Challenging Health-Related Stigma through Design

M. H. M. Vermeeren

M2.1 (Pre-FMP) project, Semester A 2019-2020

Mentor: S. C. Kuijer

Assessor: J. B. O. S. Martens

Relation to Vision

As a designer, I have a great interest in design that impacts users through its functionality, but also the larger social context through its expressed vision. Throughout my studies I have discovered that I am passionate about contributing to the values of self-actualization and social connection through my work.

Promoting personal wellbeing and challenging social taboos have been prominent aspects of my earlier bachelor and master projects, which explored these topics for several user groups and contexts. For example, design encouraging conversation with people with dementia through a personalized game, helping people with the rheumatic diseases wake up pleasantly, or helping office workers deal with stigma about workplace stress through collective awareness and discussion.

Designing for a user group that experiences health-related stigma embodies these values of my vision and earlier projects: contributing to users' wellbeing through practical design that addresses their needs, and challenging stigma in a societal context through the project's vision.
This requires a thorough understanding of both the personal and societal context, as well as respect for users' expertise living with a health condition in this context. Furthermore, I have found it is valuable to focus on the role the designer plays to shape this context to make meaningful change possible. This project aims to balance these important aspects of my vision and identity.

Abstract

This project aims to challenge health-related stigma for people with heath conditions or medical needs from a design perspective, and explores how designers can influence health-related stigma through their methods and inherent qualities of their work. Furthermore, this project aims to start a debate about the role, motivation, interest, and perspective of designers and explore how to motivate change.
Three design explorations are presented to illustrate different design approaches to challenging health-related stigma in different user contexts. The approach was strongly inspired by how the target group copes with stigma, which explored how the user can express medical identity through design and how design can support normalization strategies that challenge stigma. Insights from the designer and bystander perspective are analyzed and discussed in relation to the project and the greater context.

Introduction & Related Works

What is health-related stigma?

The following prominent definition of health-related stigma is perhaps the most illustrative introduction of this topic and its relevance:

> *"Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g., race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma"* (Weiss, Ramakrishna,& Somma, 2006).

Because stigma depends on the societal perception rather than the medical reality of a condition, it is highly dependent of cultural and social context and the type of condition (Weiss et. al., 2006; Scrambler, 2009). Furthermore, the stigma is often accepted and incorporated into the identity of individuals who suffer from a condition. This phenomenon is often addressed as self-stigma: "the individual's internalization of public stereotypes and the "self-discrimination" that follows" (Jones & Corrigan, 2014). Although this term is mainly used in regards to mental health conditions, the same process is observed in individuals with physical health conditions.
Health-related stigma and self-stigma create suffering unrelated to the medical issue itself, which may further impair the health of the affected person, and even cause people to forego diagnosis or treatment. Interventions to combat health-related stigma therefore need to be specifically designed based on the situation and type of condition (Heijnders & Van der Meij, 2006).

Visibility and hiding

The stigma one experiences is also largely dependent on the visibility of their condition to others and how it relates to "normal" standards for physical aesthetics (Joachim & Acorn, 2000b). Literature therefore typically differentiates between individuals who are "discredited", whose stigma is known or visible, and "discreditable", whose stigma is unknown or hidden (Chaudoir, Earnshaw, & Andel, 2013).

Individuals with clearly visible health conditions and discrediting attributes (such as a physical impairment or use of a mobility aid) are stigmatized by others often at first glance. Therefore, many attempt to trivialize the severity and impact of their condition in the perception of others to lessen the consequences of stigma. People even go to great lengths to hide their condition entirely to avoid stigma, sometimes at the cost of their own comfort and wellbeing. (Joachim & Acorn, 2000b). There is a great desire to control how one is perceived by others because visibility has social consequences, of which the extent and risk is not always clear. This often causes fear of being discovered and discredited. The voluntary disclosure of one's condition is therefore a difficult and sensitive topic for discreditable individuals whose condition is invisible or can be partially concealed. These dynamics of disclosure are shown in figure 1.

Reducing (Self-)Stigma through Visibility And Normalization

Joachim and Acorn (2000a) argue that it is crucial to combine the perspectives of stigmatization and normalization to understand both the impact of social context on individuals with chronic health conditions through stigma, and how these individuals themselves cope with and impact the social context. Normalization describes the strategies that individuals with chronic health conditions use to cope with the effects of their condition, feel like a part of society, counter the effects of stigma, and create a life that is "normal" to them.

An individualistic normalization strategy discussed earlier is "covering": the hiding and trivializing of one's condition to present oneself as "normal" to avoid discrediting and stigmatization. This disassociation of one's own identity from the stigmatized group is often seen in individuals with less visible conditions or conditions developed later in life, and often causes immense stress of being discovered and discredited. (Joachim & Acorn, 2000b; Nario-Redmond, Noel, & Fern, 2013)
However, normalization strategies can also be about visibility. Collective normalization strategies aim to positively redefine stigmatizing traits, for example, engaging in political activism on behalf of the group or social creativity strategies like openly valuing disability (Joachim & Acorn, 2000a).
If one is discredited or chooses to be visible, the validity of the stigma can be challenged rather than reinforced by the manner in which they present themselves.

These strategies are closely connected to an individual's personal identification with the stigmatized group. Strong group identification correlates with higher self-esteem, participation in group advocacy, and choosing visibility over hiding (Nario-Redmond et al., 2013).

Collective strategies and the group identity express the principles of the social model of disability (Oliver, 1990, 1996; Shakespeare, 1998), which views disability as a consequence of the social context rather than the consequence of a medical condition. A disability or medical condition is viewed as a trait that affects one's life, similarly to how other factors can impact one's life, such as gender or ethnicity. Challenging aspects of society that negatively impact this group, such as stigma or inaccessible spaces, can therefore reduce the harm to those of living with a chronic medical condition.
Normalization through visibility and active advocacy does not aim to create pity, but empathy and respect for the community's autonomy to facilitate these contextual changes (Corrigan & Kosyluk, 2013). It is important to note that one's choice of normalization strategy also depends on the social context and personal experiences (Taub, Mclorg, & Fanflik, 2010). Individualistic or collective strategies may be used by the same individual in different situations.

Many strategies and programs exist to combat self-stigma (Yanos et. al., 2015), but all emphasize the importance to educate people about the falsehoods of the stigma. This allows them to critically evaluate and reject the prejudicial sentiments and behaviors that they experience as a consequence of stigma rather than internalize them and the acceptance of identity. They offer techniques for the identification and correction of self-stigmatizing thoughts and behavior, such as cognitive restructuring or group discussions, and tools and experiences designed to increase or elicit hope, empowerment, and motivation to work realistically toward one's life goals.
One interesting successful program is "coming out proud", which relates the experiences of people with mental illness to those of LGBTQ people (Corrigan, Kosyluk, & Rüsch, 2013). This strategy recognizes the value of self-acceptance as well as the risks and benefits of disclosing one's identity in different contexts. For both groups, disclosure enhances self-esteem and self-efficacy, which improves mental and physical health and well-being, but its risks include physical and emotional harm, discrimination, social rejection, and self-consciousness. Therefore, this strategy helps people critically weigh the costs and benefits of different disclosure approaches to make informed choices they are comfortable with.

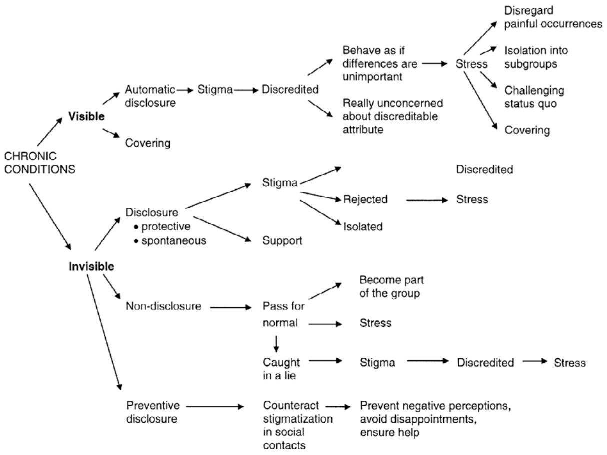

Figure 1: Stigma and factors that inluence disclosure or non-disclosure in chronic illness. (Joachim & Acorn, 2000b)

Identity, Self-expression, and Design

To design with respect to identity and normalization it is important to understand its relationship with products and self-expression.

Products and material items have long-since been considered as a part of the "extended self"; they serve to express and define our personal identity and capabilities, as well as our relation to other people and social concepts (Belk, 1988).
The strong relationship between personal identity and consumer products seems to stem from this same principle. People associate themselves with certain labels that encompass a certain category of identity, and tend to favor products, activities, brands, and other people that match this same label (Reed, Forehand, Puntoni, & Warlop, 2012). These identity labels are not always clearly defined or permanent, and any unique personal identity encompasses numerous of such labels. An identity label increases an individual's desire to embody its values in (consumer) behavior and the social signaling of this identity to others to validate this embodiment.
These relationships between identity, expression through behavior and material items, and social signaling also exist in the context of stigmatizing health conditions. Identity labels with certain associations apply to people with medical needs and disabilities, and they experience stigma as a consequence of the social signaling through this label's (voluntary or involuntary) visibility.

