

FROM STIGMA TO SILVER LININGS

**IMPROVING THE EXPERIENCES OF LONG-TERM
TRACHEOSTOMY USERS THROUGH PRODUCT DESIGN**

*This exegesis is submitted to Auckland University of Technology for
the degree of Master of Art & Design, 2017.*

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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 it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the award of any other degree or diploma by a university or other institution of higher learning, except where due recognition is given in the acknowledgements.

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Lastly, thank you to the participants whose stories populate these pages. I hope that I have done them justice.

ABSTRACT

The design of tracheostomy products has barely changed in over 100 years. Furthermore, existing literature demonstrates little understanding of what it is like to live with long-term tracheostomy. In response, this project aims to capture the stories of real tracheostomy users. It applies an action research methodology to challenge historic stagnation and advocate for the consideration of users' needs in tracheostomy product design. Where a cultural and systemic drive to minimise production costs and maintain clinical function have become the defining features of medical product design, this project uses human-centred design, and co-design approaches to bring focus to the need for emotionally sensitive aesthetics and improved usability. The findings contribute an understanding of the challenges tracheostomy users face in everyday life and the complex relationships they have with their tracheostomy products. Design outcomes include a series of artefacts intended to capture and evoke empathy for aspects of users' experiences, as well as a design proposal demonstrating a possible approach to improving tracheostomy products through enhanced choice, usability, and aesthetics. The research highlights aspects of tracheostomy user experiences requiring further research, sets a precedent for future design-led research in this area, and makes a compelling case for tracheostomy product design innovation.

GLOSSARY

ASPIRATION

The accidental breathing in of a foreign object or substance.

CANNULA

‘Inner cannula’ and ‘outer cannula’ are alternative terms for ‘inner tube’ and ‘outer tube’ respectively.

COMORBIDITY

The simultaneous presence of multiple chronic diseases or conditions in a patient.

CUFF

A balloon on the end of a tracheostomy tube that can be inflated to support the trachea or prevent aspiration.

DECANNULATION

The removal of a tracheostomy tube, usually following a weaning period.

FENESTRATIONS

Holes in a tracheostomy tube that allow air to pass through the tube and vocal cords, allowing speech.

HUMIDIFIER

Machine supplying warm, moist air to replace the functions of breathing through the nose or mouth.

LARYNGECTOMY

Surgical removal of the voicebox. Airway is disconnected from mouth and nose and redirected to a neck stoma.

OBTURATOR

A device that is inserted into a tracheostomy tube, to create a rounded end that is easier to insert.

NEBULISER

Device for breaking down thick secretions that risk blocking the tracheostomy tube.

SECRETIONS

Mucus discharged from the trachea that may build up in, or be expelled through, a tracheostomy tube.

SPEAKING VALVE

Tracheostomy tube attachment that allows speech without covering the hole with a finger.

STOMA

An artificial opening made into a hollow organ of the body such as the trachea.

TRACHEA

The tube that conveys air between the nose/mouth and the lungs, also known as the windpipe.

TRACHEOTOMY

Surgical procedure used to make an opening (stoma) in the trachea, the result of which is called a tracheostomy.

TRACHEOSTOMY

A surgically created opening in the trachea used to restore airflow to the lungs.

TRACHEOSTOMY TUBE

A curved tube that is inserted into a tracheostomy, providing an alternative airway to the mouth and nose.

INTRODUCTION

POSITIONING THE RESEARCHER

I embarked upon this research with no prior knowledge of, or experience with, tracheostomy. My approach to the research was therefore primarily shaped by my education as a human-centred designer, experiences with healthcare design, and personal values.

PREVIOUS STUDY IN HEALTHCARE DESIGN

Over the course of my undergraduate and postgraduate studies in product design, I have had the opportunity to work on several healthcare design projects through the student portal of the DHW Lab.* Through these projects I have gained experience conducting human-centred design research. I have also built an understanding of the challenges of healthcare design, while producing work that is congruent with my desire to affect positive change in the world.

In 2015 I undertook a design-led research project exploring the orthopaedic treatment experiences of children visiting Auckland’s Starship Children’s hospital. I designed an interactive children’s book about a girl named Lin who breaks her arm and visits Starship Outpatients’ Department for treatment. For this project I conducted expert interviews and observation. I also used probes to engage stakeholders and build empathy for their perspectives.

Despite my lack of tracheostomy-related knowledge, my previous healthcare design work equipped me with some understanding of the complexities of healthcare contexts and experience advocating for the needs of overlooked user groups.

** DHW Lab: The Design For Health and Wellbeing (DHW) Lab is a collaboration between Auckland University of Technology (AUT) and the Auckland District Health Board (ADHB), seeking to bridge the gap between design and healthcare. The lab has a studio space located on the Auckland City Hospital campus.*

A PRODUCT DESIGNER'S PERSPECTIVE

In addition to my healthcare design experience, my approach to this project was shaped by my product design training. In particular the argument presented within this thesis that aesthetics impact user experience is shaped by my design background.

While the design outcomes presented are integral to the research, it is important to acknowledge that they propose just one possible design approach. Although supported by arguments drawn from literature as well as primary research methods, my designs were shaped by my personal interests in craft, materiality, and minimalism.

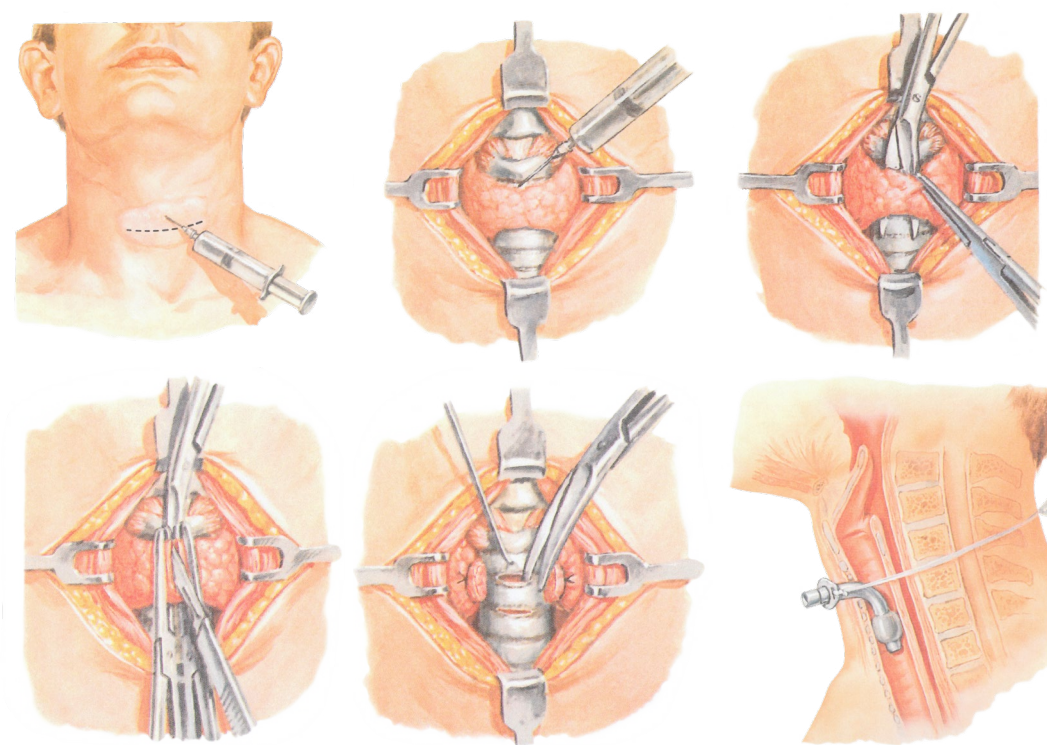
POSITIONING THE PROJECT

SRIF STUDY

This project ran alongside an AUT Strategic Research Investment Fund (SRIF) study titled: “Better Health through Design: Generating novel tracheostomy design opportunities.” The SRIF study aimed to understand and improve the experiences of long-term tracheostomy users and their families through a co-design approach. While independent from the SRIF study, this project shared the goal of understanding and improving tracheostomy user experiences. This project, however, focused on achieving this goal through tracheostomy products design.

Aspects of data collection for this project involved collaboration with the SRIF team. I was provided with transcripts and audio recordings of tracheostomy user interviews conducted by the SRIF team. I analysed this data independently as appropriate to the project. Co-design workshop participants were recruited through the SRIF study, and workshops conducted with assistance from SRIF team members. I ran the workshops alongside a fellow student researcher working on another tracheostomy-related project. I analysed workshop data independently. Because this project shared interests with the SRIF study and the project of a fellow student researcher, recruitment, data collection, and research activity coordination were discussed at fortnightly meetings involving all three parties. Auckland Hospital Otorhinolaryngology staff were also invited to assist with recruitment and discuss findings.

CONTEXTUAL REVIEW



1. Netter, (1975). Tracheotomy surgery illustrations.

TRACHEOSTOMY

WHAT IS TRACHEOSTOMY?

Tracheotomy is a surgery during which an artificial opening (stoma) is made in the front of the patient's windpipe (trachea). A tracheostomy tube is inserted into the stoma to create an artificial airway (NHS Trust, 2010; Sherlock, Wilson, & Exley, 2009). Tracheostomy is used to treat a range of conditions including congenital upper airway abnormalities, vocal cord paralysis, head or neck injury, throat cancers, sleep apnoea, and long-term mechanical ventilation (Feber, 2006; NHS Trust, 2010).



2



3

Fig. 21.—A NEW TRACHEOTOME.
By H. T. HANKS, M.D., New York.
American Journal of Obstetrics, January, 1877.
Price, \$9.00.



"A New Tracheotome"
From *The American Armamentarium Chirurgicum*
George Tiemann & Co, New York, 1878
Courtesy Health Sciences Libraries, University of Washington

4



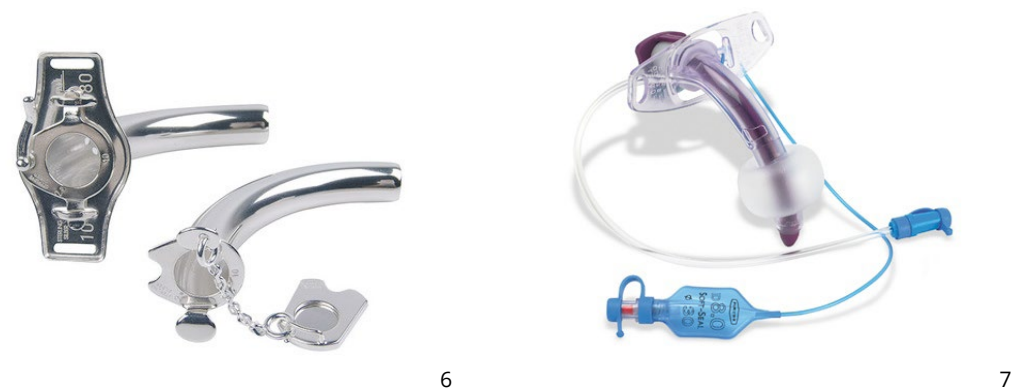
5

2. 1860s, civil war era prosthetic leg, hand-crafted from wood, leather, iron, and zinc; 3. Modern 'Flex-Run' prosthetic leg by Nike;
4. 1877 illustration of a tracheostomy tube; 5. Modern silver 'Jackson' tracheostomy tube

HISTORICAL PERSPECTIVE

Mentions of tracheotomy date back to 2000 BC, with the description of a throat incision in oral traditions that later became the ancient Hindu book of medicine known as Rig Veda. Written records of techniques resembling tracheotomy later appeared in the works of Egyptian physicians. Early descriptions of tracheal intubation using "a cannula of gold or silver" were made by Muslim physician Avicenna (980-1037AD). In 1546, Italian physician Antonio Brasavola performed the first documented successful human tracheostomy. While the use and success of tracheostomy throughout its early history was erratic, by the early 1800s it had achieved a degree of routine application (Szmuk, Ezri, Evron, Roth, & Katz, 2008).

Among 4000 years of tracheostomy history, what is most notable is how little the design of tracheostomy tubes has changed. Considering the staggering development seen in other medical devices like prosthetic limbs—which have transitioned from wooden peg legs, to carbon fibre running blades— it is surprising that modern tracheostomy devices are virtually identical to those available in 1877.



6. 'Silvervent 2000' tracheostomy tube; 7. Plastic 'Portex' cuffed tracheostomy tube

TRACHEOSTOMY PRODUCTS

Tracheostomy tubes come in a range of sizes, materials, and configurations. They can also be equipped with different features depending on the condition being treated, airway anatomy, and comorbidities (additional conditions or diseases) of the individual patient (Lewarski, 2005).

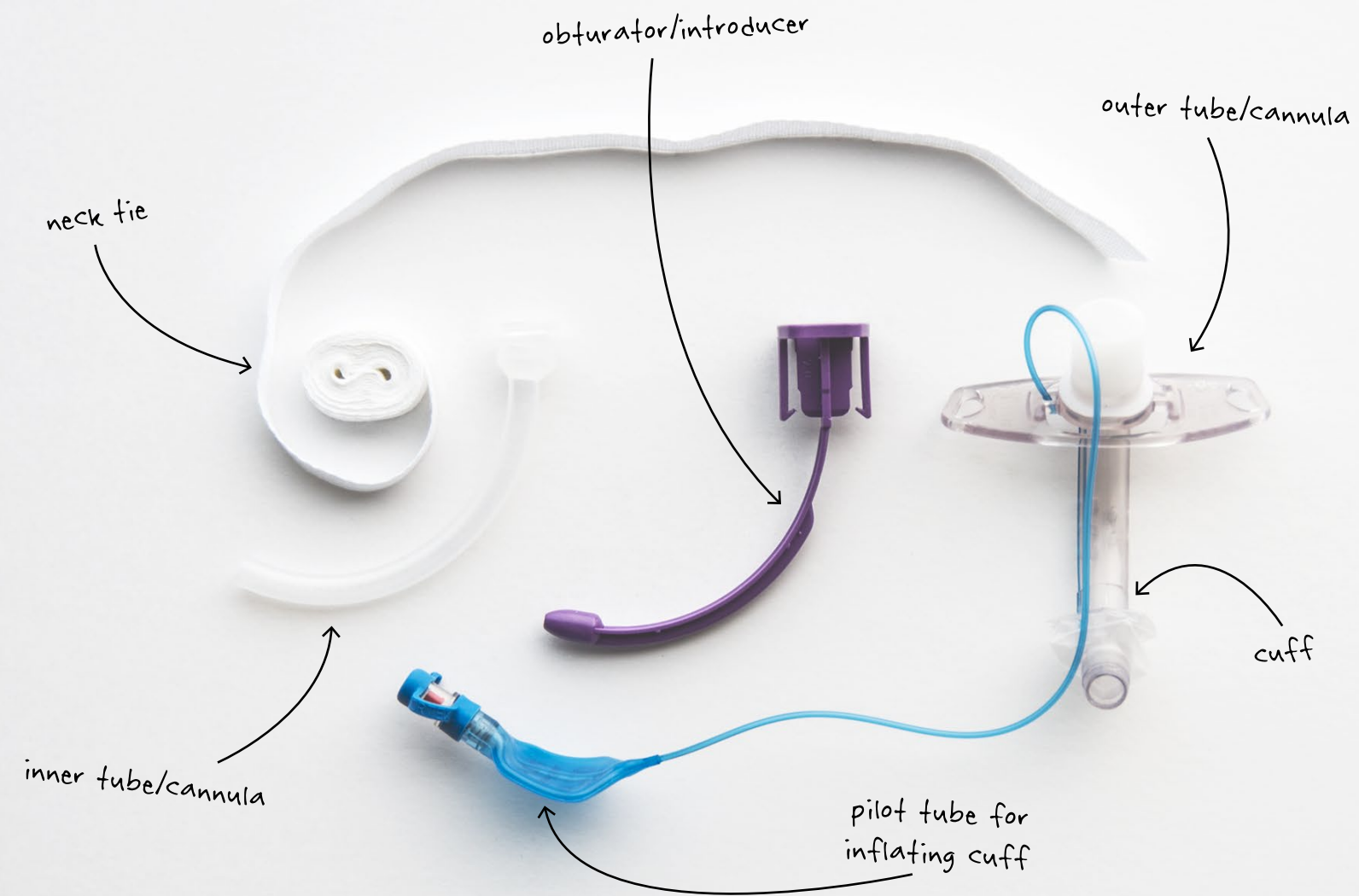
Tracheostomy tubes are predominantly made from either silver or polyvinyl chloride (PVC). Silver tubes allow for larger inner diameters due to thinner walls, are durable, and do not react against the skin. However, they are only cost effective for long-term use (Hess & Altobelli, 2014; NHS Trust, 2010). PVC tubes soften at body temperature and conform to the individual's anatomy. The malleable nature of PVC is described in tracheostomy literature as offering better comfort (Hess & Altobelli, 2014; NHS Trust, 2010).

Tubes can be angled or curved and of varying length, with the specific fit impacting comfort and effectiveness (Feber, 2006; Hess & Altobelli, 2014). Tubes with large inner diameters give better airway clearance, but large outer diameters can be difficult to insert and uncomfortable to wear (Hess & Altobelli, 2014; TRACOE Medical).

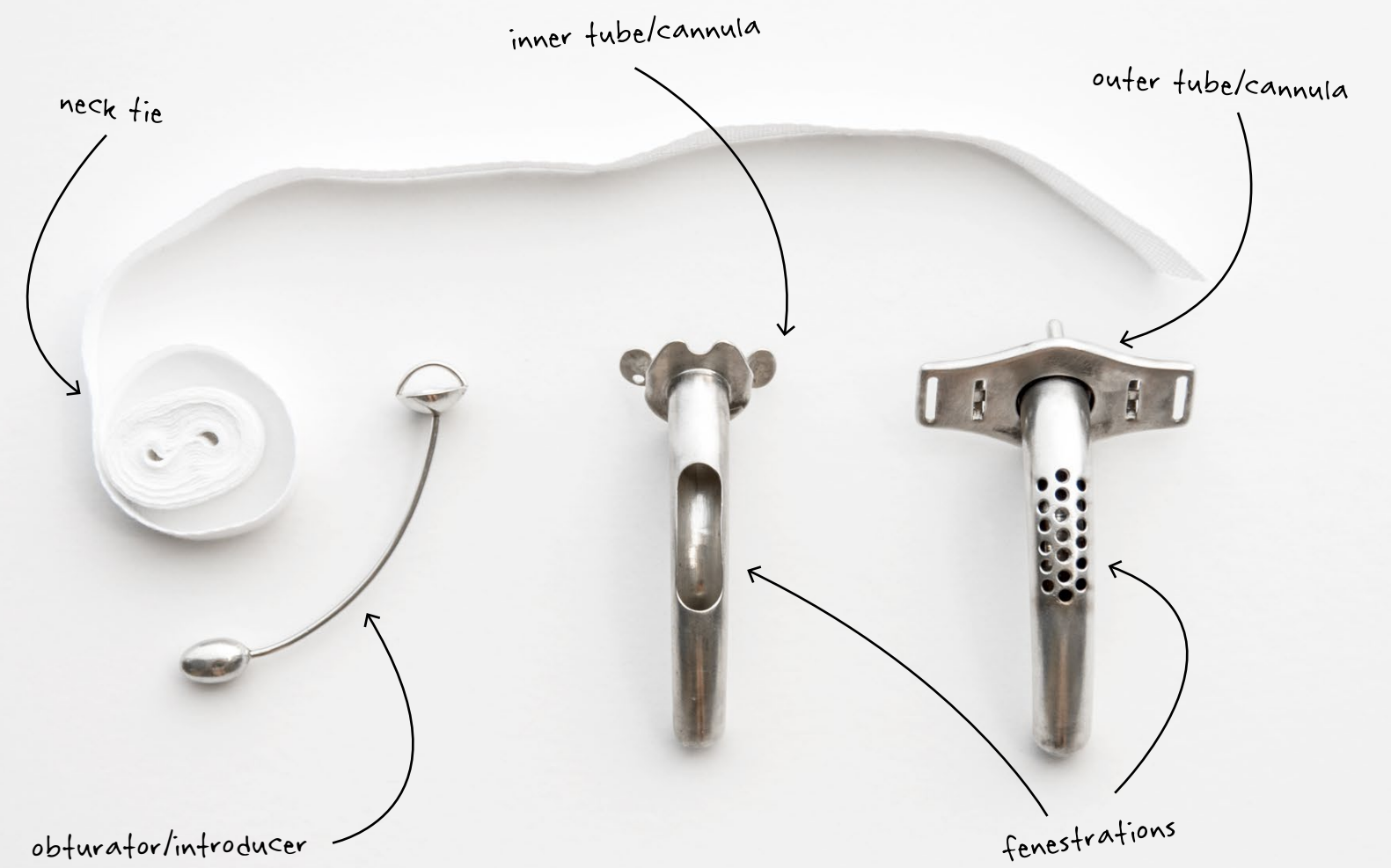
Tracheostomies consist of two tubes known as the inner and outer cannula. The outer cannula is inserted first and secured to the neck with a strap. The inner cannula slots into the outer cannula and clips in place. If the tracheostomy becomes blocked, the inner cannula can be easily removed and cleared while the outer cannula remains in place to provide the user with a safe airway (Hess & Altobelli, 2014; Lewarski, 2005).

Tracheostomy tubes may include openings, called fenestrations, in the rear section that allow air to pass through the vocal cords so that patients can speak (Hess & Altobelli, 2014; Lewarski, 2005). Some tubes have an inflatable cuff attached to the lower end to create a seal between the tube and the tracheal wall. Cuffs prevent users from breathing in fluid during long-term ventilation but can put harmful pressure on the trachea unless carefully monitored (Feber, 2006; Hess & Altobelli, 2014).

Additional products associated with tracheostomy use include: introducers to assist with tube insertion, speaking valves to facilitate speech, neck straps to hold the tube in place, humidifiers to compensate for the lost humidifying function of the nose, and suctioning devices to remove secretions.



8. Dickson (2016). Cuffed plastic 'Portex' tracheostomy set.



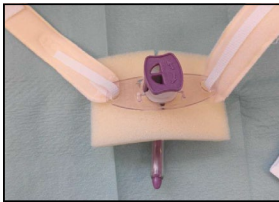
9. Dickson (2016). Cuffless silver tracheostomy set, unknown brand




Changing your tracheostomy tube

AIM: To promote hygiene, minimize risk of infection and formation of over granulation tissue (proud flesh)

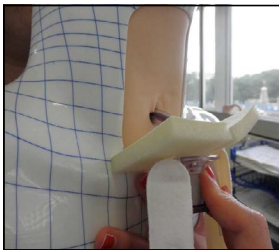
- Frequency of change
- Equipment needed
- Every 4 weeks
 - Mirror, Torch
 - New tracheostomy tube
 - Wet flannel



1. Wash Hands
Prepare new tracheostomy tube, attach the tracheostomy tie and dressing as per picture
Note: Use dressing only if needed



2. Remove old tracheostomy tube and wipe stoma and surrounding areas with wet flannel and then dry
3. Look at the stoma (hole) using a bright torch

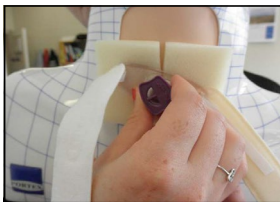


4. Insert tube gently and slowly into the stoma, the tube should slide in with a gentle push. (you may or may not experience coughing)
Note: Do not apply too much pressure when inserting, if there is resistance, take tube out and repeat **step 3**


5



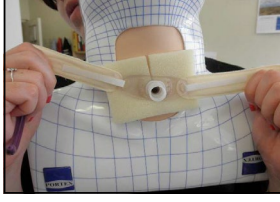
Changing your tracheostomy tube
... continued.....



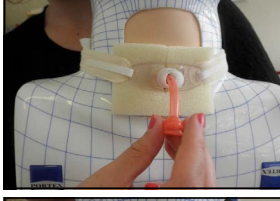
5. Once the whole tube is in, support the tracheostomy tube by putting your two fingers on top of the flange.



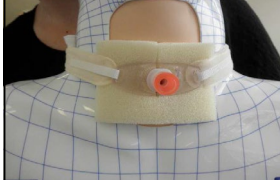
6. Twist the purple introducer and pull out ensuring that the tube is fully supported and stays in place



7. Secure the tracheostomy tube using the velcro ties



8. Insert the inner tube.



9. Check for airflow by putting your hand directly in front of the tracheostomy tube feeling for air coming out of the tube
Note: When you breathe, you should feel air coming out of the tube if it is properly in place

6

TRACHEOSTOMY CARE

Because tracheostomy users cannot breathe without their tracheostomy tubes, ongoing maintenance is imperative. As well as carrying an emergency tracheostomy kit, tracheostomy users must integrate the cleaning and changing of their tracheostomy products with their daily routine (TRACOE Medical). The frequency required for cleaning and changing different aspects of the tracheostomy tube and stoma site varies depending on the design of the device and the patient's condition.

Inner tubes typically need cleaning three to four times a day, while stoma sites should be cleaned, and neck straps changed, once a day (Capital & Coast District Health Board, 2015; Feber, 2006; Lewarski, 2005; NHS Trust, 2010; TRACOE Medical). The recommended frequency for full tube changes (replacement of both inner and outer cannulae) is largely based on local practice or influenced by product availability as determined by healthcare organisations or third-party insurance policies (Lewarski, 2005). Little objective research supports care recommendations, however an upper limit of 29 days of use is generally accepted regardless of tube type (Feber, 2006; Hess & Altobelli, 2014).

Tracheostomy tubes can irritate the trachea and increase natural mucus production. Because tracheostomy users breathe through their tracheostomy tubes, they lose the mucus-softening benefits of breathing through the nose. Thickened mucus may therefore block the tracheostomy tube and inhibit breathing. While the holes in fenestrated tubes allow users to cough mucus up through the mouth or nose, people using cuffed tubes (or who are otherwise unable to cough away secretions) may require mucus to be suctioned out.

10. Auckland District Health Board, (2000). Tracheostomy care guide sample pages

Although literature describes tube changes and suctioning as painless, some evidence suggests patients do experience discomfort during these processes (Donnelly & Wiechula, 2006; Foster, 2010; Sherlock et al., 2009). The demands of tracheostomy maintenance can limit autonomy and force patients to structure their lives around their condition.

LIVING WITH TRACHEOSTOMY

Tracheostomy tubes significantly alter an individual's physical appearance. Protruding from the front of the neck, they may be a source of shame and attract stigma (Gilony et al., 2005; Morris, M., & Afifi, 2013). Tracheostomy is also culturally associated with smoking. This may compound the stigma surrounding tracheostomy by leading others to blame patients for their condition, whether or not smoking is the underlying cause (Vaes, 2014).

Even if an individual is able to disguise their tracheostomy tube beneath a scarf, speaking difficulties and altered voice can undermine the appearance of normality. Because both face and voice shape how we identify ourselves and are identified by others, tracheostomy can negatively impact self-image and attract external stigma (Foster, 2010; Gilony et al., 2005). Poor adjustment to altered self-image and the resulting lowered self-esteem can keep users from administering effective self-care, thereby damaging their overall quality of life. For example, failing to regularly clean and change tracheostomy products can result in illness or infection (Bello, Di Muzio, & Antonelli, 2016; Hashmi, Ransom, Nardone, Redding, & Mirza, 2013).

GAPS IN THE KNOWLEDGE

Despite the many ways receiving a tracheostomy can alter life, there is a dearth of understanding of what living with a long-term tracheostomy is like. Tracheostomy literature is largely focused on clinical practicality (Bello et

al., 2016; Feber, 2006; Garruba, Turner, & Grieveson, 2009) and the function of tracheostomy products (Hess & Altobelli, 2014; Shikani & Dietrich-Burns, 2012). Literature that does discuss the users' experiences typically focuses on paediatric cases (Douglas et al., 2015; Flynn, Carter, Bray, & Donne, 2013; Hopkins, Whetstone, Foster, Blaney, & Morrison, 2009; Jiang & Morrison, 2003; Messineo et al., 1995; Patel et al., 2009; Spratling, Minick, & Carmon, 2012). Tracheostomy is sometimes treated as analogous to laryngectomy,* downplaying the differences between the procedures and their impacts on users' lives (Krouse et al., 2004). Much of the literature concerns acute care rather than long-term tracheostomy use (Donnelly & Wiechula, 2006; Foster, 2010; Sherlock et al., 2009).

Other tracheostomy literature is directed at nurses or centred on the parents of children with tracheostomies, and seldom considers the experiences of users themselves (Feber, 2006; Krouse et al., 2004; Lewarski, 2005). While Donnelly and Wiechula (2006) explore the lived experiences of tracheostomy users, they only discuss the experience of a tracheostomy tube change. Their study acknowledges psychological preparation, trust, and communication as factors that influence tube change experiences, but places the focus on physical sensation. There is little research concerning other tracheostomy care experiences and even less discussing the impact of tracheostomy on life outside of tracheostomy-specific experiences.

There is, therefore, a need to address the lack of research exploring tracheostomy users' own perspectives of both their tracheostomy care experiences, and the ways that tracheostomy impacts their daily lives. There is also an opportunity to consider tracheostomy users' psychological and psychosocial experiences in relation to existing literature on stigma, disfigurement, and body image.

** Laryngectomy: Surgical removal of the voicebox. In laryngectomy the top of the trachea is surgically redirected to an opening in the front of the patient's neck. Unlike tracheostomy, there is no longer any connection between the airway, and the nose and mouth.*



Examples of disfigured pop culture villains: 11. Davy Jones “The Pirates of the Carribean: Dead Man’s Chest; 12. Evil Queen, “Snow White and the Seven Dwarves; 13. Phantom, “The Phantom of the Opera”; 14. Beast, “Beauty and the Beast”; 15. Lord Voldemort, “Harry Potter”; 16. The Joker, “The Dark Knight”; 17. Richard III, “Richard III”; 18. Freddy Krueger, “A Nightmare on Elm Street”; 19. The Twits, “The Twits”; 20. Harvey Dent, “The Dark Knight”; 21. The Wicked Witch of the West, “The Wizard of Oz”; 22. Scar, “The Lion King”.

STIGMA

Although literature on the stigmatising effects of tracheostomy is limited, there is a wealth of research discussing general stigma, disfigurement, and body image that may be applicable to tracheostomy. Tracheostomy is a highly visible source of disfigurement with a clear potential to negatively impact self-image and draw stigmatising reactions from others.

APPEARANCES MATTER

Appearance plays an important role in human interactions (Bonanno & Esmaeli, 2011). Historically, people benefitted from the ability to judge the health, reproductive suitability, and social standing of others based on appearance (Bonanno & Esmaeli, 2011). In modern societies, where physical abnormalities are less likely to signal contagious disease, there is a residual tendency for people to project social traits onto others based on physical attractiveness. People who conform to cultural beauty ideals are perceived as kinder, more competent, and more intelligent than those considered less attractive (Bonanno & Esmaeli, 2011; Costa, Nogueira, de Souza Lima, Mendonca, & Leles, 2014).

Distaste for appearances that deviate from cultural ideals is even ingrained in the language we use to describe them. Words like ‘disfigured’ and ‘deformed’ imply that people described as such are somehow broken or ruined (Rumsey & Harcourt, 2004). Parallels between ‘ugliness’ and ‘evil’ can be found in the depiction of villains in cultural narratives from Shakespeare’s Richard III to Voldemort in JK Rowling’s Harry Potter (Bradbury, 2012; Rumsey & Harcourt, 2004; Stock, Whale, Jenkinson, Rumsey, & Fox, 2013). Furthermore, image-drenched media culture has taken our preoccupation with appearance to the extreme (Bradbury, 2012; Rumsey & Harcourt, 2004; Stock et al., 2013).

IMPACT ON VISIBLY DIFFERENT INDIVIDUALS

With such a strong cultural emphasis on the value of physical beauty, people with visible differences face constant stigma, leaving them at a distinct social disadvantage (Thompson & Kent, 2001). Visibly different individuals often struggle with forming social or romantic relationships, receive fewer offers of help from others, and are less likely to be successful job applicants (Thompson & Kent, 2001; van den Elzen et al., 2012). They often experience low self-esteem, poor body image, social anxiety, and depression (Bradbury, 2012; Rumsey & Harcourt, 2004). In public interactions they may encounter stares, rude remarks, unwanted questions, and other forms of harassment (Bonanno & Esmaeli, 2011; Stock et al., 2013; Thompson & Kent, 2001).

INTERNAL VS EXTERNAL PERSPECTIVES

The experiences of visibly different individuals can be examined from either an internal or external perspective (Thompson & Kent, 2001). The external perspective focuses on how visibly different people fare in social interactions and the measurable impact of their appearance on their experiences. Conversely, the internal perspective concerns the role of self-perception in the experience of being visibly different. Although interlinked, there can be surprising incongruities between the two perspectives, with outside perceptions of an individual's appearance proving a poor predictor of their self-image and resulting emotional experience (Thompson & Kent, 2001). In some cases, internal self-consciousness and social anxiety may drive visibly different people to exhibit ineffective social skills, leading to negative external reactions from others (Rumsey & Harcourt, 2004; Thompson & Kent, 2001). This often reinforces low self-esteem and further inhibits social skills (Rumsey & Harcourt, 2004).

FACTORS INFLUENCING EXPERIENCE

Although negative experiences appear more common among visibly different people than the general population, many visibly different people maintain positive psychosocial functioning (Costa et al., 2014). Individual experiences of visible difference are shaped by the nature of the visible condition, levels of social support, personality, and self-perception.

Counter-intuitively, severe or conspicuous instances of difference may not correlate with negative experiences (Thompson & Kent, 2001; van den Elzen et al., 2012) Those with severe, or highly visible differences may better adapt to negative reactions from others because these reactions occur more frequently (Bradbury, 2012; Rumsey & Harcourt, 2004; Thompson & Kent, 2001).

Self-perception and social support have a stronger influence on individual experiences of visible difference (Rumsey & Harcourt, 2004; van den Elzen et al., 2012). Regardless of clinical definitions, people who consider their visible difference to be severe may suffer from lower self-esteem, withdraw from social interaction for fear of rejection, and perceive stigma in the glances of others whether it is present or not (Thompson & Kent, 2001). Negative self-perception may result from lack of support from family and friends, past encounters with discrimination, or natural inclination towards self-consciousness and shame (Bradbury, 2012; Thompson & Kent, 2001).

COPING STRATEGIES

The strategies visibly different individuals employ to cope with stigma fit into three overarching categories; avoidance, concealment, and the development of social skills. Given the array of negative effects resulting from visible difference it is unsurprising that many avoid situations that might expose them to stigmatising reactions from others. They may limit social interactions to a close circle of familiar individuals (Costa et al., 2014; van den Elzen et al., 2012). Similarly, people often camouflage or conceal their visible difference using clothing, cosmetics, or postures that subtly reduce the emphasis on certain features (Thompson & Kent, 2001). Unfortunately, both avoidance and concealment can reinforce social isolation and prevent the visibly different person from adapting to their situation. Concealment can also introduce fear of discovery and discomfort with being dishonest about one's identity (Rumsey & Harcourt, 2004). In some cases, attempts at concealment can backfire and inadvertently emphasise the concealed feature (Bonanno & Esmaeli, 2011; Thompson & Kent, 2001).

Where concealment and avoidance fall short, the adaptation of positive social skills has been shown to empower visibly different people to cope with the difficult situations their differences may attract (Rumsey & Harcourt, 2004). Being "proactive" in social interactions can help people to manage the reactions of others and overcome the psychological distress they might otherwise experience (Thompson & Kent, 2001). Effective strategies for coping with social interaction include humour, actively challenging negative reactions, calmly explaining the visible difference, or using positive self-talk as a buffer against the judgement of others (Bonanno & Esmaeli, 2011).

PRODUCT AESTHETICS & IDENTITY

Beauty is an innate and universal human value (Kopelman, Rovenpor, & Guan, 2003). This has been demonstrated across cultures, with a preference for beauty even observed in infants (Townsend & Sood, 2012). As well as shaping our judgements of other people, beauty has a fundamental influence on our product choices (Townsend, 2015). Research shows that beautiful products are easier to use, improve our self-esteem, and owning them can make us appear more attractive to others (Gao, Wheeler, & Shiv, 2009; Norman, 2005; Townsend, 2015). These demonstrable effects of aesthetics call into question the frequency with which they are overlooked in the design of medical products like tracheostomy tubes.

THE ARGUMENT FOR AN AESTHETIC APPROACH TO TRACHEOSTOMY DESIGN

The tendency to perceive positive traits in attractive people can also be extended to attractive objects and the people who possess them (Townsend, 2015). Furthermore, conspicuous products have a greater effect on the way their possessor is perceived by others (Sirgy, Johar, & Wood, 1986). Tracheostomy tubes are highly conspicuous, protruding from a central and visible point on the user's body. Their placement shapes the way that tracheostomy users are perceived, and as such, aesthetic value should be considered in their design. Unfortunately, the functional focus of existing tracheostomy designs seems to have resulted in a homogenous product range of low aesthetic value. Given the relationship between product aesthetics and self-image, low aesthetic value in tracheostomy product design may contribute to lowered self-esteem for tracheostomy users (Barber, 1996; Rumsey & Harcourt, 2004; Townsend & Sood, 2012). Improving the aesthetics of tracheostomy products may therefore improve the way that tracheostomy users perceive themselves and are perceived by others.

TRACHEOSTOMY AND THE ‘EXTENDED SELF’

According to Belk (1988), some products not only reflect our identity but are also part of it, making up the ‘extended self’. Objects become part of our extended self when they extend our capabilities, when we achieve control over them, or when they exert control over us (Belk, 1988). Medical prostheses attach directly to the body, extending it literally. Prosthetic legs, not only extend into the space left by a missing limb, but are available in designs that can extend users’ running abilities to a level on par with Olympic competition, despite bearing little resemblance to biological legs (Greenemeier, 2016).

When considered as part of an extended self, tracheostomy tubes present an interesting conflict. Physiologically they are part of the extended self because they are directly incorporated into the user’s body and extend their otherwise limited ability to breathe. On the other hand, the lack of control users have over the tracheostomy products they are given, as well as their need to have a tracheostomy in the first place, makes it psychologically difficult to integrate them into their extended self-image. Because breathing is taken for granted, tracheostomy tubes may be seen as maintaining rather than extending the user’s abilities. Users who compare the quality of their breathing with tracheostomy to the way it was before the illness or injury that necessitated the tracheostomy, may even feel their abilities have been inhibited rather than maintained or extended. Difficulties with speaking and other aspects of daily life resulting from the tracheostomy may further compound this effect.

Belk (1988) also asserts that objects become part of our extended self when we create or alter them. We see objects we create as embodiments of the energy we invest in them (Csikszentmihalyi, as cited in Belk, 1988). The

association between creation and creator is even seen in the way we talk about famous artworks. For example, phrases like “this is a Picasso” imply that an artwork is an extension of the artist. Extending this knowledge to the case of tracheostomy provides the argument that allowing users to contribute to the design of tracheostomy tubes, choose from a range of designs, or select a custom configuration of components may help them to see tracheostomy as a more positive and integrated part of their extended self.

SELF-AFFIRMATION AND THE ‘SHAKEN SELF’

In a 2009 study, Gao et al. demonstrated that performing familiar tasks in an unfamiliar manner can disrupt a person’s confidence in an effect referred to as “the shaken self”. The study found, disrupting a person’s self-confidence in a particular attribute made them more likely to select products that symbolised competence in that attribute (Gao et al., 2009). For example, participants with shaken confidence in their intelligence might choose a pen. The changes to appearance and lifestyle associated with long-term tracheostomy can disrupt many facets of the user’s self-image, from physical appearance to confidence completing everyday tasks like speaking or showering (Gilony et al., 2005; Hashmi et al., 2013; Morris et al., 2013). While the lowered self-image experienced by long-term tracheostomy users is probably more deeply rooted than the momentary ‘shaken self’ explored by Gao et al, the potential for product attributes to reinforce positive self-image may still be relevant to improving tracheostomy tube design. For example, instilling tracheostomy tubes with a greater aesthetic value may help restore users’ diminished confidence in their appearances. It is, however, important to note that product attributes may not be as effective at bolstering chronic low confidence, such as that experienced by long-term tracheostomy users (Gao et al., 2009).

AESTHETICS AND SELF-AFFIRMATION

Research by Cohen, Aronson, and Steele (2000) demonstrates that self-affirmation can reduce a person's bias against points of view differing from their own. In a 2012 study Townsend and Sood identify how this, combined with evidence of the self-affirming power of aesthetics, could explain common biases against less attractive people and things. They argue that because observing beauty makes us feel secure in ourselves, we are more likely to judge attractive people fairly. By extension, they conclude that in the absence of the self-affirmation provided by beauty, we are more likely to act defensively and unfairly project negative qualities on less attractive people (Townsend & Sood, 2012). If this is the case, the poor aesthetic value of existing tracheostomy designs is likely to contribute to the stigma experienced by long-term tracheostomy users. Furthermore, improving the aesthetics of tracheostomy tube designs may help to reduce people's negative reactions to tracheostomy users.

AESTHETICS AND IDENTITY TENSION

It is widely accepted that our sense of identity is structured as a narrative made up of conflicts and resolutions (Ahuvia, 2005). Objects closely tied to our identity are those that help us resolve conflicts in our identity narrative (Ahuvia, 2005). Objects can resolve tensions by demarcating one identity over another, facilitating a compromise that combines some aspects of multiple identities, or synthesising multiple identities into a coherent whole (Ahuvia, 2005). Individuals can exercise agency in resolving identity conflicts by selecting products that reflect their conceptions of their inner self or that project a desired identity.

The acquisition of disability, particularly when sudden, can be a strong source of identity conflict (Thompson & Kent, 2001; van den Elzen et al., 2012). In the case of tracheostomy, individuals must reconcile their established self-image with the identities imposed on them by their condition and its associated products (Gilony et al., 2005; Morris et al., 2013). The functionally driven design of existing tracheostomy products can force users to compromise aspects of their preferred identity to accommodate the identities of illness and disability that these products communicate.

Because they depend on the tracheostomy tube to live, users cannot reject the identities it carries in order to demarcate their preferred identity. Furthermore, the lack of product choice available to them limits opportunities for synthesising tracheostomy with their identity. Stripped of the agency to resolve identity conflicts in a positive way, the tracheostomy event may become a source of psychological tension in the user's identity narrative.

CONSUMER VS MEDICAL PRODUCTS

RESEARCH DIFFERENCES

While an abundance of literature explores the ways people select, feel about, and identify with consumer products, there is a distinct lack of research relating these concepts to healthcare contexts (Ahuvia, 2005; Belk, 1988; Gao et al., 2009; Sirgy et al., 1986; Townsend & Sood, 2012). Perhaps this implies that little value is perceived in understanding and improving user relationships with healthcare products. This may result from a traditional monetary conception of value. While improving consumer products can increase profit margins, improving healthcare products is a more altruistic pursuit with obvious benefits only to those who use them. Highly specialised products like tracheostomy tubes are used by small and specific groups of people, leaving little room for market expansion.

CHOICE

The disparity in research is also reflected in product availability. Compared to the overwhelming product choice in mainstream markets, tracheostomy product choice is virtually null. This is partly because tracheostomy products are not purchased by their users, but instead by healthcare organisations whose primary concerns are function and cost (Barber, 1996). Because these factors drive purchasing decisions, they are the only factors visible and relevant to manufacturers. This means tracheostomy products are designed for the disability rather than the user. Barber (1996) argues that products designed in this way also tend to communicate meanings associated with disability that cause users to feel, and be perceived as, more disabled than they otherwise might.

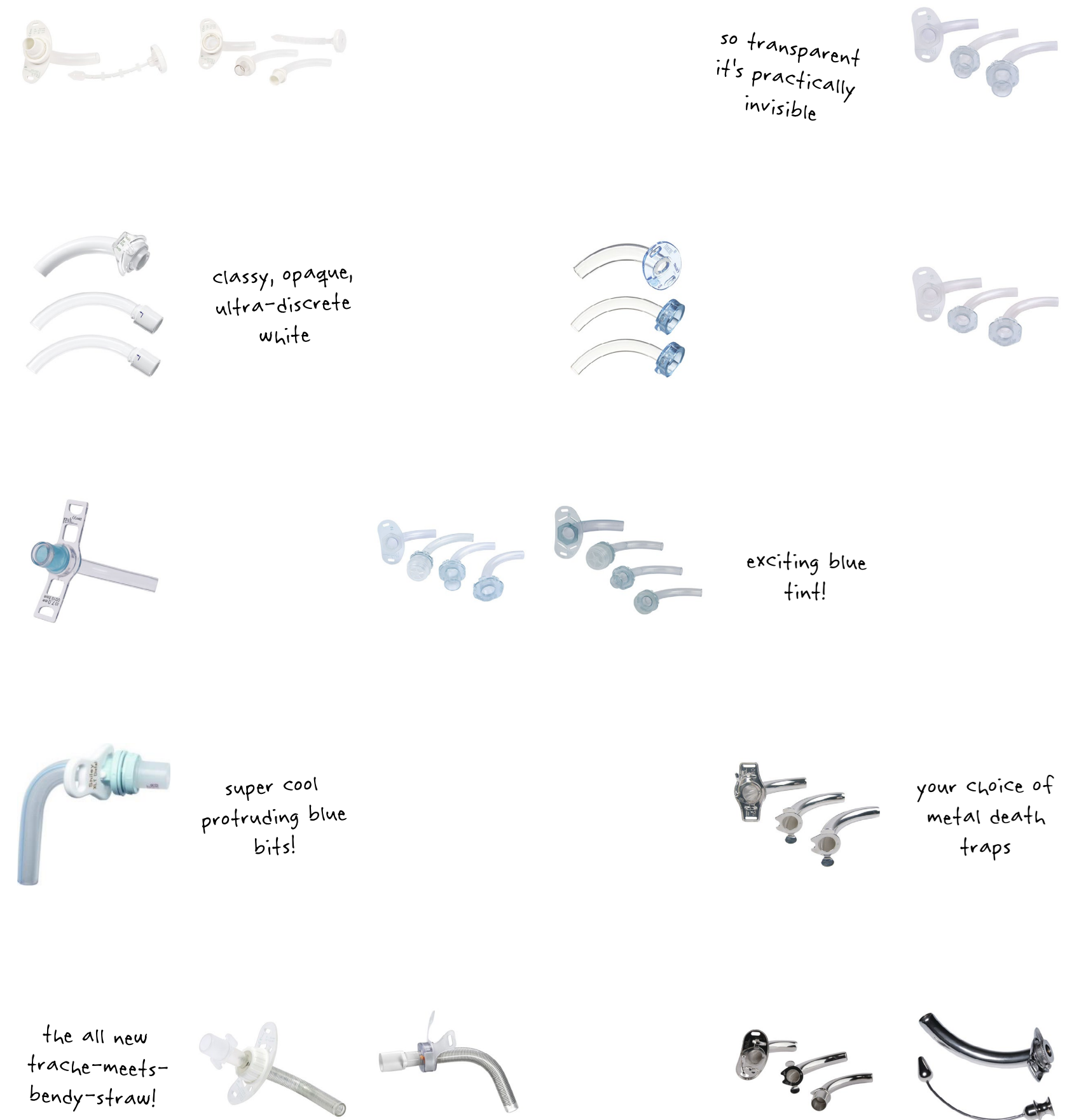
EYEGLASSES

Unlike most examples of design for disability, eyeglasses have bridged the gap between medical and consumer products to the point where they have largely shed their stigma (Pullin, 2011). At times, they are even worn as accessories by people without visual impairment (Pullin, 2011). Eyeglasses have become mainstream, in part, because the afflictions they treat are so commonplace— an advantage distinctly absent in the case of tracheostomy. Eyeglasses also share their form with sunglasses, which are already free of medical connotations, and are associated with being “cool”.

While some medical products have attained a degree of mainstream acceptance, tracheostomy is limited in its potential to do so. With such a specialised purpose requiring intrusion of the body, it is difficult to imagine anyone with unimpaired breathing choosing to wear a tracheostomy tube as a fashion statement, regardless of any aesthetic improvements. The life and death nature of tracheostomy tubes situates them firmly in the medical product category, resulting in stagnant and narrowly focused designs. Even so, few objects are worn permanently on the body with so little consideration for emotional attachment or aesthetic design.



23. Examples of eyeglasses with commentary demonstrating the range of styles available, and different messages conveyed by each about their wearer



24. Examples of tracheostomy products with sarcastic commentary highlighting the dismal range available

PATIENT IDENTITY

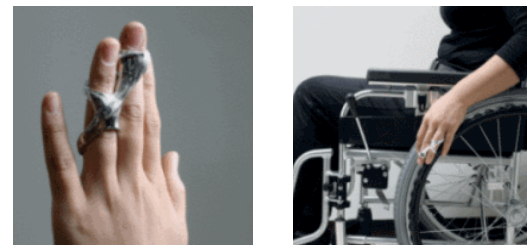
Ideally, when someone is discharged from hospital, they leave behind their patient identity and resume everyday life. However, long-term tracheostomy users continue to live with a reminder of patient identity embedded in their body months, years, and even decades after leaving hospital. Despite obvious differences between in-hospital tracheostomy care and living in the community with a long-term tracheostomy, the same products are used in both contexts. As such, tracheostomy tubes worn at home may retain features only relevant in the hospital context and lack others that benefit users in everyday life (Barber, 1996). Products used in hospital may also remind users of traumatic experiences and bring negative associations into the home (Barber, 1996). As such, there is reason to believe users would benefit from a different tracheostomy design for at-home use.

PRECEDENTS

Although Human Centred Design is by no means the norm within healthcare contexts, there is a growing stream of projects and studies advocating for the consideration of aesthetics and emotional experience in the design of healthcare products. Examples include, an aesthetically driven look at medical orthoses, hospital gowns that encourage self-expression among teenagers, and a colostomy pouch that addresses the challenge of intimacy for colostomy users (Cho & Park, 2011; Starlight Children's Foundation Canada, 2016; Tucker, 2016). These projects can serve as precedents for a human-centred exploration of tracheostomy design.



