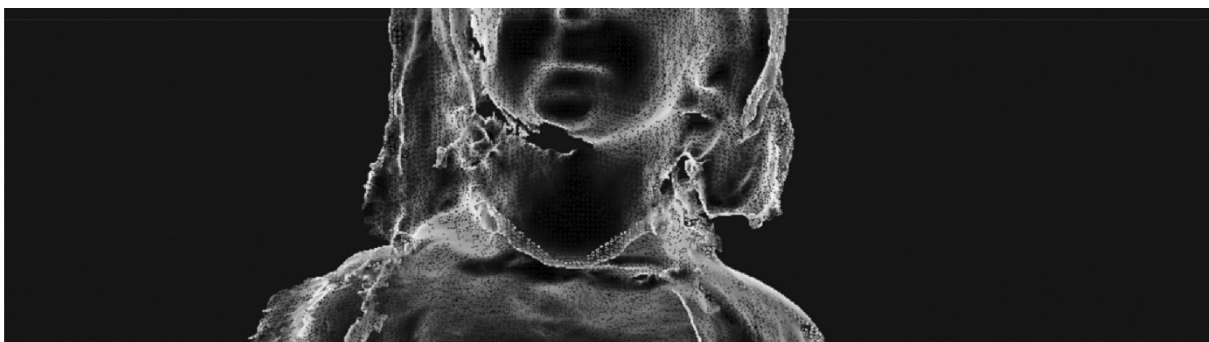
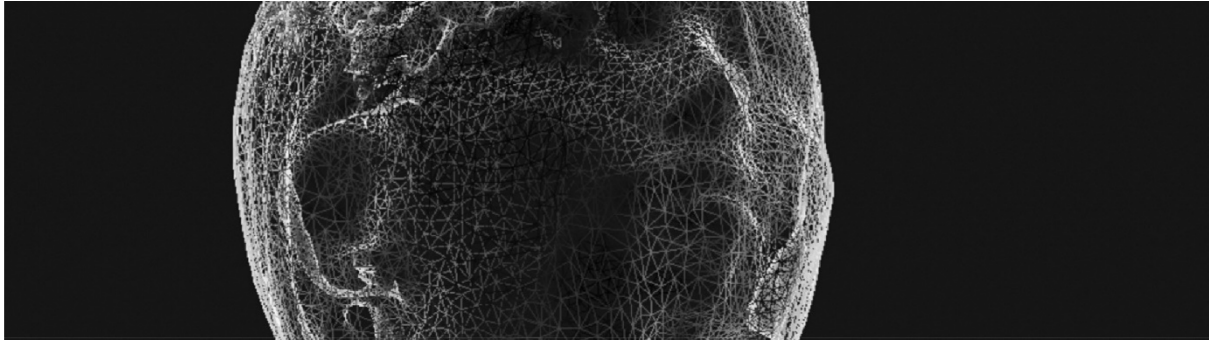
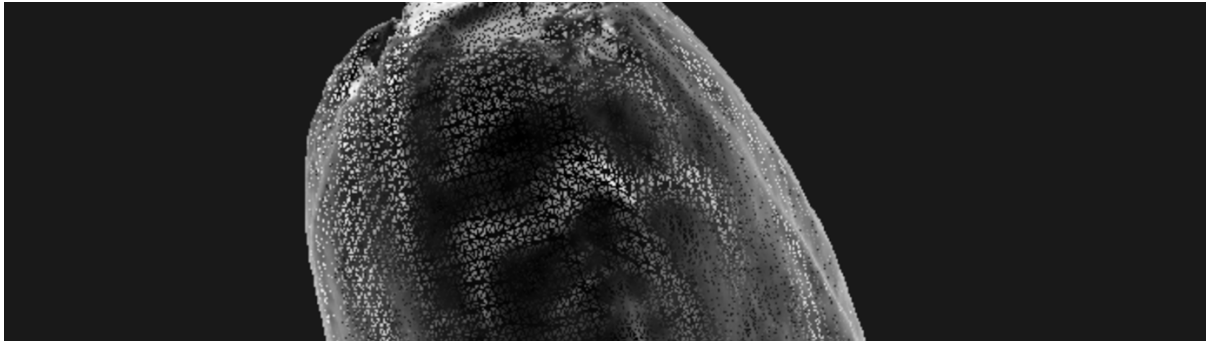




Face to Face:

Philosophy and impacts of socially engaged art with patients at the Sydney Facial Nerve Clinic.

TITLE PAGE

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Submission Statement:
A thesis submitted in partial fulfilment of requirements for the degree of Doctor of Philosophy.

Year:
2023

Statement of Originality

This is to certify that to the best of my knowledge; the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Vic McEwan

Acknowledgements

Undertaking this thesis amidst the multifaceted impact of Covid-19, and the complexities that emerge in life, posed many significant challenges. It is impossible to embark on a project of this magnitude in isolation, detached from everyday concerns. Regardless of one's stance on whether researchers should remain objectively distant, or personally connected to their subjects, it cannot be denied that pursuing a PhD is both a personal and a professional journey. It is difficult to imagine undertaking such work without being personally influenced in some way.

I began this research to gain a deeper understanding of myself and my practice. In doing so, I was seeking critique from others, as well as a testing ground for my ideas. However, one of the greatest rewards in embarking on a venture like this is the privilege of receiving the time, knowledge, and care of supervisors who are devoted to your work and your ideas. It is a profound life opportunity to have had their guidance, as it contributed to my personal and professional growth. Therefore, I extend my heartfelt gratitude to my supervisors Susan, Claire, and Paul, for their diverse and deep knowledges and care, and for understanding that my research journey was also an exploration of my own life decisions. Susan, Claire and Paul, your ability to discuss the intricacies that emerge in this work has been an invaluable learning experience. You have profoundly impacted my life, and for that, I am truly grateful.