When considering the stigma normalization strategies and self-stigma reduction strategies, the acceptance of identity labels and expression of these labels through identity signals is a central theme: The autonomy to disclose one's medical status is an important part of overcoming self-stigma and accept one’s identity, and strong identification with the group encourages the desire to disclose one’s medical status to challenge the social stigma associated with it.

Visibility Choices through Design

Choosing visibility and disclosure is an expression of identity signals, but this expression is limited by the control one has over one’s appearance. However, this choice is closely tied to embracing this identity (Nario-Redmond et al., 2013), and it is known that forced visibility in every social context is not desirable (Corrigan et al., 2013) or an effective approach to challenging social stigma (Corrigan & Kosyluk, 2013).

As designers it is therefore valuable to consider how we can contribute to the choice of visibility for these people through our work. Identity signals are important to consider in user experience design for different user groups and contexts (Kälviäinen, 2002). We can apply similar design principles to products that indicate medical status, such as a portable heart monitor, stoma pouch, hearing aid, insulin pump, or medical brace. Such medical and assistive products have an obvious function but are not often approached from an user-centered perspective but rather a medical perspective (Wiklund & Wilcox, 2005).
Design choices for such products can help people signal their identity to others in a way that they are personally comfortable with, navigating the associations and identity labels that these devices embody. Allowing this choice of visibility through product design therefore contributes to embracing their identity and applying their preferred normalization strategies in different contexts.

Project Focus

Because design specifically for challenging health-related stigma in the context of medical user products is largely uncommon, this project aims to explore how to approach design for this purpose and how to enable designers to bring this in practice.

The first goal of this project is to explore how to approach product design to positively contribute to identity acceptance and normalization strategies for the user group: people who use medical or assistive products in everyday life. The choice for this user group is largely based on the stigma and self-stigma associated with these products, which can be shaped by designers, and the normalization strategies used in everyday life as a consequence of their use. Furthermore, because the choice of visibility is a large part of overcoming social stigma and self-stigma, it is valuable to consider users whose conditions are discreditable through products that clearly signal their medical status.

The second goal is to make it possible for designers to approach health-related stigma. Therefore this project aims to create awareness about health-related stigma and ignite a constructive debate amongst designers about their influence and motivation to approach this topic.

User & Context

In this project three roles are defined in the social context of stigma: users, bystanders, and designers. Users are individuals with health-related stigmatizing traits who use medical or assistive products, bystanders are individuals who lack these traits and are a part of a user's social environment, and designers shape the medical or assistive products that users rely on. These roles each play a different part in the context of health-related stigma.

To learn how designers can contribute to challenging health-related (self-) stigma it is poigant to explore their role and influence in this context through design explorations, and get a feeling for how to approach this design. Because the overall context is broad, three smaller user contexts are defined to allow a focus on specific design challenges that represent different aspects of this larger context. A framework was used to define three segments of users who experience different kinds of stigma, challenges, and normalization strategies. For every segment the project explored how designers can influence health-related stigma through a different approach.

Segment 1: Stoma patients

A stoma is a surgically created opening that allows stool to pass from the body from the large intestine. Attached to the stoma an ostomy pouch is worn to collect the stool. There are various reasons for creating a temporary or permanent stoma, for example if the bowel needs to heal after a health problem or part of the colon needs be removed because of a condition or disease.

Health-related stigma is a common experience for people with stomas (Chelvanayagam, 2014), mostly based on social perceptions about the "grossness" of its appearance and function. Stomas also have a further stigmatizing effect due to other factors such as users' dietary requirements that differ from social norms.
Although many users greatly appreciate their health improvements from the stoma, the stigma makes it difficult to express their appreciation of the stoma in a social context (MacDonald & Anderson, 1984). Users are concerned about the visibility of the ostomy pouch (the stigmatizing feature), but also its reliability (preventing leakages and dislocations).

Figure 2: Illustrated instructions for changing an ostomy pouch

The challenge: invisible by default

Social and internalized stigma encourage hiding, which is further encouraged by the design of the pouch itself and its related products. Because stoma bags are designed to wear underneath clothing, this facilitates their invisibility by design. Most design for users with stomas aims to help secure and hide the pouch underneath their clothes with special undergarments or wraps, such as the Stealth Belt[1] and StomaSafe[2], or even inside specialized swimwear that accommodates the pouch from brands like Respond[3] and Stomalight[4]. Although many decorative fabric wraps and sleeves are available to cover the pouch, these are also intended to be worn underneath clothing and hidden.

Having a degree of control and choice over the visibility of the stigmatizing trait in different situations is an important aspect of coping with and challenging (self-)stigma (Chelvanayagam, 2014; Nario-Redmond et al., 2013; Taub, Mclorg, & Fanflik, 2010). Rather than hiding the pouch by default to avoid stigma, being able to show that it is a positive experience in one's life is important for normalization and self-acceptance of identity.
Many stoma patients already deliberately make themselves visible on social media, where they share their pictures and experiences to challenge the stigma through normalization by visibility (Frohlich & Zmyslinski-Seelig, 2016). However, in offline spaces in the physical world it takes significantly more effort to be visible in a similar manner due to the pouch's invisibility by design.

Therefore, designers have a clear influence on the persistence of the stigma through the design of products that only facilitate hiding. For that reason, this design exploration focuses on how designers can facilitate the choice to become visible on one's own terms in the design itself.

---

[1] https://www.stealthbelt.com/ostomy-belt/#ostomy-belts
[2] https://www.allwecare.nl/stomazorg/stomasafe/
[3] https://www.respond.co.uk/product-category/swimwear/
[4] https://shopstomalight.de/

○ Segment 2: Users of a wearable EEG device

Wearable medical technology is an interesting example of visible stigmatizing trait for an invisible health issue. Devices that measure a user's physical state, such as heart-, blood glucose-, or EEG monitors, are clear indications to bystanders that a user's health is being monitored for a medical purpose. Because of the necessity and continuity of measurements, users have limited control over their visibility through such devices in everyday situations.

Ambulatory EEG measurements of brain activity are sometimes done in everyday contexts on a long term. It is possible to noninvasively measure brain activity with medical wearable devices such as the TMSi MOBITA[5]. However, like many other monitoring devices, EEG monitors are very noticeable and clear indicators that a person's brain activity is being measured. This target group was chosen because of this implicit visibility, but also the general lack of knowledge amongst bystanders about the purpose of EEG measurements.

Figure 3: The TMSi MOBITA and headpiece

The challenge: Social barriers
It is addressed earlier that wearable medical technology can create social barriers for the user because it clearly indicates a (stigmatizing) medical issue. Unlike some other medical wearables that can be hidden or made to look non-medical, the EEG monitor stands out through its needed headgear. Although the social acceptability of similar wearable headgear is low, understanding the medical purpose of a device can increase its social acceptability due to the perceived necessity (Kelly & Gilbert, 2018).

The design challenge is to discover how to approach the social barrier in a way that both users and bystanders feel more comfortable. Rather than changing the device itself, the focus lies on how a user deals with the social consequences of wearing it.

○ Segment 3: Wheelchair users

Wheelchair users are perhaps the most obvious example of a user group that experiences health-related stigma. In addition to navigating obstacles in the physical environment, wheelchair users need to navigate the social consequences of health-related stigma through various social strategies and heavy emotional labor (Cahill & Eggleston, 1994).
A very common problem that wheelchair users experience in everyday life is being moved or pushed without permission by strangers (Cahill & Eggleston, 1995; Winance, 2019). These strangers often have no ill intent toward wheelchair users and are unaware of the harmful consequences and inconvenience of this action. For example, they may want to help someone get around more easily and decide to push the wheelchair without acknowledging the person in it.

The wheelchair user is put in a position where they are essentially treated as an inanimate object being moved around, disregarding their personhood and agency. Although many people would feel violated if they themselves were suddenly picked up and moved by a stranger, they do not realize that through this act they are essentially doing the same thing to wheelchair users.

The challenge: Bystanders
Because of the aforementioned effort currently required from wheelchair users in public environments, this exploration focuses on approaching stigma through design that requires little to no effort from the user but rather effort from bystanders.

---

[5] https://www.tmsi.com/products/mobita/

Process

Approach & Methods

This Pre-FMP project aims to explore the role and experiences of designers regarding health-related stigma, as an explorative preparation for the FMP project. This project explores stigma and normalization strategies in everyday contexts, approaching user-focused design for this target group, and possible contributions to normalization through design. A vision and approach were developed, executed in practice, and evaluated from the perspective of designers.

For this purpose multiple concepts were designed for different user groups that experience health-related stigma. These concepts were used to provoke discussions with designers to understand their insights about the project's goals and vision, their own perceived role in health-related stigma, and the approach. Furthermore, this project aimed to create awareness for designers about the topic of health-related stigma and the relation to their work, as a start in provoking meaningful change in the attitude and actions of designer. This design project was approached through a flexible iterative process in which a concept is reflected upon through many tests in context, according to the Reflective Transformative Design process (Hummels & Frens, 2009; Tomico et al. 2009).

Iterations

Iteration 1: exploring the design context and narrowing focus

In the first iteration the design space was explored to gain a better understanding of the topic and to help define the project's goal, scope, and approach.
The context of health-related stigma was explored through literature research on several medical and non-medical topics, a benchmark was made to understand designer approaches to medical and assistive products, and an analysis of published personal experiences of the target group was done to gain insight in user experiences. It was found that health-related stigma is a very broad topic because its specifics depend on individual health-related issues. However, people's coping and normalization strategies overlap with those of other medical and non-medical situations, which inspired the project's focus on these strategies in various contexts.