25. Cho & Park, (2011). Eye patch design



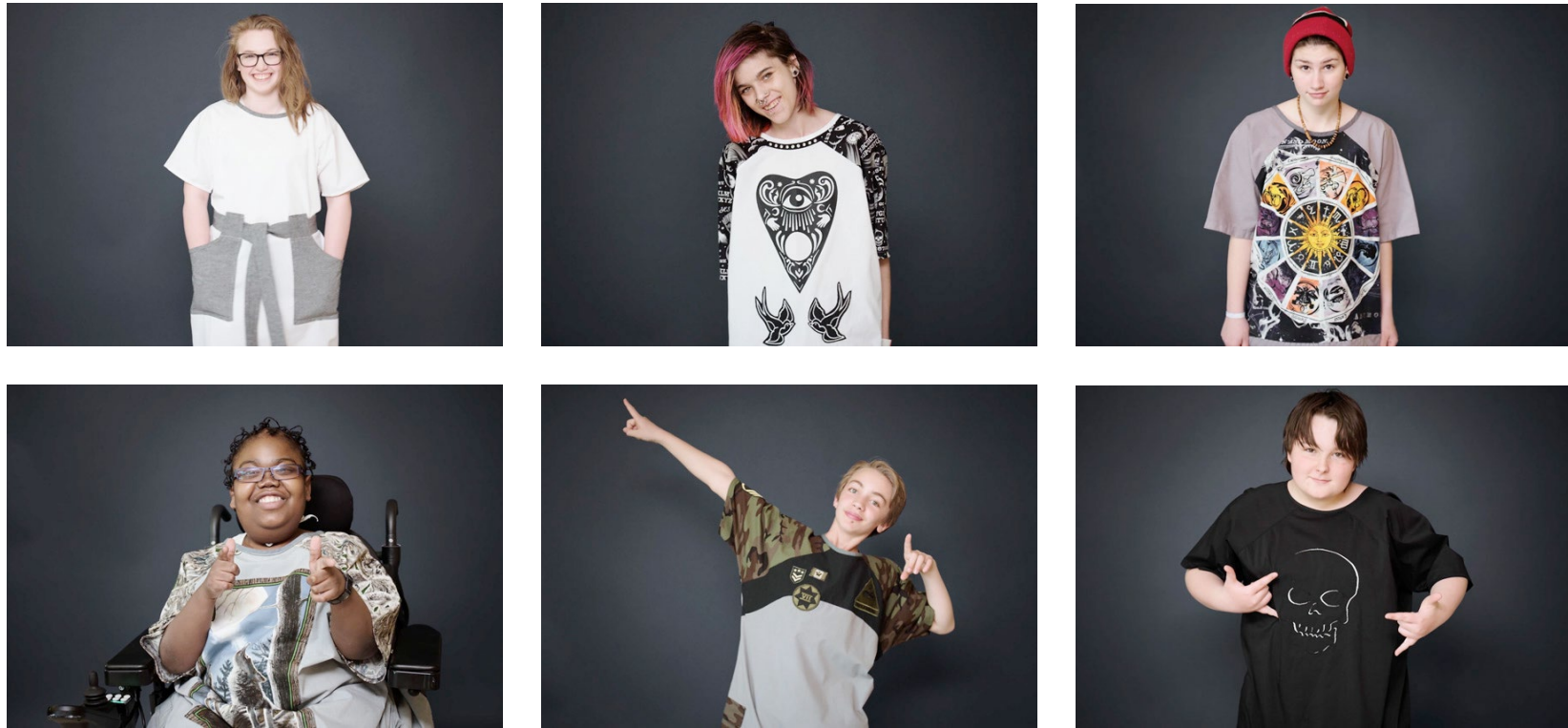
26. Cho & Park, (2011). Finger orthosis design

METAMORPHOSIS

In a South Korean study exploring the aesthetics of medical orthoses, designs were generated in response to orthosis wearers' expressions of their personalities, lifestyles, and identities (Cho & Park, 2011). The researchers sought to challenge the conception of orthoses as shameful objects by instilling each design with the individuality of its user. Through collaboration between users, designers, and orthosis makers the study resulted in the production of bespoke orthoses that radically challenge traditional approaches to medical product design.

One of the conditions that afforded the radical customisation of orthoses was the inherent need for designs to be custom-fit to user anatomy (Cho & Park, 2011). While tracheostomy tubes are sometimes customised for users with unusual anatomies, standard designs are more common. This means that completely bespoke creations may not be suitable. However, the potential remains to expand the range of options so tracheostomy users can customise their products by combining different components or express their personality through the designs they select.

Cho and Park (2011) highlight the potential for materials and construction processes to enhance users' emotional connections to their orthoses. They believe, for example, that the use of silver, as well as labour-intensive silver-smithing techniques add emotional value to their designs (Cho & Park, 2011). In reference to their finger orthosis design, they do, however, identify the cost drawbacks of such an approach. Given that some long-term users already receive expensive silver tracheostomy tubes (some of which are custom made) there may be opportunities to use other high value materials, or implement craft-based construction processes to improve the emotional value of the design without significantly increasing cost.



27. Starlight Children's Foundation Canada, (2016). Examples of WARD + ROBES designs

WARD + ROBES

In a project titled WARD + ROBES, Starlight Children's Foundation Canada gave hospitalised teenagers the opportunity to select hospital gown designs that reflect their personalities. The organisation worked with top designers to produce a range of gowns, with the aim of restoring self-expression in the hospital setting (Starlight Children's Foundation Canada, 2016). In a video about the project, one teenager said "When you can't wear what you want, you feel like you're not who you should be, or you're just your illness" (Starlight Children's Foundation Canada, 2016). The idea that being required to wear something with visual language tied to the hospital setting can lead to feeling one's personality is overshadowed by their patient identity is equally applicable to the tracheostomy context. Again, this project reinforces the idea that choice and aesthetic value in the design of products like tracheostomy can be psychologically beneficial to users.



28. Monty, (2016). Colostomy appliance design for intimate occasions

OSTOMY APPLIANCE FOR INTIMATE OCCASIONS

2016 Brunel University graduate, Stephanie Monty addressed the intimacy challenges experienced by people living with colostomy by designing a discreet colostomy pouch with a range of tattoo and lingerie-inspired silicone covers (Tucker, 2016). Intended for short-term wear, the design is significantly smaller than typical colostomy pouches. It also incorporates functional improvements like nano-technology to eliminate bacteria and reduce the risk of skin infection (Tucker, 2016).

In addition to exploring the value of aesthetics, Monty's design recognised that permanently worn medical products have to meet different functional and emotional needs in different contexts of use. Where traditional colostomy pouches provide one, all-purpose solution, focusing on a particular situation reduces the constraints on the design and makes space for exploring aesthetics without compromising function. Providing a design geared towards intimacy acknowledges the colostomy user as a complete person with a full range of experiences, rather than reducing them to their condition. Similarly, greater freedom in the design of long-term tracheostomy devices may be achieved by lifting hospital-specific constraints and placing the focus on other user experiences. Monty's design proves that invasive medical products like colostomy pouches and tracheostomy tubes can be beautiful and functional if the notion that one design must serve all situations is rejected.

PROJECT AIMS

Reviewing a range of literature, relating directly to tracheostomy as well as peripheral topics like stigma, identity, and the differences between consumer and medical product design, helped me begin to frame my approach to this project. Each avenue of the literature review highlighted further issues that might be addressed as part of the broad goal of improving tracheostomy user experiences through design.

Project aims that were formed as a result of the literature review findings included:

Disrupt the historic stagnation in tracheostomy product design.

Challenge the status quo of medical product designs and the prioritisation of clinical function, cost, and manufacturing over user experience.

Explore the relationship between tracheostomy products and user identity.

Reduce the stigma carried by tracheostomy products.

Challenge conceptions of 'appropriate' aesthetics for medical products.

Challenge the positioning of tracheostomy devices as strictly 'medical' products.

RESEARCH QUESTION

Having developed a comprehensive list of project aims, I consolidated the core objectives into an overarching research question to guide the project:

How can I use design to capture the experiences of people living with long-term tracheostomy and advocate for their needs, while challenging the status quo of tracheostomy product design?

METHODOLOGY

EPISTEMOLOGY

CONSTRUCTIVISM

According to a constructionist world-view, meaning is not inherent or discoverable, but constructed through a subject’s interactions with the world (Gray, 2014). Different, but equally valid meanings about a phenomenon may be constructed by subjects with different backgrounds and experiences (Collins, 2010). Informed by my life experiences and education as a design researcher, constructivism is the epistemological perspective through which I approached this project.

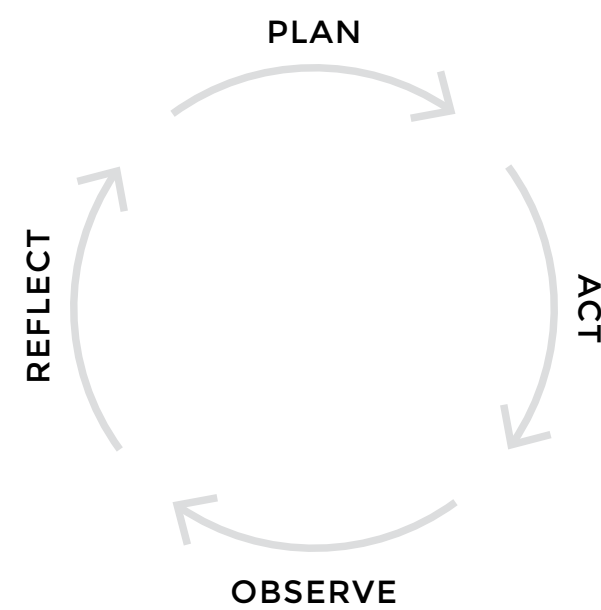
Because I have not experienced living with tracheostomy, the meanings that I constructed about tracheostomy-related experiences were unlikely to align with those constructed by tracheostomy users. Furthermore, different tracheostomy users constructed different meanings around their experiences. As such, the effectiveness of this research depended on the use of human-centred and co-design methods to build an understanding of their experiences. At the same time, it was important to acknowledge and reflect on the limitations of filtering those meanings through my own constructions of the world.

THEORETICAL PERSPECTIVE

INTERPRETIVISM

Interpretivism views reality as socially constructed when individuals attribute meanings to phenomena (Collins, 2010). While interpretivism allows for multiple valid interpretations of reality, it does not claim reality is completely subjective or that things mean whatever subjects think they do. Instead reality is shaped by the interplay between the subject, the phenomenon, and the context in which it occurs (Collins, 2010). Because interpretivism is concerned with aspects unique to the subject, phenomenon, and context, it favours qualitative methods and inductive reasoning (Gray, 2014).

In this research I explored tracheostomy users' experiences using an interpretivist perspective. This meant recognising the role participants, the research context, and myself as the researcher played in shaping the research outcomes. I used qualitative methods like semi-structured interviews and group workshops to understand the meanings participants' constructed about their tracheostomy experiences. I also recorded written reflections on my contributions to the meaning-making process.



29. Schön, (1983). Action research cycle

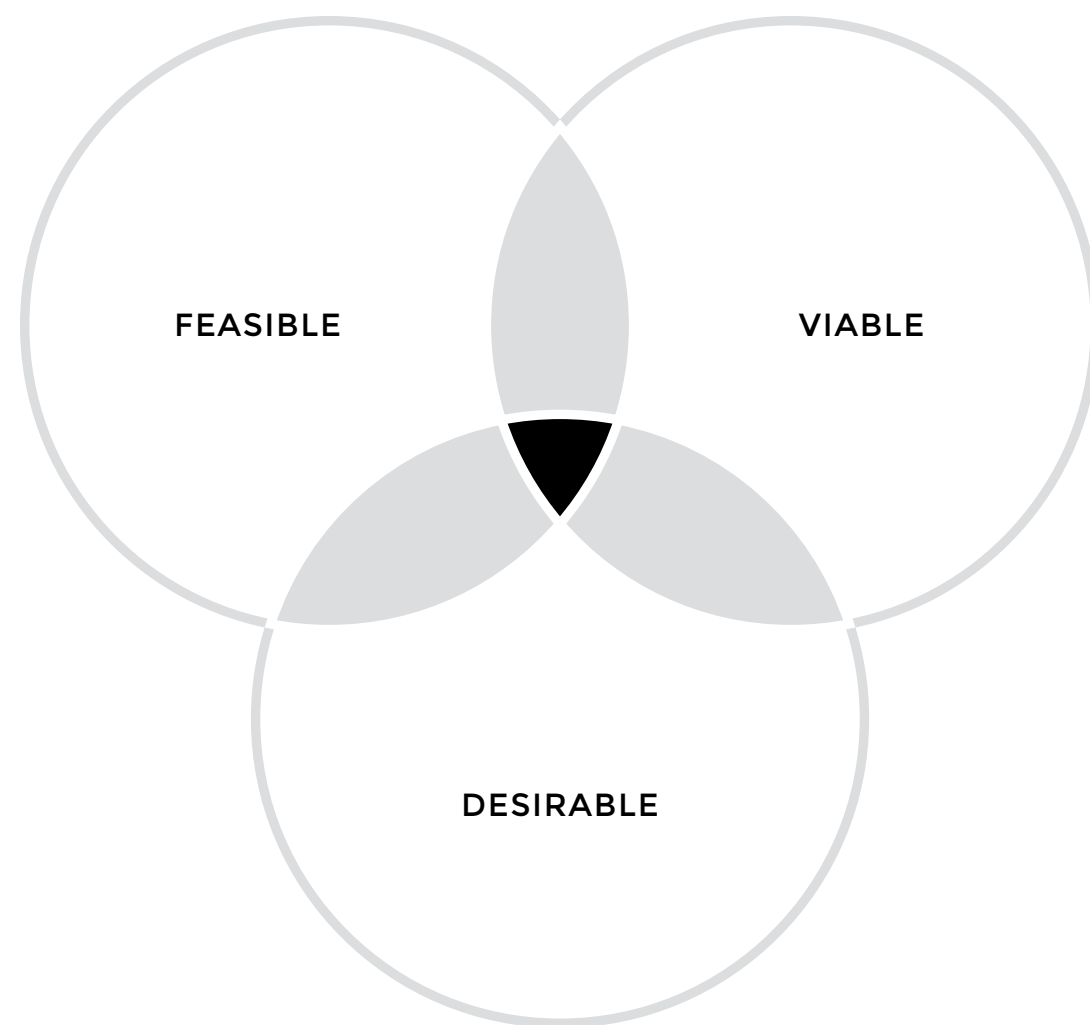
METHODOLOGICAL APPROACH

ACTION RESEARCH

Action researchers participate in the research and aim to facilitate organisational change (Archer, 1995; Collins, 2010; Gray, 2014; Koskinen, Zimmerman, Binder, Redström, & Wensveen, 2011). Action research uses iterative cycles of planning, action, observation, and reflection (Gray, 2014). Cycles are flexible, overlap, and allow the researcher to adapt their approach in response to findings (Gray, 2014; Swann, 2002). The flexibility of these cycles makes action research suitable for exploring complex, open-ended problems like improving tracheostomy users' lived experiences.

I used action research to foster change in attitudes towards tracheostomy products and approaches to their design. I combined external action research (EAR) and participatory action research (PAR) (Gray, 2014). Drawing from EAR, I worked alongside healthcare practitioners to achieve change but remained external from the hospital. Using PAR principles, I engaged participants directly in research activities and made their experiences the basis of data collection and analysis (Gray, 2014).

In keeping with an action research methodology, I aimed to shift attitudes towards tracheostomy products in the hospital organisation. I also sought to empower tracheostomy users to change their expectations of healthcare organisations with regards to tracheostomy product provision. Finally, I worked to produce a design proposal that could serve as a catalyst for further tracheostomy product design development.



30. IDEO (2008). *The three lenses of human-centred design*

THEORETICAL FRAMEWORKS

HUMAN-CENTRED DESIGN

Human-Centred Design (HCD) is a framework for keeping the needs of project stakeholders at the forefront of the design process (Giacomin, 2014; Krippendorff, 2005). Methods associated with HCD are those that help designers empathise with the people who will be impacted by their work. Building empathy for stakeholder needs provides designers with the foundation for meaningfully improving their experiences (Giacomin, 2014).

HCD principles were closely aligned with the aims of this project. Using empathy building methods like in-depth interviews, roleplaying, and group workshops helped me understand how tracheostomy products shape users' experiences. Using HCD also helped me underscore the research design with my personal values. The goal of addressing real human needs supported my conviction that design should work towards meaningful change.

CO-DESIGN

Co-design places stakeholders and designers on equal footing as collaborators in the design process (Sanders & Stappers, 2008). Where HCD gives designers a framework for understanding the people they design for, co-design is about designing in partnership with users of a product or service (Giacomin, 2014; Sanders & Stappers, 2008). Taking the view that tracheostomy users understand the world differently from others, understanding their experiences required acknowledging them as the foremost experts of those experiences (Sanders & Stappers, 2012).

Employing co-design principles also supported my use of an action research methodology. Both action research and co-design position the researcher or designer as a facilitator rather than an ‘expert’ (Gray, 2014; Sanders & Stappers, 2008). In action research, the researcher facilitates change, while in co-design the designer facilitates open discussion and generative thinking. Combining both approaches solidified my goal of empowering tracheostomy users in the design of tracheostomy products.

Although co-design workshops were my primary method for engaging with tracheostomy users and exploring their attitudes towards tracheostomy products, a full co-design process was not used for this project. This was because the research question focused on the design of tracheostomy products rather than exclusively challenging the process behind their development. The added ethical considerations and expanded timeframe required to execute a comprehensive co-design process were deemed beyond what was necessary to address the research question.

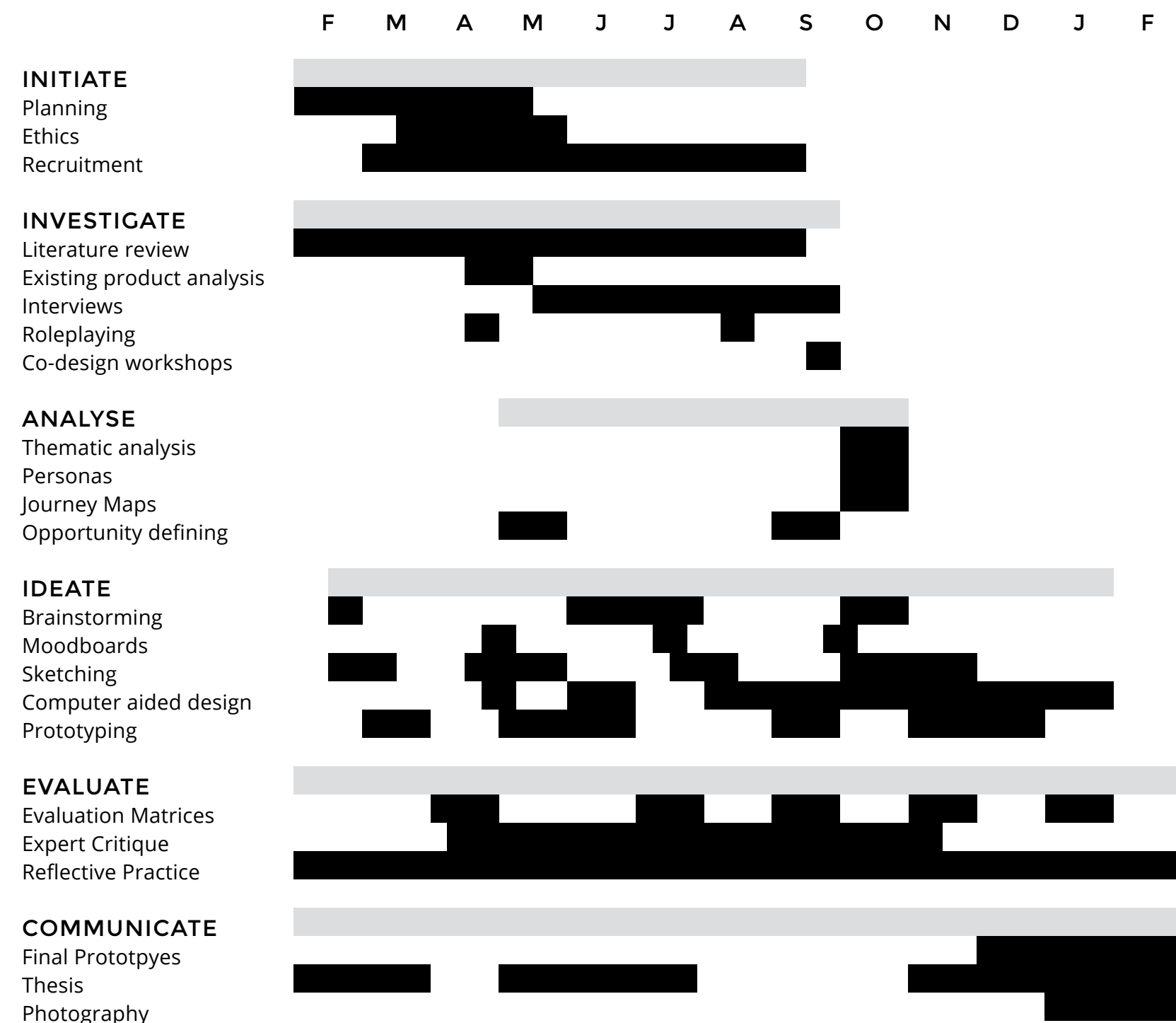
ETHICAL CONSIDERATIONS

The use of HCD and co-design frameworks meant human participation was required to ensure research outcomes reflected the needs and desires of people affected by tracheostomy products (Giacomin, 2014). Clinicians familiar with tracheostomy participated in interviews and gave expert feedback on prototypes. Tracheostomy users shaped the design direction by participating in interviews and co-design workshops. As an action researcher using co-design methods, I also played a participant role. Because participation had the potential to impact each group, there was an ethical responsibility to protect the privacy and safety of those involved (Candy, 2006; Gray, 2014).

The physical (shortness of breath, difficulty speaking, etc.) and emotional condition (stigma, self-consciousness, etc.) of tracheostomy users had the potential to make them particularly vulnerable participants (Gray, 2014). As such, I endeavoured to make participation a positive experience for this group. They were encouraged to bring support people to interviews and workshops, and measures were taken to ease transport to and from research activities.

To fulfil the ethical obligations of the project I submitted a detailed research plan to AUT Ethics Committee (AUTEC), and received approval under the number (16/165). The plan was based on the following ethical principles:

- Partnership
- Participation
- Protection



31. Dickson, (2016). Project timeline

METHODS

I divided the project timeline into six defined but overlapping stages, four of which contained the core research methods. Activities commencing and concluding the project made up the 'Initiate' and 'Communicate' stages respectively. The 'Investigate' stage comprised of data collection methods. 'Analyse' methods were used to draw meaning from data, and 'Ideate' methods to generate design concepts. 'Evaluate' methods were used to assess work throughout the project, with a particular focus on the outcomes of 'Ideate' methods.

For clarity, descriptions of research methods in this chapter are divided into categories based on the 'Investigate', 'Analyse', 'Ideate', and 'Evaluate' stages. In reality, however, multiple methods and stages often occurred simultaneously. As such, the 'Research Documentation' chapters represent research activities in approximately chronological order rather than discrete stages.

INVESTIGATION METHODS

LITERATURE REVIEW

Literature review involves gathering, summarising, and evaluating existing literature to build a base of knowledge about a given topic (Candy, 2006; Collins, 2010). A broad review of literature concerning tracheostomy, stigma, visible difference, consumer product research, aesthetics, and identity was used to understand the context surrounding tracheostomy experiences and to identify gaps in existing knowledge that might form suitable research avenues. Literature was sourced through AUT Library as well as Google Scholar's online database using a range of search terms relating to different aspects of the project context. Search results were narrowed down using filters. Any sources deemed relevant were downloaded or photocopied, with relevant information highlighted from each source. Information was then categorised according to common themes and sub-themes which eventually made up different sections of the written literature review.

EXISTING PRODUCT ANALYSIS

Existing Product Analysis is a method used by designers, which involves the close examination of the features of products from the same category as the product they are designing. Analysing existing designs of a specific product can help designers see what has been done before, understand functional requirements, and identify elements that are (or are not) successful (Parsons, 2009).

For this project, I analysed the designs of an existing tracheostomy tube and a range of tracheostomy accessories. Looking at an existing tracheostomy helped me understand how it worked and explore how the design might make users feel. By examining the range of tracheostomy accessories available I was able to gauge the level of choice available to users and how this might shape their experiences.

ROLEPLAYING

Roleplaying is a research method in which the researcher takes on the role of a particular person or group to build empathy for their experiences (IDEO, 2008; Koskinen et al., 2011; Polaine, Løvlie, & Reason, 2013). Roleplaying may be assisted by objects, costumes, or locations that lend realism to the task (Polaine et al., 2013; Steen, 2011). I used roleplaying to understand the experience of tracheostomy-related stigma. I cut the tube off a real tracheostomy tube and wore the protruding portion of the device around my neck for a day while going about normal activities.

Roleplaying as a tracheostomy user allowed me to simulate the difficulties someone adapting to a tracheostomy might encounter. I tried fastening the strap, covering the hole when I spoke, keeping the tracheostomy dry while showering, and performing other daily activities. Wearing the tracheostomy tube in public helped me understand the impact tracheostomy can have on self-confidence and social interactions. I recorded my roleplaying exercise with written notes. While roleplaying gave me a snapshot of users' experiences, the method had some limitations. For example, I could not experience the sensations of breathing through my throat, the discomfort of mucus build-up, or communication difficulties. To understand these experiences, I used methods like interviews and co-design workshops.

I also treated my first encounters with tracheostomy products (a tracheostomy kit and nebuliser kit) as roleplaying exercises. I imagined encountering these products as a new user, documenting this process through photography and written notes. Roleplaying allowed me to set aside my role as a designer and identify pain points in the experience.

INTERVIEWS

In-depth interviews are an ethnographic research tool used to understand participants' experiences in relation to a research context (Ireland, 2003; Maguire, 2001; Polaine et al., 2013). I conducted interviews with Auckland Hospital staff working in roles related to tracheostomy care including nurses, a speech therapist, and a tracheostomy nurse specialist. Interviews with 10 tracheostomy users were also conducted as part of the main SRIF study, the findings of which informed this project. The tracheostomy users interviewed had worn their tracheostomies for 1-24 years and were recruited by the SRIF team with assistance from a tracheostomy nurse specialist.

Staff interviews were semi-structured, using open-ended questions that allowed the flexibility to adapt to participants' responses. During these interviews, I asked staff to discuss their experiences working with tracheostomy users, opinions about existing tracheostomy design, and ideas for improving tracheostomy products. Although staff were not the primary stakeholder group, their interactions with tracheostomy users shaped users' experiences and their medical expertise meant they could explain the practical requirements of tracheostomy product design. Staff interviews also gave insight into the range of tracheostomy user experiences, helping me consider what areas to explore through co-design workshops.

During tracheostomy user interviews, participants were asked to talk about their experiences. I was given access to interview recordings and transcripts. Although I did not witness visual cues (e.g. facial expression, posture, etc) that may have shaped my understanding of the data had I been present at the interviews, the audio recordings provided an opportunity for me to build empathy for tracheostomy users. Hearing them speak shed light on the reality of their difficulties with speaking and breathing in particular.

CO-DESIGN WORKSHOPS

Co-design workshops typically consist of creative activities facilitated by designers and executed in collaboration with participants (Sanders & Stappers, 2008). Workshops enable participants to create artefacts, contribute ideas, and partake in discussions that build an understanding of their world (Boyd, McKernon, Mullin, & Old, 2012; Martin & Hanington, 2012; Neimeyer & Torres, 2001; Sanders & Stappers, 2008).

I used co-design workshops to empower tracheostomy users in the design process and understand their experiences. Two co-design workshop were held, each with 2-3 tracheostomy users who had participated in the SRIF study interviews. Two participants brought support people. Workshops lasted two-hours and consisted of two parts. The first part was led by a communication design student exploring the design of patient education materials. I led the second part, exploring tracheostomy product design. Workshops were video and audio recorded, then transcribed for analysis.

Going into the workshops I expected to face challenges associated with covering sensitive topics like stigma, working with people who have difficulty speaking, and my own inexperience with running co-design workshops. As such I tried to plan for these challenges where possible. Listening to user interview recordings helped to alleviate my concerns about communication challenges and talking about stigma. Participants spoke confidently and discussed their stigma experiences openly. However, acknowledging that group dynamics might be intimidating, I planned to start the workshop with an ice breaker, provided pens and paper to allow written communication, and encouraged participants to bring support people. I designed activities that would allow participants to discuss stigma without forcing them to talk about it if they felt uncomfortable. To manage my inexperience, I looked

at other studies using co-design workshops. I also sought feedback on my workshop plan from the SRIF team, as well as support in executing it.

While the first part of the workshops was not directly related to this project, I assisted with facilitating activities and participated in discussions. Listening to participants explain what they thought should be included in tracheostomy care information helped me understand some of the difficulties they had with their tracheostomy products. Even when discussions were unrelated to my research question, interacting with participants and observing them interact with one another helped me understand them as individuals.

During the second part of the workshop, I encouraged participants to discuss their perspectives on tracheostomy products and explore ideas for improving them. I began by asking participants to introduce themselves and share one frustration they had with their tracheostomy. Next I asked participants to brainstorm ways tracheostomy products limited their activities. I then asked them to consider how these limitations might be addressed. For the final activity I presented a range of prototyped tracheostomy components to serve as probes. I asked participants to assemble components they liked and talk about the reasons behind their choices.



CO-DESIGN WORKSHOP PLAN

Ice Breaker:

(5min)

Ask participants to introduce themselves and mention one thing they find frustrating about having a tracheostomy.

Activity 1:

How can tracheostomy tubes be improved?

Part 1 (15min):

As a group, brainstorm ways that tracheostomy products limit users. Use these limitations to consider how designs might be improved. Use prompt questions/categories (e.g. functional requirements, features, what should it look like? etc.) to help generate and organise ideas.

Part 2 (10min)

Ask each participant to choose the 5 most important ideas from the brainstorm and order them according to perceived importance. Have participants talk about their choices and identify commonly shared values.

Activity 2

Assembling a custom tracheostomy tube

Part 1 (15min):

Lay out tracheostomy components with different materials, forms, and mechanisms. Ask participants to mix and match components to create a tracheostomy that they would like to wear.

Part 2 (15min)

Ask participants to discuss the factors that drove their decisions (e.g. quality, personality, memory associations, gut feeling, etc.).

PROBES

Probes are co-design tools used to elicit a response from participants which the designer takes as inspiration for further work (Madden, Cadet-James, Atkinson, & Watkin Lui, 2014; Sanders & Stappers, 2014). The probes used in the co-design workshops were modular tracheostomy components, prototyped in a range of material finishes. Different options were presented for tubes, neck straps, and front pieces. Components were laid out in ordered rows to mimic the look of a jewellery counter. This was an attempt to reframe tracheostomy products from medical devices to objects with the potential for self-expression. By having participants select and combine components, I wanted to see how they responded to freedom of choice. I also hoped to determine whether certain characteristics were more favourable than others, and to understand the values influencing participants' preferences.

ANALYSIS METHODS

THEMATIC ANALYSIS

Thematic analysis is used to extract patterns of meaning from a data set. It provides a structured approach for analysing qualitative data to answer a research question (Braun & Clarke, 2014). I used thematic analysis to draw meaning from interview and co-design workshop data.

After reading transcripts and reviewing recordings to familiarise myself with each data set, I generated 'codes' capturing pertinent data points. Codes provided descriptive summaries (e.g. 'fear of tracheostomy drawing attention'), or theoretical interpretations (e.g. 'tracheostomy as a badge of honour') of portions of data content. I then reviewed codes, finding common themes related to the research question (e.g. 'improvisation', 'isolation and lack of support', 'resistance to change', etc.). I used themes to compose a story representing tracheostomy users' experiences, and make arguments in response to the research question.

PERSONAS

Personas are characters crafted to represent research findings about particular groups of people. Imbued with real traits, anecdotes, and values, they are used to organise data in a way that helps maintain humanism and empathy (Adlin & Pruitt, 2006; Maguire, 2001). I generated personas to collate data from different research methods and drive ideation. In particular, I used data from interviews and co-design workshops to ensure that personas were a reflection of my research. Once generated, I used the needs of these personas as reference points for generating and evaluating design concepts. Creating personas to represent diverse users helped me to develop design concepts from a range of perspectives, and acknowledge the complexity of the design problem while addressing real user needs.

JOURNEY MAPS

Journey maps are traditionally used in service design to explore the thoughts, feelings, and actions that occur when people use a service (Polaine et al., 2013; Stickdorn & Schneider, 2012). I used journey mapping to explore the process long-term tracheostomy users go through between receiving a tracheostomy and being discharged from the hospital. Through journey mapping, I wanted to understand how a person's earliest experiences with tracheostomy might shape their attitudes towards their condition in the long-term.

I mapped the events that make up a tracheostomy patients' journey with help from hospital staff and information from tracheostomy leaflets. At this point in the project, I did not have interview data from which to map the emotions experienced by patients throughout the journey. As such I outlined the probable emotional journey based on anecdotes from staff and imagining how I might feel in a similar situation.

DESIGN BRIEFS

I defined the design opportunities arising from my findings in the form of a written design brief. The structure of my design brief was based on the advice for "writing a product design brief", provided by Better by Design NZ (2015). The brief covered a range of specifications including purpose, aesthetics, production, and cost. Distilling the breadth of data collected throughout the research process into a defined set of specifications helped create a clear picture of how a successful design would look. Although used as an important guideline through-out the design process, the design brief was by no means inflexible, and was adjusted to reflect new insights as they emerged.

IDEATION METHODS

BRAINSTORMING

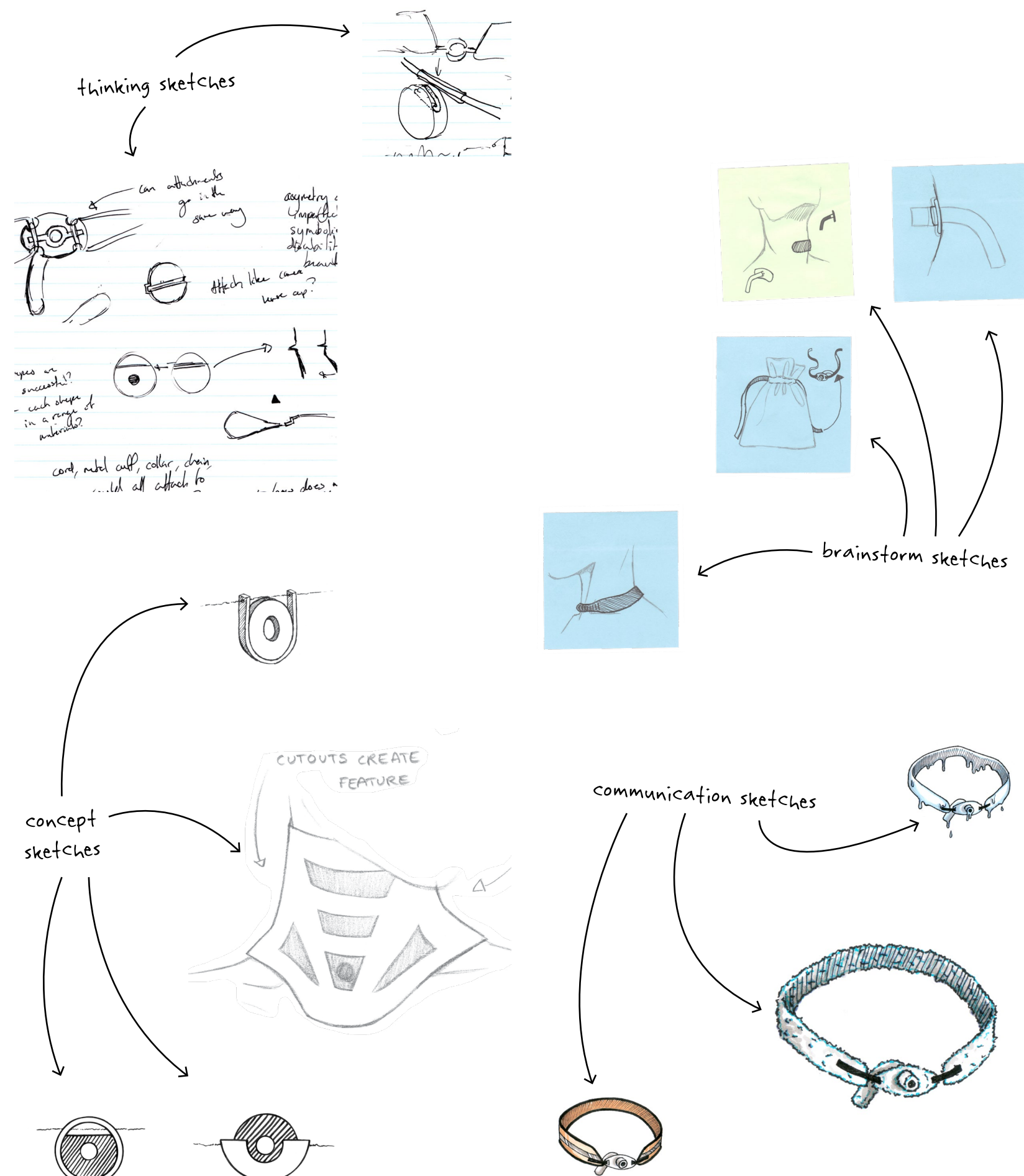
Brainstorming is a technique for rapidly generating varied ideas in a short space of time, and is especially useful for solving undefined problems. It may involve sketching or writing as many ideas as possible around a central theme (Maguire, 2001; Parsons, 2009; Wilson, 2013). For this research project, brainstorming was used as both a solo and group activity.

Prior to primary data collection I used solo brainstorming to reflect on the literature review findings and communicate my thoughts on where the project might go. Group brainstorming was used during co-design workshops, encouraging tracheostomy users to work with me to generate ideas based on their needs. In both cases, ideas were recorded on post-it notes, then organised according to common themes, and in some cases combined at random to spark fresh ideas.

MOOD BOARDS

Mood boards are collections of images that convey stylistic aspirations for a design. They provide visual inspiration for characteristics like colour, texture, materiality, tone, and form (Parsons, 2009). I used mood boards to help visualise the aesthetic I wanted to achieve before sketching and prototyping.

I searched for images using google images and pinterest.com. I used a variety of search terms describing the types of images I hoped to find. For example, when creating a mood board of inspirational jewellery styles, I used combinations of words like "jewellery", "minimal", "geometric", "silver", "marble", and "contemporary". I saved images that I found appealing and that reflected my design intentions. I experimented with arranging chosen images until I felt the mood board represented my aesthetic and thematic goals.



33. Dickson, (2016). Examples of sketch types used

SKETCHING

Sketching is a tool that is often used to explore and communicate ideas at various stages of the design process. Typically, the nature of sketches evolves alongside the designer's aims (Koskinen et al., 2011; Parsons, 2009; Purcell & Gero, 1998). In the early phases of the design process I used quick, rough sketches to capture the essence of raw ideas. Putting concepts on paper also helped me begin to define their shape and appearance without constraining my thinking with physical limitations (Parsons, 2009; Purcell & Gero, 1998). As I continued to make decisions about my design direction, my sketches became more refined with an increasing focus on details. More defined sketches were also used as a discussion point during the Co-Design workshop, continuing the involvement of stakeholders in the design process.

COMPUTER AIDED DESIGN

Computer aided design (CAD) is the use of computer software to create or modify designs (Parsons, 2009). I used a 3D modelling programme called Solidworks to generate accurate digital prototypes of tracheostomy components. I was able to 3D print CAD files to produce detailed physical prototypes with functional moving parts.

Initially I replicated the form and dimensions of an existing tracheostomy tube in Solidworks. I progressively altered this model to develop aesthetic and functional aspects of the design. I produced scale 3D prints of each concept, which I could interact with and evaluate. Throughout ideation and concept development, CAD allowed me to quickly explore ideas in finer detail than would be possible using sketches or handmade prototypes. The final design was created and fine-tuned using CAD.

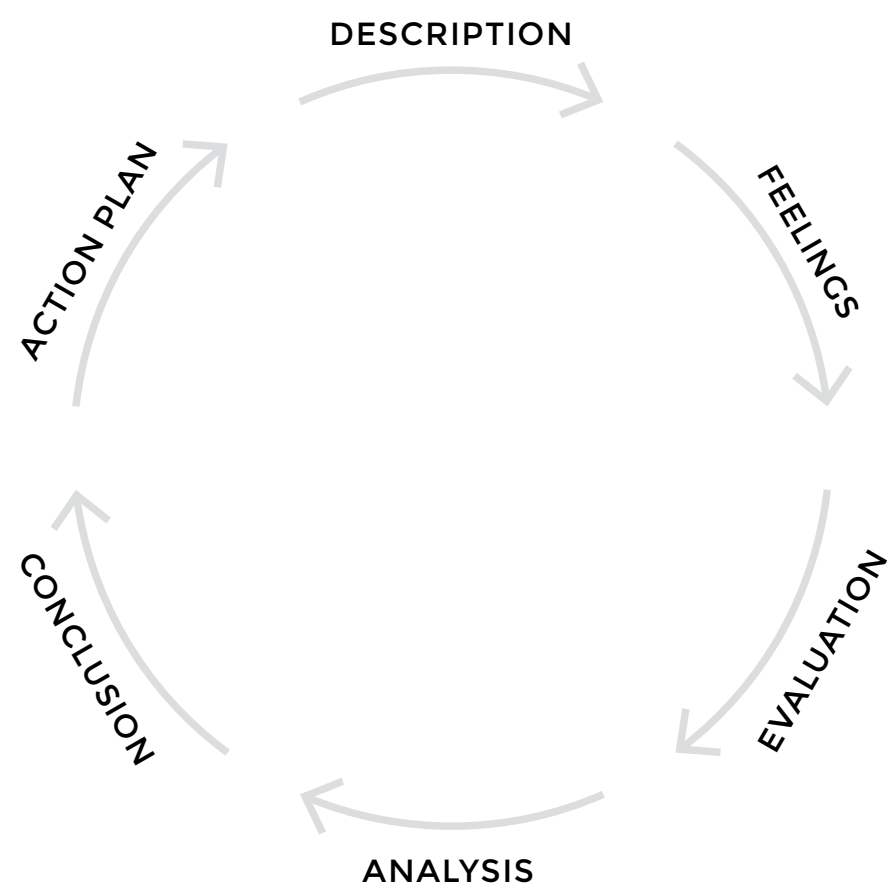
EVALUATION METHODS

EVALUATION MATRICES

I used evaluation matrices to guide decision-making both when choosing a design direction, and when selecting design concepts to develop further. Evaluation matrices involved weighing concepts against criteria drawn from my design brief to determine which were most successful (Alexis, 2011). When multiple options ranked highly, this indicated opportunities to combine successful elements of multiple options. When a concept ranked highly overall but with a low score on some criteria, I made meeting the low scoring criteria the focus of further development. Using a structured decision-making process helped to ensure my decisions were justified by my research findings.

EXPERT CRITIQUE

Working in the hospital context as an external action researcher, it was important for me to maintain ongoing communication with hospital staff (Gray, 2014). Fortnightly meetings were held with tracheostomy clinicians to ensure mutual understanding of the project objectives, and progress. These meetings, as well as more formal presentations held at key intervals in the project provided opportunities for expert critique and discussion of ideas. Critique from clinicians brought to light functional concerns that I may not have otherwise considered. Broader discussions were key to understanding how tracheostomy products are selected and distributed to patients.



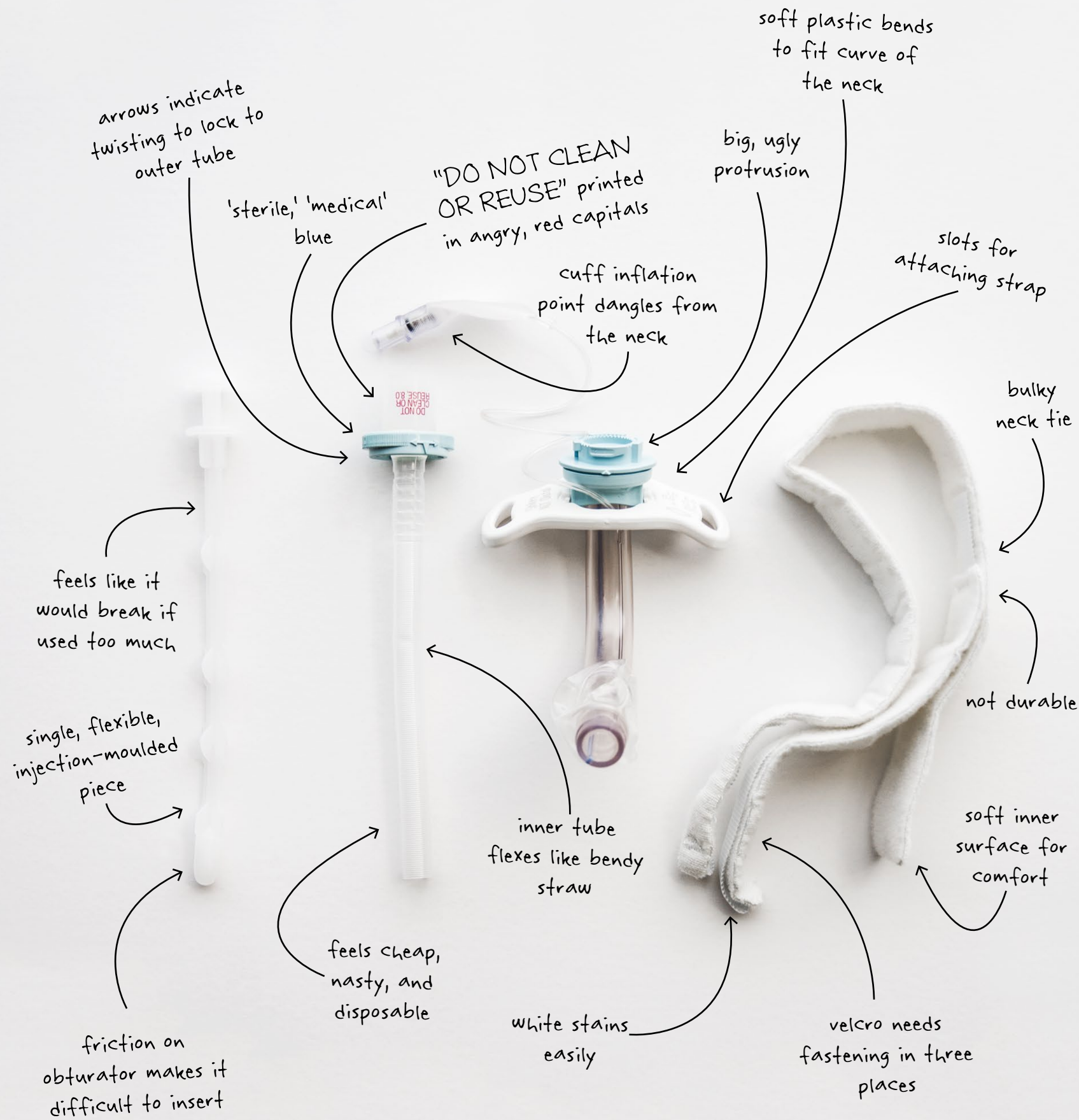
35. Gibbs, (1988). Gibbs' reflective cycle

REFLECTIVE PRACTICE

As part of my action research methodology, I reflected on each research phase. I used reflection to identify approaches that did and did not work, and to inform my approach to subsequent tasks (Gray, 2014; McMahon, 1999). I based the structure of my written reflections on Gibbs' reflective cycle (Paterson & Chapman, 2013). Each reflection described what happened and how I felt about it, followed by discussion of positive and negative aspects of the experience, analysis of why things happened the way they did, and a plan for how things could be done differently. I documented reflections in this thesis to provide insight into the process that may interest other researchers.

RESEARCH DOCUMENTATION

PHASE 1



36. Dickson, (2016). Analysis of plastic 'Shiley,' cuffed tracheostomy tube

EXISTING PRODUCT ANALYSIS

PORTEX TRACHEOSTOMY TUBE

Analysing an existing tracheostomy tube helped me understand the basic composition of the device. It also allowed me to interrogate the meanings conveyed by the materials, textures, colours, and forms used in the design.

By interacting with each component I was able to figure out how they worked and consider the logic driving their design. For example, the introducer is formed from a single piece of injection moulded plastic. It has strategically placed ridges to locate it within the outer tube while allowing it to flex and conform to the tube's curve. The front piece of the outer tube uses soft, curved plastic to fit the neck, and has slots for attaching the strap. The strap itself is composed of two fabric strips. Velcro tabs on each side allow the user to attach it to the outer tube before inserting it into the neck. The two sides overlap at the back and fasten with Velcro, keeping the length adjustable. These features ensure functionality is achieved with minimal amounts of low cost materials and simple manufacturing.

While each design feature makes sense from functional and manufacturing perspectives, the messages conveyed are not particularly supportive of users' emotions or identities. The use of clear and translucent plastic components suggests an attempt to make the product inconspicuous. This could be interpreted to mean that tracheostomy is a source of shame or something to be hidden. The use of stark white and pale blue carries associations with sterility. In combination with disposable materials, this identifies the tracheostomy tube as a medical consumable. Although the phrase "DO NOT CLEAN OR REUSE" is an important safety warning, its use of capitalised, red text on part of the device that is visible when worn shows a lack of consideration for user experience. Overall, the visual language of this tracheostomy tube labels its wearer as a patient.



37. Dickson, (2016). Analysis of tracheostomy accessory product range

TRACHEOSTOMY ACCESSORIES

In addition to the products Auckland Hospital provides, I looked at a range of accessories from tracheostomy product websites. I analysed images of tracheostomy straps, bibs, and shower guards from three different medical suppliers. I wanted to see whether sourcing their own products gave tracheostomy users more choice.

Even online, the product range was dismal. Most products were white, carrying connotations of sterility. Some products were available in beige, perhaps in an attempt to blend with skin. Once again this conveyed the idea that tracheostomy products are shameful or should be hidden. Furthermore, if the intent was to mimic the colour of skin, these products failed to acknowledge the diversity of human skin tones.

Designs also showed a lack of innovation. Products from different brands featured similar designs with no clear reason to favour one over another. All strap options found were either fabric or soft foam and attached to the tracheostomy tube using Velcro or plastic clips. Products for absorbing excess secretions looked like baby bibs and seemed like they would compromise users' dignity. Shower guards looked unrefined and resembled dust masks.

With these limited options, there would be little value in users purchasing products which offer little advantage over those supplied by the hospital.

brown paper bag feels like contraband

only first packet includes assembly diagram

no indication of what each packet is for

no explanation of how the nebuliser works

why can't this component be pre-assembled?

mask looks very medical

being hooked up to tubes seems dehumanising

pieces don't seem to fit together

38. Dickson, (2016). Photo documentation of nebuliser kit assembly roleplay

ROLEPLAYING

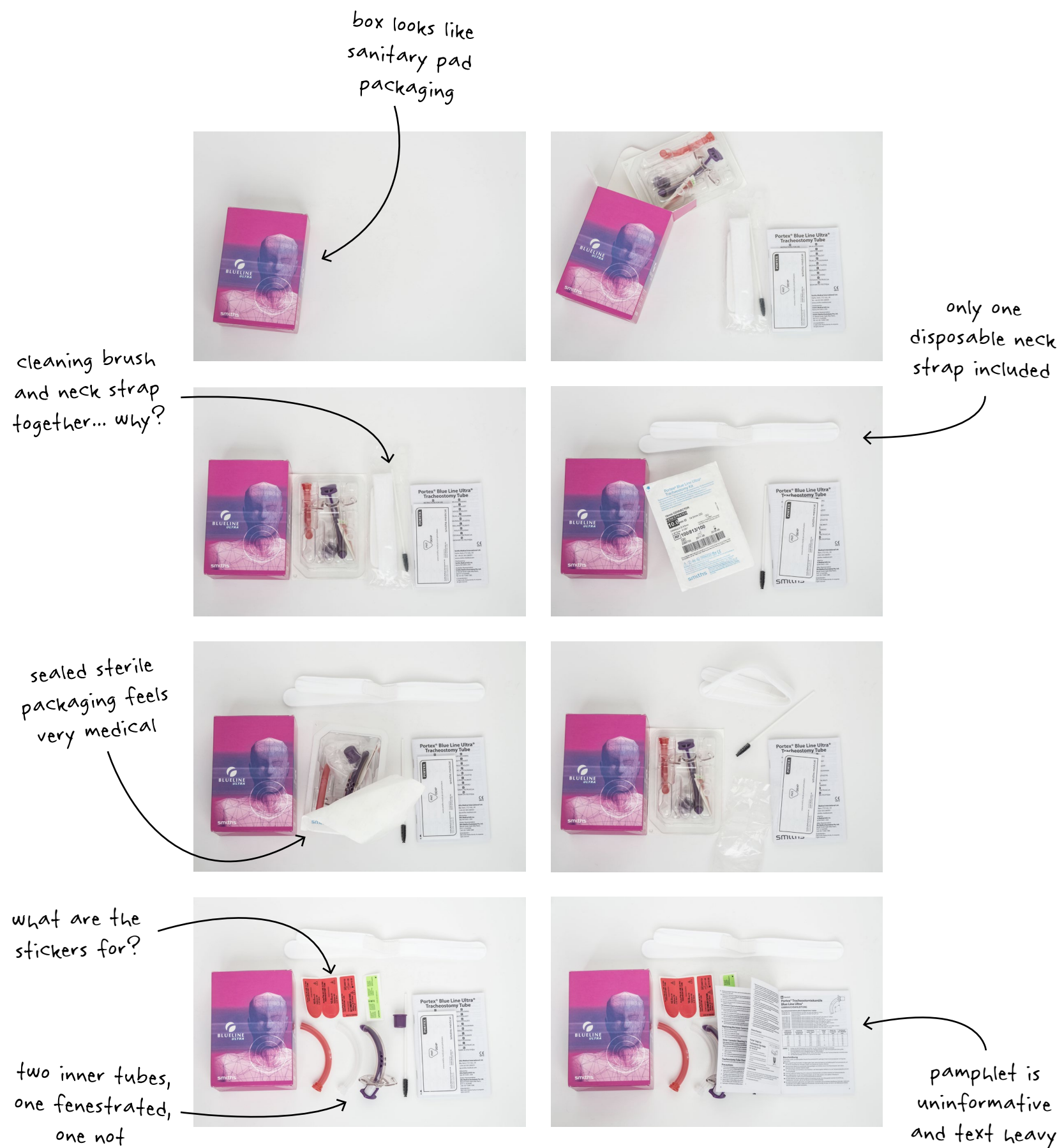
ENCOUNTERING TRACHEOSTOMY PRODUCTS

My first encounter with tracheostomy products was an opportunity to empathise with new users' experiences. Like someone waking from an emergency tracheotomy (albeit without the significant physical and emotional stress), I was faced with an array of foreign, somewhat frightening, tubes and attachments.