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To Sarah and Holly, my family with whom I share my life and who have witnessed both the highs that come from feeling deep connection and understanding, and the lows of existential doubt that come from struggling with the immensity of the task at hand. I can only express, as I often do, my deep love for both of you. I also acknowledge that part of me understanding my own identity, comes from how it is perceived by both of you. Therefore, this PhD endeavour was also a gift to us all, attempting to make sense of the work we do and the life we lead together.

I will also direct the reader to the exhibition catalogue in Appendix 1 in which I thank the many people who have contributed to the conceptualisation and creation of this work. In the early stages of drafting this thesis, I enlisted the services of Robyn Flemming, an editor I have worked with in various art contexts. Engaging Robyn's early editing assistance was a form of self-care during the uncertain times of the early stages of the Covid-19 pandemic. However, as the intense process of rewriting unfolded, I was unable to return to Robyn for further edits, so any errors within this document are my own.

Lastly, I want to acknowledge the unexpected impact that the Australian band *The Apartments* have had on this research project, particularly their album "No Song, No Spell, No Madrigal." During moments of questioning how to share artwork that explores complex and trauma-filled topics, I wondered why anyone would be interested in visiting an exhibition about Facial Nerve Paralysis or to engage with experiences of trauma in that way. In those early stages, I listened to this Apartments album, which was written following the loss of a child of the lead singer Peter and his wife Kate. Through this album, I encountered immense grief alongside immense beauty. Through these listening experiences, I was sometimes consumed by the grief it expressed, but I could also appreciate it on its own terms as music, as a sharing of beauty. This became a profound inspiration that influenced the way I approached this work – striving to create something that exists on multiple complex levels simultaneously. Something that is as much about the viewer, as about the medical encounter.

Contents

Title Page	1
Thesis Title:	2
Statement of Originality	3
Acknowledgements	4
List of figures:	8
Pre-face	11
CHAPTER ONE. Introduction	12
Clinical Concerns	13
Expressions of emotion	15
Anatomy	15
An Artist in The Clinic	17
Theoretical lenses.....	19
The Phenomenology of Emmanuel Levinas	20
Care	21
New Materialisms.....	22
Illness Experience	24
Theoretical Coherence	25
Art as research, arts and health, socially engaged arts practice	25
Structure of the thesis.....	45
Summary of Chapter One	45
Overview	46
CHAPTER TWO. Methodology	47
Research Settings	47
Study Design.....	47
Participants.....	49
Sample Size.....	49
Recruitment Procedures	49
Data Collection	49
Observation	50
Data Analysis	50
Interviews.....	51
Patient Participants	51
Healthcare Practitioner Participants	52
Art Gallery Participants	52

Guiding principles.....	52
Human Research Ethics Approvals	53
CHAPTER THREE. Results #1 Expectations and experiences of care.....	55
Methodology	55
Philosophical framework.....	55
Participants, recruitment, and data collection.....	57
Interviews	58
Data analysis.....	58
Results	63
Theme 1: Identity - Exteriority and reconfiguration of self.	64
Theme 2: The PAPAP Circle – Pathology effecting psychology effecting pathology	66
Theme 3. Time: Time as a healer, time as a barrier, time as a container of doubt.....	69
Theme 4. Expectations and experiences of care	71
Theme 5. Hierarchies of pathology: Am I just complaining?	77
Theme 6. Communication: What’s needed.....	78
Discussion – Care-ful caring.....	80
CHAPTER FOUR. Results #2 Face to Face: The New Normal	86
Method.....	87
Results and Discussion	92
Artworks	95
Conclusion	146
Connection	146
Competency	147
CHAPTER FIVE. Discussion	150
Embodied practice of care	151
Scale of Impact	152
Competency through studio-based practice	153
Connection through positive hesitancy.....	154
Communication that stops erasure	155
Performativity through Unknowingness	156
Caring for artists, caring for community.....	156
Conditions for change	157
Diffractive Practices.....	158
Conclusion	158
Limitations and future research	160
References.....	161

Appendices	181
Appendix 1: Exhibition catalogue	181
Appendix 2: Review, National Portrait Gallery	182
Appendix 3: Lindy Hume Opening Speech	182
Appendix 4: PhD CV: Presentations, papers, residencies, exhibitions	186
Appendix 5: Industry Publication	187
Appendix 6: Forbes Magazine	191
Appendix 7: A Rich Life	193
Appendix 8: ArtsHub Article	196
Appendix 9: RealTime Arts Review of Bix Anxiety exhibition	196
Appendix 10: Gallery comment sheets	198

List of figures:

Figure 1: 12 Cranial Nerves (Encyclopedia Britannica, 2023)	16
Figure 2: 5 Branches of the Facial Nerve (<i>Facial Nerve</i> , n.d.)	17
Figure 3: Charles Bell, Engravings of the Arteries (Bell, 1824, p. 17).....	17
Figure 4: Map of the art for health field (Angus, 2002, p. 42).....	29
Figure 5 Thematic content for prevention and promotion and management and treatment.....	31
Figure 6 (a,b,c): Daniel Buren, Within and Beyond the Frame (1973), John Weber Gallery, New York. Photographer unknown (University of Oregon, 2015).....	40
Figure 7: The Hermeneutic Circle - after Figure 2, Flowers, Smith and Larkin, 1992, p. 20'	56
Figure 8: The Hermeneutic Circle and the PAPAP Circle	66
Figure 9: Residency at Rex Cramphorn Performance Research Studio	88
Figure 10: Working with The House That Dan Built choir for the MRI Choir artwork.....	89
Figure 11: Early version of Lachrymal Vase electronics.....	89
Figure 12: 3-D printing of Lachrymal Vase	90
Figure 13 Sign outside the Tate exhibition	92
Figure 14: Wagga Wagga Gallery main space	93
Figure 15: Screenshot taken from 'William M' video artwork.....	96
Figure 16: Installation shot of 'William M' video artwork	97
Figure 17: Test prints (A4 size)	102
Figure 18: Installation photograph, Wagga Wagga Art Gallery.....	103
Figure 19: (a) & (b) Artwork examples from The Face that Your face feels	104
Figure 20: Artwork example	106
Figure 21: Artwork example	107
Figure 22: Installation photograph.....	107
Figure 23: Mock-up #1 of 3 screen artwork	108
Figure 24: Artwork example	108
Figure 25: Mock-up #2 of 3 screen artwork	109
Figure 26: Mock-up #3 of 3 screen artwork	109
Figure 27: Edwin Diefes holding an un-ravelling French horn.....	110
Figure 28: Edwin Diefes trying to 'play' an unravelled French horn.....	111
Figure 29: Installation of French horn	111
Figure 30: Artwork detail #1.....	112
Figure 31: Artwork detail #2.....	112
Figure 32: The Unravelling installation photograph.....	113
Figure 33: Dr Glen Croxson installaion photograph	115
Figure 34: Dr Glen Croxson artwork in development.....	116
Figure 35: Facial Nerve Harp detail	120
Figure 36: Facial Nerve Harp installation photograph.....	121
Figure 37: Facial Nerve Harp detail	121
Figure 38: Facial Nerve Harp being played in the gallery	122
Figure 39: Wall of Faces with MRI Choir installation photograph.....	124
Figure 40: Faces ready for installation	125
Figure 41: Wall of Faces detail	126
Figure 42: Pantone skin tone guide (Pantone, n.d.)	127
Figure 43: Logo from Bio-Medical Composing Machine	128
Figure 44: Bio-Medical Composing Machine installation photograph	129
Figure 45: "Playing" a pivot irrigation system at Artlands Festival (Dubbo 2016).....	132
Figure 46: Lachrymal Vase detail.....	133

