the cultural discourses dominant in medical design that were previously invisible to me as a researcher.
3. Showing there is value in considering much broader discourses than the scientific and medical understandings of products and their use.
4. Translating the process of analysis and ways of thinking into a form that allows researchers to think in new ways more quickly than they otherwise might have.

Research into alternative cures for OSA that focus on drug-based interventions and improvement of neck muscle function may produce improved treatments that do not require the use of CPAP therapy in the future. Similarly, shifting discourses around nutrition, exercise, food production and eating practices may at some point turn around the trend for a greater body mass and the larger neck circumference that is associated with OSA. In the foreseeable future however, the use of the CPAP therapy mask is an ongoing daily reality for a growing number of people. The opportunities and possibilities for improvement remain pertinent and valuable as long as the combination of symptoms continues. As such, questions emerging for further research from this study include:

- How can the findings of this study be articulated in a way that is intuitive and useful for those that might have the opportunity to shape the future of CPAP therapy mask design?
- How might design approaches be modified in light of this research to explore perceptions of other chronic illnesses and the stigma attached to device supported illness?
- How might changes to the material embodiment of the mask design affect the way it is perceived by those who may need to use it in the future?

The original aim, when I first approached this study, was to design a new mask. The study quickly became focussed on why it was so difficult to imagine a significantly different mask within the context of current medical device design. Current design approaches, such as the double diamond model, co-design and HCD provided little in the way of guidance for navigating the complex and constrained legislative environment typical of design for health. Instead, I found power and discourse useful concepts for finding a way of thinking about these issues. Along with assumptions of individualisation, they articulated for me much of the complexity experienced in the community in relation to these devices. A post-structural approach was key to finding a common language to deal with knowledges and practices as diverse as biomedicine, costume design, history, legislation, education, philosophy, co-design and making. The methods I developed and applied in this process were new for a product design study, and included resistance of dominant design practices and the use of history, materiality and gender as theoretical lenses. The application of these contextually novel approaches was key to drawing out non-normative users. Using a power analysis provided new insight into how the usual focus of clinical literature on treatment effectiveness and patient 'adherence' obscures the role of the CPAP therapy mask design and broader community context in discussions of CPAP therapy improvement. Similarly, examining the manufacturing context and legislative limitations uncovered underlying assumptions upon which the CPAP therapy mask design embodiment relies. This study highlighted the design limitations of not only focussing on the 'successful CPAP therapy mask user' but also explored the role of the 'self' as a design tool, including how it is shaped by design embodiments and clinical interactions. Bringing these aspects together in terms of powerful discourses and subject positions has resulted in insights both unexpected and, in retrospect, seemingly obvious. In short, it has resulted in new ways of thinking about CPAP therapy and design for health in the community. It has made visible the 'self-evident truths' embedded in design for CPAP therapy masks, and by so doing rendered them fragile and open to new possibilities.

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Appendices

Appendix A: Ethics approval documentation

AUTEC Secretariat

Auckland University of Technology
 D-88, WU406 Level 4 WU Building City Campus
 T: +64 9 921 9999 ext. 8316
 E: ethics@aut.ac.nz
 www.aut.ac.nz/researchethics



29 April 2016

Stephen Reay
 Faculty of Design and Creative Technologies

Dear Stephen

Ethics Application: **16/167 Strapping a hurricane to your face and trying to sleep: Foucault, discourse analysis and design for sleep apnoea therapy interfaces.**

Design for sleep apnoea therapy interfaces (short title)

Thank you for submitting your application for ethical review to the Auckland University of Technology Ethics Committee (AUTEC).

I am pleased to confirm that your ethics application has been approved in stages for three years until 28 April 2019.

Full information about future stages of this research needs to be provided to and approved by AUTEC before the data collection for those stages commences..

As part of the ethics approval process, you are required to submit the following to AUTEC:

- ☒ A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 28 April 2019;
- ☒ A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 28 April 2019 or on completion of the project;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.



All the very best with your research,



Kate O'Connor
 Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Helen Cunningham helenjcster@gmail.com

Appendix B: Participant consent form and information

Consent Form for Interviews

Project title: *Design for sleep apnoea therapy interfaces.*

Project Supervisor: *Stephen Reay*

Researcher: *Helen Cunningham*

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 29 June 2016.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a summary of the research findings (please tick one): Yes ☐ No ☐

Participant's signature:

Participant's name:

Participant's Contact Details (if appropriate):

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.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 29th April 2016 AUTEC Reference number 16/167.

Note: The Participant should retain a copy of this form.

Expert Interview Participant Information Sheet

Date Information Sheet Produced:

29th June 2016

Project Title

Design for sleep apnoea therapy interfaces.

An Invitation

Hi, my name is Helen Cunningham. I am currently a PhD student studying Art and Design at Auckland University of Technology (AUT). I would like to ask for your help with my research, which aims to find out what people with Obstructive Sleep Apnoea (OSA) and their whanau (or support people) actually want to improve their experience in healthcare and using Continuous Positive Airway Pressure (CPAP) therapy.

Your participation in this research would be voluntary and you may withdraw any time prior to completion of data collection on 30th June 2017. You may have been offered this invitation through your association with ADHB, but whether you choose to participate or not will neither advantage nor disadvantage you in with respect to ADHB.

What is the purpose of this research?

I am interested in using a Codesign process with OSA patients to understand their experience of living with OSA and CPAP and how I can contribute to making it better through design. The purpose of this research is to develop culturally safe and appropriate codesign session. find out what the needs of OSA patients are and produce a design that will help provide for these needs.

With your help the outcome of the research will be a prototype of my design which may be a new breathing interface and I will also publish results of the research in my PhD thesis and possible journal articles.

How was I identified and why am I being invited to participate in this research?

You have been approached either through my personal and professional networks, a support or community organisation you are associated with or because I approached DHW Lab, ADHB Sleep Laboratory and Greenlane Respiratory Clinic to ask if they knew of anyone who would be able to or would like to help me. You have been invited to participate because one of these organisations or contacts has indicated that you might be interested and willing to help.

What will happen in this research?

If you would like to participate in this research then I will ask you some simple questions about your experiences either in relation to developing inclusive codesign sessions or about patient OSA and CPAP (in some cases both). I will ask you to share your expertise as it relates to the research. For codesign development this will include asking you about your thoughts on appropriate group size and makeup, location of the sessions, appropriate activities, etiquette and protocols and how to approach potential participants and engage in a safe and supportive way. For Patient OSA and CPAP this will include asking you about your thoughts on the physical and non-physical aspects of the treatment and patient experience, details about the processes that take place that are associated with OSA, CPAP and patients, and any interesting observations you may have in relation to these topics. The aim of the questions is for me to understand your experience and perspective, there are no wrong answers and I am grateful for any thoughts you would like to share with me. You may also ask me any questions that you have about my research, or choose to end the conversation at any time if you change your mind about participating.

What are the discomforts and risks?

We don't expect there to be much discomfort or risk in this research; however, you may feel uncomfortable sharing your opinions with me.

How will these discomforts and risks be alleviated?

If you are uncomfortable with any question you may choose not to answer and will not be required to give any reasons. You can also choose to end your participation at any point, no questions asked. If your discomfort can be eased my more information, please feel free to ask me any questions you may have.

What are the benefits?

I benefit from this research by using the results to complete my qualification. I also get to practice my skills and gain experience running a project like this.

In return I hope that you will benefit from the opportunity to share your thoughts and experiences. You will also have the chance to contribute towards the improvement of OSA patient experiences of CPAP. I hope that this will benefit you in any future interactions you have with the department.

How will my privacy be protected?

You will be not be anonymous to me as the researcher which means that I will know your name and who you are. I will however respect and maintain your privacy and confidentiality.

For my PhD thesis no information that might be used to identify you will be included. Any information that I collect about you in the form of written notes from our interviews will be kept for a minimum of six years and then destroyed.

What are the costs of participating in this research?

There is no cost to you for participating in this research except for a time contribution. There is no mandatory time contribution, however it is expected that any interview session will take approximately thirty minutes and no more than an hour. You may be contacted at a later date for follow up interviews if your expertise is needed again in relation to the research. However, you will be under no obligation to participate in these further interviews and the duration of any interview sessions will be made flexible according to your availability.

What opportunity do I have to consider this invitation?

You will have as long as you need to consider this invitation to participate in my research. The decision is up to you, and if you do not wish to participate you will not be approached again.

How do I agree to participate in this research?

If you have considered this invitation and would like to participate in my research, you will need to let either myself (or the person who has supplied you with this information sheet) know. We will discuss the research with you including any questions you may have. If you are interested you will be asked to complete a written consent form.

You have the right to withdraw from this research at any point before 30th June 2017, no questions asked. Any data you have given will be destroyed. You also have the right to walk out of a session for any reason or to choose not to answer any questions that you are unhappy or uncomfortable with.

Will I receive feedback on the results of this research?

If you would like to receive feedback on the results of this research you may provide a contact email address where I will send a summary of my findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, *Stephen Reay*, *Stephen.reay@aut.ac.nz*, 09 021 9999 ext 6719.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, *ethics@aut.ac.nz*, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Helen Cunningham, *Helen.cunningham@aut.ac.nz*

Project Supervisor Contact Details:

Stephen Reay, *Stephen.reay@aut.ac.nz*, 09 021 9999 ext 6719.

Approved by the Auckland University of Technology Ethics Committee on 29th April 2016, AUTC Reference number 16/167.

Appendix C: Expert Interview Protocol

Expert Interview Protocol

Participants

The interviewees will be clinical staff or other knowledge experts working in the health system or otherwise associated with CPAP mask manufacture, use or design.

Interviews will take place in the expert's place of work. For hospital staff members who do not have an office space, an interview location will be found within the hospital that is comfortable for both the researcher and the participant.

Data Recording

Information will be audio recorded with the written consent of the participant. Information may also or alternatively be recorded in written note form by the researcher. This is a non-threatening form of documentation. It is suited to the nature of the research, as the information gathered will be relatively simple. The participant will be asked if they would like the opportunity to confirm the research findings from their interview which will be sent to them by email in summary form by the researcher if required.

Nature of Questions

Questions will be open ended and related to the expert's area of expertise as relevant to the research topics. For example, sleep lab staff may be asked about the processes that take place within their department, their own experiences, their observations of the experiences of people moving through their department and their perceptions of any unmet needs.

Sample Questions

- Can you give me an overview of the process/journey that Sleep apnoea patients go through within the department?
- Can you describe what your role is within the department?
- What is the nature of respiratory illnesses treated in the Respiratory ward?
- In your experience what kind of emotional state/s do patients and families experience during their time in the sleep lab, respiratory clinic or on the ward?
- What do you think the high and low points of the experience are for patients and their families?
- In cases where patients or family members are stressed, or upset what do you think are the main causes?
- How do you go about managing patients and family members in these kinds of emotional states?
- In cases where the overall experience is positive, what would you say are the main reasons?
- What aspects of your role are the most challenging and why?
- What do you think of the physical items, information, equipment available in sleep apnoea diagnosis and treatment? Which aspects do you like or dislike and why?
- In an ideal world what would you change about the way we design for sleep apnoea treatment?

Appendix D: Data table and label descriptions

Label ⁶⁸	Description	Data type
Clinical Staff 1, 2, 3, 4, 5, 6, 7, 8.	Clinical staff may refer to hospital, sleep lab, and clinic staff, particularly patient facing, may refer to sleep physiologist, sleep technician, therapy support roles including respiratory nurse, community liaison and others not specifically included under Clinical Specialist.	Anonymous expert interview recording, transcription and notes.
Clinical Specialist 1, 2, 3, 4.	Clinical Specialist may refer to specialist or management roles employed in sleep labs and clinic, including medical doctors and other with similar levels of clinical or management responsibility.	Anonymous expert interview recording, transcription and notes
Advocate 1, 2, 3, 4,	Advocate may refer to those not employed by the clinical sector who were approached to advise on cultural, social and patient considerations. Some advocates may be CPAP therapy users themselves.	Anonymous expert interview recording transcription and notes
Technical specialist	Technical specialist may refer to those expert in technical considerations relating to manufacturing, engineering design and performance of physical products, materials or processes. Technical specialists include university lecturers, manufacturing staff, design consultants, innovation specialists or	Written notes from scoping conversations.