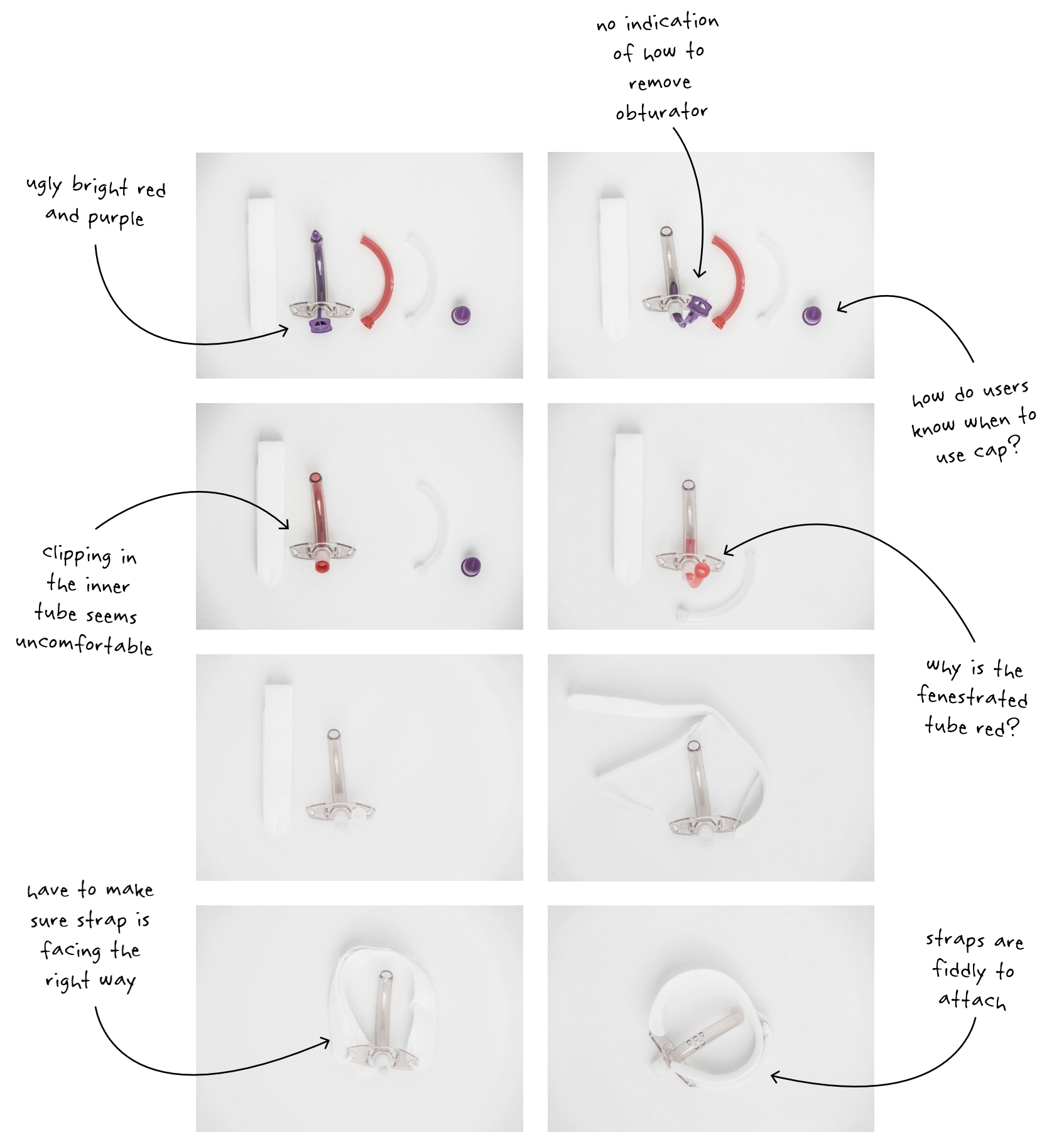
Opening packages to assemble components was, at best a lacklustre experience, and at worst frustratingly difficult. Where the packaging of consumer goods is considered part of the product experience, the tracheostomy kit and nebuliser packaging seemed strictly utilitarian. Items were sealed in plastic and plastered with information meaningless to non-clinicians. I felt daunted and out of my depth. The absence of instructions was also keenly felt.

I didn't understand why the kit included one garish red inner tube, and one transparent. Attaching the neck strap was fiddly and took me two tries to attach the right way around. The nebuliser pieces didn't seem to fit together, and I quickly realised I had no idea what I was doing. It felt like the products were packaged for experienced clinicians without thought for people who use them at home. I can only imagine how unseen and undervalued this would make tracheostomy users feel.

This roleplay gave me the impression that tracheostomy products are packaged as efficient hospital consumables, then sent home with users without consideration for their needs. This supported my literature review finding that medical products retain features intended for hospital use but detrimental to use at-home (Barber, 1996). The packaging added difficulty to the already distressing experience of adjusting to life with a tracheostomy.



39. Dickson, (2016). Photo documentation of tracheostomy kit opening roleplay



40. Dickson, (2016). Photo documentation of tracheostomy assembly roleplay

A DAY IN THE LIFE OF A TRACHEOSTOMY USER

Wearing a tracheostomy tube for a day gave me insight into the practical and emotional challenges tracheostomy users face. It was particularly interesting to see how much wearing a tracheostomy affected my confidence, and how limiting it was to have to cover the tube every time I spoke.

Going into the roleplay, I was extremely apprehensive. As a self-conscious person I was afraid people would stare or make comments. I was uncomfortable with being perceived as sick, and worried people might treat me differently. Seeing myself in the mirror with a tracheostomy for the first time only served to strengthen my fears. Although my hair covered most of the neck strap, the front of the tracheostomy seemed impossible to hide. I caught myself subconsciously tilting my head down in the hopes of making the protrusion less noticeable.

When I ventured into public spaces, I found that wearing the tracheostomy shaped my behaviour. I gave strangers a wider berth than usual and avoided making eye contact for fear of catching them noticing the tracheostomy. I also began resting my chin in my hand whenever possible to shield the tracheostomy from view with my wrist. I walked faster when passing small children, worrying they might notice the tracheostomy and ask their parents tactless questions. When wind blew my hair away from my neck I felt exposed. Despite my fears, I didn't catch anyone staring or making comments about the tracheostomy. Whether this was because my methods of evasion were successful, or because people didn't care, it did not alleviate my self-consciousness.

Although I did not experience external stigma while wearing the tracheostomy, the effects it had on my thinking were striking. I was constantly aware of the tube and brainstorming ways to keep others from

noticing it. While the self-consciousness I experienced was partly shaped by my personality, new tracheostomy users may have similar experiences. Where my discomfort was mitigated by the fact I could take the tracheostomy off at the end of the day, the psychological stress experienced by tracheostomy users may be much greater as they must accept that changes are long-term.

The largest practical challenge I faced was remembering to cover the end of the tracheostomy when I spoke. Soon after putting the tracheostomy on, I realised my fingers were too small to cover the hole. I had to hold my hand on an angle to use my thumb. The awkwardness of this gesture combined with the fact I usually speak without thinking, meant I often spoke before realising a real tracheostomy would prevent me from doing so. Roleplaying highlighted how using one hand to speak could prevent me from engaging in simple pleasures like singing to the radio while driving, or verbally greeting two dogs while patting one with each hand. It would also stop me from talking while carrying shopping bags or cutting vegetables.

The small ways that roleplaying as a tracheostomy user inhibited my ability to communicate gave me a taste of the challenges tracheostomy users face. For tracheostomy users, the frustration of not being able to multitask when speaking may be compounded by altered voice quality as well as disruptive coughing or secretions. While covering the hole to speak may become habit, the action of doing so, coupled with the quality of their voice may also impact their social interactions by drawing unwanted attention.

Wearing a tracheostomy also helped me identify other daily challenges. The strap and plastic front rubbed against my skin making me want to scratch behind or take it off. The presence of the tracheostomy distracted me from

work and made it difficult to sleep. I can only imagine how much worse the irritation of a real tracheostomy would be with secretions building up around the stoma and the sensation of the tube inside the trachea.

Showering with a tracheostomy proved surprisingly difficult. I tried to stand with my neck out of the water but failed instantly as water droplets reflected off my skin and the walls of the shower onto the tracheostomy tube. By the time I was finished the strap was damp and droplets had fallen inside the protrusion of the tube. This could have had significant consequences for a tracheostomy user who might breathe the water into their lungs. While experienced users may adapt strategies for showering, I could see how stressful this experience would be for new users even with the use of a shower guard. It would also be incredibly frustrating to struggle with something as basic as maintaining personal hygiene.

STAFF INTERVIEWS

I conducted expert interviews with four Auckland Hospital Otorhinolaryngology staff members including nurses, a speech therapist, and tracheostomy nurse specialists. Staff interviews provided information about tracheostomy causes and treatment, the challenges posed by the supply system for tracheostomy products, and the journey tracheostomy users go through following tracheotomy surgery. Some staff were also forthcoming with ideas for improving tracheostomy design.

INDIVIDUAL TREATMENT NEEDS

Staff explained that airway management and secretion management are the two main applications for tracheostomy tubes. These applications encompass treatment for a multitude of conditions, each with complex effects on an individual's experiences. This point was further reflected in my interview with a speech therapist when the answers to each of my questions were prefaced with the phrase "it depends". The speech therapist felt it important to convey how different every tracheostomy case is, and that virtually no aspect of the experience can be generalised. Talking to clinicians led me to consider how the singularity of users' experiences might impact their product needs. It encouraged me to think about designing customisable components and providing choices to suit different needs.

INFORMATION PROVISION

Staff explained that because every tracheostomy case is different, only generic care information is given to users in print form. Information specific to individual cases is conveyed verbally by nurses during a patient's hospital stay. In hospital, nurses help patients practice tasks like changing their tracheostomy tube and using a humidifier. Before discharge, nurses test patients' competence at managing their tracheostomies independently.

Although verbal information is given gradually and supported by practical demonstrations, some tracheostomy users call or visit hospital after discharge because they have questions about their care. Users may struggle to remember information received while dealing with the stress of adjusting to tracheostomy, particularly if surgery was unexpected. They may also feel nervous executing tasks without clinical supervision. While printed information can be useful, it is unlikely to answer users' situation-specific questions, driving them to seek reassurance from clinicians.

While information design was not my focus, understanding the provision of tracheostomy information improved my overall understanding of user experiences. It drove me to think about addressing the struggle users have understanding and retaining information, by designing tracheostomy products that are intuitive to use.

PRODUCT DISTRIBUTION

Nurses are responsible for sourcing the products provided to tracheostomy users. Tracheostomy nurse specialists discussed the difficulties they face in this task because of hospital procedure and New Zealand's geographic isolation. While nurses research and locate suitable products, hospital administration controls purchasing, and choices are limited by department budgets. Because tracheostomy products are not manufactured in New Zealand, staff source them from overseas. Information on different brands is often scarce, difficult to locate, and sometimes in foreign languages.

Considering even experienced clinicians find sourcing tracheostomy products daunting, it seems particularly alienating to tracheostomy users. In my experience, suppliers' websites seem targeted at clinicians and healthcare organisations using medical jargon and emphasising technical data. The system appears to take it for granted that tracheostomy users have no role in selecting products and therefore makes no attempt to appeal to their needs. This might make tracheostomy users feel frustrated and unvalued.

Staff also described instances of tracheostomy users requesting specific products based on their own research. Because the hospital arranges contracts with suppliers based on set products, staff were unable to cater to these requests. Tracheostomy users who want products that are not provided by the hospital have to purchase them for themselves. Different DHBs (District Health Boards) provide patients with different tracheostomy products, meaning users' choices are dictated by the place they receive treatment.

The fact that some tracheostomy users research products for themselves despite the difficulty of doing so indicates dissatisfaction with the products

provided to them. It also suggests a desire for involvement in their product choices and control over their situation. These ideas validated the importance of involving tracheostomy users in my research. To help me challenge the status quo, I wanted to imagine what it would be like if users, rather than healthcare organisations, were in charge of tracheostomy product decisions.

COST

Staff identified cost as another factor limiting tracheostomy product availability. While silver tubes provide better airway clearance, last longer, and are generally more comfortable to wear, they are incredibly expensive. At approximately \$1500 each, they are only cost-effective for long-term tracheostomies (people expected to require tracheostomy for at least 1 year). Plastic tubes cost approximately \$170 each and must be replaced every 4-6 weeks. Even simple fabric bibs cost the hospital \$40 per unit.

Given the already exorbitant cost of products purchased by the hospital in bulk, it is unlikely many tracheostomy users can afford to purchase their own products. They are therefore limited to the products provided by the hospital which are, in turn, limited by tight budgets. While I was unsure whether it would be feasible to produce designs that meet users' needs while reducing cost, it was important I remain aware of the role cost plays in tracheostomy product distribution. I decided to focus on improving the design of silver tubes as I felt a \$1500 price limit would give me freedom to explore more radical ideas.

DESIGN

Staff gave primarily practical or technological suggestions for improving tracheostomy product design. They were focused on functional aspects like keeping a small outer diameter and large inner diameter to optimise airway clearance. More radical ideas included a portable humidifier, a tracheostomy tube with a self-inflating cuff, and optional adaptors for attaching humidifiers and speaking valves while minimising the front protrusion.

Staff's ideas for improving tracheostomy design demonstrated their awareness of, and concern for, the inadequacies of user experiences. While most of their suggestions prioritised function, the idea of reducing the front protrusion showed that staff recognise users' concerns about the visibility of existing designs. Although each idea focused on a practical improvement to a single facet of user experience, it was clear that staff believed in the importance of this project and were eager to see change.

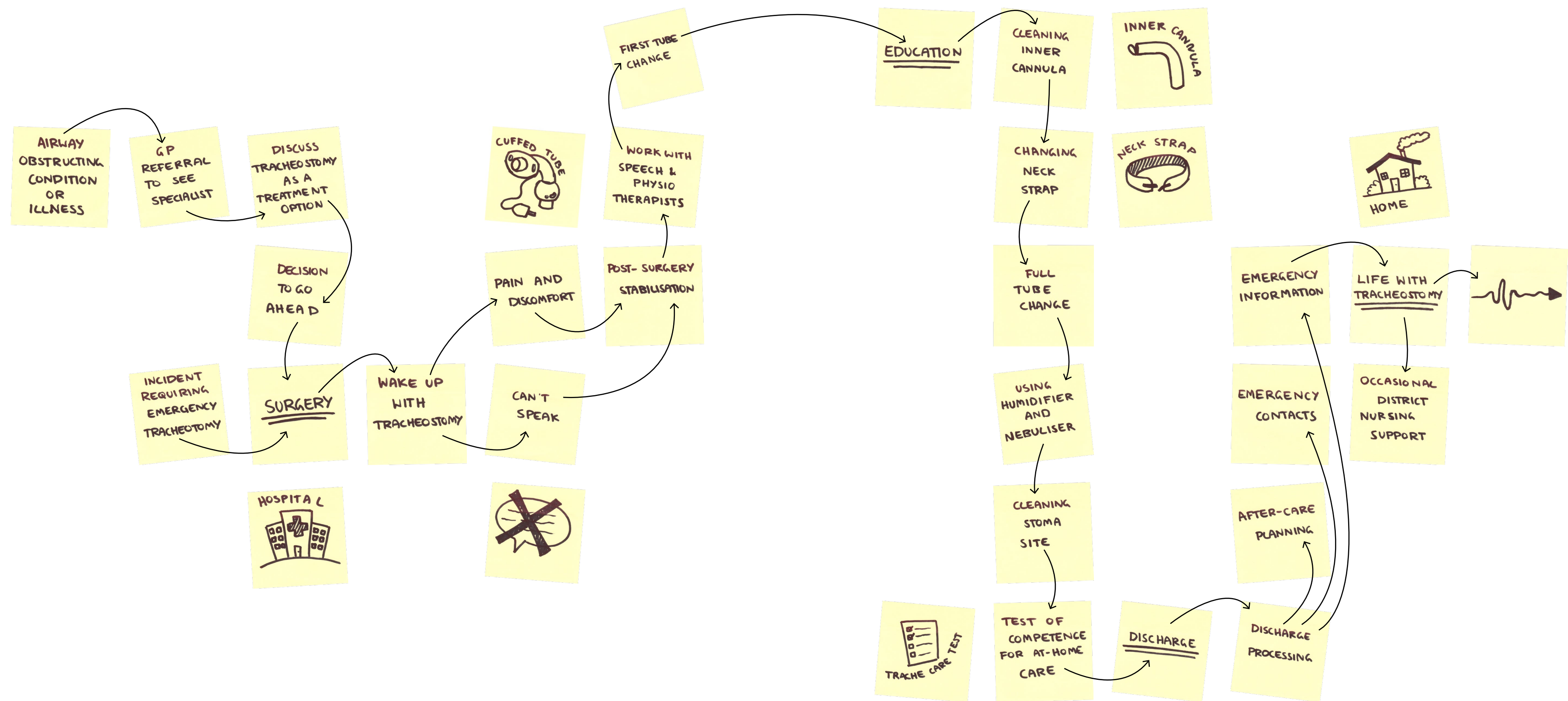
JOURNEY MAPPING

JOURNEY TO HOSPITAL DISCHARGE

By talking to ORL staff I was able to map the journey of someone first receiving a tracheostomy. Mapping the journey helped me identify touchpoints like waking from surgery unable to communicate, learning to manage tracheostomy and its associated products, and hospital discharge (Polaine et al., 2013; Stickdorn & Schneider, 2012). Understanding the context surrounding these events also helped me consider how users’ earliest tracheostomy experiences might shape their attitudes towards tracheostomy throughout long-term use. I could see how the distress of being unable to communicate could make users resent tracheostomy or how learning to manage alone might give them lasting pride and reclaimed independence.

While the journey map describes the formative experience of receiving a tracheostomy, the events occurring once users leave hospital are arguably more important. For long-term users, tracheostomy experiences after hospital discharge make up a significant portion of their lives. However, because each user has different life circumstances, these experiences are impossible to generalise and difficult to map.

The clinical focus of tracheostomy product design reflects this problem. Because experiences taking place in hospital are known and can be described, it is easier to design products to suit this context. Conversely, there is lack of research into long-term use experiences and a lack of designs catering to the needs associated with them. While a journey map may not be effective for describing what happens after hospital discharge, talking to long-term users could provide the foundation for developing designs that consider the long-term experience.





42. Dickson, (2016). Explorative tracheostomy tube concept sketches

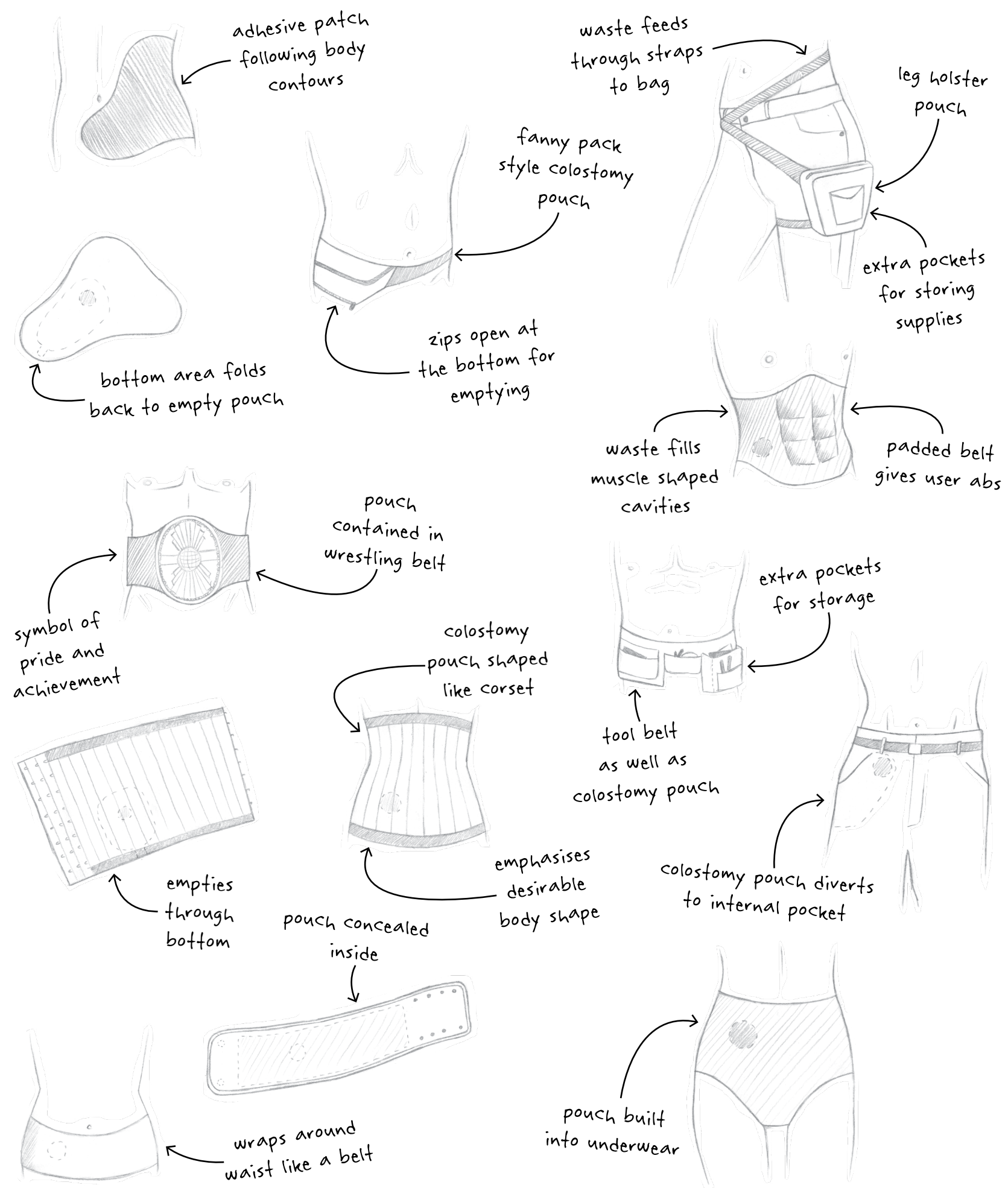
STIGMA CONCEPTS

Having completed the contextual review, I was unsure how to begin the lofty task of addressing my research question. To ease into the project, I set myself an explorative sketching exercise focusing on stigma. I aimed to generate concepts for reducing stigma associated with three medical devices; colostomy pouches, cochlear implants, and tracheostomy tubes. I included multiple devices to encourage broad thinking. I took a freeform approach, allowing myself to sketch ideas that came to mind without judgement until I was finished.

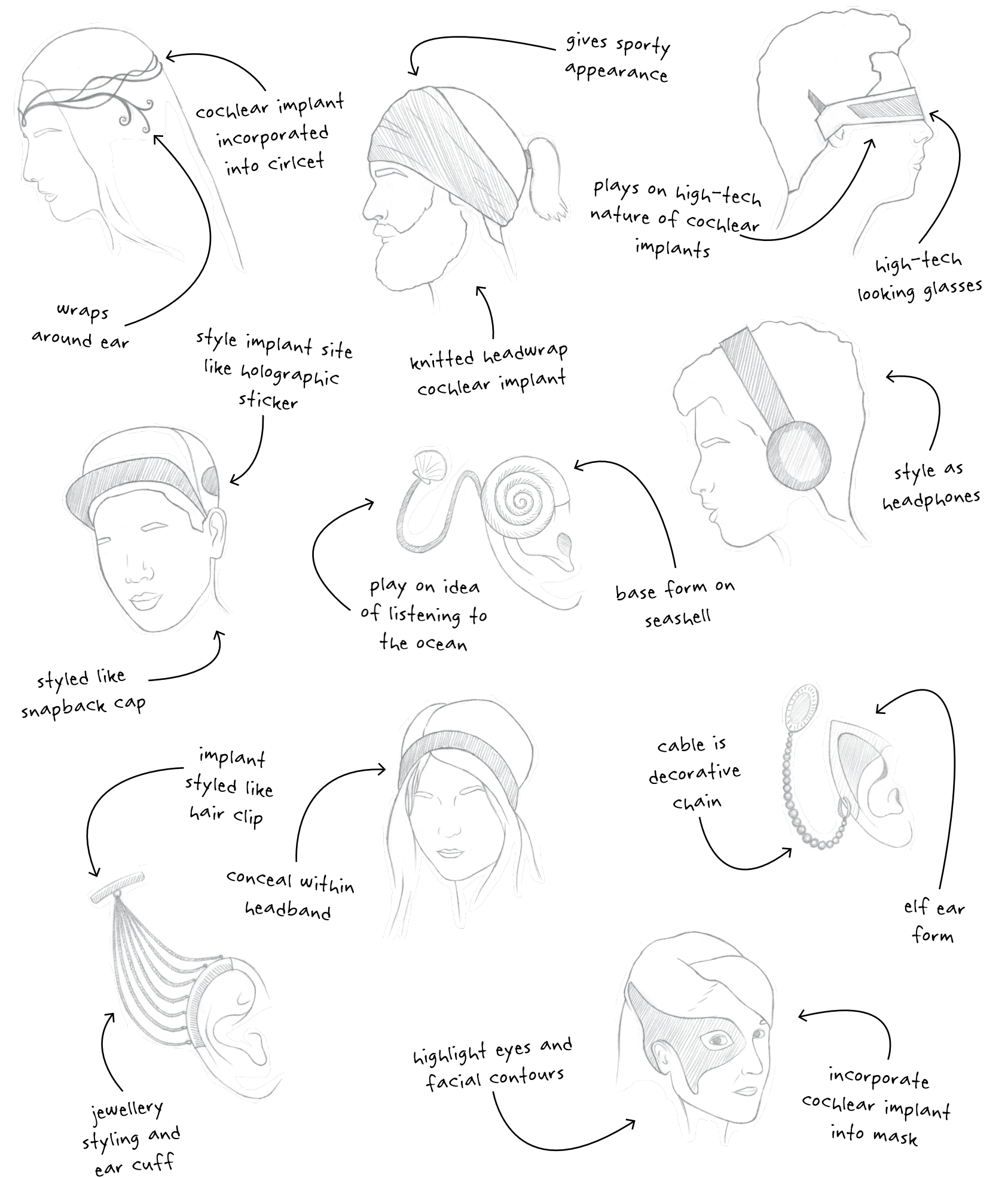
Reflecting on my sketches, I found most showed ideas for hiding the devices. Considering my literature review findings that concealment is ineffective at managing stigma (Bonanno & Esmaeli, 2011; Rumsey & Harcourt, 2004; Thompson & Kent, 2001), my intuitive approach to medical product design demonstrated my own susceptibility to stigma against visible difference.

Exploring concepts for three different products created opportunities for comparison. While most of my ideas involved concealment, I found generating celebratory concepts easier for cochlear implants and tracheostomy tubes than for colostomy pouches. This was interesting given colostomy pouches are generally worn beneath clothing anyway.

The variation in approaches that felt appropriate to each product indicated differences in the nature of the products and their associated conditions. Because colostomy products deal with private bodily functions, discretion felt more important than it did for tracheostomy tubes and cochlear implants. Furthermore, the neck and head where tracheostomy tubes and cochlear implants are worn are more natural positions to wear decorative items (like necklaces, ties, or earrings) than the abdomen.



43. Dickson, (2016). Explorative colostomy pouch concept sketches



44. Dickson, (2016). Explorative cochlear implant concept sketches



45. Dickson, (2016). Map of possible project directions

SELECTING A DIRECTION

To round off the first research phase I mapped out possible project directions based on my findings so far. Each direction could result in vastly different design outcomes, emphasise different priorities, and tell a different story about tracheostomy. From the map I selected four directions to explore: an incremental approach focused on function and usability; a radical fashion approach introducing aesthetic concerns; a discreet approach exploring subtle ways of integrating products with the body; and a consumer product approach looking at the product system including packaging and distribution.

I chose not to pursue technical innovation because I felt this approach might be better tackled by someone with an engineering background. I also felt engineering approaches were already dominant in the design of tracheostomies and other medical products. I rejected a critical design approach because I felt that other approaches better served the goal of measurably improving tracheostomy user experiences. Aspects of critical design were introduced later in the project as I realised its value as a tool for challenging the status quo.

PHASE 2

INITIAL DESIGN BRIEF

To guide my ideation around the approaches selected during the first research phase, I devised a rough design brief. Because I wanted to explore four different approaches I kept criteria broad. To guide the aesthetics of the design I also included separate criteria for each approach.

PURPOSE

- Facillitate breathing
- Keep user alive

PERFORMANCE

- Easy to insert, fasten, and remove tracheostomy
- Easy to insert and remove inner tube
- Able to attach tracheostomy to a humidifier

AESTHETICS

- Discrete with subtle colours and subtle organic forms
- OR
- Refined version of existing functionally driven medical aesthetic
- OR
- Celebratory and fashion driven with high-end materials and finishes

PERCEIVED QUALITY

- Feel trustworthy with materials that look like they will last
- Look clean

RELIABILITY

- Last for at least 10 and ideally 30 years
- Components showing wear and tear should be replaceable

PACKAGING

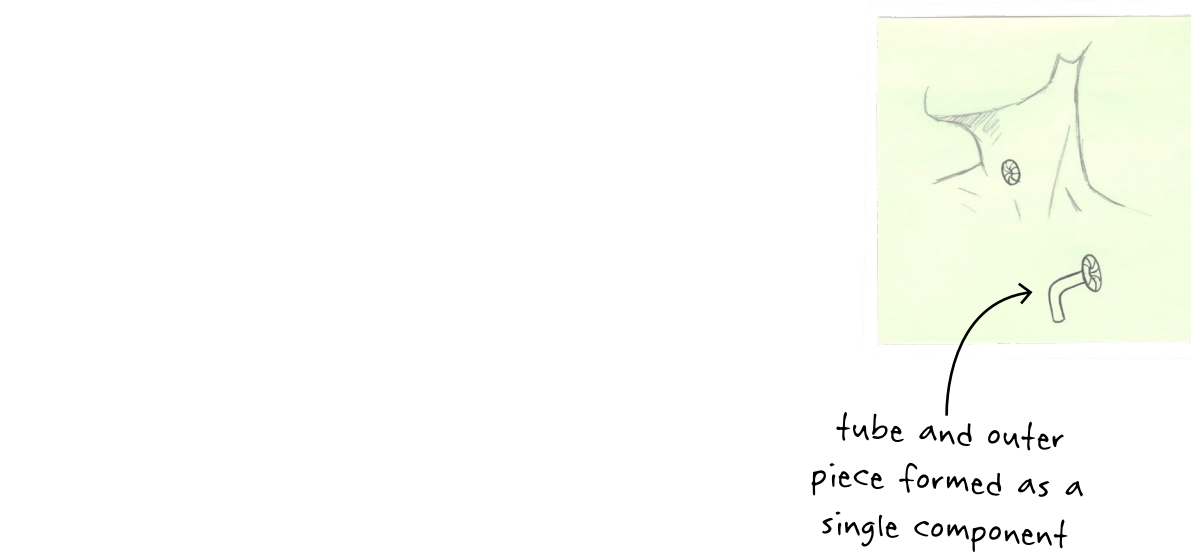
- User friendly
- Free of medical product numbers and jargon
- Clearly labelled parts
- Include assembly diagrams and instructions for use

COST

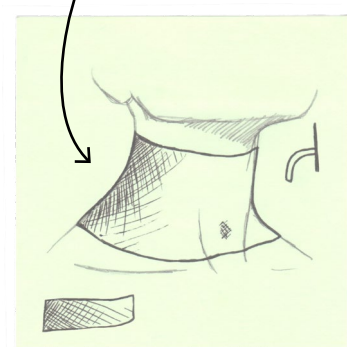
- Ideally less than \$1500 for one tracheostomy

IDEATION STAGE 1

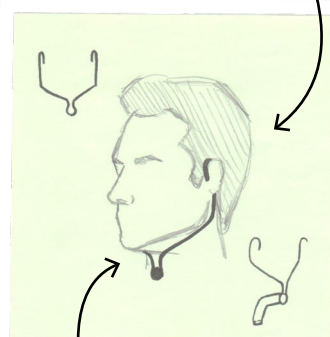
Having selected four design approaches (discreet, fashion, incremental, and mass consumer), I set about sketching a series of concepts inspired by each. The goal was to generate ideas spanning diverse possibilities for tracheostomy design that could be evaluated and combined to shape the direction of the project.



seamless, woven second skin

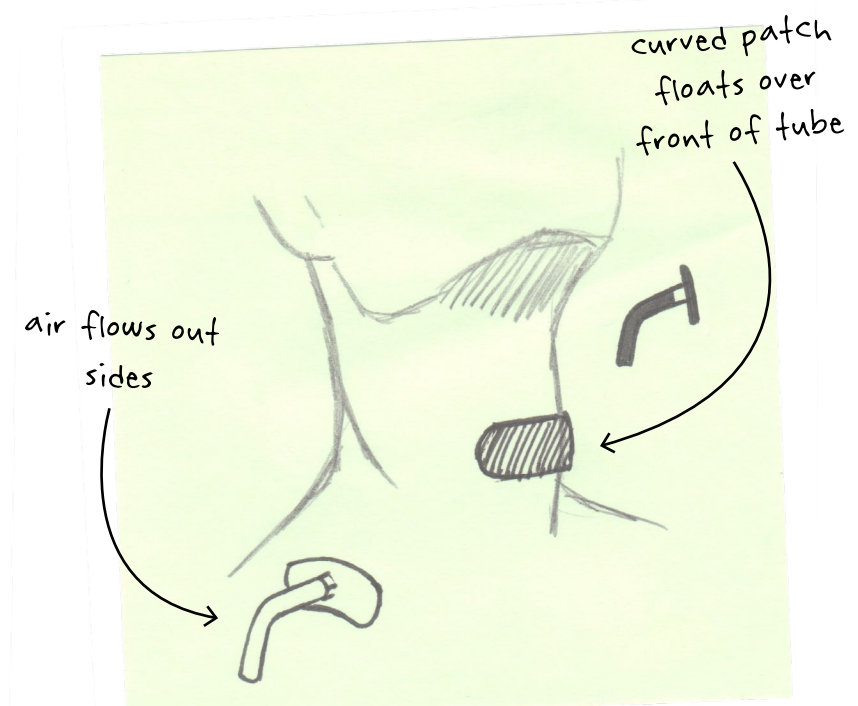
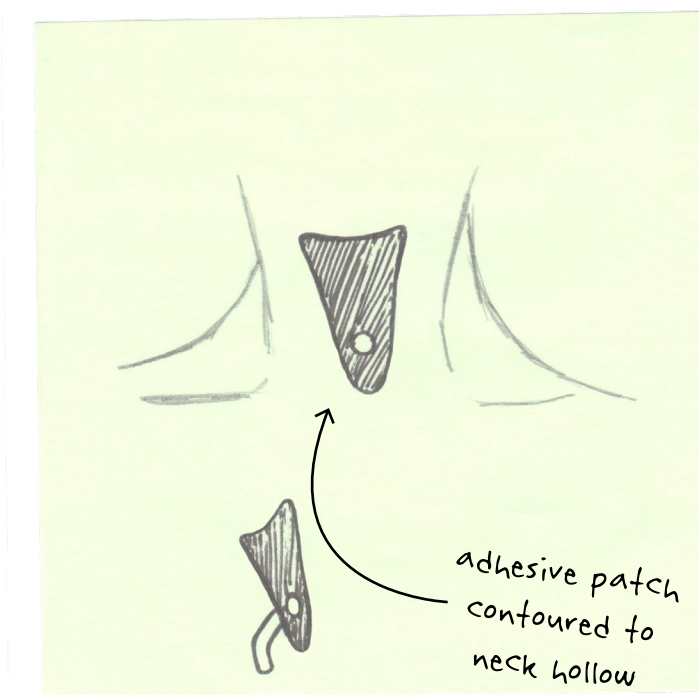


hidden from view by chin



strap follows jawline

DISCREET APPROACH



46. Dickson, (2016). Concept sketches exploring a discreet approach

With these sketches I sought ways of making a tracheostomy tube as discreet as possible so it would cease being the most noticeable thing about a person. I looked at ways of designing discretion into the form rather than relying on transparent or "skin-coloured" materials. I wanted to reduce the visual presence of the strap and eliminate the front protrusion.

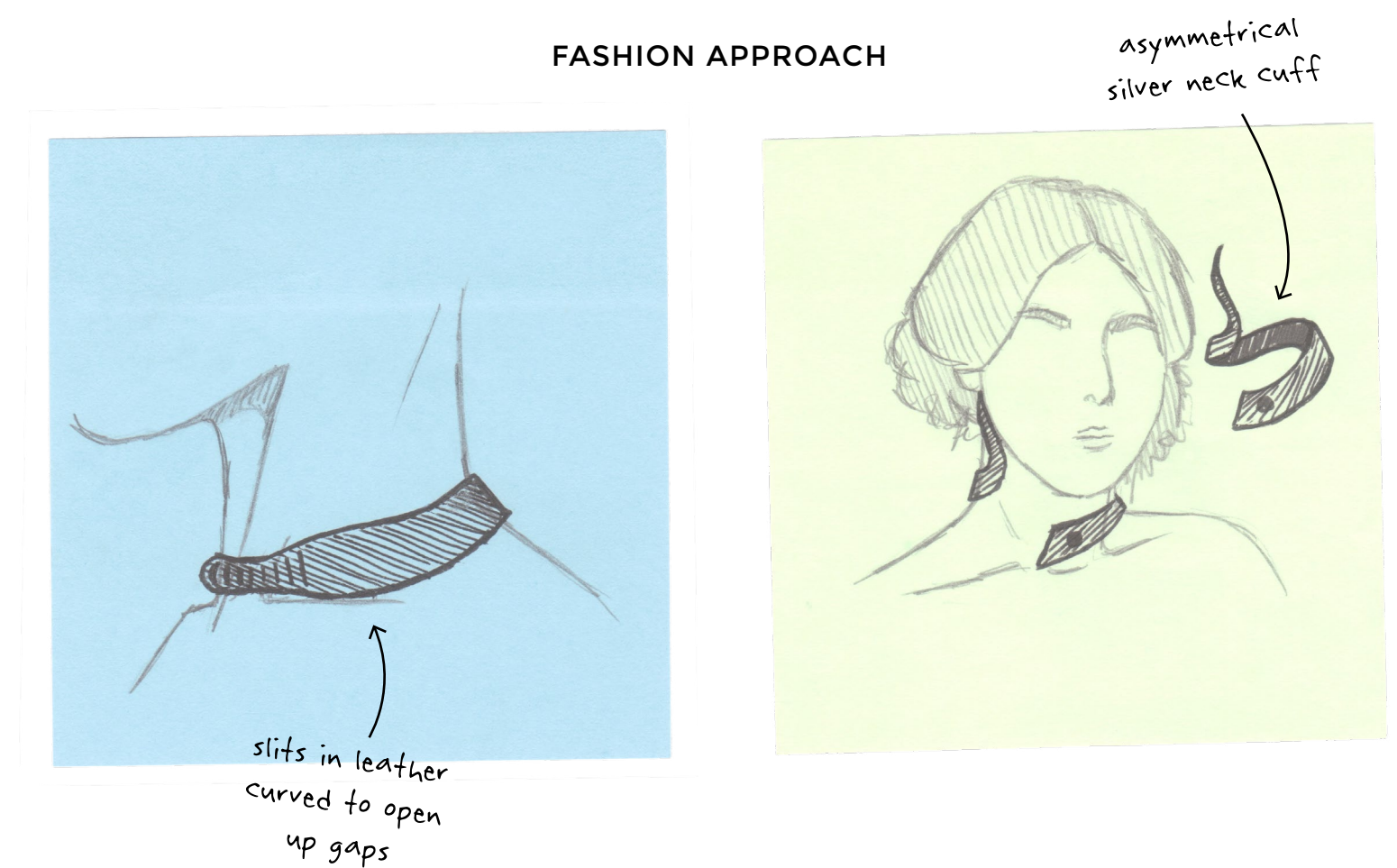
47. Dickson, (2016). Chosen concepts representing a discreet approach

The concepts I selected as being most discreet were attaching the tube to the neck with an adhesive patch, and creating a curved shield to obscure the hole from view without obstructing breathing. I felt these concepts balanced discretion with innovation that would challenge the status quo of existing tracheostomy designs.



48. Dickson, (2016). Concept sketches exploring a fashion approach

These concepts explore what it might be like if expression was seen as more important to tracheostomy design than cost and functionality. Reversing the priorities allowed me to challenge tracheostomy design conventions and alter the product meaning. I took inspiration from a range of items used to adorn the body including shirt collars, necklaces, armour, chokers, and hoods.



49. Dickson, (2016). Chosen concepts representing a fashion approach

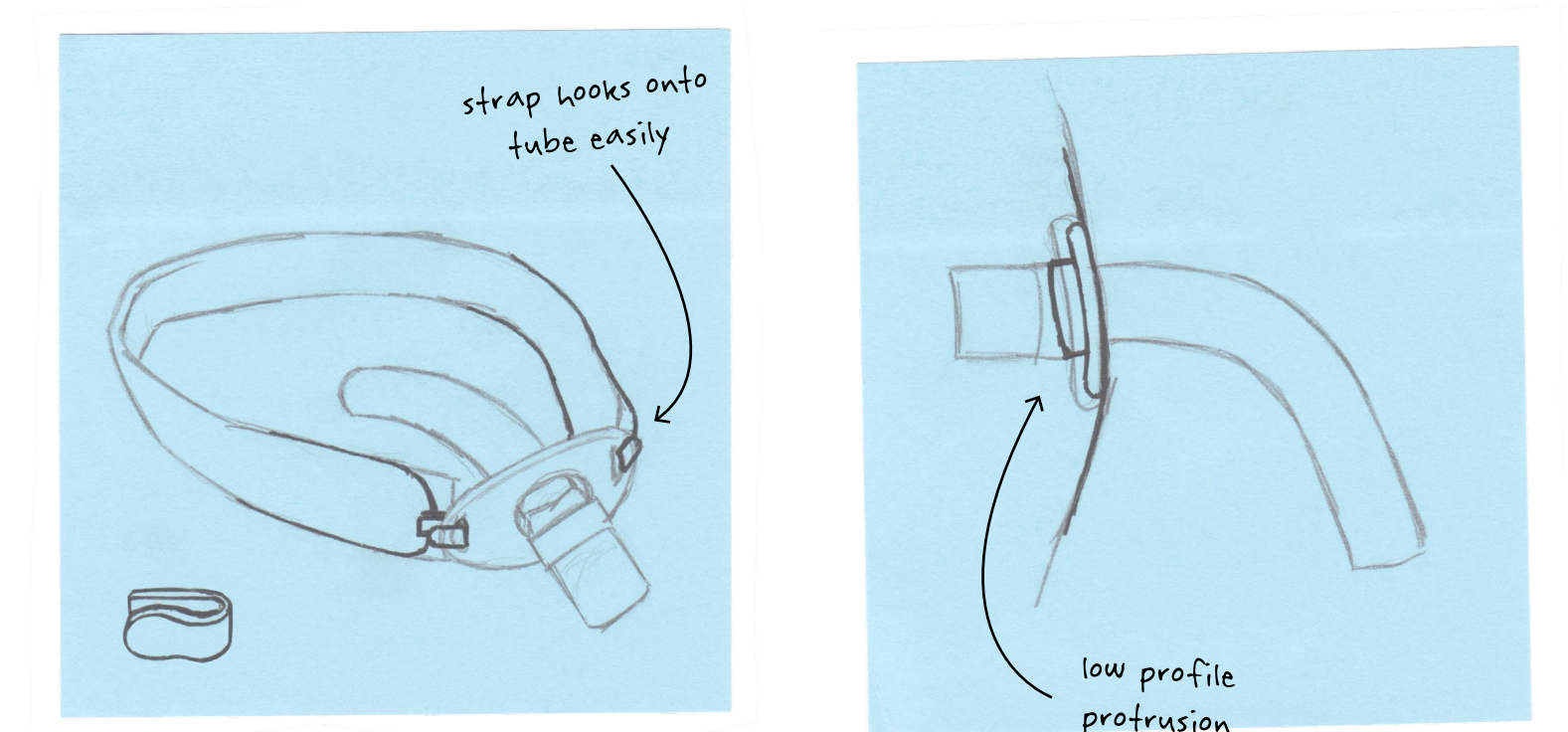
The concepts I felt were most successful were those with abstract forms. I was interested in aligning the aesthetics of the tracheostomy to its purpose without resorting to medical product conventions. I used patterned slits to evoke the form of gills and ideas about breathing. I also explored how asymmetry could create an interesting relationship with the wearer's body.



50. Dickson, (2016). Concept sketches exploring a incremental approach

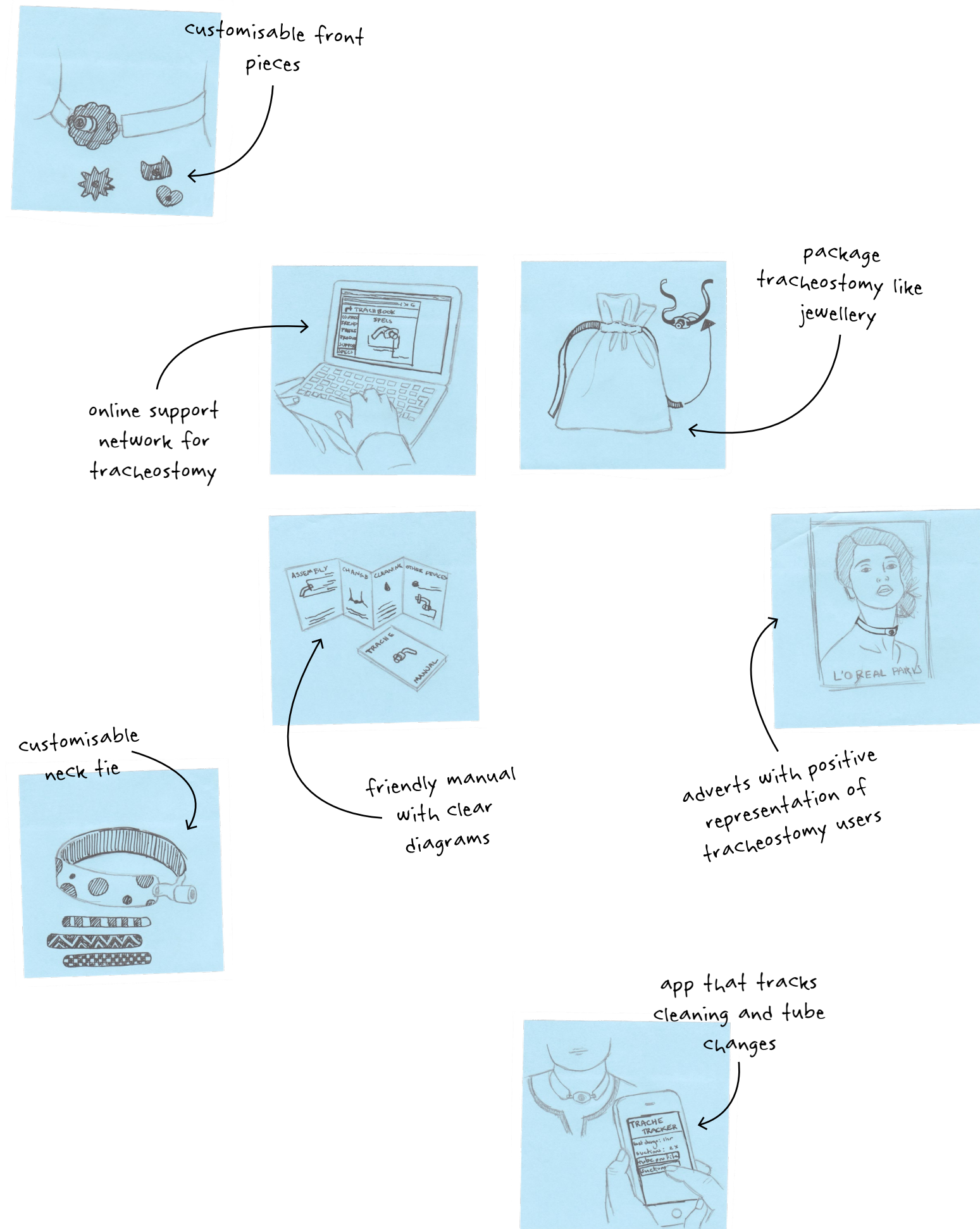
This approach involved considering various elements of tracheostomy tube designs that might be improved through straightforward changes as opposed to a radical overhaul. This included easier ways of securing the tube or inserting it without the need for a separate part.

INCREMENTAL APPROACH



51. Dickson, (2016). Chosen concepts representing an incremental approach

I selected the two ideas I felt would make the greatest difference to tracheostomy users. The first was to add simple clips to make attaching the strap to the tracheostomy easier. The second was reducing the profile of the external protrusion. These two ideas represented the essence of concepts that required exploration of the best way to execute them.