Figure 47: Lachrymal Vase installation photograph	134
Figure 48: The Crying Room installation photograph.....	136
Figure 49: The Crying Room detail #1	137
Figure 50: The Crying Room detail #2	138
Figure 51: Artwork Removed installation photograph.....	140
Figure 52: (a) & (b) Preparing jigsaw	141
Figure 53: Self Portrait installation photograph.....	142
Figure 54: Screen shot from video artwork Duet	143
Figure 55: Installation photograph of Hospital Rubble artwork.....	144
Figure 56: Installation photograph of Process Room	146

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

Louis Lasagna, 1964, "A Modern Medical Hippocratic Oath" cited in (Imber, 2008, p. 4)

Pre-face

The decision to enroll as an artist-researcher to complete a PhD in the faculty of Medicine and Health raises many questions about the expectations and 'norms' of research methodologies and translation. My intention in this undertaking is to respectfully create a cross-disciplinary partnership that acknowledges the benefits made possible by combining approaches from different disciplines. As an artist-researcher, my aim is to not be entirely subsumed by standard medical research practices, instead I aim to try gently and care-fully to understand how these different approaches might work together to create new understandings.

My assumption is that this thesis will have diverse readers, from the arts to medicine. My request to the reader is that during those times where the writing steps outside the norms of your discipline, that this be understood in its intention of an expansion of the ways we seek, understand, and share knowledge, rather than an indication that I am ignoring the traditions of scholarship that your fields of study have established.

This research doesn't seek a radical new interpretation of the scholarly thesis; however, I do acknowledge that on occasion the expectation of standard conventions might be stretched. I see this as an inevitable consequence of my overall claim that the arts have a role to play in the clinical exploration of illness and trauma.

To borrow a term from Affect theory scholars Gregg and Seigworth, it acknowledges the "thresholds and tensions, blends and blurs" (Gregg & Seigworth, 2010) that arise when we seek to move outside the "easy compartmentalisms" that single disciplines might encourage.

CHAPTER ONE. INTRODUCTION

I begin this thesis with the observation that the “arts” are concerned with more than just the aesthetic qualities of “beautiful” objects. Therefore, what lies ahead in these pages is an in-depth account of how the arts have the potential to explore complex topics, encourage debate, enable communication, and effect change. Inspired by this potential, and as part of what is often referred to as a “social turn” within contemporary art, many artists are shifting their practice to move beyond the hermetically confined constraints of the “typical” artist’s studio, to instead engage face to face with the complexities of the world. This is the direction in which I, myself, as a professional artist have been moving for many years, and within this thesis, I turn my attention to a practice where the worlds of art and health meet.

The focus of this thesis is the human face, specifically the potential for art as a form of care in the context of patients who are dealing with the impacts of facial nerve paralysis. While representation of the face has long been the story of artistic genres such as portraiture, this thesis seeks to move beyond mere representation, to delve deeply into the impact on human faces when they experience medical trauma. As a form of socially engaged art making, this thesis enacts the idea of art as a responder to the concerns and traumas of contemporary life. It sets out to offer a responsible, agile, and ethical art practice that engages with people who are in a position of great vulnerability as they experience health outcomes following an episode of facial nerve paralysis.

This thesis draws on four-years of immersive, emergent, and relational artistic research with patients and healthcare professionals at the Sydney Facial Nerve Clinic (SFNC), part of the Chris O’Brien Lifehouse, a not-for-profit comprehensive cancer hospital in Sydney, Australia. Throughout this research my aim has been to explore what benefit might arise from involving an artist in the clinical experience of the facial nerve patient, how creative/artistic research outcomes can contribute to the process of care, and how an artist might contribute to understanding and articulating the patient experience.

To be an artist-in-residence in such a clinical setting, to participate in the clinical examination and treatment of patients, and to be the first artist accepted into the PhD program of the Faculty of Medicine and Health at the University of Sydney, is an unusual, perhaps unique undertaking, albeit one towards which I have been working for some time. I come to this research as an artist with a 16-year career in establishing partnerships between arts and non-arts sectors including with the Department of Primary Industries ([Wirramarri](#)), SunRice ([A Night of Wonder](#)), The Murray Darling Basin Plan ([Tipping Point](#)) and Health ([The Harmonic Oscillator](#)). I have also recently co-established the [CASE Incubator program](#), a professional development opportunity for socially engaged artists to come together for mentorship, networking, development of their field and to create a community of practice.

