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Co-design to understand the tracheostomy product experiences of long-term tracheostomy users

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ABSTRACT

Tracheostomy product designs have barely changed in 100 years. Furthermore, there is limited research into the experiences of people living with long-term tracheostomy. Existing tracheostomy designs focus on minimizing costs and maintaining clinical function, often at the expense of user experience. Because tracheostomy user numbers are relatively small, their needs are overlooked despite the significant impact on their everyday lives. In response, this research aimed to capture tracheostomy users’ stories, advocate for greater consideration of their needs and challenge historic stagnation in tracheostomy design. Co-design workshops were used to give tracheostomy users a voice, build a better understanding of the daily challenges they face and explore the complex relationships they have with their tracheostomy products. Research findings were captured in a series of critical design artefacts intended to evoke empathy for users’ experiences and highlight problems with existing tracheostomy products. 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. The critical design artefacts are part of ongoing work concerning the design of tracheostomy products, and will be used to build support for improving tracheostomy users’ experiences.

Introduction

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). 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). Because tracheostomy is used in various treatment contexts, it is difficult to determine how
many people it affects. However, Garruba, Turner, and Grieveson (2009) suggest that approximately 7000 tracheotomies are performed annually in Australia and New Zealand. A small percentage of these cases are likely to result in long-term tracheostomy use.

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. 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. By the early 1800s tracheostomy had achieved a degree of routine application (Szmuk et al. 2008). Despite 4000 years of history, tracheostomy tube designs show little change.

Tracheostomy tubes come in various sizes, materials and configurations depending on the condition being treated, airway anatomy and comorbidities (additional conditions or diseases) of the patient (Lewarski 2005). Tubes may be angled or curved and of varying length, with the fit impacting comfort and effectiveness (Feber 2006; Hess and Altobelli 2014). Tubes with large inner diameters give better airway clearance, but large outer diameters can be difficult to insert and uncomfortable to wear (TRACOE Medical 2011; Hess and Altobelli 2014). 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 removed and cleaned while the outer cannula remains in place to provide a safe airway (Lewarski 2005; Hess and Altobelli 2014).

Tracheostomy tubes are predominantly made from either silver or polyvinyl chloride (PVC) (see Figures 1 and 2). Silver tubes have thinner walls and larger inner diameters, allowing users to breathe more easily. They are also durable, and do not react against the skin. However, they are only cost effective for long-term use (NHS Trust 2010; Hess and Altobelli 2014). PVC tubes soften at body temperature and conform to the individual’s anatomy. PVC is more malleable, and is described in tracheostomy literature as offering better comfort (NHS Trust 2010; Hess and Altobelli 2014).

Some tracheostomies include openings, called fenestrations, in the rear section that allow air to pass through the vocal cords so patients can speak (Lewarski 2005; Hess and Altobelli 2014). PVC tubes sometimes 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 and 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.
Figure 1. Features of a cuffless fenestrated silver tracheostomy tube set.

Figure 2. Features of a cuffed plastic ‘Portex’ tracheostomy tube set.
Because users cannot breathe without their tracheostomy tubes, they often carry an emergency tracheostomy kit, and must integrate maintenance of their tracheostomy products with their daily routine (TRACOE Medical 2011). 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 and Coast District Health Board 2015; Feber 2006; Lewarski 2005; NHS Trust 2010; TRACOE Medical 2011). The recommended frequency for PVC tube changes (replacement of both inner and outer cannulae) is largely based on local practice or influenced by product availability as determined by health care organizations 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 for PVC tubes (Feber 2006; Hess and Altobelli 2014). Silver tubes last approximately 10 years but must also be cleaned regularly.

Tracheostomy tubes can irritate the trachea and increase natural mucus production. Because 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 through the mouth or nose, people using cuffed tubes (or those unable to cough away secretions) may require mucus to be removed using suction. Although tube changes and suctioning are often described as painless, some evidence suggests patients do experience discomfort during these processes (Donnelly and Wiechula 2006; Foster 2010; Sherlock, Wilson, and Exley 2009). The demands of tracheostomy maintenance can limit autonomy and force patients to structure their lives around their condition (Barnett 2006).