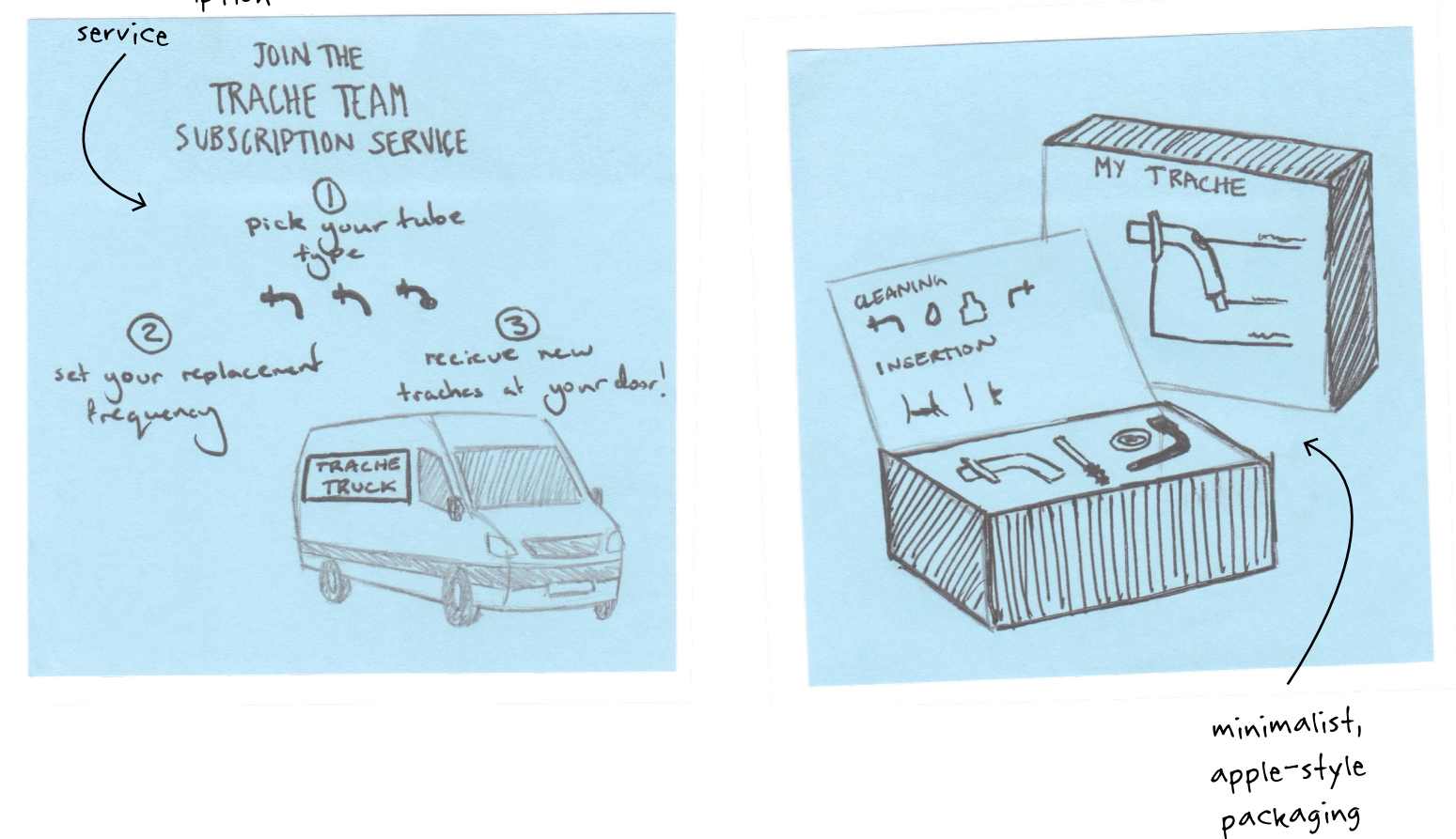


52. Dickson, (2016). Concept sketches exploring a mass consumer approach

These concepts challenge the difference between the way tracheostomy tubes and consumer products are packaged, marketed, and distributed. This approach allowed me to consider the ecosystem shaping tracheostomy users' experiences. My ideas were inspired by consumer market trends like online sock subscription services, and products supported by smart phone apps.

tracheostomy product subscription service

MASS CONSUMER APPROACH



53. Dickson, (2016). Chosen concepts representing a mass consumer approach

The concepts I felt best represented this approach were distributing tracheostomy products via online subscription and treating packaging as an important part of the product experience. I felt these ideas could be combined with other design approaches to create a holistic solution.

REFLECTION

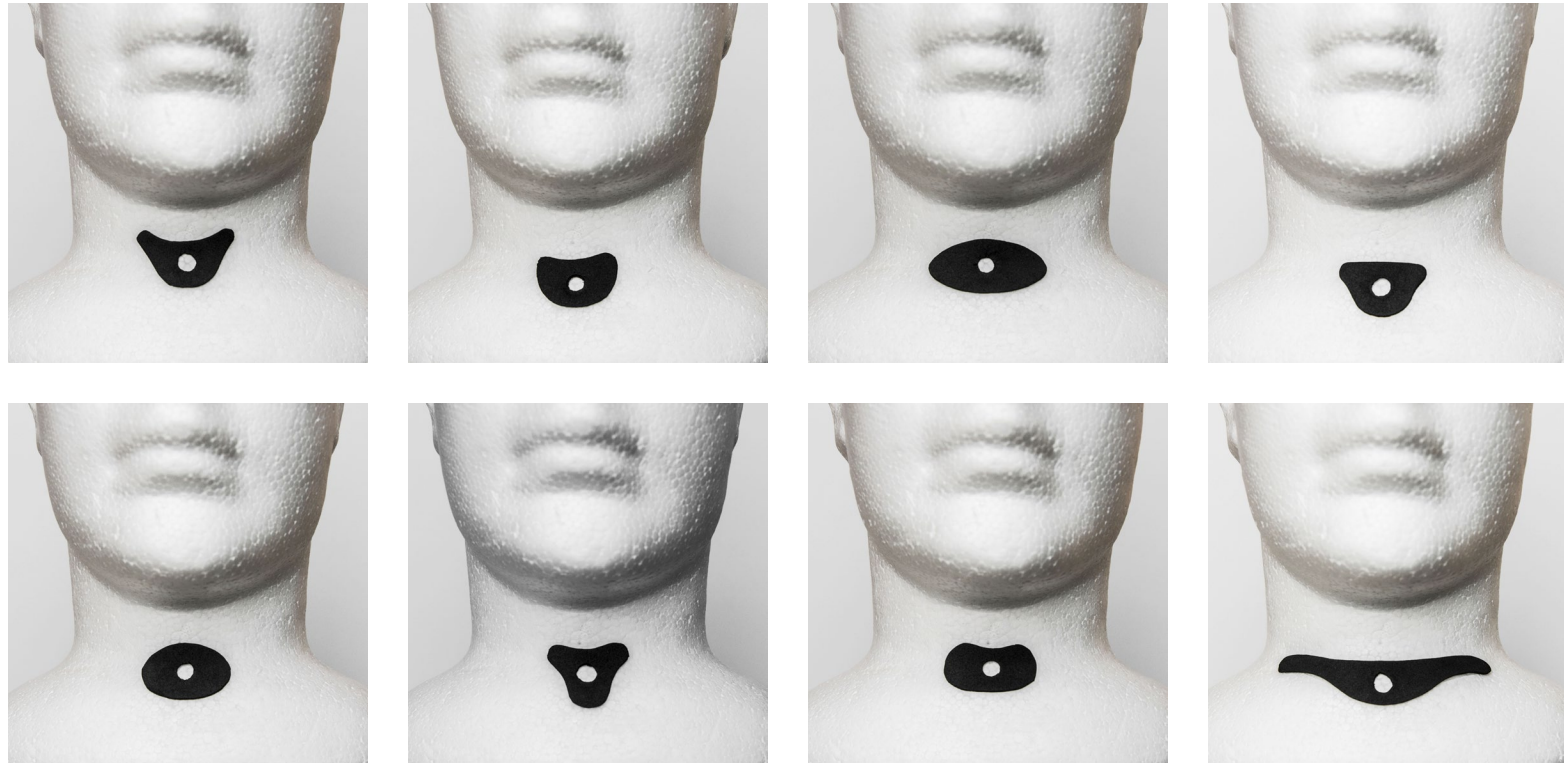
IDEATION APPROACH

Exploring four distinct approaches helped me generate diverse ideas. Each approach encouraged me to consider different aspects of the user experience that could be improved. As such, I felt features of ideas from each category could be combined a subtle, easy to use, and beautiful design, supported by a strong product system. Ideas from the consumer product approach exploring packaging and distribution would bolster user experience whether the final tracheostomy design focused on discretion, incremental improvement, or fashion.

I selected two ideas from each approach to develop and set the goal of generating 10 prototypes for each idea. Because my ideas were guided primarily by theoretical research rather than user insight it was difficult to evaluate ideas in a structured manner. Instead, I allowed my decisions to be guided by my impressions of which ideas were both interesting and offered practical benefits. For incremental improvement I chose to focus on making the strap easy to attach and creating a low profile design. For the fashion approach I was interested in exploring asymmetry, and creating gill-like structures. To develop the discreet approach, I chose to prototype ideas for eliminating the strap, and covering the tube hole without obstructing airflow. From the consumer product approach, I was interested in redesigning packaging with a focus on shaping user experience, and distributing tracheostomy products using a subscription system for replacement components.

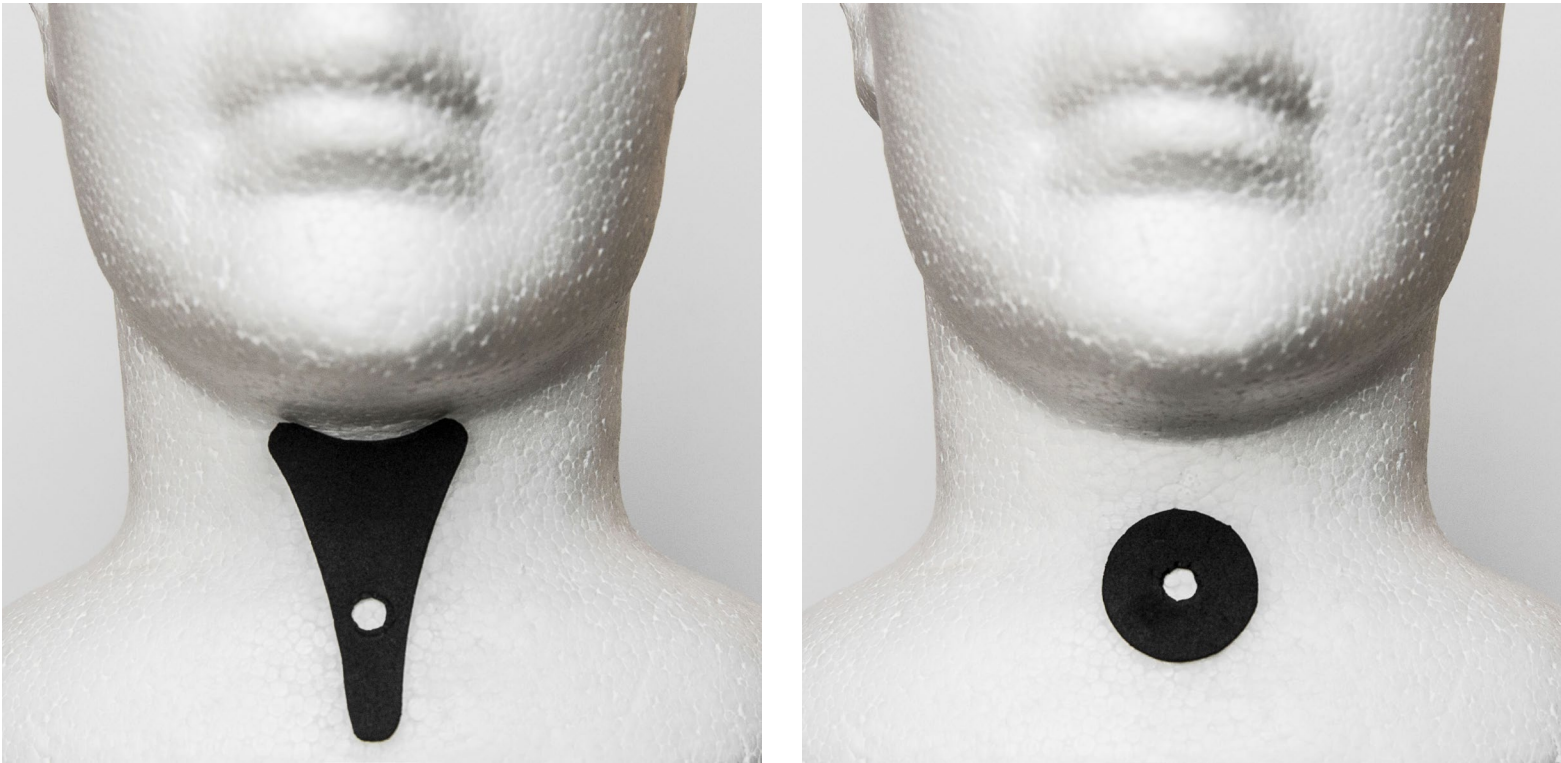
IDEATION STAGE 2

Continuing with the four design approaches (discreet, fashion, incremental, and mass consumer), I set about developing ideas selected from the previous round of sketching; this time using 3D prototypes.

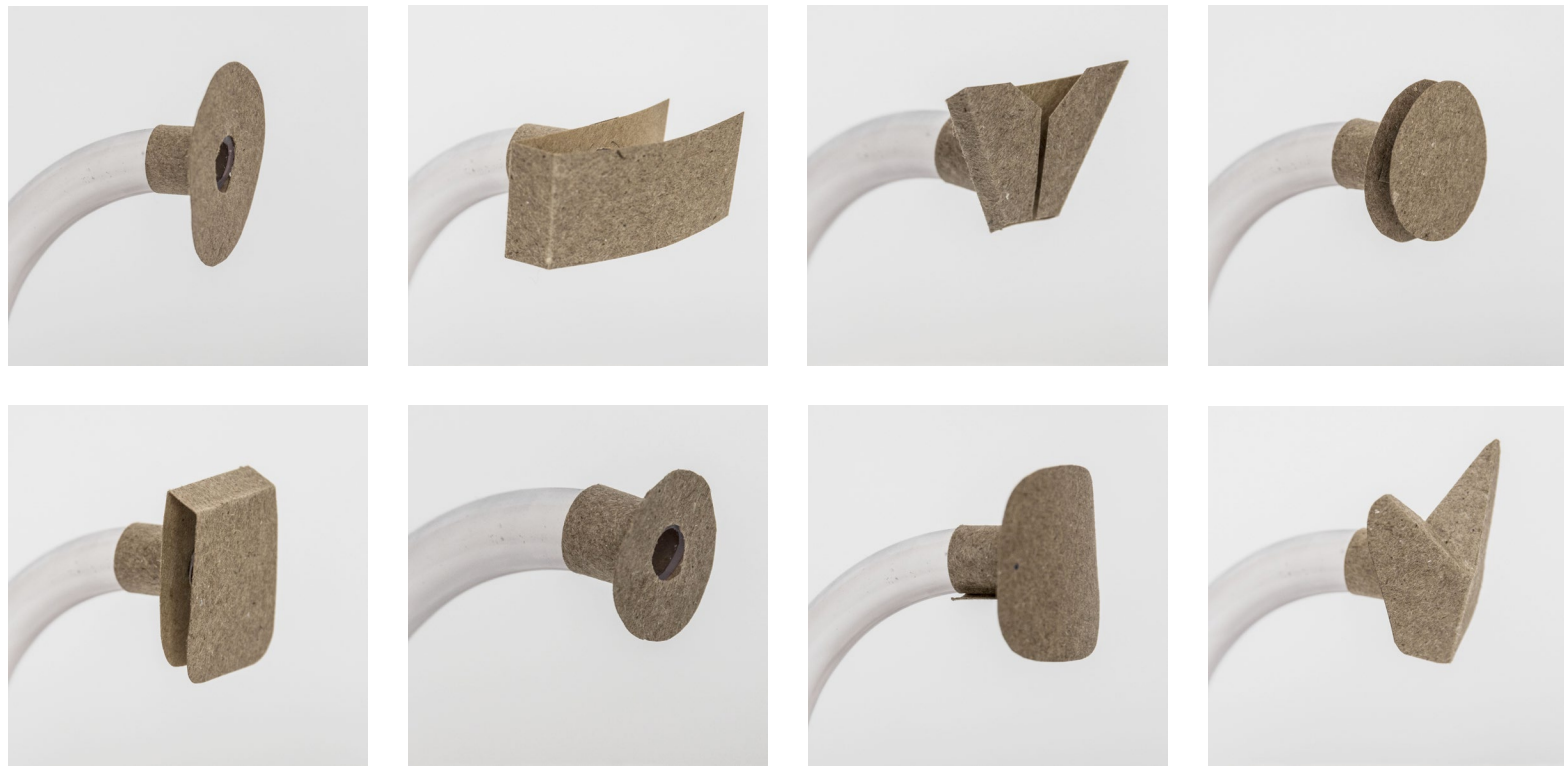


54. Dickson, (2016). First set of prototypes exploring a discreet approach
 These prototypes explore the idea of making tracheostomy tubes more discreet by incorporating them into a low profile adhesive patch that could be worn without a neck strap. I experimented with minimising the size of the adhesive patch as well as choosing forms that reflect the contours of the neck and collarbone.

DISCREET APPROACH SET 1



55. Dickson, (2016). Chosen prototypes representing a discreet approach
 After exploring this approach, I felt that producing a flush design would be too difficult in practice, as it would inhibit the use of humidifiers and speaking valves. Furthermore, adhesives might cause irritation or risk of infection around the stoma site. Although, I rejected the adhesive concept, I applied the ideas of following the contours of the neck and using simple geometry to later concepts.

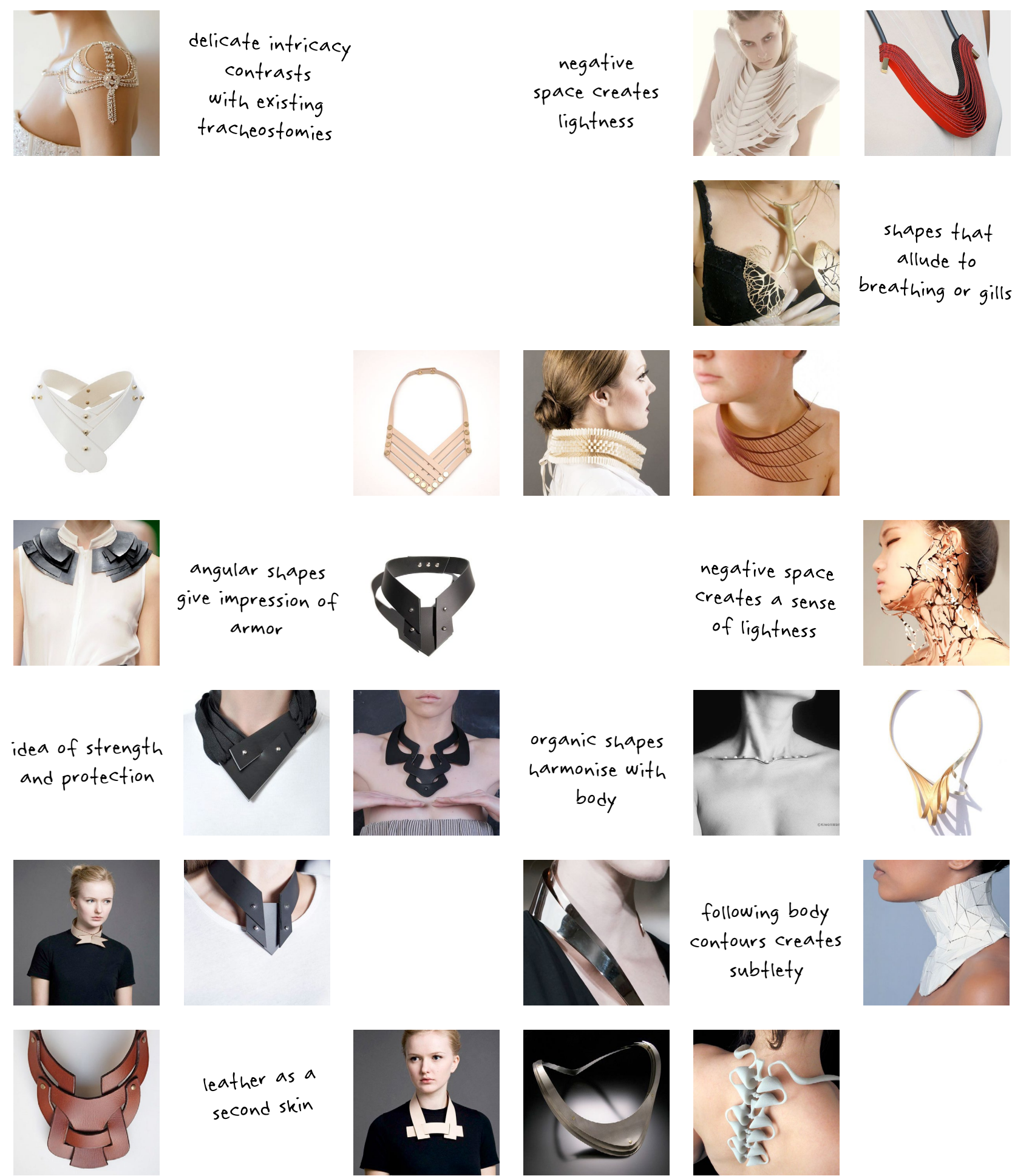


56. Dickson, (2016). Second set of prototypes exploring a discreet approach
 The aim of these concepts was to see whether a more discreet design could be achieved by obscuring the opening of the tracheostomy from view. I also considered whether creating some sort of guard in front of the opening might help prevent users from breathing things in accidentally, and offer discretion when coughing up secretions.

DISCREET APPROACH SET 2



57. Dickson, (2016). Chosen prototypes representing a discreet approach
 I noticed that in some of my prototypes the guard component could be pressed back to fully cover the hole, which would be useful for speaking. I wanted to try devolping this idea to allow the use of attachments and to avoid inhibiting users' breathing. I was also interested in applying the detail of curving the front piece to fit the neck to other designs.



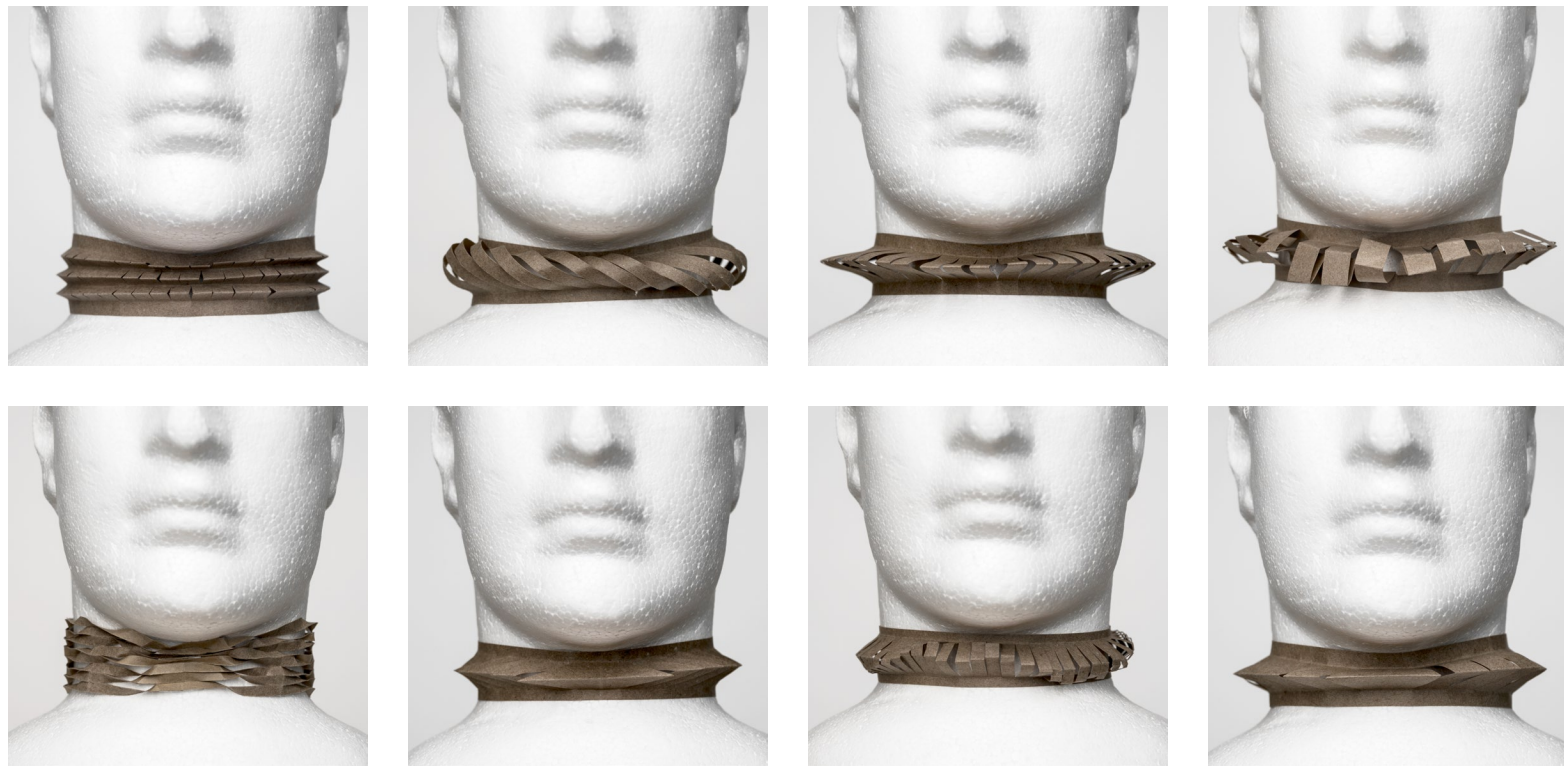
58. Dickson, (2016). Fashion approach mood board

FASHION APPROACH MOOD BOARD

As I developed a second phase of concepts for a fashion approach to tracheostomy design, I found it useful to create a mood board as a visual aid for generative thinking. I collected examples of neck adornment I found aesthetically interesting. Because my goal in exploring a fashion approach was to radically challenge existing tracheostomy designs I found myself drawn to avant-garde ideas.

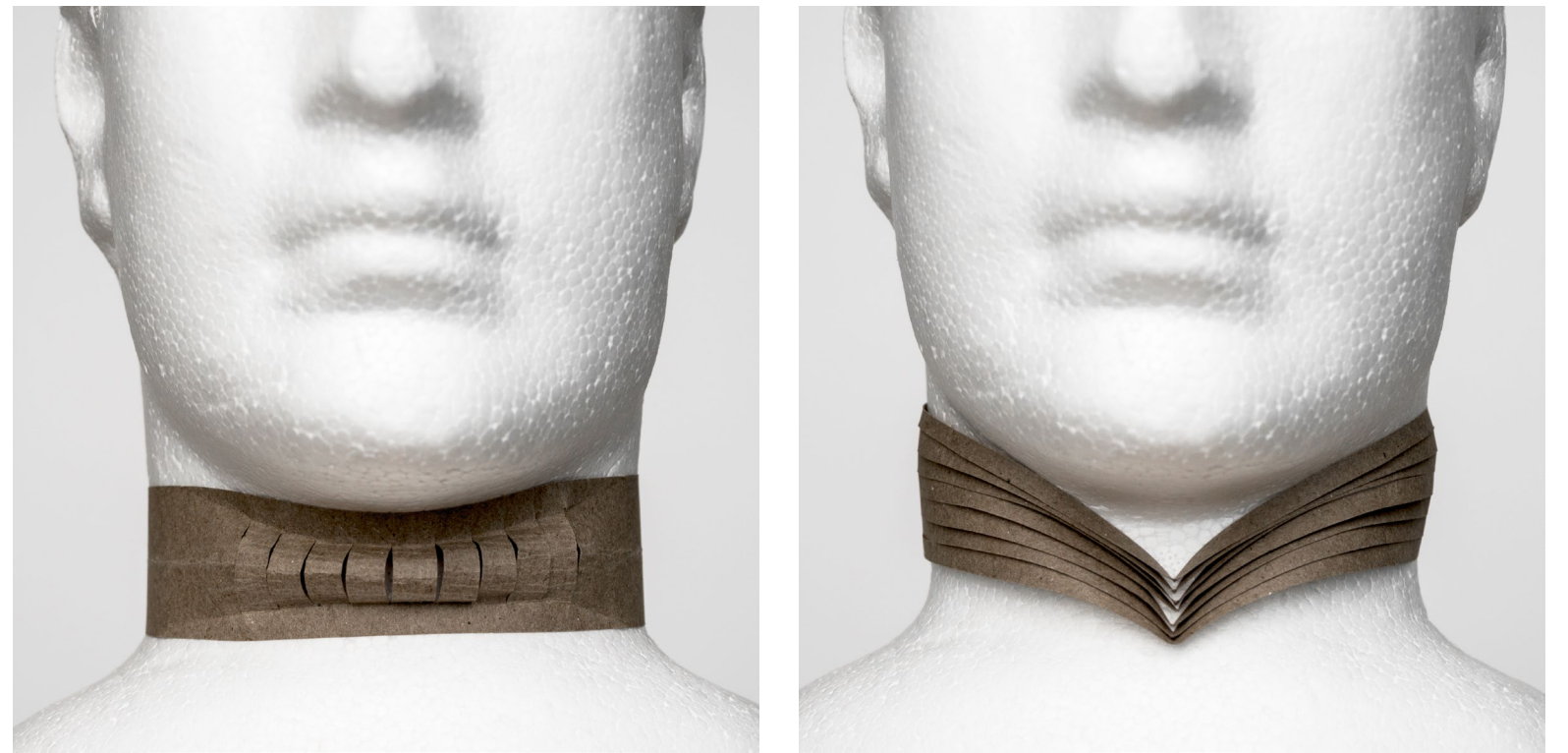
Designs using angular forms and materials like leather and metal rivets reminded me of armour and evoked ideas of strength and protection. I was interested in how these ideas could be used to reframe tracheostomy tubes as products that protect and strengthen the wearer. I was also drawn to designs that arranged flat planes into 3D forms and used negative space to create texture. These designs reminded me of gills, and often used sweeping forms evoking ideas about air and breath. I was inspired to explore integrating the breathing hole of a tracheostomy with the negative space of a sculptural 3D form.

I also began to think about the relationship between product aesthetics and the form of the human body. I noticed organic shapes served as natural extensions of the body while angular and geometric shapes served as bold features. I was also interested in the effects of symmetry and asymmetry. Symmetry was more common in objects worn around the neck, perhaps reflecting natural tendencies to perceive beauty in human symmetry. However, I wanted to explore asymmetry as a symbolic celebration of the ‘imperfection’ of visible differences like tracheostomy.

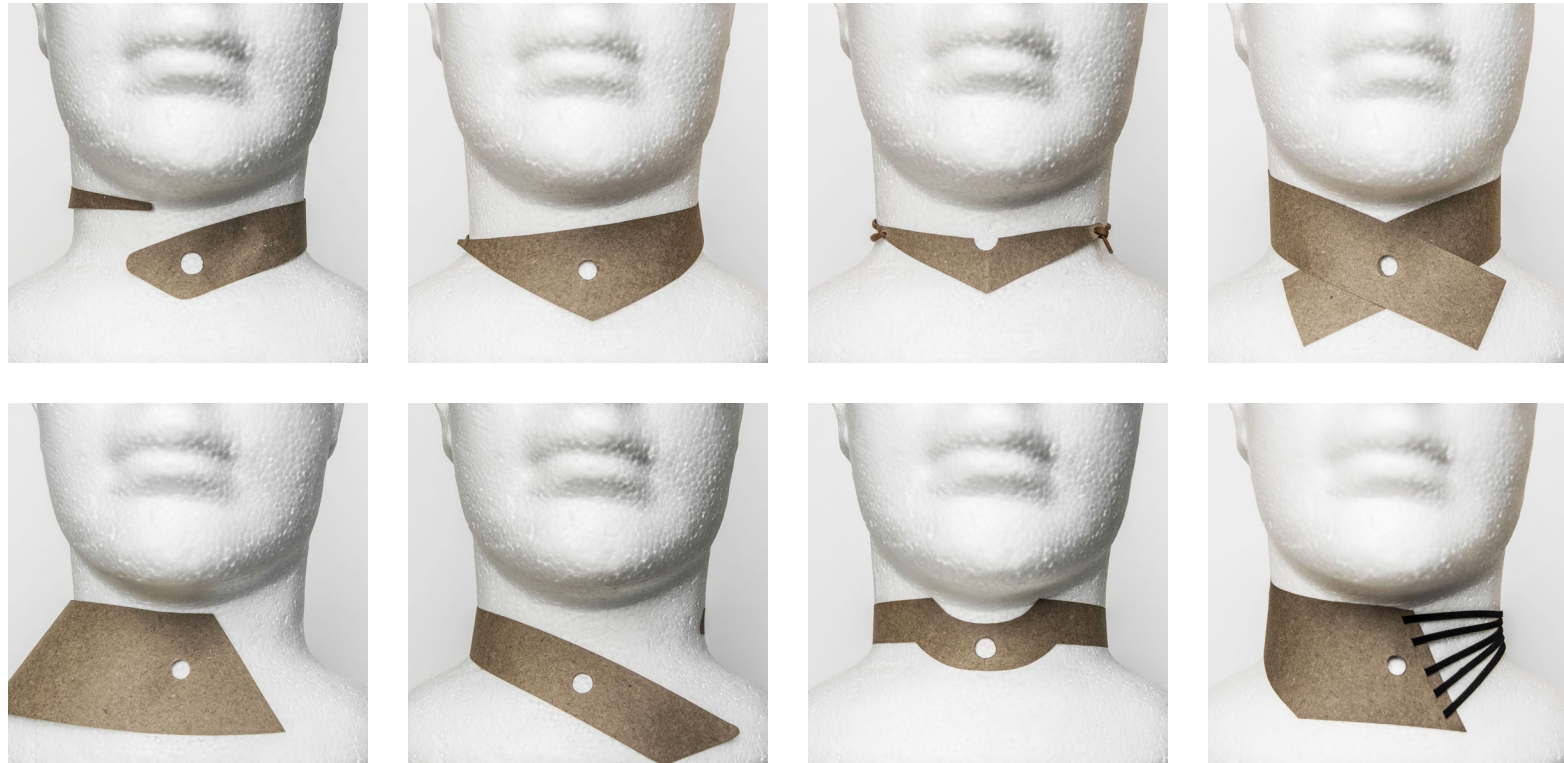


58. Dickson, (2016). First set of prototypes exploring a fashion approach
The prototypes in this series were inspired by the idea of gills as a breathing mechanism, using varied forms of patterned slits to allow the passage of air while covering and distracting attention from the stoma site. I aimed to create interesting, sculptural forms that were radically different from existing tracheostomies.

FASHION APPROACH SET 1



59. Dickson, (2016). Chosen prototypes representing a fashion approach
While these fashion concepts introduced texture and visual interest, they were too “avant-garde” to be practical. I felt that pursuing the simpler forms had the strongest potential for shielding the stoma and avoiding stigmatising reactions without inadvertently drawing unwanted attention.



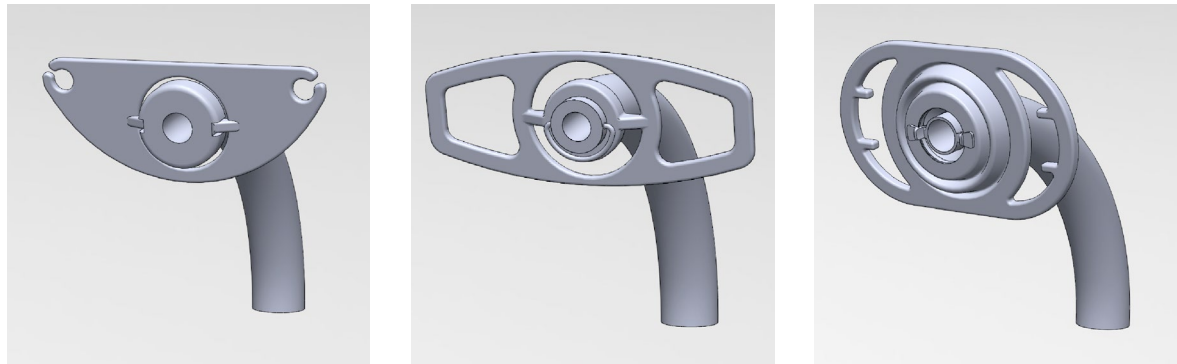
60. Dickson, (2016). Second set of prototypes exploring a fashion approach
For these prototypes I took a more pared back approach, using flat planes wrapped around the neck. Rather than covering and distracting from the stoma site, I tried to treat it as a compositional feature. I also made a point of exploring asymmetry as a means of challenging the form of existing tracheostomy tubes. I envisaged these concepts as pieces of silver crafted statement jewellery.

FASHION APPROACH SET 1



61. Dickson, (2016). Chosen prototypes representing a fashion approach
I found that reframing tracheostomy as a high-end accessory gave me the freedom to explore it's potential as an item of self-expression. I was eager to move forward with this approach as I felt it could help me improve the visual language of the design while still addressing the functional needs.

INCREMENTAL APPROACH SET 1



62. Dickson, (2016). First set of prototypes exploring an incremental approach
With these concepts, I tried to explore different ways of clipping in the inner tube, attaching the neck strap, and helping the neck piece conform to the user's anatomy. While attempting to execute this approach I quickly became stuck and had to pause for reflection.

REFLECTION

HITTING A ROADBLOCK

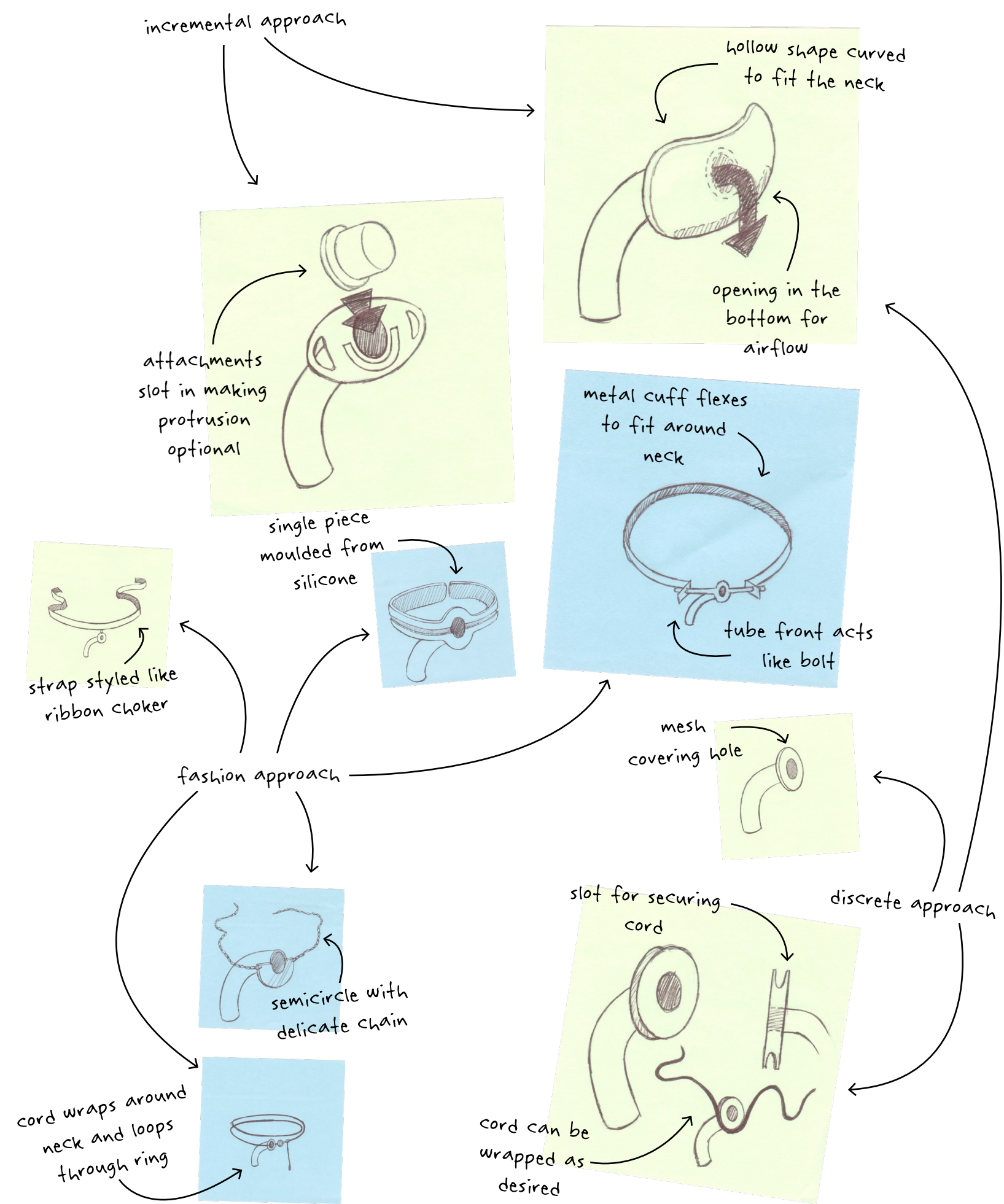
When developing CAD (rather than handmade) prototypes for the second phase of incremental concepts, I found myself in a creative rut. I generated three concepts, but found the process tedious and more time-consuming than the results could justify. I felt I was making changes that were not necessarily improvements.

Initially I was disheartened and frustrated with myself. I felt I lacked the skill and knowledge to achieve good incremental designs. Upon reflection, however, I realised other factors may have contributed to the difficulties I experienced. For example, an incremental approach was not a natural progression from the themes developed through my literature review. The use of CAD may also have limited my thinking, requiring a greater level of detail than was appropriate at this stage of ideation (Parsons, 2009). Being rigid with my goal to generate 20 concepts for each approach without allowing for the inherent inconsistencies of the design process may have stifled my thinking as well.

While working my way out of this creative block took time, I decided I would be better off following my design instinct rather than forcing a direction that wasn't working. I felt the historic stagnation in tracheostomy product design provided enough indication that an incremental approach was unlikely to incite the kind of change needed. Furthermore, because I was more inspired by the opportunities of the other approaches, I was more likely to produce strong work by pursuing them.

I was also struggling to think of ways to begin prototyping ideas for the consumer product approach. I felt improvements to packaging and distribution needed to harmonise with tracheostomy tube design. As such, I decided it would be better to address aspects of a consumer product approach once the design of the main tracheostomy products had taken shape. This left me to explore the contrasting fashion and discretion approaches.

PHASE 3

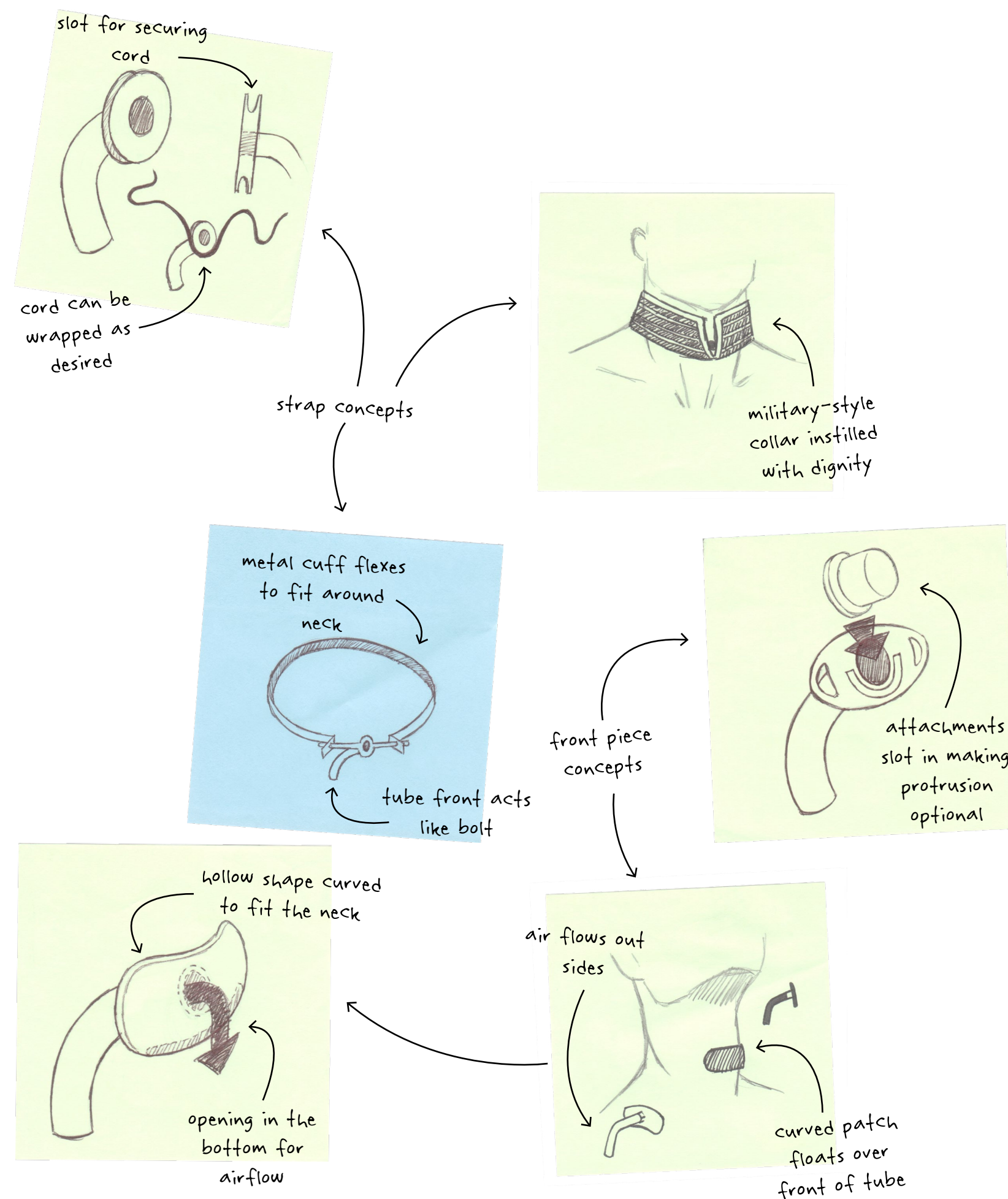


63. Dickson, (2016). Brainstorm of new ideas

GENERATING NEW IDEAS

My first attempt at getting the project back on track involved freely generating new ideas. I discarded my self-imposed goal of producing 20 concepts for each approach. While constraints had been useful for driving my ideation to this point, setting them aside helped me reset my thinking and generate fresh ideas. After sketching these ideas, I was able to link them back to the different approaches. Despite my earlier struggles, some even fit the category of incremental improvement.

This exercise was useful for breaking an unproductive thought cycle. It also led me to generate several ideas with potential for development. For example, I sketched an idea for making the protrusion on the front of the tube an optional attachment. This idea stemmed from staff suggestions and provided an incremental solution to creating a more discreet design. I also sketched a concept building on some of my discreet approach prototypes, covering the tracheostomy hole by making the front piece a hollow form with an opening at the bottom. Again this combined incremental and discreet approaches. Two sketches explored different ways of making the strap easier to attach using either a metal neck cuff, or a piece of cord wrapped around the tracheostomy. I felt each of these ideas was worth taking forward because they presented improvements on previous concepts, reflected research findings, and combined aspects of discreet, fashion, and incremental approaches.



64. Dickson, (2016). Map of ideas selected for next stage of development

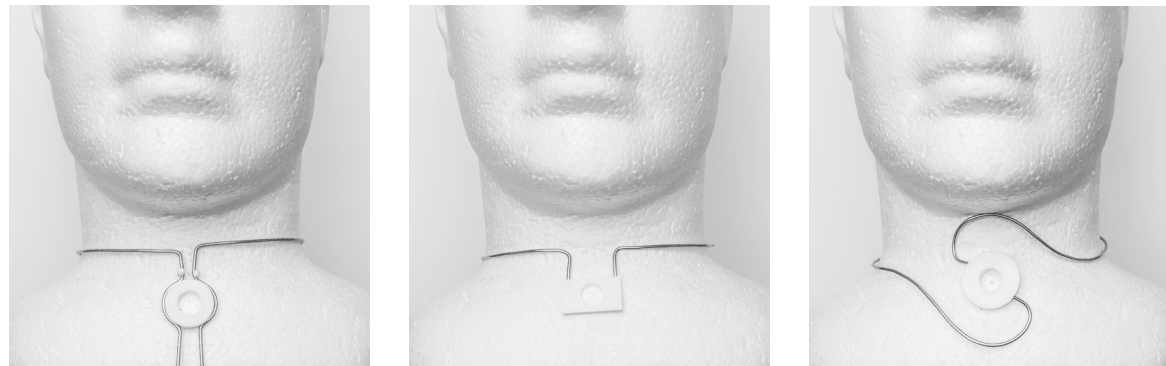
SELECTING IDEAS

After generating new ideas, I decided to revisit earlier sketches and review both new and old ideas to make a decision about how to progress with prototyping. From the earlier set of sketches, I was still eager to develop the idea of providing discretion by shielding the tracheostomy hole from view. I was also interested in replacing the neck strap with a fabric collar. While I had not selected this concept for my initial round of prototypes, I felt it had the potential to be both fashionable and discreet and opened up good prototyping opportunities.

I decided to make these two ideas, as well as the four selected from the newer set of sketches, the basis of my next round of ideation. Of the six total ideas, three focused on the neck strap, and three on the front portion of the tracheostomy tube. The three front piece ideas were closely related and could be prototyped in combination by making the piece covering the tracheostomy hole an optional development. The neck strap ideas, on the other hand, were disparate and needed to be developed separately. As such I proceeded with four rounds of prototyping; metal cuff concepts, cord concepts, collar concepts, and attachment concepts.

IDEATION STAGE 3

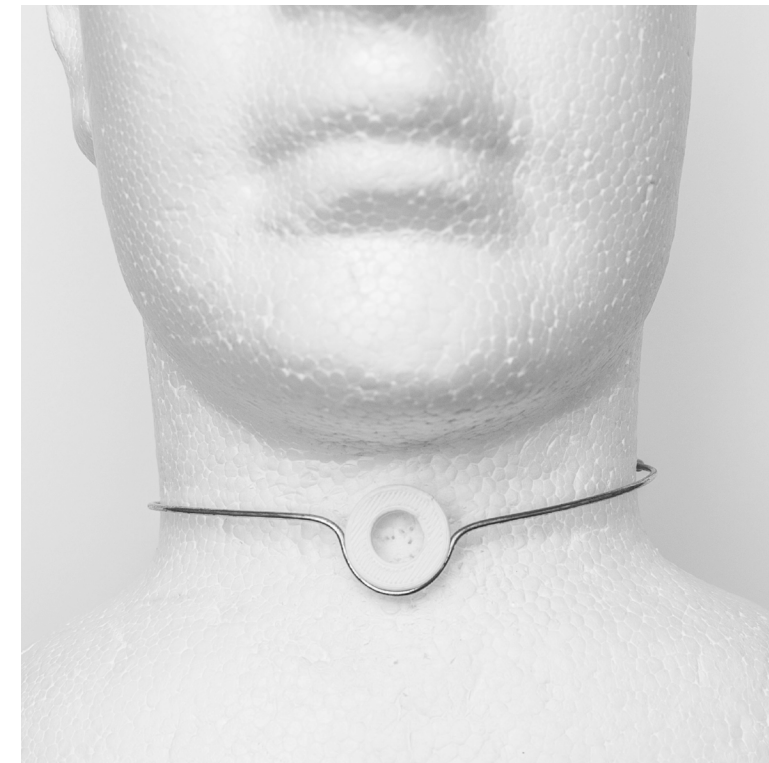
For the third stage of ideation, I produced prototypes developing four previously selected concepts; metal cuff concepts, cord concepts, collar concepts, and attachment concepts.



