This design case presents the process to develop Empathear, a system that simulates the experience of “hearing voices”. Hearing voices can be a symptom of mental illness such as schizophrenia. The voices can affect greatly the life of voice hearers. Empathear aims to show family members a part of the experience their loved ones live everyday, with the goal of creating the conditions for empathy. Empathear consists of a wearable device that records environmental noise and wirelessly plays voices that react to the environments through subtle earphones. An accompanying App manages the system. Initial testing with families of people with schizophrenia and assessments by the Supporting Families Organisation New Zealand indicate that Empathear can be a helpful tool for creating a better understanding of hearing voices.
Second Caplet Scarf Fabric Pattern:

I created the second design as a mixture between a caplet and a scarf. I wanted to give the overall shape of the garment more structure so it would easily marry with the electronic 3D Printed parts. For this piece I also wanted to create stronger folds in the back structure and collar playing with the lining to reveal a different visual element.

empathear

Design of a system to elicit empathy in siblings of voice hearers

A thesis by Sarah Mokhtar
empathear
Empathear: Design of a system to elicit empathy in siblings of voice hearers

By Sarah Phoebe Anne Binte Mokhtar

A 90 point thesis,
submitted to the Victoria University of Wellington,
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abstract
Empathy is the driving concept of this research, challenging the ability of a designed devices ability to elicit empathy. Through the design of a wearable technology scarf and smart phone App (both entitled Empathear) created to emulate ‘voices’, this thesis has developed and tested, a product-service system that provides family members a simulated voice hearing experience which can be undertaken in the family home and out in the general public. These voices adapt to the wearer’s environment, becoming louder, softer, more intense or relaxed. Using Empathear outside of the home is very important to this research as it allows family members to see what it is like to speak to members of the public with the distraction of voices.

This research identified four common themes expressed by those interviewed:
- Distraction and Concentration
- Personal Adaption into a Progressional Experience
- Empathy and Appreciation
- Positivity for the Future

Empathear fills a gap in the market, helping families to take control, becoming their own instigators of positive change. From a case study of user testing of the chosen design output – the Empathear App, it was found that this research was successful in achieving improved empathetic concern, with all sibling participants acknowledging a change in empathy towards their loved one. This generated a motivation, especially in younger participants, to improve the future of their loved one akin to Daniel C. Batson’s Altruism (Chapter 5.1 Types of Empathy).

This research worked to avoid personal distress in participants by allowing them the option to turn the App off at any stage, giving participants free range on how they wanted to orchestrate their personal voices experience. Empathear has given premise to understanding that distinguishing the illness from our loved one can be achieved through understanding our own reaction to voices. Participants were given an experience of how their personality could be tested by this adversity, allowing them to recognize the reasons behind their loved ones day to day actions and reactions.

ABSTRACT

It is said that one in five adults will be affected by some form of mental disorder every year, and nearly half the population (45%) will experience a mental disorder at some stage in their life (SaneAustralia, 2004).

This research poses the question: ‘How can design elicit empathy in siblings of voices hearers? Testing and using a designed device to simulate dynamic Auditory Hallucinations or ‘Voices’ in order for family members to experience an in-depth understanding of their own reaction to hearing ‘voices’. With multiple studies affirming that families are crucial to recovery, this thesis research targets families to provide an education on how to positively perpetuate the recovery of a loved one suffering from hearing voices.
1

INTRODUCTION
1

INTRODUCTION

1.1 A sane response.
For us, ‘normal people’, the symptoms of mental illness are a scary unknown, seeing those who are ‘different’ as potentially dangerous. Most of us are oblivious to the link between these symptoms of psychosis and the strong affect they have on the everyday life of those affected, especially when interacting with the general public. Sadly, we often only see the illness and not the person behind it.

The key to addressing this issue is to provide the general public a more in depth understanding of their own reaction to a common symptom of mental illness - voices.

It is said that one in every four adults will be affected by some form of mental disorder every year and nearly half the population (45%) will experience a mental disorder at some stage in their life (SaneAustralia, 2004). While this is a heavy statistic, it does not tell us the percentage of everyday people whose lives experience significant upheaval as a result of a family member’s illness.

1.2 Primary Thesis Question and Topic
This project challenges the question, ‘How can design elicit empathy in siblings of voices hearers?’ The primary method of testing will be achieved through a device that simulates dynamic ‘Auditory Hallucinations’ or ‘voices’ where family (focusing on female Siblings) can experience an in-depth understanding of their own reaction to hearing ‘voices’.

1.3 Empathy.
What is empathy and how can it be achieved?
The main form of empathy this thesis will address is ‘Empathetic Concern’ (Batson, 2011) as it includes empathizing and also having a positive regard or a compassionate concern for the affected person. What this research wants to avoid is ‘Personal Distress’ where the participant experiences indifference, rather than well-calibrated caring.

The empathy evolution in individual family members is very important to the research validation. This will be found through user testing of a constructed persona. More detail explaining Empathy can be found in Chapter 5 Empathy.
1.6 Intention through design.
I wish to improve empathy in those with close contact with voice hearers (family, caregivers, and practitioners) and hope that this extends to the general public. This is to be addressed through a daylong (maximum) experience of ‘voices’.
During this research, a range of physical forms will be investigated as options that could be created as products post culmination of the thesis. Options could include an App for smart phones, jewellery, belt, vest etc.

My overall intentions for the output of this thesis are as follows:
- Provide a dynamic experience with voices that will challenge participants mentally.
- The Microphones automatically adapt the volume of the voice tracks and the frequency of voices. The variance of this ‘voices orchestration’ is determined by the user’s environment.
  E.g.  Loud environment = more voices +more distressing/angry temperaments + louder volume.
  Quiet environment = less voices +more personal or comforting +quieter environment.
- Have questionnaires before, during and after the experience to gauge the users change in empathy.

1.7 Summary.
In summary, I am proposing a device that simulates dynamic voices. This will be used by family members of voice hearers, primarily siblings, to help create awareness and positive discussion about mental health. I hope to improve the level of understanding of the affect mental illness has on a sufferers daily ability to function by giving family the opportunity to witness first-hand their own reaction to hearing voices. The device is called Empathear.
MOTIVATIONS
Living with a sibling who has schizophrenia has given me strong personal experience and insight into this type of family unit. This thesis has facilitated my ambitions to give back to the ‘Supporting Families in Mental Illness NZ’ (SFMI) community.

The psychology behind the progression of my positive evolution of attitude is outlined by Stalberg, Ekerwald, & Hultman (2004) where ‘care giving’ is recognised as a positive coping technique, which helps siblings create better relationships with their affected love one. Stalberg, Ekerwald, & Hultman (2004) hypothesise that it is healthier to have an active involvement in your loved one’s life than to sit on the side-lines.

My initial motivation for pursuing this topic is my sister. My older sister was diagnosed with schizophrenia when she was 13. My family, especially my brother and I, did not know what to expect or how to deal with this new situation. I found it hard to communicate with her and had felt that I had lost my older sister, lost that person who was supposed to be a role-model, a protector and life-long friend. Needless to say it was life-changing, not only for my sister but for our entire family.
If siblings are not living a mentally positive life style, how can they cause positive change in their loved ones lives? How can they lead the voice hearer to recovery? We need to have a deeper level of understanding of the illness (voices) so we can assess situations in a constructive and informed manner. We need to bring the illness a sense of normality so we can accept our loved one for who they are now.

Siblings have described themselves as strong advocates for their loved one, expressing the positive influence and personal strengths they have as a result of living with mental illness in their families. The study of siblings carried out by Kinsella, K. B. and Anderson, R. A. (1996) spoke of sibling positive attitudes towards their affected sibling. ‘They spoke of a heightened gratitude for life and an eagerness to live life fully. Some discussed having insight into the priorities of life, while others described their ability to make meaning out of life’s events and problems’. (Kinsella, K. B. and Anderson, R. A. 1996).

I hypothesise that, considering these sibling sentiments and my own personal experience, this appreciation of the personal strengths comes with an eagerness to celebrate the sibling bond between the healthy sibling and the voice hearer. This hypothesis is strengthened by statements made in Section 2.4 Effecting Positive Change, where the desire to maintain the relationship is explicitly expressed (Kinsella, K. B. and Anderson, R. A. 1996).

The discovery of this glowing positive sentiment expressed by the well sibling empowered me to think more critically about the final design form. I intend to bring this ‘Celebration of the Sibling Bond’ into physical form through the final device design.
If we can relate our feeling of a ‘normal life’ to the notion of ‘comfort and understanding’, and an ‘abnormal life’ to ‘confusion and the unknown’ we can perhaps make the statement:

For a ‘normal life’ in mental illness we need to have a deep understanding about our loved ones illness. If we do not understand our loved ones illness, confusion and a fear of the unknown can become barriers to recovery and can create a rift in the family which can lead to an ‘abnormal’ life.

Evidently, to affect positive change in ours and our loved ones life, we must first reinstate the sense of ‘normality’ into our day to day family life.

This statement illustrates the need for siblings to have positive coping techniques such as seeking support, objectifying the illness, acquiring information and constructive escape (Kinsella, K. B. and Anderson, R. A. 1996) when dealing with a mentally ill sibling. It also gives us an indication of how positive coping techniques can be utilised not only to manage but improve the recovery with out relapse, allowing the voice hearer to flourish.

The study carried out by Kinsella, and Anderson, (1996) found siblings stressed that they had to separate the illness and their loved one, emphasising it was constructive for them to be angry at the illness and not their loved one. This statement highlights the importance of my research, stating the need to distinguish the illness from the person. Kinsella, and Anderson, (1996) also found their participants desire and ability to maintain a healthy relationship with their loved one was increased when practicing this separation between the illness and their affected family member.

What these studies fail to discuss is how this ‘separation’ can be achieved. I propose that to distinguish the illness from our loved one we must understand its effect on them, therefore we must put ourselves in their position. We must see our own reaction to voices, as it will give us an indication of how a symptom of mental illness (voices) can affect us personally, how our personality is tested by this adversity and relate that experience to our loved ones day to day actions and reactions.

2.4 Effecting positive change

MOTIVATIONS

Creating positive, constructive emotions in siblings can help to instill a sense of normality and in the long run, can be greatly beneficial to all involved. I want to help siblings achieve this sense of normality in their families by educating them with ‘Empathear’ so that they can experience their own reaction to hearing voices. ‘We found that feelings of love made the situation of having a mentally ill sibling easier to handle. This powerful, positive feeling of affection was also a reason to support the patient’ (Stalberg et al. 2004).
2.5 Criteria

MOTIVATIONS

Criteria taken from research findings for design development. The design needs to address these issues found in chapter 2:

2.2 Sibling Bond and 2.3 A sense of normality - utilise siblings and celebrate the sibling bond. Provide siblings the opportunity to understand their loved one and therefore help them create normality in mental illness.

2.4 Effecting positive change – create constructive emotions in siblings and positive coping techniques that could help prevent relapse. Help maintain/establish a healthy relationship between the family member and the voice hearer.
THESIS STRUCTURE IN FOUR PARTS
THESIS STRUCTURE IN FOUR PARTS

The complexity of my thesis topic has led me to divide my research into four parts. The first of these parts addresses the Social Challenge (SC) presented by the families/community of those who suffer from Auditory Hallucinations.

The second considers the Technical Design (TD)(electronics, apps, outsourcing) elements and the third part centres around considerations of the Physical Design/ scarf + app (PD).

The final part focuses on Before, During and After questionnaires on ‘Psychological Change’ (PC) of empathy in family.
BACKGROUND
Psychosis: (from the Greek ψυχή “psyche”, for mind/soul, and -ωσις “-osis”, for abnormal condition or derangement).
Schizophrenia (a form of psychosis) is seen as a profound disruption in cognition and emotion that affects the most fundamental of human characteristics: language, thought, perception, affect, and sense of self (schizophrenia.com 2010).
Within the past year, 20% of the population or 1 in 5 New Zealanders have experienced some form of mental illness (Mental Health Foundation 2014) and around 280 million people hear voices worldwide. It is believed that between 3-5% of New Zealanders hear voices but only around 1% are diagnosed with an illness (Hear Voices Network, 2014).

Psychosis

Symptoms, while wide ranging, frequently include psychotic manifestations, including experiencing visual hallucinations and/or hearing internal voices. This research concentrates on the symptom of Auditory Hallucinations or ‘hearing voices’ as hearing voices is the most common hallucination among people with Schizophrenia (mayoclinic.com 2013).

‘Hearing voices’ is not isolated to Schizophrenia - voices can be experienced by those with Bipolar disorder and Depression. It is interesting to note that voices can also be heard by people who are ‘healthy’ and do not require a diagnosis of mental illness.
4.2 Hearing Voices

The content of voices can vary, with some experiencing very stressful loud and angry voices, others hearing voices with calming and motivating personalities, and, most commonly, hearing sounds and undistinguishable whispers (Mental Health Foundation, 2014). The Mental Health Foundation have a very relatable explanation for non-voice hearers of how voices intrude thoughts and are hard to ignore:

“a good example of this is the experience of recalling a rhyme or tune, which you find yourself repeating unconsciously under your breath and which keeps going through your head again and again. You can even find yourself humming it. You never took a decision to start thinking of it and it’s difficult to stop thinking about it...” (Mental Health Foundation, 2014).

There are many different ways to hear voices. They can be experienced in the head, from outside the head or even in the body. It may be one voice or many voices and the voice may talk to you or about you (Mental Health Foundation, 2014).
Research across many European countries shows that families are consistently frustrated at the lack of information given to them by those in positions of great knowledge (Clinicians, Psychiatrists) (Kinsella, K. B. and Anderson, R. A. 1996). If families are expected to take on the role of caregiver (a role that historically has required a very high level of education) then useful information should be made readily available to them at the beginning of the enquiry into their loved ones illness (Kinsella, K. B. and Anderson, R. A. 1996).
4.4 Importance of Siblings

BACKGROUND

Families have been charged with the care of their ill family member but have not been given tools to support and promote an active recovery of their loved one (Kinsella, K. B. and Anderson, R. A. 1996). Although not commonly known, New Zealand has effective support groups for families of sufferers to call on when in need, offering advice, and are there to lend an ear when needed e.g. Supporting Families in Mental Illness.

With female siblings being identified as instigators of positive change (Stalberg, Ekerwald, & Hultman, 2004) support networks, such as Supporting Families in Mental Illness (SFMI), should be looking at promoting the sibling bond that exists in these families. At the moment SFMI members are predominantly family members belonging to an aging population. Siblings and offspring in particular remain largely without appropriate services that could enhance their ability to adapt and cope with the burden of mental illness, (Kinsella, K. B. and Anderson, R. A. 1996). The new generation of members that should be educated and utilised for recovery are siblings of voice hearers.
The workshop is set up as a class room where each participant is given various tasks to do individually eg. Math and English questions, while listening to a looped recording of voices through headphones playing off an MP3 player. The workshop demonstrates the distraction of voices when trying to concentrate on tasks in a controlled environment. What the workshop lacks is the right kind of technology to simulate ‘voice’s’. The looping of tracks meant the voices do not adapt to the users environment and after a time they become predictable and can be blocked out by the listener. Also the workshop provided minimal time spent interacting with the general public, a task that is known to be very stressful while hearing voices.

The facilitators of the workshop have expressed their desire to offer this workshop over a longer period of time and in public spaces. With the implementation of the device Empathear, the workshop could address these issues.
Supporting Families in Mental Illness (SFMI)

**BACKGROUND**

Supporting Families in Mental Illness (SFMI) is a support network New Zealand wide that aids the family members of those ailed by mental illnesses.

They have a variety of support roles including:
- Providing free support for families (education, advice etc.)
- Developing peer support networks
- Advocating and promoting the rights and needs of families and their loved one.

Their mission is to provide the best possible education, support and advocacy for family/whanau of people experiencing a major mental illness. ‘We believe that families and whanau can play a key role in the recovery process for someone who experiences a mental illness’, (Supporting Families 2013).
Changing Minds group is a non-profit group based in Auckland, New Zealand. They provide a number of resources for those who want active involvement in the mental health community. Their aim is to ‘work on strengthening the voice of mental health and addictions service users to ensure that people are treated fairly, with dignity and respect, and that every individual is given opportunity to live their life in the way in which they choose whether they have a diagnosis of a mental health issue or not’ (Changing Minds, 2012).
4.8 Criteria

BACKGROUND
Criteria taken from research findings for design development. The design needs to address these issues found in chapter 4:

4.2 Hearing Voices - simulate a voices experience that is synonymous to that of the voice hearer’s real world experience.

4.3 From Hospital to Home - provide an easily accessible experience that can be used by families when they require it.

4.4 Importance of Siblings - Address the new generation of supporters: siblings

4.5 to 4.7 Networks – SFMI and the Hearing Voices Workshop will have custodian access to the device and will be the main network providing support before and after each users experience.
5

EMPATHY
Leader in empathy research, C. Daniel Batson concludes that ‘empathic concern’ seems to be a product of (a) ‘perception of another as in need’ and (b) ‘intrinsic valuing of that other’s welfare’, (Batson D., 2007).

To determine ‘How design can elicit empathy in siblings of voices hearers’ we first need to understand ‘what is empathy?’ and what forms of empathy are relevant to this research. As mentioned in the introduction, this thesis focuses on the ‘evolution of empathy’ as a means to improve the life of the sufferer and their family unit.
5.1 Types of Empathy

Empathy has many sub-contexts that categorise its meaning. Here are three mainstream types of Empathy.

The first type is called “Cognitive Empathy.” A person with this type of empathy is said to be able to know how another person feels and what they might be thinking—i.e. ‘putting yourself in someone else’s shoes’. This inside knowledge is useful to those in professions which deal with negotiations or motivating people. Cognitive Empathy can also be used to inflict pain, as it enables an understanding of what the victim might be feeling, yet not requiring sympathy.

The second type of empathy is called ‘Emotional Empathy’ where the affected responds to another’s perceived emotional state by experiencing feeling of a similar sort. Emotional Empathy makes someone well-attuned to another person’s inner emotional world” (Goleman 2007). This form of empathy is often confused with basic empathy.

The final type is called ‘Empathetic Concern’ or ‘Compassionate Empathy’. Empathetic Concern includes empathizing (Emotional Empathy), but it also requires having a positive regard or a compassionate concern for the other person - to not only understand a person’s predicament and feel with them, but also be spontaneously moved to help, if needed. (Goleman 2007).