⁶⁸ Broad categories have been used to protect individual identities as the sleep services community in New Zealand is small.

	others with detailed specialist knowledge.	
Scoping notes	Notes from scoping conversations.	Written notes
Visit notes	Sleep lab visit, notes about processes, procedures and documentation taken during scoping visits.	Written notes
Observation notes	Notes taken while observing sleep study or clinic interactions during scoping visits.	Written notes

Appendix E: Systematic review assessment materials

(NB. All data is quoted from listed source).

Author/year, Country, Quality	Study Design	Treatment, illness, setting and sample	Study Focus	Key themes & findings
Ando et al., 2015, UK, Quality Score: 7/10	Qualitative Original article Prospective longitudinal study, ideographic and phenomenological approach Semi-structured interviews	NIV Motor neurone disease Hospital Nine patients	Reasons for why 30% of those offered NIV treatment in a main study declined or withdrew. The threat to the self, the sense of loss of control, and negative views of NIV resulting from anxiety were more important to these patients than prolonging life in its current form.	Preservation of the self, negative experience with health care services, not needing NIV, maintenance of perceived self, autonomy, dignity, and quality of life.
Arnold et al., 2011, UK, Quality Score: 7/10	Qualitative Original article Prospective constant comparative analysis, grounded theory approach Semi-structured face-to-face interviews	Long term oxygen therapy COPD Community-dwelling Twenty-seven patients using NHS prescribed ambulatory systems	Patients with COPD on long term oxygen therapy frequently do not adhere to their prescription, and they frequently do not use their ambulatory oxygen systems as intended. Reasons for this lack of adherence are not known. The aim of this study was to obtain in-depth information about perceptions and use of prescribed ambulatory oxygen systems from patients with COPD to inform ambulatory oxygen design, prescription and management.	Participants reported that they: received no instruction on how to use ambulatory oxygen; were uncertain of the benefits; were afraid the system would run out while they were using it (due to lack of confidence in the cylinder gauge); were embarrassed at being seen with the system in public; and were unable to carry the system because of the cylinder weight. The essential role of carers was also highlighted, as participants with no immediate carers did not use ambulatory oxygen outside the house.
Ayow et al., 2009, Canada, Quality Score: 7/10	Qualitative Original article Prospective purposive sample, descriptive constant comparative case study, inductive approach Semi-structured interviews	CPAP Obstructive sleep apnoea (OSA) Sleep disorder clinics Eight patients	Perceived physical, psychological, and social factors that facilitated and prevented CPAP use.	(CPAP) therapy among adults with obstructive sleep apnoea (OSA) facilitators and barriers toward CPAP therapy, the way these factors were perceived were in opposition, social comparison and stigma. Patients were the recipients of negative comparisons and were stigmatized by their peers. Rejection seemed to drive patients to act in ways that would lead to acceptance from their peer group. The absence of supportive relationships has been identified by nonusers as a factor toward not using CPAP.
Bakker et al., 2011, New Zealand, Evidence level - IV (9/12)	Quantitative Cohort checklist Original article Prospective Observational study questionnaires	CPAP OSA A university-based sleep laboratory. 126 consecutively consenting CPAP-naïve patients	Aimed to investigate the influence of ethnicity on adherence to continuous positive airway pressure (CPAP) in a sample of New Zealand patients.	The disparity in CPAP adherence demonstrated between Māori and non-Māori can be explained in part by lower education levels and socioeconomic status.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
Borak et al., 1991, Poland, Evidence level - IV (7/12)	Quantitative Cohort checklist Original article Prospective Psychological evaluation study Detailed clinical Interview and questionnaires	Long-term oxygen therapy. COPD Home Forty eight patients, 34 males and 14 females, mean age 57 yrs with a range 34-75 yrs	Psychological status of COPD patients on long term oxygen therapy	The study demonstrated that the great majority of patients presented a high degree of anxiety, depression and psychological tension, bad low self-esteem and did not believe in the efficiency of therapy. The following factors were found: increased or high level of anxiety in 18 patients, increased or high level of depression in 7 patients, lack of life goals and conviction about inability to perform any work in 38, lowered self-esteem in 36, a feeling of high psychological tension in 34, difficult financial circumstances in 28, lack of confidence in the positive outcome of treatment in 24, very narrow range of interests in 24, loneliness in 22, and age above 60 in 20 patients.
Briscoe et al., 2010, Canada, Quality Score: 7/10	Qualitative Original article Prospective hermeneutic phenomenology Semi-structured, in-depth interviews	Long-term mechanical ventilation (LTMV) chronic respiratory failure respiratory out-patient clinic 11 ventilated individuals	Transition journey was revealed to be a time of psychological, physical, and spiritual challenge	"Sustaining self", complex nature of transition to technological reliance, 'Self' had become subsumed within the tyranny of the symptoms: feeling disembodied, Self in peril characterised what it meant to recognise one's nearness to death (a) making a decision, (b) being in the intensive care unit (ICU), and, (c) being ventilated. Having no choice, which was revealed to mean that they had only two options-ventilation or death compromised ability to communicate resulting in feelings of frustration, dependence, vulnerability, isolation, and a diminished sense of self: Awakening to a paradox, experience renewed energy or vigour, concurrent with new restrictions, struggling for autonomy. Life goes on with a reclaimed self. Living with uncertainty. Perception of a threat to control.
Carnevale et al., 2006, Canada, Quality Score: 7/10	Qualitative Original article Prospective Interpretivism, Zaner's interpretive framework Semi-structured interviews and fieldwork observations	Ventilation via tracheostomy or face mask (1) abnormal ventilatory control, (2) neuromuscular disorders, (3) spina bifida, and abnormalities resulting in upper airway obstruction Home 12 children	Daily living with distress and enrichment.	(1) confronting parental responsibility; (2) seeking normality; (3) conflicting social values; (4) living in isolation; (5) the voice of the child; and (6) questioning the moral order. Devaluation of the Life of the Child With Disabilities
Charmaz 1983, Americans, Quality Score: 8/10	Qualitative Original article Prospective symbolic interactionist, grounded theory approach in-depth interviews	Various Varied diagnoses. Cardiovascular disease, diabetes, cancer, multiple sclerosis, lupus and so forth. Home 57 chronically ill persons, two-thirds of the respondents were women.	Understanding the loss of self as a fundamental form of suffering in the chronically ill	A narrow medicalised view of suffering, solely defined as physical discomfort, ignores or minimises the broader significance of the suffering experienced by debilitated chronically ill adults. A fundamental form of that suffering is the loss of self in chronically ill persons, who observe their former self-images crumbling away without the simultaneous development of equally valued new ones. As a result of their illnesses, these individuals suffer from (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited and (4) burdening others. Social isolation is a major consequence of a restricted life.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
Charmaz 1990, USA, Quality Score: 6/10	Qualitative Original article Retrospective social constructionist grounded theory, theoretical and methodological discussion in-depth interviews	Various Different chronic illnesses Various	'Discovering' chronic illness: using grounded theory	A social constructionist version and application of grounded theory, grounded theory method which is presented as a method having both phenomenological and positivistic roots. These phases include: (1) developing and refining the research and data collection questions, (2) raising terms to concepts. (3) Asking more conceptual questions on a generic level and (4) making further discoveries and clarifying concepts through writing and rewriting.
Chasens et al., 2005, United States and Canada., Evidence level - III (9/11)	Quantitative Case Controlled checklist Original article Retrospective Quasi-experimental, multisite study of the effectiveness of CPAP treatment Secondary analysis of data from a prospective study	CPAP OSA Seven sleep centres 153 participants Secondary analysis of data from a prospective study	This study evaluated the effect of claustrophobia, an abnormal dread or fear of closed spaces, on adherence to continuous positive airway pressure (CPAP) therapy.	Some patients express claustrophobic tendencies when wearing a CPAP mask, especially when positive airway pressure is applied thus retrospectively differentiating adherent versus non-adherent users. Participants with poor adherence to CPAP had significantly higher claustrophobia scores than more adherent participants. Claustrophobia scores decreased over time thereby suggesting that exposure to CPAP reduces the severity of claustrophobia in some participants.
Currow et al., 2009, Australia, Evidence level - IV (8/12)	Quantitative Cohort checklist Original article Prospective 4 -year consecutive cohort Multi-variable analysis using binary logistic regression	Palliative home oxygen Refractory dyspnoea Regional community palliative care service Of the study population (n = 5862), 21.1% (n = 1239) were pre- scribed oxygen, of whom 413 had it before and after data that could be included in this analysis	Palliative oxygen for refractory dyspnoea is frequently prescribed, even when the criteria are not met. Little is known about how palliative home oxygen affects symptomatic breathlessness.	Oxygen prescribed on the basis of breathlessness alone across a large population predominantly with cancer does not improve breathlessness for the majority of people.
Dantas et al., 2015, Portugal, Evidence level - II (9/11)	Quantitative RCT checklist Original article Prospective randomised, controlled design. Patients were randomly allocated to an intervention group (IG) and two control groups (CG1 and CG2).	APAP OSA Sleep Disorders Unit 61 patients diagnosed with OSAS, meeting the criteria for APAP therapy	Investigated the effectiveness of a brief educational intervention using motivational strategies in treatment adherence among patients with OSA.	Brief interventions using motivational strategies can improve a patient's adherence to APAP.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
Doi 2003, Japan, Evidence level - III (7/11)	Quantitative Case Controlled checklist Original article Prospective Convenience sample Questionnaires	Long term oxygen therapy Chronic respiratory disease Department of Respiratory Medicine at the Osaka Prefecture Habikino Hospital A total of 144 patients receiving LTOT were compared with 100 chronic respiratory patients (RES) non- LTOT, and a control group of 51 healthy subjects.	The psychosocial impact of the progress of chronic respiratory disease and long-term domiciliary oxygen therapy (LTOT) was examined to develop an appropriate intervention strategy for pulmonary rehabilitation programmes.	The negative emotions ranged from 'feeling helpless', 'feeling being a burden and miserable', 'denying LTOT', and 'feeling dependent and anxious'. Carrying the oxygen device can damage one's body image and make one avoid meeting others. It is thus understandable then that those under LTOT tend to score low on such ADL items as 'going out', 'walking and shopping', and 'taking public transportation'.
Eastwood et al., 2009, Australia, Quality Score: 7/10	Qualitative Original article Prospective exploratory descriptive design convenience sample thematic analysis approach Face-to-face semi-structured interviews	Oxygen therapy (17 cardio-thoracic: 20 medical surgical) ICU 37 adult patients, 25 intensive care unit nurses	Patients' and nurses' perspectives on oxygen therapy	(i) Device comfort; (ii) ability to maintain activities of daily living; and (iii) therapeutic effect. With Nasal Prongs, patients felt that they were able to eat and drink more easily, but the device needed to be removed to blow the nose and some stated that their ears became sore because of the tubing being looped over them. Insertion of the NPO catheter was reported by some patients as uncomfortable, but, on the whole, NPO was comfortable and did not become displaced or mal-positioned as did NPs or FMs. With the mask you can't see beyond the mask...I don't think I would be able to read fine print. People don't really understand what you're saying, so you have to remove it to converse.
Engleman & Wild 2003, UK	Qualitative Clinical review Retrospective Literature review based on broad interpretation of this subject area, encompassing but not circumscribed to the library of high-technology based randomised controlled trials (RCTs). By greater inclusiveness, its aim is to enhance the potential explanatory and interventional power of existing and future models of CPAP adherence through the	CPAP Sleep apnoea/hypopnoea syndrome Peer reviewed academic literature 59 articles referenced	Document and interpret available evidence on CPAP use and CPAP related interventions, propose a heuristic, testable model of escalating interventions for low CPAP use.	The literature on CPAP use has focussed on bio- medical determinants of CPAP tolerance and continuation, such as disease severity and physiological side-effects. The biomedical viewpoint, while possessing explanatory power, may be limited in its scope and applications. We have argued that many associates of low CPAP use, including the female sex, a lower BMI or "nuisance"-related problems, may be informed and modified by a psychosocial perspective.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
	addition of cognitive constructs.			
Glimelius Petersson et al., 2015, Sweden, Quality Score: 7/10	Qualitative Original article Prospective Descriptive and comparative Diary and control group study	NIV Acute illness ICU 96 patients, 52(54%) received a diary, 44 did not	Many patients lack a clear recollection of their ICU-stay. The diary's value seems to be as a source for understanding what happened, as an act of caring and as a tool to open up for discussions with relatives.	Diaries seem valuable in understanding what happened, as an act of caring and as a tool for discussion with relatives and friends. The 'breathing mask' was remembered by 27(37%) patients. Many patients described verbally and in comments the breathing mask (non-invasive ventilation mask) as a frightening experience.