I have been encouraged throughout this research by the increasing attention paid to the arts within health organisations. For instance, in 2019, The World Health Organization (WHO) – which defines health expansively as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (World Health Organisation, 1946) published a scoping review of over 3000 studies that explored the role that the arts can play in addressing health aims.

... a major role for the arts in the prevention of ill health, promotion of health, and management and treatment of illness across the lifespan. (Fancourt & Finn, 2019)

The field of Arts and Health has grown rapidly over the last few years, as it has been provided with a substantial evidence base, including, reviews of evidence such as the 2019 WHO review, the Victorian Health Foundation Rapid Review titled *The Arts and Creative Industries in Health Promotion Review*

(Davies & Pescud, 2020), summary reports, such as that produced by A New Approach “Transformative Impacts of Culture and Creativity” (Fielding et al., 2019)¹ and the recent substantial publication by the *Social Behavioural Research Group* entitled ‘The Impact of Arts and Cultural Engagement on Population Health’ (Fancourt et al., 2023), amongst a wealth of other research findings. This considerable body of research identifies that the arts can have positive and diverse impacts on mental health and wellbeing, for example on serotonin levels (Heiberger, 2011), cortisol levels (Fancourt et al., 2016; Kaimal et al., 2016), anxiety (Grossi et al., 2019; Kim, 2017), depression (Fancourt & Steptoe, 2019; Fancourt & Tymoszek, 2019), and social connection (Pearce et al., 2015; Tarr et al., 2014).

Whilst these research outcomes make important contributions to the field of arts and health, they primarily focus, instrumentally, on the benefit of the arts, *for* health. This means there is a lack of research that explores how this union of arts-health also nurtures and develops the very thing that it relies upon, artistic practice. (Clift et al., 2021; Mirza, 2007; Putland, 2008; Raw et al., 2012; Rooke, 2014). Therefore, this thesis proposes that, if we fail to develop both health outcomes *and* arts processes, then we risk diluting the potential of the inherent qualities of artistic practice that the research identifies as beneficial. I therefore seek to avoid this *dilution by instrumentalisation* by developing a “philosophy” of socially engaged arts practice which simultaneously contributes to the care of people experiencing medical trauma. I seek to nurture artistic practice so it can nurture others.

In this introductory chapter of the thesis, I lay out some of the major concerns of, and influences on, my research. I begin with clinical issues in the work of the SFNC, including a brief review of the impacts of facial nerve disorder, the anatomical factors involved, and some historical antecedents for art practices related to this area of medicine and health. I then summarise the key research questions that I took with me into my role as a contemporary artist-in-residence at the Facial Nerve Clinic. I follow this with a preliminary discussion of the theoretical lenses that have informed my research, and then a more detailed account of how arts practice constitutes a form of research in its own right, how the field of “arts and health” has been developing in recent years, and the relation of arts and health practices to the broader field of “socially engaged arts practice”. Even though my thesis explores the role of a contemporary artist within a medical clinic, I generally prefer the term socially engaged arts practice to the narrower term “arts and health”, partly to acknowledge the “social turn” mentioned above. Whilst this concept is explored in-depth later in this thesis, for now I use the words of American artist Chloe Bass to propose that socially engaged art practice is a type of practice that engages our “ability to think critically about the interpersonal environments we find ourselves in” (Sholette et al., 2018, p. 3). For the purposes of this research, the environment that I find myself in is the personal, intimate environment of another person’s face while they are experiencing trauma and care.

Clinical Concerns

The Sydney Facial Nerve Clinic describes itself as:

... a specialised multidisciplinary collaboration which aspires to achieve the highest level of care for patients suffering from facial nerve injury or facial palsy. Our expertise includes plastic and reconstructive surgery, head and neck cancer, ear nose and throat surgery, neurosurgery, cosmetic surgery, and specialised rehabilitation. Our goal is to improve patient outcomes through shared knowledge and experience, holistic care and a proactive team approach. (Sydney Facial Nerve Clinic, n.d.)

It was established in 2013 by a group of surgeons (otolaryngologists, head and neck, and plastics/reconstructive), physiotherapists and speech pathologists² who envisioned a place for

¹ Noting that The New Approach have also recently published a new report titled “The Big Picture 3: Expenditure on Artistic, Cultural and Creative activity by in Australia in 207-2008 to 2021-21 (Vivian, A, et al, 2023)

² Despite several attempts, at the time of my research there was no psychologist as part of the SFNC team.

treatment and research, donating their time to expand knowledge of the facial nerve among healthcare professionals, and to service a perceived need in the care of patients with facial nerve paralysis, who travel from around the country to attend³. This research has been made possible due to the SFNC's founding philosophy of valuing the multidisciplinary model, which has laid the foundation for this *expanded multi-disciplinarity* that looks outside medical and healthcare disciplines altogether to find value in the contributions that can be made by other fields such as the arts.

When a patient arrives at the Sydney Facial Nerve Clinic, a medical doctor conducts an initial assessment in a breakout room with just the patient and their family or support people present. This initial assessment is then presented to the assembled healthcare practitioners before the patient is brought into the main clinic. Once the patient is introduced and seated, one doctor will lead the consultation while the other attending healthcare professionals observe. The lead doctor examines the patient, asks questions of them and their support person, and invites questions from the other healthcare professionals, who may also ask to conduct further examinations. The patient is then led outside, where they are asked to wait while the team discusses their case. At the conclusion of this discussion, one of the clinic's healthcare practitioners exits the main room to talk with the patient, informing them of their management options.