Iteration 2: defining the design brief and approach

A simple concept was created from initial insights about how design could support normalization strategies. Although this first concept was a shallow exploration, it became clear that it could be valuable to approach medical and assistive products in the context of personal (medical) identity and self-expression.
The design brief was created based on the outcomes and insights of the first iteration and this iteration. The goal, methods, and scope of the project were determined. From these followed a next step to design for a target group that uses medical or assistive products from the perspective of stigma normalization strategies, largely intended to gain a further experience and understanding about approaching health-related stigma as a designer.

Iteration 3: design explorations

Because this project aims to understand the role of designers in the broad context of health-related stigma, it was important to avoid a narrow focus. Rather than approaching one kind of user group that deals with group-specific stigma, three varied groups were chosen for a holistic approach. This allowed for the application of the project's vision for different types of stigma through different design approaches. This resulted in three different outcomes designed to support normalization for the specific stigma and context of users. Insights about their design process were analyzed. Furthermore, a brief autoethnographic study (see Appendix D) was done to improve the understanding of the project's target group through personal lived experience.

Iteration 4: evaluation

The design explorations were used in the Demo Day exhibition to provoke discussion in the evaluation phase. These outcomes also functioned to demonstrate different ways the project's goal can be implemented by designers, based on the context and specifics of the stigma.
The work was presented to designers and bystanders as a starting point for interviews and discussions to better understand designers' insights about the project's goals and vision, their own perceived role in health-related stigma, and approach. These responses also helped to gain insight in both the reactions of designers and bystanders to the outcomes of this approach to design and the awareness of health-related stigma. The interviews and discussions were analyzed through qualitative methods.

Design

Segment 1: Stoma patients

In this design exploration several iterations were made to facilitate the pouch’s visibility or invisibility to make this normalization strategy possible for users.
From initial research and insights, the opportunity was found to create a visible wearable that reflects the function of the pouch as an aesthetic property. Much of inspiration was taken from expandable origami, which’ unique physical properties could be used to create a natural expansion as the pouch fills up over time. Acrylic felt was chosen for its physical sturdiness, processability, and aesthetic qualities. These allowed for the creation of a wearable without obvious medical or functional associations for bystanders.

An important criterium for the wearable to avoid leakage and dislocation of the pouch. The attachment of the bag to the flange as a leakage risk was explored by adding electronic detection of leakage or detachment and a subtle warning through vibration feedback to the user. However, this was not implemented in the final concept because it shifted the focus of the exploration to security, and the criterium could be more easily solved by a currently available elastic band mechanism to keep the flange in place.

Concept

The resulting concept allows an existing ostomy pouch to be worn above one’s clothing, allowing users the choice to make the stigmatizing trait visible. However, its aesthetic properties do not immediately indicate its medical function. The origami fold is used for the outer bag for its aesthetic properties and expandabe functionality to accommodate the pouch as it fills up. This outer bag connects to a brace which is secured to the flange. Because the concept accommodates an existing stoma pouch, users can choose to either wear their pouch in the hidden, original, manner or choose to wear it visibly.

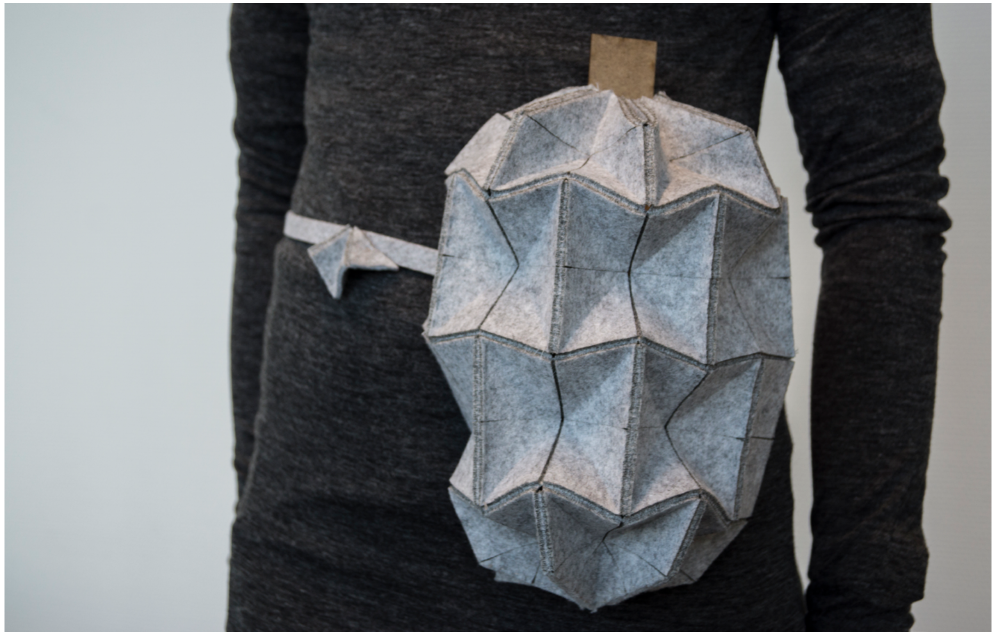

Figure 4: Concept prototype of the visible stoma bag

Figure 5: The concept prototype deconstructed

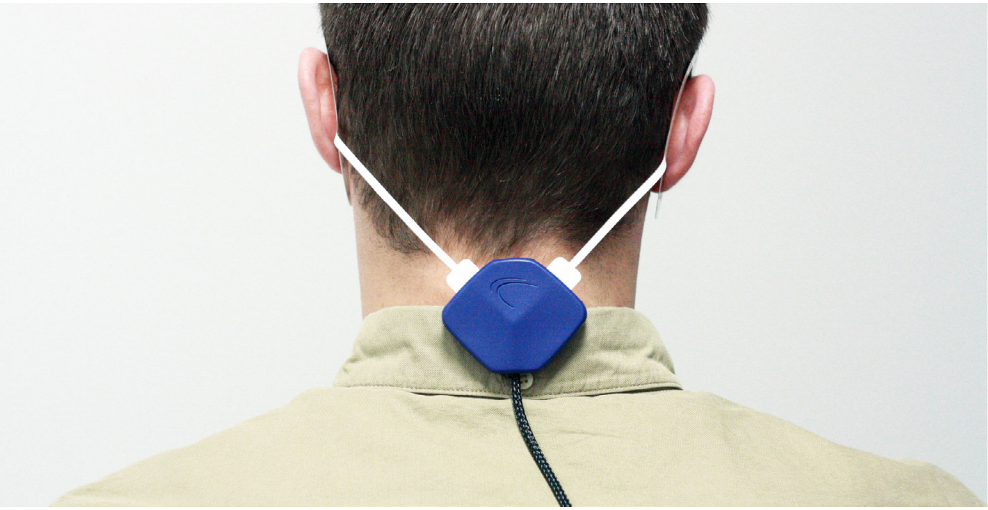

Figure 6: The TSMi MOBITA headpiece in use

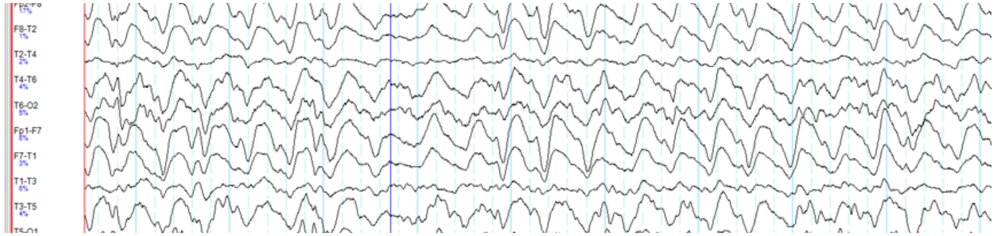

Figure 7: EEG measurements

Figure 8: Concept rototype of the EEG display tie

○ Segment 2: Users of a wearable EEG device

Rather than transforming the device itself, this exploration focused on transforming how using the device is perceived in a social context.

The goal of this exploration is to challenge stigma by voluntarily showcasing one's medical identity, an extension of choosing visibility. This was partially inspired by the comedians such as Jochem Meijer, who uses his ADHD as a focal point for his shows and engagement with his audience. By showcasing a stigmatized aspect of identity through humor it becomes possible to discuss it more openly and reduce the social barrier.
Humor is commonly used to diffuse awkward situations and encourage discussion of uncomfortable topics such as disability and chronic illness, while simultaneously creating an opportunity to provide new insights on these topics and educate the audience (Jensen, 2018; Reid, Stoughton, & Smith, 2006). Through the use of humor a stigmatized person can emotionally connect to their audience and change their perceptions and ideas, and can be seen as a useful tool for challenging health-related stigma (Germeroth, 1998).

This exploration therefore aimed to facilitate these behaviors for EEG monitor users. By displaying their measured brain activity through an artifact users can literally "bring it out in the open" to use it in everyday communications.
Throughout the exploration, it became desirable that the artifact should attract attention but also be perceived as more socially acceptable to wear than the EEG monitor to avoid increasing stigma. This lead to the design choice to use a tie, a common and familiar accessory often used as an "eye-catcher". The use of an e-ink display to communicate brain activity was motivated by its aesthetic properties, which allowed a similar look and feel as paper printouts of EEG measurements, and its common application displaying static images, which consumes less electricity than conventional displays.