Physical appearance plays an important role in human interactions (Bonanno and Esmaeli 2011). Historically, people benefitted from the ability to judge the health, reproductive suitability and social standing of others based on appearance (Bonanno and Esmaeli 2011). People who conform to cultural beauty ideals are perceived as kinder, more competent and more intelligent than those considered less attractive (Bonanno and Esmaeli 2011; Costa et al. 2014). On the other hand, distaste for appearances that deviate from cultural ideals is 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 and Harcourt 2004). Furthermore, image-drenched media culture has taken our preoccupation with appearance to the extreme (Bradbury 2012; Rumsey and Harcourt 2004; Stock et al. 2013). 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 and 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 and Kent 2001; van den Elzen et al. 2012). They often experience low self-esteem, poor body image, social anxiety
and depression (Bradbury 2012; Rumsey and Harcourt 2004). In public interactions they may encounter stares, rude remarks, unwanted questions and other forms of harassment (Bonanno and Esmaeli 2011; Stock et al. 2013; Thompson and Kent 2001).

Tracheostomy tubes significantly alter users’ appearances, causing shame and attracting stigma (Gilony et al. 2005; Morris, Lupei, and Afifi 2013). Even if an individual manages to disguise their tracheostomy 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 (Gul and Karadag 2010; Hashmi et al. 2013). For example, failing to regularly clean and change tracheostomy products can result in illness or infection (Bello, Di Muzio, and Antonelli 2016; Hashmi et al. 2013). Tracheostomy is also culturally associated with smoking. As a result, tracheostomy users are sometimes blamed for their condition, whether or not smoking is the underlying cause (Vaes 2014).

Despite the significant impacts tracheostomy has on many facets of tracheostomy users’ lives, there is a lack of literature exploring the relationship between the lived experiences of tracheostomy users and tracheostomy design. Because tracheostomy tubes are usually just part of the treatment for other conditions, the impact the tracheostomy tube itself has on users is often overlooked. Long-term tracheostomy is also relatively uncommon, further contributing to the lack of understanding of tracheostomy users’ experiences. The aim of this research was to address this lack through a co-design approach, bringing long-term tracheostomy users together in collaborative workshop sessions to explore opportunities for improving tracheostomy design.

Methodology

The research builds on a related prior study (Wrapson et al. 2017) that aimed to understand the lived experience of users of long-term tracheostomies. The findings from these interviews helped inform this research, and specifically the need to explore how the products associated with long-term tracheostomy were perceived by users. As such, co-design workshops were used to empower tracheostomy users in the design process and understand their experiences. They enabled participants to create artefacts, contribute ideas and partake in discussions that built an understanding of their world (Boyd et al. 2012; Neimeyer and Torres 2001; Sanders and Stappers 2008).

A range of participants were sought to ensure good representation across gender, age, ethnicity and diagnosis. Participants had to have had a tracheostomy for at least three months. They also had to be able to communicate either
verbally, or assisted by a support person. Those who could not understand English were excluded from the research.

Potential participants were approached by Auckland District Health Board’s (ADHB) Otorhinolaryngology (ORL) clinicians based on their knowledge of people who met the participation criteria, and invited to participate in the research. Participants had used their tracheostomies for between 1 and 25 years and ranged in age from 25 to 75. Causes for their tracheostomies included neck tumour, stroke, human papillomavirus and vocal cord paralysis. Seven participants identified as female, and three as male. Four participants were NZ European, and one was of mixed Maori and NZ European decent. Two participants brought support people. Two one-hour-long co-design workshops were held in the Design for Health and Wellbeing Lab (DHW Lab) at Auckland City Hospital (Reay et al. 2016). Workshops were video and audio recorded, then transcribed for analysis. Ethics approval was obtained for the study (approval number 16/165).