Goldbart et al., 2013, UK, Quality Score: 7/10	Qualitative Original article Prospective exploratory descriptive from the perspective of key informants and analysed using thematic network analysis approach. Focus groups, semi-structured interviews	Long-term oxygen therapy COPD patients and carers living in a single Primary Care Trust (PCT) 31 participants Semi-structured interviews and focus groups:	The aim of the study was to explore the views and experiences of COPD patients, their carers and the healthcare professionals who deliver these services, on the long-term use of oxygen therapy.	Patients and carers reported the benefits of LTOT including increased social activity, perceived improvements in health status and self-management in routine daily activities. Concerns were raised regarding stigma, dependency on LTOT and deterioration in health status. Staff accounts included negative perceptions, suggesting that LTOT was often inappropriately prescribed and under-used but recommended active patient management to address this challenge.
Johnson 2004, Australia, Quality Score: 9/10	Qualitative Original article Retrospective Qualitative methodology, Heideggerian phenomenology	Long-term mechanical ventilation Critical illness or injury critical care unit (CCU) nine participants	Explore the meanings former patients attributed to being on long-term mechanical ventilation in a critical care unit. What does it mean to be on long-term mechanical ventilation in a critical care unit?	Comfort from the presence of nurses and their families, sought control over their treatments, questioned and interpreted the environment, reclaimed self.
Kelly & Madden 2014, UK, Quality Score: 8/10	In-depth interviews Qualitative Original Article Retrospective Systematic search and meta-ethnography Critical interpretative synthesis of the literature	Acute oxygen therapy, domiciliary oxygen therapy and oxygen for palliation of symptoms. Chronic respiratory disease, COPD, interstitial lung disease	How do respiratory patients perceive oxygen therapy	Explored how respiratory patients perceive oxygen therapy, positive - feeling safe, enabled and comforted, negative - fear, oxygen versus self, restriction and embarrassment, impartiality - mixed blessings.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
		Published literature 42 studies		
Lewis et al., 2003, New Zealand, Evidence level - II (9/11)	Quantitative RCT checklist Original article Prospective Systematic evaluation study before and after a standard field test, using a randomised, placebo-controlled, single-blind design. Dyspnoea was self-rated by subjects using the modified Borg scale.	Short-burst oxygen therapy COPD, Dyspnoea Outpatient respiratory clinic Twenty-two clinically stable COPD patients	Short-burst oxygen therapy (SBOT) remains an unproven treatment for reduction of exertional dyspnoea in chronic obstructive pulmonary disease (COPD).	Short burst oxygen immediately before and after exercise is ineffective in non-hypoxic COPD patients.
Lewis et al., 2006, UK, Evidence level - II (8/11)	Quantitative RCT checklist Original article Prospective single-blinded, randomised, case-controlled, interventional study Questionnaires, CPAP machine usage recordings and attendance data	CPAP OSA Home Seventy-two consecutive patients starting CPAP for SAHS (Sleep Apnoea Hypopnea Syndrome) CPAP-naïve. 72 patients (62 males)	Single-blinded interventional study. Randomised to receive standard follow-up or extra early support. Simple interventions improve re-attendance when treating the sleep apnoea syndrome.	To assess the effectiveness of simple interventions on clinical outcomes and patient attendance at follow-up clinics, we conducted a long-term randomised, controlled trial of intensive early support against standard clinical follow-up. Re-attendance rates were higher in the intervention group at 1 month (PZ0.04), 6 months (PZ0.07) and 12 months (PZ0.12). Those who defaulted tended previously to be poor users of the CPAP machine. For those who re-attended there was no difference in machine use or other outcomes. Simple interventions while commencing CPAP improve re-attendance with maximal benefit early on.
Lightowler et al., 2003, UK, Evidence level - I (10/10)	Quantitative Systematic review checklist Systematic review Retrospective Cochrane systematic review and meta-analysis. Systematic review of randomised controlled trials that compared NPPV and usual medical care with usual medical care alone in patients admitted to hospital	Non-invasive positive pressure ventilation Respiratory failure resulting from exacerbations of chronic obstructive pulmonary disease Hospital 8 studies	To determine the effectiveness of non-invasive positive pressure ventilation (NPPV) in the management of respiratory failure secondary to acute exacerbation of chronic obstructive pulmonary disease.	This systematic review shows a clear benefit of NPPV as an adjunct treatment to usual medical care in the management of patients admitted to hospital with respiratory failure secondary to an acute exacerbation of COPD.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
	with respiratory failure resulting from an exacerbation of chronic obstructive pulmonary disease.			
Mehta & Hill 2001, Canada, Quality Score: 7/10	Qualitative State of the Art review Retrospective Evaluation of the literature using a multimethod approach. MEDLINE search from 1966 through June 2000	Non-invasive Ventilation Acute and chronic respiratory failure MEDLINE search from 1966 through June 2000 341 articles	Review following a resurgence in the use of non-invasive ventilation, largely because of the development of nasal ventilation, which has the potential of providing ventilatory assistance with greater convenience, comfort, safety, and less cost than invasive ventilation.	Explores trends in the use of non-invasive ventilation and then provides a current perspective on applications in patients with acute and chronic respiratory failure. The discussion considers the rationale for use, currently available techniques and equipment, evidence of efficacy, selection of appropriate patients, and general guidelines for application, monitoring, and avoidance of complications.
Neri et al., 2006, Italy, Evidence level - III (9/11)	Quantitative Case Controlled checklist Original article Prospective Open, multicentre, observational study promoted by the Italian Association of Hospital Pulmonologists (AIPO) Educational Group. Questionnaire administered to consecutive outpatients on domiciliary LTOT for at least 6 months referred to one of 20 clinics throughout Italy. Blinded to this result, the physician who cared for the patient completed another questionnaire.	Long-term oxygen therapy COPD Home care 1504 patients (mean age 71.6 years; males 64%; 74% suffering from COPD)	Evaluation of the behaviour and the knowledge regarding LTOT in a large group of patients mainly using liquid oxygen. Questionnaire administered to consecutive outpatients on domiciliary LTOT for at least 6 months referred to one of 20 clinics throughout Italy. Blinded to this result, the physician who cared for the patient completed another questionnaire.	The widespread use of liquid oxygen did not automatically assure optimal adherence to the prescribed treatment as regards times and modality of oxygen use. A better education of patients, relatives, and the general public, as well as increased self-assessment on the part of health caregivers would improve the practice of LTOT in Italy. A large number of patients either did not respond to this question or said that they were ashamed of being seen by passers-by with the portable device.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
Sawyer et al., 2011, USA, Evidence level - III (8/11)	Quantitative Case Controlled checklist Systematic Review Prospective longitudinal study Following full-night diagnostic/CPAP polysomnograms, home CPAP use was objectively measured at 1 week and 1 month. The Self Efficacy Measure for Sleep Apnoea questionnaire (SEMSA), measuring risk perception, outcome expectancies, and self-efficacy, was collected at baseline, post-CPAP education, and after 1 week CPAP treatment.	CPAP OSA Home 66, middle-aged (56.7 yr \pm 10.7) subjects (34 [51.5%] Caucasians; 30 [45.4%] African Americans) with severe OSA (AHI 43.5 events/hr \pm 24.6)	Nonadherence to CPAP increases health and functional risks of obstructive sleep apnoea. The study purpose was to examine if disease and treatment cognitive perceptions influence short-term CPAP use. The Self Efficacy Measure for Sleep Apnoea questionnaire (SEMSA), measuring risk perception, outcome expectancies, and self-efficacy, was collected at baseline, post-CPAP education, and after 1 week CPAP treatment.	Cognitive perceptions influence CPAP use, but only within the context of knowledge of CPAP treatment and treatment use.
Shapiro & Shapiro 2010, Canada, Quality Score: 7/10	Qualitative Review Retrospective This review takes a broad health perspective and independently reviews multiple variables that are formative in CPAP adherence. Thematically based literature review	CPAP OSA Published literature 95 articles	This paper examines a multiplicity of factors that influence CPAP adherence. These factors are traditionally thought of in terms of patient and equipment variables, but in addition physician, family, healthcare facility, and governmental issues all contribute to CPAP adherence. These factors are reviewed and pragmatic recommendations are made for improving clinical practice.	There are specific initiatives that may greatly improve CPAP adherence if implemented at temporally appropriate intervals. Considering the important CPAP adherence in effectively treating OSAS, initiatives to improve adherence should be usefully and vigorously incorporated into OSAS patients' treatment plan.
Smith et al., 2009, USA, Evidence level - II (10/11)	Quantitative RCT checklist Intervention Prospective Mixed methods. Placebo controlled, randomised, experimental intervention study with contextualising comments Measurements of adherence and clinical factors, written diary, satisfaction survey	CPAP OSA Large sleep laboratories 97 patients with 53 males (55%) and 44 females (45%). Moderate to severe apnoea/hypnoea scores (per sleep laboratory data) and medical diagnosis of OSA were required for study inclusion.	Patient education combined in a music and habit-forming intervention for adherence to continuous positive airway (CPAP) prescribed for sleep apnoea. A theory-based intervention using music to support habit formation was designed to improve CPAP adherence at onset.	The intervention materials included directions for CPAP nightly use, a diary for recording nightly use and writing about CPAP benefits or problems. In addition, an audiotape with softly spoken instructions for placing the CPAP mask comfortably, using deep breathing and muscle relaxation along with the slowly decreasing music tempo was provided to listen to at bedtime each night. Patients' diary data and satisfaction survey results indicated the intervention was rated as helpful and guided formation of a relaxing, habitual routine of CPAP nightly use. The intervention had a strong effect for improving adherence to CPAP at 1 month.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
Sørensen et al., 2014, Denmark, Quality Score: 8/10	Qualitative Original Article Prospective and retrospective Constant comparative, classic grounded theory study Participant observation during the treatment, interviews after treatment	Non-invasive ventilation (NIV) Chronic obstructive pulmonary disease hospital setting, three ICUs and one general respiratory ward Observation of 21 patients, interviews with 11 of the patients, largely NIV naïve.	The aim of this study was to develop a theoretical account of the pattern of behaviour in patients with ARF due to COPD who undergo NIV in a hospital setting. What is the main concern during NIV for patients with COPD when admitted to the hospital with ARF? what strategies do the patients use to resolve this concern?	Behaviour was related to their breathlessness, sensation of being restrained by the mask and head gear, and the side effects of non-invasive ventilation. What was it like to be ventilated with the mask? Struggled with the discomfort related to the very first sensation of being ventilated and restrained by the mask and head gear, controlling discomfort.
Torheim & Gjengedal 2010, Norway, Quality Score: 7/10	Qualitative Empirical study Retrospective purposive sample, phenomenological approach In-depth interviews, focus groups	Bi-level positive airway pressure (BPAP) mask Chronic obstructive pulmonary disease Norwegian university hospital five patients, eight experienced nurses	Experiences of mask treatment in patients with acute chronic obstructive pulmonary disease exacerbations	Feeling of being trapped in a situation of complete dependence on others, combined with a will to mobilize inner strength. Factors in coping with the mask. Anxiety, panic and loss of control, regaining control and trust through skilled help, and a mobilisation of willpower. Mask treatment can be a traumatic experience for the patients
Ward et al., 2014, New Zealand, Quality Score: 7/10	Qualitative Clinical review Retrospective Systematic integrative literature review Systematic search and quality criteria assessment	CPAP OSA Published literature 22 of 538 identified papers met inclusion criteria	What is known about the experiences of using CPAP for OSA from the users' perspective? This manuscript identifies and synthesises international evidence about users' personal experiences of using CPAP.	Three themes: 1) users' beliefs about CPAP influence users' experiences of CPAP; 2) CPAP users are primed to reflect negatively on experiences of CPAP; and 3) spouse and family influence users' experiences of CPAP. Users' perspectives of CPAP are constrained by researchers' concern with non-compliance. Typically experiences are not defined by the user, but from an 'expert' healthcare perspective, using words which frame CPAP as problematic.
Williams et al., 2007, UK, Quality Score: 7/10	Qualitative Original article Prospective Exploratory study, grounded theory approach In-depth semi-structured interviews	Oxygen COPD Home Six patients	This paper describes an exploratory study investigating what is most important to people living with COPD.	They considered engagement in specific activities to be very important (walking, household maintenance and driving), even though these activities were mainly centred around the home environment, or within confined spaces, due to their physical limitations. This restriction led to feelings of social isolation that these patients tried to overcome through social participation (holidays, social interaction).
Worsnop et al., 2010, Australia, Evidence level - II (10/11)	Quantitative RCT checklist Original article Prospective A randomized, parallel group design Adherence was measured with a timer built into the pumps. Nasal symptoms	CPAP OSA Home 25 in the humidification group and 29 in the non-humidification group.	The aim of this study is to determine if heated humidification would reduce nasal symptoms and improve adherence with CPAP treatment in all patients with sleep apnoea irrespective of whether they had nasal symptoms initially.	The routine use of heated humidification with CPAP in all patients with sleep apnoea reduced nasal symptoms, but did not improve adherence.