Concept

The outcome of this exploration is a tie that can be worn in combination with the EEG monitor. The tie contains a small e-ink display that shows a simplified visualization of measurements from the EEG monitor that updates on regular intervals. This concept is intended as an extreme example of showcasing to facilitate humor through its unconventional function.
Similarly to how Jochem Meijer showcases his ADHD, showcasing in this casual and prominent manner creates a focal point for connection with bystanders in the social context.

Segment 3: Wheelchair users

This design exploration focuses on creating a behavioral intervention that encourages self-reflection when strangers approach the wheelchair from the back to grab its handles without permission.

Various methods to deter bystanders from grabbing the handles without the user's knowledge or permission were explored. This motivated the use of a very clear signal to communicate to bystanders that this is a hostile and unwanted action. The use of retractable spikes is inspired by the defensive behavior of animals such as porcupines, whose sharp quills are used to deter predators from engaging.

Furthermore, the concept should require little to no effort from users. Therefore, an automatic deterrent reaction was needed, and a simple on/off switch was created to allow the user to easily stop the deterrent reaction when permission was granted to push the chair.

Concept

This resulted in a concept for deterrent wheelchair handles. These handles make use of a proximity sensor and react by growing spikes when a stranger comes near to discourage being grabbed.

This reaction is intended as a clear signal to bystanders not to touch the wheelchair and as a sudden intervention to encourage a re-evaluation of their own behavior. If bystanders wish to push the wheelchair after experiencing the deterrent behavior, the easiest perceived course of action would likely be asking users for permission.

This concept aims to change the behavior of bystanders that enforces social stigma, rather than placing the responsibility to change stigma on the behavior of users.

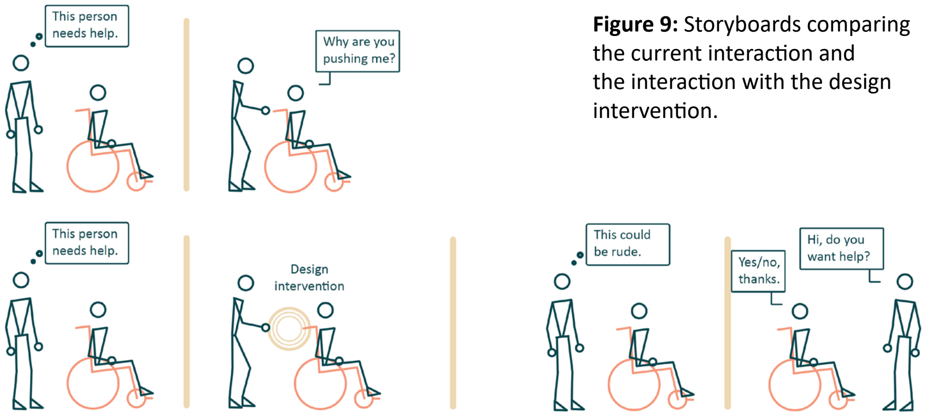

Figure 9: Storyboards comparing the current interaction and the interaction with the design intervention.

Figure 10: Concept renders of the deterrent wheelchair handles

Evaluation

Informal interviews were conducted at the demo day presentation to gain insights from designers and bystanders, and to promote awareness about health-related stigma and its relation to design.

These interviews were semi-structured talks with a duration between 3 and 10 minutes, depending on the engagement and content of the discussion. After a prospective interviewee showed initial interest in the project, the interviewer gave a brief explanation of the project using the prototypes as examples. The reaction of the interviewee was observed, and a further discussion of interesting topics was encouraged by the interviewer through asking open questions. A wide range of topics was discussed with the participants relating to both design and stigma. These included their own experiences, opinions, and insights, as well as their understanding of the project, personal interest, and relation to current practices. Interviewees' responses and observations by the interviewer were recorded in writing for further analysis with verbal permission.

Analysis

A qualitative thematic analysis was conducted from all collected interview data, in which the data was grouped and sorted into themes. Relevant categories and findings are described below, supported by relevant quotes from participants and observations made by the researcher to further illustrate these findings. A full overview of the data and themes can be found in Appendix C.

Distance and discomfort

Designers and bystanders expressed that they experienced a social obstacle when interacting with users. They often used words such as "uncomfortable", "worry", and "hesitation" to describe this obstacle. This hindered their interactions with users and created a distance.
They believed these feelings were caused by their uncertainty how to interpret both the health-related issue and the user's experience with it, which also made them uncertain how to behave. Identifying with users was perceived as difficult, and interviewees were worried that addressing a user's health-related issue would be rude or even hurtful. However, they felt that they needed to know more about the user and issue to ease these uncertainties and interact more comfortably, and tried to find reassurance that the user was not suffering.

> *"As a "not-sick"* person I find it often difficult to imagine how these people feel about themselves and about others helping."*
> **= The interviewee wants to be respectful towards users but lacks the vocabulary to express this comfortably.*

> *"Yeah, I recognize situations like these. Personally speaking, sometimes I find it difficult to estimate if people want to talk openly about their medical issues. I actively try not to judge others, but I don't know if it's rude to ask someone questions."*

> About EEG measurements: *"I would be very curious why someone was wearing [an EEG device], but also worry that something serious is wrong with that person. (...) It's more reassuring to see that that person wears the tie, it's like they're having a little fun with the measurements and aren't very worried."*

The designer as bystander

Many designers identified their own role as a bystander in the social context. With this insight, they recognized that they often lacked awareness of stigma when designing for a target group with a medical condition. They also believed this awareness is valuable for understanding the user, their needs, and the context more completely.

> *"I haven't considered the relation between stigma and design before. It makes a lot of sense to "zoom out" to consider how our work affects people."*

> *"It's very interesting to consider these situations, you're not aware of them as an outsider."*

Understanding and awareness through concrete examples

The interviews and discussions involved discussing the prototypes as possible outcomes that help challenge stigma. The method of communication proved to be very effective to help interviewees understand not only stigma itself, but also the user need to deal with stigma, and the value of involving stigma in the design approach.
Furthermore, designers stated that the use of examples made them view the goal of "challenging stigma" as a concrete user need or design challenge rather than a vague idea. They believe this makes it possible to understand health-related stigma and design for it in practice.

> *"As designers we're not treating [someone's medical issue] as a problem, but a user need. Coping with stigma should also be considered to better design for users' needs."*

The design approach

Designers often immediately relate the prototypes and the purpose of the project to their own design practices. They suggest that making designers aware of stigma and normalization strategies can help them easily integrate these into their design process as requirements or insights.
Understanding stigma and normalization is seen as a part of contextual user research, and normalization strategies such as choosing (in)visibility or behavioral interventions are related to user experience and interaction design.

> *"We design for specific user needs. I like that [the need to confront stigma or hide from it] is treated with the same consideration. This makes it possible to understand achieve in our designs."*

Relation to other design contexts and opportunities

Designers also stated that they expect the project's approach and methods can be applied to users who experience similar or less severe stigma, but also different kinds of stigma. They suggest new target groups who could benefit from the normalization strategies that the prototypes help enable.

> *"You can apply this kind of visibility to other challenges and contexts for users who are facing similar taboos or find it difficult to show their confidence."*

> *"You're focusing on quite severe cases of stigma in your project. I think the same principles could be applied to less severe cases of stigma. Understanding the social dynamics in this way can be very valuable for users that experience a more minor stigma."*

Interviewees also connected their own perspective as bystanders to that of users, and suggested opportunities that addressed both bystander and user needs.

> *About the wheelchair concept: "This stops people from helping when it's not needed, or even causes problems. But what about the opposite? It would be incredibly useful if I could easily know when someone does need my help."*

Relation to familiar situations

Interviewees often related the prototypes and design contexts to familiar situations and experiences. This involved personal anecdotes and descriptions of people they knew who experienced health-related and other stigma. Most interviewees suggested an overlap between aspects of the project and a familiar situation or person, through which they claimed to gain insight or empathy.

Confrontation and reaction

The wheelchair concept is considered to be very provocative and confrontational, but it also encourages interviewees to try understanding the situation and the perspective of users. This could suggest that this behavioral intervention is a useful method to communicate for interest and awareness.

> *About the wheelchair concept: "I feel like this is a lesson in manners. (...) I wonder if it's just as confrontational for people in wheelchairs to be grabbed"*

> *About the wheelchair concept: "I like that it would make me stop and think without the person in the wheelchair having to do anything. If you're in a wheelchair it's probably a relief that you don't have to worry about this kind of thing anymore."*

The project itself also provokes reactions from interviewees. They feel like the exhibited stand encourages questions and debate. Besides creating awareness about the user group's experiences and the influence of designers, interviewees often discuss how its approach has value as a starting point for attitude change.

> *"It's more speculative. You're asking "Why not?", and that can be quite valuable to make change happen."*

> *"It's interesting to see this provocative design that helps create understanding. It's like you shake people awake and "force" understanding through this confrontation."*

Identifying personally with user needs

Interviewees actively take the perspective of the user and imagine their needs and obstacles. The realization that users experience health-related stigma is often followed by an attempt to relate to their experiences.

Especially the normalization strategy expressed in the stoma concept is often related to experiences with stigmatized aspects of one's own identity. The ability to choose the stoma's visibility or invisibility dependent on the context and the user's preference is often compared to the choice to be open about one's sexual identity or mental health problems. These interviewees expressed a strong desire to be in control over the visibility of such aspects and imagined that users experienced the same.