An undesired effect that can occur through experiencing empathy is ‘Personal Distress’. ‘Personal Distress’ can happen to people when the empathetic experience they are having is so close to the other persons condition that they begin to lack the ability to manage their own distressing emotions, leading to psychological exhaustion. Personal Distress can cause indifference, rather than well-calibrated caring.

The type of empathy this thesis wishes to address is Empathetic Concern or Altruistic Empathy termed by C. Daniel Batson (1991) to describe a motivational state with the ultimate goal of increasing another’s welfare (Batson, 1991). He explains Altruism as a way to include the benefits of another as a means to benefit oneself. This theory provides an interesting aspect to my research as it points out the two parts of motivation when caring for someone’s welfare.

The kind of empathy my research works with needs to;

Firstly, be motivated by the passion to better the life of their affected family member; AND,

Secondly, address the desire to improve Quality of Life for themselves (healthy sibling) as part of the family unit.
5.2 Criteria

**EMPATHY**

Criteria taken from research findings for design development

The design needs to address these issues found in chapter 5:

- 5.1 Types of Empathy - address the improvement of empathy and avoid personal distress
  - address the individuals as a way of addressing the family unit
This research will investigate designed devices that have resulted from social challenges. It will evaluate psychology literature that informed design decisions, assess the niche the Empathear fits in, and clarify potential and significance to the mental health community.
The workshop found five respondents that specifically expressed their increase in empathy and three respondents that expressed increased confidence when in contact with people who hear voices. People also requested the workshop be developed further, one request being the length of the workshop from three hours to a two day programme.

Another comment was about the technology used, where someone requested better quality headphones, as the ones they were given hurt. Another participant said that participants should have different tapes, different voices to broaden the experience of learning.

Xavier Amador’s book *I’m Not Sick, I Don’t Need Help* (Amador, 2010) is based on his theory of the LEAP (Listen, Empathise, Agree and Partner) technique. This technique is a means to helping someone suffering from mental illness accept treatment. This book is instructive on the poor insight those with mental illness have on their lives and how regaining this insight is imperative to recovery. What Amador does not consider is the families collective role in the process of recovery.

James Caravan, writer of the medical paper *The Role of Family in Mental Illness* (Caravan 1999) introduces the idea of ‘EE’ (Expressed Emotion). ‘EE’ is alluded to by the workshop as Pearson’s intention is to create an understanding between the person suffering and the people associating with them, including family. With a new perspective on what their affected family member is coping with on a daily basis, the families EE should decrease meaning a decrease in stress in the family unit resulting in a decrease in relapse for the affected member.
6.2 Sibling Bond and Healthy Coping Patterns

This reading also infers that female siblings are more likely to provide care than their male counterparts. Siblings of Patients with Schizophrenia: Sibling Bond, Coping Patterns, and fear of Possible Schizophrenia Heredity (Stalberg, Ekerwald, & Hultman, 2004) studies siblings of those with schizophrenia and identifies the coping strategies used by family members. These strategies include 5 positive and negative methods that can be classified into three groups: (1) Avoidance and Isolation, (2) Normality, and (3) Care Giving and Grieving. Unlike Bernable, Gaudine, Bennet, and Meadus (2006), Stalberg, Ekerwald, & Hultman, (2004), conducted a study of 16 participants all of which were siblings of patients.

What this study brought to light was the strikingly similar thinking between siblings regardless of their age, gender, or generation. ‘An unifying theme appeared to be an emotional sibling bond characterised by feelings of love, sorrow, anger, envy, guilt and shame’ (Stalberg, Ekerwald, & Hultman, 2004).

Both papers assessed siblings need for ‘normalisation’ in the eyes of those around them and their inherent powerful sympathy for the ill siblings burden of having Schizophrenia. ‘Our interpretation is that grieving is a way to process the loss of the earlier sibling relationship and to seek emotional balance in the involvement and care of the ill sibling’ (Stalberg, Ekerwald, & Hultman, 2004).

Alongside this, both papers discussed negative feelings siblings had about the treatment of their family when dealing with Clinicians and the lack of useful information supplied by the Clinicians.
The second empathy scale investigated was The Geneva Emotion Wheel, (Scherer, 2005). This scale is more visual than the Interpersonal Reactivity Index (Davis, 1980) and asks participants with more specific questions about their emotions relating to specific objects or circumstances. While both these scales are useful for questioning the general public, neither are adequate in addressing the needs of this thesis - addressing empathy in a specific group that has been greatly affected by extraneous life experience. Existing questionnaires weren't specific enough for the goals of this thesis, so a bespoke survey was created.

To remedy this, my pilot study created two empathy questionnaires that were an adaptation of the existing scales mentioned above. These can be found in Chapter A1.2.
6.4 Criteria

**FAMILY CARE**

Criteria taken from research findings for design development. The design needs to address these issues found in chapter 6:

6.1 Importance of Family care:
- Create an experience that is an extension of the HVW and also can be used independently with the guidance of SFMI.
- Create insight into a symptom of mental illness 'voices' and generate an understanding between the sufferer and those around them.

6.2 Sibling Bond and Healthy Coping Patterns:
- Utilize female siblings as a positive force in recovery.
- Recognise the similarities/motivations siblings share and their need for a normal life within the mental illness.
INITIAL DESIGN CRITERIA
I have identified issues in the previous chapters that can be addressed as a series of Initial Design Criteria.

These issues are as follows:

- Utilising female siblings as a positive force in recovery.
- Recognise the similarities/motivations siblings share and their need for a normal life within the mental illness.
- Address the improvement of empathy and avoid personal distress.
- Address the individuals as a way of addressing the family unit.

- Simulate a voice hearing experience that is synonymous to that of the voice hearer’s real world experience.
- Provide an easily accessible experience that can be used by families when required.
- Address the new generation of supporters: siblings.
- Utilise siblings and celebrate the sibling bond. Provide siblings the opportunity to understand their loved one and therefore help them create normality in mental illness.
- Create constructive emotions in siblings and positive coping techniques that could help prevent relapse. Help maintain/establish a healthy relationship between the family member and the voice hearer.

SFMI and the HVW will have custodian access to the device and will be the main network providing support before and after each users experience.
DESIGN REVIEW
**DESIGN REVIEW**

This design review researches design that demonstrates the following attributes:

- A medical/psychological education device that’s user function is synonymous to the actual illness.
- A change in the way the user perceives their surroundings.
- The users process of recovery while the device is in use, helping to inform users of healthy living.
- Empowerment and taking control of one’s own health and the health of others around them.
- Mental health design looking at Quality of Life of the user.
- Promotion of emotional interaction with Industrial device.
- The link between people and health.
- Portability, fun and interaction.
8.1 Significant Designs

**DESIGN REVIEW**

Bodily gestures are an interesting avenue to develop in the context of wearable technology. A research project, named ‘Assembly’ (2011), by student Lorea Sinclaire, explores different bodily gestures to interact with a mobile phone.

This concept skims the possible gestural and bodily interactions any user can have in the interface with devices. It begins to open up a dialogue of imagination where body language becomes an innovative way to communicate with our electronic objects.

What this project does not cover is the personal emotional aspects that emerge when interacting with a device and how this can effect how a person wants to interact with it.

The whiSpiral (2005), developed by MIT Media Lab Europe student Stefan Agamanolis, addresses this issue in an interesting manner. The design is a shawl that allows the user to record short messages that can be replayed later as whispers to the next user (friends and family) upon touching and caressing specific areas of the fabric. It explores how we can enhance the way we evoke memories of loved ones.
This emotional interaction is somewhat addressed by ‘Jerry’ the teddy bear developed by Aaron Horowitz and Hannah Chung “Childs Play” (Horowitz, A., & Chung, H. 2009). It is said to “empower children with a chronic illness to take control of their own disease,” (Horowitz, A., & Chung, H. 2009). Together with the ‘Therapeutic Robots’ (Kazuyoshi Wada, 2004), developed in Japan for the elderly, they have had great success in helping improve the lives of their target audience.

The product Jerry from ‘Childs Play’ gives its user (children with type 1 Diabetes) the ability to look into their own illness and learn how to manage their condition. Jerry also instills an empathy in its user and with this an added sense of responsibility (Horowitz, A., & Chung, H. 2009).
The Beagle Scarf Hoodie, designed by Leo Chao’s is an attentive and thoughtful design response to the needs of Autistic children. The scarf hoodie addresses the range in severity of the Autism spectrum, and how the condition interferes with people’s emotions. The scarf hoodie uses sound, smell, and texture to help alleviate the condition (Chao, L. 2009).

What this scarf does not do is incorporate the family into the experience. Both of these products help to improve the lives of those they target yet neither investigate a way to bring the product, user AND the users family together for collective learning. In other words, neither seems to address a more holistic approach where the issue of mental wellbeing for the family unit is specifically promoted.
Another aspect to this smart phone App was the ‘Mindfulness application’ (hoastoolshop, 2011). This part of the application was loaded with audio tracks which enhanced ‘mindfulness’. The user could track their own progress by registering which tracks they listened to more frequently. The developer of this App, Hoa’s Toolshop, states that “People like to gather data which makes their own development concrete,” (hoastoolshop, 2011). This understanding of one’s development / improvement is similar to the ideas of ‘Childs Play’.

Unlike the Therapeutic robot and ‘Childs play’, ‘Viary’ concentrates more on the holistic wellbeing of the client. The app gives the user confidence to do everyday tasks but also considers the importance of social contact between the user and their family/people closest to them.

The second part to the App ‘Mindfulness’ emphasized the importance of the participants’ spiritual wellbeing by applying audio tracks akin to those used in musical therapy.
What these design examples do not capitalise on is the great potential family have to influence recovery. ‘Childs Play’ and the app ‘Viary’ have a design philosophy that is most similar to Empathear. As mentioned earlier, Jerry the teddy bear allows his user the ability to look into their own illness and learn how to manage their condition. Empathear allows its wearer a unique look into their loved ones illness and, through their own first-hand experiences, learn how to help manage the symptom of hearing voices.
Two Apps for those with mental illness have surfaced in the past year. The ‘Pause Emote’ App was designed by Amy Goldfeder, graduate of the Rhode Island School of Design. The App helps diagnose and treat patients with mental illnesses, allowing them to document their life as it is happening. Its aim is to aid in communication between the user and their psychiatrist (Rhode Island School of Design, 2013). The second App, produced by PhD candidate Josef Johann Bless from UiB, helps people with Schizophrenia block the unwanted voices they hear, training them to focus on other sounds (Drønen, 2014). These two Apps verify the growing trend of creating Apps for the mental health community and prove that others are seeing this as a viable market to create positive solutions for improving Quality of Life.
8.2 Conclusions

Design Review

Studies show that family care givers can be an imperative influence, at times more successful than Clinicians when it comes to convincing a voice hearer to take the road of recovery. With multiple studies affirming that families are crucial to recovery, it is puzzling that this thesis research has not found any designed device aimed at families like mine allowing an education on how to positively perpetuate that recovery.

The device Empathear will fill this gap in the market, helping families to take control, and become their own instigators of positive change.
PROCESS/METHODS.
This chapter explores the process and methods followed to generate the design prototypes. To start with, questions were asked as to what the design needed to achieve, then enquiries were made into what established practices expressed the same aims and how this practice could be used as an industry partner.

Social and Technological design issues that influence the Physical design were then researched.
However while they did express ‘Empathy’ they did not seem to express ‘Empathetic Concern’. This may have been due to the participants distance from the experience as none of them were directly affected by a voice hearer and therefore, it can be surmised, had no emotional attachment prior to the experience. Having used the prototype myself, I found that one full day of ‘voices’ was incredibly intense and was verging on becoming ‘Personal Distress’. The conclusion was made, that while an hour may not be enough time to gain ‘Empathetic Concern’, one full day is perhaps too intense and comes dangerously close to creating ‘Personal Distress’. Evidence from the study can be found in Appendix A1.1.

What do the families of voices hearers want and need? And how could this research communicate a design for social change, on their level. I found that I could use a persona to answer this question (persona can be found in 9.4.1). My persona is ‘Extreme Users’ (IDEO 2012), people like me, female siblings of voice hearers. I could use my own experience as a template to addressing the issues of ‘want’ and ‘need’ and use myself as a potential client for social change.

- What kind of voices do people hear and what triggers them? Blogs and forums have been very clear, getting quick statements direct from current voice hearers from all over the world about their personal experiences. Another appealing aspect of this avenue as a source for answers was that it did not require questionnaires or an interview process. The content of the Audio tracks was sourced from the Hearing Voices workshop; therefore the content of the voices has been approved by a reputable international source.

9.1.1 Questions

PROCESS/METHODS

This research was based on the following questions:

- How long does it take to instill empathy? One hour? One day? One week? More? I realised that I needed to make an informed decision about the length of time the family members ‘voices’ experience would last.

In the pilot study, the general public were tested with Empathear’s voices experience. It was found that, in this test group, an experience of voices for one hour was generally enough time for people to have an impression of what hearing voices is like.
9.2 Initial Enquiries

The disadvantages of the workshop are:
- Using a standard music player is that the earphones are visible to those you interact with,
- The recordings of voices were on a loop and repetitive

This research has not found any devices that focus on offering this sort of voice hearing experience over a long period of time. Initial findings with the workshop and the advice, allowed an informed decision to be made in developing the initial criteria to base my design:

**INITIAL CRITERIA**

The design should:
- Be able to integrate into daily wear of user
- Present voices in randomised order
- Voices should react to environment changes
- Be able to be worn as long as possible, perhaps taken home for a few days to be used by multiple members of the family.

Contact was made with Arana Pearson from the Hearing Voices Workshop to start the initial inquiry into what could be designed and also to see whether a collaboration of sorts could be made between myself (designer/sibling) and the educational workshop (Mr Pearson).

During a semi structured interview with Mr Pearson, the workshop was discussed along with improvements that could be made. He expressed the desire to offer the workshop over a longer period of time where the participant would have more opportunity to interact with the general public. The new intention of the device was to not only be an extension of the workshop but an improvement of it.
how the topics were clustered

how the topics were addressed} in progressional order

figure 5 Original infographic by Author (2014)
To answer this thesis question ‘How can design elicit empathy in siblings of voices hearers’ and address the needs of the SF community, the research was segmented into four areas:

Social Challenge (SC)
Technical Design (TD)
Physical Design (PD)
Psychological Change (PC)

These have been clustered together because issues related to Social Change influence the testing, questionnaires and interview sessions involved in Psychological Change.

These have been clustered together because issues related to Technical Design greatly influence the physical design.
This research comes from a designer’s perspective but is using psychology and social design as tools to develop, and have greater influence on, the outcome. With this in mind I have created a very simple graphic to explain where this thesis sits on the scale between a psychological thesis and a purely design thesis.
9.4.1 Social Challenge

Persona

PROCESS/METHODS

The population I am aiming my device at: Lamb and Sutton-Smith (1982) identify the persona most likely to affect positive change in Schizophrenic Patients as Female Siblings, as sibling relationships are unique in that they are long-lasting and involve common social, genetic and cultural heritage. Research shows ‘that siblings provide more support when parents are not available, with sisters generally providing more care than brothers’ (Greenberg et al.1997).

Research has shown that case studies that interview siblings of voice hearers use similar criteria’s for their recruitment processes. ‘Having a Sibling With Schizophrenia: A Phenomenological Study’ (Barnable, Gaurdine, Bennet, Meadus, 2006), describes most of their participants as having relatively frequent contact with their affected sibling. This research also recognises that, like with most illnesses, early intervention can greatly impact the recovery rate. As most Schizophrenia diagnoses happen in the age range of 16-25 (Schizophrenia.com, 2004) we can likely assume that most siblings of patients will fall into this same age bracket. With this in mind we can surmise that it is logical to produce a persona that reflects female siblings of a young, tech savvy age group.

Students (high school or Uni)/Working Male
Female
Social
Self-motivated
Have relatively frequent contact with voice hearer.
Understand technology
Starting to understand responsibility
Have active input into their loved ones life and future
Different perspective on ‘strange’ people, inside info of what their lives are like.
Sad to see someone who hears voices on their own, homeless, jobless etc. Want to make sure their loved one does not become like this.

I will be using myself as the dominant persona as I am the most accessible real world personality for this thesis. My own life experience allows me a unique view into the psyche of others in my position, their wants and needs, their priorities, concerns, and hopes for the future. Once this persona has been tested, further research can be made into how the design works with a wider population.
Stigma

As family are often the first contact the affected person has, it is very important that this relationship is strong and forgiving, on both sides. For voice hearers and their families, we can divide the stigma into three distinct types: A. Society View; B. Family self-stigmatisation; C. Sufferer self-stigmatisation (Gonzalez-Torres, Oraa, Arisegui & Fernandez-Rivas, 2006).

The key to addressing the negative feelings family experience towards their loved one is to change their perspective on the illness. In other words, addressing the stigma family harbour towards hearing voices and create a positive path that allows them to let go of the negative feelings surrounding mental illness.

figure 7 Original infographic by Author (2014)
Social Challenge

Criteria

PROCESS/METHODS

Criteria taken from research findings for design development. According to aspects from chapter 9.4 the Final Physical Design should address:

- Personas aesthetic (gender, age, relationship to voice hearer)
- Stigma that could be related to it
- Expression of Celebration of Sibling Bond
- The idea of community, multi-use by different people.
- Allowing the family to create positive attitudes around mental health and their family member

Details of the exterior design of the garment process of this prototype can be seen in the Physical Design chapter.

Design Criteria: Scarf + earbuds

Provide a dynamic 'hearing voices' experience.
Can be integrated into the users daily life.
Physical garment can be removed from body but voices still play.
Designed to suit persona (age group, gender).
Engage peoples thinking.
Provide a sense of community.
Simple to use.
Avoids stigma.
Create positive and optimistic thinking.
The technical design takes into account details involving the electronics needed to produce the prototype. The Technical Design also required code to be written and a Maintenance and User App to be developed.
Technical design

Working prototype

PROCESS/METHODS

The production of the working prototype was pivotal to the success of the overall design research question. The question of empathy could not have been answered without having a working prototype to test it against.

The prototype works by:

- Providing a dynamic experience with voices that will challenge participants mentally.
- Using microphones to automatically adapt the volume of the voice tracks and the frequency of voices. The variance of this ‘voices orchestration’ is determined by the user’s environment.

E.g. Loud environment = more voices +more distressing/angry temperaments + louder volume.

Quiet environment = less voices +more personal or comforting +quieter environment.
The construction of electronic components was outsourced to Tiago Rorke. Our brief for collaboration is outlined in Appendix A3.1 Outsourcing, Tiago Rorke. A range of different electronics that fit my Initial Criteria were investigated for their suitability.