Author/year, Country, Quality	Study Design	Treatment, Illness, setting and sample	Study Focus	Key themes & findings
	were measured with a 10-cm visual analogue scale.			
Wrench 2012, UK, Quality Score: 7/10	Qualitative Letter Prospective phenomenological approach, analysed using Colaizzi's seven stage process, which involved extracting significant statements and identifying common themes to produce an exhaustive description of the phenomenon. Semi-structured interviews	Long-term oxygen therapy (LTOT) COPD, chronic respiratory failure At home 7 patients (6 females and 1 male, mean age 73yrs) and 4 carer participants (3 female and 1 male, mean age 53.5yrs)	A subset of patients with chronic obstructive pulmonary disease (COPD) and significant respiratory failure clearly benefit from long-term oxygen but little is known about the personal impact of this demanding treatment. We therefore sought to gain insight into the experiences of patients and their carers on commencing long-term oxygen therapy (LTOT).	All described an initial reaction of fear at the recognition of the severity of their chest disease. For some, it served as a reminder of their own mortality. Some then talked in terms of disbelief that the treatment was really necessary. Some remained unconvinced that it was beneficial; this was despite the fact that the clinical reasons for LTOT and the long-term benefits had been discussed at each assessment. Patient participants related feelings of anxiety about the personal impact of home oxygen but also struggled with feelings of guilt at the impact of their chronic illness on their carers. The participants outlined a complex personal journey. Emergent themes included fear, anger, frustration, and finally acceptance through personal adaptation, emotions which echoed the grief process, with striking similarities between the narratives of patients and carers.

Appendix F: Identified governmental regulation mechanisms

Jurisdiction	System	Requirements	Oversight
US - FDA	Quality regulation system	Product recall for material deficiency or defect or faults in design or manufacture.	The FDA regulates the introduction, manufacture, advertising, labelling, packaging, marketing, distribution and record keeping of medical products in order to ensure that products distributed in the US are safe and effective for their intended use
Europe - European Union community (EUC) and inspector TUV Product Service.	Medical Devices Directive 93/42 EEC (adopted into law in member states)	This directive provides several options for products to gain acceptance for distribution in the EUC, including product approval, type testing or quality management system.	Quality management approval is the preferred method for FPH with certification complying with the directive under several European standards, including ISO9001 and EN46001. The CE mark indicates to purchasers of the company's products in the EUC that its medical devices are designed and manufactured under controlled conditions in compliance with the medical devices directive. FPH must also register its manufacturing facility with the European Regulator for product traceability systems, responding to any product complaints and maintaining records of any adverse product incidents.
New Zealand - Ministry of Health	Good Manufacturing Practice Regulation - Medicines Act 1981	If the New Zealand Ministry of Health considers any of its medical devices to be unsafe, it may be required to withdraw them from sale, and destroy, the offending devices.	New Zealand Ministry of Health's therapeutics section may inspect the company's facility.
Australia - Australian Register of Therapeutic Goods.	Good Manufacturing Practice Regulation - Therapeutic Goods Act 1989	Requires medical device inclusions in the Australian Register of Therapeutic Goods. To be listed on this register, medical devices must comply with manufacturing, labelling and quality standards established and assessed by the Conformity Assessment Branch of the Therapeutic Goods Administration.	FPH must either supply the Therapeutic Goods Administration with an acceptable form of evidence of Good Manufacturing Practice or the Good Manufacturing Practice and Licensing Section must audit them. The healthcare business must also comply with prescribed reporting and record keeping responsibilities, including the requirement to report any serious incidents arising from the use of its medical devices.

Source: Summarised data is quoted from Fisher & Paykel Industries Limited (2001, pp. 21-23).

Appendix G: Design process reflection and images.

Reflection

The following data is a selection of images and excerpts from data generated in the early stages of the study, when I approached the design of a new CPAP therapy mask with a human-centred design approaches and the tools to facilitate this. The process I used was broadly in line with the double diamond process (UK Design Council, 2019), which is a model that indicates the different phases a design project will go through. I used a number of tools associated with HCD during this phase of the process, including role play by attempting to use a CPAP therapy mask device during sleep for four nights over a long weekend, assumption mapping, insights and opportunity statements and personas as part of my preliminary analysis of scoping and expert interviews. I used creative processes to iterate and variate ideas through processes of ideation. These processes involved sketching ideas over photographs and quick-fire rapid prototyping of concepts. The design brief I developed for myself was focussed on improving the experience for users of CPAP therapy and initially seeking insights from expert users on how the product could be improved. I also worked on making prototypes as a way to better understand the challenges in designing for the face, improve my understanding of materiality and explore the potential for new design opportunities. I experimented with using different materials such as hand moulded wax, variations on home-made silicon moulding, latex substitutes and plasticine. I also investigated plastic inflation and sewing fabrics as possible avenues. I had a 3D scan of my face completed and used this to create a partial wax face mould to assist in prototyping with fabrics and plastics. As can be seen from the following images, I used 3D digital modelling software to develop masks but also study the make-up of faces and the shapes needed on the contours. In the later stages of the project, I diverted my efforts from figuring out how to create masks from raw materials and shapes to focussing more on discourses of the home. I made three different probes, but only two were used in the market exhibitions. Finally, I used a great deal of mind-mapping and visual image association in my analysis of the data and the final write up. During the main parts of the study I had most of my material experiments on display and they facilitated many interesting discussions about the project and what was happening. I found this approach to be beneficial as Ideas that are made in a physical form are much easier to consider and discuss with others. I found this to be a benefit of using a design approach to post-structural analysis.

Introduction

The work in this portfolio is carefully selected examples to best represent my design process based on the model in Figure 1 from the Design Methods Toolbox.

1. Initiate	2. Investigate	3. Generate	4. Ideate	5. Evaluate	6. Communicate
TEAMWORK	KNOWLEDGE GATHERING	OPPORTUNITY DEFINING	IMPOSE CONSTRAINTS	CONCEPT MATRIX	STORYTELLING
BEGINNERS OUTLOOK	ROLE PLAYING	BRAINSTORMING	SKETCH IDEATE	SCENARIO TESTING	
ASSUMPTION MAPPING	OBSERVATION	MINDMAPPING	QUICK-FIRE PROTOTYPING		
REFLECTIVE PRACTICE	INTERVIEWING	LOTUS BLOSSOM			
	EMPATHY MAPPING	SIX THINKING HATS			
	PERSONAS	IDEA HARVESTING			
	NEEDS & INSIGHTS				
	POINT-OF-VIEW (POV)				

Figure 1 Design Thinking Tools

Project Aim

To apply Design Thinking methods and processes to improve the experiences of people using CPAP for treatment of Obstructive Sleep Apnoea.

Mission Statement

To make a positive contribution to business and the community through practical and innovative responses to design problems and opportunities. To deliver on time, on budget designs of visually striking and functionally innovative products that provide a net improvement to the social, economic and environmental concerns of its stakeholders.

Personal Project Goals

Personal project goals may be summarised as follows:

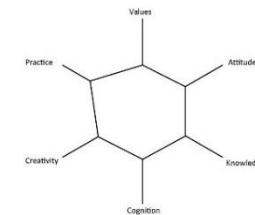
1. Focus on sticking to my plan and effectively using the time available
2. Set goals specific and appropriate to the project parameters
3. Find new and unusual sources of information in the research phase including books, design blogs and social media
4. After researching widely focus in on the ideas and inspirations that have shown promise
5. Widen my creative exploration output to get a broader range of ideas
6. Include more research in the creative exploration phase when I feel stuck.
7. Be prepared to make late changes to the development concept when it is necessary to product a more innovative and interesting result.
8. Use a decision matrix to assess key decisions, write the criteria for this at the start of the project.

INITIATE

9. Develop simple and quick but realistic test scenarios for concept testing.
10. Discuss ideas and test concepts with classmates to get broad input into designs.
11. Carefully select aspects of the project that require inclusion in communications.
12. Work on photoshop, layouts and image processing to improve visual communication.

Strengths and Weaknesses

Based on the six learning outcomes from the previous assignment I can see there is room to grow in all the key areas.



The Assignment Brief (Initial)

Design Criteria:-

The final design shall adhere to the Buckminster criteria as follows:

Visionary – puts forth original ideas or synthesizes existing ideas into a new strategy that creatively addresses a critical need.

Comprehensive – applies a “whole-systems” approach to the design and implementation process; aims to address multiple goals, requirements and conditions in a holistic way.

Anticipatory – factors in critical future trends and needs as well as the projected impacts of implementation in the short and long term.

Ecologically Responsible – reflects nature’s underlying principles while enhancing the ability for natural systems to regenerate.

Feasible – relies on current technology, existing resources and a solid team capable of implementing the project.

Verifiable – able to withstand rigorous testing and make authentic claims.

Replicable – able to be adapted to similar conditions elsewhere.