> *"Strategically expressing yourself, or protecting yourself is very important. It really depends on who you're with and how comfortable you are."*

> *"As long as the option is there. Some days you want to hide something, and some days you don't. Whatever it is."*

> *"It's complicated, because you want to be open about it, but you don't want people to treat you strangely."*

Other interviewees speculated that if they had a medical problem such a choice could be appealing to them. They tried to imagine for themselves and others what the value of being visible and the value of hiding personal information would be.

> *About hearing aid users: "I think there are people who are very open to [their hearing aid] being visible, but also people who prefer not to do that. Such a choice seems important, at least, to me it would be important if I wore one."*

> *"I wouldn't be comfortable showing everyone that I have [a medical issue], but there are probably people who do. I wonder how many would wear something like that."*

Understanding stigma in a social context

Both designers and bystanders mention gaining new insights that relate strongly to the Social Model of Disability: the obstacles and problems of users are framed in context of the relationship between the user, other people in the social context, and the physical space in which they exist.

> *About stomas: "The pouch itself is good, it doesn't really need to be improved. However, the relationship people have with the pouch needs to be improved."*

> *"When you really think about it, these problems aren't caused by a stoma pouch or a wheelchair or something else... They're caused by how the people around you treat you, and how it's hard to do things like get around in buildings."*

> *"I like that these examples are very varied. It's just like the types of prejudices that people deal with, each is different from the other. Some things are judged more negatively than others, even if they're very similar when you start thinking about it. For example, why are people with glasses treated differently from people with hearing aids? Both correct a sense that's functioning badly."*

A pleasant user experience?

Interviewees often indicate that they personally find the stoma and EEG concepts appealing. Despite not being a part of the target group, they imagine that using them will be a pleasant experience and appreciate their aesthetics. Although this suggests they view these concepts separately from the medical product, they seem to relate their positive interpretation to the health-related issue itself.

> *"It's nice that it looks so pretty. You're staring to think "oh I wouldn't mind having a stoma too"."*

> *"It's almost like a kind of jewelry, you can be proud of showing it."*

> *"I like that it's a gadget. I would show it off to people, like "look, here's my brain!"."*

Because they imagine using these concepts is pleasant and not stigmatized, interviewees also speculate this design approach can be a positive experience for users. They mostly imagine the approach could motivate users to become visible and feel more confident.

> *"The interaction seems very pleasant and I like the design. It's very positive and accommodates the bag. I imagine people would find it less uncomfortable to show than just the pouch itself."*

> *"[My friend] can get a bit nervous about [someone noticing her cochlear implant]... It would be great if you could help to empower her and people like her to feel less self-conscious about it."*

Discussion

In this discussion insights from the interviews and overall insights about the process are related to the practice of design to challenge health-related stigma, and how designers can be motivated to adopt this practice. The approach to design and implementation of new practices are discussed, and future steps are addressed.

Practical insights for design

Based on both my experience designing the concepts and the insights from other designers, I derived four concrete tips as practical recommendations for designers. Two of these concern how to increase their understanding of stigma, and two are specific for the practice of designing.

1. **General knowledge.** Based on my experiences in the research phase, I recommend broadly researching stigma and normalization strategies, because it helped me to find concrete words to describe the user experience and a structure to understand the context. It is potent to learn the dynamics of stigma in a social context of users and bystanders, how users cope with stigma and how they choose the strategy they employ, and how stigma can be challenged or enforced.

2. **Specific user segment research.** The next recommended step is to narrow the research focus to the specific user segment. My observations from user segment research indicated each one experienced very different types of stigma, consequences of stigma, and employed different normalization strategies. Investigate the specific stigma users experience and how they currently cope with it. Furthermore, it is beneficial to research uncommon and alternative coping methods currently employed by users, which could indicate an opportunity to address through design.

3. **Consider the impact of current design.** After research through these previous steps, it became possible for me to compare it with the existing design in the context and gain insights in specific “points to improve”. Investigate the specific qualities of the work that influence the current behavior of users or limit other behaviors, and the implicit assumptions from designers about the user group. Consider the consequences of these findings and prompt questions. (For example: Is it possible that designers have based their understanding of the target group on unfounded assumptions or incomplete information? Does the design largely focus on the medical need or the user? Are bystanders involved in the context?)

4. **Understand that no “one-size-fits-all” exists to tackle stigma.** As is often addressed throughout this report, stigma is a complicated and broad topic, and it is important to allow those who experience it to choose how to cope with it.
   The choice of normalization strategy can be limited by current design, but this does not indicate that these current normalization strategies are undesirable for users. (For example, reflecting on one of my own concepts: it is very likely that the stoma bag is not suitable for all users, because not all users desire visibility. The conventional stoma pouch can be a much better fit for users who prefer covering, while my own concept could appeal to users who do not.)
   Design that allows one strategy is also likely to hinder another, therefore a diversity of designs can provide a choice for users what strategy (not) to employ.

Creating change

Designers expressed that becoming aware of health-related stigma and normalization strategies could help them to understand the user in context and allow them to involve this in their own design approach. The concepts presented at the stand functioned as concrete examples of implementation, which helped to effectively communicate to designers.
Interestingly, this awareness also made them identify their role as bystanders, which they thought hindered their understanding of user needs. They often speculated how more awareness of health-related stigma could increase this understanding and contribute value when designing for users.

Although the project was intended to spark debate, it was unexpected how quickly and enthusiastically interviewees began to search for connections with familiar topics unprompted by the interviewer. Not only did they draw connections to familiar situations, but also to the greater social context and design practices.

This seems to be an interesting first step to help designers enact change in their practices. However, it remains to be seen if creating awareness about the topic and providing information can have a meaningful impact on their methods and design outcomes. It would be valuable to research if designers are able to work from this awareness and implement changes to design.

My findings do suggest that this is possible. The relation between design and stigma was unfamiliar for most interviewees. Although designers are largely aware how they can influence behavior through design choices, they did not previously consider the existence of stigma when making these choices. The designers found that stigma becomes a more tangible challenge, relating the need to understand stigma to the need to understand the user and context, and relating the support of appropriate normalization behaviors to user or interaction requirements. Their perceived overlap between the problem statement and their own practices seems to suggest the possibility to integrate this insight into their current practice.

To determine the approach to this next step, it is relevant to reflect on how these outcomes were achieved in the previous step.

A large contributor to these outcomes was the designers' provocative experience of the project, and the diversity of the presented concepts that addressed several different segments of the context.
The provocative interpretation of the project challenged designers to become curious, ask questions, and engage in discussion. The diversity of the concepts increased the possibility for designers and bystanders to relate these to a familiar experience, example, or personal vision. They recognized themselves as participants in uncomfortable situations or recognized other examples where stigma influenced users, of which they formulated problem statements. This generated a strong desire to solve these self-addressed problems. However, they also realized that their own lack of knowledge would impact their ability as designers to approach these challenges, and they sought to remedy this lack of knowledge.
It could therefore be valuable to use a similar communication strategy in the next step to create awareness and curiosity.

Unknown factors that need to be further explored are the practical limitations (such as limits to designers' influence on product development) and the effectiveness of creating awareness for designers.

The presented concepts are designer-centered and meant to spark discussion, rather than user-centered examples to replicate for success. It is yet uncertain if designers that became aware are able to implement this awareness into a suitable approach to challenge stigma for the target group or integrate this into their design process.

To learn more about practical limitations about implementing design for challenging stigma, it could be valuable to organize an in-depth discussion with a group of professional designers to gain meaningful insights about two key topics: Firstly, do they become aware of health-related stigma and strategies to challenge it, and is there an overlap with Demo Day interviewees? Secondly, what challenges and obstacles do they perceive to implement this in their practices from a standpoint of industry experience as well as practicality?
From these insights a strategy can be derived to overcome these obstacles and implement effective change in practice to help designers to challenge health-related stigma through their work.

Appendices Overview

A: Bibliography

B: Personal Reflection

C: Qualitative Analysis

D: Autoethnographic observations

A: Bibliography

Brankaert, R. (2016). *Design for dementia: a design-driven living lab approach to involve people with dementia and their context.* Technische Universiteit Eindhoven.