People with facial nerve paralysis confront many challenges, ranging from physical to social and emotional issues. Their eyelid might not be able to completely close, putting their cornea at risk; their face may no longer be symmetrical, meaning they present to the public with (sometimes severe) facial difference causing stigma, ostracisation and self-consciousness; their mouth may not function correctly, which causes problems with eating, drinking and talking; they may not be able to smile or laugh or express emotion in the way they used to, all of which can cause emotional distress. Research indicates that people experiencing facial paralysis express depressive symptoms three to five times greater than the general population (Pouwels et al., 2016; VanSwearingen et al., 1998; Walker et al., 2012) coupled with broader issues around mental health and societal perceptions of facial difference (Ishii et al., 2012; Nellis et al., 2017; Ning et al., 2019; P. Su et al., 2017; VanSwearingen et al., 1998). Researchers also indicate that within 1/100th of a second of seeing someone's face, we are already making judgements about a person's attractiveness, likeability, trustworthiness, competence, and aggressiveness (Willis & Todorov, 2006). Concepts such as the "Attractiveness Halo" account for perceptions of attractiveness impacting the way we judge people in these key areas (Verhulst et al., 2010; Zebrowitz & Franklin Jr, 2014) while inversely, disfigured faces have been shown to activate negative behavioural and neural responses from others, leading to the perception that people with facial disfigurement are less honest, employable, trustworthy, optimistic, effective, capable, intelligent, popular and attractive (Hartung et al., 2019; Lyford-Pike & Nellis, 2021). Professor of Psychology Alexander Todorov's research shows that while these "first impression" presumptions exist, they are generally inaccurate assessments, caused by the bias of the viewer (Todorov, 2017).

[N]ot only do faces attract our attention more strongly than everything else does, but in our visual worlds there are no items that we see with so much alertness, discrimination, and responsiveness. (Van de Vall, 2008, p. 50)

In 2012, Professor of Sociology Arlie Hochschild published *The Managed Heart*, a project for which she embedded herself within Delta Airlines to research a theory of *emotional labour*. During her fieldwork, she observed that the airline advised flight attendants-in-training that they had the authority to deny boarding for any passengers with facial deformity as it was possible that they might have a negative effect on the "emotional memory of other money-paying passengers" (Hochschild, 2012, pp. 51–52).

³ During the writing of this thesis, the COVID-19 pandemic saw the clinic move to being both in-person and via Zoom.

This (financially led) concern for protecting passengers from the unease of viewing someone with a non-typical face, speaks not only to the role that the human face plays in our perception of self-identity, but to the way we are judged and evaluated by others.

This system of facial expression is fundamental to one's sense of well-being and ability to integrate into a social network. The face is the primary source of identification for human beings, displays emotions effectively, and enhances communication between individuals. (Byrne, 2004, p. 332)

Expressions of emotion

Charles Darwin and psychologist Silvan Tomkins made claims that the expression of emotion via the face was universal for all people. American psychologist Paul Ekman continued and expanded on these claims, arguing that there are seven universal facial expressions: happiness, sadness, fear, disgust, anger, contempt and surprise⁴ (Ekman, 1971, 1989). Despite the universality of his hypothesis being disputed on the grounds of cultural (Jack et al., 2012; Matsumoto, 1990; Yrizarry et al., 1998) and conceptual (Gendron et al., 2012; Roberson et al., 2007) difference, his teachings have had a major impact on the clinical consideration of facial expression in cases of facial nerve paralysis.

Facial disfigurement has the potential to interrupt the enacting of these universal (or non-universal) expressions, (as well as the subset of micro-expressions identified by Ekman), causing problems in day-to-day life, with the building of relationships, sense of self identity and for basic survival⁵.

These attributes of the human face — the ability to convey subtleties of emotion or mood; to indicate or elicit understanding; to register another's presence — these are all compromised by severe facial trauma. (Biernoff, 2017a, p. 57)

The potential for the face to express the complex affective state of the individual is disrupted when facial nerve paralysis stops it from working as expected, or when synkinesis (involuntary facial movement) occurs. Expressions of affect are not only absent but are re-coded into an expression that is unaligned with the emotion felt by the patient or expected by the observer – for example, when a smile inadvertently looks like a grimace. I propose, therefore, that the SFNC is a place that brings multidisciplinary biomedical treatment into relationship with issues of trauma, self-identity, self-worth, hierarchy, and power. The multi-disciplinary competencies of the healthcare professionals are therefore required to navigate complex relationships between identity and anatomy, and relational practices of care form a much-needed part of this navigation.

Anatomy

How our face presents to the world, and undertakes its various functions, is dependent on many factors including a small network of nerves called Cranial Nerve VII – The Facial Nerve. Within our head, there are twelve cranial nerves which emerge from the brain, or brain stem. These control various functions that we rely on for both active and passive regulation and control of bodily processes.

⁴ As well as a range of micro-expressions.

⁵ The face as an early warning system.