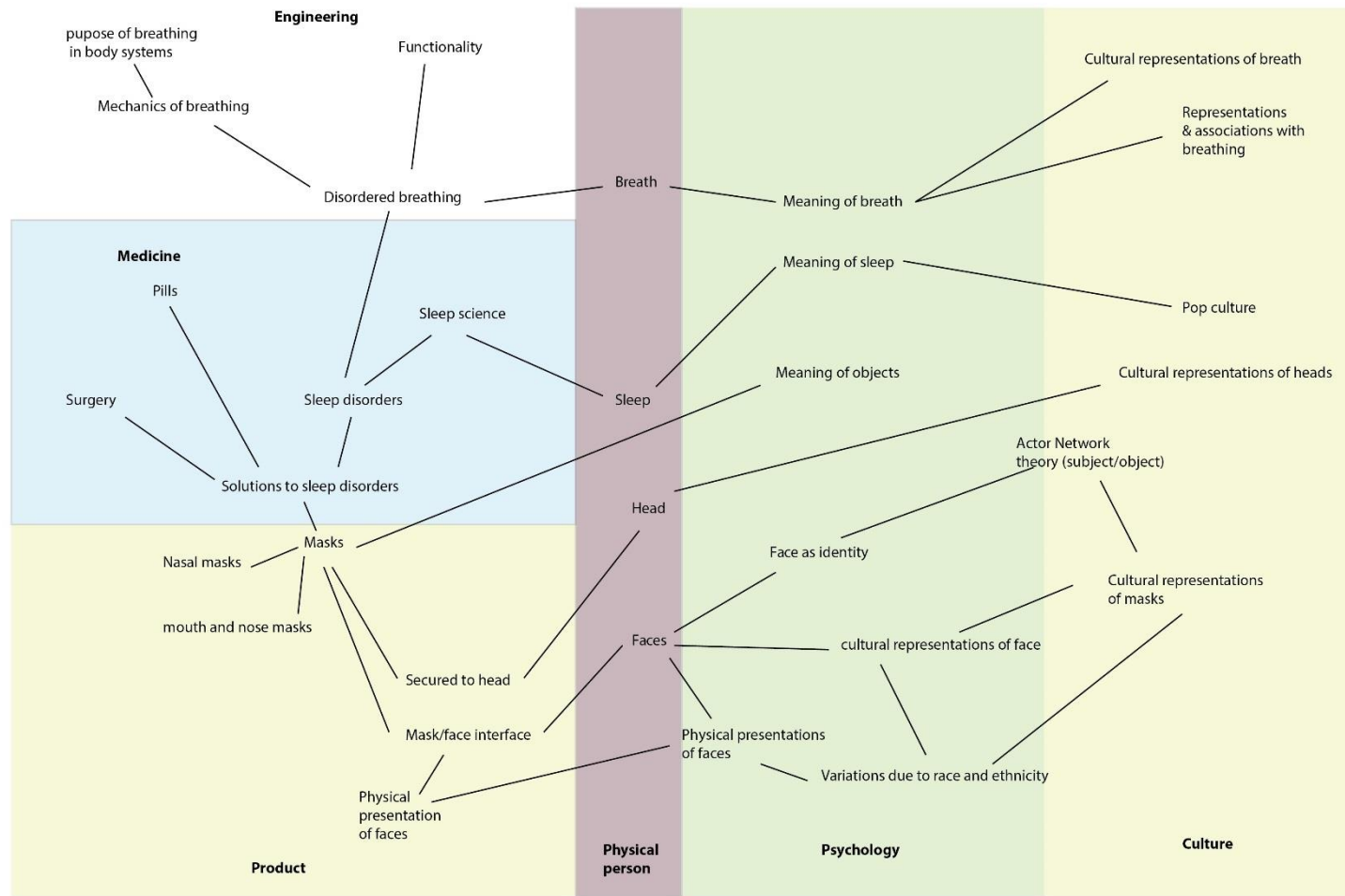
Learning outcomes

To have:-

- Effectively analysed the design brief, planned the design process with particular emphasis on human-centred and socially responsible design.
- Collaboratively and effectively research the experiences of OSA suffer’s and CPAP users using publicly available material, role play and design tools primarily.
- Analysed the research to identify key users, insights and themes and product design opportunities.
- Used these to explore a range of creative and innovative product design concepts and ideas.
- Resolved and tested the final design concept/s using prototypes and mock ups; and
- Communicated the design proposal via a blog, verbal means, a project process portfolio, and 2D and 3D work

BRIEF

Appendix Figure 1. Preliminary design brief focussed on improving the experience of expert users of CPAP therapy masks.
Source: Author’s image.

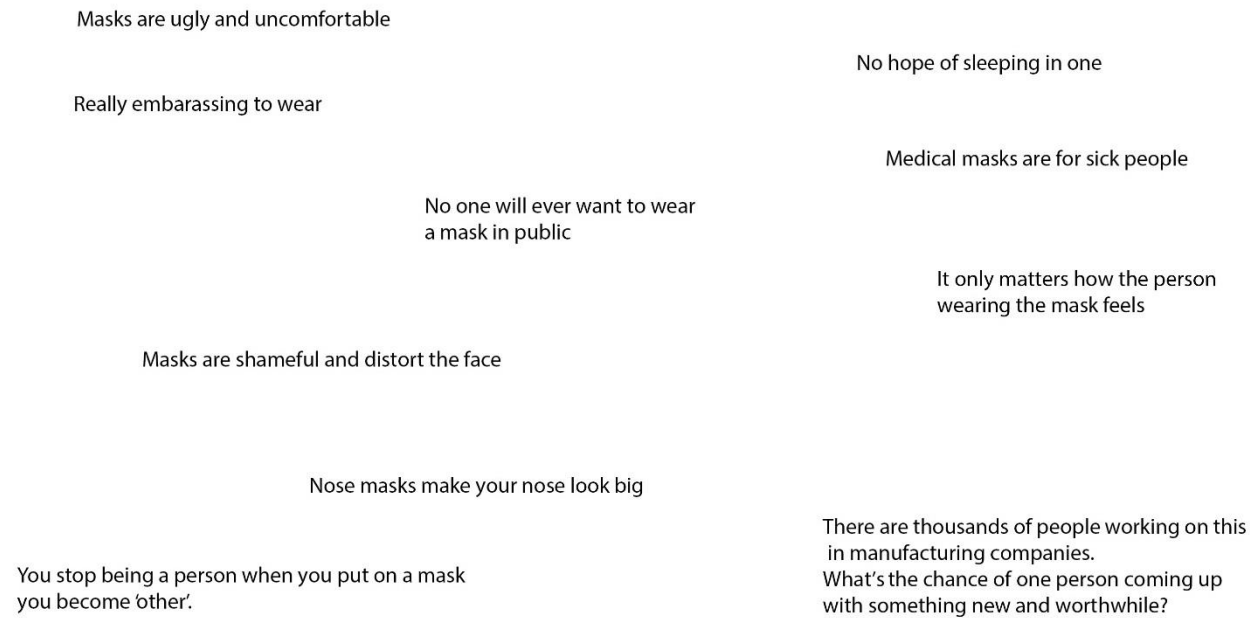


Object

FACE MASK MIND MAP

Appendix Figure 2. Mind mapping the areas that touch of CPAP therapy design.
Source: Author's image.

Assumption mapping - mask design/development



Appendix Figure 3.
Preliminary assumption
mapping.

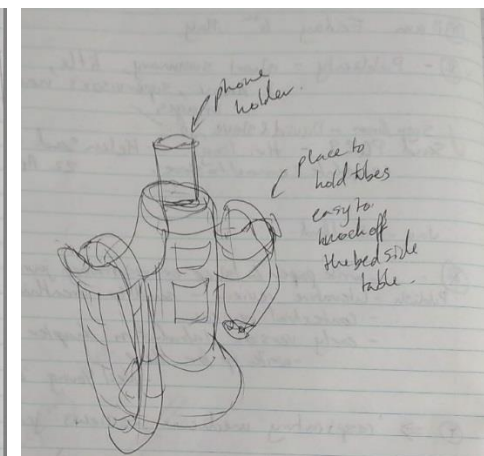
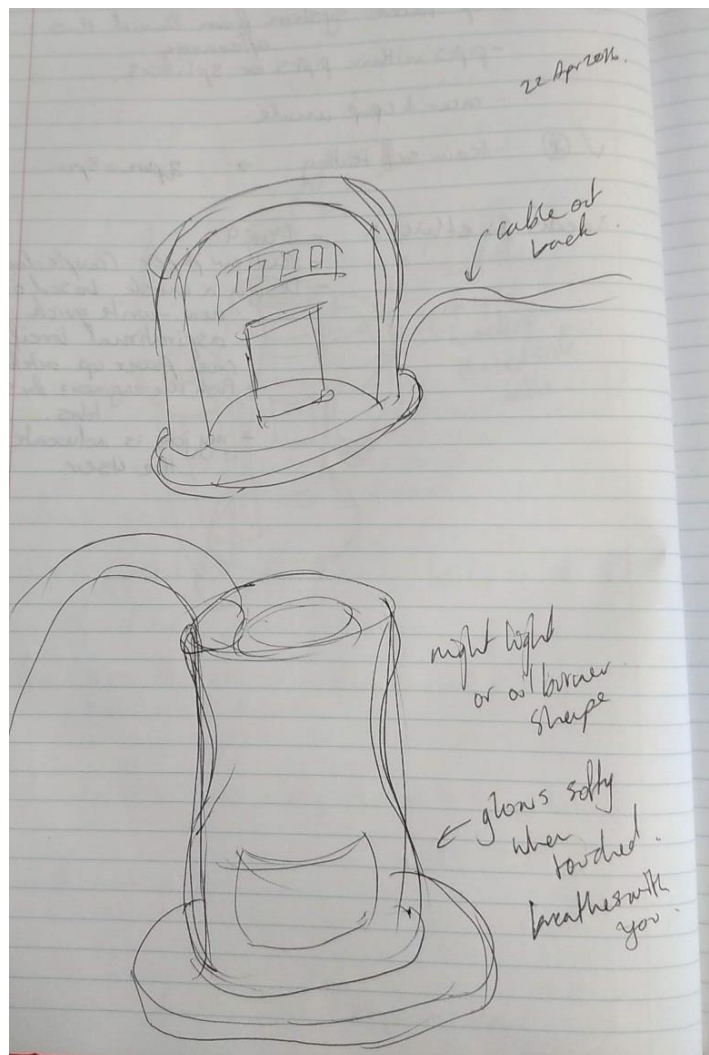
Source: Author's image.

ASSUMPTION MAPPING - INITIATION

24 Apr. 2016.
I have had 2 attempts with CPAP now.
Both time 1.5-2 hrs in I start to feel
breathless like I'm hyperventilating & begin to
panic abit. At this point I'll take it off and
decide to try again tomorrow.
Some it feels abit like I'm not able to breathe
out fully. I get the same sort of effect ~~with~~
hiking or climbing stairs if I don't manage
my breathing and keep it slow. Once I
breathe too fast I get breathless & have to
stop. I haven't fallen asleep with it yet.
I tend to take a long time to fall asleep.
anyway sometimes up to 2 hrs so this isn't

22 Apr. 2016.
CPAP 1st use role play with vancouver.

- 10pm today night - I'm tired, can't really be
bothered setting this up.
- have to make space on my bedside table.
 - wonder how I'm going to find my glasses.
→ place to put them on the night stand
be good.
 - Also dim touch night light so I
can see my way to adjust
things.
 - Power cable in the front means power lines
everywhere & tangles with my plug cable
phone.
→ phone car charger also might be
useful.
 - don't see why it's so low profile.
maybe to stay away from the lamp.
but I can't put anything on it!
 - stability.
 - should have something to hold/store the
tubes & mask.