From the semi structured interview with Mr Pearson we created this criteria:

For the ear piece we began by looking into small, unnoticeable technologies like spy wear and hearing aids. This is the criteria we worked from:

<table>
<thead>
<tr>
<th>Scarf + Earpiece: Design Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be as invisible as possible (wireless). Present voices in a random order. Voices should react to environment changes (microphones telling the device what voices would suit the environment; Loud or Quiet). Be able to be worn as long as possible, perhaps taken home for a few days to be used by multiple members of the family.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ear piece CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small.</td>
</tr>
<tr>
<td>Comfortable.</td>
</tr>
<tr>
<td>Unnoticeable.</td>
</tr>
<tr>
<td>Allows ‘real’ sounds to be heard at the same time as voices. Wireless. Cost effective. Bluetooth capabilities.</td>
</tr>
</tbody>
</table>
Because of the limitations of budget only ‘off the shelf’ technologies were acquired meaning that some parts sourced were large and bulky. Ideally, custom made ‘flexible’ parts would be made to allow for smaller components and more movement in the garment. If I were to make a hard cover device (like many of the industrial products I am used to designing) it would need to be quite large to accommodate the electronics that could be afforded.

To accommodate this, the device was manifested as a wearable technology garment. This allowed flexibility to explore the design. A detailed account of the Technical design process can be found in Appendix A4 Technical Design.
The APP should:
- Consider layout for maintenance app
- Allow the user to change volume, frequency of voices according to environment and how it listens to the environment.

The DEVICE should consider:
- Large/awkward shaped parts need to be comfortable.
- Size and number of parts and the placement of these parts.
- Power charging points on exterior.
- On/off ‘switch’.
- Placement of microphones.

Details of the exterior design of the garment process of this prototype can be seen in the chapter Physical Design.
9.5.1 Technical design

Criteria

**PROCESS/METHODS**

Criteria taken from research findings for design development. Things considered in Final Physical Design and app design:

- The DEVICE should:
  - Be small.
  - Be comfortable.
  - Be unnoticeable.
  - Allow 'real' sounds to be heard at the same time as voices.
  - Be Wireless.
  - Be Cost effective.
  - Have Bluetooth capabilities.
9.6 PHYSICAL DESIGN

PROCESS/METHODS

So, why a scarf? Wearable technology fashion is an up and coming way for technology to integrate itself into the wearer’s everyday living. It was this ideal of integration of electronics and fabrics that persuaded me to create Empathear as a piece of wearable technology.

During the physical design process I needed to address the design implications discovered in the previous chapters Social Challenge and Technological Design. This thesis recognises that many different physical manifestations could fit this brief, but as the most accessible realworld persona for the design we can assume that even if not all siblings in my position would prefer the scarf, some percentage would.

The length and width of a scarf allows the electronics the space and insulation they need without being bulky and noticeable by the wearer and those around them. With this form the user has the ability to physically remove the scarf but not stop the voices from playing and reacting to the environment.

Design Criteria: Scarf + Earpiece

Scarf and Ear Buds should:
- Provide a dynamic ‘hearing voices’ experience
- Be able to be integrated into the users daily life.
- Physical garment can be removed from body but voices still play.
- Be designed to suit persona (age group, gender).
- Engage peoples thinking.
- Provide a sense of community.
- Be simple to use.
- Avoid stigma.
- Create positive and optimistic thinking.
figure 10 Original Photograph by Author (2014)
9.6.1 Physical design

Creation of prototype exterior
 Scarf and Head set

**PROCESS/METHODS**

The exterior design of the device should relate explicitly to the persona identified in Social Challenge. As the prominent identifier of this persona is a ‘female sibling’, the decision was made to relate the exterior design to females between the ages of 16 and 25 (Schizophrenia.com 2013).
At this stage I was very interested in making the design minimalistic and therefore able to be worn by any person despite personal taste, age or size. I sourced some basic stretch cotton in two colours, grey and white.

---

*figure 11 Original drawings by Author (2014)*
The white fabric was used to create an initial casing around the electronic insert to protect the electronics. The grey fabric was used as the outer cover that could be washed, and was the visual aesthetic seen by the wearer. The white inner was kept open so the electronics could still be accessed for maintenance.
figure 13-15 Original Photograph by Author (2014)
These three images demonstrate the outer, inner, and electronic layers. The first image depicts the outer washable layer. The second image shows the white protective inner cover and the third image reveals the electronic layer.

figure 16-18 Original Photograph by Author (2014)
Detail of inner electronics

Detail of dome

Detail of outer stitching

figure 19-21 Original Photograph by Author (2014)
Top of scarf
Middle of scarf
Bottom of scarf

figure 22-24 Original Photograph by Author (2014)
For the headset, the criteria outlined in 9.5 was used to determine the base shape size, material and aesthetic. To create a base shape for the inner ear a mould was made by hearing aid specialists Courtenay Hearing Centre. This mould was then scanned with a 'Next engine' 3D scanner.
Once successful completing this scan, the quality was enough to get a basic STL to then bring into Maya where mesh holes were repaired. Finally, 3DS MAX was employed to manipulate the texture and make the final universal size and shape. This Process can be found in Appendix A5 3D Process.

The development of the aesthetic can be found in the Final Design Chapter 11.3.1

figure 26 Original Photograph by Author (2014)
figure 27-29 Original graphic by Author (2014)
9.6.2 Physical design

User App aesthetics

**PROCESS/METHODS**

The computer App interface aesthetic was to be basic, light hearted in nature and exude hope. This desire came from issues already outlined in 2.2 sibling bond and 2.3 sense of normality. Ideally it would not look like most health related Apps and allow the user and families to become light hearted in their approach to interacting with it.

*figure 30 & 31 Original graphic by Author (2014)*
Figure 32 & 33: Original graphic by Rorke (2014)
9.6.2 Physical design

App Design

Maintenance App TIAGO

PROCESS/METHODS

The decision to create a computer maintenance app came from the realisation that:

- I needed to have a certain amount of control over the voices (intervals, volume, what sound levels trigger them).

This maintenance app is for myself and the SFMI staff to use. It controls the volume of the voices, the intervals they play, their frequency and shows sound data (where the mics pick up loud environments and quiet environments) from each persons experience.

figure 34 Original graphic by Rorke (2014)
10

FINAL DESIGN CRITERIA.
Alongside the social issues outlined in Chapter 7, and the gaps in current design seen in Chapter 8, this criteria creates the guidelines for the final product criteria.

**FINAL DESIGN CRITERIA.**

- Expose/reveal electronics as an expression of celebration of sibling bond.
- SFMI and the Hearing Voices Workshop will have custodian access to the device and will be the networks providing support before and after each user’s experience.
- Creating a positive path that allows family to let the negative feelings go.
- Recognise the similarities/motivations siblings share and their need for a normal life within the mental illness.
- Have an expression of Celebration of sibling bond.
- Utilising female siblings as a positive force in recovery. Address the new generation of supporters: siblings.
- Create constructive emotions in siblings and positive coping techniques that could help prevent relapse. Help maintain/establish a healthy relationship between the family member and the voice hearer.
- Embrace and reflect the beauty of sibling bond through embracing the beauty of its electronics.
- Address the improvement of empathy and avoid personal distress.
- Address the individuals as a way of addressing the family unit.
- Provide an easily accessible experience that can be used by families when they require it.
- Personas aesthetic (gender, age, relationship to voice hearer)
- Stigma that could be related to it.
A medical/psychological education device that’s user function is synonymous to the actual illness. A change in the way the user perceives their surroundings. The users process of recovery while the device is in use, helping to inform users of healthy living Empowerment and taking control of one’s own health and the health of others around them.

Mental health design looking at Quality of Life of the user.
Promotion of emotional interaction with industrial device.
The link between people and health.
Portability, fun and interaction.

Technology
research
CRITERIA

Bulky parts need to be comfortable.
Placement of microphones to not have exterior sounds blocked off.
Be integrate into users daily wear.
Simulate a voices experience that is synonymous to that of the voice hearer’s real world experience. Voices should react to environment changes (microphones telling the device what voices would suit the environment; Loud or Quiet). Present voices in randomised order.
Expose/reveal electronics as an expression of celebration of sibling bond.
SFMI and the Hearing Voices Workshop will have custodian access to the device and will be the networks providing support before and after each users experience.

Design
research
CRITERIA
Second Caplet Scarf Fabric Pattern:
I created the second design as a mixture between a caplet and a scarf. I wanted to give the overall shape of the garment more structure so it would easily marry with the electronic 3D Printed parts. For this piece I also wanted to create stronger folds in the back structure and collar playing with the lining to reveal a different visual element.
Second Caplet Scarf Fabric Pattern:

I created the second design as a mixture between a caplet and a scarf. I wanted to give the overall shape of the garment more structure so it would easily marry with the electronic 3D Printed parts. For this piece I also wanted to create stronger folds in the back structure and collar playing with the lining to reveal a different visual element.
11

**FINAL DESIGN CRITERIA.**

The following chapter will present a break down of the Final Physical Design. Section 11.1 covers the final design criteria which is the driver for Final Design decisions. Section 11.2 introduces iterations of the final scarf creation. Section 11.3 outlines how reflecting beauty in the electronic components was achieved and finally, Section 11.4 presents the final design images pulling together the entire design.

As mentioned in this chapter criteria, I wish to use the opportunity to reveal beauty in the garment as a way of avoiding personal distress and embrace the celebration of sibling bond. I chose to explore this concept through the exposure of the electronic features of the garment, celebrating that these electrical components, that are usually hidden, are where the voices come from.

Section 11.5 of this chapter will introduce a Smart Phone App, intended for SFMI support groups to utilise when helping families in the future and section 11.6 discussion conclusions made at the culmination of the design phase of this research.

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**figure 37 Original graphic by Author (2014)**
Design Criteria

FINAL PHYSICAL DESIGN

As a result of my user testing in the pilot study and using the device myself, I gained a great understanding of the difference between ‘Empathetic Concern’ and ‘Personal Distress’. I pose that, using the opportunity to reveal beauty and creating pride around wearing the garment, we can avoid extreme personal distress.

Research into all four areas Social Challenge, Technical Design, Physiological Change and Physical Design (detailed in Chapter 9 and Chapter 10) changed the criteria for the final design, creating more complex requirements needed when designing the final wearable piece.

This is a condensed version of the criteria laid out in Chapter 10, relating to the style/look of the final physical design.

Be used for prolonged periods of time, without forcing its use. Can offer repeat use if desired.
Aim to produce empathetic concern and avoid personal distress. Creating a positive path that allows Siblings/family to start letting go the negative feelings attached to their loved ones illness.
Recognise the similarities/motivations siblings share and their need for a normal life within the mental illness. Embrace and reflect the beauty of sibling bond through embracing the beauty of its electronics.
Subtly suggest what it is, with the opportunity to reveal beauty fully if desired relating to the Celebration of Sibling Bond and avoiding personal distress.
A medical/psychological education device that’s user function is synonymous to the actual illness. A change in the way the user perceives their surroundings.

These criteria formed the basis of the outlines of the final design and also provide a tangible set of objectives to assess the success of the design.
The process to create the Final Design started with research into different garments that looked at ‘explorative’ and elaborate design, more Avant Garde than ever-day wear. This research exposed many designs made for the purpose of ‘wearing’: jewellery, caplet, wearable art etc.

Research into elaborate design highlighted the concept of a combination of scarf and caplet. This chapter will show the visual process of the first, second and third iterations.

The research started an investigation of precedents of wearable garments that were on the border between something ‘usual’ that wouldn’t grab people’s attention but would also express its own identity when looking closer. The Empathear design is an experiment between reflecting the garments own identity and its function, and blending with the wardrobe of the persona.
figures 39-42 Precedent images for elaborate design inspiration
figures 43-45 Precedent images for elaborate design inspiration
figures 46-49 Precedent images for elaborate design inspiration
To make the first Caplet/Scarf pattern the display bust was used. Light pattern making cloth (frost cloth) was cut creating the basic pattern shapes, following the curves of the display bust to generate a rough fit. Then the basic pattern was translated to scrap fabric.

**Final design**

**First Iteration**

**FINAL PHYSICAL DESIGN**

*Caplet Graphic Options:*

These are small basic studies of how the caplet/scarf pattern could look like. Things considered include: neck line, drape at front, sleeve cap and embellishment of back seam. Along side this consideration was given to the placement of electronic parts.
These are small basic studies of how the caplet/scarf pattern could look like. Things considered include: neck line, drape of front, sleeve cap, and embellishment of back seam. Alongside this consideration was given to the placement of electronic parts.

*figure 51 Original Illustrator Explorations by Author (2014)*
These images demonstrate the pattern cutting process where the cut pieces were placed on the display bust to create a form fitting garment.
Once sewn, the First iteration was then placed back onto the bust to see how well it fit. The garment was too short in length and did not hold its shape. The chosen material was also not very flattering on the display bust and would need to be ironed regularly.
While this was a great first iteration, the pattern needed these adjustments:

- To be larger
- Allow for more fabric to enhance the draping affect and hold its shape
- Fit the bust
- Become a size that could fit majority of body sizes and shapes
Taking into consideration the first iteration, a new pattern was cut around the first pattern and laid out onto the bust to get an idea of the fit. As this fit looked successful, different material samples were sourced where a fabric that responded to the Final Design Criteria stated in Chapter 10:

- Personas aesthetic (gender, age, relationship to voice hearer)
- Stigma that could be related to it
- Creating a positive path that allows them to let the negative feelings go.
- Have an expression of Celebration of sibling bond.
- Utilising female siblings as a positive force in recovery.
- Create constructive emotions in siblings and positive coping techniques that could help prevent relapse.
Individual pieces of second iteration pattern.
The new pattern was used to cut out the garment from the lavender fabric. After sewing the pieces together, the pattern making cloth was adapted to create an inner pattern for the lining, placing the sewn outer piece on top of the cloth and cutting around it.

An inch border for left for sewing seam allowance. This out line was cut into two parts for easy sewing into the outer piece.
Two fabrics were chosen, both alluding to the feminine style this design aims to achieve. The first was a light fabric of pastel lavender with a soft texture. The second was a slightly heavy, mustard coloured fabric of slightly courser material and raised ribbing. Along side these two outer fabrics, three different white fabric options were chosen for the inner/lining that would house the electronics.
Images showing the lining of the second iteration. The lining for this iteration was cut into one piece but was found to be quite difficult to sew with clean seams.
The garment was then placed onto the bust to test its fit. While this Second iteration was a better fit on the display bust than the First iteration, it still required some tweaking as this time, it was too big and still did not hold its shape as desired.

figures 73-75 Original photos by Author (2014)
Taking into consideration the First and Second iteration, a re-adapted pattern was constructed for the third time and placed it onto the display bust to check the fit. The pattern was then laid out onto the mustard material, and cut out. The process carried out for the Second iteration was followed again and when all sewn up, the garment was laid onto the display bust to check its fit. This Third iteration was the best fit because of:

- The material used
- Stitching use and detail
- Size and shape of the pattern pieces
- Modern colour

The Third Iteration also answered specific criteria outlined in the first paragraph of Chapter 11:

- Aim to produce empathetic concern and avoid personal distress. Creating a positive path that allows Siblings/family to let the negative feelings go.
- Recognise the similarities/motivations siblings share and their need for a normal life within the mental illness. Embrace and reflect the beauty of sibling bond through embracing the beauty of its electronics.
- Subtly suggest what it is, with the opportunity to reveal beauty fully if desired.
Individual pieces of Final iteration pattern
figure 81-83 Original photos by Author (2014)
Images showing the lining of the third and final iteration. The lining for this iteration was cut into three pieces to aid the sewing process. To see full electronics see Appendix A4 Working Prototype.
figure 87 & 88 Original photos by Author (2014)
figure 89 & 90 Original photos by Author (2014)
These images exhibit the exterior make-up of the third iteration and the two different ways the garment can be worn.

figure 91 & 92 Original photos by Author (2014)
This is a detail shot of the third and final iteration showing the shoulder stitching details, material qualities and makes suggestion towards the 3D printing aesthetic of the next chapter ‘11.3 From Bulky Electronics to Beautiful Jewellery’.

figure 93 Original photos by Author (2014)
From the criteria outlined in the first paragraph of this Chapter (11) this section of the thesis aimed to explore how to embrace and reflect the beauty of sibling bond through embracing the beauty of its electronics. This was achieved through creating jewellery casings for the electronic components that follow the aesthetic of the Voronoi pattern. Voronoi is a system that divides space into stuctured yet organic systems.

This type of patterning was used to create physical flexibility in the print allowing multiple users, comfort and a good fit. This style also adds a jewellery detail aesthetic to the ear pieces that adds to the feminine qualities of the design.

figure 95 Original drawing by Author (2014)
The 3D model of the ear mould was then taken into 3DS MAX where it was manipulated to reference Voronoi design patterning. The Voronoi pattern was chosen as it would allow the electronics a strong frame and would allow ventilation for batteries. It also gave a visual precedence to the electronics signifying their importance.
To start with, research was made into the shape of the ear and the usability/functions needed for this project's ear piece. How could I construct an ear piece that would cater to multiple users and be able to be worn for hours at a time? In other words, the ear piece needed to be comfortable and hygienic.

**Final Physical Design**

To start with, research was made into the shape of the ear and the usability/functions needed for this project's ear piece. How could I construct an ear piece that would cater to multiple users and be able to be worn for hours at a time? In other words, the ear piece needed to be comfortable and hygienic.
Ear piece and electronic components:
These three iterations were used to test print material (resin and rubber) for inner ear comfort and aesthetic value.
This first iteration of the ear form casing was printed with hard resin only. It was printed to gain an understanding of the aesthetic form and size.

figure 99-101 Original photos by Author (2014)
This second iteration of the ear form casing was printed with both hard resin and rubber. It was printed to gain an understanding of the aesthetic form, size and for comfortable fit.

figure 102-104 Original photos by Author (2014)
This Third iteration of the ear form casing was printed with both hard resin and rubber. It is the final adaption of the earpeice and considers comfort and aesthetic values.

This iteration was the chosen ear piece for the final design.

Figure 105-107 Original photos by Author (2014)
Bluetooth module, for neck piece
To be ‘wireless’, cited in Chapter 9.5.2, the Earpiece required a blue tooth module. Many designs were considered for this part; where it would be housed on the body (sitting in a pocket, on the neck), how it could be incorporated alongside the ear piece and the scarf aesthetics.