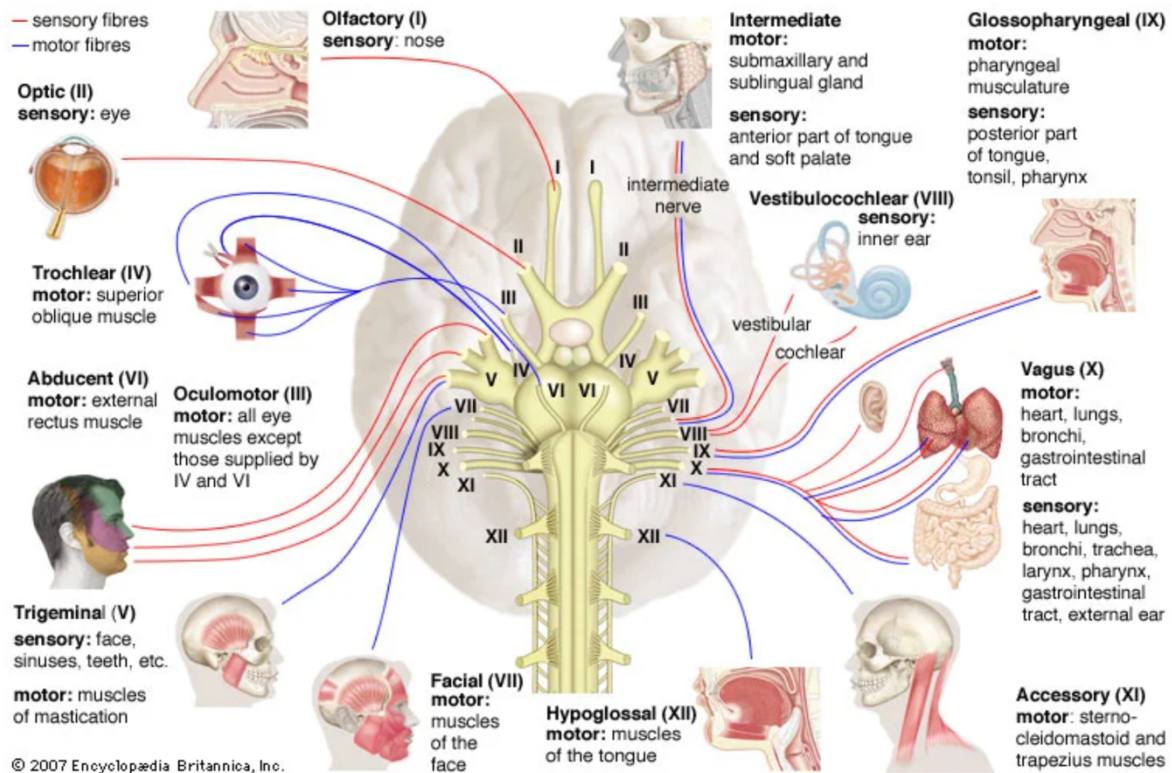


Figure 1: 12 Cranial Nerves (Encyclopedia Britannica, 2023)

Cranial Nerve VII is the facial nerve, which is responsible for facial expression, salivation, and various eye, mouth, nose, and brow movements. Much of the way our face functions and appears to the world is due to this facial nerve which consists of two parts, the intra-cranial and the extra-cranial facial nerve. The intra cranial section is situated within the cranium and serves purposes for the middle ear, tongue, and various glands (mucous, lacrimal, submandibular and sublingual glands). The extra-cranial portion then runs under the skin of the face in 5 main branches, spanning the face on either side (bilaterally).

These branches, from top to bottom, and their main functions are the:

Temporal Branch: Enables brow movements

Zygomatic Branch: Responsible for Eye closure

Buccal Branch: controls Moving the nostrils, lip, eye blinking, raising the corner of the mouth to smile.

Marginal Mandibular Branch: Assists in Depressing the lower lip

Cervical Branch: Allows anterior neck tension

The location of the 5 branches of the facial nerve is shown below in a representation of the five branches of the facial nerve. If any of these nerve branches sustain damage through pathologies such as head and neck cancer, Bell's palsy, trauma, and others, the facial nerve can become paralysed.



Figure 2: 5 Branches of the Facial Nerve (University of Colorado, n.d.)

An Artist in The Clinic

For the purposes of this research, the multidisciplinary team that provides care for the facial nerve is expanded by the inclusion of me as a contemporary artist. While it is an atypical practice to place a contemporary artist within a Faculty of Medicine and Health and within a facial nerve clinic, we can look not only to medicine, but to the history of the study of the facial nerve itself to find examples of art and its potential contribution to health. Dr Charles Bell, after whom Bell's palsy is named, was a surgeon, anatomist, physiologist, artist and author who made numerous discoveries, including identifying the discrete functions of the motor and sensory nerves – a central development in our knowledge of the facial nerve. Bell used his skills as an artist to advance medical knowledge while also impacting artistic practice through written works such as his *Essays on the Anatomy of Expression in Painting* (Bell, 1806).

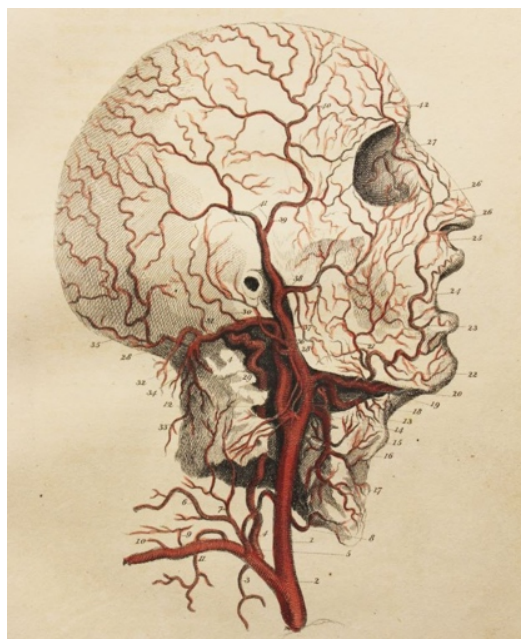


Figure 3: Charles Bell, Engravings of the Arteries (Bell, 1824, p. 17)

Similarly, otolaryngologist Harold Gillies, who is regarded as the father of modern plastic surgery, described these emerging medical techniques as a “strange new art” and further declared that he was:

... uplifted by the idea that the activities of the plastic surgeon were essentially creative, that they demanded the vision and the insight of the artist. (Biernoff, 2017a, p. 80)⁶

While we can acknowledge that surgical practices include artful skills and creative considerations of aesthetic concerns such as form, volume and shape, this thesis rethinks this union of medicine and the arts, proposing that experimental and contemporary artistic practice has a substantial and responsive role to play in amongst the all-too-human processes of the health experience.

Despite the legacy of these founding healthcare professionals and past art practices that have previously explored concerns of the face, such as within painting (Bianucci et al., 2016), or indigenous masks (Canalis & Cino, 2003; El-Mallakh & Hartman, 2019), an analysis of the WHO review, and a search of the databases of PubMed, Scopus, Medline and Google Scholar, failed to locate any research that specifically identifies the use of art in the patient and healthcare professional experience of facial nerve paralysis. Therefore, this research has been established to investigate the care needs of humans as they experience, in this case, facial trauma.