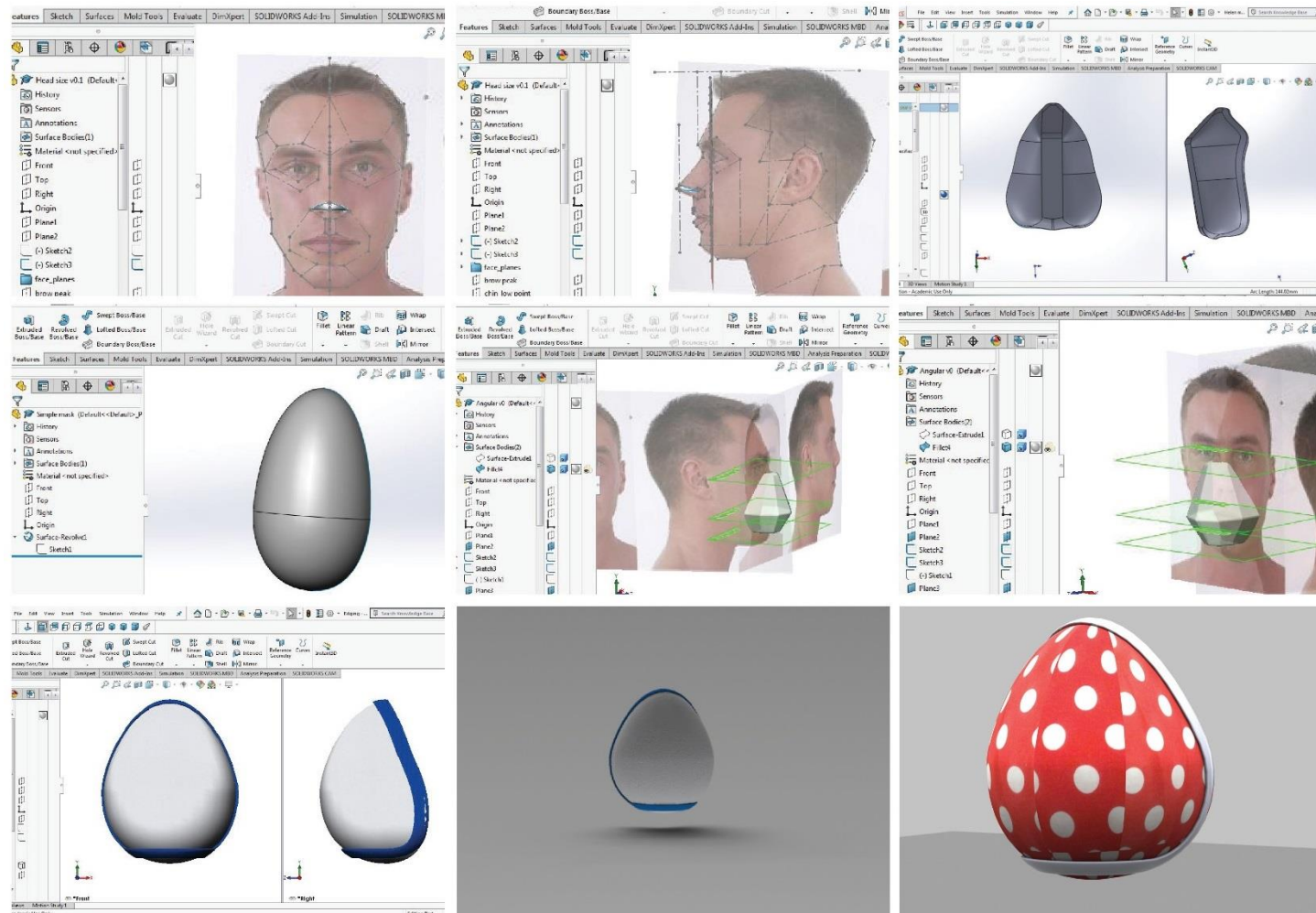


Appendix Figure 4. Design sketches and notes from role play – sleeping using CPAP therapy mask.

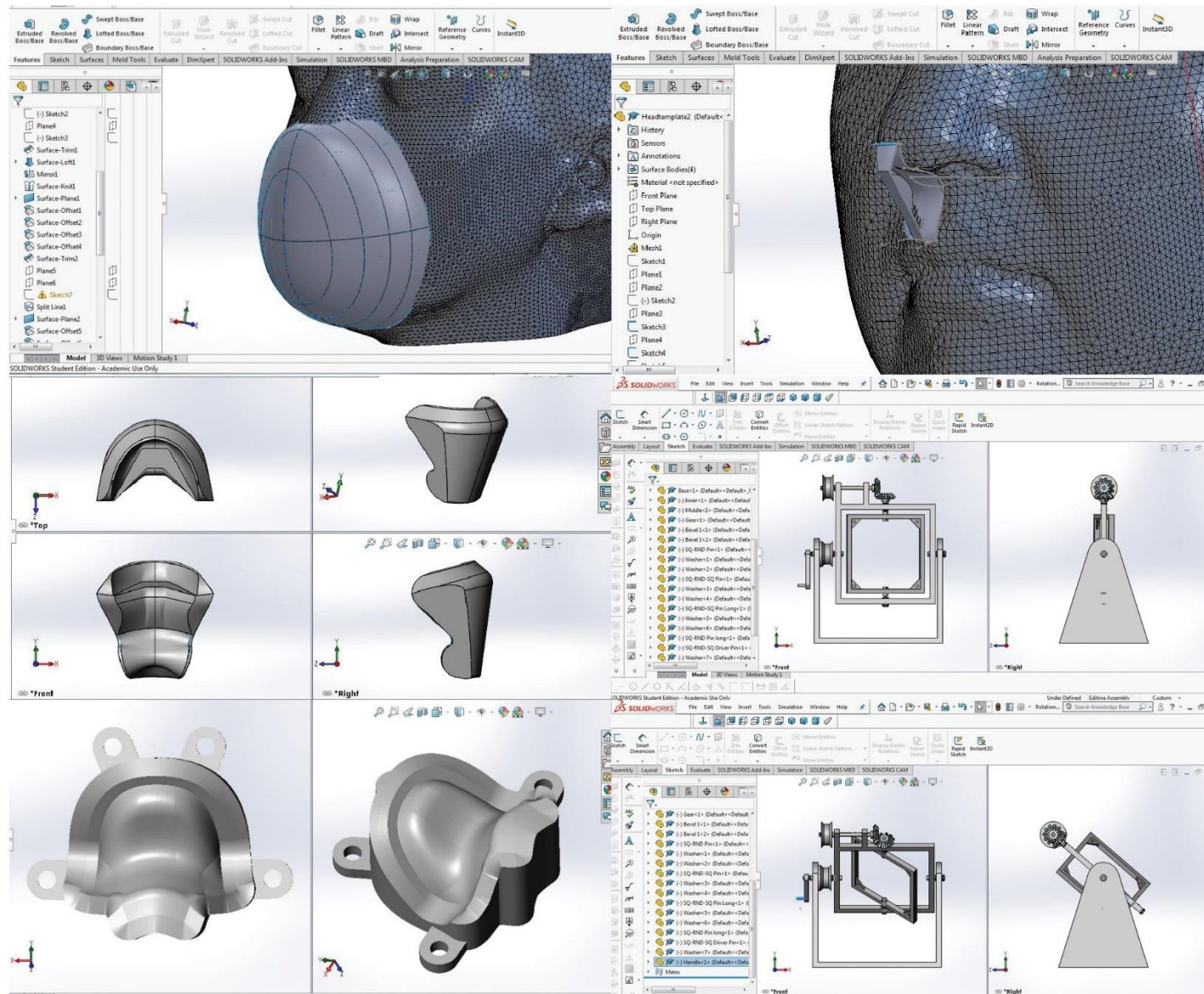
Source: Author's photographs of sketches and notes.



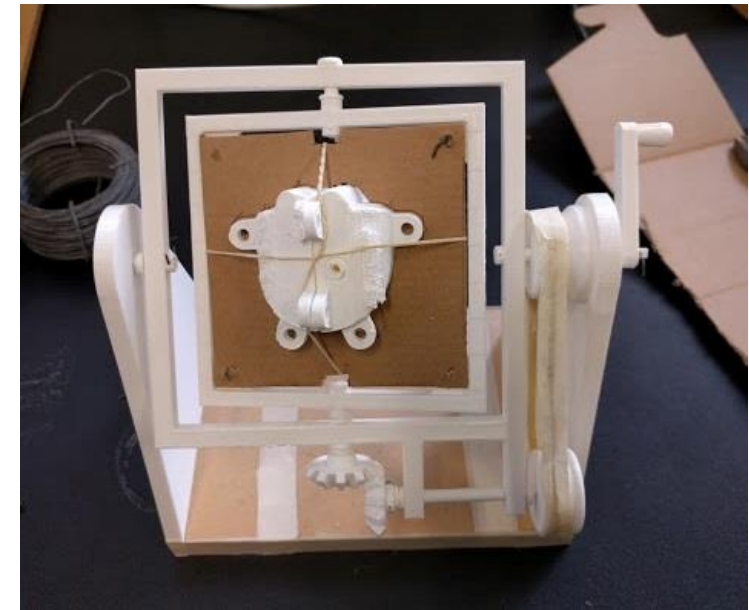
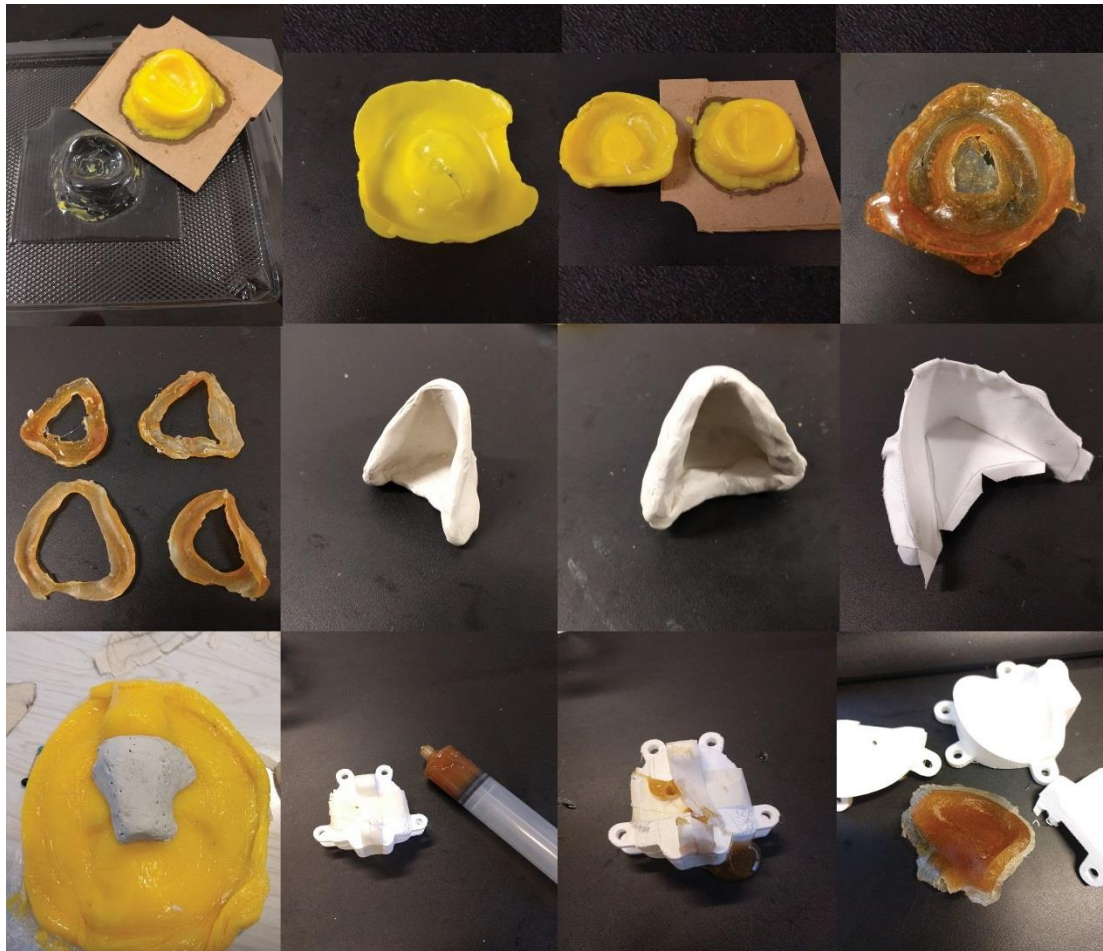
Appendix Figure 5. Selection of ideation images including quick-fire sketches on photos, paper models on mannequin and a range of models and prototyping approaches completed prior to the market exhibitions. Source: Author's photographs and images.