A neck piece was decided upon because:

- Could fit into the jewellery aesthetics
- Easy to expose/express the beauty of the electronic
- Still protected by the neck cuff of the scarf.
- Simple to create a ‘one size fits all’ neck piece.

FINIAL PHYSICAL DESIGN

From Bulky Electronics to Beautiful Jewellery

Neck piece

figure 109 Original photo by Author (2014)
This neck piece that was printed by Shapeways, exudes feminine qualities. It is light and ephemeral and can function as jeweley and as a casing for the electronic components of the ear peice - bluetooth module and lipo battery.
The above picture shows the back of the neck where the bluetooth module and lipo battery are housed. More details of this can be found in images from Chapter 11.4.
There are 14 electronic parts inside the scarf, all of varying size and shape. The jewellery casings for these parts also follow the same design aesthetic of Voironio pattern. The visual process of creating them considered:

- Could fit into the jewellery aesthetics.
- Easy to expose/express the beauty of the electronic.
- Still protected by the neck cuff of the scarf.
- Simple to create a ‘one size fits all’ neck piece.

**FINAL PHYSICAL DESIGN**

figure 113 Original photo by Author (2014)
When it came to outsource to Shapeways, both metal prints and flexible plastic were made. Shapeways sent back a few of my files to be altered before they could print. This resulted in printing only some parts in both materials. The development process of the scarf electronic casings is presented here.
Shapeways, FLEXIBLE PLASTICS

figure 115 Original photo by Author (2014)
A PowerCell module provides a charging circuit for a LiPo battery, and boosts the battery voltage to 5V.
The scarf prototype is built around a Sparkfun Pro Micro Arduino-compatible microcontroller, which coordinates activity between various other modules.
figures 121 - 124 Original photo by Author (2014)
Bluetooth module regulates its own power via a second LiPo battery. Two Mp3 Trigger modules provide two layers of stereo audio, which is mixed down via a custom passive mixer module to a single stereo audio output, and fed to the Bluetooth module. The audio is picked up by the Bluetooth receiver on the wireless ear piece.
Shapeways, BRONZE METAL
OpenLog module logs to a microSD card, logging data from the scarf that can be accessed through the maintenance computer App.
Custom passive audio mixer module to a single stereo audio output
mixes layers of stereo audio provided by the two Mp3 Trigger modules

Where it sits inside
the scarf.

schematic of the electrical part
AUDIO MIXER

figures 135-138 Original photo by Author (2014)
The custom switchboard module has a 3.3V regulator for the microphones.

Where it sits inside the scarf.

schematic of the electrical part

SENSOR FILTER

figures 139-142 Original photo by Author (2014)
After receiving the 3D prints from Shapeways, the beauty aspect declared in the Final Criteria was further explored through glass. Having glass blown into the metal print that would act like a draping frame inside the metal bars to protect the electronics. Two techniques were trialled:
- Heating the a thin sheet of glass over the metal frame, keeping it hot enough so it would drape into the void
- Blowing an orb shape of glass, and trying to force it into the metal frame.

Unfortunately both of these processes were not as effective as desired and proved impossible for Mr Frankin to achieve the beauty required.

figures 143-146 Original photo by van Polanen (2014)
Both the plastic and the metal prints are successful but the white plastic prints provide more striking contrast with the chosen fabric of the final design.
Final Design

**FINAL PHYSICAL DESIGN**

The Final Design of the scarf is an aesthetically pleasing design, demonstrating the celebration of sibling bond that Empathear wishes to accentuate in each wearer. The design embodies the ideals set out in the criteria’s mentioned in chapters 4, 5, 6, 9, 10, 11.

The final scarf design consists of:
- Wearable Technology Scarf
- Ear/neck lace piece

Both of these pieces, together, emanate beauty, femininity, pride and celebration.

figures 150 Original photo by Author (2014)
figures 148 & 149 Original drawings by Author (2014)
Detail images of final overall wearable technology scarf design 'empathear'. Includes electronic jewellery casings - white plastic Shapeways prints.

Figures 151 & 152 Original photo by Author (2014)
Details of electronic jewellery casings from shapeways. Including both bluetooth module casings - one for the wearable technology scarf (found on the shoulder of the garment) and the other for the ear/neck piece (found on the back of the neck piece).

figures 153-155 Original photo by Author (2014)
Detail image of neck piece from the front. This image also shows where the discrete ear piece sits.

Figures 156-158 Original photo by Author (2014)
Ear/neck piece - Houses Bluetooth module, Lipo battery and mini speaker
Wearable technology scarf - Houses all other components including Arduino pro mini.

figures 161 Original photo by Author (2014)
figures 164 Original photo by Author (2014)
**FINAL PHYSICAL DESIGN**

In this one day scenario it is important to see both the family and general public interactions with the user while they are wearing the device as both these types of interactions will be significantly different.

Scenario:
One day time-line of empathear user.
Users timeline from SF office - home - work - home - and back to SF office.

- The user
- Interactions with family
- Interactions with General public

note: amount of circles = number of people in that interaction

figures 165 Original schematic by Author (2014)
11.5 Smart Phone

**App Design**

**FINAL PHYSICAL DESIGN**

The Smart Phone App is additional to the physical garment design and was constructed to appeal to users of the tech-savvy generation. It was chosen as a relevant avenue because of the many functions that can be controlled from the App, as they need to be mobile and be accessed during the wearer’s everyday activities.

The graphic layout of the app was designed to the same aesthetic as the Maintenance and User App. The App development was outsourced.

The App process started with a discussion between myself, Mr Guerin and Mr Loader to decide upon how the app would function, look and whether it would be on both Android and iOS. The quote/brief we agreed on can be found in Appendix A3.2
An important opportunity that the App taps into is periodical questionnaires. These questionnaires happen throughout the experience, popping up every 40 minutes. These questionnaires could provide valid information on the users experience and would be ideal when testing the device before mass use, helping to further understand the effectiveness of the experience.

These questions can also be used to help bring the users attention back to the purpose of the experience - Empathetic Concern for their loved one and avoiding personal distress in the process.

Another section of the App I wanted to address was the ‘information/introduction’ page and the consent for use. The content of both of these pages would be same as the ethically approved information and consent forms used in the testing phase, Chapter 12.
On February 24th I was invited to present my Device and App creations to the SFMI Annual Managers Meeting. After I had presented, these questions were raised:

- **How can SFMI ensure the mental safety of users?**

There were two answers to this question. One being the first questionnaire timed to pop up 20-30 minutes into the experience giving the user the option to discontinue use if they are feeling too disturbed.

This same question could pop up multiple times during the day to ensure the users safety. The user can also stop the App at any time if feeling distressed and if they do, the users SFMI support worker would be notified and a follow up process can be instigated.

The second being a password access (possibly achieved through restricted age access) that pops up when the user has ‘agreed’ to terms and conditions. Discussion did more to suggest that this might not even be problem as the ‘Hearing Voices Workshop’ has been running for 10 plus years with no serious negative incidences reported.
What is the cost to get the App up and running for the wider community to use?

The App developers and I decided on another budget and brief for this question. It can be seen in the Appendix A3.2

What questions could they have on the device? Can they add more Questions later on? Can you add more voice tracks? What would obtaining this information mean to individual SFMI groups and the users from their communities? Consent given by users?

SFMI can have any questions/voices loaded to the app and can change these whenever suits them. The only thing that limits them is the size of the App and how much information it can store.

Information obtained from this App could be used to tailor fit support to individuals and also to get a wider response/idea of the effectiveness of the App. Consent for this kind of mass data collection on individuals by SFMI would require SFMI to have users consent. This user consent information can be found on the App consent page at the start of the experience. This consent from can be found in appendix A7 App Information and Consent for into screen.
The final Design addressed all criteria laid out in the beginning of this chapter. These will now be addressed in more detail.

- Be wearable.

The scarf aspect of the design is very wearable, does not discriminate age or body size. The size restriction of the electrical parts means that the scarf garment is more for Autumn, Winter, Spring wear. This category (be wearable) does not apply to the Smart Phone App.

- Be used for prolonged periods of time, without forcing its use. Offers repeat use if desired.

The garments can be worn for as long as the user wishes, from a couple of hours to an entire day. As it can fit into most every day wear, the user can take it off and on as desired. Can collect scarf form SFMI in the future if in need of repeat use. Empathear extends the social interaction side of the Hearing Voice workshop well beyond the 15minutes.
Aim to produce empathetic concern and avoid personal distress, creating a positive path that allows family to let the negative feelings go. Embrace and reflect the beauty of sibling bond through embracing the beauty of its electronics.

The design of the garment does not allude to being a ‘medical device’, helping the user to disconnect it from the ‘clinical’ aspect. The beauty found in the garment's makeup also expresses the celebration of sibling bond, creating pride around the garment and around the act of attempting to understand and help the affected family member.

Subtly suggest what it is, with the opportunity to reveal beauty fully if desired.

The electronics are well integrated into the folds of the garment and so are only really noticeable if the wearer wishes to share the technology with others around them. This can be done by flipping up the lapels of the garments collar. As the earphones are not completely invisible, we expect people around the wearer to notice them. This can provide the wearer the opportunity to reveal the beauty by offering those around them a closer inspection of the garment and its electronics.

- A medical/psychological education device that creates an experience synonymous to the actual illness. Demonstrates a change in the way the user perceives their surroundings.

Empathear simulates Auditory Hallucinations/voices that can be tailored by the user to replicate the voices the affected family member hears (angry male, passive aggressive female etc). This orchestration of voices allows the user (siblings) to experience their own reaction to those specific voice personalities chosen. Therefore we can surmise that the device replicates an accurate experience of voices and with this, can change the user’s perception on their loved ones illness.

figures 176 Original photo by Author (2014)
The ultimate test for this design was not only to ensure that the final design and device would answer to the Final Criteria that my research had determined, but also to anticipate the wants and needs of the NZ SFMI community. At the beginning of this research I decided SFMI would be my client before introducing them to my idea, without knowing if the mental health community would even want a device like this.

Having viewed the final device and the App, SFMI have unequivocally announced their support and funding to completing my thesis ambitions. A formal proposal of SFMI funding can be found in appendix A9 SFMI Funding Proposal). This is a great achievement for me personally and for my design, proving the design thinking and strategy behind the device has rung true and that the ultimate design (Scarf and App) is highly valued. Examples of their support through website and other media promotion can be found in appendix A10 Mental Health Community Publications.
Triumphs and Pitfalls of the design, why App and not Scarf?

- If the garment was implemented into the SFMI Support community it would need constant maintenance throughout its lifetime.
- If not custom made, bulky parts are most at risk of damage.
- Custom made parts could help reduce the risk of damage to the garment but would still need some form of maintenance throughout its lifetime.
- If not using the designed custom made parts, the scarf can be quite heavy and warm so would be season specific.
- Scarf does not offer a real time questionnaire to provide more insight into how to provide individual, tailored support for each user after their experience.
- Would require a waiting list.
- Would require an SFMI worker to keep clean and hygienic.
- Production cost is expensive for making multiples.
- Hard to provide a repeat use or extended.
11.6.2 Conclusions

Triumphs and Pitfalls of the design, Why App and not Scarf?

FINAL PHYSICAL DESIGN

On the other hand, the App for smart phones can resolve all these issues:

- Once up and running, does not require maintenance throughout its life time.
- Cannot be damaged with over use.
- Is not season specific.
- Has real time questionnaire for support workers to use after experience for tailored care.
- Does not require a waiting list, is easily accessible to anyone in the SFMI community, anywhere in the country.
- Production costs = if you pay for one you have paid for them all.
- Can easily provide a repeat use or extended use.
12

PSYCHOLOGICAL DESIGN
This chapter presents the testing phase of the research, where ‘extreme users’ (siblings of voice hearers) participate in a one day experience with Empathear (IDEO, 2014).

At the conclusion of this thesis - NZ SFMI will purchase the App produced by this research to use in their nationwide community.

This research testing was approved by the Victoria University Human Ethics Committee, approval number: 20013 Appendix A6
To ensure all participants would be in a safe environment with support if required, Susan O’Connell, manager of SFMI Nelson, and Vicky Pomeroy, experienced Fieldworker, were present throughout the testing sessions. Participants were sourced solely from Mrs O’Connell’s SFMI Nelson data base and were people she recommended and knew well. All participants were siblings of someone who hears voices.

I started the case study with an introduction to the project and the testing, with the participants invited to attend a small meet and greet in the Nelson SFMI office at 7pm 10th March 2014. This small get together was an opportunity for me to introduce myself and background, present my intentions for the voices experience, earn their trust, and understand their individual backgrounds and motivations.

Each participant was given an information packet that included a before questionnaire, a booklet explaining the research; and, an information flyer that demonstrated how to use the App, and my business card. A schedule for this event and the documentation of the information packet can be found in Appendix A8.2.

This case study was conducted in Nelson, New Zealand during the Schizophrenia Awareness Week 2014 (SAW), using the App for smart phones.

PSYCHOLOGICAL DESIGN

To understand the empathy family members have for their loved one and affect their empathy with a positive evolution, I asked participants to complete a before questionnaire, a live questionnaire during the experience and conducted informal interviews after. I undertook this research using a qualitative approach including case studies and interviews (Leedy, P.D., Ormrod, J.E. 2013).
At this end of the introduction to the research, those who were interested in partaking in my research were given an information sheet, a consent form and a ‘prior to testing’ questionnaire. They also were given a ‘prior to testing’ questionnaire. These preliminary questionnaires were kept by myself, to refer to during each participant’s conclusion interview. Participants then made a time to be interviewed by myself (with an SFMI worker present).

The App was then uploaded to their smartphones so that they could use the app from then until their interview at the conclusion of their experience.

Once participants completed their voices experience, individual interviews were undertaken with each participant. Because of the nature of this research and the sensitivity of each participant’s backgrounds, I needed to work with a level of subtly when conducting the case studies.

After these interviews each participant was offered my contact details and the opportunity to receive the results of the testing session and the completed thesis. After each interview, the SF worker present would recommend whether to keep or remove the App from the phone and each participant was given a ‘help’ booklet to take home (Appendix A8 Testing Sessions).
Preparation for Testing Sessions

PSYCHOLOGICAL DESIGN

Goal
- To elicit empathy in siblings of voices hearers through a designed device

Context
- An everyday context within the general public or at home, using a ‘natural’ environment. In this case testing will be carried out by participants undertaking their usual daily tasks. The testing will be used to show the participants the difficulties of having voices while doing activities they would usually take for granted.
TESTING SESSIONS
All four participants completed at least two hours of the experience, with four hours being the longest continuous time spent ‘hearing voices’. Participants were interviewed five days after being introduced to the App. These interviews lasted between 15-30 minutes and were attended by the participant, myself and a Nelson SFMI worker.

During these interviews the following questions were asked:
- During the testing did you find the need to take the ear phones off? Did you specifically remove the ear phones when talking with others?
- Did you come in contact with anyone while hearing the voices? How did you find this experience?
- Do you believe your understanding and tolerance of your loved one has changed, if so, how?
- Would you recommend this to others in your position?
- If you could suggest any changes, what would they be?

If the SFMI Nelson worker present in the interview supported the decision, participants could keep the App after the interview. Participants could then reference the App in the future, and further their own personal development. The first stage of testing proved to be very successful providing me with data to enhance the design and experience. The following chapter presents an analysis of the data gained from testing sessions.
FINDINGS
All participants found the voices to be incredibly distracting and that their experience of hearing voices required them to push their personal ability to concentrate when interacting with others. Three of the four participants adapted the voices experience to suit their particular coping level. The data has shown explicitly that all participants felt a shift in their personal empathy for their affected loved one.

All testing session data, including quotes, can be found in Appendix A8.4
At some stage during their testing, all participants removed the voices entirely as a coping method when the voices became more intrusive, with participant 3 saying, “My daughter read me a story while I was listening to the voices and I had no recollection about what the story is about, I didn’t even know what she had just read to me. I found myself saying to people ‘ask me that later’. I had to get my thoughts together; it’s too hard while listening to the voices. I was on edge all the time, you know?”

Participant 4 (the only participant to use the App while interacting with the general public) had undertaken the experience while working, commenting that they found speaking with customers problematic. The participant noticed this particularly when customers were asking questions that required specific details, and had to put the device down to understand what people were saying. “I was trying to ignore the voices but couldn’t and had to put the device down completely, when I was talking to children, I kept hearing the voices saying ‘trees, trees, trees’, and I could only think about trees when I should have been answering the customer’s simple questions.”

Participant 1 stated that she couldn’t have the voices going in both ears so spent their experience with only one side of the head phones in, especially when listening to others as other background noise alongside the recorded voices and sounds made things more difficult.

All participants commented on the intense concentration they needed to implement to focus on conversations with relatively simple subject content.

Participants found the voices were not only at times, disturbing in content but they also inhibited them in social situations, preventing them from participating in everyday family conversations. All participants commented on the intense concentration they needed to implement to focus on conversations with relatively simple subject content.

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Concentration

14.1 Distraction and Concentration

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All participants commented on the intense concentration they needed to implement to focus on conversations with relatively simple subject content.

Participants found the voices were not only, at times, disturbing in content but that they also inhibited them in social situations, preventing them from participating in everyday family conversations.

FINDINGS
14.2

Personal Adaption into a Progressional Experience

As each participant had a unique family background they all adapted their own personal experience to what they judged they could cope with. I have termed this theme, ‘Personal Adaption into a Progressional Experience’, to reflect the users readiness to progress through the experience, altering/increasing intensity in their own time/at their own rate. Two main scenarios emerged in testing:

The first scenario for Progressional Experience:
- Participants could start the experience by themselves, where they become acquainted with the voices in a safe, quiet environment.
- Then once they have become more comfortable with the voices, the user can begin using the App around family members. Again this would be a safe environment and the user can start to attempt simple conversations.
- And finally to move to a more public setting like a supermarket, where the user does not require much social interaction, but enough interaction to increase the complexity of the task.

The second scenario for Progressional Experience:
- The user is more selective about the voices they hear through the App, where they could choose to start the experience with just one gender and happy voices.
- The user can slowly go back into the app and add more genders and voice moods as they feel comfortable with.

FINDINGS

A second theme emerged due to the distraction of the voices, reflecting on the usability of the App - ‘Personal Adaption into a Progressional Experience’.