65. Dickson, (2016). Prototypes developing metal cuff concept

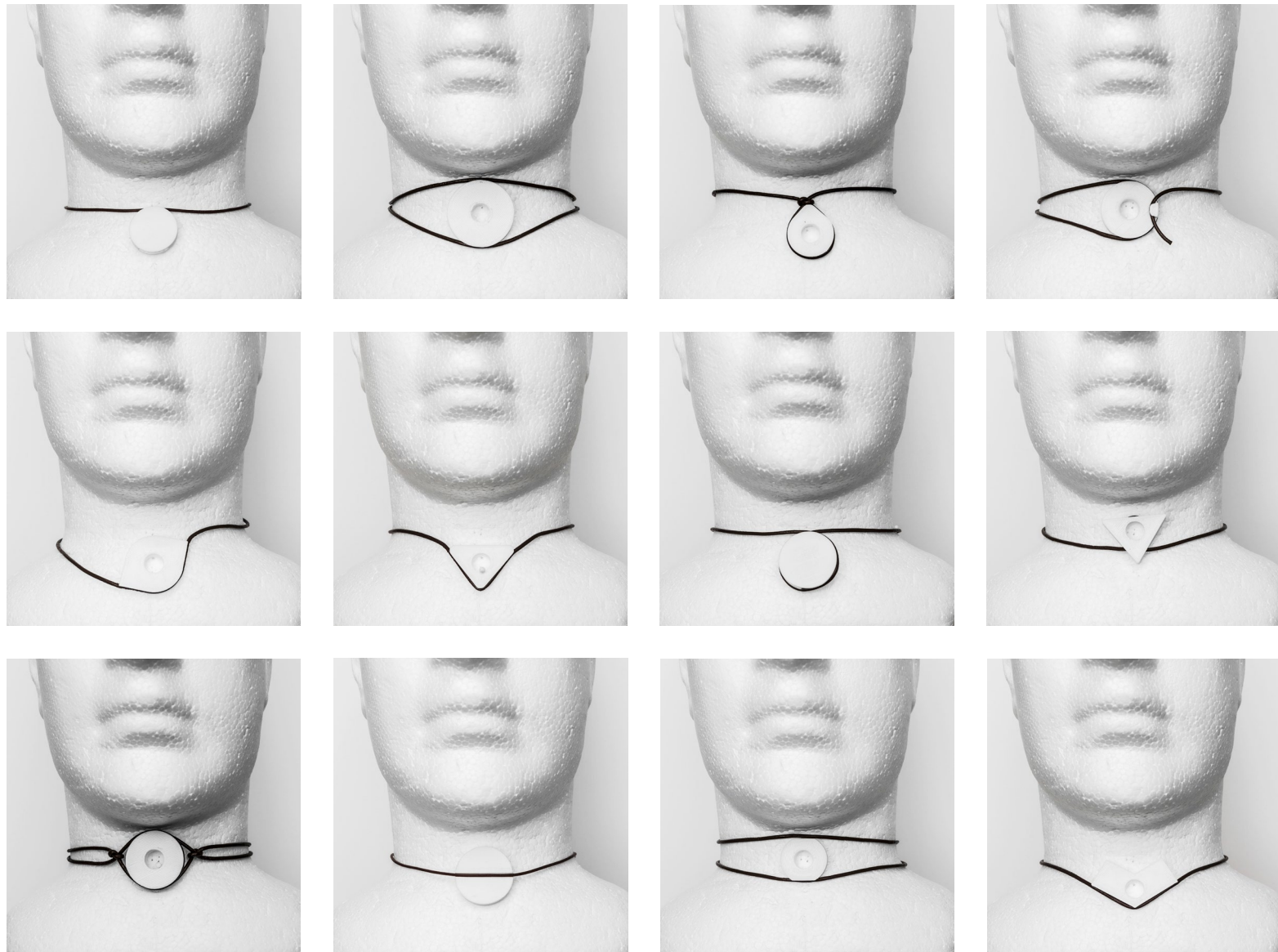
For these prototypes I took a minimalist approach, using a geometric silver cuff to clip the tube in place. As well as creating a jewellery-inspired aesthetic, the aim was to make securing the tracheostomy tube a simple, one-step process. A silver cuff would also be suitable for long-term use and easier to clean than existing fabric straps.

METAL CUFF CONCEPTS



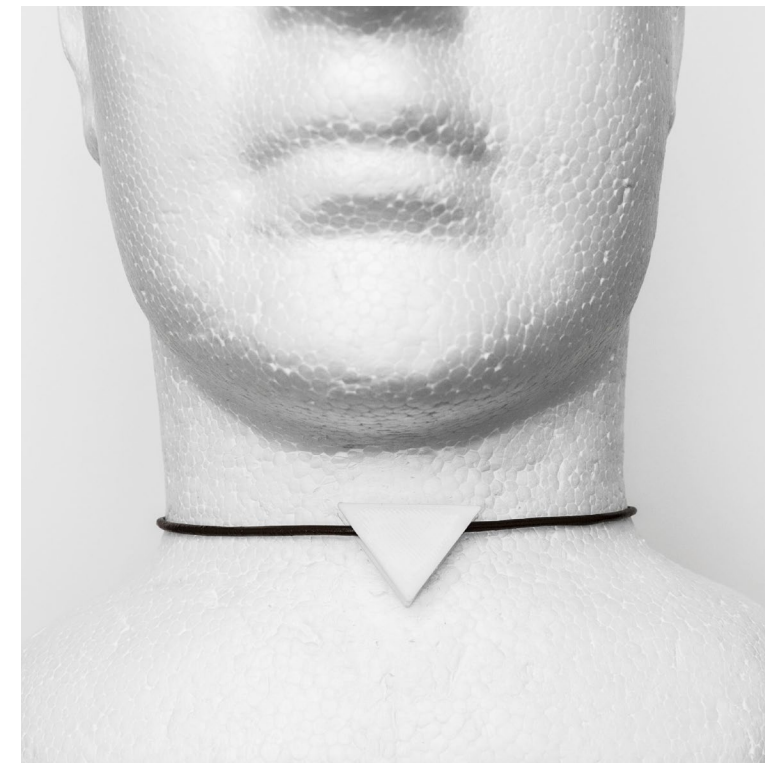
66. Dickson, (2016). Chosen prototype representing metal cuff concept

I found that the cuff was not as effective at holding the tube in place as I had hoped. Attaching the cuff required both hands, meaning the user could not hold the tracheostomy in place at the same time. I also had concerns about the comfort of a rigid design. I decided the issues with this concept outweighed the benefits and chose to explore other directions. I did, however, feel there was potential in the idea of supporting the tracheostomy from below using a rigid 'U'-shaped piece and kept this idea in mind for later stages of development.

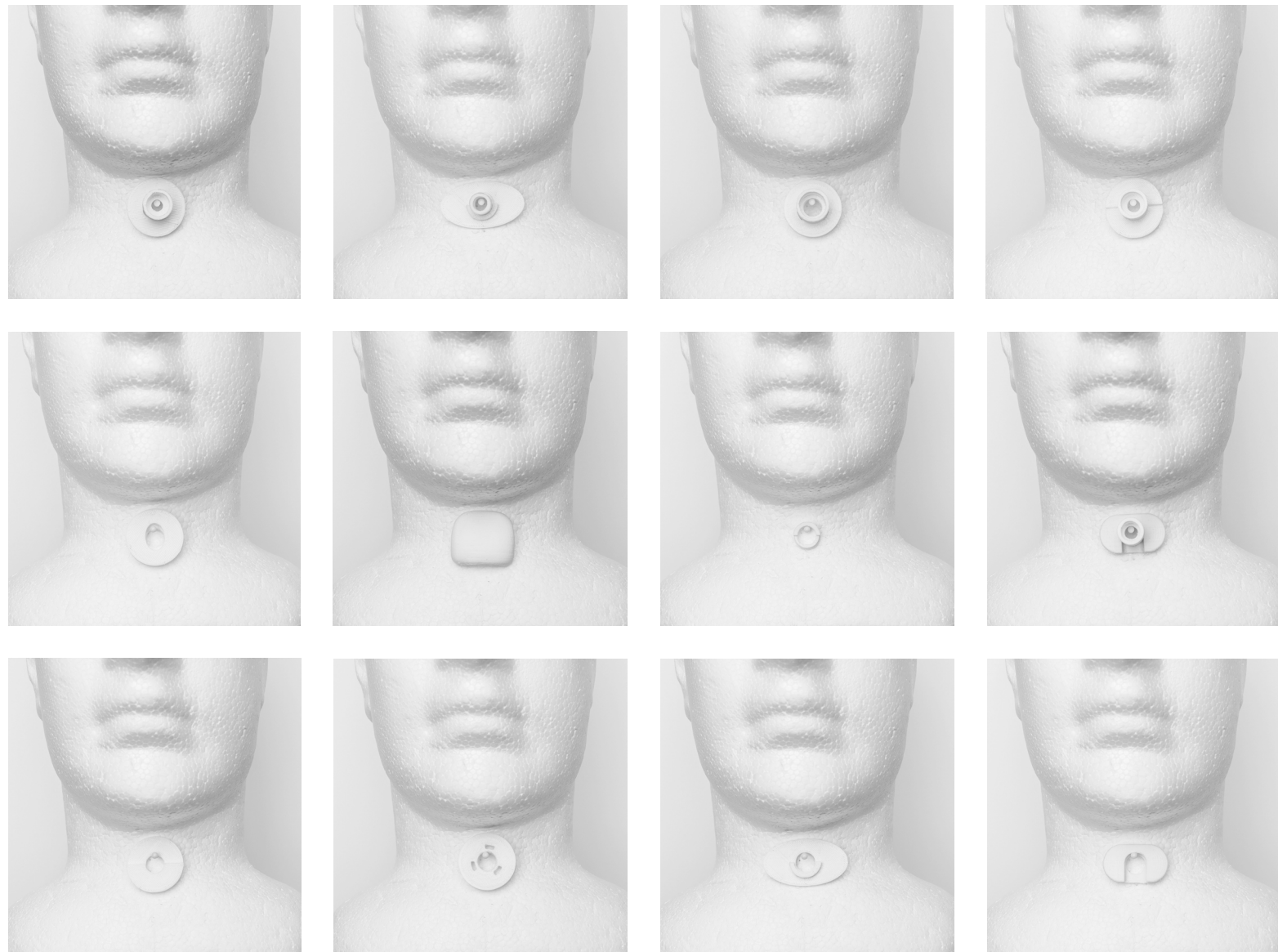


67. Dickson, (2016). Prototypes developing cord concept
 These concepts focused on making the tracheostomy easy to fasten to the neck by looping cord in different arrangements. The use of looped and knotted cord also evoked the idea of cultural jewellery, with the tracheostomy tube taking on the role of a carved pendant.

CORD CONCEPTS



68. Dickson, (2016). Chosen prototype representing cord concept
 Once again, I found that my ideas were not as effective in practice as in theory. Looping cord around the tracheostomy proved fiddly and impractical. However, through exploring variations on the basic principle, I produced one concept I wanted to develop further. This concept involved incorporating a slit through the front of the tracheostomy so it could clip over a cord like an old-fashioned clothes peg.

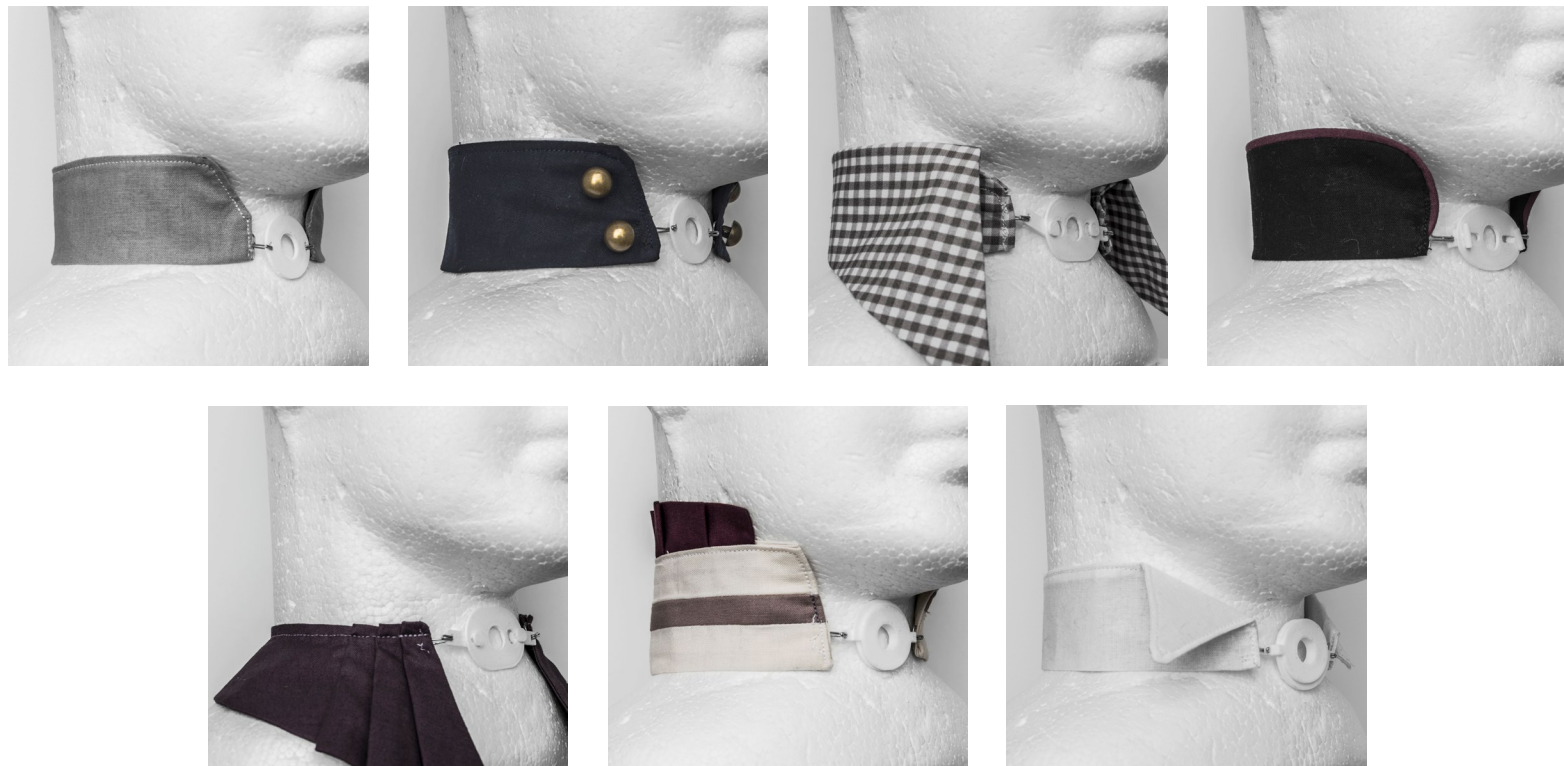


69. Dickson, (2016). Prototypes developing attachment concept
 These concepts transformed the protrusion on the front of tracheostomy tubes into an optional attachment. They also explored the possibility of using an attachment to obscure the hole from view. The aim was to offer users choice in the configuration of their tracheostomy, making it adaptable to different situations.

ATTACHMENT CONCEPTS

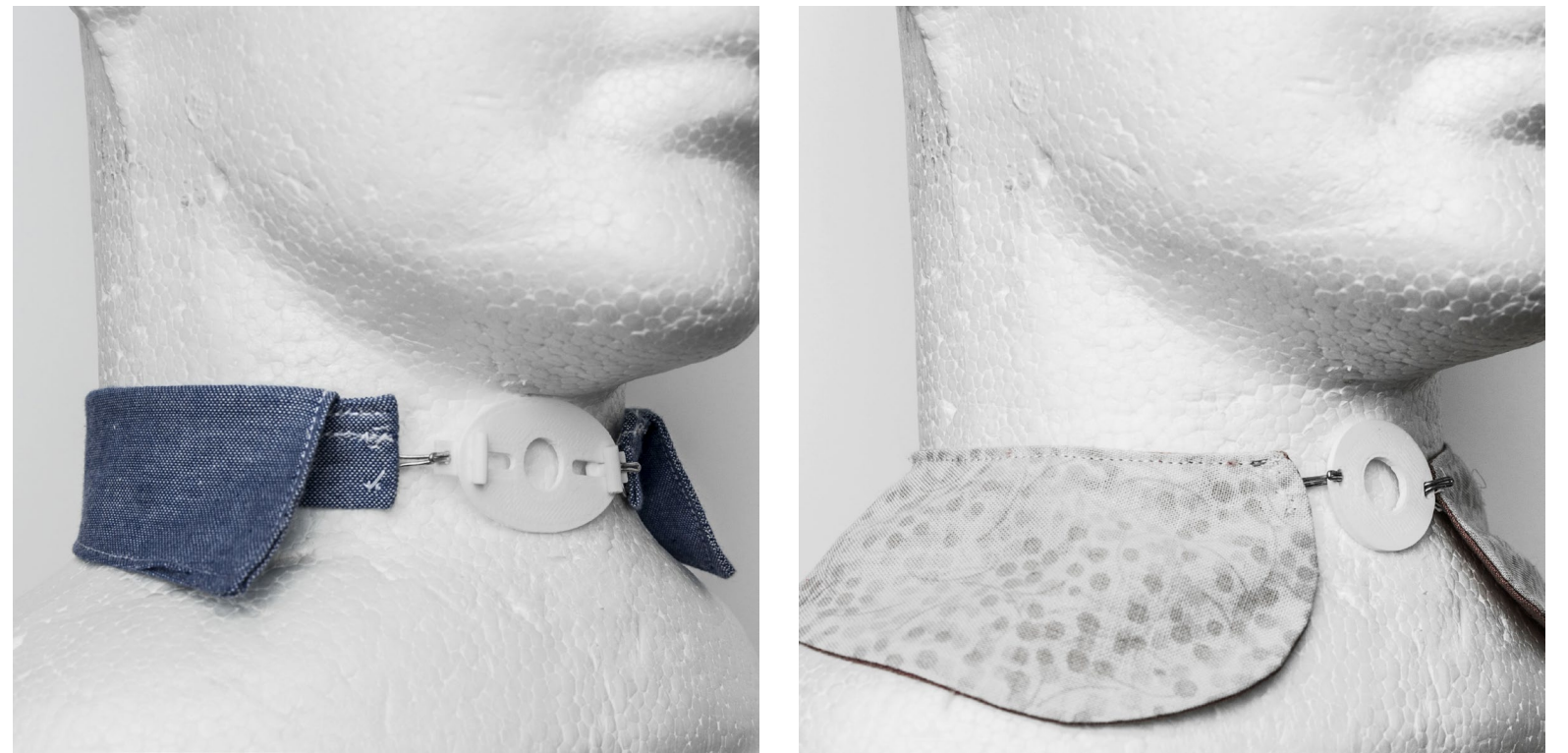


70. Dickson, (2016). Chosen prototypes representing attachment concept
 I felt that making the protrusion optional would make the tracheostomy more discrete, and offering user's choice could help them feel more in control of their experiences. As such I decided to pursue these concepts further with a focus on ensuring attachments were easy to use and did not inhibit airflow or speech.



71. Dickson, (2016). Prototypes developing collar concept
 These concepts replaced traditional neck straps with washable fabric collars. The concepts were intended to be more comfortable, longer lasting, and more discrete than existing strap designs. Different collar designs constructed from different fabrics could also be chosen to suit different personalities and occasions. I also explored different designs for clipping the collars to the tracheostomy.

COLLAR CONCEPTS



72. Dickson, (2016). Chosen prototypes representing collar concept
 While some of the more intricate collars seemed unlikely to appeal to a broad user group, I felt that the simpler designs pictured above warranted further development. Moving forward with the collar concept would require finding a way to make the length adjustable to accommodate changes in neck circumference due to swelling.

REFLECTION

BACK ON TRACK

With these prototypes, I did not impose a quantity goal for each set of ideas. I found a relaxed approach more successful, as I could move on to the next set of ideas if I became stuck. This ensured my attention was focused on doing a good job of executing ideas that came easily rather than wasting time on forced ideas.

The use of 3D printing, combined with additional materials, helped me achieve more complex forms than was possible with cardboard and foam prototypes (Parsons, 2009). This allowed me to make interlocking parts on a scale appropriate to tracheostomy design. 3D printing was also time-efficient as I could prepare a range of CAD models, then work on handmade components like fabric collars while plastic components were printing.

To prepare for the upcoming co-design workshops, I selected two prototypes from each set to refine and present to tracheostomy users for feedback. I chose the prototypes I felt best executed each overarching concept, and would offer a range of shapes and details for participants to comment on.

PHASE 4

USER INTERVIEWS

Interviews with 10 participants who had lived with tracheostomy for at least 3 months were conducted as part of the SRIF study. I had access to audio recordings and transcripts of these interviews to independently analyse as appropriate to my project. While participants’ stories were unique, some common themes were identified and used to frame discussion of the interview data. Quotes in participants’ own words were drawn from interview transcripts to illustrate each theme and capture different voices.

Themes included:

Everyone is Different

Improvisation

Modification

Plastic vs Silver

Self-Advocacy

Independence

Communication

Stigma, Social Life, and Self-Consciousness

Inexperienced District Nurses

Hope

EVERYONE IS DIFFERENT

Of the 10 participants interviewed, no two received tracheostomies for the same underlying condition. The causes for participants’ tracheostomies included neck tumour, heart transplant, ingestion of poison, and obstructive sleep apnoea. No participants required tracheostomy to treat a smoking-related condition.

The diversity of conditions leading to tracheostomy goes some way to explaining why statistics about long-term tracheostomy users are scarce. Because tracheostomy is usually a side effect of another condition, patient information is stored according to that condition leaving no database pertaining specifically to tracheostomy.

Participants ranged from 25-75 years of age. 7 participants were female, and 3 male. 5 participants identified themselves as NZ European. 2 were of mixed Maori and NZ European decent. The 3 remaining participants were Indian, Tongan, and British. Despite exhibiting reasonable demographic diversity, the homogeneity of tracheostomy design meant that there was little discernible difference in the products each participant described using. There were, however, considerable differences in the ways participants managed their tracheostomies.

IMPROVISATION

Several participants were relaxed about tracheostomy care, regularly going against clinical recommendations and tracheostomy care leaflets. Participants cleaned their tracheostomy tubes using Q-tips, wore them without inner tubes, inserted them without introducers, and used saline solution instead of nebulisers to release blocked secretions. None of these methods are described in the care guides currently distributed to tracheostomy users at Auckland Hospital.

In some cases, improvisation was driven by unique incidents encountered during at-home use. One participant stopped wearing her inner tube when gardening after it fell out and she ran over it with a lawn mower.

“I generally wear it, but not while I’m in the garden or doing the lawns”
- 67-year-old female, 20+ years with tracheostomy

This incident suggests the latch securing the inner tube on silver tracheostomies is not sufficient for all activities a user might undertake in daily life. Rather than allowing their tracheostomies to limit their activities, users find ways to make their tracheostomies work for them.

Participants attributed instances of improvisation and ‘bumbling along’ to inadequate preparation for life with tracheostomy. One participant was expressly against improvisation, but agreed he had received insufficient

information. When asking clinicians for instructions, he received the comment:

“there’s only one instruction, don’t go swimming”
- 60-year-old male, 1 year with tracheostomy

This participant responded by undertaking research to establish guidelines for his own tracheostomy care.

As well as being scarce, some participants felt information was overly focused on hospital contexts and impractical for long-term, at-home use.

“When you wear one every day you can’t afford to be too hygienic about it”
- 55-year-old female, 24 years with tracheostomy

Because tracheostomy care information does not reflect users’ needs once they re-join the community, they are driven to find tracheostomy care strategies that fit their daily lives.

Differences in lifestyle and personal preference magnified by limited variation in tracheostomy products may also drive users to improvise. With most products, users choose from a range of designs that suit different

situations and lifestyles. People are free to choose novelty socks, plain work socks, or high-performance sports socks according to their needs and preferences. By contrast, tracheostomy users have no choice but to fit existing products into their lifestyles.

Furthermore, for many products there is no expectation that all users will use them in exactly the same way. However, the medical status of tracheostomy products, and the risks associated with their misuse, introduce the need for established guidelines. Because healthcare organisations may be liable for harm incurred by information they distribute, care guidelines are formulated to be cautious. In addition to legal necessity, the disparity between care information and tracheostomy users' care practice may stem from a lack of consideration for the range of circumstances that users encounter over the course of long-term use. Regardless, the fact that 10 different people have successfully lived with tracheostomy (often for many years) using a range of management strategies suggests tracheostomy care can be more flexible than guidelines allow.



MODIFICATION

Even more striking than participants' deviation from care recommendations was the effort some put into modifying their tracheostomy products. Two participants replaced their straps with silver chains, and a third used recycled bra straps. One participant described an extensive history of modifying her tracheostomies, dying the straps to match her skin tone and grinding down the front protrusion to create a flat profile. This participant had also experimented with painting her plastic tracheostomy tubes with skin tone model paint and "didn't care even though [she] knew it wasn't good for [her]" (55-year-old female, 24 years with tracheostomy). The drive to modify her tracheostomy came from deep dissatisfaction with the options available and an unmet desire for discreet design. Reasons given for modifications included aesthetic preference, sense of quality, practicality, hygiene, and the desire for a reusable strap.

In essence, tracheostomy users responded to the lack of choice by designing and prototyping alternatives. Their proactive behaviour indicates frustration with existing designs, particularly when considering the monetary investment required for a silver chain or the on-going effort of dying single-use straps. Furthermore, the factors driving individuals to modify their tracheostomies give insight into pain points in the user experience. It is noteworthy that aesthetics, quality, and reusability are all traits of less relevance from a clinical perspective. However, examples like the WARD + ROBES project and Stephanie Monty's colostomy pouch for intimate occasions, demonstrate these factors as important to users, becoming more so for long-term use. This supports the argument that long-term tracheostomy users' needs cannot be met sufficiently by designs based on the hospital context.

PLASTIC VS SILVER

Some participants expressed an almost evangelical preference for silver tracheostomy tubes, while others were fervent about plastic. Preferences were explained by users' values, with different reasons given even by those with the same preference. For example, one participant strongly preferred plastic despite admitting to finding silver more comfortable. This participant valued the discretion offered by see-through plastic over the comfort of silver alternatives. Another participant felt plastic tubes provided better traction to prevent the embarrassment of accidentally coughing secretions onto other people. One participant favoured silver for its perceived quality, while another advocated its functional benefits, citing among them superior hygiene and robustness.

Rather than highlighting either material as superior, this seems to indicate both options have a place. Particularly considering material difference is one of few ways existing designs cater to the aforementioned diversity of tracheostomy users. There may be opportunities to adapt silver tubes to incorporate the benefits of plastic and vice versa. It may also be useful to explore other materials with different properties and benefits.

SELF-ADVOCACY

Several participants described themselves as vocal and unafraid to advocate for themselves. They discussed these traits in relation to their tracheostomies, telling anecdotes about proactively seeking information from clinicians, or defending themselves against discrimination. One participant described his attitude with the phrase:

"I've been in the system long enough to stick up for myself"
-55-year-old female, 24 years with tracheostomy

Another described herself as "very intense and strong" (67-year-old female, 20+ years with tracheostomy).

It was difficult to parse whether participants learned these traits because of their tracheostomies or possessed a pre-existing tendency towards outspokenness. The reality may differ between individuals or be a mixture of both, with the trials of living with tracheostomy amplifying existing personality traits.

Participants also felt self-advocacy was necessary for obtaining tracheostomy products. They had to push to find out about alternative products, with one participant claiming he "had to yell and scream to get anything done" (62-year-old male, 2 years with tracheostomy). Some said they were not supplied with enough consumable products, like disposable neck straps, and had to request more. This suggests current systems for distributing tracheostomy products do not adequately consider users' experiences. This could be particularly problematic for reserved users who are less likely to push for their needs to be met.

INDEPENDENCE

Most participants held independence in high regard, preferring to manage tracheostomy care alone. Even those who felt people close to them were competent and comfortable providing aid preferred to change their tracheostomy tubes and ties without assistance.

“I’ve got a wife and adult son who are very caring, involved, and supportive but I try very hard not to include them in the process”
-60-year-old male, 1 year with tracheostomy

Some experienced physical discomfort when others touched their tracheostomies, but for most, the preference for independence seemed psychological. There was the feeling that tracheostomy had taken control away from them, and managing it independently helped them reassert some of that control.

Unfortunately, some participants suffered from conditions preventing them from managing independently. Two participants relied on hospital visits for tube changes. One elderly participant depended on her daughter for tracheostomy care. The daughter believed this made her mother feel, at times, like a burden. Although some health conditions limit tracheostomy users’ autonomy, improvements to product usability could improve independence in less extreme cases.

COMMUNICATION

One of the greatest sources of tracheostomy users’ distress related to speaking difficulties, particularly in the early stages of living with tracheostomy. One participant was unable to speak for 7 months after receiving a tracheostomy and used a laptop to communicate with clinicians in hospital. Another participant had her bottom jaw removed to treat an underlying condition and is permanently limited in her ability to speak. This participant relied on her daughter to communicate for her. In the early stages of living with tracheostomy, one participant described the difficulties of phone conversations:

“if my Mum phoned I said to my boys ‘tell Nana that I will bang one for yes and two for no but she’s got to ask me questions cause I can’t talk to her”
-67-year-old female, 20+ years with tracheostomy

Even after undergoing speech therapy, users’ quality of speech is not restored to its pre-tracheostomy state. Furthermore, users must place their finger over the front of their tracheostomy to push air through their vocal cords and produce sound. This makes it difficult to speak while performing other activities. Alternatively, speaking valves allow speech without using a finger to cover the hole but some participants disliked the way valves altered their speaking patterns.

STIGMA, SOCIAL LIFE, AND SELF-CONSCIOUSNESS

Participants expressed varying degrees of tracheostomy-related self-consciousness. Those who'd had their tracheostomies over a decade generally claimed they were no longer bothered by staring, or other stigmatising reactions, using phrases like "I've got past it now" (55-year-old female, 24 years with tracheostomy). Even so, most recalled times when they felt the effects of tracheostomy-related stigma. One participant said strangers stared at her out of curiosity if she ate in public. Another claimed tradespeople tried to take advantage of her because of her condition. A participant with a more recent tracheostomy, acknowledged feeling uncomfortable in social situations but believed this was due to his own self-consciousness rather than real judgement from others. Another participant felt her tracheostomy had "stuffed up [her] social life big time" (55-year-old female, 24 years with tracheostomy).

The experiences of participants reflected literature on stigma and demonstrated its effects in the tracheostomy context. This further supports the case made in the literature review that there is value in reducing the stigma through improved tracheostomy design.

INEXPERIENCED DISTRICT NURSES

Many participants whose transition to at-home tracheostomy use involved working with community nursing services felt the district nurses they met with had never encountered a tracheostomy. Some felt district nurses were as uncomfortable changing a tracheostomy tube as they were to begin with. When a community nurse helped one participant with her first at-home tube change, she recalled feeling like it was a case of "the blind leading the blind" (70-year-old female, 14 years with tracheostomy).

Given the uncommon nature of tracheostomy and need for district nurses to have broad-ranging expertise, it is unsurprising that some lacked specialised knowledge about tracheostomy management. It is, however, concerning that tracheostomy users felt they had been left to fend for themselves during an already frightening time.

HOPE

Regardless of how long they had lived with their tracheostomy, each participant expressed lingering hope of having it removed. One participant was even hopeful technological advances would allow voice box transplants so she could have her tracheostomy taken out. This hope is indicative of the negative impact tracheostomy has on participants’ lives and their unwillingness to accept it as a part of themselves.

REFLECTION

HEARING USERS’ STORIES

Listening to interview recordings was my first opportunity to hear tracheostomy users' stories in their own words. Each recording yielded a wealth of insight and helped me empathise with users' experiences. Aside from the information conveyed by participants, I was struck by their desire to contribute to improving the experiences of others like them. The enthusiasm that came across in the recordings showed participants had given a lot of thought to their situations and felt strongly that the problems they encountered ought to be solved.

In some cases, listening to recordings was a weighty experience. It was uncomfortable hearing participants struggle through coughing fits to partake in interviews, as it showed the discomfort some users live with on a daily basis. The way that participants persisted through speaking difficulties and insisted there was nothing to worry about, showed that difficulty and discomfort had become part of their norm. While other participants were long-accustomed to speaking with a tracheostomy, everyone had experienced significant hardships as part of their tracheostomy journey.

Although hearing about participants’ struggles was difficult, understanding them helped me contextualise the value of this project as a means of advocating for users’ needs, making their experiences known, and taking steps towards improving them. The interview recordings were instrumental in grounding the project and reminding me of my accountability to real tracheostomy users.

PHASE 5



74. Dickson, (2016). Selection of ideas from co-design workshop group brainstorm

CO-DESIGN WORKSHOPS

WHAT HAPPENED?

The plan for the workshop sessions was to engage participants in two 30-minute activities relating to tracheostomy design. The first activity had participants contribute to a group brainstorm of ideas for improving tracheostomy products. Once the brainstorm was complete, the plan was to ask each participant to select and discuss three characteristics they believed were most important. The second activity involved asking participants to mix and match prototyped tracheostomy components to create their own designs. They would then explain the factors informing their selection.

In reality, it was difficult to get participants to engage with the brainstorming activity. Instead of writing or verbally sharing ideas, they became distracted with tangential conversations. While these did involve discussion of flaws in existing tracheostomy designs, it was up to me to listen and extract thoughts to frame as ideas for improving designs. Even when prompted to focus on specific components like the strap or front protrusion, participants found it difficult to think of ideas. Overall the result of this activity was that participants engaged with one another in general discussions about tracheostomy experiences, but did not actively contribute to the brainstorm as intended. As a result, it also became difficult to direct them to discuss which brainstormed ideas and characteristics they felt were important.

Difficulties with fostering engagement were also encountered with the mix-and-match activity. Participants were dismissive of concepts shown, quickly listing reasons each would not work. The most vocally negative participants were unwilling to interact with the prototypes at all, deeming them unsatisfactory on sight. They fixated on functional issues and could not think beyond literal forms to imagine how different aspects might be developed into a functional design. While a few participants seemed open to new ideas and interested in interacting with the prototypes, their voices were overpowered by others and they still did not partake in the planned activity. Because participants did not combine prototypes to create their own designs, I was unable to ask them to explain the thoughts and feelings driving their choices. They did, however, identify some prototype components they felt had potential, and I was able to ask them to unpack these preferences to some extent.

WHY DID IT HAPPEN?

A number of factors may have contributed to the disparity between my plan for the co-design activities, and the way that participants engaged with them in practice. The goal of the sessions may have been unclear, the activities may have demanded a type of thinking that was difficult for non-designers, participants may have been disappointed that prototypes did not meet their expectations, long-term users may not have been the ideal participant group for the activities, and the opinions of outspoken group members may have discouraged some participants from sharing their thoughts. Furthermore, my expectations for the outcomes of the workshop may simply have been unrealistic.

LIMITATIONS OF A SINGLE SESSION

Participants may not have fully engaged with co-design activities because they did not have a clear understanding of what they were asked to do. They went into the sessions with little knowledge of the work completed prior to the workshops. This may have shaped their contributions to the brainstorming activity, giving the impression they needed to cover basic tracheostomy product information to ensure I was adequately informed. For the mix-and-match activity, participants could not see the thinking behind the concepts shown. Furthermore, they may not have understood the design process well enough to imagine how radical concepts could be developed into functional designs. Without context, they may have felt understandably frustrated at the idea of a design student dreaming up impractical and uninformed ideas about what they needed. This may have led them to respond defensively and disengage from the activity.

These issues might have been resolved by structuring the co-design component of the research to include more workshops scattered throughout the project. Establishing regular contact may have allowed participants to collaborate with me to shape the project. Participants would have had time to adjust to a design-led approach and I would have had the opportunity to better empathise with, and cater to, their personalities, needs, and desires. Both myself and participants would probably have developed rapport over time and found effective ways of working as a group. Unfortunately, the scope of this project made a more comprehensive co-design process difficult, particularly given the length of time taken to recruit even a small sample and plan one workshop session for each group.

LONG-TERM VS NEW USERS

Through early discussions with the SRIF team, long-term users were selected as the focus of data collection. We believed users with tracheostomies for over three months would be able to discuss their experience of returning to the community with a tracheostomy. New users may end up needing tracheostomy for only a short time, in which case improving the design of tracheostomy products may not greatly benefit them. Furthermore, we thought participation may cause unnecessary stress for people newly adjusting to the challenges of living with tracheostomy.

Working with long-term users in co-design workshops, led me to believe including new users may have added depth to data collected. Long-term users' resistance to new ideas seemed to stem from their history with tracheostomy products. Having struggled to learn to manage existing designs, they seemed opposed to change. Furthermore, they had firmly established notions of what medical products should look like and felt tracheostomy products should remain within this mould. It would have been interesting to see whether new users were more receptive to radical ideas. It would also be useful to compare new users' attitudes towards tracheostomy product aesthetics with those of long-term users.

MANAGING PERSONALITIES

The mixed personalities making up each workshop group also influenced the outcome of co-design activities. Despite the small groups, each session included one particularly outgoing and vocal participant. Outgoing participants led conversations and made leading statements projecting their opinions onto others. As such, data collected represented the stories of these participants more clearly than their quieter counterparts.

Ideally, careful group structuring would have avoided this issue. Grouping participants based on personality may have allowed quieter participants to come out of their shells, while outgoing participants would have held their own among others like them. Unfortunately, scheduling logistics meant groups were dictated by availability rather than purposeful structuring. Another option may have been to work with participants individually, eliminating group dynamics altogether. However, this approach would have been complicated and time consuming to organise, and may have sacrificed some of the rich insights group sessions yielded.



75. Dickson, (2016). Co-design workshop strap options



76. Dickson, (2016). Co-design workshop fabric collar prototypes



77. Dickson, (2016). Co-design workshop tracheostomy tube prototypes

WORKSHOP THEMES

While workshop activities did not pan out as expected, this did not inhibit the richness of data. Interacting with tracheostomy users in person and observing their interactions with one another was an invaluable opportunity to understand their experiences. The richness of workshop data did not come from co-designed artefacts as I had expected. Instead I was able to analyse participants' candid stories and behaviours for themes.

Key themes identified from user interviews were reinforced during co-design workshops. Many of the same stories were shared in the group situation and participants corroborated one another's experiences with stories of their own. Insight was added by the opportunity to observe group dynamics, participants' mannerisms, and responses to design probes. The ways in which activities diverged from my intentions were also a source of learning.

Key workshop findings were categorised under the following themes:

Eagerness to Share

Isolation and Lack of Support

Resistance to Change

Identity

Product Choice

EAGERNESS TO SHARE

From the outset of each workshop session it was clear participants had given a lot of thought to their experiences and were passionate about contributing to improving the experiences of others like them. They were also eager to discuss shared experiences.

The amount of thought one participant had given to his experiences was clear when he mentioned measuring how long he spends on tracheostomy maintenance (roughly two hours) everyday. This participant also came equipped with a list of tracheostomy care products and a range of tracheostomy tubes to discuss. He explained his eagerness to participate with the words:

“this is my opportunity to express my annoyance”
- 60-year-old male, 1 year with tracheostomy

Another participant expressed a similar sentiment, saying, “I’ve been waiting for this for years” (55-year-old female, 24 years with tracheostomy). It was evident that participants harboured numerous frustrations with their experiences and wanted to do something about them. These attitudes validated the importance of the research in giving tracheostomy users a voice.

The stories participants told also demonstrated what the workshops meant to them. They often shared the same thoughts and anecdotes they had during interviews. This was understandable, given for many this was their first chance to share with people who could relate. Sharing with other participants seemed to be cathartic, especially in light of the isolation many experienced because of their tracheostomies.

ISOLATION AND LACK OF SUPPORT

Several participants remembered feeling isolated while adapting to their tracheostomies. They felt others couldn’t understand what they were going through and support from clinicians was inadequate for easing the transition. Isolation was also connected to themes identified during interviews. Interactions with inexperienced district nurses, communication difficulties, and self-consciousness of their acquired visible difference contributed to participants feeling isolated and unsupported. These feelings also drove participants to improvise tracheostomy care, and become self-advocates.

One cause for participants feeling isolated was the rarity of long-term tracheostomy. Participants had little knowledge about tracheostomy prior to their treatment and none had met others like them before participating in the workshops. One participant thought meeting another long-term user would have been invaluable in the early days of her own experience:

“I wanted to meet someone who already had one... who could show me ways of washing my hair and all that sort of stuff. But no, there wasn’t anyone at that time available”
- 55-year-old female, 24 years with tracheostomy

In the absence of support from—or knowledge of—other tracheostomy users, participants felt alone; a feeling compounded rather than alleviated by interactions with clinicians and healthcare systems.

Participants believed their needs were neglected in comparison to more common conditions. Several said hospitals and district nurses seldom keep adequate stock of tracheostomy products. Some had even been encouraged by clinicians to wash and reuse single-use, disposable neck straps, which

fall apart when wet. In some cases, participants had to purchase items like nebulisers or saline solution themselves. One participant was frustrated, saying:

“I know it’s not as common as a lot of other things, but we’re entitled to be funded for different things as well”
- 55-year-old female, 24 years with tracheostomy

Lack of support was also attributed to the fact their conditions were no longer acute. One participant compared the support she received to that offered to people with other conditions; “they have a lot of support; we have none at all.” This participant was indignant that her experiences were not given due consideration, complaining clinicians don’t “really know what it’s like to have a tracheostomy... unless you’ve been there, you don’t know” (55-year-old female, 24 years with tracheostomy).

RESISTANCE TO CHANGE

While participants identified aspects of tracheostomy care that were initially difficult, they seemed to feel the resulting struggles were negated by the competence and confidence they had since attained at managing these aspects. They used phrases like “you get used to it” (67-year-old female, 20+ years with tracheostomy), and “we’re here, alive, and capable” (60-year-old male, 1 year with tracheostomy), to explain the belief that improving tracheostomy product design would not improve their experiences. These attitudes were surprising given the passionate dissatisfaction many expressed with the treatment they had received and the products available to them.

When discussing existing designs, participants identified aspects they were unhappy with, but when presented with tangible prototypes they seemed resistant to change and said things like:

“I’d rather it just look like a trachy”
- 55-year-old female, 24 years with tracheostomy

Even when asked direct questions about whether they would like a smaller front plate or easier way to adjust the strap, they responded by pointing out the front plate needed to be that big for the straps to be attached, and they no longer had trouble adjusting the strap. This was somewhat surprising given they had previously expressed a general sense of dissatisfaction with their tracheostomy products. A possible explanation for resistance to change

was captured in one participant’s response to a question about whether she would like different designs for different occasions:

“It’s too late for me now... but if I could have had a designer one when I first got my trachy it would have been great”
- 55-year-old female, 24 years with tracheostomy

Having worn a tracheostomy tube for multiple decades, (aside from incremental improvements) this participant didn’t want a design she was unfamiliar with. Other participants possessed similar attitudes, indicating long-term tracheostomy use had cemented their conceptions of what a tracheostomy tube is and should be. This led me to conclude that establishing a new norm for tracheostomy design may require targeting new users, free of preconceptions and open to the benefits of a different approach.

IDENTITY

Participants were afraid of being defined by their tracheostomies rather than their personalities. For several participants this led to a counterintuitive desire for their tracheostomy to look ‘like a tracheostomy’ rather than being disguised. One participant worried a tracheostomy tube that looked like jewellery would draw attention, followed by shock or disgust when people realised what it was. Another participant was adamant tracheostomy products needed to reflect their medical function. Preferences for obviously medical aesthetics might be explained by reluctance to accept tracheostomy products as part of the extended-self. Perhaps participants felt as long as the medical function of their tracheostomy tube was visibly evident, it would maintain its role as an object imposed by necessity rather than a willing expression of identity.

Despite participants’ fears, their stories showed being tracheostomised had altered their lives and inevitably shaped their identities. As previously mentioned, participants began workshops by embarking on unprompted, enthusiastic retellings of tracheostomy-related stories and jokes they had shared during their interviews. They even used the same phrasing and punch lines. During her interview and co-design workshop, one participant joked:

“It would be nice if they did do vocal chord transplants, I’d have Michael Jackson’s”
- 55-year-old female, 24 years with tracheostomy

The sense given was that tracheostomy stories were part of participants’ life narratives and they were excited to share them with fellow tracheostomy users. Several participants’ experiences were inextricably linked to formative events like unexpected family deaths occurring around the same time,

and relationship struggles brought about by the challenges of living with tracheostomy.

The significance of these stories to participants’ lives may also explain their preference for medical-looking designs. Tracheostomy tubes may have become symbols of the adversities overcome while learning to live with them. Participants may see their tracheostomies as ‘badges of honour’ and associate the appearance of existing designs with this idea.

The nature of tracheostomy in shaping users’ speech also impacted my perceptions of their identities. Using a speaking valve gave one participant measured and commanding diction punctuated by deep breaths, giving the impression of thoughtfulness. By contrast, participants who covered their tracheostomies with their fingers to speak were fluid and nimble in conversation. One participant’s tracheostomy became part of the way she communicated. The guttural sounds of her tracheostomy were integrated into her exaggerated laughter and body language. I came to perceive this as an endearing and vibrant part of her personality.

PRODUCT CHOICE

Participants’ discussions about tracheostomy product choice were contradictory but yielded valuable insights. They were dissatisfied with lack of choice, but believed a ‘good’ design would remove the need for choice altogether. Their beliefs did not reflect the diverse personalities, needs, and preferences they described during interviews and co-design sessions.

While my research showed tracheostomy users lack choice, one participant disagreed. Although having a tracheostomy was not a choice, he felt he had “a lot of choice around how to maintain and use it to best effect” (60-year-old male, 1 year with tracheostomy). This was the same participant who believed there should be one ‘best practice’ approach to tracheostomy care. He also referenced having choices available to him in tracheostomy accessories. Again, this was surprising given he had resorted to modifying his own tracheostomy with a silver chain.

One participant desired more product choice, saying:

“You should have a choice. I mean they make prosthetic limbs to match a person’s skin colour or the size, and we just get given whatever”

- 55-year-old female, 24 years with tracheostomy

Her statement reflected feelings of injustice at inadequate choice and awareness that customisation is feasible in other medical contexts. At another point in the workshop, she shared a contradictory belief that

tracheostomy design should be improved by providing one solution to meet everyone’s needs:

“if they make a good choice, people won’t need to choose”
- 55-year-old female, 24 years with tracheostomy

While contradictions made unpacking participants’ attitudes difficult, inconsistencies might be explained by the limited consideration currently given to their needs. Perhaps participants don’t believe product choice is feasible because they are used to receiving inadequate support. This idea is supported by comments like:

“I think practically, and because of the cost implications, you’ll probably need to have a lot less choice. I think the concern is that it needs to be cheap”
-60-year-old male, 1 year with tracheostomy

Participants may be cautious of asking too much because they know healthcare product design is driven by cost (Barber, 1996). They may have learnt to hedge their bets and fight only for attainable improvements.

REFLECTION

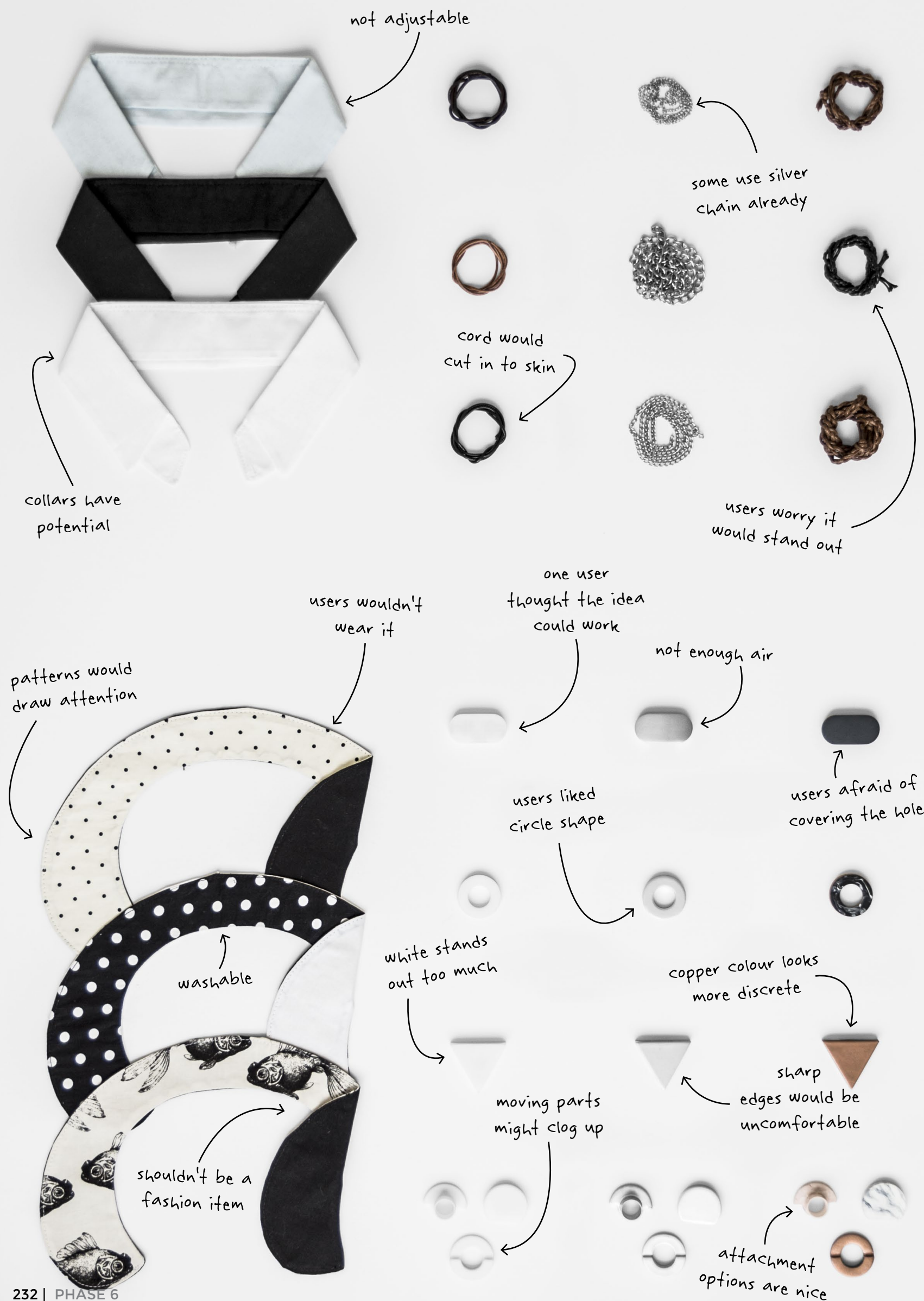
CO-DESIGN VS CHALLENGING THE STATUS QUO

Following the co-design workshops, I found myself in the uncomfortable position of disagreeing with participants’ ideas for improving tracheostomy design. Although my research led me to advocate introducing aesthetic and emotional concerns to tracheostomy design, workshop data opposed this direction. Even so, I felt an aesthetically considered approach was validated by my research and could be valuable for challenging the status quo. My conversations with participants left me questioning the validity of my opinions and feeling I had to choose between following my design instincts and doing co-design well.

Having consulted tracheostomy users to involve them in the design process and ensure their needs were addressed, continuing down the path I was on seemed to risk devaluing their opinions and going against the tenets of HCD and co-design. At the same time, I felt following users’ recommendations would result in an incremental design, perpetuating rather than challenging the problems with existing designs. For example, maintaining a medical aesthetic would negate findings that long-term users’ needs are not met by designs tailored to the hospital context. While participants advocated for meeting everyone’s needs through a single design, I felt the lack of variation in existing designs proved this approach inadequate. Furthermore, the contradictions permeating participants’ discussions would make it impossible to reach a unified solution by following their requests. During my analysis of the workshop data I found speculative explanations for participants’ contradictory and change-resistant attitudes, but was conflicted about whether I was simply fishing for ways to rationalise my own biases.

Talking to my supervisors and the SRIF team helped me resolve these conflicts and find confidence progressing with the project. I came to understand doing co-design well did not mean sacrificing my agency as a designer or following participants' requests to the letter. Rather it meant including participants in the process, listening to their voices, and using my expertise to develop an appropriate course of action (Sanders & Stappers, 2008). I retained some concern tracheostomy users might feel I had not listened and was arrogantly prescribing a design they disagreed with by pursuing an aesthetically considered approach. I sought to manage this concern by making my biases transparent in the research and presenting my designs as potential options, not prescribed solutions. I also tried to find ways of capturing participants' stories without following their recommendations literally.