Cahill, S., & Eggleston, R. (1994). Managing Emotions in Public: The Case of Wheelchair Users. *Social Psychology Quarterly,57*(4), 300-312. https://doi.org/10.2307/2787157

Cahill, S., & Eggleston, R. (1995). Reconsidering the Stigma of Physical Disability: Wheelchair Use and Public Kindness. *The Sociological Quarterly, 36*(4), 681-698. https://doi.org/10.1111/j.1533-8525.1995.tb00460.x

Chaudoir, S. R., Earnshaw, V. A., & Andel, S. (2013). "Discredited" Versus "Discreditable": Understanding How Shared and Unique Stigma Mechanisms Affect Psychological and Physical Health Disparities. *Basic and Applied Social Psychology, 35*(1), 75–87. https://doi.org/10.1080/01973533.2012.746612

Chelvanayagam, S. (2014). Stigma, taboos, and altered bowel function. *Gastrointestinal Nursing, 12*(1), 16–22. https://doi.org/10.12968/gasn.2014.12.1.16

Corrigan, P. W., & Kosyluk, K. A. (2013). Erasing the Stigma: Where Science Meets Advocacy. *Basic and Applied Social Psychology, 35*(1), 131–140. https://doi.org/10.1080/01973533.2012.746598

Corrigan, P. W., Kosyluk, K. A., & Rüsch, N. (2013). Reducing Self-Stigma by Coming Out Proud. *American Journal of Public Health, 103*(5), 794–800. https://doi.org/10.2105/AJPH.2012.301037

Frohlich, D. O., & Zmyslinski-Seelig, A. N. (2016). How Uncover Ostomy challenges ostomy stigma, and encourages others to do the same. *New Media and Society, 18*(2), 220–238. https://doi.org/10.1177/1461444814541943

Germeroth, D. (1998). Should we laugh or should we cry? John callahan's humor as a tool to change societal attitudes toward disability. *Howard Journal of Communications, 9*(3), 229–244. https://doi.org/10.1080/106461798247005

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3), 353–363. https://doi.org/10.1080/13548500600595327

Hummels, C., & Frens, J. (2009). The reflective transformative design process. In *CHI'09 Extended Abstracts on Human Factors in Computing Systems* (pp. 2655-2658). ACM.

[Illustrated instructions for changing an ostomy pouch] Colostomy: Changing Your Pouch. (n.d.). Retrieved from https://www.saintlukeskc.org/health-library/colostomy-changing-your-pouch

Jensen, P. R. (2018). Undignified Dignity: Using Humor to Manage the Stigma of Mental Illness and Homelessness. *Communication Quarterly, 66*(1), 20–37. https://doi.org/10.1080/01463373.2017.1325384

Joachim, G., & Acorn, S. (2000a). Living with Chronic Illness: The Interface of Stigma and Normalization. *Canadian Journal of Nursing Research.*

Joachim, G., & Acorn, S. (2000b). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243–248. https://doi.org/10.1046/j.1365-2648.2000.01466.x

Jones, N., & Corrigan, P. W. (2014). Understanding stigma. In P. W. Corrigan (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 9-34). Washington, DC, US: American Psychological Association. http://dx.doi.org/10.1037/14297-002

Kälviäinen, M. (2002). Product design for consumer taste. In W. Green & P. Jordan (Eds.), *Pleasure with Products: Beyond Usability.* London, UK: CRC Press. https://doi.org/https://doi.org/10.1201/9780203302279

Kelly, N., & Gilbert, S. B. (2018). The wearer, the device, and its use: Advances in understanding the social acceptability of wearables. *Proceedings of the Human Factors and Ergonomics Society, 2*, 1027–1031. https://doi.org/10.1177/1541931218621237

Leder, H., Forster, M., & Gerger, G. (2011). The Glasses Stereotype Revisited. *Swiss Journal of Psychology.* https://doi.org/10.1024/1421-0185/a000059

MacDonald, L. D., & Anderson, H. R. (1984). Stigma in patients with rectal cancer: A community study. *Journal of Epidemiology and Community Health, 38*(4), 284–290. https://doi.org/10.1136/jech.38.4.284

Nario-Redmond, M. R., Noel, J. G., & Fern, E. (2013). Redefining Disability, Re-imagining the Self: Disability Identification Predicts Self-esteem and Strategic Responses to Stigma. *Self and Identity, 12*(5), 468–488. https://doi.org/10.1080/15298868.2012.681118

Oliver, M. (1996). Understanding Disability: From Theory to Practice. *The Journal of Sociology & Social Welfare*

Oliver, M. (1990) The Individual and Social Models OF Disability, presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals, 1990.

Reid, D. K., Stoughton, E. H., & Smith, R. M. (2006). The humorous construction of disability: "Stand-up" comedians in the United States. *Disability and Society, 21*(6), 629–643. https://doi.org/10.1080/09687590600918354

Sanders, E. B. N., Brandt, E., & Binder, T. (2010, November). A framework for organizing the tools and techniques of participatory design. In *Proceedings of the 11th biennial participatory design conference* (pp. 195-198). ACM.

Scambler, G. (2009). Health-related stigma (Review Article). *Sociology of Health & Illness, 31*(3), 441–455. https://doi.org/10.1111/j.1467-9566.2009.01161.x

Shakespeare, T. (1998). *The disability reader.* London: Cassell.

Taub, D. E., Mclorg, P. A., & Fanflik, P. L. (2010). Stigma management strategies among women with physical disabilities: Contrasting approaches of downplaying or claiming a disability status. *Deviant Behavior, 25*(2), 169–190. https://doi.org/10.1080/01639620490269012

[The TMSi MOBITA and headpiece] TMSi – MOBITA. (n.d.). Retrieved from: https://www.tmsi.com/products/mobita/

[The TSMi MOBITA headpiece in use] TMSI | STUDIO MANGO. (n.d.). Retrieved from: https://studiomango.nl/portfolio/tmsi/

Thimbleby, H. (2008). Understanding User Centred Design (UCD) for People with Special Needs. In K. Miesenberger, J. Klaus, W. Zagler, & A. Karshmer (Eds.), *Computers Helping People with Special Needs* (pp. 1–17). Berlin, Heidelberg: Springer Berlin Heidelberg. https://doi.org/10.1007/978-3-540-70540-6_1

Tomico, O., Frens, J. W., & Overbeeke, C. J. (2009, April). Co-reflection: user involvement for highly dynamic design processes. In *CHI'09 Extended Abstracts on Human Factors in Computing Systems* (pp. 2695-2698). Boston, Massachusetts: ACM. https://doi.org/10.1145/1520340.1520389

Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health and Medicine, 11*(3), 277–287. https://doi.org/10.1080/13548500600595053

Wiklund, M. E., & Wilcox, S. B. (2005). *Designing Usability into Medical Products.* CRC Press. Retrieved from https://books.google.nl/books?id=HfDLBQAAQBAJ

Winance, M. (2019). 'Don't touch/push me!' From disruption to intimacy in relations with one's wheelchair: An analysis of relational modalities between persons and objects. *The Sociological Review, 67*(2), 428–443. https://doi.org/10.1177/0038026119830916

Yanos, P. T., Lucksted, A., Drapalski, A. L., Roe, D., & Lysaker, P. (2015). Interventions Targeting Mental Health Self-Stigma: A Review and Comparison. Psychiatric *Rehabilitation Journal, 38*(2), 171–178. https://doi.org/http://dx.doi.org/10.1037/prj0000100

B: Personal Reflection

In this project my main development goals related to the competencies Technology & Realization and User & Society. Furthermore, I aimed to develop my Vision and Identity and find a client for collaboration in the FMP semester.
During the process my focus shifted from user-focused design for a physically disabled user group to approaching the larger social context of health-related stigma and the role of designers, which changed my goals and priorities in this semester. This also created new learning opportunities such as the engagement of designers and material explorations.

The initial brief for my Pre-FMP semester was to design a concept that contributed to social engagement and autonomy of a physically disabled user group, related to an industry contact that could fulfill a client role. This required a user-focused design project for one target group, but in the process it became clear to me that the designer perspective could be more valuable to enact meaningful change for a larger user group. I was reminded of the value of investigating the broader social context, and identied how current design contributed to or challenged stigma. Rather than solving one user group's problem through the design of a product or service, this project refocused on enabling a needed change that could address the underlying contributions from design to greater problem.

The shifting focus from users to designers was an interesting challenge. I usually take a very user-centered approach to design, but it was preferable to employ a different approach for the Pre-FMP project. Although I have focused previously on evaluating and changing the designer perspective, especially in my M1.2 project, this was a follow-up from insights from contextual user studies with a narrow target group. In this project the shift was motivated by broader contextual research of the user group, which indicated the possible influences of designers as a more interesting challenge. It was therefore necessary to focus on the broader context rather than specific user groups, and indirect research about multiple segments of the user group. I decided to approach design for these segments by translating normalization strategies into design opportunities. Furthermore, I aimed to find methods to engage designers into provoke discussions and critical evaluation of current practices. Because achieving necessary insights in this challenge prioritized evaluations with designers, no user evaluations were done. Originally a short-term user evaluation was planned as an addition to the designer evaluations, but it was estimated to contribute too little value to the project as it developed further. However, my approach will shift back to user-centered in the FMP project, which will focus on a narrower context, and requires gaining a thorough understanding of the target group through direct methods. It will be crucial to conduct contextual user studies and involve users in the design process through participatory design methods balance their needs with, client(s), designers, and eventual other stakeholders.

An unexpected drawback this semester was my difficulty in finding a client for my FMP project. I researched the department's industry contacts and met with the ID network coordinator to discuss possible clients in reltion to my Vision and Identity. Although I contacted and negotiated with a couple of interesting parties, I have not yet secured a client. I believe this is in part because of the project's niche topic, in which they often expressed personal interest but hesitated to collaborate professionally. The project and approach was still taking shape during most contact with clients, which may have hindered clear communication about its value. In the next few weeks I will resume my search and initiate contact with possible clients again, in which I will communicate more directly about my current project and my plans for next semester.

A personal goal in this project was to gain basic proficiency creating models in Solidworks, with which I had no previous experience. I devoted a fixed amount of time over the course of a few weeks to practice tutorials and work in the program to develop this skill to a sufficient level to apply in my project. This structured approach proved quite useful due to the steep learning curve that I experienced. I was able to apply what I learnt by creating a model and render for one of the concepts. I wish to continue developing this skill in this manner, because I believe it can be useful in future projects and a great asset to my professional skills. This will allow me to create more ambitious models in future projects for sketching, rendering, or 3D printing.