I designed the app to be used for one day, but withheld this information from participants to see what patterns of use emerged. It was interesting to note that all participants tailored their experience to their level of comfort in one way or another, some spreading their experience over a couple of days by using the app for an hour or so each time, and others progressively adapting the content of the voices.
Participant 2 adapted their experience to this second example using the female gender and the happy mood to start and with then after they were comfortable, they slowly added more genders and moods. Participant 1 used the app on and off at different instances throughout the week, all for short lengths of time. This participant also specifically requested to have the app as a permanent fixture on her phone to refer to in the weeks to come so she can increase her preliminary tolerance/patience level of 2/5 (which, she stated, was a 4/5 at the time of the interview) to a ‘5/5’.

Unfortunately, the ‘live’ questionnaires did not function as intended during the testing session, so participants were unable to use this part of the App. This was due to a bug in the app code that has since been resolved.
Participants 3 mentioned how they now can forgive specific social behaviours:

“...I can understand some of his behaviours, they are not just being antisocial or rude, and there is a reason.”

All participants attested to the change in empathy they felt within themselves but they also all recognised that this voices experience was a generalised mimic of the Schizophrenia. Participants acknowledged that while this app was not a full, true experience of auditory hallucinations, just having a small taste of what hearing voices could be like in their everyday lives provided a valuable lesson they otherwise would not have had. One Participant identified that, while they have the privilege of going back to their normal lives their family member did not have that luxury. All participants’ agreed that they cannot imagine living every day with voices in their head.

Those in the older age bracket, who’s loved ones were diagnosed 20 or so years ago, wished that they had this experience earlier on in life. Participant 3 reflects this sentiment in the following comment:

“To have had this experience so easily available when I was younger, to understand why a bit, why he was behaving the way he was would have been greatly beneficial. Now I can put some memories into context as to what was going on at the time. It makes me feel sad; I could have been more supportive”

14.3 Empathy and Appreciation

In the individual interviews, all participants mentioned their new appreciation for their loved one and their shift in empathy that has come from undertaking the voices experience. All participants expressed their new appreciation of what it is like to hear voices while trying to participate in conversation and how this basic social activity that most of us take for granted can become daunting, participant 1 stated,

“I can imagine that exposure to these voices for long periods of time can be truly crippling, to the point of inhibiting my ability to function well as an active member of society. I now understand why she is the way she is when talking with others, and I have a new appreciation of what she goes through every day.”

FINDINGS

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“I can imagine that exposure to these voices for long periods of time can be truly crippling, to the point of inhibiting my ability to function well as an active member of society. I now understand why she is the way she is when talking with others, and I have a new appreciation of what she goes through every day.”
Participant 2 remarked on their experience, alluding to what their family could be like now if they had been able to access this app and experience earlier in life,

“I might have been able to help, it would have helped when communicating with my brother when he was really unwell, to have that understanding 20 years ago would have been quite good”.

Considering these sentiments, if participants reacted so strongly to this simulated experience, then we can surmise that a stronger, more intense experience that is directly synonymous to the real thing may cause participants extreme personal distress. It is plausible that Personal Distress could lead the user to stop the experience and ultimately not allow the sibling the opportunity to develop appreciation and increase their empathy for their family member.
Positivity for the Future

FINDINGS

Two of the participants spoke specifically of their new curiosity towards exploring and creating situations that would lead them to talking to their loved one about the voices they hear. Three participants alluded to their positive attitudes for the future development of their relationship with their loved one.

For some participants, this testing opened their eyes as to what they could do to help their family and improve the outlook of their family unit’s future. Only Participant 2 did not speak of the future with their sibling.

Participant 1 in particular was highly motivated to make significant positive changes in her relationship with her affected sibling and expressed her desire to play a more active role in her sibling’s daily life.

This participant has constructed a routine for this active input where she would keep using the App in the future to:
- have a voices experience
- then have contact with her sibling,
- then have another voices experience
- then have more contact with her sister and so on.

She expressed her excitement about the future of the relationship and how she could develop it, requesting extra information and ideas to help her help her sibling and the ultimately the rest of her family. This participant was also highly interested in the future of the App, stating that she would recommend the app experience to her siblings caregivers and close family friends etc. She also held out hope that her other sibling would one day be comfortable using the App too.

Participant 3 whose sibling diagnosis was around 20 years ago, conveyed the importance of using this App early on in the loved ones diagnosis,

It was very worthwhile to do; I can see it would be particularly worthwhile for families that have been newly diagnosed, valuable for family members and even friends of family.
14.5 Conclusion of Findings

FINDINGS

The testing used qualitative research along with a semi structured interview guide which inform the a base for the inductive reasoning and identification of major common themes.

These four common themes: ‘Distraction and concentration’; ‘Personal Adaption into a Progressional Experience’; ‘Empathy and Appreciation’; and ‘Positivity for the future’, aid in the ability to successfully assess the responses towards the App experience giving premise to the possibilities it creates for the future of sibling bond and indeed the family unit as a whole.

This first-hand understanding of how their loved one copes every day may create inroads to minimalise the ‘family self-stigma’ mentioned in 9.4 Social Design.

This App has given these siblings the ability to assess situations in a constructive and informed manner, using their new found knowledge as a key to affect positive change in their loved ones life.

Stalberg, Ekerwald & Hultman (2004) acknowledged that ‘care giving’ is recognised as a positive coping technique, which helps siblings create better relationships with their affected love one.

User testing of the App has instilled a positive coping technique of active motivation in Participant 1 (25%), opening her eyes to what she could do to help their family. The experience has ignited her want to achieve positive change in her loved one’s life, helping with the understanding that it is healthier to have an active involvement in her loved ones life than to sit on the side-lines. Through this participant’s driven empathy and hope for the future we can see Daniel C. Batson’s true expression of Altruism (see above chapter 5.1 Types of Empathy).
DISCUSSION
DISCUSSION

This discussion will first look at the design outcomes, comparing the scarf and the app discussing why the app was chosen for development, market and testing. Following this will be a discussion around the testing session and what its findings could mean for the future.
The first design solution for the simulation of voices culminated in the form of wearable technology. This research recognises that this garment could have taken on many different forms but the scarf was selected as it met the social design and physical design criteria. This research intended the scarf to be the product carried through to industry and used by family members involved with the support network SFMI.

The scarf design successfully addresses most of the criteria outlined in chapter 11.1 Design Criteria by capitalizing on the opportunity to reveal beauty and create pride around wearing the garment. This has been achieved through material choice, patterning structure and beautiful electronics, helping the user to avoid personal distress while promoting the Celebration of Sibling Bond.

The main drawback of developing the scarf further was the costs involved with creating the prototype, and the additional costs to refine the design and reproduce the garment to an industry ready standard.

While the scarf design meets most criteria laid out in section 11.1 - Design Criteria, questions of usability and maintenance issues if in long term use in the SFMI community were left unanswered by the design. Because of this, a new criteria was developed to help resolve the issues (refer 'Section 11.6.2 - Triumphs and Pitfalls of the Design').

The final stage of the research concluded that an App was required to answer the usability issues. The App would allow users from all over the country (and potentially the world) to access the experience easily. The App also provided greater stability and flexibility during testing. Logistics/waiting time for people to experience the voices was minimal with the app compared with the scarf scenario, which could only be used by one participant at a time and was at constant risk of breaking.

15.1 Scarf vs App

DISCUSSION

This research seeks to answer the question ‘How can design elicit empathy in siblings of voices hearers’, and resulted in two separate outputs both serving the same purpose - of simulating dynamic Auditory Hallucinations or ‘voices’ where family (focusing on female Siblings) can experience an in-depth understanding of their own reaction to hearing ‘voices’. These two outputs are:

- A wearable technology scarf
- An App for smart phone for both Android and iOS platforms.

As they are individual stand-alone outcomes, they will be discussed individually. Following that, the future implications of the chosen output (App) according to the Schizophrenia Awareness week user testing findings will be discussed.
The App is tremendously cost effective in comparison with the scarf (refer to Appendix A3 Outsourcing). Only one App needs to be developed (once the original is made, any number more can be copied) and can be used by multiple people at one time. The App does not require the reproduction costs necessary for the scarf option, and ‘wear and tear’ and maintenance are a non-issue. The App is simple and easy to download/use and is easily integrated into the users every day wear. Finally the App appeals to the target market/persona of siblings in the early stages of their loved ones diagnoses.

The scarf design is still relevant as an interactive physical garment but ultimately the App was the chosen solution for user testing and for SFMI to use in the future as it fulfilled the criteria that the scarf lacked.
The diversity in age revealed strong indicators of the different mind-set of those siblings with relatively new diagnoses of their loved one to those in their 40's who’s family member was diagnosed 20 years earlier. The younger participants emerged from the testing with a positive outlook for the future in what they could achieve in their loved ones life; while the older participants emerged with a positive outlook for the knowledge they had gained but also a sense of sadness for what they could have done in the past.

While the younger participants spoke of a new found motivation, wanting a more active input in their loved ones life, the older participants, who both had families of their own, were not as focused on being actively involved.

These two age groups give an indication of the possible implications this App could have on families. While it could be considered too late for the older participants to affect significant positive change, younger participants still have the opportunity and the motivation to have a positive impact earlier on in their loved ones’ diagnoses, particularly during the adolescent years.

As those who were tested were predominantly female, it attested to earlier research conclusions where female siblings are known to be more actively involved than their male counterparts (Stalberg, Ekerwald, & Hultman, 2004). Although all participants were open minded about participating, it is interesting to note that it took the male participant significantly longer to initiate his first voices experience (five days after App was loaded onto phone) than the females (between one and two days after App was loaded on phone). A single participant is not enough to draw conclusions but a larger male testing sample would have enabled greater insight into why male siblings tend to stay on the side-lines. This insight could have lead the research to design avenues that help promote male involvement in the future.
Participant 5, who withdrew from the user testing was a twin of the affected family member. While we cannot be certain, she may have pulled out due to the particular relationship she had with their loved one. Another factor that may have prevented their participation could be the relative newness of their sibling’s diagnoses.

It is important that this research recognises that while it seeks to target the App towards siblings of newly diagnosed patients, it does understand that everyone’s experience with their affected family member will be different and therefore some siblings will need to warm to the idea of undertaking such an experience. Considering this, it is interesting to note that Participant 1, who was the most motivated after the experience was the older sibling of Participant 5, who withdrew from the testing.

The analysis of data from the March 2014 testing sessions provide several implications for mental health practice and research. The first implication is the future of the App in the SFMI community and how it should be used according to findings in the testing phase. The first public release of the App will be through SFMI NZ during the 2015 Schizophrenia Awareness week. During this release users will have multiple options for using the App, including:
- To be used during a Hearing Voices Workshop
- To be used after a Hearing Voices Workshop
- To be used in a smaller group setting with SFMI
- To be used individually for personal growth

When the App goes live, SFMI will have field workers guiding people through the App ensuring users are well supported during and after their experience.

The second implication is the need for further testing of the App to understand the possible improved psychological and social behaviours within the family, and how these changes promote feelings of growth.
This thesis recognises that this simulated experience is not a full, true experience of ‘Auditory Hallucinations’ but I and SFMI NZ recognise that it is better to have some kind of experience than none at all. From the response gained through the testing sessions, the App appears to produce increased empathetic concern and a desire to understand voice hearers. To validate this evaluation of empathy, another study needs to be conducted with psychological researchers.

Thirdly, new research into other designed devices is required to help families initiate change. This research would respond to the findings of extended user testing (mentioned above), where user intentions would lead to more designed device solutions that families would require in the future.

And finally, research to help further enforce the sense of ‘normality’ in the family unit. As mentioned in chapter 2.4 to achieve a ‘normal life’ in mental illness we need to have a deep understanding about that mental illness; to affect positive change in ours and our loved ones lives we must first reinstate the sense of ‘normality’ into our day to day family life.

While I do not believe that this testing session has helped give siblings back the sense of normality in their lives, I do believe it has opened up their minds to the possibilities of how important ‘empathetic concern’ and understanding can be to the future happiness of their family. And if understanding can lead to ‘normality’ then this research has at least ignited the path for siblings to follow.

For some participants, this research has given them the power of knowledge where they would have otherwise stayed in the dark, and that this knowledge could ultimately gain back that sense of normality in their lives. While this initial stage of testing has opened up the possibilities of instigating normality it has by no means solidified the concept. To better prove the App’s potential, a second testing session would be required with a larger sample group over a longer period of time.
CONCLUSION
Despite being superceded by the App, the scarf met final design criteria (Chapter 11.1) and so is still relevant as an interactive physical garment expressing the importance of celebrating sibling bond. However the scarf failed to meet practicality criteria (maintenance, longevity and cost) and was ‘shelved’, with preference given to the App.

With other Apps recently emerging to cater towards communicating, coping and understanding mental illnesses, it is clear that this is a viable market solution that makes important information and experiences available to anyone with a smart phone. The barriers and misconceptions surrounding mental illness are slowly being broken down. The advantage of the empathear App is that it interacts with the user and the environment, delivering a multi-dimensional insight into hearing voices. Participants were given a taste of how their personality could be tested by this adversity, allowing them to recognize the reasons behind their loved ones day to day actions and reactions. This enables a powerful experience for the user which helps to instil positive constructive outlooks for the future.

From the initial testing session it can be concluded that the product developed through this research, an App called ‘Empathear’, has made some significant inroads to affect a positive evolution of sibling empathy. The informal interviews undertaken soon after the first voice hearing experience, created a positive, driven motivation in 25% of sibling participants. However this research can only provide a tentative analysis of how the App could improve positive relations between family members. Firstly the sample size of the testing group was insufficient to draw sound conclusions. Secondly because the interviews were carried out so soon after the introduction to the voices, the long term effects on sibling empathy could not be identified, with this long-term progression of the sibling bond having the potential to reveal further findings not anticipated in this research. I propose that the App be utilised as an essential step in engaging siblings to trigger positive active involvement in their loved ones life.

CONCLUSION

This research answers the question ‘How can design elicit empathy in siblings of voices hearers?’, and has produced two separate design outputs, both simulating dynamic Auditory Hallucinations or ‘Voices’. Family (focusing on female Siblings) can experience an in-depth understanding of their own reaction to hearing ‘voices’ by using either output, and in doing so can improve the empathy they feel for their loved one.

The two outcomes produced are, a wearable technology scarf and an App for smart phone for both Android and iOS platforms. The final design composition successfully fulfills the criteria established in chapters 2-8 by producing a design outcome that elicits empathy in siblings of voice hearers. This criteria was used to assess and gauge the appropriateness and success of the final outcome (App) when user testing.
The advantage of the empathear App is that it interacts with the user and the environment, delivering a multi-dimensional insight into hearing voices. Participants were given a taste of how their personality could be tested by this adversity allowing them to recognize the reasons behind their loved ones day to day actions and reactions. This enables a powerful experience for the user which helps to install positive constructive outlooks for the future.

From the initial testing session we can conclude that the product developed through this research, an App called ‘Empathear’, has made some significant inroads to affect a positive evolution of sibling empathy. The informal interviews, which were undertaken soon after the first voices experience, created a positive, driven motivation in 25% of sibling participants.

To further validate this research, another study needs to be conducted over a longer period of time to assess how the participants relationship with their loved one has progressed with continuous use of the App. This further testing should be undertaken alongside psychological researchers.

In summary, it can be extracted that if you give siblings the tools to affect positive change early on in diagnoses, there is the possibility to change the otherwise inevitable future of that family unit. The empathy evolution seen in siblings has helped validate the research and solidify the significance the App could have for those in the SFMI community. The greatest testament to the value of this design and the strategy used to create the scarf and App is that it is highly valued by those within the Mental Health community in New Zealand and has been recognised internationally (refer Appendix A10).

Empathy was the driving aspect of this research, with the research question only able to be validated through a case study of user testing of the design output - Empathear App. This research was successful in its goal to achieve improved empathetic concern in siblings, with all user testing participants acknowledging an improvement in empathy towards their loved one. This generated a motivation for improving the future of their loved one akin to Daniel C. Batson’s Altruism (chapter 5.1 Types of Empathy).

Through the design of a device, this thesis targets the crucial family unit and allows an education of how to positively perpetuate the recovery of a loved one that suffers from Schizophrenia.
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PILOT STUDY
Overview of Pilot Study

Process and findings

Goal
- to achieve empathy through a wearable technology scarf that simulates dynamic voices.

Methodology
I used ethnographic research as my methodology during this testing phase. This type of research needs to report what is experienced or observed, avoid interpretation or evaluation. This style of methodology allowed me to gain insight into people’s behaviours and unarticulated motivations, drivers and needs. There are two examples of ethnographic design approach: Shadowing and self-observations. I will use the ‘shadowing’ approach during my testing.

- Shadowing is used to understand a person’s real-time interactions with products, services or process and their shifting contexts and needs over the course of a day. In the case of my study, the yes/no gestures are the real-time interaction and expression of the participants feelings.

Context
- an everyday context in general public, using a ‘natural’ environment. In this case testing will be done during the day where participants will carry out their usual tasks. The testing will be used to show the participants the difficulties of having voices while doing their everyday activities.

Variables
- independent variable (characteristics of design).
  - types of voices, content of script; how the voices are triggered, the duration they run for, the limit of intensity they reach,
- dependant variable (people’s reactions).
  - How it effects the participants question/answer gestures, empathy/personal distress.

Participants
- For first testing stage, Participants are Victoria University Masters students for the design school.
- In the final testing stage the participants will be ‘real participants’ (personas, people like me with siblings) ‘extreme users’ with life experience of living with someone who hears voices.
Findings
For this stage of testing I have a total of seven participants. This included four female and three male and all were of similar age (20-24). All participants were given the scarf and ear phones to wear and listen to during their everyday tasks for max 30mins. They were told that they could remove the scarf and head phones at anytime if uncomfortable or distressed.

All participants completed the 30mins with both scarf and headphones on. During the testing I subtly watched the participant to gauge how they were finding the yes/no questions using gestures. Four of the seven seemed comfortable and looked at ease with using the gestures. Three participants looked awkward and puzzled when attempting them.
Overview of Pilot Study

After having the experience with voices the participants were asked to complete a simple four question questionnaire. For the first question:

- How did you find the wearing experience of the scarf and ear phones?
  Majority of the participants agreed on the physical experience, including the comfort of the scarf and the need for better head phones. One person commented that the they felt uneasy about moving the scarf around as they were worried they might break it.
  Another participant commented that the ear pieces fell out a couple of times when they moved too vigorously.

Three people said that some of the aggressive voices weren’t very compelling as they new it wasn’t real but the sudden bursts of dialogue or sounds made them react physically (giggle, gasp). The passive encouraging male track was unanimously found to be funny.
  One person commented that the experience was “unnerving especially when I (they) were doing something difficult. When I (they) was struggling with something and there were harsh voices it made me feel worse than I (they) normally would”.
  Another participant found they could block out the voices while doing basic CAD work until it came to writing on the computer “I found myself struggling to remember what to write”.