In a specifically structured place such as a medical clinic, where time is perceived to be in short supply, the inclusion of an artist brings with it a set of challenges. Some of these are common in artistic practices that step outside their field to engage with the world around them, while some are unique to the medical clinic. Throughout my career, I have identified certain prejudices and hesitations that (I propose) arise from a lack of knowledge regarding the potential for creative practices within non-arts settings. Therefore, I aim to contribute to the “normalization” of this concept, with the long-term aim of establishing safe and professional working environments where artists are not seen as being at odds with the core business of the site. By bringing artistic practices into relationship with biomedical practices, I acknowledge that while “[t]he biomedical model of healthcare is clearly relevant for many disease based illnesses, has intuitive appeal, and is supported by a wealth of supporting biological findings” (Wade & Halligan, 2004), multiple health researchers also argue for an expanded understanding of healthcare. For example, the biopsychosocial model of healthcare, developed by the Psychiatrist George Engel (1977) encourages healthcare professionals’ attention to be drawn to the biological, psychological, and social dimensions of illness, arguing that the subjectivity of the patient has a role to play within the science of medicine.

The dominant model of disease today is biomedical, and it leaves no room within this framework for the social, psychological, and behavioural dimensions of illness. A biopsychosocial model is proposed that provides a blueprint for research, a framework for teaching, and a design for action in the real world of health care. (Engel, 1977, p. 394)

The biopsychosocial model is both a philosophy of clinical care and a practical clinical guide. Philosophically, it is a way of understanding how suffering, disease, and illness are affected by multiple levels of organization, from the societal to the molecular. At the practical level, it is a way of understanding the patient’s subjective experience as an essential contributor to accurate diagnosis, health outcomes, and humane care. (Borrell-Carrió et al., 2004, p. 1)

⁶ The work of performance artist ORLAN is a kind of inversion of this idea.

This work aligns with medical Anthropologist, Arthur Kleinman whose definition of illness proposed a consideration of the *meanings* and *qualities* of patient experiences, or:

... how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability. (Kleinman, 2017, p. 3)

Following these influences, my presence at the SFNC aims to examine the role an artist might make in collaboration with biomedical and biopsychosocial processes, with illness and disease. In doing this, I do not position myself against what some researchers cite as the *biomedical reductionism of Western medicine* (Bishop. J, 2008; Viney et al., 2015) outlined above in the work of Engel and Kleinman, nor am I positioned in service of biomedical science; instead, this work aligns with Critical Medical Humanities scholarship, which argues for:

... recognition that the arts, humanities and social sciences are best viewed not as in service or in opposition to the clinical and life sciences, but as productively entangled with a “biomedical culture”. (Viney et al., 2015, p. 2)

From this place of joyful entanglement with biomedical culture, I honour the potential of cross-disciplinary practice by developing research questions that aim to jointly impact the patient experience of facial nerve paralysis, while contributing to an emerging theory base of socially engaged practices while exploring its relevance to bio-medical and biopsychosocial practices. These research questions include:

Q1 How can my role as an art practice-based researcher enhance the experience of care for individuals affected by facial nerve disorder.

Q2. In what ways can I contribute to the development of the fields of arts and health and socially engaged arts practice.

Theoretical lenses

A significant body of philosophical scholarship has articulated that the modern world has been discursively shaped by post-Enlightenment thinking that was structured in terms of binary oppositions such as rational/emotional, mind/body, social/natural, public/private, knower/known, subject/object, active/passive. It proposed that this resulted in power imbalances that favoured one side of the perceived binary. Modern scientific medicine emerged in this period, through the dichotomies of modernity, to produce the ‘biomedical model’ which reduced disease to physical processes that were given meaning through scientific methods where the doctor was positioned as the active knower of the passive patient’s body. This had the effect of reducing the patient to being a subject entirely dependent on the doctor’s knowledge (Latour, 1993). As a result of this dichotomy, the role of ‘Caring labour’ was relegated to the embodied work of (female) nurses (Smith et al., 2021).

Although practices such as patient-centred care, illness narratives and lived experiences have prompted a ‘re-evaluation’ of these binary dynamics by highlighting the links between psychological and physical aspects of illness, it does not mean that these binaries and their impact on the patient experience have ceased to exist. Consequently, the theoretical lenses that inform this research can be conceptualised as a *diffracted research practice* that actively resists the constraints of a singular theoretical framework. Physicist and feminist scholar Karen Barad, who will be discussed in this chapter, introduced the term *diffracted research* to describe an approach that proposes no ‘sharp’ boundaries between disciplines, encouraging “respectful engagements with different disciplinary practices” (Barad, 2007, p. 93) which she claimed could increase the potential for creative and innovative thought.

Therefore, this thesis draws upon various theoretical perspectives including those that can be broadly termed ‘new materialisms’, alongside ‘illness experience’, ‘care ethics’, and the phenomenological ethics of Emmanuel Levinas. Although these perspectives encompass expansive and varied bodies of scholarship, they broadly align around core ideas of relationality, critiques of dualisms, and the importance of ethics. In this thesis, I synthesise these perspectives as being concerned with what I will term the ‘ethics of relationality’, and I propose that they play a role in guiding our ethical orientation to actively hear, acknowledge and value the voice of another person on their own terms and in relationship with others. The applied application of this is practiced in methodologies such as community based/co-design research methods which support communities in “critical decision-making about their health” (Iniesto et al., 2022, p. 273) and in the concept of epistemic justice, which critiques the ethics of epistemology (Fricker, 2007). Health Systems researcher Seye Abimbola argues that “respecting the dignity of the patient as a knower suggests that expertise should also include the expertise of patients—on their body, their experience of pain or joy, and how they weigh the risk of harm against benefit” (Abimbola, 2023).

Having proposed the broad commonalities that exist between these theories, I will now give an overview of the relevant concerns of each knowledge area, before completing this section with a statement about how their different positions offer both similarities and contradictions which can be made ‘coherent’ through a commitment to diffractive research practices.