Workshops consisted of two creative activities facilitated by designers and executed in collaboration with participants (Sanders and Stappers 2008). The aim was to explore user experiences in relation to tracheostomy product design. The first activity was a group brainstorm of ideas for improving tracheostomy products. The second activity involved asking participants to evaluate and select prototyped tracheostomy components to create their own designs (the mix-and-match activity), then discuss the factors informing their selection (e.g. perceived quality, personality, gut feeling, memory associations, etc.). Boer, Donovan, and Buur (2013) described this ‘provotyping’ (provocative prototyping) as a critical approach used in generative design research to foster collaboration and facilitate discussion. Prototypes were conceptual form studies generated specifically for this research. They explored a range of aesthetic and functional approaches to help users imagine possible alternatives to existing designs.

Data were unpacked using thematic analysis to extract patterns of meaning from workshop findings (Braun and Clarke 2014). Workshop footage and transcripts were reviewed and ‘codes’ were assigned to key 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 data content. Codes were further organized into themes relating to the research aims (e.g. ‘improvisation’, ‘isolation and lack of support’, ‘resistance to change’, etc.). The resulting themes and sub-themes are described in the following sections.

Following thematic analysis, a critical design approach was used to translate key findings into physical objects. Critical design uses design practice to provoke critical reflection in its audience, often highlighting and challenging the ideologies underlying designed objects (Bowen 2007; Dunne and Raby 2011). For this research, critical artefacts were produced that provoke observers to identify and question five aspects of existing tracheostomy designs that negatively impact tracheostomy users’ experiences. By challenging the status quo of existing
tracheostomy product designs, the critical artefacts contributed to the ongoing research, helping to express the need for change.

Results

Initially participants tended to become distracted with tangential conversations about their experiences of living with tracheostomy, rather than engaging directly in the workshop activities. Through these conversations, it became apparent that most participants had not met other people with tracheostomies. The workshops appeared to provide a unique opportunity to share their stories with each other. During the brainstorming activities, participants identified flaws with existing designs but found it difficult to generate ideas for improving them. Difficulties with fostering engagement were also encountered with the mix-and-match activity. Most participants were dismissive of concepts shown, quickly listing reasons why 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 struggled to think beyond the literal forms of the prototypes to imagine how different aspects might be developed into a functional design. A few participants were open to new ideas and interested in interacting with prototypes. These participants were able to identify prototypes they felt had potential for development.

Participants’ responses to prototypes provided insight into the practical reasons they disliked some ideas. Prototypes which received positive feedback indicated potential for development. Participants’ feedback also provided insight into their experiences and relationships with tracheostomy products. In this sense, prototypes fulfilled their role as generative probes, stimulating discussion and bringing new information to light.

Participants preferred more conservative and familiar ideas. They worried a cord strap would cut into skin but were comfortable with 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 (see Figure 3 for prototypes and corresponding participant feedback).

Two concepts were presented for covering the front surface of the hole and redirecting airflow out the bottom. It was assumed 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).
While workshop activities did not run exactly as intended, this did not inhibit the richness of data. Interacting with tracheostomy users in person and observing their interactions with one another helped build a better understanding of their experiences.

Key workshop findings were categorized as follows:
Eagerness to share

From the outset of each workshop session, it was clear that 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.

One participant spent two hours each day on tracheostomy maintenance, and came to the workshop 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.’ Another participant expressed a similar sentiment, saying, ‘I’ve been waiting for this for years.’ It was evident that participants harboured numerous frustrations with their experiences and wanted to do something about them. The stories participants told also demonstrated what the workshops meant to them. For many, this was their first chance to share with people who could relate. This 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 life with tracheostomies. They felt others could not understand what they were going through and that support offered by clinicians was inadequate for easing their struggles. Interactions with inexperienced district nurses, communication difficulties and self-consciousness of their acquired visible difference contributed to participants feeling isolated and unsupported. One key cause for participants’ feelings of isolation was the rarity of long-term tracheostomy. Participants typically had little knowledge about tracheostomy prior to their treatment. 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.’ In the absence of support from – or knowledge of – other tracheostomy users, participants felt alone in their struggles.