- Did you interact with others around you while wearing the scarf and ear phones? With this in mind, how did you find the hearing experience?
  Six people interacted with others, leaving only one who didn’t. Those who said yes found it difficult to concentrate on conversing with others, finding it hard to listen to other peoples sentences and to respond to them. Some people found them selves “vacant on occasions while someone was talking” to them.

- What suggestions do you have to improve the experience?
  This was a mixed response. Two people mentioned the audio recordings/ quality of sound needs to be improved. One person stated the earphone quality greatly affected the sound quality. Another person, who was walking around a lot during the experience, mentioned that the sound keep cutting out reminding them the experience was simulated.

- Do you feel your understanding about ‘hearing voices’ has changed and how?
  All except one of the participants agreed that their understanding of voices had changed.
  One person said that they found it ‘definitely made conversation more difficult’ and they could now understand how challenging a task it is to have a basic conversation while hearing voices. Another person commented that when they were specking with a ‘real’ person and a strong voice started playing they couldn’t remember if they had told the ‘real’ person “sorry I cant hear you properly or if I (they) had just thought it”. This same participant found the voices to be ‘un-motivating’ and found themselves laughing out load at the voices and then thinking “I probably looked like i was acting really weird and it didn’t take much so I’ll try not to automatically perceive people talking/laughing to themselves as ‘weird’ in the future”.

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Conclusion of findings

After each participant had answered the questionnaire I asked them basic questions in conversational style about their experience. I found that people were more receptive to this approach than the written questionnaire. This casual approach gave me more specific answers and allowed me to understand each person's experience in more detail. Having specific data on personal experience has given me better insight into how I can adapt the design. None of the participants experienced Personal Distress.

For the next stage of testing I have more insight into these elements:
- yes/no gestures need to be made more intuitive, basic prompting to answer could be vocalised through the headset rather than relying on the participant to read the questions off of paper.
- Length of time needed to gain empathy, might only need to be one day of voices.
- Participants respond better to informal ‘chat’ as a ‘questionnaire’ better than answering questions on a paper.
- Need to work on form fitting ear phones to create better sound quality to the voices.

This stage of testing proved to be very successful in giving me data to enhance the design and experience. It has also given much needed insight into how users of the ‘general public’, who have little to no understanding or contact with mental health, feel about hearing voices.
Overview of Pilot Study

Persona 200 WORDS:
Leading expert C. Daniel Batson defines altruism as a way to include the benefits of another as a means to benefit oneself. This theory provides an interesting aspect to my research as it points out the two parts of motivation when caring for someone’s welfare. The kind of empathy my research needs to work with:
Firstly, must be motivated by the passion to better the life of their affected family member; AND, secondly, address the desire to improve Quality of Life for them-self as part of the family unit.

The persona criteria will use ‘Existential Phenomenology’/ ‘Reflective Interiority’. I will be using my self as the dominant persona as I am the most accessible real world personality for this thesis. My own life experience allows me a unique view into the psyche of others in my position, their wants and needs, their priorities, concerns and hopes for the future.
I have decided to manifest the physical output of my thesis as a wearable technology scarf and headphones.

Parents
- Working
- Don’t use apps (older generation)
- Worried about future
- Wanting to comfort their loved one
- Needing the comfort in knowing that their child will be looked after and understood. QOL
- Already have asked for help from SF or Keepwell. Want to actively make changes for the family.

Siblings
- Students (high school or Uni)
- Working
- Social
- Understand technology
- Starting to understand responsibility
- Different perspective on ‘strange’ people, inside info of what their lives are like. Sad to see someone who hears voices on their own, homeless, jobless etc. Want to make sure their loved one does not become like this.
Brief 200 WORDS:

In the first half of this project I performed a small study on six of my classmates where I videoed them using gestures with the scarf to answer yes/no questions. I found that:

- The majority answered ‘yes’ with the scarf hanging open around their necks and ‘no’ with the scarf hanging around their necks with the ends crossed over at the chest.

As these seem to be the most common gestures to ‘yes’/‘no’ answers I decided to use them for this stage of the project.

In this next stage of the project I will test my classmates with my voices simulation prototype.

First, students will be sent off to wear the device for 30 minutes while working and interacting with others around them. During this time the participants will be exposed to the experience of ‘hearing’

For this stage only a select group of voice tracks will be chosen and will respond to two levels of environment. This means that the scarf microphones will register sound levels that indicate a) a quiet environment, b) a loud environment. The scarf will choose from the audio tracks a ‘voice’ or characteristic which responds to the environment. For instance, for a quiet environment, a series of quiet voices or whispers/sounds.

During this testing phase, the wearer will be given a simple ‘yes/no’ question on a piece of paper every 10mins. These questions will be answered with the popular ‘yes’ and ‘no’ gestures found in the first stage.

At the completion of this experience the participant will answer a second questionnaire about the overall experience.

All the information received from the questionnaires will be used to inform design changes, ensuring the design and function of the scarf are both justified.
A1.2 Empathy Questionnaires

Interpersonal Reactivity Index

Adapted for 'Empathear' testing. Empathetic concern vs personal distress

The following statements inquire about your thoughts and feelings in a variety of situations. For each item, indicate how well it describes you by choosing the appropriate letter on the scale below. When you have decided on your answer, fill in the letter inside the circle next to the question.

READ EACH ITEM CAREFULLY BEFORE RESPONDING. Answer as honestly as you can. Thank you.

Answer Scale:            A               B               C               D               E

I often have tender, concerned feelings for people less fortunate than me (sibling)

Sometimes I don't feel very sorry for my sibling when they are having problems.

When I see my sibling being treated unfairly, I sometimes don't feel very much pity for them.

I am usually pretty effective in dealing with emergencies.

Which of the three questionnaires did you prefer and why?

While interacting with others around you, how did you find the hearing experience?

What suggestions do you have to improve the experience?

Do you feel your understanding about 'hearing voices' has changed and how?

Other comments about the experience

Questions about experience

Figures 177 Questionnaire adapted by Author (2014)
I sometimes feel discouraged when thinking about my future responsibilities with my sibling. I sometimes worry about my sibling in society when I am not there to protect them. I sometimes feel disappointed in how my friends react to my sibling. I sometimes feel embarrassed about my sibling. I sometimes feel disappointed at how the general public treats my sibling. I sometimes feel disappointed in how my family life dynamic has turned out. I sometimes become sad when thinking about my sibling’s future.

I have great interest in my siblings daily affairs/goals/wishes. I enjoy spending time with my sibling. I often feel tenderness at interacting with the general public. My sibling brings me joy.

I sometimes feel proud of my sibling when they are able to become more involved with society. It makes me happy when others have time and patience for my sibling. I feel nostalgia for a positive future for my sibling. I sometimes get excited when thinking about my sibling’s future. I sometimes feel excited about my sibling.

I often feel contempt for society when I come across examples of how people, like my sibling, are misrepresented in journalism/films. I often feel tenderness at my own negative attitude towards my sibling. I feel sympathy for a positive future for my sibling. I sometimes feel removed from my family and others around us. I sometimes become excited about a sibling like mine. I am often surprised at my own positive reaction to my sibling.

I feel contempt for my sibling. I feel shame when I see my sibling being mistreated by the general public. I feel pride when I see my sibling succeed. I often feel irritation/anger when I see my sibling being overlooked by the general public. I often become jealous of the “normal” lives of my peers. I often feel irritation/anger when I see my sibling being overlooked by the general public. I feel contempt for society when I am not there to protect them.

I am often surprised at people partaking in activities “normal” people partake in. I feel nostalgia for a positive future for my sibling. I often feel tenderness at my own negative attitude towards my sibling. I feel sympathy for a positive future for my sibling. I sometimes become excited about a sibling like mine. I am often surprised at my own positive reaction to my sibling.

I feel contempt for society when I come across examples of how people, like my sibling, are misrepresented in journalism/films. I often feel irritation/anger when I see my sibling being overlooked by the general public. I often feel tenderness at my own negative attitude towards my sibling. I feel sympathy for a positive future for my sibling. I sometimes become excited about a sibling like mine. I am often surprised at people partaking in activities “normal” people partake in. I feel nostalgia for a positive future for my sibling. I often feel tenderness at my own negative attitude towards my sibling. I feel sympathy for a positive future for my sibling. I sometimes become excited about a sibling like mine. I am often surprised at my own positive reaction to my sibling.
A1.3

Other Infographics

Mics the sense the user's environment, this information is then sent to the arduino where the appropriate 'voice' track from the voices library is played through the earpieces. The scarf / earphones are inconspicuous ear pieces connect to the scarf via Bluetooth. Dynamic voices are played through the earpieces.

The type of voices and their frequency are determined by the arduino and in connection to the user's environment. The scarf gestures are used by the wearer as a way to answer simple 'yes/no' questions. Participants used these yes/no gestures when answering simple questions about their experience.

Participants found interacting with others more difficult than expected. They also felt their hearing experience changed their opinion about those who 'hear voices'. Some users acted out gestures comfortably.

Number of users: 288

figures 179 Original infographic by Author (2014)
2. Place on headphones.
Mics the sense the user's environment, this information is then sent to the Arduino where the appropriate 'voice' track from the voices library is selected.

3. Converse with those around you while 'hearing voices'.

INSTRUCTIONS

BLUE TOOTH EAR PHONES SENSORY SCARF

1. To turn the scarf on un-clip this set of domes...

After playing with the scarf and headphones complete the questionnaire provided.

Where does your basic understanding of voice hearers come from?
Film    Literature    Journalism    Other.
Do you think this source has accurate knowledge for portraying information about voice hearers?
Yes    No
How would you react to an acquaintance if you found out they heard voices?
Positive    Negative
How would you react to when someone 'strange' is being loud and asking for assistance (e.g., to use someone's phone)?
Yes    No
Me as society
Society's view on voice hearers (from a personal perspective)

Before testing

Where does your basic understanding of voice hearers come from?
Film    Literature    Journalism    Other.
Do you think this source has accurate knowledge for portraying information about voice hearers?
Yes    No
How would you react to an acquaintance if you found out they heard voices?
Positive    Negative
How would you react to when someone 'strange' is being loud and asking for assistance (e.g., to use someone's phone)?
Yes    No

After testing

figures 180 Original infographic by Author (2014)
Support from the Community

Communication with Arana Pearson (HVW) fell through. Because of this, the Hearing Voices workshop was no longer a viable platform to stage my first testing session.

Fortunately, the SF Nelson group who have been deeply supportive and encouraging throughout this thesis process offered their assistance for any information exchange and support for testing sessions. They have been greatly impressed and intrigued by the device, offering a funding grant towards the completion of the thesis and to produce multiple devices or an APP.

SFMI wish for the devices or APP to be used by families in Nelson in Mental Health Awareness week, March 2014. This opportunity would ensure that this Masters thesis would be well validated and could be extended into the wider SF community, achieving the desired positive effect as early as May 2014.
A3
OUTSOURCING
### SCHEDULE AND MILESTONES

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</table>

**Prototyping**
- progress meeting
- review functional prototype

**Testing and Refinement, and Final assembly**
- Audio output, sensor inputs, power mgmt
- custom electronics fab & enclosure design
- Shape sensing experimentation
- progress meetings/work sessions
  - User Testing
  - Troubleshooting/Debugging

**Interface and Workflow**

1) Check audio output/earpieces and test some audio files.
2) Review basic functionality and plan overall physical design. Start experimenting with user interaction/shape sensing, and conduct material experiments. Order remaining components.
3) Begin integrating electronics into overall design, finalise material selection.
4) Final design assembly and testing.
5) Begin a number of user tests – resolve workflow, identify any potential issues.

*Figures 181 Original information by Rorke (2014)*
“Voices” Responsive Wearable Audio Experience

FUNCTIONAL PROTOTYPE PROPOSAL

tiago rorke
12/05/2013

PROTOTYPE REQUIREMENTS

WEARABILITY
The device will be built into a scarf-like wearable accessory. The electronics must be suitable for integration into such a form factor and allow for the typical handling of such an item of apparel.

AUDITORY SIMULATION
Through some kind of earpieces, the device will playback pre-recorded speech samples that will use binaural recording or pre-processing techniques to simulate the effect of hearing voices in the surrounding space, as well as from inside one’s own mind. The goal of this is to create a simulation of auditory hallucination.

RESPONSE TO THE ENVIRONMENT
The device will monitor surrounding audio levels, and will regulate its own audio output according to these measurements.

USER FEEDBACK
The user should be able to manipulate the prototype in a way that can be measured and recorded by the device.

MUSIC PLAYBACK
The prototype will mix music into its audio output, according to pre-programmed parameters set by the user or a supervisor.

LOG DATA
Measurements taken by the device, such as surrounding audio levels and feedback from the user, as well as a record of audio playback, will be recorded throughout the entire period of user testing.

USABILITY
The prototype will need to be able to be worn by a participant for up to a number of days, during which time it will need to function without the attention of a supervisor.

INVISIBILITY
All aspects of the prototype should be as unobtrusive as possible so as to inflict minimal presence on the user. A wireless connection is also required between the scarf and the earpieces.

USER/SUPERVISOR INTERFACE
A laptop based interface is required for configuring and programming the prototype, as well as for retrieving recorded data.

figures 182 & 183 Original information by Rorke (2014)
INDUSTRIAL DESIGN

The initial prototyping stage will produce a functional prototype in a temporary configuration. This will be used to test and prove all the desired functions of the device. In the second stage of development this will then be redesigned and designed alongside all physical aspects of the scarf and headband unit, taking into consideration access to the various ports and the design of visual indicators such as charging and bluetooth connection status LEDs. In this stage additional components and hardware will be sourced such as wiring and connectors that best meet the design constraints (Digikey/Various suppliers).

The ability of the scarf to detect physical manipulation by the user (see: sensing scarf manipulation) will require close integration between the electronic and textile design of the device, and will depend on a healthy amount of collaboration to be successful. Aside from this, much of the electronic design will be quite flexible in accommodating design constraints of the scarf.

Design of the headband depends largely on the outcome of initial experimentation of the audio induction coils and chosen earpieces. This will also require some collaboration, but the electronic components in the headband are minimal compared with those in the scarf.

RISKS AND CHALLENGES

RELIABILITY OF SOUND MONITORING

Layers of material or clothing can have an adverse effect on the audio reception of microphones. For this reason using two microphones in different positions is suggested in order to increase the chances of having clear reception. Textiles in contact with the mics can also create noise, and so material test experiments with together with the microphones will be necessary. If there are substantial issues with noise, a filtering circuit could be introduced.

SHAPE SENSING

This is an unproven concept based on several precedent projects and technologies. Much will be learned through material experimentation before a successful outcome can be proven. If the initial idea proves to difficult to achieve however, there are many other options for providing user feedback functionality, most of which will have little impact on the overall electronic design of the prototype.

BLUETOOTH RELIABILITY

Bluetooth reliability varies between devices and testing this will be a priority during the prototyping stage. The backup wired connection will be very useful for testing and debugging purposes, but may also be valuable in user testing if the bluetooth connection is problematic. If the modules used have particular issues, different modules could be tested at additional cost.

POWER REQUIREMENTS AND BATTERY LIFE

Actual power requirements for the device are difficult to estimate before it is built and tested. If the selected power supply is insufficient to be practical for user testing purposes, this can be upgraded in the final prototype at some additional cost. The use of a wireless bluetooth connection has particularly high power requirements, and using the backup wired connection could be a way to mitigate power usage.

CUSTOM EARPIECES

Because of a lack of suitable commercially available earpieces at a reasonable cost, custom earpieces will be built instead. These will use a type of micro speaker commonly found in hearing aids, however because they are being built from scratch, these will require some testing and experimentation before reaching an effective design. This will also be a priority during the prototyping stage.
COMPONENTS AND FUNCTIONS

MICROCONTROLLER
The prototype is based on the open source Arduino prototyping platform. The Arduino platform allows wide use to be made of existing project examples and prebuilt libraries. An Arduino Pro Micro (or similar, such as the Teensy 3.0) is used to co-ordinate audio playback, readings from the sensors, sending data to be logged, and interfacing with a laptop.

AUDIO OUTPUT
Two MP3 Trigger boards are used to playback recorded audio files. Each board has its own cpu, which takes considerable load off of the central microcontroller. Audio files are stored on a microSD card on each board, and the boards can play any track at any time dynamically control the output volume. One board hosts voice tracks whilst the other hosts music. A pair of passive, dual-channel mixing circuits are used to take the two stereo audio outputs and mix these down to a single stereo output.

AUDIO PLAYBACK
The audio output signal is sent wirelessly to a headband unit using a bluetooth transmitter/receiver pair. When both switched on, the scarf and headband will connect automatically while in range. For debugging and testing purposes, 3.5mm stereo jacks allow for a wired connection. Custom earpieces built using micro-speakers commonly found in hearing aids, are connected to the headband unit. These earpieces sit inside the ear canal without obscuring the hearing of the user.

SOUND MONITORING
A pair of microphones are used to monitor sound levels in the environment. These are placed one toward each end of the scarf, to minimise muffling from the scarf itself and to help ensure clear audio reception. Low profile MEMS microphones are used, such as those commonly found in cellphones, to minimise bulk.

SENSING SCARF MANIPULATION
Some manipulation of the form of the scarf, such as rolling, folding and twisting, is measured by the device as a way to collect passive feedback from the user. This will be achieved through some experimentation with conductive threads and fabrics, and by measuring analog signals from a selection of points on the scarf. Some filtering may be necessary to achieve a clear and reliable reading.

DATA LOGGING
The OpenLog module is used to keep a history of activity from the prototype. Using timestamps this will log external sound levels, shape sensing feedback, power levels and all audio playback. A real-time clock module is used as the source of timestamps. The data is stored on a microSD card that is then read using a card reader, and the data is then interpreted by the desktop app used to configure and control the prototype.

POWER AND CHARGING
A single 2000mAh lithium polymer cell is used to power the scarf, whilst a smaller 850mAh cell powers the headband. Ideally these will power the devices for around 8 hours, but this will be subject to experimentation. Both units are charged via a mini usb port and can be charged from a laptop or power adaptor. The real time clock module has its own button cell battery power source that does not need to be recharged.

LAPTOP INTERFACE
A desktop app built in Processing will provide an interface to configure and communicate with the prototype, and will also interpret and visualise data collected from the device. This will be designed in collaboration, and can be highly customisable.