A new learning opportunity presented itself when the direction of the project changed, and addressed the relationship between aesthetic properties and stigmatizing design. I explored material and visual properties that could aid in creating a aesthetic qualities and for a different user and bystander experience. This led to new choices for materials that I had not previously worked with and new insights about their application possibilities, like the use of laser cut felt to translate the physical qualities of paper origami to a wearable concept and provide both a functionality and a look and feel. These insights can prove useful for future applications, not only because of what I learnt specifically, but also because I gained a more open mindset to explore unfamiliar materials and applications.

In this project I also worked with unfamiliar technological components such as the e-ink display module. I noticed that although working with unfamiliar components was an obstacle in the past, it has become almost second nature to seek them out and learn to use them during my design process. I believe that my previous technical and programming experience contributed to overcoming this obstacle, as well as the knowledge that new components can bring value to the design through function and interaction possibilities. For further development I will aim to continue seeking out new technological challenges in the future.

Development of Vision and Identity

In this semester I evaluated my Vision and Identity in a broader context, by relating this to the work of other designers and professionals, literature about the role of design and technology in society, and my own project. Furthermore, I reflected on my journey as a design student to understand how my current Vision and Identity developed and related to my earlier work. I realized that in my Bachelor I first gained the impression that some designers for target groups with disabilities focus on changing users' behavior to the demands of their environment, instead of aiming to create an environment that better accommodates their needs. This had struck me, as I found it essential to design for any target group from a perspective of respect for the users' agency and capabilities. My experiences in the Master made me realize that this is a very complicated task, but I was still eager to approach this challenge. I was therefore motivated to focus on exploring the role the designer plays and can play to shape this context to make meaningful change possible in the next phase.
The insights gained from these evaluations contributed to a more complete and grounded revision of my Vision and Identity, which I will discuss with my coach in my M2.2 PDP for further feedback.

C: Qualitative Analysis

Group 1

This is a very personal thing, I imagine. Everyone is scared to be judged, but this is a bigger judgement.

Stoma: It can bother people if everyone is able to see what's "wrong" with them. It's good to have the possibility to keep things private.

It's complicated, because you want to be open about it, but you don't want people to treat you strangely.

Stoma: As long as the option is there. Some days you want to hide something, and some days you don't. Whatever it is.*

* Interviewee relates personal experiences to those of the target group and sees similarities

Stoma: It looks like a nice bag. You can disclose more information if you want but it's not obviously a stoma.

Stoma: Strategically expressing yourself, or protecting yourself is very important. It really depends on who you're with and how comfortable you are.*

* Interviewee relates personal experiences to those of the target group and sees similarities

Stoma: I suppose there are two sides to this. Being visible has positive and negative consequences, but so does being invisible.

I guess this is like coming out... It can be scary and it makes you vulnerable. Some people you thought you could trust could turn out to be assholes.

* Interviewee relates personal experiences to those of the target group and sees similarities

You're giving [users] control over if and how they are seen by others.

Stoma: It's incredibly personal to exhibit that the bag is full, normally others don't really notice it if you need to use the bathroom. To what extent do users want to inform other people about the bag's function?

Stoma: I think most people with stoma bags would want to hide it. It's private.

Stoma: I wouldn't be comfortable showing everyone that I have [a medical issue], but there are probably people who do. I wonder how many would wear something like that.

It could be very useful, but I don't think [this kind of design] is everyone's cup of tea. It feels more like a niche.

It's important to get back to users and make sure there's an actual interest in these ideas.

(Re: hearing aid users) I think there are people who are very open to [their hearing aid] being visible, but also people who prefer not to do that. Such a choice seems important, at least, to me it would be important if I wore one.

Stoma: It's a matter of private information about your body and its functions. How to express or not express such a thing heavily depends on the context, type of engagement, and users' personal views and preferences.

Stoma: I think there are less flashy ways to wear a pouch on the outside. People could be more comfortable with that.

Choosing / control

- Strongly related to self-expression ~~[illegible]~~
- Understanding judgement
- assuming people want to hide vs. understanding that they want to choose

Group 2

Stoma: Because you normally don't see it it stays a bit scary, a bit stigmatized. It's not normal.

Stoma: There could be many people with stomas that I meet or walk past every day. I wouldn't know that because it's invisible. That makes it seem like no one has one.

Tie: I have no idea what I'm seeing, but that might make me curious enough to ask about it.

Stoma: If people realize a lot of their acquaintances have a certain medical issue, they'll probably be less judgmental.

Handles: As a "not-sick"* person I find it often difficult to imagine how these people feel about themselves and about others helping. I guess there are many things I take for granted that can be difficult for them, stuff like opening heavy doors. Usually I don't really think about it so I don't know until I see it happen.

*= The interviewee wants to be respectful but doesn't have the vocabulary to talk comfortably about disability, medical conditions, etc. Avoiding the words "normal" and "healthy" are important to this person but its is difficult to find better/different words.

Yeah, I recognize situations like these. Personally speaking, sometimes I find it difficult to estimate if people want to talk openly about their medical issues. I actively try not to judge others, but I don't know if it's rude to ask someone questions.

Distance

- Caused by feeling scared of confrontation
- Aware of own discomfort

Handles: I'm often not sure if I should get up for others in the bus or not. If an elderly or pregnant or disabled person comes in should I ask if they want to have my seat or would they feel offended? Should I ask if they need help?

Tie: It's a kind of ice breaker. It's funny… It's very abstract but it slowly starts feeling more comfortable to me.

I'm not sure if I can ask people questions about their medical issues. I want to learn about those things, but I can imagine people want to keep things like that to themselves.

- Scared of medical issue
~~but~~
- Reassuring bystanders

Tie: I would be very curious why someone was wearing [an EEG device], but also worry that something serious is wrong with that person.

Tie: It's more reassuring to see that that person wear the tie, it's like they're having a little fun with the measurements and aren't very worried.

Tie: It's less serious, I feel like whoever wears it doesn't find it a serious topic to talk about.

Tie: [Wearing the EEG device] seems much less serious because of the display.

Group 3

Tie: I like that it's a gadget. I would show it off to people, like "look, here's my brain!".

Stoma: This is very appealing to me, and to a lot of people without a stoma.

Stoma: The interaction seems very pleasant and I like the design. It's very positive and accommodates the bag. I imagine people would find it less uncomfortable to show than just the pouch itself.

Stoma: It's nice that it looks so pretty. You're staring to think "oh I wouldn't mind having a stoma too"?

A friend of mine has a cochlear implant. When we go out together she always puts her hair down so you can't see it. She can get a bit nervous about [someone noticing]... It would be great if you could help to empower her and people like her to feel less self-conscious about it.

It changes you, but it doesn't define you. It's only one part of who you are. It's too bad some people tend to focus only on that one thing.*

* Interviewee relates personal experiences to those of the target group and sees similarities

Stoma: It's almost like a kind of jewelry, you can be proud of showing it.

Stoma: I find it very interesting that it's allowed to be seen.

It's important to accept yourself. Others accepting you can help a great deal with that.*

* Interviewee relates personal experiences to those of the target group and sees similarities

is design still making gadgets?

Experienced as positive by bystanders/ designers

My cousin has had a prosthetic leg since early childhood. Last summer she was very proud about going outside in shorts for the first time in years. That was very important for her, she's a lot more confident now. I think many people are in a similar situation, but sometimes they just decide it's better to wear shorts in summer than to worry about what other people think.

quantitatieve test waarin je vergelijkt hoe mensen de producten zouden adopteren als ze wel vs niet de afwijking hebben.

- contributing to confidence & self-acceptance
- wanting to support people to feel confident

- Social issue, not medical
- Bystanders are more bothered by the medical issue than the user

As a child you usually don't have a problem understanding or accepting things that are difficult for many adults. In my elementary school class there were two kids with hearing aids. Since our classroom had a lot of ambient noise the teacher used a small microphone to amplify her voice for them. She explained to us how it worked in a very normal way so we all considered it normal. For us, explaining how it worked to a substitute teacher was pretty much the same as explaining how to calibrate the electronic chalkboard. Many accommodations for kids work that way. Especially if something is more well-known and if adults don't treat it weirdly, kids won't find it strange or scary.

Things just are the way that they are. I don't really find anything weird [about other people's medical needs]. We can keep judging each other, that's probably easier, but that way we don't achieve anything. People need to become more tolerant.

I don't think it's possible to normalize everything, especially medical stuff. But people can become more respectful about certain things, even if they don't find it normal.

- this feels very confrontational
- It helps me understand the problem

It's more speculative. You're asking "Why not?", and that can be quite valuable to make change happen.

This very much is design for debate.

Handles: Maybe it's better to intervene a bit more gently, this is a bit aggressive.

It's interesting to see this provocative design that helps create understanding. It's like you shake people awake and "force" understanding through this confrontation.

Handles: I feel like this is a lesson in manners.

Handles: I wonder if it's just as confrontational for people in wheelchairs to be grabbed.

People are always imagining a "normal" standard, if someone diverges from that mental image they are immediately considered pitiful. It's good to make people question that assumption.

Handles: I like that it would make me stop and think without the person in the wheelchair having to do anything. If you're in a wheelchair it's probably a relief that you don't have to worry about this kind of thing anymore.