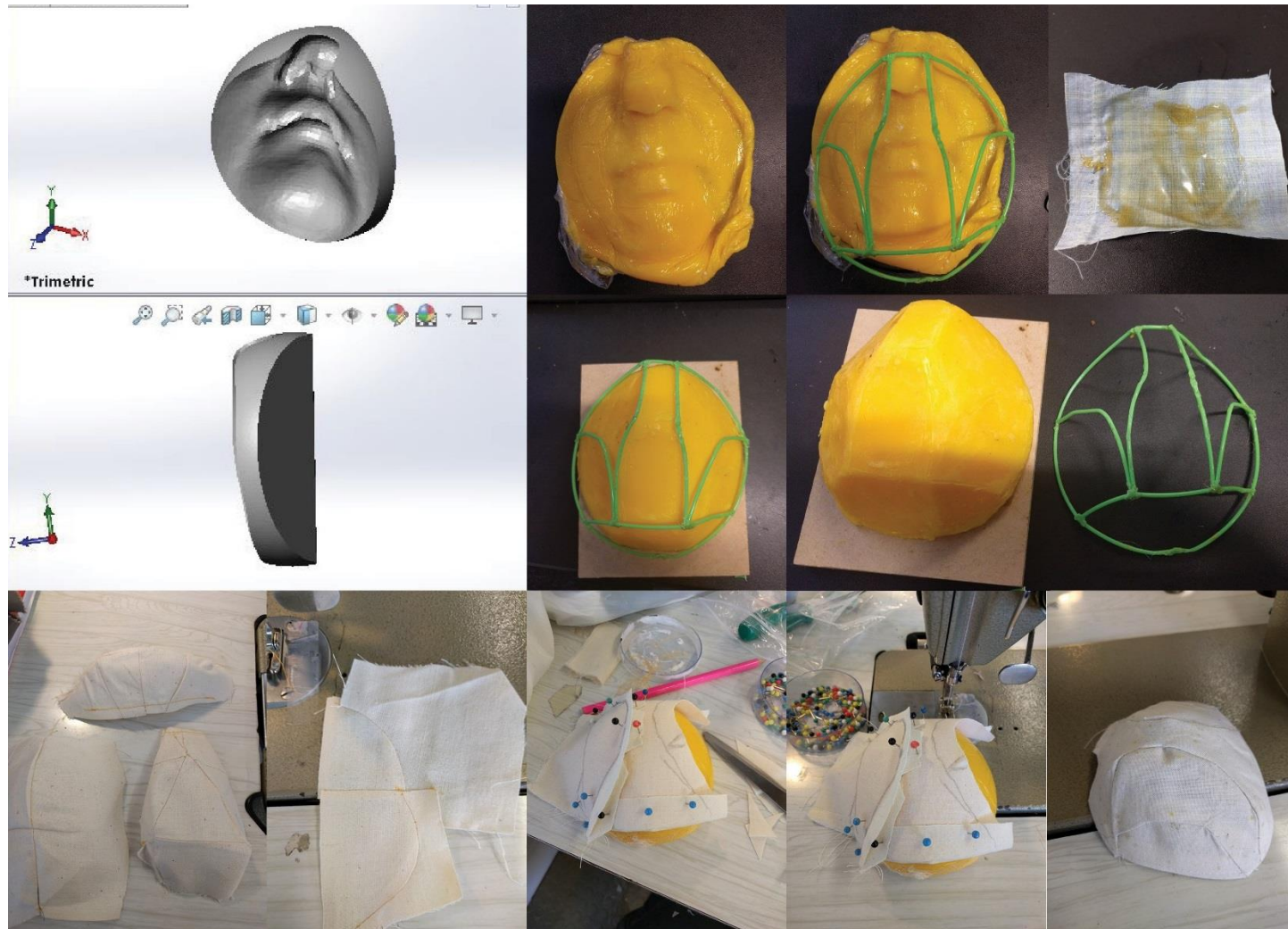
Appendix Figure 6. Face study, colour, form experimentation, curves vs angular forms, use of pattern and clothing elements.
Source: Author's images.



Appendix Figure 7. 3D scan of author's face with in-situ study of mask shape and design, experimentation with low profile under nose form. Consideration of injection mould design to create an injection moulded form, and exploration of rotational moulding process and desktop machine design for creation of hollow forms.
Source: Author's images.

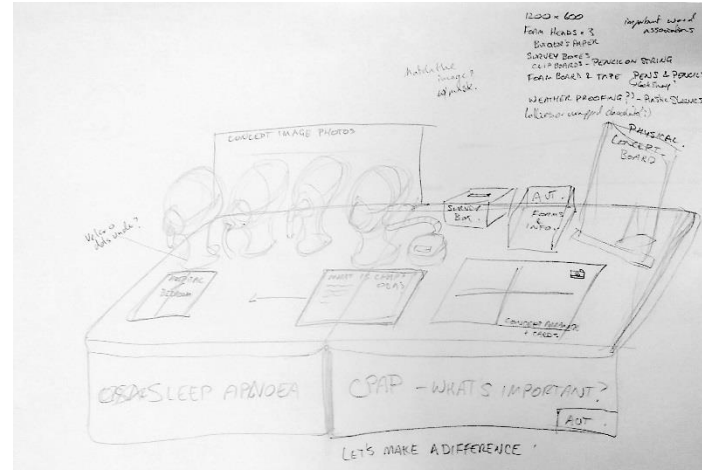
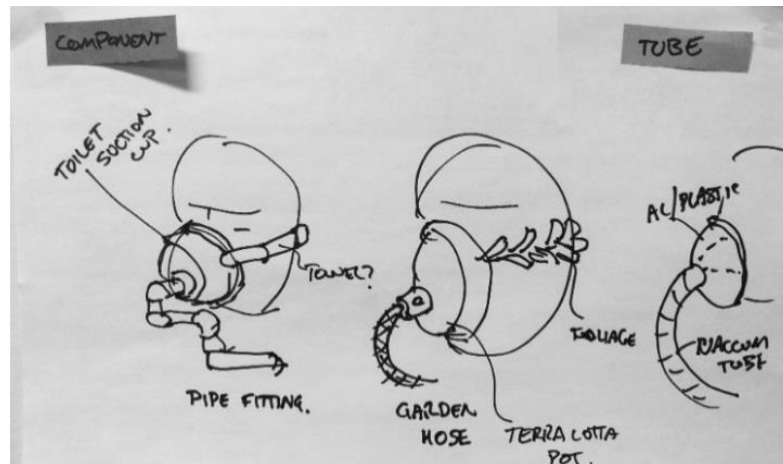
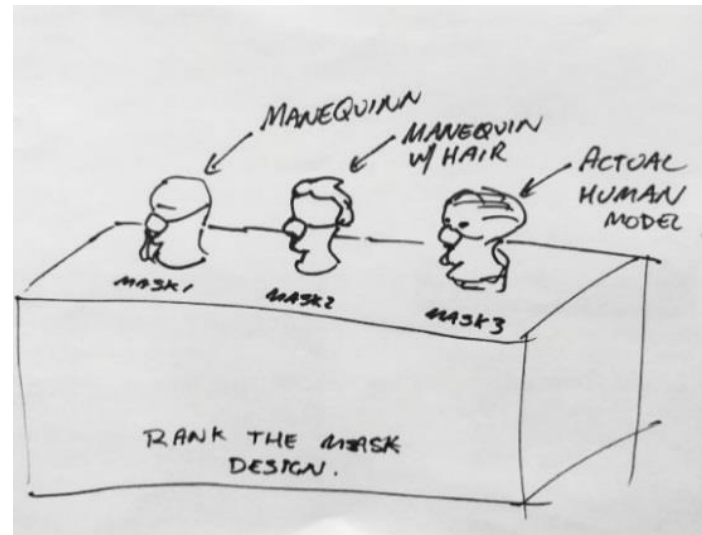
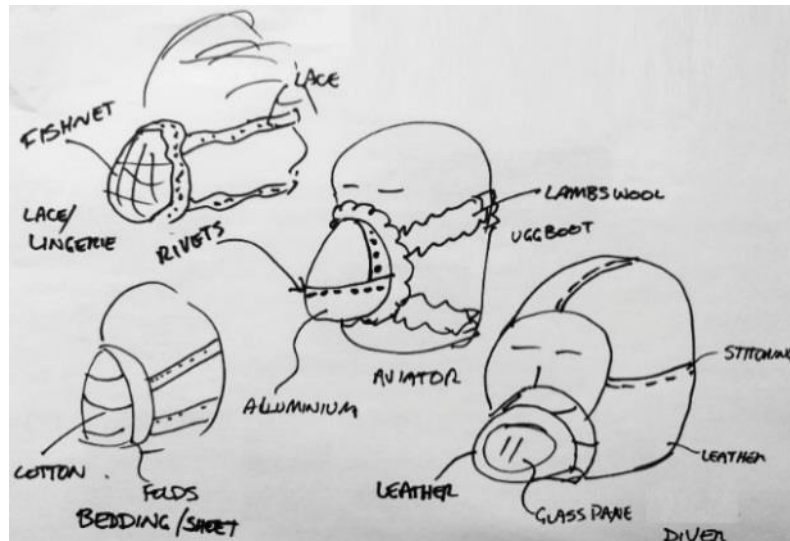


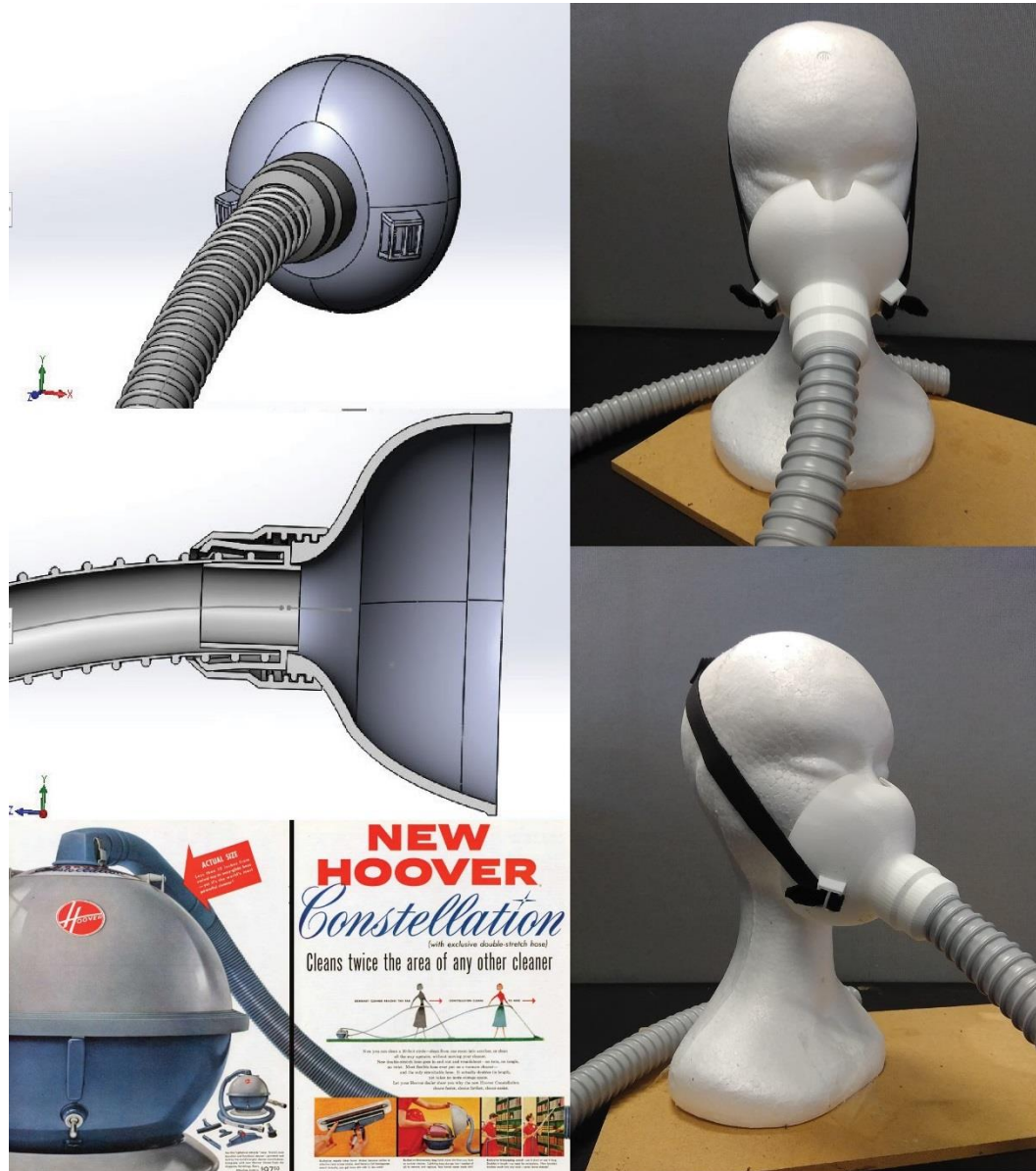
Appendix Figure 8. Physical models and exploration of ideas from early 3D digital modelling studies. Successful injection moulding of soft elastomeric form for the under-nose model. Image shows wax face mould developed for prototyping based on 3D print of digital face scan. Source: Author's photographs.



Appendix Figure 9. Fabric making exploration process including sewing 3D mask forms from calico, prototyping the form using 3D printer filament heated to bending with a soldering iron. Digital design of the 3D printed mould used to cast the wax face is also shown.