PHASE 6

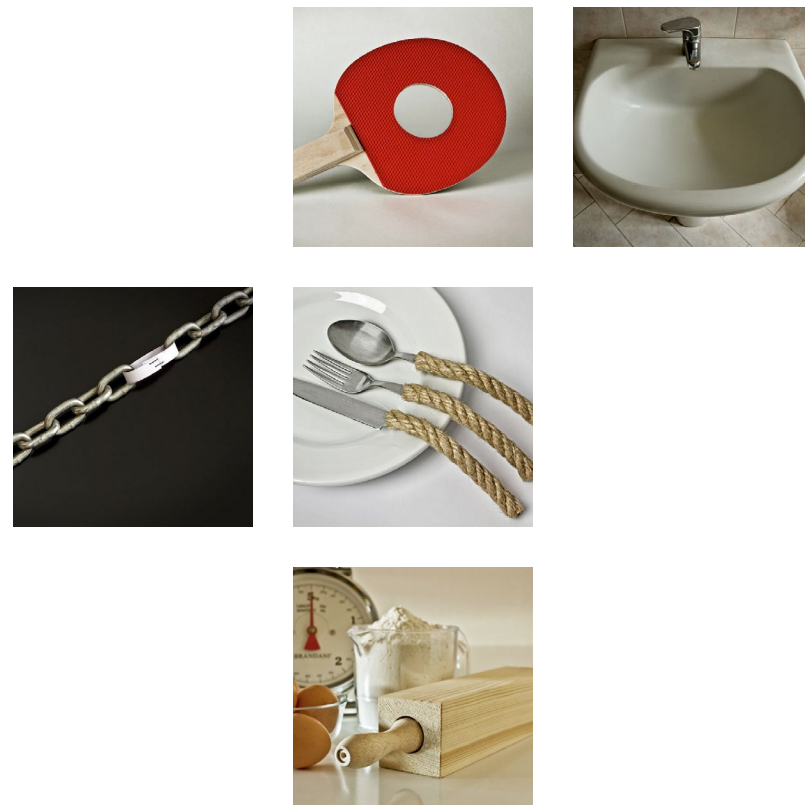


UNPACKING WORKSHOP FEEDBACK

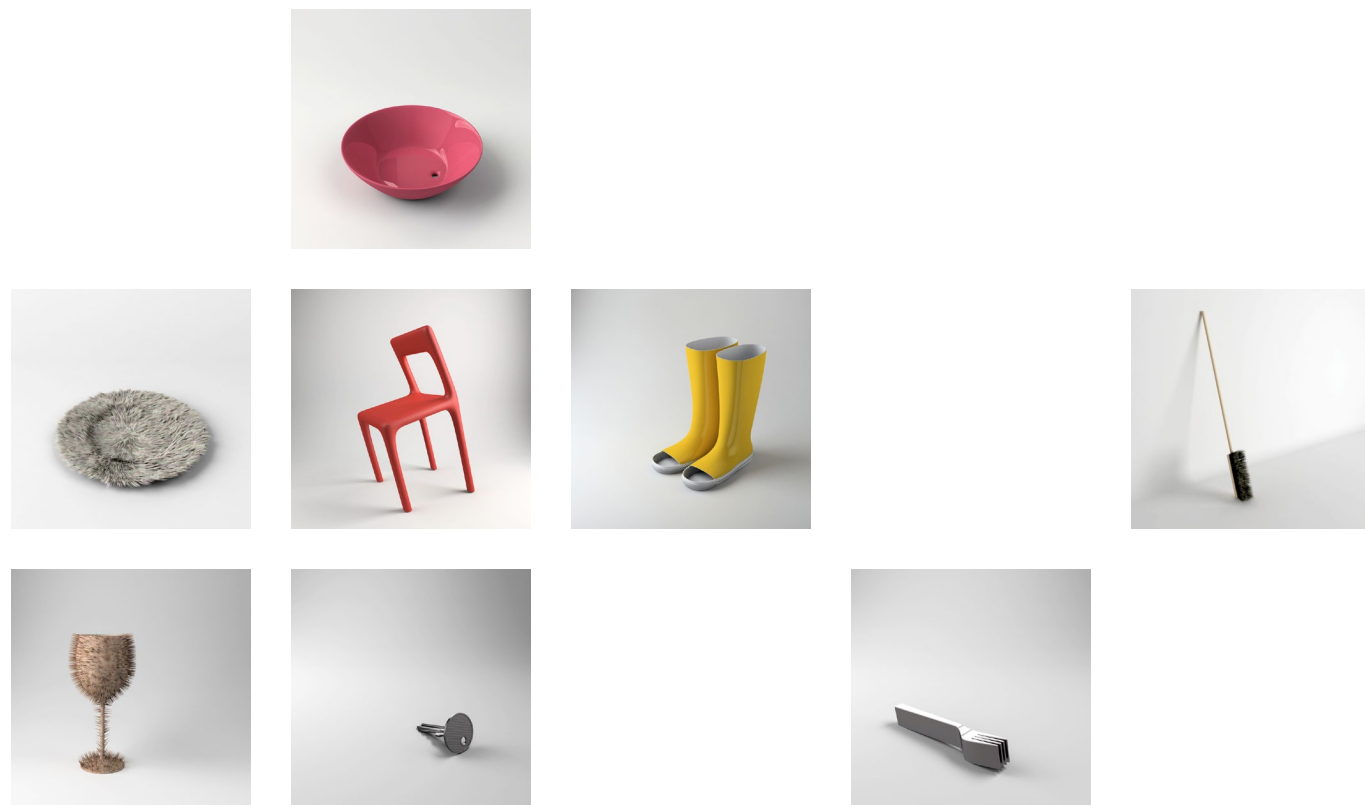
While the mix-and-match activity did not go to plan, participants' responses to prototypes provided insight into the practical reasons they disliked some ideas. Aspects receiving positive feedback indicated potential for development. When isolated from participants' descriptions of their desires for tracheostomy designs, their feedback contained points that could be used to develop radical, aesthetically driven designs. In this sense, prototypes fulfilled their role as generative probes, stimulating discussion and bringing new information to light.

Participants worried a cord strap would cut into skin but were comfortable with the chain, since some had replaced their own straps with silver chain. They were put off by patterned peter pan collars but not averse to plain shirt collars. They responded positively to circular front pieces with reduced surface area, favouring simplicity and discretion. They felt angular shapes would be uncomfortable, and liked the idea of making the protrusion optional, but were cautious of moving parts that might clog with secretions and be difficult to clean.

I presented two concepts for covering the front surface of the hole and redirecting airflow out the bottom. My assumption behind these ideas was that users would be self-conscious of other people noticing the hole in their neck. Although participants mentioned this concern, it was outweighed by the fear that covering the hole would risk blocking the airway, with one participant stating "I can't think of anything worse" (55-year-old female, 24 years with tracheostomy). This exchange demonstrated the importance of consulting users about their needs and interrogating the assumptions behind design concepts.



79. Colarusso, (2013). *Improbabilia*



80. Kamprani, (2014). *The uncomfortable*

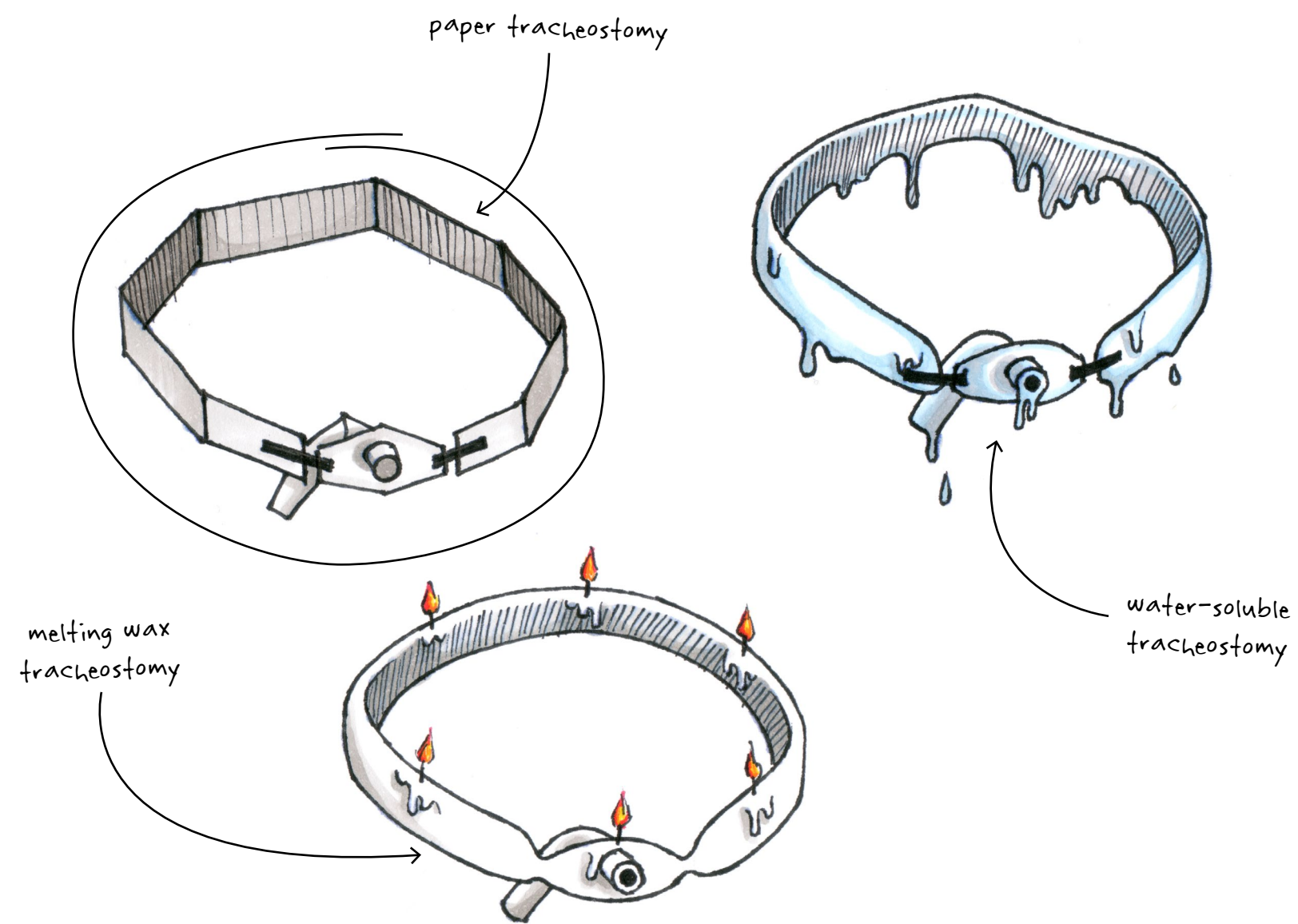
CRITICAL DESIGN

UNLIKELY AND UNCOMFORTABLE OBJECTS

Before progressing with the main tracheostomy design, I wanted to find a creative way of capturing participants' experiences. To do this, I revisited the critical design approach I first considered in my map of possible project directions (Boer, Donovan, & Buur, 2013; Koskinen et al., 2011; Malpass, 2015; Mazé & Redström, 2009). I was inspired by the works of photographer Giuseppe Colarusso and designer Katerina Kamprani to produce concepts pointing out the absurdity of the problems users encounter with existing tracheostomy products.

Both artists produce images of familiar objects with minor alterations that undermine their functionality, rendering them absurd (Jobson, 2013; Maddux, 2014). The images convey humour while asking viewers to consider why everyday objects are designed the way they are. When you think about it, it's obvious a rolling pin's function depends on its roundness, and a cereal bowl with a hole in the bottom would leak milk. For the most part, however, we don't think about it.

Although most people are unfamiliar with tracheostomy products, their medical aura provokes the assumption they are carefully designed for specialised function. Interviews and workshops with tracheostomy users, however, revealed overlooked flaws with existing designs. For example, tracheostomy straps draw unwanted attention, stain easily, and fall apart when wet. Taking cues from Kamprani and Colarusso, I aimed to point out these flaws through a series of prototypes making simple alterations to existing design solutions. I hoped this approach would make aspects of what it's like to live with long-term tracheostomy visible.



81. Dickson, (2016). Sketched concepts representing the idea that existing tracheostomy straps disintegrate with use



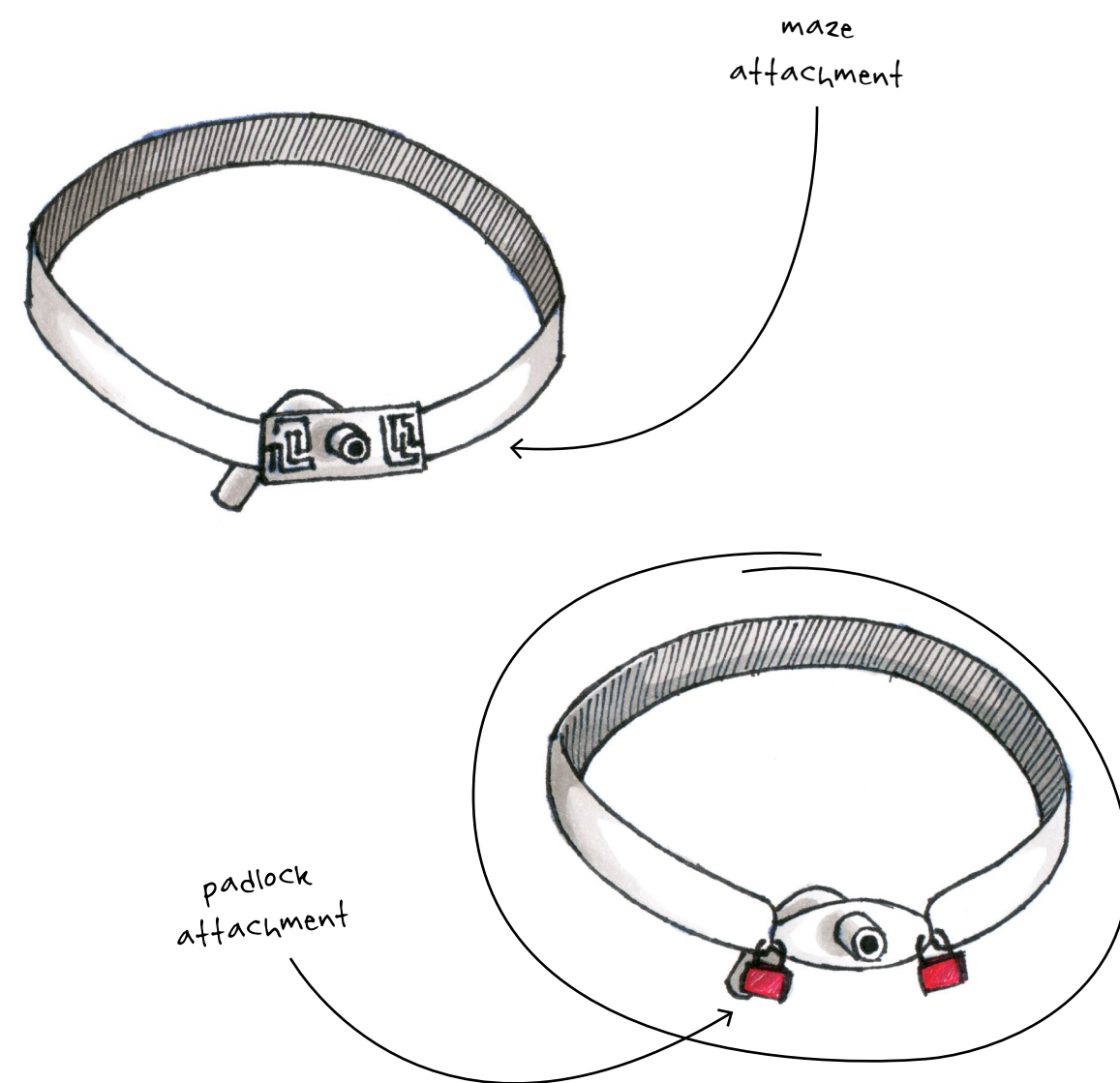
82. Dickson, (2016). Paper tracheostomy strap conveying the problem of existing straps disintegrating with use

This prototype is inspired by the following user quote:

"If they made decent ones we wouldn't need to replace them. We can't wash them, they fall to pieces and stick to everything else in the washing machine."

- 55-year-old female, 24 years with tracheostomy

The use of paper helps observers empathise with this quote by creating a visual analogy to the familiar experience of accidentally putting paper through the wash. While few people know what it's like to live with a tracheostomy, most people have opened the washing machine to find bits of soggy paper clinging to all their clothes and a ruined scrap forgotten in a coat pocket.



83. Dickson, (2016). Sketched concepts representing the idea that existing tracheostomy straps are difficult to attach

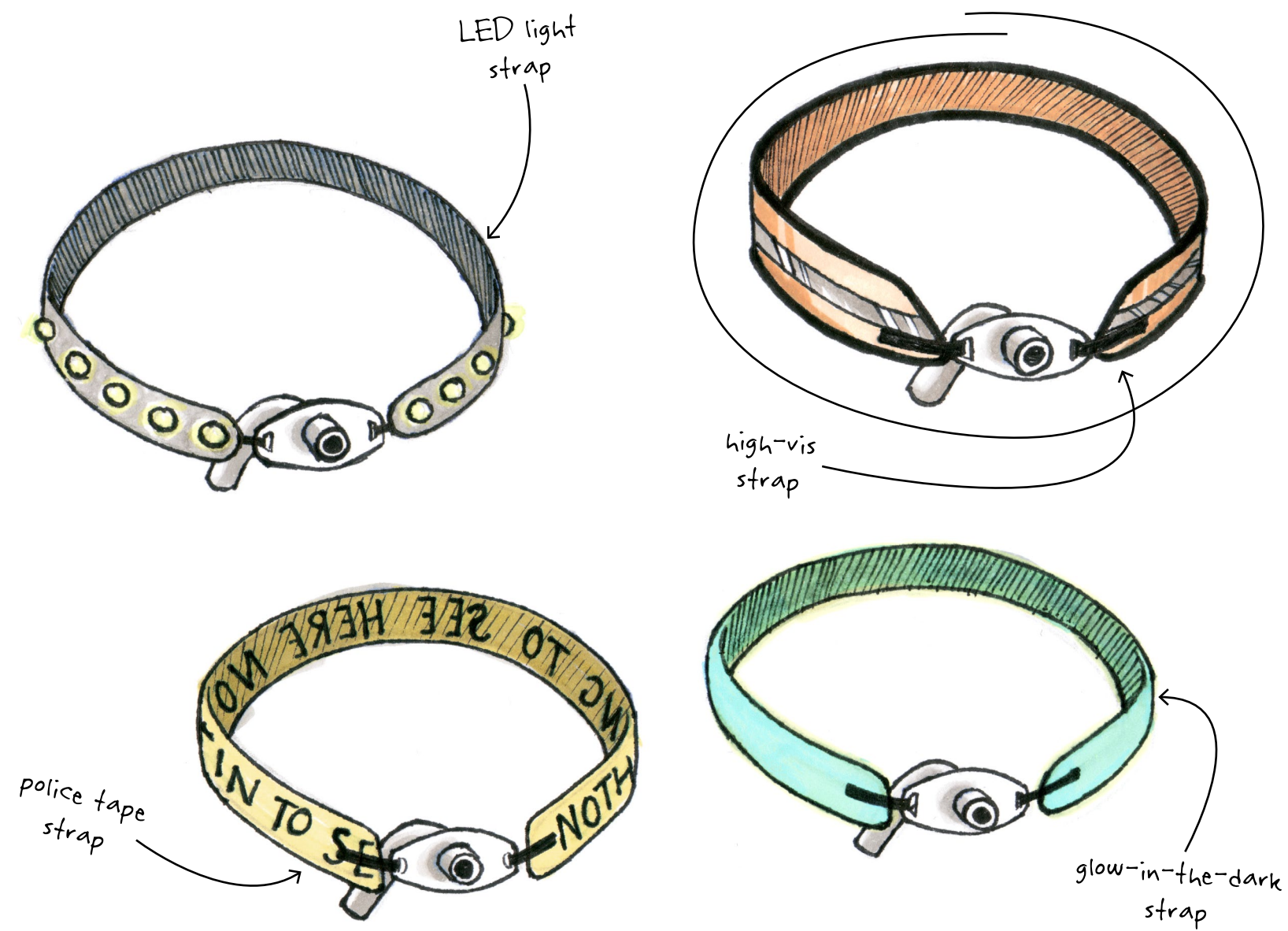


84. Dickson, (2016). Padlocked tracheostomy strap conveying the difficulty of fastening existing straps to the tracheostomy tube
This prototype is inspired by the following user quote:

"If you're doing it yourself, you've got to find the end and if you've got sight issues, it's quite hard."

- 60-year-old male, 1 year with tracheostomy

While the velcro fastenings on existing tracheostomy straps seem simple to use, in practice it can be difficult to thread the velcro through the holes in the tracheostomy tube, especially on one's own neck. The challenge is even greater for users with arthritis or impaired vision. The use of padlocks makes the idea that tracheostomy tubes are difficult to attach immediately visible.



85. Dickson, (2016). Sketched concepts representing the idea that existing tracheostomy tubes draw unwanted attention

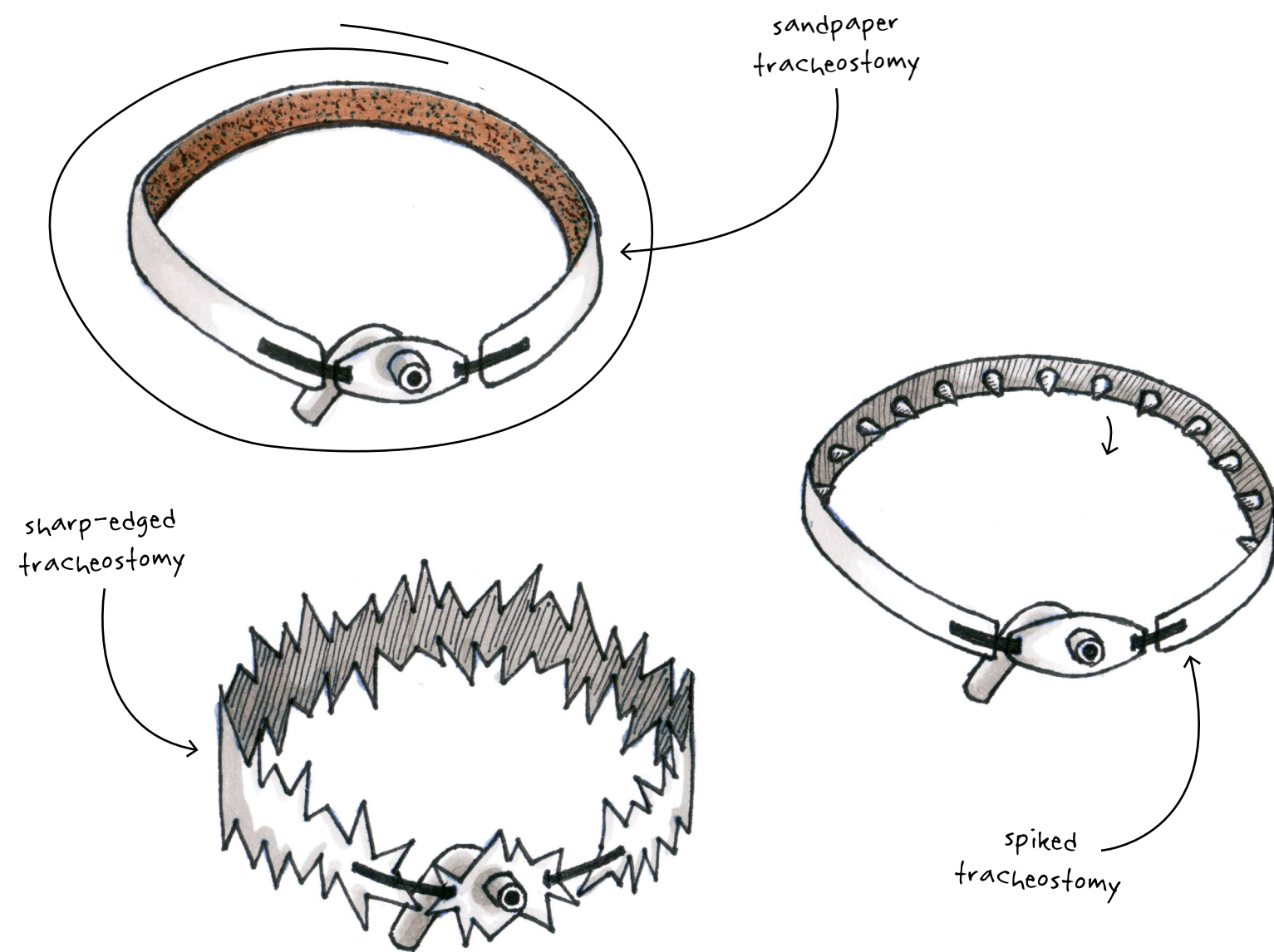


86. Dickson, (2016). Hi-visibility strap conveying the idea that tracheostomy tubes draw unwanted attention
This prototype is inspired by the following user quote:

"It sticks out like a sore toe."

- 55-year-old female, 24 years with tracheostomy

It uses the visual and material language of a hi-vis vest to emphasise the idea that tracheostomy tubes draw stigmatising reactions and unwanted attention. It aims to help observers imagine how it would feel to wear something that makes them feel like everyone is staring.



87. Dickson, (2016). Sketched concepts representing the idea that existing tracheostomy tubes are uncomfortable to wear



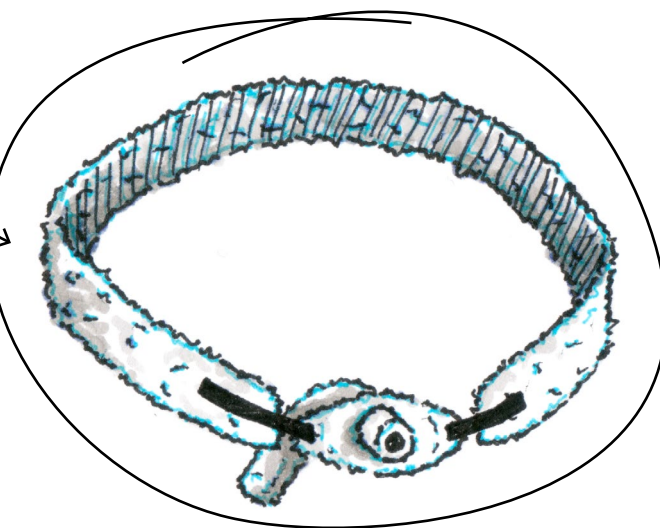
88. Dickson, (2016). Sandpaper tracheostomy strap conveying the idea that tracheostomy tubes are uncomfortable to wear
This prototype is inspired by the following user quote:

"You know when your bra strap is too tight and you get those dents? That's what happened."

- 55-year-old female, 24 years with tracheostomy

The discomfort of wearing a tracheostomy tube is particularly invisible to observers as it is difficult to imagine the physical sensation of a foreign body sitting inside your trachea, or the irritation of the strap and front piece rubbing against your neck. Existing straps may look soft and comfortable, however their constant presence combined with sweat and mucus secretions can cause significant discomfort. This prototype uses coarse sandpaper to prompt observers to imagine tracheostomy users' discomfort.

furry
tracheostomy



89. Dickson, (2016). Sketched concepts representing the idea that existing tracheostomy tubes are difficult to clean



90. Dickson, (2016). Furry tracheostomy strap conveying the idea that tracheostomy tubes are difficult to clean

This prototype is inspired by the following user quote:

"Any tracheostomy has difficult places to clean."

- 60-year-old male, 1 year with tracheostomy

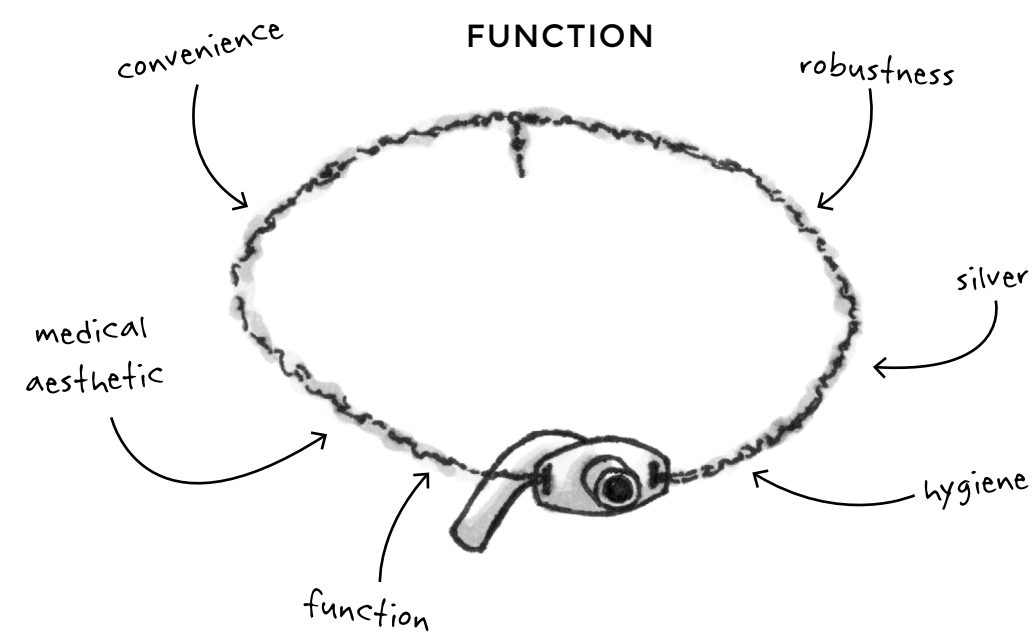
A layperson looking at a tracheostomy tube may not be aware of how difficult they can be to clean. Crevices in plastic or metal components can build up with mucus secretions, and fabric straps quickly become soiled with sweat, make-up residue, and secretions. This prototype uses a strap made from white faux fur, smudged with graphite to capture this aspect of tracheostomy users' experiences.

PERSONAS

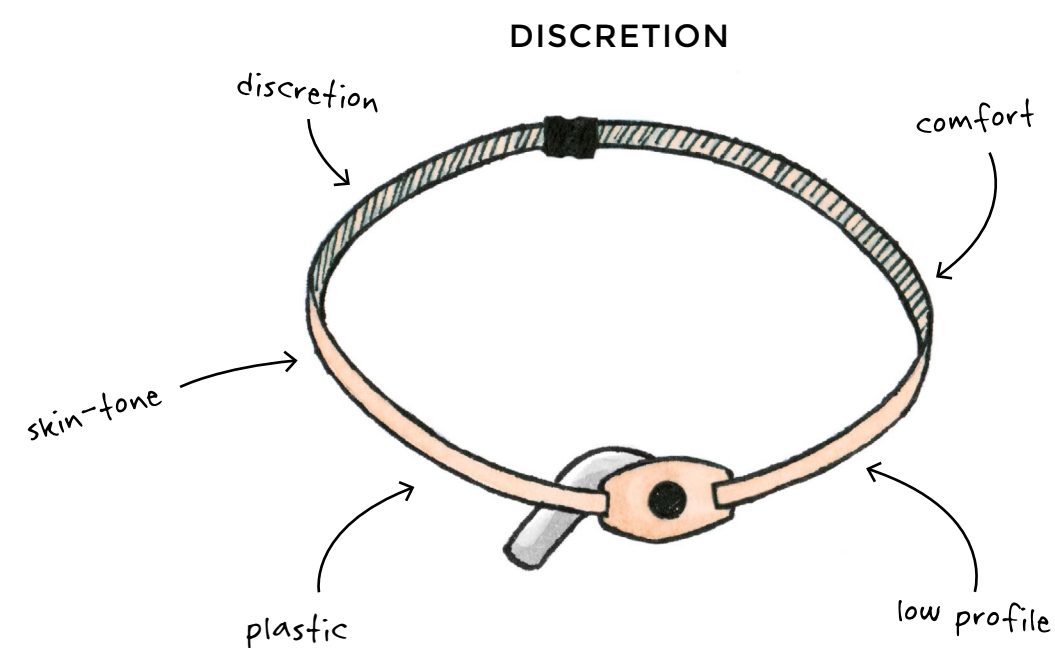
CHOOSING A DIRECTION

To decide how to progress from co-design workshops, I generated personas loosely based on participants' tracheostomy design attitudes, writing briefs for design approaches based on each (Adlin & Pruitt, 2006; Maguire, 2001). I derived design criteria from participant discussions and group brainstorm. I used criteria to draft sketches demonstrating the possible outcomes of each direction.

Because participants' opinions about tracheostomy design were contradictory, I felt it would be difficult to combine them into a cohesive design. By visualising the likely outcomes of each direction, I hoped to identify which approaches might lead to the strongest design solutions. Having already identified a need to challenge the status quo, I wanted to choose the direction best fitting this goal.



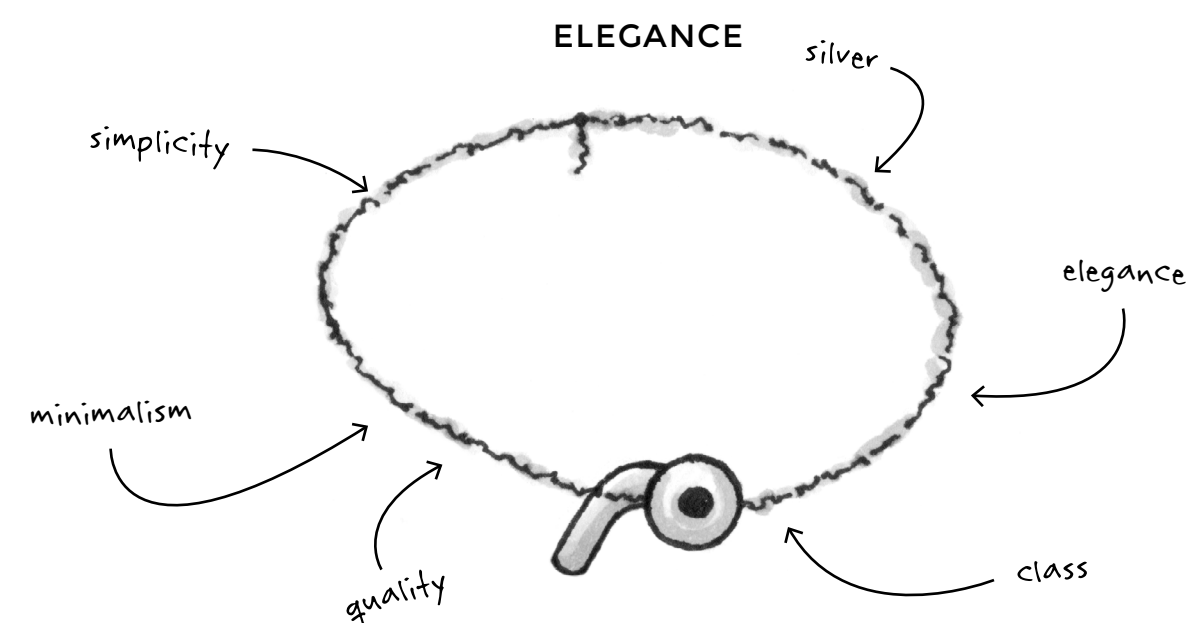
91. Dickson, (2016). Sketch representing potential design outcome based on function-driven persona



92. Dickson, (2016). Sketch representing potential design outcome based on persona favouring discretion

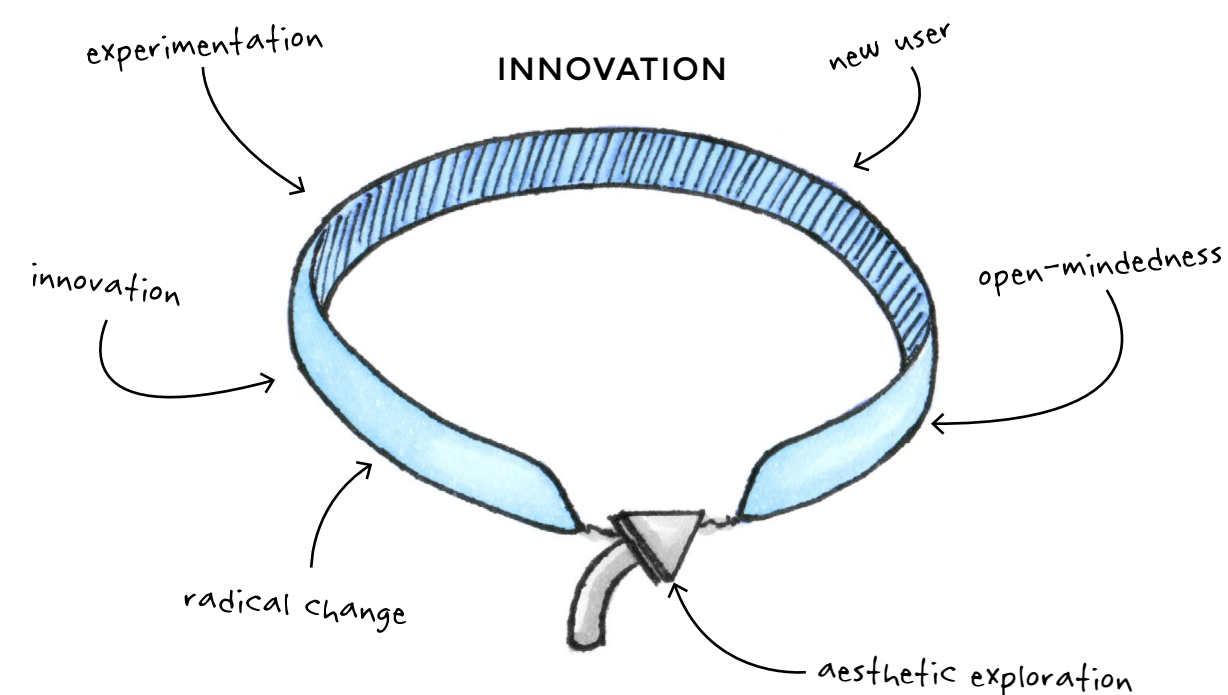
PERSONA CONCEPT SKETCHES

Sketches focusing on function and discretion looked similar to the modified tracheostomies participants already wore. While users should not have to modify products to suit their needs, I felt that replicating user modifications would not disrupt the stagnation of tracheostomy design. Furthermore, developments like changing the strap to a silver chain or matching it to users' skin did not seem adequate outcomes for a year-long research project. I decided to retain some criteria from each of these designs (robustness, hygiene, comfort, and discretion) and incorporate them into a more radical approach.



93. Dickson, (2016). Sketch representing potential design outcome based on persona seeking elegance

The sketch exploring elegance remained close to existing tracheostomy designs but with a minimalistic approach and freedom to explore form. In focusing on quality and simplicity, it achieved some of the same benefits as sketches looking at function and discretion. It demonstrated that quality materials could provide durability, and minimalist shapes could keep designs discreet, low profile, and easy to clean. To me, this sketch represented a feasible approach to reframing conceptions about appropriate aesthetics for medical products without compromising function and usability.



94. Dickson, (2016). Sketch representing potential design outcome based on persona valuing innovation

Based on a 'new user' persona, the sketch exploring innovation varied most from existing designs. During the workshops, a participant who'd had a tracheostomy for less than a year was open to concepts disguising the hole, and allowing different straps for different situations. While the sketch is not necessarily a good design, it demonstrates the flexibility for radical thinking afforded by an open-minded approach.

I felt combining ideas from these two approaches would provide a suitable path for introducing aesthetic and emotional considerations to tracheostomy design, while maintaining essential functions and improving usability.

REFLECTION

DEFINING A DESIGN DIRECTION

The activities completed during this research phase helped me unpack the overwhelming information uncovered through user interviews and co-design workshops. They allowed me to make decisions about which data to focus on when developing my design proposal.

Using critical design prototypes to capture some of the experiences tracheostomy users described relieved the pressure I initially felt to produce a design that would solve all of the problems with existing tracheostomy products. Because these prototypes served my goals of capturing users’ experiences and advocating for their needs, completing them gave me the freedom to focus the efforts of my final design on challenging the status quo. I also felt, in making tracheostomy users’ experiences tangible, these prototypes could serve as interesting companion pieces to contextualise the final design (Boer et al., 2013; Koskinen et al., 2011; Malpass, 2015; Mazé & Redström, 2009).

Developing personas based on the main attitudes of research participants also helped me consider how best to feed co-design and user interview data into my final design approach (Adlin & Pruitt, 2006; Maguire, 2001). Producing sketches to project the kind of outcomes I might expect from approaches based on each persona allowed me to quickly identify which approaches would help me answer my research question.

Having completed these tasks, I felt comfortable crafting a design brief that would incorporate my research findings and shape a design that would meet the project objectives.

PHASE 7

REFINED DESIGN BRIEF

After unpacking co-design workshop data and completing prototypes to communicate what it’s like to wear a tracheostomy, I was ready define my focus for the final tracheostomy design. Having acknowledged and represented users’ feelings, I felt able to set aside some of the ideas that might prevent me from meaningfully challenging existing approaches to tracheostomy design. I devised the following design brief using criteria grounded in findings from various research stages. I tried to incorporate users’ feedback by including a concern for usability and maintenance, but allowed myself freedom to explore aesthetic possibilities by considering how tracheostomy tube aesthetics might impact newer users. To keep my aesthetic choices from veering too far from what participants were comfortable with, I placed the focus on achieving elegance and minimalism.

PURPOSE

- Facillitate breathing
- Allow verbal communication
- Complement the body and users' self-image

PERFORMANCE

- Integrate with users' lifestyles
- Be adjustable to fit comfortably and securely
- Easy to attach, remove, and clean components

FEATURES

- Low profile design with optional attachments for different needs
- Choice of strap design
- Precious stone accents

AESTHETICS

- Jewellery-inspired
- Made primarily from silver
- Minimalist, geometric forms
- Clean lines

PERCEIVED QUALITY

- Befitting of premium bespoke jewellery
- Intrinsically valuable materials
- Refined details and finishing

RELIABILITY

- Last for at least 10 and ideally 30 years
- Components showing wear and tear should be replaceable

PACKAGING

- Befitting bespoke jewellery
- Treat tracheostomy care rituals with reverence
- Include carry pouch for emergency tracheostomy kit
- Provide a station for storing tracheostomy products at home

COST

- Ideally less than \$1500 for one tracheostomy

JEWELLERY

To guide me in developing the jewellery-inspired aesthetic outlined in my design brief, I undertook research into traditional and contemporary jewellery. By building a foundational understanding of the background of jewellery, I hoped to find inspiration for applying jewellery design principles to the tracheostomy product context.

OVERVIEW

The concept of jewellery as self-adornment has been present among humans since prehistoric times, and has since remained culturally and historically ubiquitous (Gregorietti, 1979; Seven Thousand years of Jewellery, 1989). Where the value of crafts like hand weaving and pottery has diminished over time, jewellery has retained its value as decoration, status symbol, amulet, and heirloom (Cohn, 2012).

Perhaps the staying power of jewellery is, in part, due to its intimate relationship with the human body. Its contact with the skin makes it a more direct extension of the self than most products (Cohn, 2012). This close bodily relationship is something shared between jewellery and tracheostomy, however the medical necessity of the latter creates a stark contrast between the ways that each is designed and perceived. Applying the material language and emotionally driven approach of jewellery design to tracheostomy products would be a radical shift in thinking that might help people integrate tracheostomy with their identity and accept it as part of their extended selves.

PRECIOUS MATERIALS AND INTRINSIC VALUE

One hallmark of traditional jewellery is the use of precious materials. Combined with intricate designs requiring skilled craft, precious materials lend jewellery intrinsic value making it a symbol of wealth and social standing (Cohn, 2012; Gregoriotti, 1979; Ogden, 2009). The existence of silver tracheostomy tubes, however, proves precious materials alone do not produce positive product meanings or alleviate social stigma. While positive meanings associated with silver are currently overpowered by the negative associations of illness and disability carried by tracheostomy products, this may be overcome by thoughtful alignment with other aspects of jewellery design. For example, introducing other precious materials and construction techniques that bring artistry to the functional benefits of silver and applying jewellery's compositional considerations to the design of tracheostomy tubes could instil them with positive social symbolism.

CONTEMPORARY JEWELLERY

Compared to traditional jewellery, contemporary jewellery occupies a more challenging position, skirting the line between art and design, and frequently adopts a critical stance. It retains a focus on the body, but explores broader object-body relationships. The critical approach of contemporary jewellery makes it suitable inspiration for challenging the status quo of tracheostomy design (Cohn, 2012; Contemporary jewelry in perspective, 2013).



INTERACTION WITH THE BODY

Traditional jewellery usually fits into a few categories based on the area of the body that it adorns; rings for fingers, earrings dangle from ear lobes, bracelets encircle wrists, and necklaces adorn necks (Contemporary jewelry in perspective, 2013). Contemporary jewellery extends these boundaries to include objects with a near unlimited range of relationships with the body (Cohn, 2012).

While tracheostomy tubes are not classed as jewellery, their relationship with the body does not deviate significantly from the categories of traditional jewellery. The strap that circles the neck could be described as a necklace with the protruding portions of the tube forming a pendant. The tube itself pierces the body in a way similar to earrings or other piercings. The main difference is that tracheostomy tubes have a distinct functional role, where jewellery is seldom utilitarian. In any case, contemporary jewellery, with its broad scope, certainly provides a valid lens through which to explore tracheostomy design.

95. Diadem, Jaesun Won; 96. Folds Backpiece, Abigail Brown; 97. Ramus, Jaesun Won; 98. Pain, Sooyeon Kim; 99. Gestures I, Leonor Hipolito; 100. Sixth Finger, Gerd Rothmann; 101. Ear Frames, Leonor Hipolito; 102. Ornamental Hand, Jennifer Crupi; 103. Nostril, Gerd Rothmann; 104. Pain, Sooyeon Kim; 105. IO, Katerina Reich; 106. Achilles' Heel, Gerd Rothmann



107. Gaia, Leonor Hipolito; 108. Beyond Emotions, Leonor Hipolito; 109. Thinking of You, Benjamin Lignel; 110. Necklace Inter-Act, Katja Prins; 111. Necklace Inter-Act, Katja Prins; 112. Necklace Hybrid, Katja Prins; 113. Brooch Anatorium, Katja Prins; 114. Brooch Hybrid, Katja Prins; 115. Splendour of Wearability, Leonor Hipolito; 116. Brooch Continuum, Katja Prins; 117. Tools for the Subconscious, Leonor Hipolito; 118. Gaia, Leonor Hipolito; 119. Wrinkles, Noa Zilberman; 120. Wrinkles, Noa Zilberman.

REFERENCING MEDICAL PRODUCTS AND THE BODY

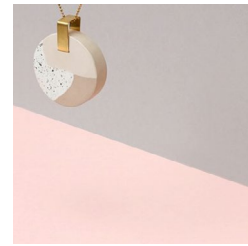
Contemporary jewellery's concern for object-body relationships makes medical products, particularly implants, a suitable subject for exploration. Contemporary jewellery designers often reference medical products and body parts in their work.

Katja Prins, in particular, engages with ideas about the body's relationship with medical products. She uses materials associated with medical contexts including recycled medical device fragments and red sealing wax that conjures the image of blood (Schrijver, 2014). The abstract organic forms she creates from silicone allude to real body parts and artificial prostheses. Prins' work is concerned with how technology and medical products manipulate the body and become part of the extended self. Essentially it presents a speculative proposition that the body is "the sum of its parts; organic and mechanical" (Ilse-Neuman, 2003).