- It's a bit ~~scary~~ uncomfortable as a designer to start thinking in this way, but after a while it's less scary
- relate to personal experiences

(Re: hearing aid users) Products like hearing aids are less extreme than stoma bags in terms of stigma. They're more familiar, and it's a lot clearer to understand why someone needs one.

The first time that someone explained to me they had an epipen and how it should be used, I was a bit scared. After a while I got used to it, I'm glad I know what to do in an emergency. I think it works the same for many other health-related things, it seems scary at first but you get used to it quite easily.

It takes a little time to get used to accommodating someone, but it's usually not difficult or uncomfortable. After a while you start doing it automatically.

A lot of problems are easy to solve with little effort. At our student bar most of us learnt a few things in sign language so we can more easily talk to a deaf bartender. People often don't realize that it's not a big deal to accommodate someone with a disability, they act like it's a big problem.

Group 5

I haven't considered the relation between stigma and design before. It makes a lot of sense to "zoom out" to consider how our work affects people.

Stoma: We design for specific user needs. I like that [the need to confront stigma or hide from it] is treated with the same consideration. This makes it possible to understand achieve in our designs.

Stoma: You can apply this kind of visibility to other challenges and context for users who are facing similar taboos or find it difficult to show their confidence.

As designers we're not treating [someone's medical issue] as a problem, but a user need. Coping with stigma should also be considered to better design for users.

I guess when you really think about it, these problems aren't caused a stoma pouch or a wheelchair or something else... They're caused by how the people around you treat you, and how it's hard to do things like get around in buildings. That stuff can make you feel like you're the problem instead.

Stoma: The pouch itself is good, it doesn't really need to be improved. However, the relationship people have with the pouch needs to be improved.

Method worked:
showing how to
implement the
"solution" made
designers understand
how to approach
stigma

Handles: It's a strange situation; people deciding to treat you like luggage. I'd feel very violated if someone just picked me up and moved me. I guess they don't fully realize there's a person in the chair.

*People mention having new insights that are very similar to the Social Model of Disability: the obstacles are framed in context of the relationship between the user, other people in the social context, and the physical space in which they exist.

I like that these examples are very varied. It's just like the types of prejudices that people deal with, each is different from the other. Some things are judged more negatively than others, even if they're very similar when you start thinking about it. For example, why are people with glasses treated differently from people with hearing aids? Both correct a sense that's functioning badly.

*Interviewees share a lot of personal anecdotes of stories about people they know inside the broader target group. They usually aren't familiar with the specific user groups in the examples, but they relate the examples to something familiar to them that seems similar. They frame a problem or solution in a context they know.

It's very interesting to consider these situations, you're not aware of them as an outsider.

Group 5 (continued)

Stoma: If you want to develop this further, you should talk to a lot of people with stomas and make sure the usability is really good. It would be a shame if wearing this was less comfortable.

Handles: This stops people from helping when it's not needed, or even causes problems. But what about the opposite? It would be incredibly useful if I could easily know when someone does need my help.

(Re: hearing aid users) I think you should focus on the role it plays in someone's life rather than the technological challenge. The hearing aid is improving all the time, but social stigma still exists even though the tech and UX improve.

You're focusing on quite severe cases of stigma in your project. I think the same principles could be applied to less severe cases of stigma. Understanding the social dynamics in this way can be very valuable for users that experience a more minor stigma.

I feel that this can help a lot of people feel more comfortable around others. A lot of us don't really consider we may be making them uncomfortable. I would be very sad if a friend didn't trust me enough to tell me about a medical problem.

People are open to implementing things if you tell them why and how

Designers are bystanders too

Criticize the objectivity of designers
→ perspective taking & misplaced assumptions of tragedy

D: Autoethnographic observations

Purpose and goal

A brief autoethnographic study was conducted for the purpose of extending my sociological understanding of the project's target group through personal lived experience. This study describes my experiences as an invisibly, or discreditable, disabled person who was made visible, or discredited, through the use of a mobility aid. I discuss these experiences, my insights on them, and reflect on the role that visibility plays in the experience of social stigma and my main insights. These are purely my own obervations, without theoretical additions.

Description of personal narrative and context

I am a 25 year old chronically ill woman whose physical condition is invisible to strangers. I am Dutch, white, and of average height and weight. On an everyday basis I experience chronic pain, lessened muscle strength and durability, fatigue, loss of mental focus, and varying other physical symptoms such as nausea or consequences of muscle overuse. I believe I am decently capable of balancing my health-related needs with my activities and goals in everyday life and consider myself a motivated student.

Over a period of fourteen days I used a walker for the dual purpose of evaluating its usefulness for my physical needs and for gaining more understanding of target group users through this experience. I had not seriously used any mobility aid before conducting this study. By using the walker my previously invisible disability was made visible to others, which was a new experience for me. I recorded notable interactions and observations in writing, which I summarized below.

Experiences and observations

Throughout the two-week period, I experienced many new interactions that I attribute to the use of my walker. Although I have often experienced the consequences of invisible health-related stigma before and have researched the experiences of visibly disabled users, this lead to many new insights.

The immediate physical benefit of the walker was the lessened physical burden on my muscles when walking, especially when carrying a bag, which prevented much fatigue and overuse. Furthermore, the ability to sit down comfortably instead of needing to stand up helped to reduce a lot of physical strain. However, there were also immediate physical disadvantages of using a walker. Because the environment is not fully accessible there were many new obstacles to navigate, and because I needed to use two hands to steer it my movements were limited. Over time, it became more and more clear to me how inaccessible my familiar environment was for walkers, as it was filled with stairs, steps, narrow paths, bumpy floors, cramped revolving doors, heavy doors, and so on. Although I already experienced difficulty with stairs and heavy doors, the use of a walker increased this difficulty tremendously.

Traveling by bus immediately became a more difficult task due to the increased obstacle to enter and exit with a walker, but mostly by the behavior of bystanders. I was surprised by the frequency in which strangers tried to provide me assistance in the bus, despite the fact that I rarely needed or asked for help. I noticed that especially the actions of entering the bus and folding the walker attracted such offers of help from bystanders. Most of these bystanders asked if I needed any help and listened to my response. However, a few did not wait for my response or did not ask, and instead tried to fold my walker for me.
On one notable occasion when I entered the bus before a driver had arrived, a middle-aged man grabbed my walker and moved it further down the aisle to collapse it, leaving me behind without it. This was a very strange situation for me. After a few seconds I responded to his action by asking if I could have it back, after which he complied and quickly apologized for taking it from me. Although this was an extreme case of receiving unwanted help, it was very similar to my other experiences with bystanders in the bus.
After a few bus trips I became hesitant to travel by bus with my walker due to these obstacles. Although every bus had ramps and enough space to park my walker, the offers of help on most trips made me feel like I was seen as being in the way or being less capable of getting around. This was a sharp contrast with my previous experience as invisible, in which I was not offered help but had much greater difficulty walking around and standing uptight. Although I think most bystanders had good intentions, it felt as a judgement.

Another notable difference was that I was often asked about my medical conditions and reason for using of the walker by strangers. This happened between one and four times on most days, depending on the location and context. In situations where people wait or are sitting still, such as queuing, traveling by bus, or working at university, bystanders were likely to start conversations by asking these questions. I tried to give a short, polite, and cheerful answer without giving much private information, which seemed to satisfy most people’s curiosity. Commonly they either reacted by wishing me luck using my walker or expressing mild pity at my situation. Others were insistent on asking many follow-up questions about my young age and specifics of my condition. I saw this as an opportunity to tell bystanders that my disability is a normal aspect of my everyday life and I do not really experience this as sad or tragic, but I am not sure if I succeeded in convincing them of this.

I noticed that I strongly preferred to have a more open conversation about this topic on my own terms, as I am used to doing, rather than being expected to please the curiosity of strangers. This did give me an interesting insight in social obstacles that I was not aware could be so prominent in the target group’s experience. It was difficult for me to imagine in advance how many questions visibly disabled people usually navigate when going about their day, and how much responsibility some feel to leave a good impression.

Although these are very noticeable changes to my regular experience, there were also smaller changes. After becoming visible, I came under the impression that I was being looked at by others more than before, possibly because I did not want to be asked questions again and/or possibly because seeing a young person with a mobility aid is uncommon and therefore draws attention. If the amount of social response from my walker can be taken as an indication, I estimate that the latter is very likely.

Furthermore, I noticed that although it offered a great physical benefit, these new negative experiences were exhausting and impacted my health.

It is important to not that in most everyday situations these negative experiences were negligible. However, after the two weeks I decided after carefully weighing the positive and negative aspects to stop using the walker. This was largely motivated by the impact of these negative experiences, and the relatively small added benefit of a walker compared to my current methods to cope with exhaustion. The walker’s positive contributions to my energy levels and pain reduction were a great value to me. However, I felt I was able to adequately function without. If my physical condition had been affected more, these consequences may weigh less heavily against the benefits.

Conclusion

I was able to experience firsthand how the visibility of an impairment through a design product changed the social treatment of its user. Especially interesting was the reaction of bystanders to this visibility, which created an obstacle that I did not previously experience. This largely overlapped with insights from research about the everyday experiences of wheelchair users and health-related stigma. However, I found that the precise impact of this visibility was difficult to anticipate in advance.

Overall, my experiences provided little new information, but were useful for identifying with the perspective of the user.