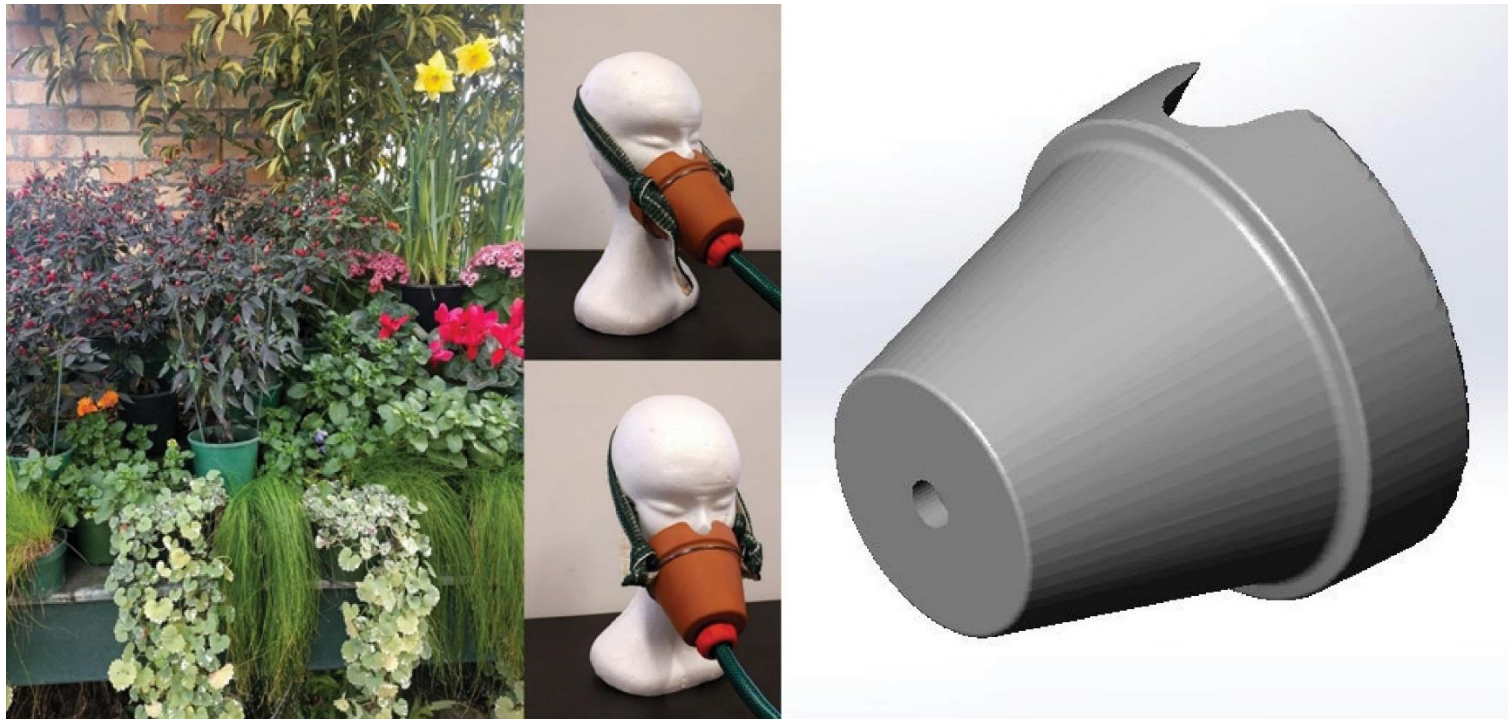
Source: Author's photographs and images.





Appendix Figure 11. Mask probe developed based on interview data likening the CPAP therapy experience as being ‘like a vacuum cleaner’ (Clinical Staff 3 – see Appendix D).

Source: Lower left: Hoover - Constellation Vacuum by Mid-Century Pretty, Retrieved from <https://www.flickr.com/photos/robotbastard/74855067>, Attribution-NonCommercial 2.0 Generic (CC BY-NC 2.0) see <https://creativecommons.org/licenses/by-nc/2.0/> Other images: Author’s photographs and images.



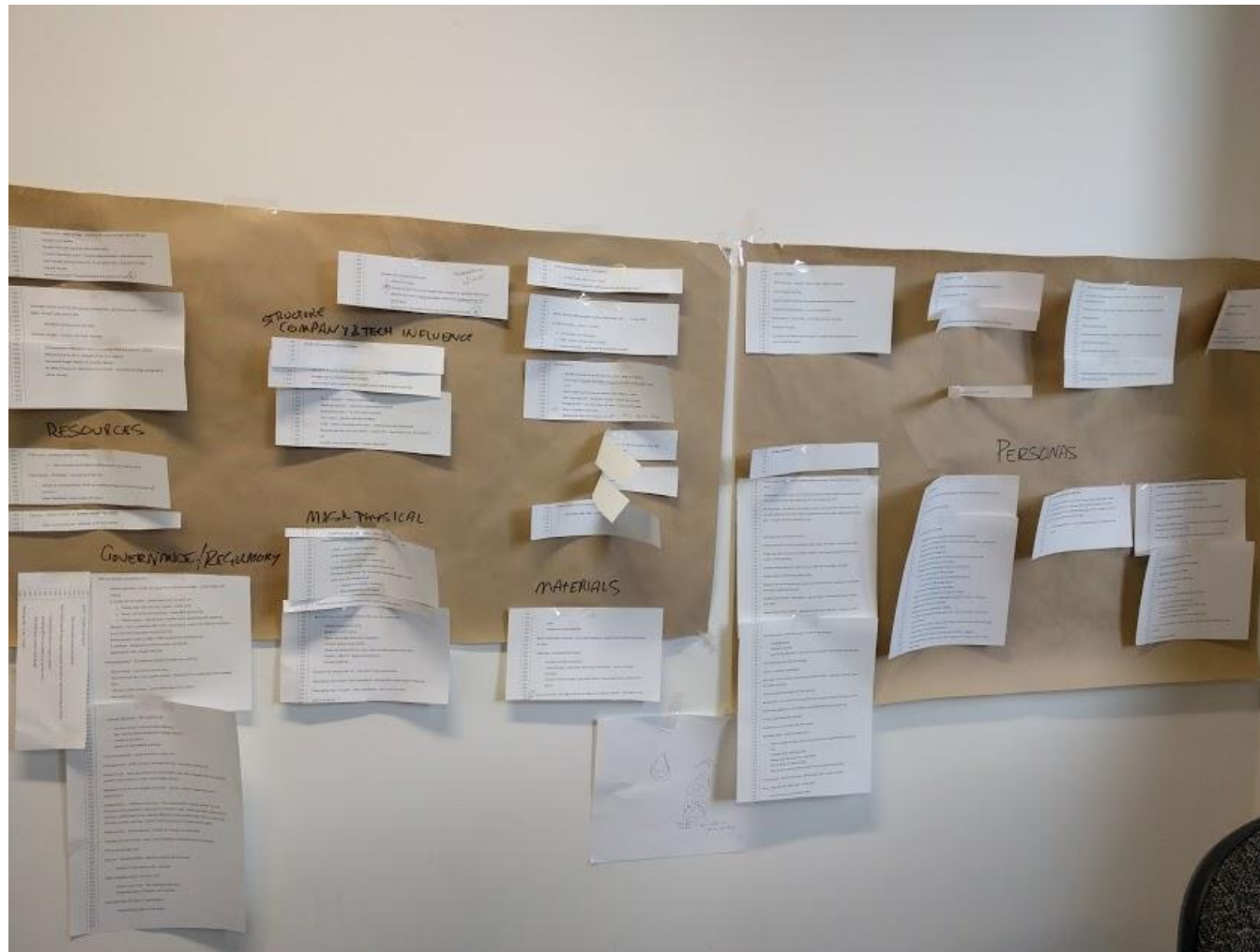


Appendix Figure 13. Mask probe development focussing on areas and shape already common in the home, in this case the bathroom.

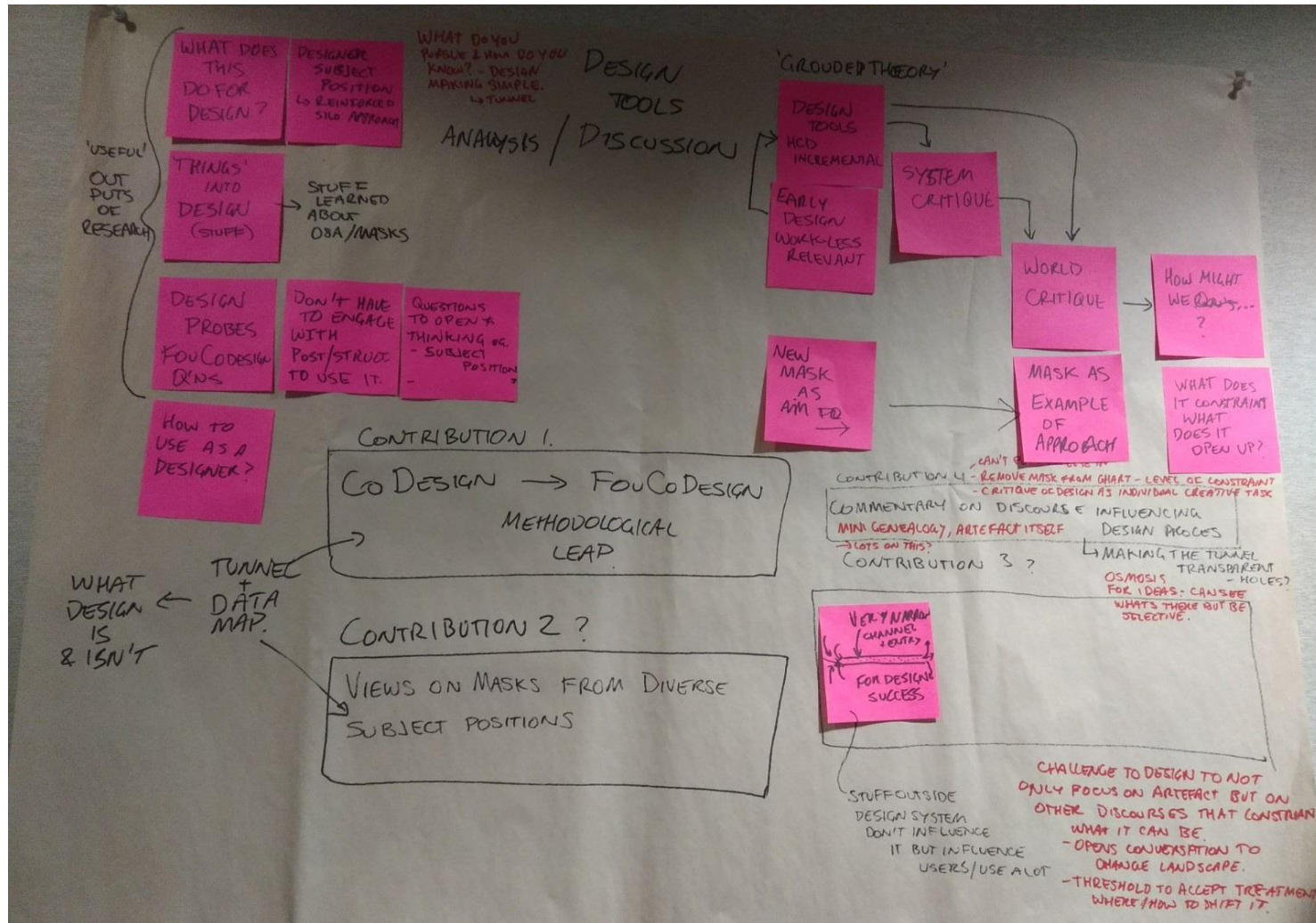
Source: Author's photographs and images.



Appendix Figure 14.
Image of prototypes
displayed near my
workstation prompted
discussion and insights
with colleagues and the
supervision team.
Source: Author's
photographs.



Appendix Figure 15. Early analysis of interview and scoping data focussed on areas of design interest such as developing personas, materials and looking for insight and opportunity statements. Source: Author's photograph.



Appendix Figure 18.
Mind mapping used in
data analysis,
considering the process
and framing
contributions.
Source: Author's
photograph.