COSTING
Some costs are estimates and will depend on what is required during development.

BILL OF MATERIALS

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A3.2 Francis Guerin and Ryan Loader
Empathear App

Publishing to both iOS and Android app stores requires the acceptance of the app by the store. To publish to app store, without any additional changes from the development version:

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If a small number of tracks are to be added sometime in the future to the app you will be billed at $18 per hour. The addition of a set of sounds is quick, a small number should not take longer than an hour.

If a significant number (greater than 10/ if you want to continuously to add tracks) of new audio tracks are to be added to the app we will need to change the file storage from local (on your phone) to the cloud (on a server accessed by the internet). This is because we are already pushing the limits of what can be stored locally and still have a reasonable app size and app responsiveness. If the addition of new tracks are to be ongoing, the hourly rate will apply to additional work. Work other than audio addition will need to be quoted separately.
Working prototype.
Because of the limitations of budget only ‘off the shelf’
technologies were acquired meaning that some parts sourced
were large and bulky. Ideally, custom made ‘flexible’ parts would
be made to allow for smaller components and more flexibility in
the device. If I were to make a hard cover device (like many of
the industrial products am used to designing) it would be large
to house the electronics that could be afforded. To
accommodate this, the device was manifested as a wearable
technology garment. This allowed me the flexibility to explore
the design. Alongside this I started looking into 3D Knitting and
the design opportunities that this could hold.

Ear Piece
It was found that while spy wear would fit the design aesthetic
its technologies didn’t meet my criteria for function as they
lacked Bluetooth capabilities (to make the ear piece ‘wireless’) and
while high end hearing aids had the right kind of technology
capabilities the price was exorbitant. As a result of this, I decided
to make the head set from scratch using these components:

While not attached to the Wearable technology, the ear piece
could not be entirely ‘wireless’. This means that the wearer is
able to remove the wearable garment (for comfort etc.) but
still maintain the voices experience as the ear piece has its own
Bluetooth and Battery Pack components.

The ‘volume’ nob and the charging connector point attached so that later I could design
these parts to suit and work in with the final garments aesthetic design and function.

Main body components
All components needed to create a functioning prototype were assembled, soldered and
tested by Tiago Rorke.
Small, light Lipo rechargeable batteries were chosen for the design as they would provide me
flexibility when considering aesthetics and comfort of the design. Battery choice was quite
significant as it could become a major restriction on the design. The batteries would connect
to the power cell and to the Bluetooth components (one on the scarf and one on the head
set). These needed to last for up to 8 hours (a full day of voices listening), to be small and
light, and they needed to be rechargeable.

The final circuit diagram was translated into a physical diagram which was placed on
fabric and then traced with colour correlating wire. This was then sewn on to a strip of fabric
Alongside this, a schematic was created in illustrator to send to the AUT 3D Knitting
machine where the blue lines represent conductive thread that carries the power and the
general grid pattern denotes basic stretch cotton. This image was the first test schematic
used to get an understanding of the conductive thread, whether it could carry enough power
to each component. So with this in mind and the knitting costs, an A3 sized pattern for the 3D
Knitter to knit was sent to AUT.

Small ‘plug-in’ parts were created to facilitate a quick and easy transfer of the electronic
components from the prototype to the final 3D Knitted garment. Tiago created a schematic
for custom made pieces which was sent to the Victoria University main campus science
department When these parts come back, Tiago then soldered them to connector parts.
For functionality, many different ways to embed the electronic wires into the fabric were
investigated.
This technique where wires are placed on the surface of the fabric and sewn over with sewing machine was chosen for the final production. The exposed electronics were insulated by simply adding fabric over the top of each component. This fabric could then be unstitched or drawn to the side when accessing electronics for maintenance and when interchanging them between garments.

**Code**

Code was required to control the electronics inside the scarf. An Arduino, the brain of the scarf, is loaded with this code where it can send orders to the individual components. The code is crucial to the scarf's ability to function properly. Many versions of the code that drives the scarf's microcontrollers were produced. The code was slowly adapted to refine how the scarf responds to the environment. What this code needed to do was:

- Allow the user to choose tracks that are of the same temperament as their loved ones voices
- Allow the microphones to recognise the wearers environment and change the voice tracks according to that environment.
- Control the orchestration of voices, which voice is chosen according to voices selection and when they play
- Allow for implementation of live questionnaire to be asked ‘during’ the experience
- Allow for musical tracks to be chosen and played along with the voices (to help concentration)
- Gather and store data that can be accessed on demand after each voices experience

The final device will provide a voices experience for between one hour to one day. The final code (version 13d) allowed the scarf’s microphones to be a lot more sensitive to the environment than the original code, providing a more dynamic experience of voices for a shorter amount of time.

**Computer Apps- Maintenance and User**

Alongside the creation of the Arduino code, User and Maintenance apps were also trialled and refined. The original intention of the User app is to allow a personalisation of the voices. It would be used by the SF worker during a meeting between the sibling and affected loved one where they determine what gender and temperament the voice hearer hears.

The intension of the maintenance app is for SFMI workers to the change volume, the frequency of voices according to environment and how it listens to the environment. There is also a log where sound activity that the microphones pick up on is displayed.
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<tr>
<th>Criteria</th>
<th>Original Device</th>
<th>Spywear</th>
<th>Bluetooth Hearing Aid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>✅</td>
<td></td>
<td>✅</td>
</tr>
<tr>
<td>comfortable</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>unnoticeable</td>
<td>✅</td>
<td></td>
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<tr>
<td>allows ‘real’ sounds to be heard at the same time as voices</td>
<td>✅</td>
<td></td>
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</tr>
<tr>
<td>Wireless</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost effective</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bluetooth capabilities</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

figures 192 Original graphic by Author (2014)
Technical design

**Ear Piece**

**PROCESS/METHODS**

For the ear piece we begun by looking into small, unnoticeable technologies like spy wear and hearing aids. This is the criteria we worked from:

- Small
- Comfortable
- Unnoticeable
- Allows ‘real’ sounds to be heard at the same time as voices
- Wireless
- Cost effective
- Bluetooth capabilities

![Diagram of ear piece](figures)
It was found that while spy wear would fit the design aesthetic its technologies didn’t meet my criteria for function as they lacked Bluetooth capabilities (to make the ear piece ‘wireless’) and while high end hearing aids had the right kind of technology capabilities the price was exorbitant. As a result of this, I decided to make the headset from scratch using these components.
While not attached to the Wearable technology, the ear piece could not be made entirely 'wireless'. This means that the wearer is able to remove the wearable garment (for comfort etc.) but still maintain the voices experience as the ear piece has its own Bluetooth (that connects to the scarf to access voices tracks) and Battery Pack components. The 'volume' nob and the charging connector point attached so that later I could design these parts to suit and work in with the final garments aesthetic design and function.
The final circuit diagram was translated into a physical diagram which was placed on fabric and then traced with colour correlating wire. This was then sewn on to a strip of fabric.

Alongside this, a schematic was created in illustrator to send to the AUT 3D Knitting machine. This image was the first test schematic used to get an understanding of the conductive thread, whether it could carry enough power to each component. So with this in mind and the knitting costs, an A3 sized pattern for the 3D Knitter to knit was sent to AUT.
Technical design

Main Body Electronics

PROCESS/METHODS

All components needed to create a functioning prototype were assembled, soldered and tested by Tiago Rorke.

Small, light Lipo rechargeable batteries were chosen for the design as they would provide me flexibility when considering aesthetics and comfort of the design. Battery choice was quite significant as it could become a major restriction on the design. The batteries would connect to the power cell and to the Bluetooth components (one on the scarf and one on the head set). These needed to last for up to 8 hours (a full day of voices listening), to be small and light, and they needed to be rechargeable.
Small ‘plug-in’ parts were created to facilitate a quick and easy transfer of the electronic components from the prototype to the final 3D Knitted garment. Tiago created a schematic for custom made pieces which was sent to the Victoria University main campus science department (SHOW HERE). When these parts come back, Tiago then soldered them to connector parts show here.

For functionality, many different ways to embed the electronic wires into the fabric were investigated. (images)
This fabric could then be unstitched or drawn to the side when accessing electronics for maintenance and when interchanging them between garments.
This technique where wires are placed on the surface of the fabric and sewn over with sewing machine was chosen for the final production. The exposed electronics were insulated by simply adding fabric over the top of each component.

figures 229-231 Original photos by Author (2014)
The above image is of the inner ear a mould made by hearing aid specialists Courtenay Hearing Centre. This mould was then scanned with a ‘Next engine’ 3D scanner. The Images to the right of this are screen shots from solid works depicting the 3D scan as a 3D model ready to be imported into 3DSMax for manipulation.
The 3D process of creating beautiful Jewellery for electronics Started in solid works where an abstract from was created over the basic electronic shape. Then the STL object was taken into 3DS Max where the voronoi pattern was applied to produce the jewellery aspect. This process was repeated for all jewellery components.

For the ear piece, the model was cut into two parts for dual material print on the Conex printer. The inner ear section was printed in soft rubber and the outer ear section was printed in hard resin.

figures 249-256 Original images by Author (2014)
A6

ETHICS APPROVAL LETTER
TO  Sarah Mokhtar
COPY TO  Edgar Rodriguez
FROM  Dr Allison Kirkman, Convener, Human Ethics Committee
DATE  2 March 2014
PAGES  1
SUBJECT  Ethics Approval: 20013
How can industrial designed products that replicate schizophrenic symptoms, primarily ‘voices’, help improve the relationship between the sufferer and their family members?

Thank you for your request to amend and extend your ethics approval. This has now been considered and the request granted. Your application has approval until 3 May 2014.

If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with your research.

Allison Kirkman
Human Ethics Committee
A7

APP INFORMATION AND CONSENT FOR INTRO SCREEN
INFORMATION PAGE

Information to be read before agreeing to use ‘empathear’
Empathear is an App that simulates dynamic Auditory Hallucinations or ‘Voices’ where family can experience an in-depth understanding of their own reaction to hearing ‘voices’.

The user will have one day undertaking their everyday tasks while listening to the voices (in the family home and out in society with the general public). These voices adapt to the wearer’s environment, becoming louder, softer, intense or relaxed.

Using the App outside of the home is very important as it will allow the user to see what it is like communication with members of the public while being distracted by voices.

Periodical ‘live questions’ will pop up during the experience, giving the user an opportunity to reveal how they are coping with the distraction of voices. These answers will be sent to my SFMI support worker.

You are strongly advised to ‘end’ this app if the experience becomes too distressing.

The Support network ‘Supporting Families in Mental Illness’ NZ, are available for assistance and support for users of this app. Support workers of the network will contact you after the experience to offer their support.

If you wish to have further information about the App feel free to contact SFMI. You can find your branch contact details at this web address www.supportingfamiliesnz.org.nz

CONSENT

I have been provided with adequate information relating to the nature and objectives of this app. I have understood the information and have been given the opportunity to seek further clarification or explanations from SFMI.

I understand that I may end this App at any time during the day. Data that has already been sent to my SFMI Support worker will be confidential and this data can be destroyed at my request.

I understand that the App provides an experience that touches on sensitive topics and because of this, all users of this app must be vetted by an SFMI staff member to ensure each individual’s safety.

• I have been given and understood an explanation of this App
• I have volunteered to use this App
• I understand I can stop the experience at any time,
• I understand that the data from live questionnaires during the experience will be sent to my SFMI support worker
• I am satisfied that only SFMI staff will have access to this data
• I understand that I can ask for data relating to my personal experience to be destroyed
• I understand that the results may be published
• I have had the chance to ask questions www.supportingfamiliesnz.org.nz
QUESTIONS
If you are finding this experience to distressing, please end now.

END NOW..........................................................Continue

I have noticed a significant difference when undertaking your daily activities?
Agree...............................................................Disagree

I have noticed a great difference in the way I am interacting with others around me?
Agree...............................................................Disagree

I am finding it harder to concentrate on tasks I would usually find easy.
Agree...............................................................Disagree

I have found myself unwillingly reacting to the content of the voices, eg giggling, gasping at loud voices.
Agree...............................................................Disagree

I have tried to avoid conversation with others. Please provide more explanation if desired.
Agree...............................................................Disagree

I am finding it difficult to zone the voices out when interacting with others
Agree...............................................................Disagree

I am finding it harder to concentrate on other peoples conversations
Agree...............................................................Disagree

Is this experience changing your outlook on your loved ones day to day life?
Agree...............................................................Disagree

Would you recommend this experience to others in your position?
Agree...............................................................Disagree
A8.1 Information and Consent forms

Empathear
Consent form for participants

‘How can design elicit empathy in siblings of voices hearers’. This can be achieved through a device that simulates dynamic Auditory Hallucinations or ‘Voices’ where family (focusing on female Siblings) can experience an in-depth understanding of their own reaction to hearing ‘Voices’.

I have been provided with adequate information relating to the nature and objectives of this research project, I have understood the information and have been given the opportunity to seek further clarification or explanations. I understand that I may withdraw from this study at any time before the final analysis of data by 20 March 2014 without providing reasons. Data that has already been provided before the participant withdraws will be destroyed.

I understand that I may withdraw from this study at any time before the final analysis of data by 20 March 2014 and if I decide to do so, the recordings of my participation will be deleted.

I have volunteered to take part in this project
I understand that the recordings will be stored securely
I understand that the results may be published
I understand that Audio recording will be taken
I have had the chance to ask questions

Please indicate if Participant wishes to be sent a summery of the research: yes / no

Contact details:

Name of Participant: Date:

I understand that any information or opinions I provide will be kept confidential and reported only in an aggregated/non-attributable form. I understand that the information I have provided will be used only for this research project and that any further use will require my written consent. I understand that when this research is completed the information obtained will be retained by the investigator Sarah Mokhtar for future mental health reference.

- I have been given and understood an explanation of this research project
- I have volunteered to take part in this project
- I understand I can stop taking part at any time, during and after the trials, up until the publication of the results in 20 March 2014, and if I decide to do so, the recordings of my participation will be deleted
- I am satisfied that the recordings will be stored securely
- I understand that the results may be published
- I understand that Audio recording will be taken
- I have had the chance to ask questions

Sign:
**Empathear**

**Information to be read before agreeing to participate in this research:**

This research will be undertaken by:

Sarah Mokhtar : 
Supervisor Dr Edgar Rodriguez-Ramirez : Edgar.Rodriguez-Ramirez@vuw.ac.nz

I am a Masters student in design innovation at the School of Architecture and Design at Victoria University of Wellington. My thesis research will include interviewing and testing human participants. For this type of research Victoria University requires ethics approval to be obtained.

My research centres around improving families’ understanding of hearing voices to develop empathy towards the family member with schizophrenia, and achieving a higher quality of life (QOL) of the family unit as a whole.

The research will address the question:

‘How can design elicit empathy in siblings of voices hearers’. This can be achieved through a device that simulates dynamic auditory hallucinations or ‘voices’ where family (focusing on female siblings) can experience an in-depth understanding of their own reaction to hearing ‘voices’.

Each family member will be given the device to use for one day undertaking their everyday tasks while listening to the voices (in the family home and out in society with the general public). These voices adapt to the wearer’s environment, becoming louder, softer, intense or relaxed.

Using the device outside of the home is very important as it will allow each participant to see what it is like communicating with members of the public while being distracted by voices. Each participant will wear the wearable technology ear piece and a scarf or use the smart phone APP, both named ‘Empthear’.

In preparation for using my device, participants will hear an introduction to the project by myself with the guidance of Supporting Families in Mental Illness (SFMI), Nelson. At this time participants will be asked to choose between the wearable technology scarf or the smart phone APP to carry out the ‘voices’ experience. They will then be given a quick questionnaire asking about their current understanding of hearing voices. Participants would then be given the device for the day and asked to engage in all their usual activities, such as going to their job, buying lunch, carrying out errands etc - all while listening to the voices.

The introduction to the research and the interview process will take place in Nelson’s Supporting Families’ in Mental Illness office. Throughout the interview process audio will be recorded as a means of note taking.

After the testing session, participants will be asked to have a 30 minute interview with myself and an SFMI worker. This will be a semi structured interview about the participant’s personal experience with voices and how this has affected their thinking. And, ultimately, did it improve empathy?

With the APP there is also be the option of doing a real time questionnaire while wearing the device.

Participant identity and response to the testing will be kept confidential. Information given by the participants will be electronic and be subject to password for access (only the investigator myself - Sarah Mokhtar and Supervisor Dr Edgar Rodriguez will have access). I intend for the data on the device effectiveness to be reported and published by mental health/schizophrenia organisations.

Participants have the right to view the interview notes upon request.

Data/Audio collected will be destroyed at the end of the project. Anonymous quotes will be used in publications and exhibitions. This research may be published a journal, conference or an industry publication.

If participants would like to have a summary of the aggregated results, the consent form for participation will give them the option of indicating a ‘yes’ or ‘no’.

If participants would like to withdraw from the project, they may do so without question at any time before the data is analysed by 20 March 2014. Any data collected that relates to the person withdrawing will be destroyed.

If participants require any more information about the project, please contact myself - Sarah Mokhtar at, sarah.mokhtar@vuw.ac.nz or my supervisor Dr Edgar Rodriguez, edgar.rodriguez@vuw.ac.nz, at the School of Architecture and Design, at Victoria University, P O BOX 600, Wellington.

Thank you for your time and I hope to be working with you on my thesis research,

Sarah Mokhtar

Signed:
Preliminary Questionnaire

In general, what do you know about 'hearing voices'?

In your opinion, which everyday task does your family member find the most challenging while hearing voices. Please provide a specific example.

What level of tolerance/patience do you have for your family member's strange actions. 1 being no tolerance and 5 being highly tolerant.

1 2 3 4 5

How often do you make voluntary contact with your voice hearing family member?

Once a day  Once a week  Once a fortnight  Once a month
Hi there! My name is Sarah and I have an older sister who hears voices. For my masters thesis I have created a device that simulates dynamic voices. The purpose of this device is to improve empathy and understanding in family units like mine.

As a society, it is time we finally understand that the only thing that differentiates ‘them’ from ‘us’ is a sane response to an insane situation.

Empathear allows family members a unique opportunity to understand their own ‘sane’ reaction.

I would love for you to help me validate this research by participating in a one day testing session – wearing the scarf and headphones OR using my App.

- after the voices experience, a casual interview with myself and an SF worker to get your perspective on Empethear and your level of empathy.