Feelings of isolation were compounded by participants’ interactions with clinicians and health care 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. Clinicians had even encouraged participants to wash and reuse single-use, disposable neck straps, which fall apart when wet. In some cases, participants had to purchase items like nebulizers or saline solution themselves. One frustrated participant said: ‘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.’ Lack of support was attributed to the fact that their conditions were no longer acute. One participant was
indignant that her experiences were not given due consideration, explaining that clinicians don’t ‘really know what it’s like to have a tracheostomy... unless you’ve been there, you don’t know.’ The lack of adequate support drove participants to improvise their tracheostomy care and become self-advocates for their treatment.

**Resistance to change**

While aspects of tracheostomy care were initially difficult, participants felt these struggles were negated by the competence and confidence they had since developed. 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, 20 years with tracheostomy on and off), to explain the belief that improving tracheostomy product design would not improve their experiences. This was in sharp contrast to the passionate dissatisfaction many expressed with the treatment they had received and the products available to them.

Participants identified aspects of existing designs they were unhappy with, but resisted change when presented with tangible prototypes, making comments like; ‘I’d rather it just look like a trachy.’ 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. 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.’

Despite having worn a tracheostomy tube for multiple decades and regularly customizing her own tracheostomy accessories, this participant did not 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.

**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 realized what it was. Another participant was adamant that tracheostomy products needed to reflect their medical function.

Despite participants’ fears, their stories showed how being tracheostomized had altered their lives and inevitably shaped their identities. Participants began workshops by embarking on unprompted, enthusiastic retellings of
tracheostomy-related stories and jokes. One participant joked; ‘It would be nice if they did do vocal cord transplants, I’d have Michael Jackson’s.’

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. Tracheostomy tubes became symbols of the adversities overcome while learning to live with them. Participants’ stories suggested they saw their tracheostomies as ‘badges of honour’ and associated the appearance of existing designs with this idea.

The nature of tracheostomy in shaping users’ speech reinforced 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. This was perceived 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 co-design sessions.

One participant felt that, although having a tracheostomy was not a choice, he had ‘a lot of choice around how to maintain and use it to best effect.’ This participant also believed there should be one ‘best practice’ approach to tracheostomy care. He mentioned having choices available to him in tracheostomy accessories but contradicted this belief by resorting to modifying his own tracheostomy with a silver chain.

Another 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.’ Her statement reflected feelings of injustice at inadequate choice and awareness that customization is feasible in other medical contexts. Later, 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.’

Perhaps participants saw product choice as unfeasible because they were used to receiving limited support. One participant demonstrated reluctance to expect more choice with the statement; ‘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.’

**Discussion**

A number of factors may have contributed to the disparity between the co-design workshop intentions and the way that participants engaged with activities 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, expectations for the workshop outcomes may have been unrealistic. Given their experiences with health care systems, participants may have struggled to envisage how more radical concepts could be implemented. The contradictory attitudes expressed by some participants made unpacking their attitudes more difficult.

However, these contradictions might be explained by their experiences of having their needs neglected by health care systems. Participants may be cautious of asking too much when they know health care product design is largely cost driven (Barber 1996). They may have learnt to hedge their bets and fight only for improvements they see as attainable. Regardless, participants’ depth of engagement in the workshops validated the importance of the research in giving tracheostomy users a voice.

People who had had tracheostomies for at least three months were initially selected as the focus of data collection because they would be able to discuss their experience of living in the community with a tracheostomy. However, 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 using existing products, they were 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. New users may be more receptive to change and more radical designs, and should therefore be included in future research in this area.