Prins' work shows that a 'medical' aesthetic can be beautiful if materiality and composition are carefully considered. While designs evoking blood and internal organs may not be appropriate to tracheostomy, contemporary jewellery's exploration of medical products as bodily extensions is a useful framework for jewellery-inspired tracheostomy design.



contrast precious
metal with
natural stone



mix neutral
colours and
textures for
subtle refinement

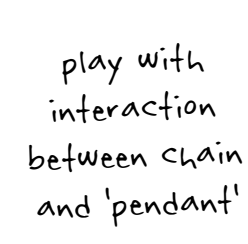
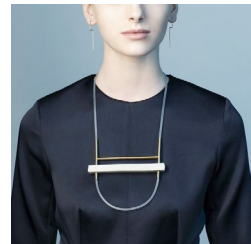
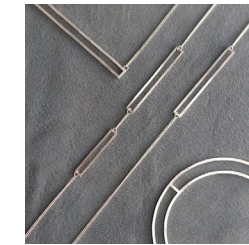
can create
preciousness
with unexpected
materials through
careful design



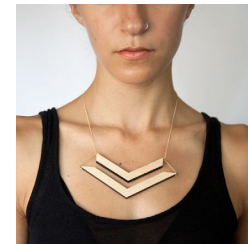
simple geometry
as the basis for
effective designs



balance of
positive and
negative space



play with
interaction
between chain
and 'pendant'



circle based
compositions suit
tracheostomy



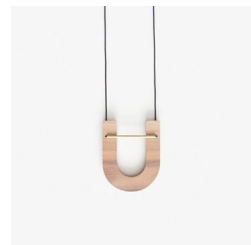
bottom heavy
compositions can
offset unnatural
position of
tracheostomy



symmetry mirrors
facial symmetry

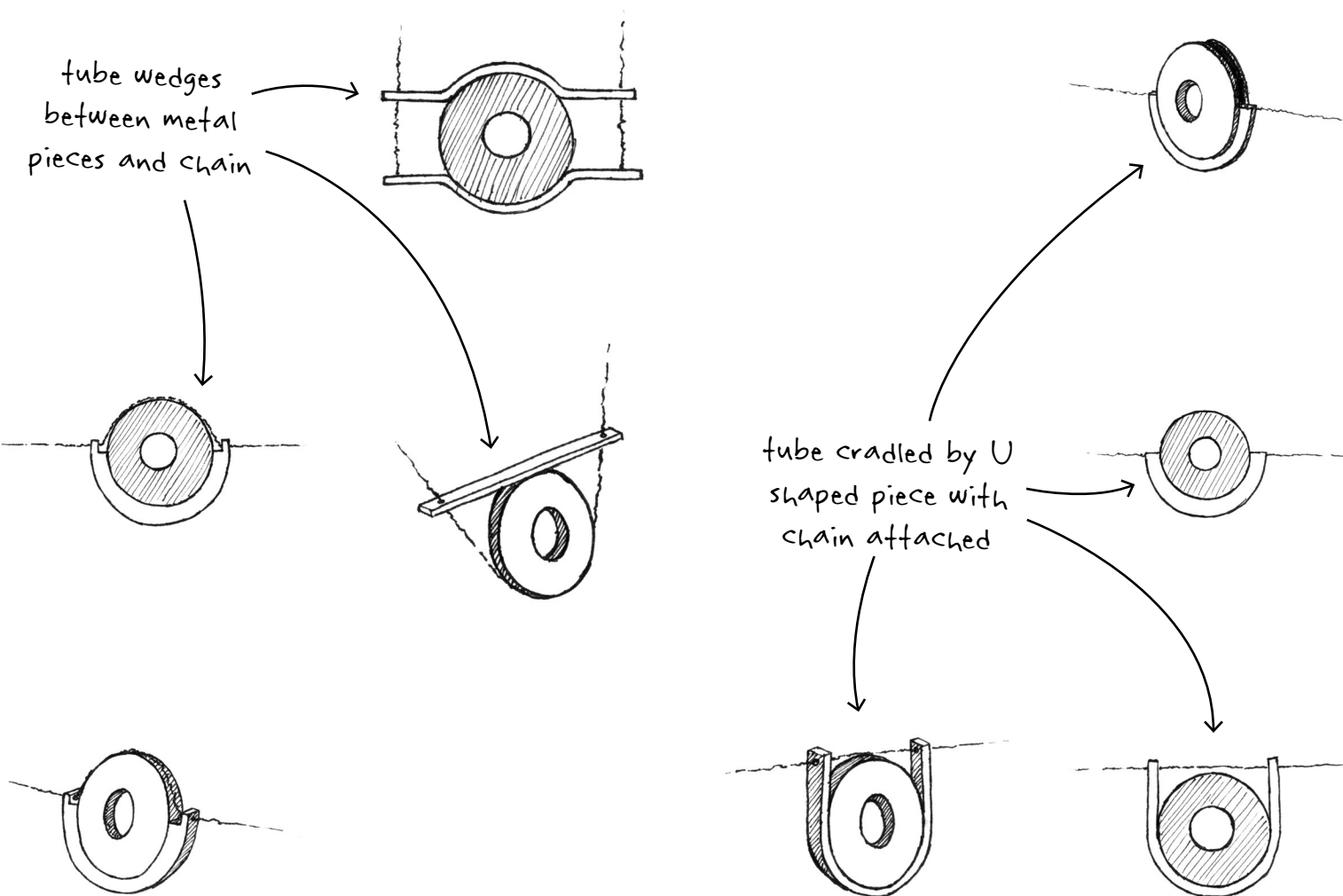
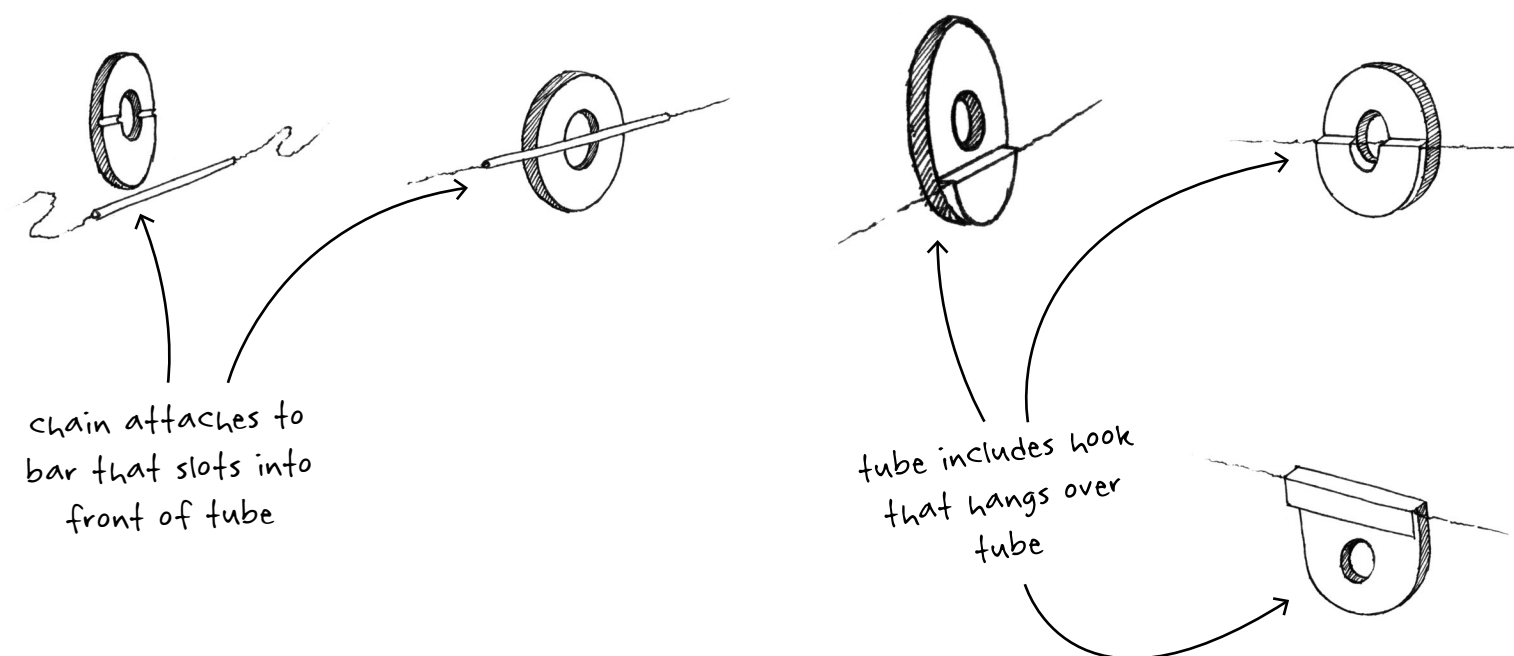


idea of cradling
gives sense of
security



consider chain
as part of the
composition





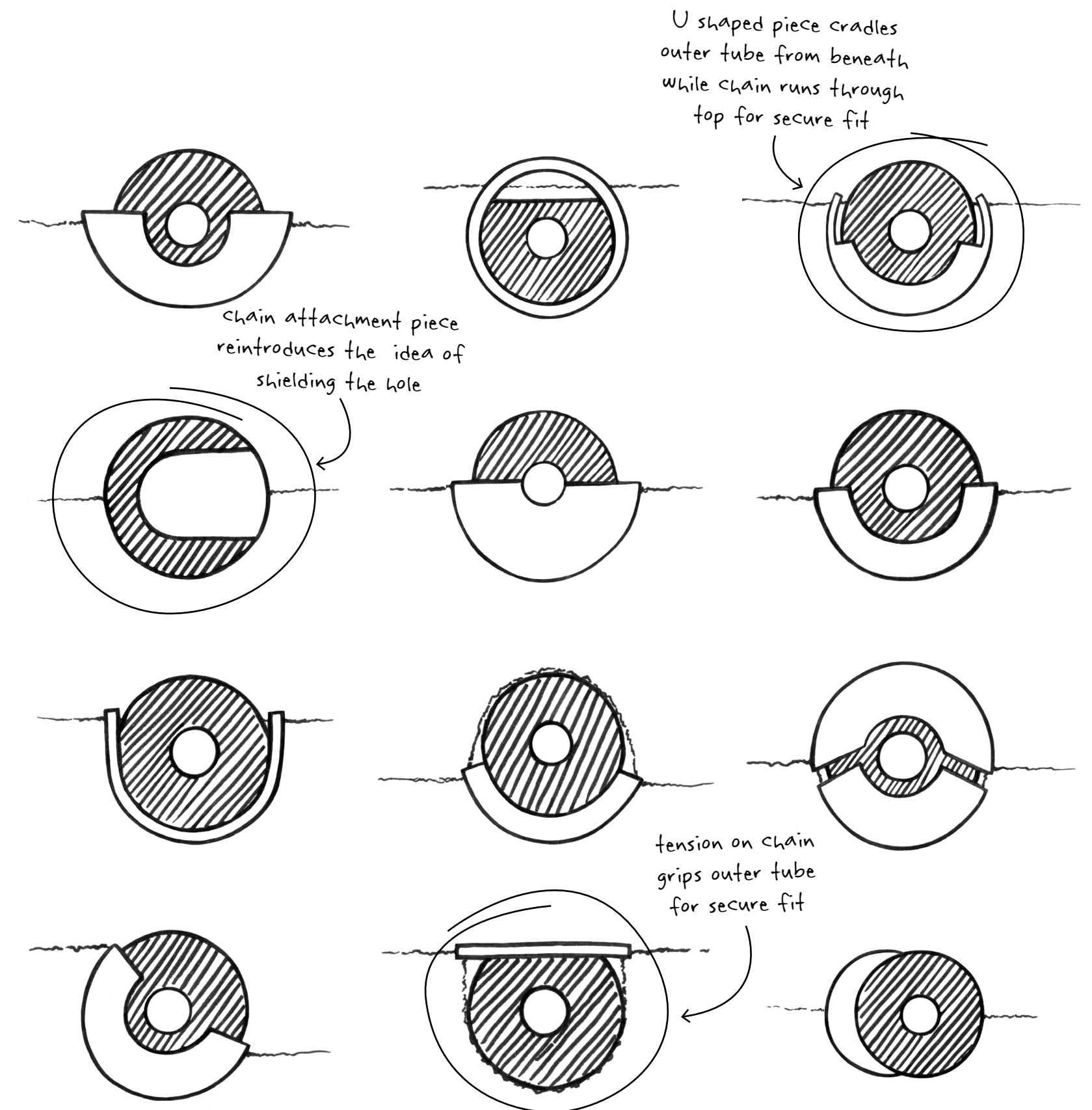
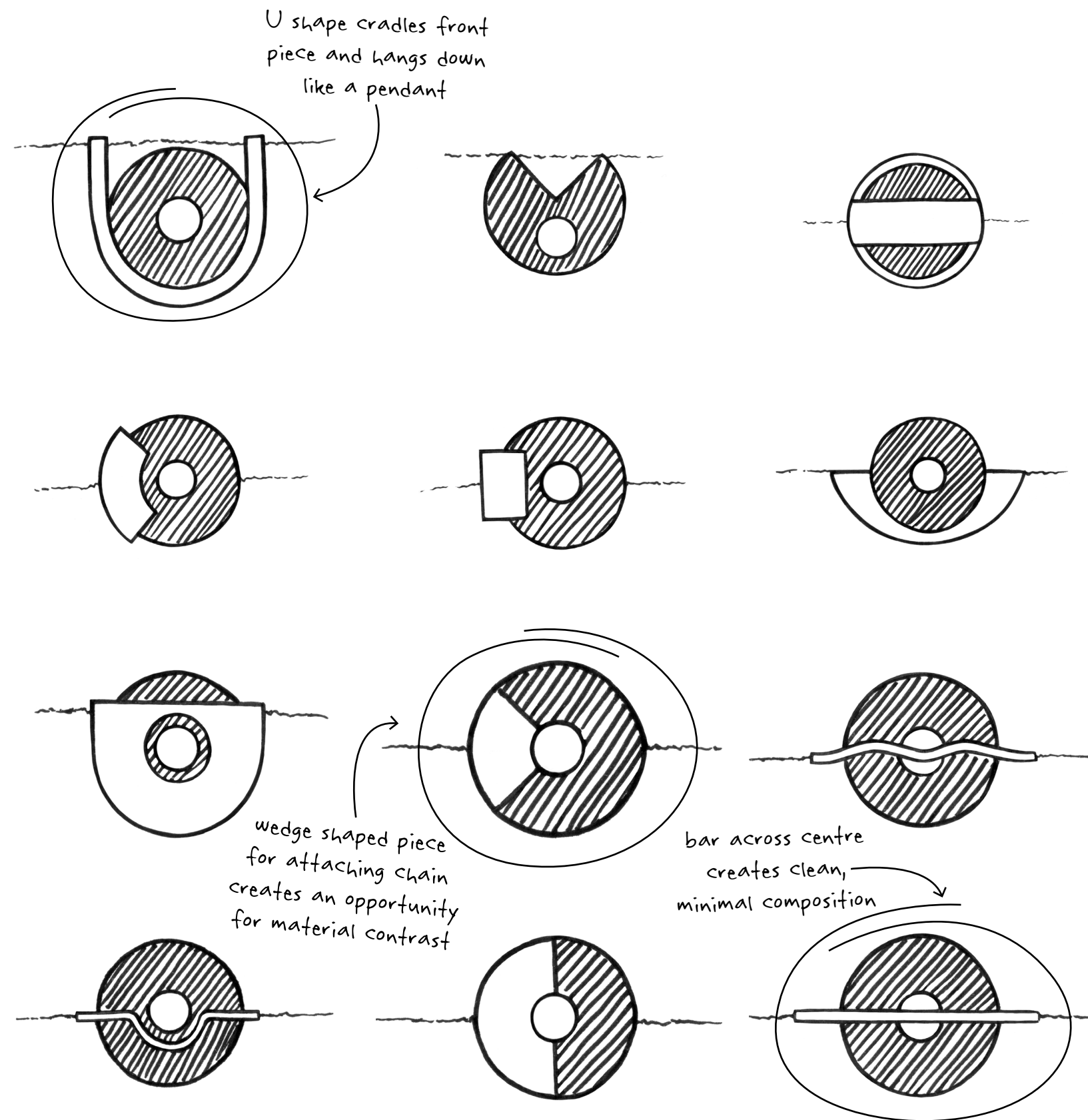
STRAP ATTACHMENT DEVELOPMENT

To manage the task of meeting the criteria for a functional tracheostomy, I began this stretch of ideation by focusing solely on the means of attaching the outer tube to the neck strap. I brainstormed ideas drawing on research insights, design brief criteria, and mood board images.

Responding to user feedback, I chose to make a circular front piece the basis of my ideation. Circles were a logical choice for complementing the circular tube opening. Because I was working toward designs that could be constructed from silver, I brainstormed ways of attaching the strap without complex plastic mechanisms. I wanted to create minimalist forms with interesting compositions around the circular front piece.

I used brainstormed ideas as the starting point for a more detailed sketching, producing variations on the initial concepts with a strong focus on geometric composition.

122. Dickson, (2016). Strap attachment development brainstorm





124. Dickson, (2016). Strap attachment concept 1

In this concept, one end of the strap is connected to the outer tube and the other to a wedge shaped piece. To fasten the tracheostomy to their neck, the user inserts the outer tube, wraps the strap around the back of their neck, and clips the wedge piece to the front of the outer tube. This design would be easy to attach, create a flush surface for easy cleaning, and achieve a minimal aesthetic. However, it would require development to make the strap adjustable.



125. Dickson, (2016). Strap attachment concept 2

For this concept, a U shaped component cradles the outer tube from beneath, while the strap runs through a slit in the top. The design keeps the outer tube securely in place but may be difficult to attach and remove. Furthermore, small crevices would make it difficult to clean and the complex shapes create a busy aesthetic. These issues would need to be addressed to make the concept fully functional.



126. Dickson, (2016). Strap attachment concept 3
 This concept uses tension from the strap wrapped around the outer tube and threaded through a metal bar to hold it in place. The resulting composition is bottom heavy, giving the impression that the tracheostomy sits in a lower, more natural position on the neck. The design requires development to make the strap less fiddly to attach, and to reduce the risk of it slipping off the edge of the outer tube.



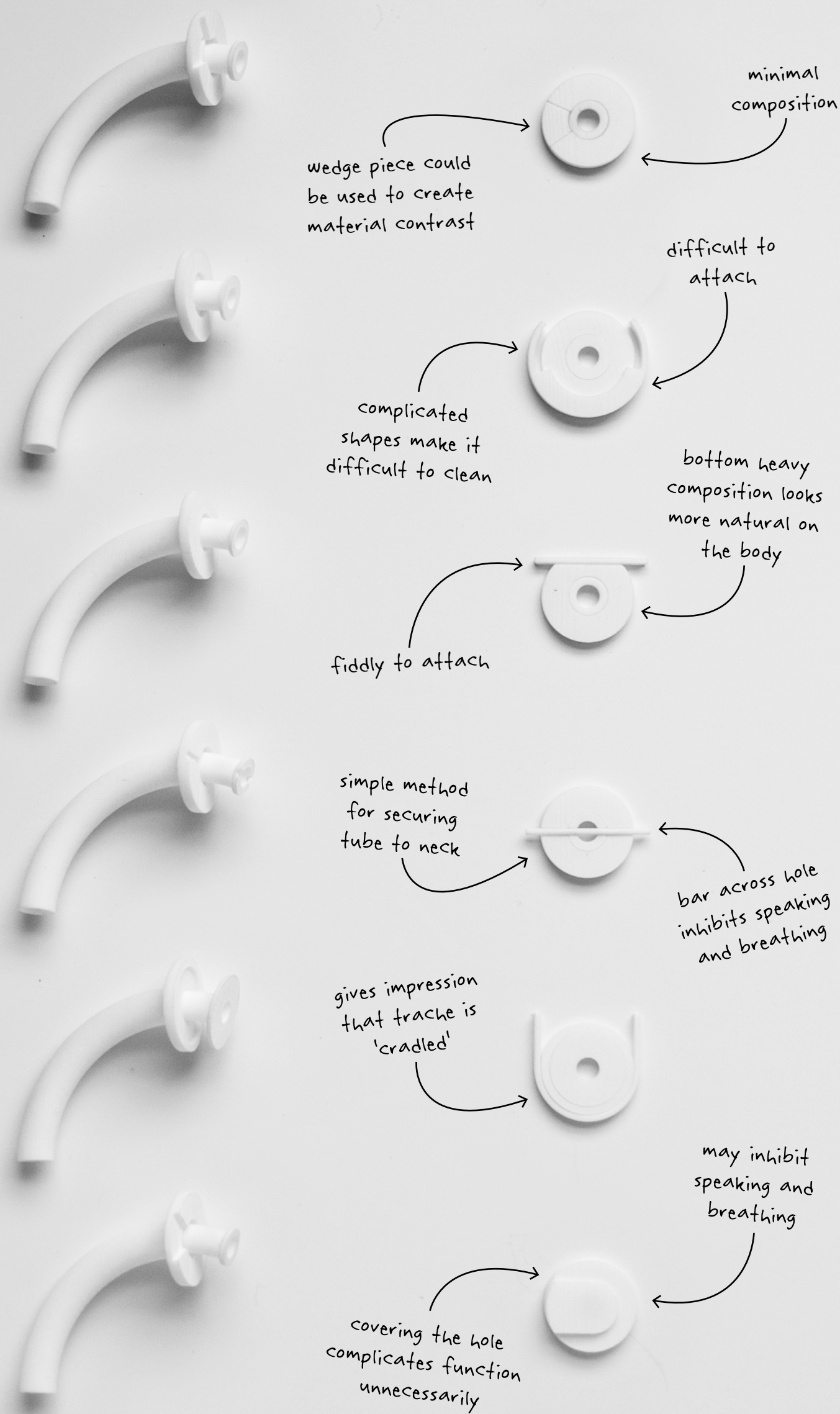
127. Dickson, (2016). Strap attachment concept 4
 For this concept, the strap is attached to either end of a bar that sits across the front of the outer tube holding it against the neck. The cross bar sits in a groove in the outer tube, preventing it from slipping out of place. While crossing the middle of the outer tube creates a symmetrical composition, it risks obstructing users' breathing or preventing them from putting their finger over the hole to speak.

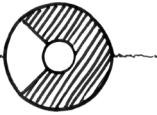
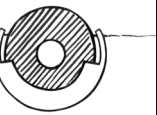
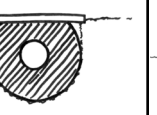
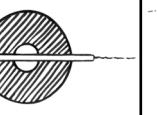
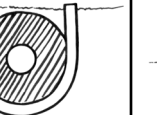
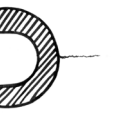


128. Dickson, (2016). Strap attachment concept 5
The outer tube in this concept is cradled by a U shaped piece which hangs from the strap. As with some of the other concepts, the bottom heavy composition makes the tracheostomy appear more like jewellery. This concept provides a more minimal aesthetic than the other U shaped concept but is less secure.



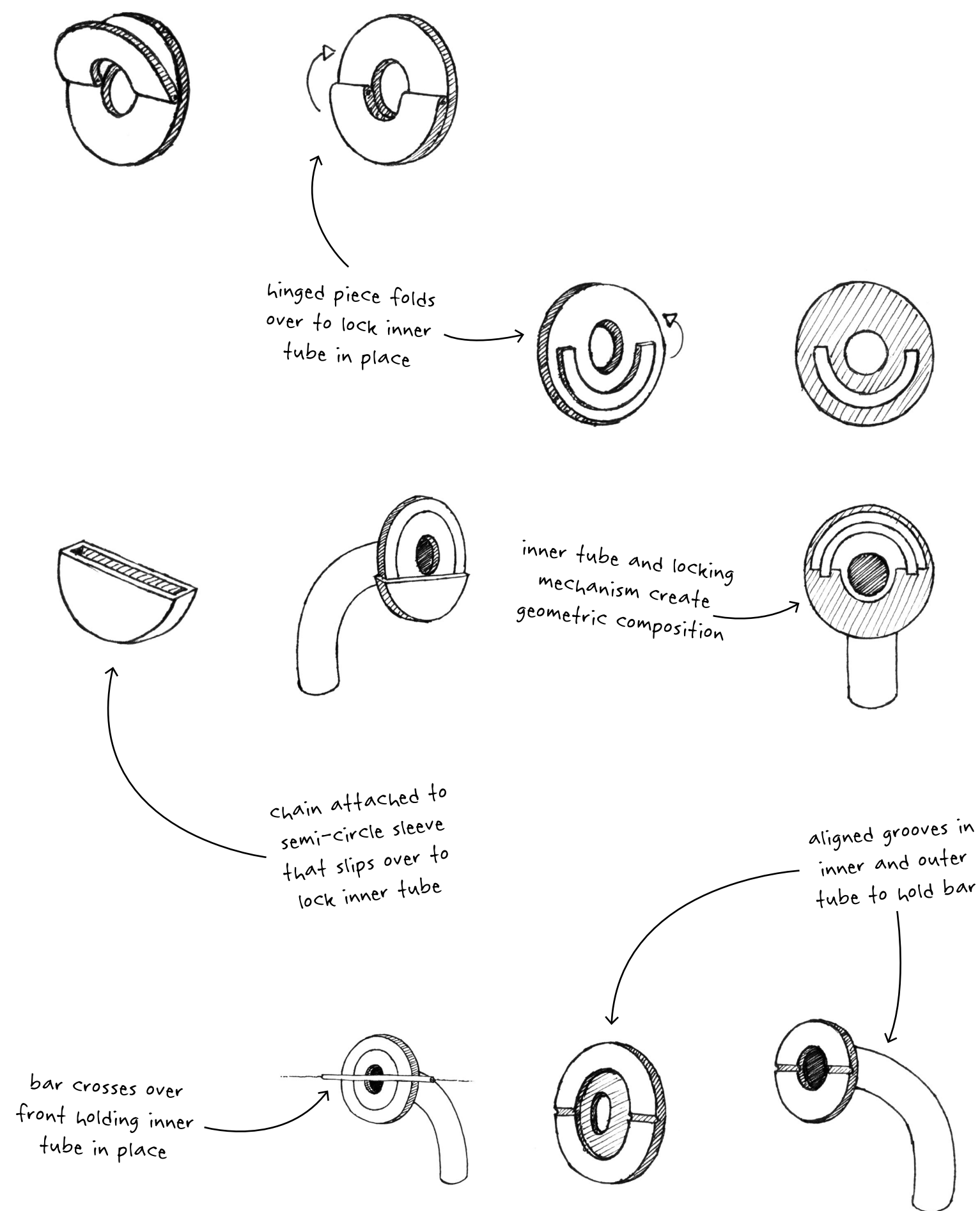
129. Dickson, (2016). Strap attachment concept 6
This concept functions similarly to the design with the wedge shaped piece but incorporates the idea of covering the tracheostomy hole. Again one end of the strap is attached to the outer tube and the other to a clip that is used to fasten it around the neck. While the portion of the design that covers the hole allows for air to flow out the sides, it also makes the design harder to clean and would require significant development to enable the user to close the hole completely to speak.



						
easy to clean	6	1	4	5	3	2
easy to attach	5	1	2	6	3	4
aesthetic	4	2	5	6	3	1
allow breathing	6	6	6	5	6	4
allow speaking	6	6	6	3	6	2
secure	3	6	5	4	5	3
	30	22	27	29	26	16

130. Dickson, (2016). Strap attachment concept evaluation matrix

The six prototypes were ranked against five key criteria from the design brief. Where multiple concepts satisfied a criteria equally (e.g. all concepts with an uncovered hole allow the user to breath equally well), equal scores were given. The three concepts with the highest overall scores were selected to develop further.



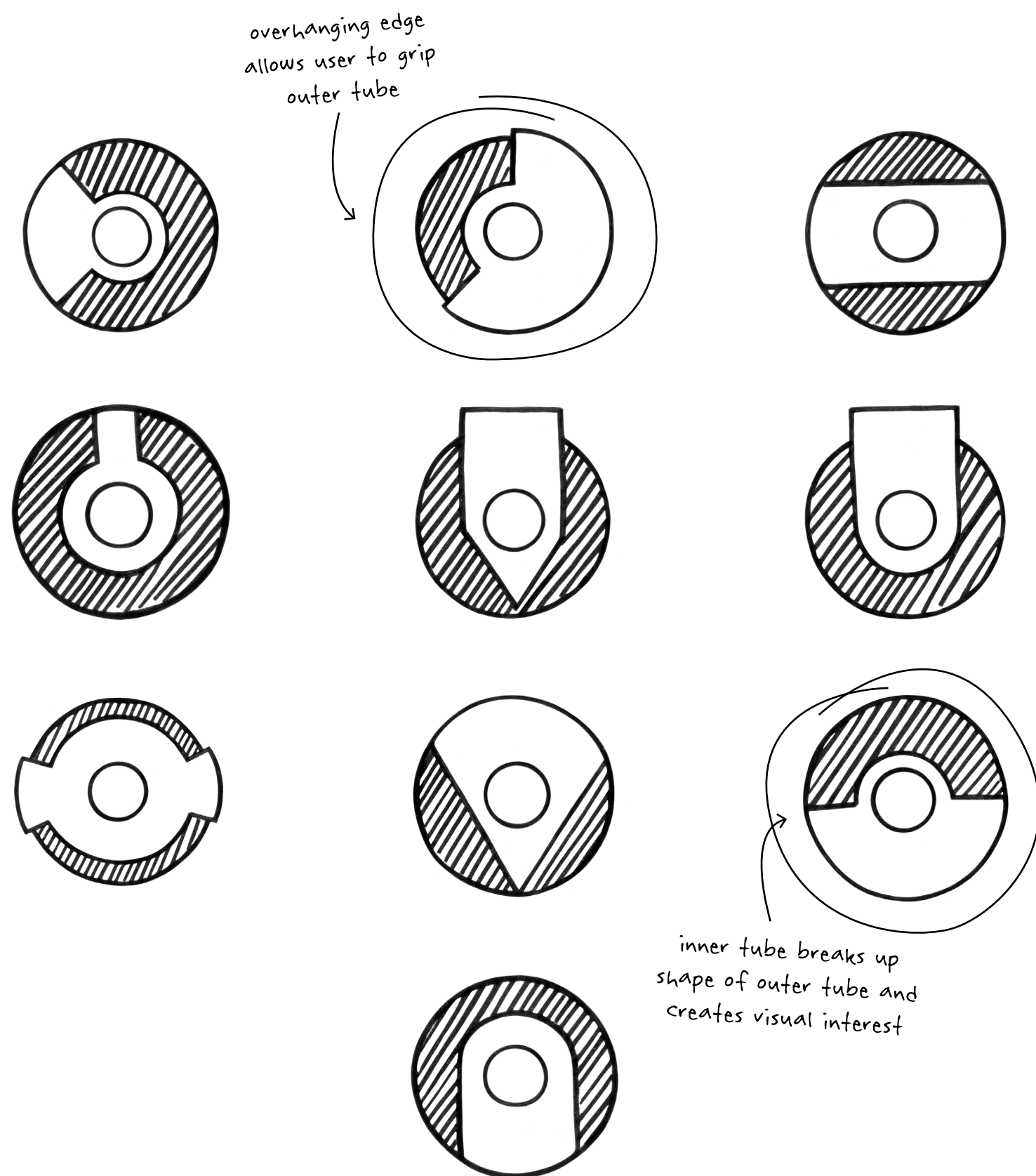
132. Dickson, (2016). Inner tube development brainstorm

INNER TUBE DEVELOPMENT

INNER TUBE ATTACHMENT DEVELOPMENT

For these sketches I focused on designing ways of securing and removing the inner tube. I found it difficult to devise mechanisms that would be easy to make from silver, use, secure, and clean, while remaining aesthetically pleasing. Ideas involving a hinges did not seem like an improvement on the hinged latches on existing silver tracheostomy designs, and my other ideas required the introduction of a separate component to keep the inner tube in place.

When reflecting on these challenges, I devised the idea of using magnets. Strong magnets would secure the tube while remaining discreet and easy to use. They would also allow greater freedom to experiment with the form of the inner tube.



133. Dickson, (2016). Inner tube development sketches

Having decided to secure the inner tube using magnets, I set about exploring different shapes for the front of the inner tube. I experimented with using the geometry of the inner tube to divide the circle of the outer tube in different ways. While generating these sketches, I also came up with the idea of having the edge of the inner tube extend further than the edge of the outer tube to provide a means of gripping it.

Although the shapes generated were interesting, I felt they might create a cluttered composition in combination with my ideas for attaching the strap to the outer tube. I therefore decided to shape the inner tube to complement my existing concepts and focus on developing the idea of overlapping the edge to provide grip.



134. Dickson, (2016). Inner tube concept 1
I tried to resolve the speaking and breathing difficulties identified in the previous iteration of this concept by placing the cross bar above the hole, rather than through the middle. This also made the tracheostomy appear to sit at a lower, more natural point on the neck. I made a recess in the outer tube so users could remove the inner tube by wedging their fingers between the two parts. When testing a 3D print of this concept, I found it was hard to grip.



135. Dickson, (2016). Inner tube concept 2
As the previous iteration of this concept scored highly on all criteria, I focused on developing it by making the inner tube easy to remove. I made the circle of the inner tube larger than the outer tube. When testing the prototype I found this made the inner tube very easy to grip and remove.



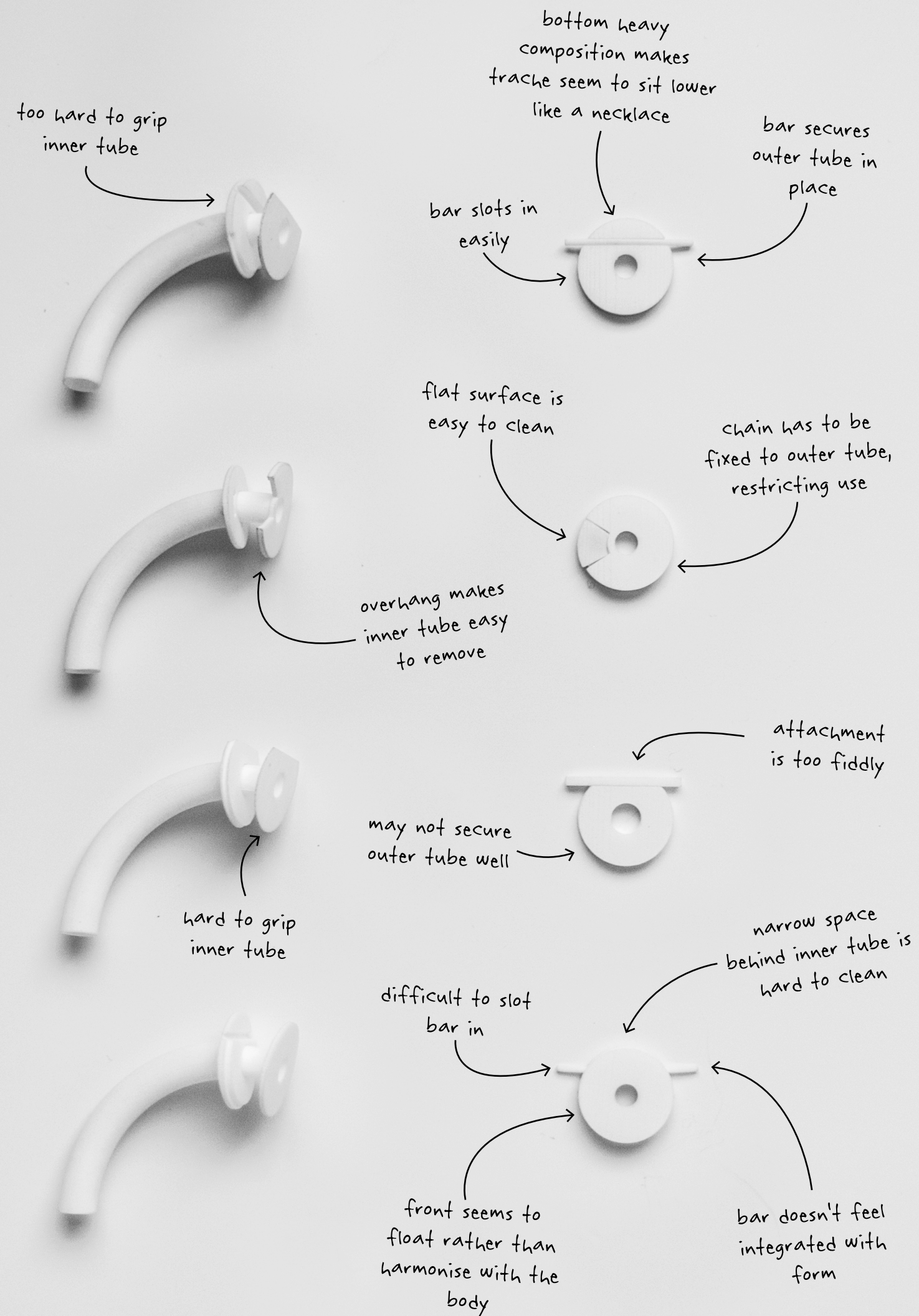
136. Dickson, (2016). Inner tube concept 3

The main shortcoming with the previous iteration of this concept was the difficulty of attaching the strap to the outer tube. To make the strap sit in place more easily I tried adding a groove around the edge of the outer tube, and adding channels in the bar crossing the top. These refinements helped but the concept still proved more fiddly to use than the others. I also struggled to make a ledge for gripping the inner tube as the strap got in the way.



137. Dickson, (2016). Inner tube concept 4

This prototype provided an alternate iteration of the cross bar concept. Instead of crossing the front of the design, the bar slotted into a gap between the inner and outer tube. This created distance between the two tubes, making the inner tube relatively easy to grip. However, I felt that placing the cross bar behind the inner tube weakened the aesthetic result.



easy to clean	3	4	2	1
easy to attach	4	3	1	2
aesthetic	4	2	3	1
grip inner tube	3	4	1	2
	14	13	7	6

138. Dickson, (2016). Inner tube concept evaluation matrix

The four prototypes were ranked against four key criteria from the design brief. Criteria for ease of breathing and speaking were dropped from this round of evaluation because all concepts had achieved equally on these criteria in the previous round. Because the focus of this set of prototypes was to develop the form of the inner tube, criteria for how easily the tube could be gripped and removed was introduced. The concept with the highest score was selected to be refined.

STAFF FEEDBACK

I met with ORL staff including a surgeon, nurse, and tracheostomy nurse specialist to discuss my chosen design approach. I wanted to gauge clinicians’ reception of my ideas and obtain feedback on the functionality of my prototype. I wanted to know whether magnets would be suitable for securing the inner tube, and whether my proposed method of securing the tube to the neck would be easy enough to use.

Staff were enthusiastic about my ideas. They responded positively to the use of magnets as well as my design for securing the tracheostomy to the neck. With regards to the latter, staff encouraged me to consider placing the fastening mechanism either at the front or the side of the neck as some users have difficulty reaching backwards.

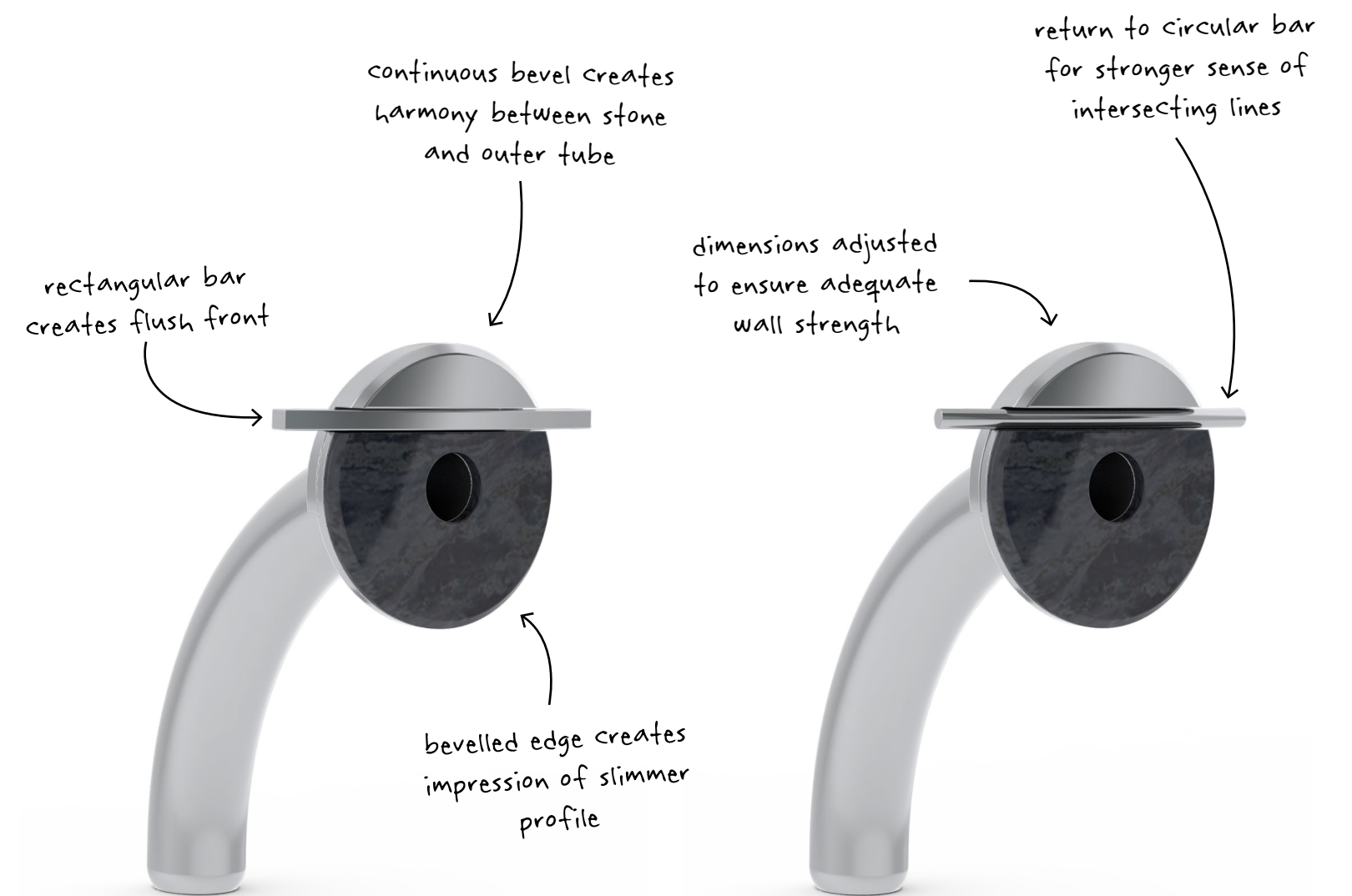
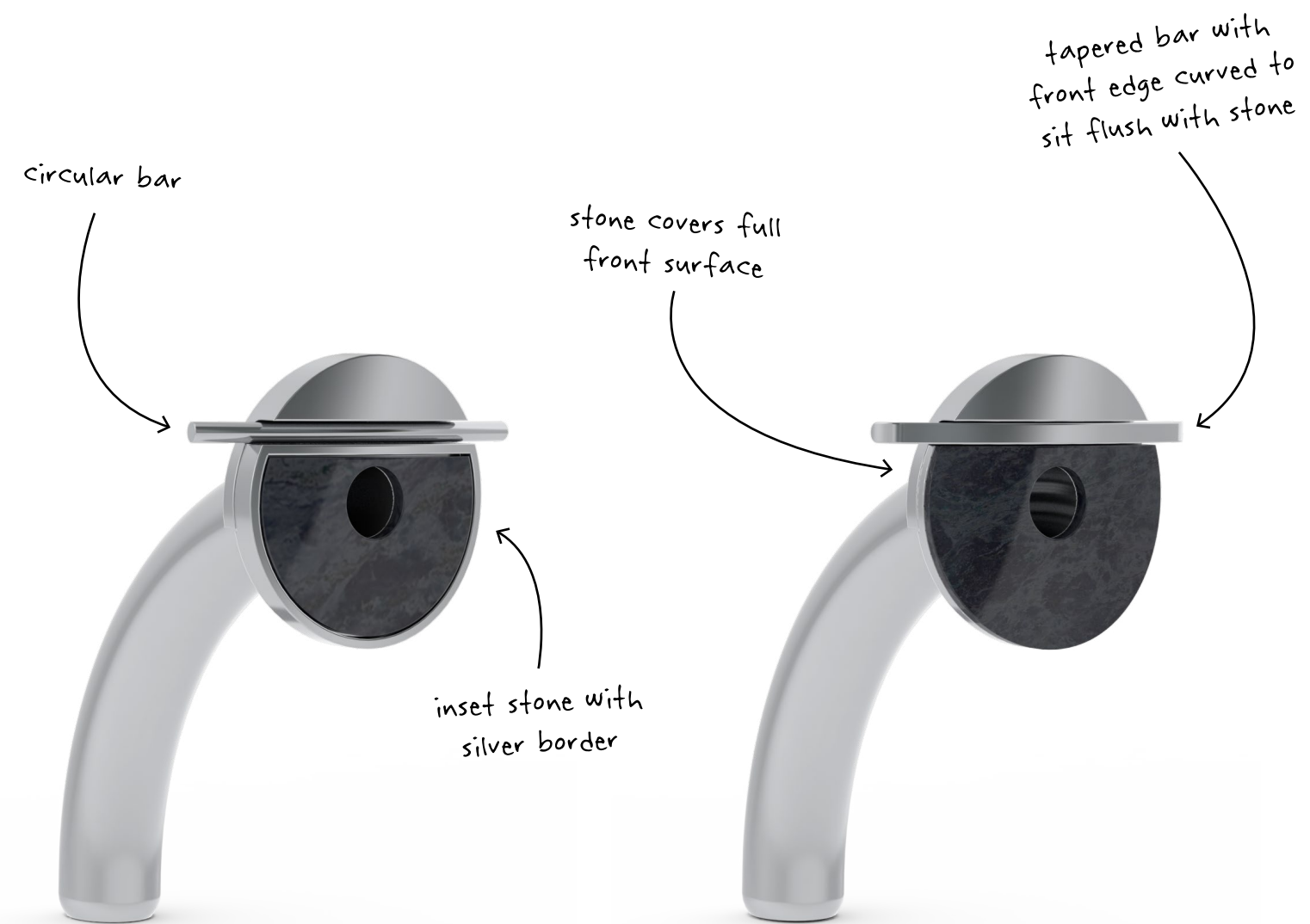
Staff also took interest in 3D printing as a potentially viable manufacturing method. They were surprised that silver can be 3D printed and were interested in the opportunities this might allow for customising tubes to user anatomy. They were taken aback that the estimated cost of a 3D printed silver prototype was less than the cost of existing silver tracheostomy tubes. They were interested in the continuation of the project beyond this thesis and even willing to test 3D printed prototypes with users in future.

As well as providing feedback for refining designs, this meeting confirmed clinicians’ prioritisation of cost, function, and manufacturing. Although positive about my designs, staff were more interested in discussing 3D printing and how it might benefit cost and functional objectives. At the same time, the meeting validated my design as a means of introducing aesthetic and user-centred concerns without compromising cost or function.

PHASE 8

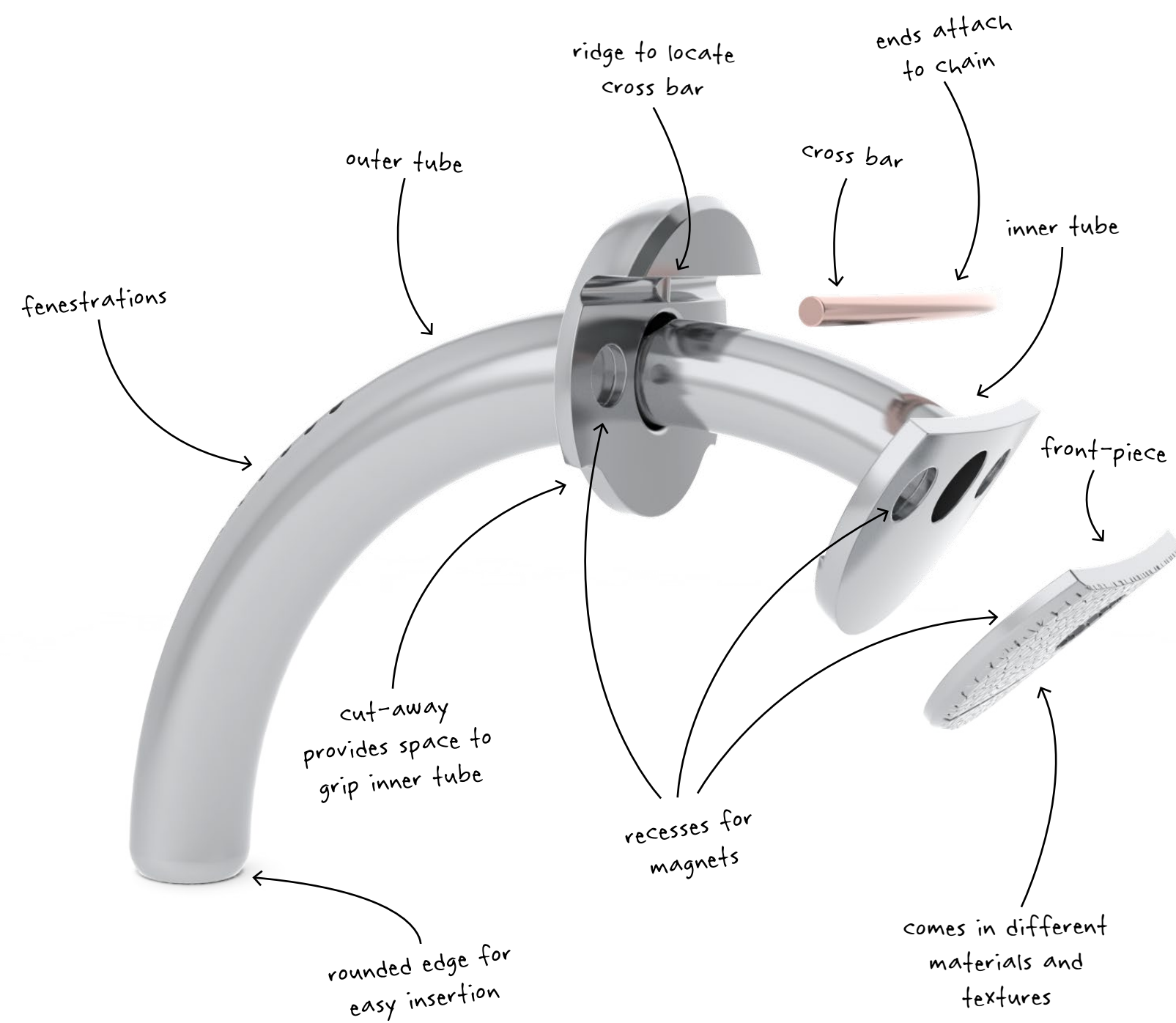
CONCEPT REFINEMENT

Bolstered by staff's positive reception of my prototype, I set about refining the usability and aesthetics of my proposed design through a series of iterative CAD models.



140. Dickson, (2016). Outline of CAD development for final tube design

These images show the progression of the chosen concept through iterative refinements using CAD software. I began these developments by introducing a stone embellishment to the front of the design as a means of adding aesthetic value. My idea was to allow users to choose different types of stone to customise their tracheostomies and add an element of self expression. I experimented with different details for integrating the stone piece with the existing design. I also refined the proportions of the design for aesthetic effect and to ensure the wall thicknesses of the silver components provided adequate strength.



141. Dickson, (2016). Exploded view of final design showing key features



MATERIAL EXPLORATION

POLYMER CLAY EXPERIMENTS

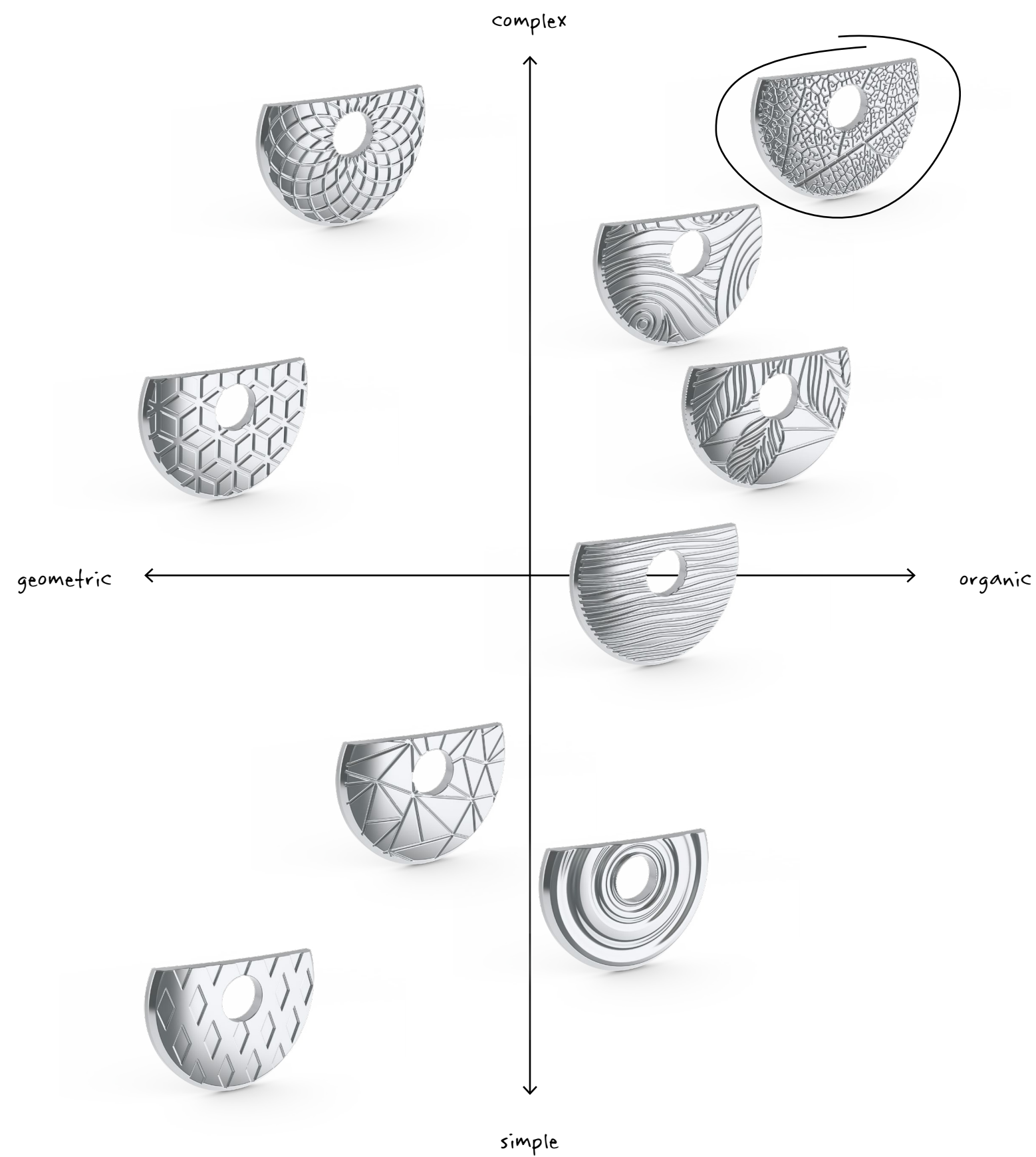
To develop the idea of embellishing my design with carved stone, I explored the aesthetic effects of different colours and materials. I used polymer clays to produce a palette of colours and patterns inspired by my jewellery mood board. Using clay gave me the flexibility to mix colours and textures freely while capturing the randomness of real stone grain. From these experiments, I was particularly drawn to the black marble effect, which I felt would create a strong contrast with the silver tube. I felt marble would convey an air of prestige that could help reposition tracheostomy tubes as valued objects.



MARBLE

Having explored material effects in polymer clay, I next looked into the practicalities of sourcing and shaping real materials. I sourced marble and granite offcuts from bench-top makers. The range of colours and textures available offered a promising means of providing tracheostomy users with choice. Unfortunately, my enquiries into getting these materials CNC or hand-cut to shape proved fruitless.