Instructions for scarf:
1. To turn the scarf on, un-clip the set of brass domes.
2. Place on headphones
3. Go about your day and converse with others around you while ‘hearing Voices’

Instructions for APP:
1. To turn the APP on, click on the App icon
2. Place on headphones and follow live App instructions
3. Go about your day and converse with others around you while ‘hearing Voices’
What is Empathear?

Empathear is both a Wearable Technology Scarf and an APP for smartphones. It simulates dynamic Auditory Hallucinations or “Voices”, providing family members the opportunity to experience and understand their own reaction to hearing ‘voices’.

figures 260 & 261 Original image by Author (2014)
1. To turn the APP on, click on the App icon in your smart phone.

2. Place on headphones.

3. Go about your day and converse with others around you while “hearing Voices.”

Instructions for scarf:

1. To turn the scarf on, unclip the set of brass denses. To turn-off, clip back together.

2. Place on headphones.

3. Go about your day and converse with others around you while “hearing Voices.”

Instructions for scarf:

To start, the user sits down with SF staff and is asked to choose voice tracks to create a voices library that is synonymous with the ‘voices’ they have heard.

- They are then given the scarf to take home to use in their daily routine.

- The next day the user turns on the scarf by unclipping the brass denses and places on the ear phones. Throughout the day the microphones recognize the wearer’s environment and change the voice tracks according to that environment.

- The voices are played in a randomised order throughout the day. User has to attend to each task during the new distraction of voices.

- After the day is over, the user returns the scarf to SF. SF has a small recording up that with them (for support purposes) and gives them the day by day help booklet.

The user downloads the app from the SF website. Turns on the APP and is asked to choose voice tracks to create a voices library that is synonymous with the ‘voices’ they have heard. Once they are satisfied with the the user loads the app to the smartphone and the user experience. The user can use their smartphone as they usually would, the app will still play voice in the background.

- Throughout the day the microphones recognize the wearer’s environment and change the voice tracks according to that environment.

- Loud environment - multiple voices, louder volume

- Quiet environment - one voice, quiet volume

- The voices are played in a randomised order throughout the day. User has to attend to each task during the new distraction of voices.

- After 3pm the user can add musical tracks that are chosen via shuffle technique from the app's musical tracks library. These are played along with the voices to help concentration.

figures 262-264 Original images by Author (2014)
During the testing did you find the need to take the ear phones off? Did you specifically the ear phones when talking with others? Did you come in contact with anyone while hearing the voices? How did you find this experience?

1- understand those voices going on, and I didn’t realise how bad the destruction would be, can now empathise and understand to communicate with someone while they have voices is a really hard thing. I can imagine that exposure to these voices for long period of time can be truly crippling, to the point of inhibiting my ability to function well as an active member of society.

2- interaction with her daughter, saying ‘what’ all the time, very distracting cant relax. just dont know what coming just over two hours. Found the horrible voice made her think wow what is...having to deal with all the time, have an understand of what he has to deal with every day. will see him soon, tolerance has changed. My daughter had read me a story while I was listening to the voices and I had no recollection about what the story is about, I didn’t even know what she had just read to me’. Found myself saying to people ‘ask me that later’. I had to get my thoughts together, its (conversation) too hard while listening to the voices’. I was on edge the whole time you know? We take for granted just to be able to go home and relax it was very worthwhile to do; I can see it would be particularly worthwhile for families that have been newly diagnosed, valuable for family members and even friends of family.

3- yes, did want to take them off, didn’t like the experience. Two hours afters, after kids when to bed. had conversation with the husband. found it really hard to concentrate, had to make such an effort, had to think before I spoke, what he had said and how to respond had to ask to repeat things. had to make an effort to pick what she was going to focus on. chose the happy voice, was easier, then started to adapt the moods, they shouted then she jumped and her husband asked her if she was alright. when her husband left, she didn’t like to be alone. thinks people should do it as a progression, could be more of a gradual experience. felt quite different from having the happy voice and moving to the other voices, did change the experience a lot.

4- fell of the tread mill at the gym. had only one ear, couldn’t handle both. found conversation hard to listen to others, other background noise as well made things more difficult, random sounds quite distressing. her laughing, laughing her self at the kind of voices, kind of laughing at funerals, like whats going on. participant used the app on and off at different instances throughout the week, all for short lengths of time.
Do you believe your understanding and tolerance of your loved one has changed, how?

1- when people when asking questions about the job he was doing, specific details, had to put the device down so he could understand them was trying to ignore the voices but couldn't and had to put the device down completely, heard the voices say trees trees trees trees and could only think about trees. I know understand why she is the way she is when talking with others, and I have a new appreciation of what she goes through everyday.

3- tolerance before has changed from the middle, has more of an understanding of what he goes through in a day, more empathy. cant imagine living that way every day.

4- tolerance from level 2 before to a level 4 after the experience - hopes to get her self to a 5. hasn't seen sibling since, but wants to go and talk to her more about her voices, made her understand that she has a lot going on, instance with the put luck was a lot of people there, understand why her sister my have kept to herself. sister (the twin of the voice hearer) couldn't do the experience. want to organise things to do with her next week, test her knew understanding

Would you recommend this to others in your position?

1- yes, definitely. cos then they can experience what it is like to have minor expose of how distracting voices can be then they could understand what their sibling is going through and empathise more with them. yes, if i knew someone who had the illness in the family, because it gives you a lot of insight into what they live with every day.

2 - yes, empathy thing, understanding on a small scale what it is like on a daily basis, same as above.

4 - would recommend this app to others: recommend her sisters care givers to use it so they have a better understanding of what is going on, close friends who she knows would want to use it. Hopes that one day her younger non affect sibling will be ready to use it. questions didn't work as well good for siblings, have our phones on us all the time, can just plug them in, can use it again when getting frustrated with sister, can use it use it again to remind.

2 - yes, empathy thing, understanding on a small scale what it is like on a daily basis, when you dont have voices you just dont know, we can take it off, can understand some of his behaviours, they are not just being antisocial or rude, there is a reason.
A8.4 Semi-Formal Interviews

If you could suggest any changes

1- not so repetitive, more variety.
   didnt answer the questions that came up.
   It is good as an app as it is easy to download and easy to use, don't have to wait around for
   a group and its free.

2 - liked how the voices had a bit of silence and then the voices. liked how it did that.

3 - simple to use, if you are stressed easy to turn off, good to have the different options of
   voices so you can choose what you want to listen to. for me I'm glad that I did start with the
   happy voices and then add the other more distressing voices as a progression.

4 - would like to keep it on her phone, would like some more variety.
   Liked how she could just access it when she wanted, could then use it on and off as she
   pleased. Was easy to use and download.
   having a bit of a hearing the voices then having contact with member, then more
   experience then more contact. Is excited about how her relationship can develop.
   wants to find new solutions for her sister, wanting more ideas on how she can help her
   sister.

Do you think that you would have appreciated this experience earlier on in life?

3 - probably, I think have might have help with
   communicated with my brother when he was really unwell,
   to have that understanding 20 years ago would have been
   quite good.

2 - yes. he unwell from quite a young age, felt like I didnt
   have a brother. To have had this experience so easily
   available when I was younger, to understand why a bit, why
   he was behaving the way he was would have been greatly
   beneficial. Now I can put some memories into context as to
   what was going on at the time. It makes me feel sad, like I
   could have been more supportive.
A9
FUNDING PROPOSAL
EMPATHEAR

Purpose: The purpose of this device is to improve empathy and understanding in family units where a family member hears voices. Its creator, Sarah, believes as a society, it is time we finally understand that the only thing that differentiates people who hear voices, from the rest of us is their sane response to an insane situation. Empathear allows family members a unique insight into their own response to hearing voices – and chance to understand their own ‘sane’ reaction, and that of their family member.

Amount requested: $4000.00 quote attached.

Because the APP has been created by students at Victoria University, we are in the enviable position of receiving a heavily subsidised product. Quotes from mainstream software companies to create the same APP ranged from between $20,000 to $27,000.

About the APP and Wearable technology scarf: What is it?
Empathear is both a Wearable Technology Scarf and an APP for smart phones. It simulates dynamic Auditory Hallucinations or ‘Voices’ providing family members the opportunity to experience and understand their own reaction to hearing ‘voices’.

How does it work? refer to the flier – copy in instructions for using the APP and how it works.

Once the APP is the property of SFNZ, The App will be easily accessed by all branches via password. Fieldworkers can then instruct families how to download the device to their phone, and explain to them what to expect from the experience, including safety if they become distressed. Once the family has completed the experience the fieldworker will make contact to discuss the experience with the participant. The research was successful in its goal to achieve improved empathetic concern in siblings, with all user testing participants acknowledging the change in empathy they have towards their loved one. This resounded strongly, especially in younger participants, generating a motivation for improving the future of their loved one.

Feedback from Sibling volunteers who tested the APP:
As concluded by participant testament in the testing sessions, early intervention of families in the first stages of their loved ones diagnoses has the potential to activate sibling interest in involving themselves actively in their affected sibling’s life. I hypothesize that, if you give siblings the tools to affect positive change early on in diagnoses, there is possibility to change the otherwise inevitable future of that family unit. The empathy evolution seen in siblings has helped validate the research and solidify the importance the App could be to those in the SFMI community.
Benefits to Families and whanau:

- Availability:
  - Cost: Because the APP is a one off purchase, there is no extra cost to the branch or family to use it.
  - Accessibility: People can access the training when they are ready for it, and do not have to wait months for the next hearing voices workshop.
  - Families can have the hearing voices experience in their own home, when it suits them.
  - Families can share their experience with other family members ie share the headphones.
  - Young people (siblings) are reluctant to engage with SF services. However, they are happy to use an APP as this is the modern way they communicate and learn. (Sarah, have you some research or findings to back this up?)
  - Connection with SF: The APP provides opportunity (ie click yes on the screen) for participants to indicate if they would like someone from SF to contact them about their experience if they want to know more.
  - Knowledge: The younger the sibling is supported and informed, the more receptive and energetic they are to respond to the needs of their sibling. Sarah’s research indicates that siblings who are informed actively look for changes to support their family member, the wider family and can better cope themselves.

One young participant (25% or testing group) expressed her excitement about the future of the relationship and how she could develop it asking for information and new ideas to help her help her sibling and the ultimately the rest of her family. This participant was also highly interested in the future of the App, stating that she would recommend the app experience to her siblings caregivers and close family friends etc. She also held the hope that her other sibling would one day be comfortable using the App.

- Safety:
  - An R18 pass can be put on the APP store so young people’s experience can be supervised by other family members.

- Workforce development training Mental Health providers:
  - The learning experience for mental health staff at traditional hearing voices workshops will be enhanced by using the APP. SF branches can deliver this training, or Hearing Voices Aotearoa can. Permission will be given to them to use the APP?? (Is this correct Sarah – no problem if it is not though, or should they purchase it as well?) I think perhaps an agreement between Hearing voices aotearoa and SF should be discussed.
PUBLICATIONS FROM THE MENTAL HEALTH COMMUNITY

Web links to view Audio and Video publications of my thesis achievements:

Radio Nz interview:
http://www.radionz.co.nz/national/programmes/afternoons/audio/2588857/schizophrenia-app

Changing Minds exhibition video:
https://www.youtube.com/watch?v=k2LMG2kU3bQ

Dominion Post Interview:
http://www.stuff.co.nz/national/health/9907261/Student-gives-voice-to-schizophrenia-sufferers
App helps understand schizophrenia

SARAH DUNN

Last updated 12:55 13/03/2014

A Nelson graduate student has created a device which will allow the families of people with schizophrenia a glimpse of the overwhelming world their loved ones live in.

Former Nelson College for Girls student Sarah Mokhtar, 24, is studying at Victoria University towards a Masters degree in design innovation. Interested in creating products and industrial design, Sarah has spent the last year working on a programme called "empathise" that works through a download able app and a "wearable technology" scarf. Wearing these items will let those close to people who hear voices in their heads understand what the experience is like.

She said her inspiration for empathise grew out of the years she spent growing up in Wakefield alongside her older sister, who has struggled with schizophrenia. Among the services offered when her sister was first diagnosed was a "hearing voices" workshop that the whole family did together 10 years ago.

Ms Mokhtar said the workshop involved listening to voices on a looped tape that were meant to simulate those heard by people with schizophrenia. She set out to create an extension of that workshop, using the tape's script to make new devices that could be taken outside and worn in everyday environments for a more accurate experience of a schizophrenic person's life.

The voices played by the app are looped, but the scarf changes the tracks it plays based on the environment around it. The empathise programme behind both devices was developed in collaboration with fellow graduate student and "tech genius" Tago Roke, who is now based in London.

"I did a lot of research around psychology, ethics, and what kind of groups this would be useful for," Ms Mokhtar said. "Ultimately, [my goal is] to change the quality of life for the whole family unit."

She said her sister had told her that empathise's recorded voices were not very similar to those she heard as her own were "happy" and less aggressive. Due to ethical constraints set down by Victoria University, Ms Mokhtar was not permitted to write the voices script herself, but she hoped to be able to reflect what her sister heard one day.

Once the programme was ready, Ms Mokhtar wore the scarf around Wellington for an entire day so that she could understand its full effect. She found the hardest activities were concentrating, talking to people and responding appropriately while the voices were constantly competing for her attention.

"For me personally, it's changed the way I am with my sister. I [find myself] wanting to be more involved in her life."

"I hope that people can use it for a day and go about their usual tasks and see how different they are."

Her mother Anne said the experience had been valuable for her as well. She spoke of an "incredibly stressful" experience where she wore the scarf out shopping one day only to find herself becoming confused while trying to buy an item. When her cellphone started ringing as she stood at the counter, she felt overwhelmed. "I have a far deeper understanding and respect for my daughter," Ms Mokhtar said.

"Now we know why she speaks so loud, because she's talking over the voices."
Empathear, The New Smartphone / Tablet App to Help Family People Understand Schizophrenia

Web site article By Schizophrenia.com a very useful resource for families and those wanting to know more about schizophrenia. (Admin, Schizophrenia.com 2014)
Web site article By Supporting Families in Mental Illness, the main support community for this thesis (SFMI, 2014)
Sarah Moktar, who has qualifications in architecture and industrial design and is working towards a Master of Design Innovation, is creating a wearable, interactive installation device. Her inspiration is her older sister’s experience of hearing voices and Sarah hopes that the finished project will encourage empathy for others who also hear voices.

“I believe the key to generating empathy is to allow people a more in-depth understanding of a common symptom of mental illness – voices,” Sarah says. “For many of us, the symptoms of mental illness are a scary unknown, seeing those who are ‘different’ as potentially dangerous,” she continues. “Sadly, we often only see the illness and not the person behind it. Most of us are oblivious to the link between these symptoms of psychosis and the strange effect they have on the everyday life of those affected.”

“My wearable device, called ‘Empathear’, will give people an experience of hearing voices and – I hope – create awareness and positive discussions about mental health.”

Above all, Sarah hopes her project will breed more than just tolerance but magnanimity towards those who are otherwise seen as ‘strange’. “As a society, it is time we finally understand that the only thing that differentiates ‘them’ from ‘us’ is a sane response to an insane situation.”

The final winner, Fraser Hoffe, developed his unique style in Pablos and Vincents community art studios. He says his finished artwork will be fluid and original because he avoids straight lines in his work. “To me, framing or surrounding an artwork with straight lines restricts the imagination and suggests captivity or ownership.”

“Auckland regional consumer organisation Changing Minds, which manages the Mental Blocks Creative Grant Fund, is looking forward to seeing the completed projects in early 2014. Project Manager Margaret Lockhart says, “We are really excited about the Mental Blocks project. Creative expression is so often part of a personal journey towards recovery, as well as a powerful medium to convey these experiences of mental illness to others in the wider community, while also raising awareness and challenging stigma.”

Changing Minds’ mission is to ‘lead brave conversations in mental health and addictions in Aotearoa’.”

MARGARET LOCKHART, PROJECT MANAGER, CHANGING MINDS

For more information about Mental Blocks, please contact Margaret Lockhart, Project Manager, at Changing Minds on (09) 923 1752 or Margaret@changingminds.org.nz. Go to www.changingminds.org.nz/mentalblocks.

Changing Minds’ mission is to lead brave conversations in mental health and addictions in Aotearoa, so we see this initiative as a starting point for people to explore and challenge their perceptions about these issues.”

Changing Minds would like to acknowledge and thank ASB Community Trust, which funded Mental Blocks, and the 2013 judges – Maggie Grisson, San Barrett, Dave Mann and Damin Radford.

By Cate Hennessy
19 FEBRUARY - 13 MARCH
ARTSTATION
1 PONSONBY RD
A MIXED-MEDIA EXHIBITION EXPLORING THE OTHER SIDE
OF MENTAL DISTRESS, ADDICTIONS AND HOMELESSNESS
MARK STRACHAN + JUSTINE LAW
SARAH MOKHTAR + FRASER HOFFE
DI TOCKER

WHAT'S BLOCKING YOU?

Poster By Changing Minds, Mental Blocks Exhibition 2014. (Orchard, 2014)
Photos of me with my wearable technology scarf working prototype on display at Changing Minds, Mental Blocks Exhibition
Hi there! My name is Sarah and I have an older sister who hears voices. For my Masters thesis I have created a device (Empathear) that simulates dynamic voices. The purpose of this device is to improve empathy and understanding in family units like mine.

As a society, it is time we finally understand that the only thing that differentiates ‘them’ from ‘us’ is a sane response to an insane situation.

Empathear allows family members a unique insight into their own response to hearing voices - understanding their own ‘sane’ reaction.

I would love for you to help me validate this research by participating in a one day testing session by wearing the scarf and headphones OR using my App on your mobile phone and after the voices experience, a casual interview with me and an SF support worker to get your overall perspective on Empethear.

If you or someone in your family has a sibling, or other family member who hears voices, and would like to volunteer please contact Susan at SF Nelson on 545 8162 or email office@sfnelson.org.nz.

Participants can opt to use either the App or the scarf for the testing session and will meet with Sarah on Monday 10th March at 7pm for introduction and instructions on what to do. Support will be available to participants at all times.

After testing, SF Nelson hopes to purchase the APP and scarf for educational purposes for families and whanau and mental health staff, both locally and nationally.

Your support of this project would be greatly appreciated.
Face Book Recognition from the Victoria University site
Student gives voice to schizophrenic sufferers

Sara Hamlin has opened the feature developing an app that engages technology that allows people to hear voices and understand that experience in.

Check out the Video at:
http://www.stuff.co.nz/national/health/9907261/Student-gives-voice-to-schizophrenic-sufferers

Artical and Video by the Dominion Post, (Stewart, 2014)