Overall, the co-design workshops contributed to a rich understanding of what it is like to live with a long-term tracheostomy. To capture findings and convey participants’ experiences in a way that could help drive ongoing research, a series of critical design prototypes were produced to illustrate tracheostomy users’ critiques of the products they use (Boer, Donovan, and Buur 2013; Koskinen et al. 2011; Malpass 2015; Mazé and Redström 2009) (Figures 4–8). In particular, the works of photographer Giuseppe Colarusso and designer Katerina Kamprani inspired the development of prototypes that point out the absurdity of the
Figure 4. Critical design prototype using a paper tracheostomy strap to convey the problem of existing straps disintegrating with use. This prototype was inspired by the following workshop participant 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 creates a visual analogy to the familiar experience of accidentally putting paper through the wash. While few people know what it is like to live with a tracheostomy, most people can relate to finding soggy paper clinging to their clean washing.

Figure 5. Critical design using a strap fastened with padlocks to communicate the difficulty of fastening existing tracheostomy tubes. This prototype was inspired by the following workshop participant 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, 20 years with tracheostomy on and off). It can be difficult to thread the Velcro through the holes, particularly for users with arthritis.
Figure 6. Critical design prototype using a sandpaper strap to convey the discomfort of wearing a tracheostomy tube. This prototype was inspired by the following workshop participant quote: ‘You know when your bra strap is too tight and you get those dents? That’s what happens.’ (55-year-old female, 24 years with tracheostomy). Existing tracheostomy straps may look comfortable, however, their constant presence combined with sweat and mucus secretions can cause significant discomfort.

Figure 7. Critical design prototype using a faux fur strap smudged with graphite to convey the difficulty of cleaning existing tracheostomy tubes. This prototype is inspired by the following workshop participant quote: ‘Any tracheostomy has difficult places to clean,’ (60-year-old male, 1 year with tracheostomy).
problems users encounter with existing tracheostomy products (Colarusso 2013; Kamprani 2014). Colarusso and Kamprani both produce images of familiar objects with minor alterations that undermine their functionality, rendering them absurd (Jobson 2013; Maddux 2014). The images convey humour while encouraging viewers to consider why everyday objects are designed as they are.

Although most people are unfamiliar with tracheostomy products, their medical aura provokes the assumption that they are carefully designed for specialized function. Co-design workshop findings revealed overlooked flaws with existing tracheostomy products. For example, tracheostomy straps draw unwanted attention, stain easily and fall apart when wet. The critical design artefacts were developed using familiar colours, textures, materials and objects to the form of a tracheostomy strap to guide the way each artefact would be interpreted. The goal was to make aspects of tracheostomy users’ experiences visible, tangible and immediately comprehensible to observers, regardless of their knowledge of tracheostomy products. Where the challenges facing tracheostomy users are largely overlooked due to the relative rarity of their condition, these artefacts will serve as compelling tools to promote empathy for their experiences and encourage ongoing efforts to address their needs.

This research, and the prior study described in this issue (Wrapson et al. 2017) together help demonstrate the role of design to reconsider products and the experiences that result from their use for long-term health conditions. More

Figure 8. Critical design prototype using a hi-visibility tracheostomy strap to convey the idea that tracheostomy tubes draw unwanted attention. This prototype was inspired by the following workshop participant quote: ‘It sticks out like a sore toe,’ (55-year-old female, 24 years with tracheostomy).
specifically, this research provides an example for how the use of creative practices and design-led approaches can draw rich and often complementary insights from users. Furthermore, the use of visual methods help give greater visibility of the challenges and opportunities faced by users, and can be a powerful way to advocate for those users whose voice may be seldom heard in complex health care systems.

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Disclosure statement
No potential conflict of interest was reported by the authors.

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R. Douglas, after spending time working in traditional product design, helped establish the Design for Health and Wellbeing Lab in Auckland City Hospital where he is currently employed. His work ranges from applied areas such as furniture design, wayfinding solutions and communication design to helping manage a mixed discipline studio environment. He also has a focus on mentoring postgraduates and interns who are interested in using their design skills in the health context.

I. Nakarada-Kordic is a qualitative researcher with a background in human factors and health psychology. Her work at the DHW Lab focuses on user experiences in the health care context. As part of the Lab’s multidisciplinary team, she is currently involved in various co-design projects involving patients, designers, researchers and clinicians in the Auckland area.

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