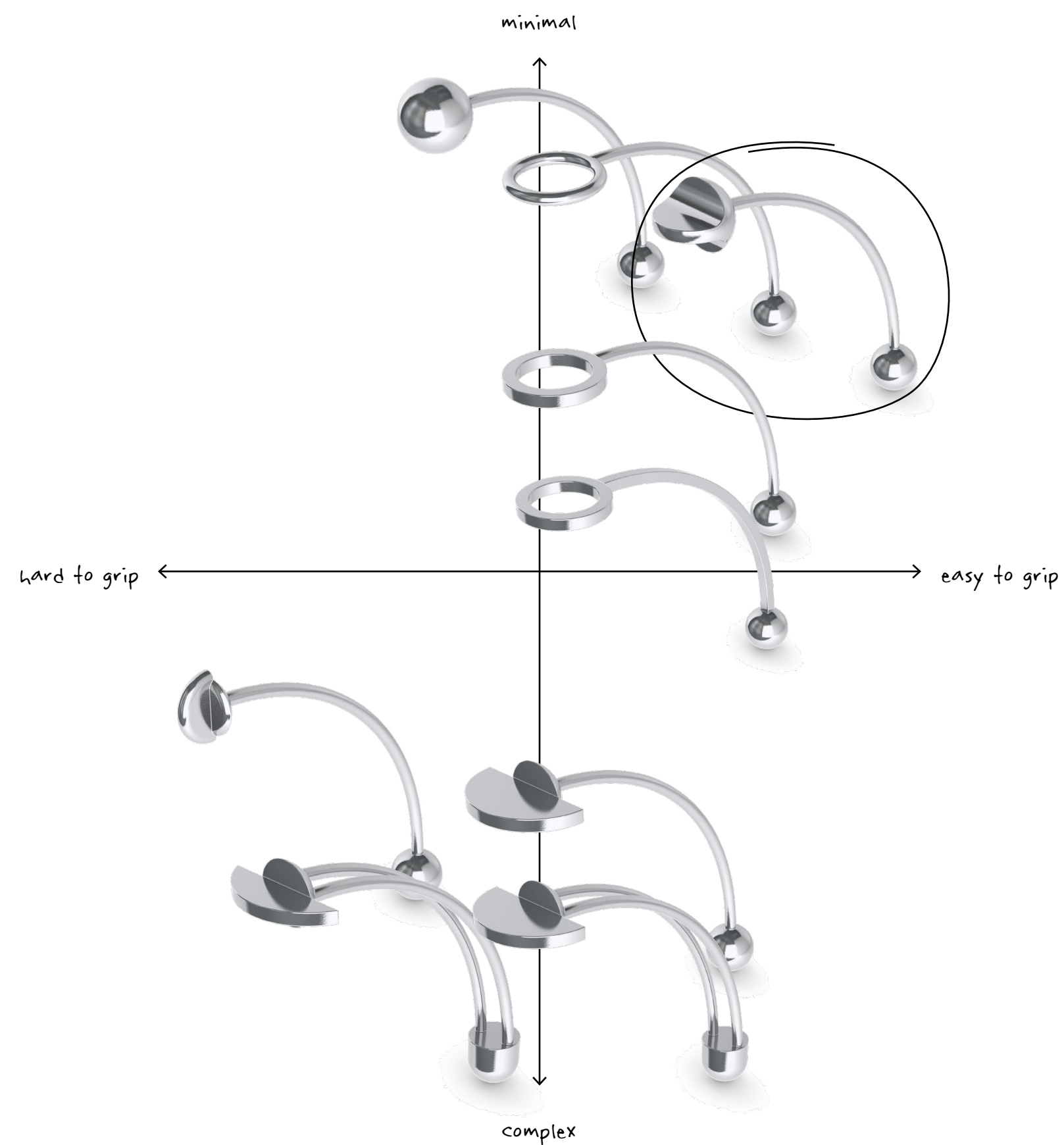
I also enquired with jewellers and craftspeople about the feasibility of cutting the desired shape from precious stones like greenstone or turquoise. While stonecutters confirmed it would be possible, I was unable to find someone with the necessary skills and tools to produce a prototype. Furthermore, I was concerned a hand-cut piece may not be accurate enough to work with a 3D printed tube.



144. Dickson, (2016). Texture concept evaluation

APPLYING TEXTURE

In response to difficulties sourcing and shaping stone to fit my design, I experimented with applying texture to silver. I tested textures of varying complexity and ranging from geometric to organic. I found complex, organic patterns to be most successful, contrasting with the geometric quality of my tracheostomy tube design. I also felt nature-inspired textures contributed to the jewellery-like aesthetic, as natural motifs are found in jewellery throughout history. I chose a leaf vein texture for prototyping purposes, however I designed the 'stone' component to be detachable so different materials and textures could be applied to suit user preferences.



145. Dickson, (2016). Introducer concept evaluation

INTRODUCER DEVELOPMENT

Having designed the main tracheostomy components, I wanted to redesign the introducer to be aesthetically complementary while making sure it was easy to grip. I used CAD to generate concepts using circles as the primary form. I experimented with strengthening the form by doubling up the rods connecting either end, and using a ring shaped grip that users could hook their finger through.

I preferred designs with single connecting rods for their minimalism and efficient material use. I felt the concept with different sized spheres on either end of the rod was most minimal but did not provide a clear point of grip. It could also be difficult to determine which end was which. Furthermore, the spherical design did not provide lines that would harmonise with the outer tube design. By contrast, the design based on a sphere with sections cut away provided a clear grip and created a horizontal line that mirrored the lines used in the other tracheostomy components.



146. Dickson, (2016). Packaging inspiration mood board

To find packaging design inspiration, I searched for examples of packaging used for high-end fashion driven items like sunglasses, jewellery, and watches. I wanted to collect images that captured a minimal aesthetic supported by the use of beautifully finished, quality materials. The ideas that particularly appealed to me were the use of natural wood, and forms that create designated spaces for each item.

PACKAGING DEVELOPMENT

Revisiting the idea of designing for the wider ecosystem of tracheostomy products, I wanted to design packaging to accompany my tracheostomy tube design. I developed the following brief to drive a simple design that would further enhance users' experiences.

PURPOSE

Store and protect tracheostomy products

PERFORMANCE

Provide a place for each item
Protect tracheostomy products against wear
Easy to open, place, and remove items

FEATURES

Provide a place for each tracheostomy care item
Include a pouch for carrying emergency tracheostomy kit
Polishing cloth to maintain silver

AESTHETICS

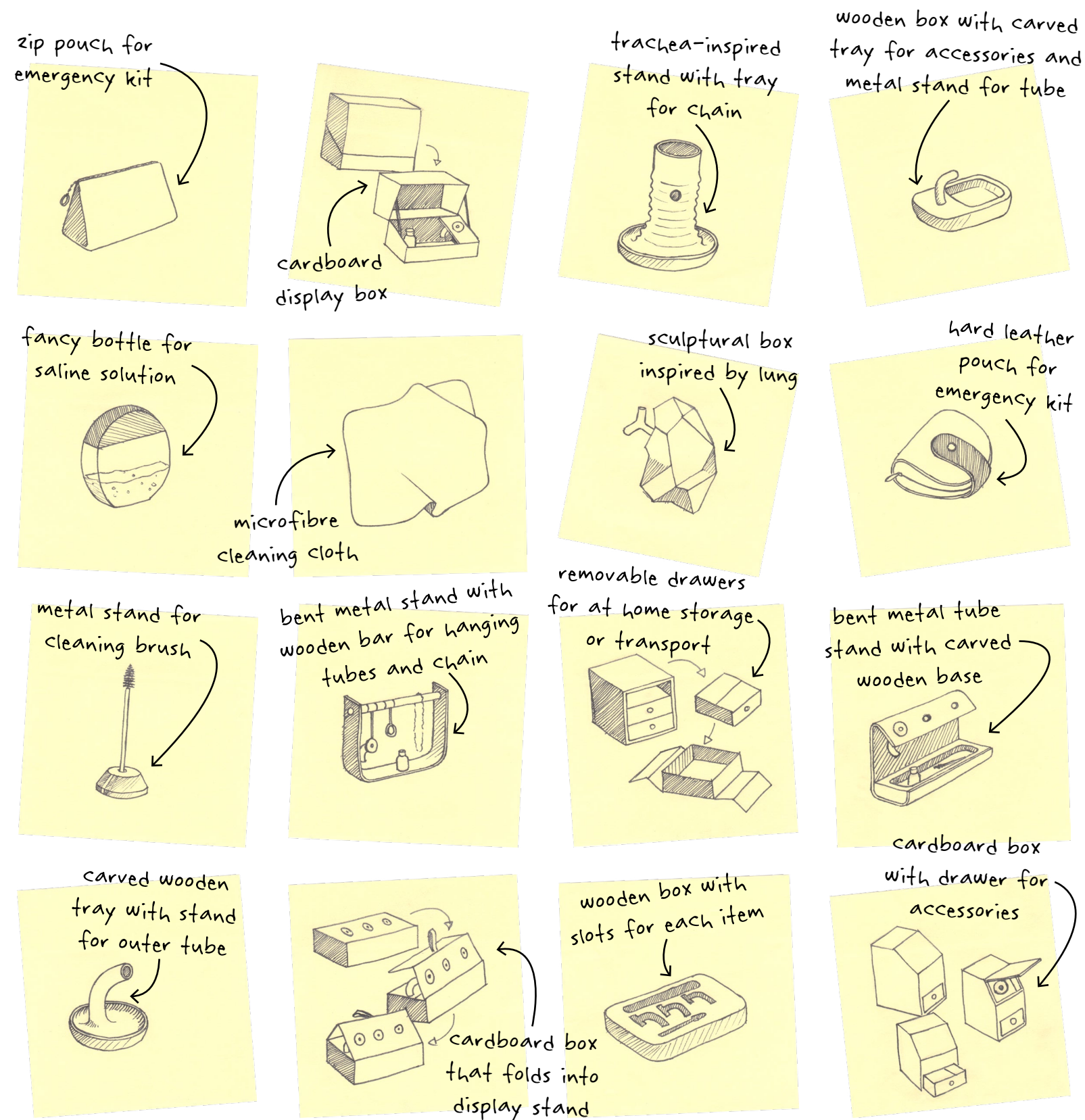
Befitting of bespoke jewellery
Cohesive with tracheostomy design
Simple, minimal form

PERCEIVED QUALITY

Intrinsically valuable materials
Refined details and finishing

RELIABILITY

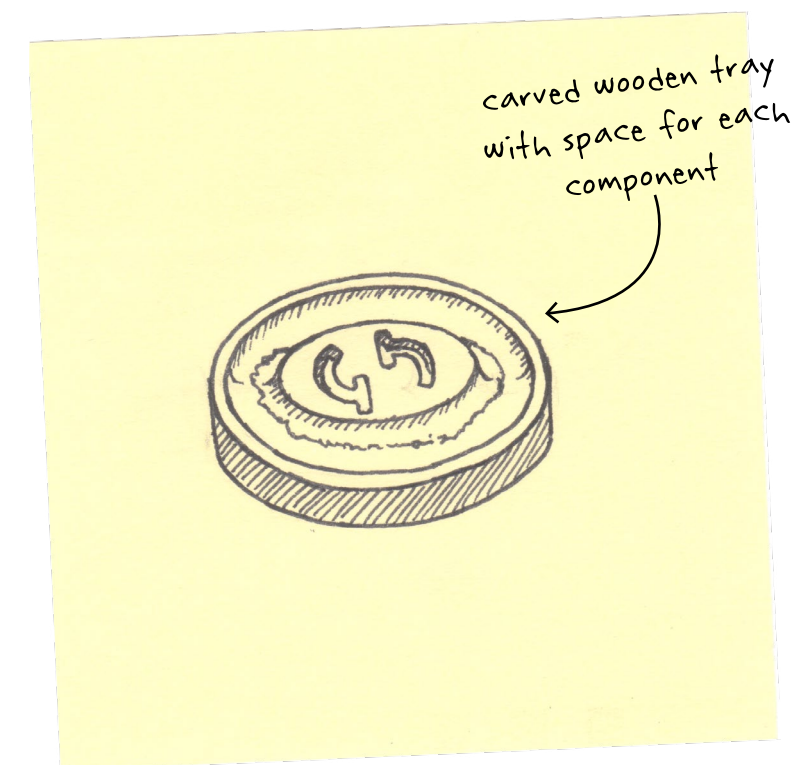
Last at least 10 and ideally 30 years



147. Dickson, (2016). Sketches exploring a range of packaging concepts

Inspired by the criteria from my packaging brief and the images from my mood board, I roughly sketched a range of concepts for storing, transporting, and cleaning my tracheostomy designs. I included concepts for more cardboard boxes as well as more permanent designs based on jewellery stands. I also gave some thought to redesigning the cleaning brush to suit my tracheostomy tube design.

PACKAGING CONCEPTS



148. Dickson, (2016). Packaging sketch selected for development

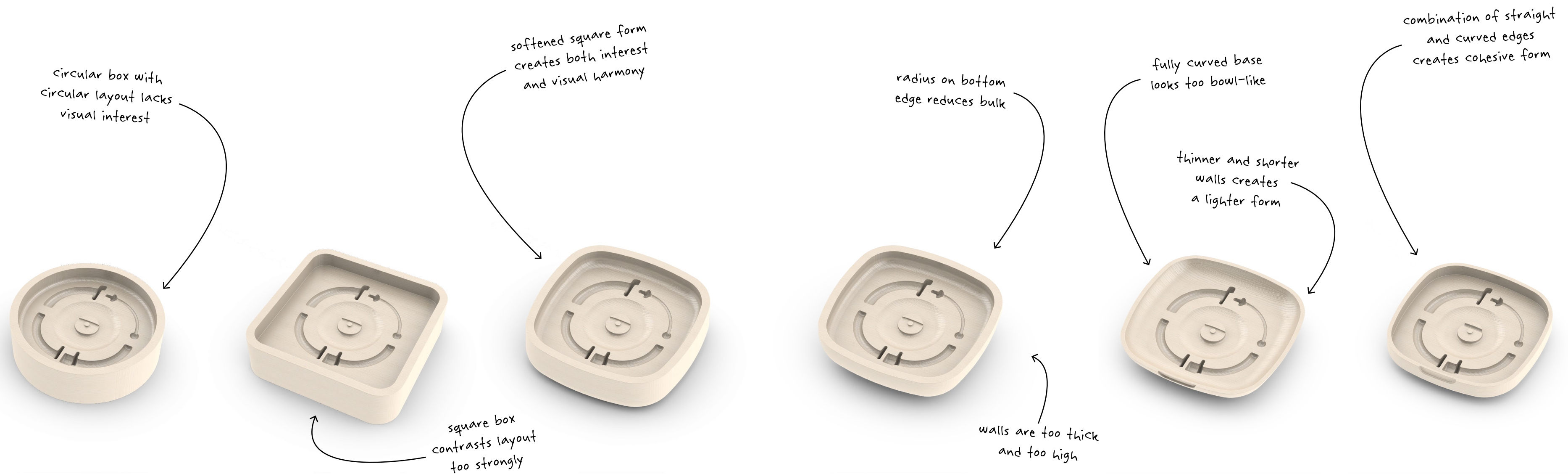
While there are many ways to improve tracheostomy packaging, I focused on creating a box that would complement my tracheostomy design, and convey a sense of care and value rather than sterility. I chose a simple concept to demonstrate how packaging can re-frame the experience of using a tracheostomy tube. I wanted to design a minimal box, carved from nice wood, with designated spaces for each item. My focus for developing this was careful composition and elegant finishing details.



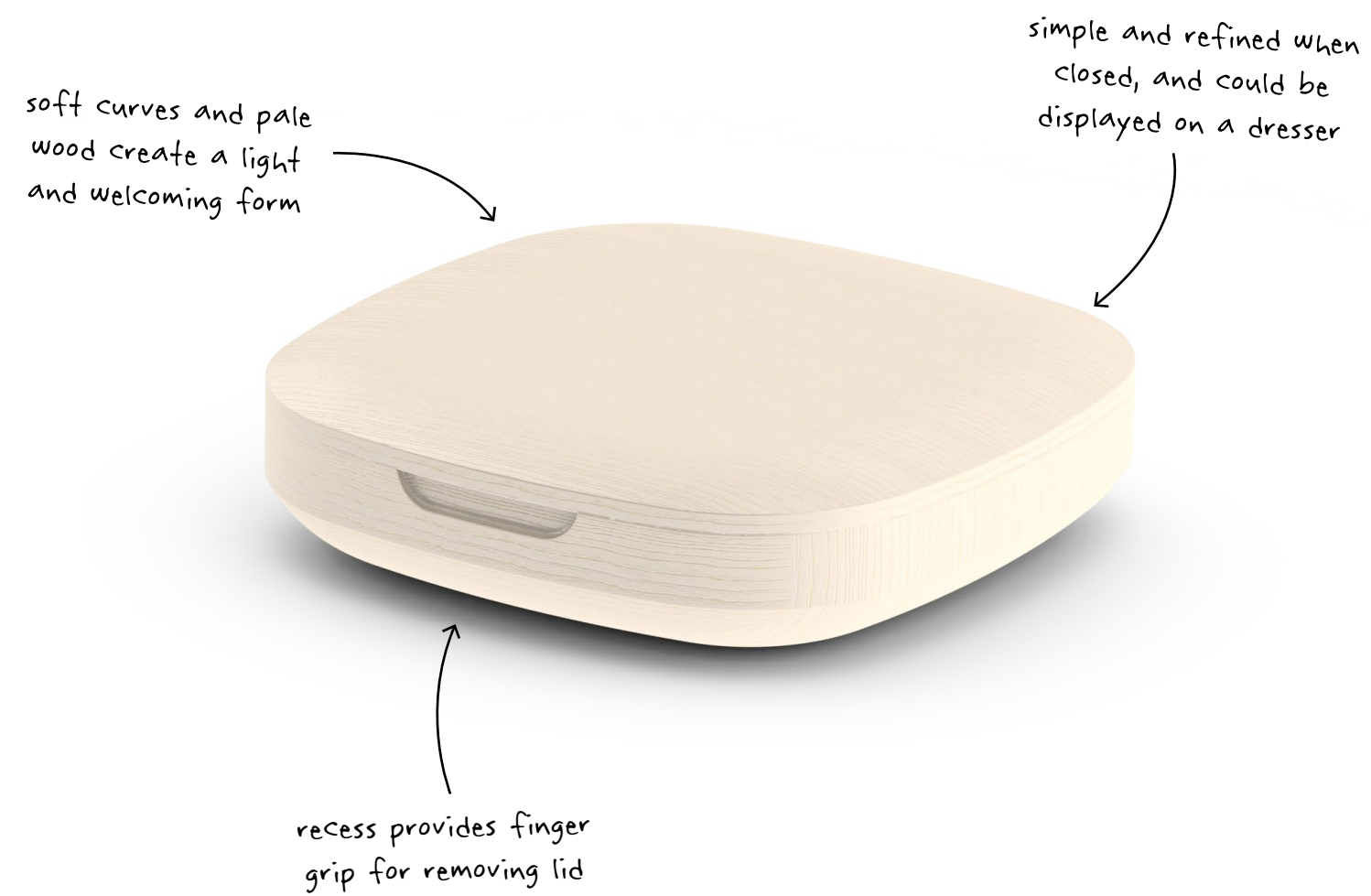
149. Dickson, (2016). Packaging layout exploration sketches

LAYOUT DEVELOPMENT

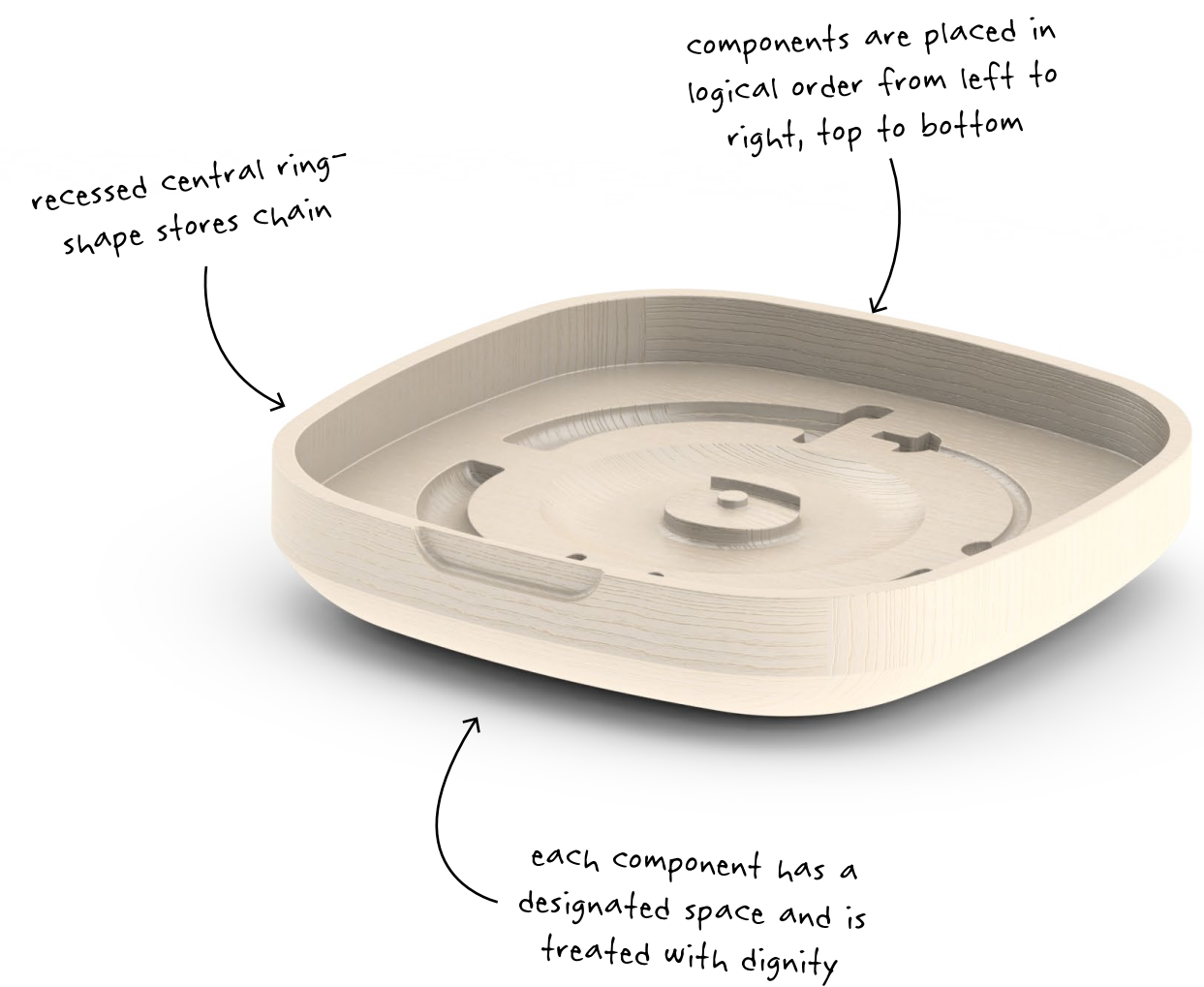
To develop the wooden box concept, I explored different arrangements of tracheostomy components using paper cut-outs. I experimented with three geometric box shapes to maintain a minimalist approach. I felt arranging components in a circle produced compositions that complemented the tracheostomy design and kept parts easy to locate. The circular layout allowed parts that would be used first (outer tube and introducer) to be placed at the top, the two types of inner tube at the bottom, and the decorative front piece and chain in the centre. I decided to further explore the use of a circular layout in both a square and circular box using CAD to get a sense of scale and proportion.



150. Dickson, (2016). Outline of CAD development for packaging design
 When testing selected packaging layouts in 3D form, I found that a circle box highlighted the fact that the tracheostomy components don't align in a perfect circle. The square box was an improvement but felt too rigid. Softening the square shape created a nice middle ground. Having selected the base shape I then refined the form by experimenting with radii, wall thicknesses, and the overall box depth to reach a subtle, refined, and welcoming design.



151. Dickson, (2016). Render of final packaging design with lid



152. Dickson, (2016). Render of final packaging design open

DISCUSSION



INTRODUCTION

The literature review completed at the outset of the project uncovered a glaring absence of research about the experiences of people living in the community with tracheostomies. I sought to address this gap in the literature and use my research to capture and convey what it is like to live with a long-term tracheostomy. This goal was supported by the use of human-centred and co-design methods to actively engage tracheostomy users, and bolster their voices in the academic conversations that concern and affect their experiences. Where much of the existing literature reduced tracheostomy users to percentages and quality-of-life metrics, I applied a qualitative approach to demonstrate the value and nuance that real people’s stories can contribute to the field of knowledge. My hope is that this research sets a precedent for using human-centred design and co-design approaches to understand and improve people’s healthcare experiences in relation to tracheostomy as well as other under-researched medical conditions.



RESEARCH CONTRIBUTIONS

TRACHEOSTOMY USER DISSATISFACTION

Through listening to users’ stories, I began to paint a picture of the tracheostomy-related dissatisfaction many experience – one largely absent from existing literature. Participants felt unsupported in the transition between hospital and at-home care, unprepared for managing their tracheostomies independently, and frustrated with the impact tracheostomy had on their daily lives. Furthermore, the choice of products available to them was negligible and failed to meet their needs and desires. As well as validating the goals of the project, this information highlighted areas where further investigation is needed to determine how healthcare organisations and clinicians can better support long-term users.

SYSTEMIC EXCLUSION OF USER NEEDS

While unpacking tracheostomy users’ dissatisfaction, it became clear many of their challenges stemmed from underlying systemic issues. For example, tracheostomy product distribution systems seem to be formed without input from, or consideration for, users. Because tracheostomy products are purchased by healthcare organisations, manufacturers are incentivised to fulfil functional requirements at budget-friendly price points. It is more cost-effective to provide a limited range of products that hospitals can purchase in bulk than invest in specialised designs catering to different users’ needs. As a result, long-term users are provided with the same products used in hospitals despite facing different challenges to those associated with hospital treatment. The needs of long-term users simply do not factor into the equation driving tracheostomy product design.

THE CASE FOR INCLUSION

While established tracheostomy product distribution systems exclude users, this research highlighted how eager they are to be included in the decisions shaping their experiences. Users were enthusiastic about participating and generous with their stories. They shared anecdotes and frustrations while demonstrating a complex grasp of factors contributing to the challenges they face. They were cognizant that cost and manufacturing considerations limit the products available to them and had considered ways of working within these constraints to improve tracheostomy designs. The rich discussion stimulated by approaching the research from the co-design philosophy that users are experts in their own experiences presents a compelling argument for making user engagement the baseline of future tracheostomy research.

INTENDED VS ACTUAL USE

This research re-contextualises existing tracheostomy literature by identifying the ways users' experiences diverge from what existing literature describes. In comparison to the discrete, linear processes described in tracheostomy care guidelines (Capital & Coast District Health Board, 2015; Dhand & Johnson, 2006; Feber, 2006; NHS Trust, 2010), users' approaches to maintenance were surprisingly idiosyncratic. The decisions they made about whether and how to use their tracheostomy products were as diverse as users themselves. Choosing not to wear the inner tube, clearing blockages with saline solution, and replacing straps with silver chain were all ways users managed the inadequacies of tracheostomy products and adapted them to suit their lifestyles. Again this reflected users' dissatisfaction with their experience. It signalled the need for products designed to meet the challenges of at-home use and varied lifestyles.

TRACHEOSTOMY AND STIGMA

While undertaking the literature review I found plenty of resources discussing body-image, stigma, and visible difference, but few applying these concepts to tracheostomy (Bonanno & Esmaeli, 2011; Bradbury, 2012; Rumsey & Harcourt, 2004; Thompson & Kent, 2001; van den Elzen et al., 2012). Even so, I speculated that the psychological effects of tracheostomy would reflect findings about other types of visible difference. While this project was not a study of tracheostomy's psychological impacts, my interactions with users confirmed my hypothesis. Tracheostomy users experienced internal and external stigma and demonstrated coping strategies aligned with categories identified in the literature review (concealment, avoidance, and the development of social skills). Drawing the link between literature on stigma and tracheostomy users' experiences was instrumental in shaping the design outcomes emerging from this project.

TRACHEOSTOMY AND IDENTITY

One of the most striking research outcomes was an understanding of the complex ways tracheostomy interacts with users' identities. While long-term users do not allow their tracheostomies to define them, their stories leave no doubt being tracheostomised is a life-altering event (Bello et al., 2016; Gilony et al., 2005; Hashmi et al., 2013). As much as they are frustrated by the struggles of having a tracheostomy, they are also proud of the resilient nature facing these challenges brings out in them.

Using a qualitative approach helped me unpack the myriad meanings tracheostomy users construct around their products. Beyond the expected role of assistive breathing device, users see tracheostomy tubes as bodily invaders, eyesores, necessary evils, minor inconveniences, inhibitors, reminders of formative events, and symbols of hardships overcome. That

these meanings were primarily negative reflected poorly on existing designs. Existing tracheostomies impose set meanings on users, but engaging them in the design process altered this dynamic, putting control back in users’ hands (Belk, 1988).

For the final design proposal, I used modular elements to give users the option of using their tracheostomy for self-expression. I hoped choosing the configuration of the design would help users integrate tracheostomy products with their extended self-image (Ahuvia, 2005; Belk, 1988). By instilling prototypes with improved usability and refined aesthetics, I wanted to reframe the tracheostomy tube as a sidekick, assisting users with the challenges brought about by their conditions, rather than a villainous obstacle.

DESIGN OUTPUT

My goals for the design outputs of this project were threefold:

Capture tracheostomy users’ experiences

Advocate for their needs

Challenge the status quo of existing tracheostomy designs

My intent was not to dictate a tracheostomy design solution, but to highlight the need for development after hundreds, if not thousands, of years of stagnation. Informed by literature, primary data, and shaped by my design perspective, the final prototypes present one approach to fulfilling the project goals. They should be viewed in the context of the wide range of brainstormed, sketched, and prototyped concepts that populate the thesis and give a snapshot of other valid approaches.

BROAD EXPLORATION

The concepts explored throughout the thesis play a role in capturing users’ experiences and advocating their needs. The range of approaches tackled capture different aspects of tracheostomy users’ experiences. I generated more concepts in a year than is evident in the history of tracheostomy. Not because I am an unprecedented visionary, but because the need to reflect the spectrum of user experiences seems to have gone unrecognised. Through my design work I hoped to underline how absurd it is that the complex, multifaceted needs of tracheostomy users are presumed to be met with a narrow range of homogenous solutions. While ongoing discussion about ways of balancing industry, design, and healthcare is needed, I wanted to make the case that many valuable approaches exist and should be explored.

MY APPROACH

As demonstrated by the array of approaches explored throughout the project, it was difficult to produce one solution to reflect the experiences of all tracheostomy users. While the final prototypes address some common user needs (e.g. magnets make components easy to assemble, simple forms make cleaning easy, modular components give users control over configuration, etc.), they ignore or contradict others. This is because I made a conscious decision to challenge the status quo, and felt synthesising all user needs would compromise this goal. Although several participants were pointedly against it, I felt a jewellery-inspired approach would emphasise values typically absent from medical design. Furthermore, the critical stance of contemporary jewellery design provided a framework for questioning what medical products should do, be, and look like (Cohn, 2012; Contemporary jewelry in perspective, 2013). Prioritising aesthetic considerations, I sought to reposition tracheostomy tubes as objects that adorn, rather than invade, the body, and to integrate them with the extended self (Ahuvia, 2005; Belk, 1988).

My packaging design also played a role in critiquing existing tracheostomies. When roleplaying as a tracheostomy user, I felt sterile tracheostomy kit packaging was clearly designed for clinical contexts rather than at-home use. While users did not take issue with tracheostomy packaging, I saw their unconcern as symptomatic of unquestioned expectations for medical product design (Barber, 1996). I felt a true repositioning of tracheostomy required considering the product ecosystem, including packaging. As such, I designed a wooden box as a permanent vessel for keeping tracheostomy products in the home. I aimed for a minimal aesthetic to complement my tracheostomy design and incorporated carved niches to instil each component with a sense of reverence.

CAPTURING USER EXPERIENCES THROUGH DESIGN

In addition to the main product proposal, I felt it important to communicate key findings about tracheostomy users' experiences through supporting artefacts (Boer, Donovan, & Buur, 2013; Malpass, 2015; Mazé & Redström, 2009). I produced a range of tracheostomy prototypes to critique specific shortcomings of existing designs. Each prototype captured key quotes from user interviews and co-design workshops. I applied familiar colours, textures, materials, and objects to the form of a tracheostomy strap to guide the way each artefact would be interpreted. My aim was to make aspects of what it's like to wear a tracheostomy visible, tangible, and immediately comprehensible to observers, regardless of their knowledge of tracheostomy products. I hoped these artefacts would serve as compelling tools for promoting empathy for tracheostomy users and driving efforts to address their needs.



RESEARCH PROCESS

Overall my research methodology, theoretical frameworks, and methods proved suitable to answering the research question and achieving my objectives. Applying action research principles ensured change-making remained a central goal of my research and design processes (Gray, 2014). Supported by human-centred design and co-design theory, it helped me place users at the foreground of the investigation in a way that was atypical of existing tracheostomy literature (Giacomin, 2014; Sanders & Stappers, 2008). User interviews and co-design workshops captured powerful insight into users' experiences. By combining traditional research documentation and creative methods—like sketching and prototyping—I was able to instil every aspect of the research with understanding of users' voices and concern for addressing their needs. Among the overall success, challenges were encountered with recruiting participants, managing complexities of the research subject, and balancing co-design data with the need for radical innovation.

RECRUITMENT

Recruitment posed a significant challenge to the research. Despite assistance from ORL staff who work closely with tracheostomy users, it took 9 months to recruit and interview 10 participants. The difficulties encountered with recruitment stemmed from limited numbers of people meeting the inclusion criteria (living with tracheostomy for at least 3 months), and the lack of records that could be used to find participants. We relied on staff remembering people they had treated who might be willing to participate.

From the pool of potential participants, it was difficult to find people able to commit to the demands of the research process. Limited mobility, transport, location, timing, and lack of interest were all factors preventing participation. In particular, recruitment highlighted the difficulties of doing research with

individuals who have complex health problems and multiple comorbidities. While recruitment was slow, the people who agreed to participate despite the challenges were enthusiastic about contributing towards positive change by sharing their experiences.

MANAGING COMPLEXITY

One of the greatest challenges faced was managing the complexity of the tracheostomy context. Tracheostomy users are diverse people dealing with an array of medical conditions. Tracheostomy tubes must reliably perform their life-sustaining function across a range of hospital-based and at-home situations. These complexities are compounded by the dramatic physical, emotional, and social impacts wearing a tracheostomy can have on users (Bello et al., 2016; Gilony et al., 2005; Hashmi et al., 2013; Morris et al., 2013). Beginning the project with no prior knowledge of tracheostomy, these factors were, at times, overwhelming. Considering the lack of attention traditionally given to users' concerns I felt a responsibility to solve as many of their problems as I could. At the same time, I recognised that taking on too much would compromise the value of the research outcomes given the limited project scope. To manage these concerns, I worked to make decisions that would best serve the research objectives. Rather than solving all of users' problems, I focused on capturing their experiences, advocating for their needs, and challenging the status quo for tracheostomy product design.

BALANCING CO-DESIGN

Related to managing the overall complexities of the research, I sometimes struggled with balancing co-design principles with the goal of challenging the status quo. To effectively question the lack of innovation in tracheostomy product design, I felt I needed to take an approach that might seem radical to users in comparison to existing designs. However, as a co-design facilitator, my role was to acknowledge tracheostomy users as experts of their experiences (Sanders & Stappers, 2008). When co-design participants expressed opposition to designs that looked radically different from existing tracheostomy products, I felt conflicted about my role. I was able to resolve my internal conflict by recognising the difference between treating participants as experts of their experiences and treating them as experts of design. In making this distinction, I realised I could address many of users' needs and desires in my designs while allowing my expertise to influence the forms, materials, and aesthetic elements I used.



RECOMMENDATIONS

Given additional scope, a number of steps could be taken to expand upon the findings and design outcomes of this project. Design outcomes could be tested and validated through a comprehensive co-design process with collaboration between a wider group of tracheostomy users, manufacturers, suppliers, and clinicians. Further attention could also be given to the product ecosystem, with deeper consideration of packaging, accessories, and a wider range of aesthetic choices.

CO-DESIGN

Due to limited project scope, and my own inexperience with co-design, co-design methods may not have been used to their full potential. Time constraints only allowed for two co-design sessions held over the course of a single day. This made it difficult to familiarise participants with the project and build rapport. It also limited opportunities to use knowledge gained from co-design sessions to develop more effective methods and approaches. To develop this project, I would therefore recommend implementing a longer term co-design strategy designed to build understanding and generate ideas over time. The outcomes of this project could serve as a starting point to probe discussion and inspire the generation of new ideas.

SELECTING PARTICIPANTS

To improve my co-design strategy I would reconsider participant selection criteria. Although long-term users were identified as ideal participants at the outset of the project, interview and co-design workshop findings indicated new users may also offer valuable input. Long-term users were selected based on experience with tracheostomy and familiarity with its long-term effects. It was also assumed aspects like comfort and aesthetics would be of greater concern to people living with long-term tracheostomy. Furthermore, new users may only require a tracheostomy for days or weeks.

While long-term users contributed rich insight, they had difficulty remembering how they felt when they first received their tracheostomies. They were used to managing the challenges of living with tracheostomy and had learnt to overcome issues with existing designs. This made it difficult to explore ways easing the process of adjusting to life with tracheostomy. As such, future research may benefit from comparing the experiences of long-term and newer users. It would be interesting to see how new users react to the final design proposal, and whether they would be more receptive to radical changes. Ideally, users who have newly received silver tracheostomy tubes would be targeted, as the experience of accepting tracheostomy as a long-term fixture would be fresh in their minds.

As well as including a broader range of tracheostomy users, including other stakeholders (like clinicians, district nurses, and manufacturers) in the co-design process could benefit future research. Working with diverse stakeholders would give each group insight into one another's priorities, stimulate inclusive discussion, and breed empathy. In particular, understanding tracheostomy users' experiences may alter the way clinicians and manufacturers perceive tracheostomy products and drive practical steps to improving them. Clinicians' and manufacturers' expertise would be useful for validating or critiquing the design outcomes of this project.

THE PRODUCT ECOSYSTEM

While my research advocates the need to consider the ecosystem of products and services surrounding tracheostomy tubes in order to meaningfully improve user experiences, I was unable to fully explore this avenue. The packaging included in my final design proposal demonstrates the role supporting objects can play in product-user interactions. However, further research should consider other supporting products and systems including cleaning devices, instruction manuals, methods for transporting tracheostomy essentials, and systems for product distribution. Research into these areas may require input from other areas of design expertise, such as service or communication design.

FUTURE RESEARCH

As well as expanding on the outcomes of this project, future research could address peripheral issues. There may be opportunities to use 3D scanning and printing technologies to manufacture tracheostomies customised to individual anatomy. A combination of engineering and design expertise could be applied to develop technological solutions for assisting tracheostomy users with speech. While I focused on improving silver tracheostomy tubes, a similar approach could be taken to improving plastic designs. Investigation of other materials could also lead to radical innovation. Research could be conducted to improve education for district nurses who may encounter tracheostomy users. Finally, specific efforts could be made to produce designs allowing users to shower and participate in water-based activities safely.







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APPENDICES



Hello, my name is Charlotte Dickson. I am currently a Master's student studying Product at Auckland University of Technology (AUT). I am interested in designing products that help people.



Hello, my name is Kolo Chen. I am currently an honours student studying Graphic Design at Auckland University of Technology (AUT). I am interested in designing communicative education materials.

As part of our postgraduate study, we are currently working on research with the aim of finding out what the experience of living with a long term tracheostomy is like for tracheostomy users, their family members, and their partners and how we might use design to help improve those experiences.

WHOM DO I CONTACT FOR FURTHER INFORMATION ABOUT THIS RESEARCH?

Researcher Contact Details:
Charlotte Dickson:
charlottedickson93@gmail.com

Kolo Chen:
kolo.chen94@gmail.com

Project Supervisor Contact Details:
Stephen Reay: Stephen.reay@aut.ac.nz,
09 021 9999 ext 6719

HOW WILL MY PRIVACY BE PROTECTED?

You will not be anonymous to us or to other people participating in the workshop. This means people will know your name and what you say during the workshop. It is expected that you and the other workshop participants will respect each other and maintain each other's privacy.

For our research documentation the names relating to any examples, photos, videos, or audio recordings will be changed with your permission so you cannot be identified. Everything that we collect will be kept for a minimum of six years and then destroyed.

WILL I RECEIVE FEEDBACK ON THE RESULTS OF THIS RESEARCH?

If you would like to receive information about the results of this research you can let us know and we will send you a summary report of the research.

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.

WHAT WILL HAPPEN DURING THIS RESEARCH?

All of the sessions will be photographed, as well as video and audio recorded so we can focus on working with you instead of writing notes.

The research session will consist of a two-hour long, interactive workshop that will be broken up into two parts. You will be asked to share your experiences of living with a long-term tracheostomy. You will also have the opportunity to look at and share your opinions about a range of design concepts relating to tracheostomy.

Part one:

For the first part of the workshop you will be working with Charlotte Dickson. You will be shown a range of tracheostomy tube design concepts in the form of sketches and prototypes. You will be asked to discuss these concepts in relation to your experience of living with a long-term tracheostomy.

Part two:

For the second part of the workshop you will be working with Kolo Chen. You will look at a range of design concepts focusing on the way information about tracheostomy is communicated to tracheostomy users. These concepts may take the form of printed or digital materials (e.g. printed booklets, digital animations, etc.). You will be asked to discuss these concepts in relation to your experience of living with a long-term tracheostomy.

WHY AM I BEING INVITED TO THIS WORKSHOP?

You have been invited because you participated in an interview relating to this study and expressed your interest in participating in this workshop. You will now have 2 weeks to consider whether you would like to participate. If you would like to participate you can let us know by sending an email to either kolo.chen94@gmail.com or charlottedickson93@gmail.com. If you do not wish to participate you will not be contacted further.

WHAT IS THE PURPOSE OF THIS RESEARCH?

We are interested in understanding what it's like to be a long-term tracheostomy user and how we can help to make it a better experience through design. The purpose of this research is to understand the needs of tracheostomy users and to produce product and graphic designs that will help to provide for these needs.

With your help, the outcome of the research will include product and graphic design prototypes intended to improve the experience of living with tracheostomy. The results of this research will also be published in a Master's thesis and an Honour's dissertation.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS RESEARCH?

There is no cost to you for participating in this research other than a maximum of 2 hours of your time. To cover the travel expenses associated with participating, you will receive a \$20 petrol voucher and a monetary contribution to cover 3 hours of parking at Auckland City Hospital.

PARTICIPANT INFORMATION SHEET

A co-design workshop for improving the lived experience of tracheostomy users.

2016

WHAT ARE THE BENEFITS?

We benefit from this research by using the results to complete our qualifications. We also get to practice our research skills and gain experience running a project like this.

In return we hope that you will benefit from the opportunity to contribute towards the improvement of the experience of living with a long-term tracheostomy. We hope that the outcomes of our research will benefit.

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 in a group situation, or feel tired because the sessions are too long.

You are most at risk from other people who are also taking part who may not keep information you give confidential.

HOW WILL THESE DISCOMFORTS AND RISKS BE REDUCED?

To help you feel more comfortable sharing your thoughts and ideas, you are welcome to bring a family member or partner with you to participate in the workshop.

You can also talk to any of the researchers involved in the workshop at any time if you have questions or concerns about the workshop. You can leave the workshop at any time, no questions asked, and you can withdraw at any time up until the end of the workshop.

Co-Design Workshop Protocol

Participants

Co-design workshop participants will be long term tracheostomy users and their family members or partners.

The workshops will take place in a private meeting room at Auckland City Hospital.

Data Recording

Workshops will be video and audio recorded and later transcribed. Artefacts generated by participants as part of their participation in the workshop (for example ideas drawn or written on post it notes and prototypes made from simple supplied materials like plastercine or paper) will also be collected and photographed. Participants will be made aware of the data recording methods via the participant information sheet and reminded again verbally at the start of the workshop.

Purpose of the Workshop

The overall purpose of the workshop is to allow participants to share their experiences of living with a long term tracheostomy and to contribute ideas towards the development of design solutions. As part of the workshop participants will also be shown a range of design concepts in the form of sketches and prototypes and have the opportunity to offer feedback on these concepts.

Content of the Workshop

The workshop will last for two hours and will be an interactive session, broken up into two parts. The first part of the workshop is the part that relates to this ethics application. A brief overview of the second part of the workshop is also included for clarity, but is not part of this application.

Workshop Part One:

The first part of the workshop will be approximately one hour long and will be led by the student researcher (Charlotte Dickson). This part of the workshop will focus on the design of tracheostomy tube products and will begin with an icebreaker activity, followed by the two main activities. The icebreaker activity will last approximately ten minutes. The two main activities will last approximately twenty-five minutes each.

Icebreaker Activity: At the beginning of the workshop participants will be asked to briefly introduce themselves including their name, background, and their background in relation to tracheostomy. They will also be asked to answer the following open ended question:

- Can you tell us what the most annoying thing about living with tracheostomy is for you?

Activity One: Participants will be shown a range of tracheostomy product design concepts generated by the student researcher (Charlotte Dickson) in the form of sketches and prototypes. The concepts will reflect four possible approaches to tracheostomy product design (aesthetic focus, usability focus, discrete approach, and treating tracheostomy as mass consumer product). The researcher will give a brief explanation of each approach and use the concepts as a starting point for discussing what aspects of tracheostomy product design are most important to participants. The researcher will gauge the responses of participants and focus the discussion on the design approaches or specific concepts that best reflect the interests of the group. Participants will be encouraged to share their thoughts and opinions about the design concepts. Questions that may be used to facilitate the discussion during this activity are:

- Which of these approaches do you think would most improve your experience of living with tracheostomy?
- Are there any concepts you see here that you are drawn to? Which concepts? Why?
- Are there any concepts you see here that you dislike? Which concepts? Why?
- What problems can you identify with this concept that would make it difficult or otherwise unpleasant to use?
- What do you think about this particular concept? Does it remind you of anything? Would you be comfortable wearing it?
- How would this concept fit in with your everyday life? How would it fit in with the other products you use as part of tracheostomy care?

Activity Two: Participants will be asked to contribute towards a collective brainstorm of ideas for improving tracheostomy product designs. Participants will be given post it notes and writing tools and encouraged to note down as well as discuss any ideas they have. Questions that may be used as prompts for brainstorming and discussion are:

- What might your ideal tracheostomy tube (or associated product such as speaking valve or humidifier) look like?
- What is one feature of your tracheostomy tube (or associated product) that bothers you the most? How do you think it could be improved?
- Of the concepts you saw earlier, which features could you combine to make a better design?
- Of the ideas generated by other participants in this brainstorm are there any that you think could work together to make a better design?

Workshop Part Two:

The second part of the workshop will be run by Kolo Chen and will last for approximately one hour. During this part of the workshop, participants will be asked to look at and give feedback on a range of design concepts focusing on the way information about tracheostomy is communicated to tracheostomy users. These concepts may take the form of printed or digital materials (e.g. printed booklets, digital animations, etc.). Participants will be asked to discuss these concepts in relation to their experience of living with a long term tracheostomy.

Expert Interview Participant Information Sheet



Date Information Sheet Produced:
19 April 2016

Project Title
Designing out stigma: Improving the experiences of long-term tracheostomy users through product design

An Invitation
Hello, my name is Charlotte Dickson. I am currently a Master’s student studying Product at Auckland University of Technology (AUT). I am interested in designing products that help people. As part of my Master’s degree, I am currently working on research with the aim of finding out what the experience of living with a long term-tracheostomy is like for tracheostomy users, their family members/partners and how we might use design to help improve those experiences. I am also interested in the perspectives of clinical staff on the experiences of tracheostomy users and the roles that staff play in tracheostomy care.

What is the purpose of this research?
I am interested in understanding the experiences associated with tracheostomy use and exploring how I can contribute to improving these experiences through design. The purpose of this research is to find out what the needs of tracheostomy users (including clinicians) are and to produce product design concepts that will help to provide for these needs. With your help, the outcome of the research will include product design prototypes intended to improve the experience of using a tracheostomy. The results of this research will also be published in my Master’s thesis, which you will have access to once finished.

How was I identified and why am I being invited to participate in this research?
You have been approached because I approached the ORL Department at Auckland City Hospital to ask if they knew of anyone who would be able and willing to help me. You have been invited to participate because the ORL Department 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, I will ask you some open-ended questions about your experiences in relation to tracheostomies. I will ask you to share your expertise as it relates to the research. This will include asking you about your thoughts on the physical design of existing tracheostomy tubes as well as your perspective on the physical and emotional impacts of tracheostomy tubes on their users. 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 potential improvement of tracheostomy tube design.

How will my privacy be protected?

You will be not be anonymous to me as the researcher. This means that I will know your name and who you are. I will however respect and maintain your privacy and confidentiality.
For my Master's 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 the 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, 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 copy of the finished thesis.

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?

Researcher Contact Details:

Charlotte Dickson, *charlottedickson93@gmail.com*

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 13 May 2016, AUTC Reference number 16/165.

Expert Interview Protocol

Participants

The interviewees will be clinical staff or other experts working in the health system.

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 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.

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, ORL nursing staff may be asked about their interactions with tracheostomy users as well as their own experiences of using tracheostomy products.

Sample Questions

- Can you describe what your role is in the treatment with tracheostomy users?
- Can you tell me about your experiences with using tracheostomy products?
- In your experience what kind of emotional responses do tracheostomy users have to living with tracheostomy?
- What do you think the hardest parts of living with tracheostomy are?
- What do you think of the design of tracheostomy tubes and other tracheostomy products (humidifiers, speaking valves, etc)? Which aspects do you like or dislike and why?
- Can you think of any changes that could be made to the design of tracheostomy products what would improve your experience of dealing with tracheostomies, or the experiences of people living with tracheostomies?
- What aspects of working with tracheostomies and tracheostomy users are the most challenging and why?



AUTECSecretariat

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9 May 2016

Stephen Reay
Faculty of Design and Creative Technologies
Dear Stephen

Ethics Application: 16/165 Designing out stigma: improving the experiences of long-term tracheostomy users through product design.

Thank you for submitting your application for ethical review. I am pleased to advise that a subcommittee of the Auckland University of Technology Ethics Committee (AUTECS) approved your ethics application subject to the following conditions:

1. Provision of the observation protocol, as indicated in the response to section A.5.1 of the application form;
2. Provision of the indicative interview questions for staff interviews;
3. Revision of the section C.3.5 recruitment sections of the application form that customises the responses for this application (including recruitment of staff for interviews, as well as workshop attendees);
4. Completion of section K.4.2 of the application form;
5. Completion of section M of the application form;
6. Provision of a detailed protocol outlining what is going to happen for participants and what they are being asked to do in this part of the research;
7. Amendment of the Information Sheet (interviews) to include advice of whether the interviews are recorded, and if transcription will be available for review;
8. Amendment of the Information Sheet (workshop) as follows:
 - a. Alteration of the withdrawal statement to say ' you can withdraw at any time up until the end of the workshop (rather than data collection);
 - b. Advice that a summary report rather than research documents, (thesis & dissertation) are available;
 - c. Inclusion of advice of the length of time participants have to think about the invitation to take part in the workshop, having received the invitation at the completion of the interview phase;
 - d. Completion of the discomforts and risks section "you are most at risk from other people...."
9. Amendment of the Consent Form (workshop) to include appropriate statements with respect to the videos and photographs, as well as statements pertaining to group confidentiality.

Please provide me with a response to the points raised in these conditions, indicating either how you have satisfied these points or proposing an alternative approach. AUTECS also requires copies of any altered documents, such as Information Sheets, surveys etc. You are not required to resubmit the application form again. Any changes to responses in the form required by the committee in their conditions may be included in a supporting memorandum.

Please note that the Committee is always willing to discuss with applicants the points that have been made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

Once your response is received and confirmed as satisfying the Committee's points, you will be notified of the full approval of your ethics application. Full approval is not effective until all the conditions have been met. Data collection may not commence until full approval has been confirmed. If these conditions are not met within six months, your application may be closed and a new application will be required if you wish to continue with this research.

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.

I look forward to hearing from you,

Yours sincerely

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Charlotte Dickson charlottedickson93@gmail.com

SURGEON’S FEEDBACK

To obtain feedback on the final prototype and gauge the potential for developing the design further, I held a meeting with the surgeon who initially identified the project opportunity. The surgeon responded positively to the overall design, recognising the value of features like the use of magnets and the simple bar for attaching the tracheostomy to the chain. The only change suggested was reducing the wall thickness to make the tube lighter. This tweak can easily be made now that the initial prototype has demonstrated proof of concept.

The greatest benefit of the design as identified by the surgeon is it’s bespoke nature and the opportunity to use 3D printing to customise tracheostomy tubes to fit user anatomy. Where existing tubes come in standard sizes, my design could use dimensions taken directly from scans of users’ tracheae. In light of this, the surgeon was eager to assist with further development by finding user data to produce a custom tube.

With regards to further development, the surgeon also offered some insight into the regulatory processes for the design of medical devices in New Zealand. This would likely involve completing documentation to demonstrate that the design meets established safety requirements. The surgeon believed this process could be relatively straightforward given the basic form and materials used in the design are similar to those of existing silver tracheostomies.