The Phenomenology of Emmanuel Levinas

Central to this body of work is the philosopher Emmanuel Levinas whose philosophical tradition of phenomenology explores the study of “phenomena” via the understanding of consciousness and experience. This philosophical tradition consists of a range of views, debates, and approaches, for example, Edmund Husserl’s original conception of phenomenology was concerned with cognitive understandings of phenomena, while phenomenologists like Merleau-Ponty, sought to ‘trouble’ this mind-body divide by rejecting the concept of the “objective body” to instead propose the concept of the “lived body”. Whilst Merleau-Ponty made numerous philosophical contributions relevant to this thesis, such as the proposal that art, as much as science, is a process through which to understand our perception of the world, it is Emmanuel Levinas that I will primarily focus on due to his examination of ethics, which I will later argue is a defining feature of socially engaged arts practice. The main contribution of Levinas work, which can be considered to be the ‘ethics of ethics’, was his claim that ethics begins with *the Other*, rather than with *the self*.

The being that expresses itself imposes itself, but does so precisely by appealing to me with its destitution and nudity – its hunger – without my being able to be deaf to that appeal. Thus in expression the being that imposes itself does not limit, but promotes my freedom, by arousing goodness.(Levinas, 1979, p. 200)

This “ethical reversal” (Large, 2015, p. 2) is perceived as being in opposition to what is commonly understood as the Enlightenment subject, which is self-constituting and defined by reason. Levinas proposed that when you stand *face-to-face* with *the Other*, you are *ethically obliged to respond to their call* (Levinas, 1979, p. 39). However, his frequent use of the term *the face* didn’t refer to the physical face at all; rather, it referred to the subjectivity that is encountered when we engage with another person. Through this concept, he proposed that if I understand the other person through my own pre-conceived ideas, then I actually exclude them from ethics – “a kind of subjective colonialism” (Nealon, 1997, p. 129) . This proposal aligns with my own socially engaged artistic practice which proceeds with the understanding that if I enter a process of art making with the outcomes already defined, then I am restricting myself from the potential of ideas that will come from the *relational* experience of the encounter. I would therefore argue that predefined socially engaged processes and outcomes have the *potential* to be devoid of important elements of nuance such as the unspoken, the contradictory, the personal and the jointly located, and therefore have the potential to exclude the

Other. Levinas's theories are relevant to the relational and emergent methods within this thesis as they aim to avoid categorisation as they work with the human face as it experiences a state of trauma, arguing that identity simultaneously lies within *and* beyond it.

Care

The SFNC describes itself as “a specialised multidisciplinary collaboration which aspires to achieve the highest level of care for patients suffering from facial nerve injury or facial palsy” (*Sydney Facial Nerve Clinic*, n.d.). This description, which highlights *care* as the highest aim of the clinic, resonates with my proposal that care is one of the defining outcomes of socially engaged arts practice. Through this concept we can reconcile the perceived distance between health and the arts, to validate the inclusion of socially engaged arts practice within the medical clinic.

The concept of care in medicine, as defined in the *Merriam-Webster Dictionary* (2011) is characterised as “responsibility for or attention to health, well-being, and safety”. However, the concept of care extends beyond a mere definition, and is intertwined with the experiential phenomenon of care, also known as the lived experience of care, which is explored and shared by participants in Chapter 3. Care as a scholarly discipline relating to health has predominately been examined within nursing literature to propose understandings such as that *caring* involves “those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway” (Leininger, 1981), and is made up of concerns such as “accountability, empathy, competency development and holistic service” (Roland, 2014).

Given that my own introduction to the concept of *care* came from the Environmental Humanities, I also include relevant understandings from that discipline, whose scholars have defined care as “a vital affective state, an ethical obligation and a practical labour” further proposing that “the vital necessity of care means standing for sustainable and flourishing relations, not merely survivalist or instrumental ones” (de la Bellacasa, 2012, p. 6).

As an affective state, caring is an embodied phenomenon, the product of intellectual and emotional competencies: to care is to be affected by another, to be emotionally at stake in them in some way. As an ethical obligation, to care is to become subject to another, to recognise an obligation to look after another. Finally, as a practical labour, caring requires more from us than abstract well wishing[:]; it requires that we get involved in some concrete way, that we do something (wherever possible) to take care of another. (van Dooren, 2014, p. 292)

The growing interest in the concept of ‘care’ within the medical humanities (Kristeva et al., 2018) highlights its significant relevance and necessity at the present moment. Thus, one of the aims of this research is to understand socially engaged arts practice as a form of care. To this end, I will examine the field of knowledge known as *care ethics* which has been examined in multiple health studies (Laurin & Martin, 2022; Nortvedt et al., 2011). As a field, care ethics initially arose through feminist scholarship and the work of Harvard Professor Carol Gilligan. Gilligan’s work explored the “different voices” that she felt were ignored within accepted notions of moral philosophy (Gilligan, 1993). Gilligan argued for a type of care ethics that is “inductive, contextual, psychological, rather than deductive or mathematical” (Gilligan, 2011). Another early care ethics theorist, Nel Noddings, introduced care as being a form of labour that was responsive to and driven by the context, rather than by the universal.

Care ethics advises us to maintain a caring relation – that is, to keep communication alive and remain prepared to care. (Noddings, 1986, p. 207)

Noddings introduced distinctions such as *caring-for* (applied acts of care) and *caring-about* (the caring intention) (Noddings, 1986, p. 17), proposing that it is more important to care for the intimate other than for someone not known to you. This led to criticisms of parochialism (Noddings, 1986, p. 330; Tronto, 1993, p. 142), while her writings about care as a gendered practice have led to criticisms of essentialism (Hoagland, 1991; Tronto, 1993). Theorists such as Professor of political science Joan Tronto and philosopher Virginia Held, among others, have sought to address these issues of parochialism and essentialism by linking ideas of care with global, political and economic concerns (Held, 2006; Tronto, 1993) – in effect, bringing care out from the confines of Noddings’ proposed *intimate relation* and into relationship with broader society. Held argues that care ethics:

[...] especially values caring relationships, obviously at the personal level within families and among friends and less obviously at the most general level of all human relationships [...] It is appropriate for the wide but shallow human relations of global interactions, as well as for the strongest and most intimate human relations of care in families. (Held, 2006, pp. 5–6)

Tronto originally proposed that *care* consisted of four elements which she described as attentiveness, responsibility, competence, responsiveness (1993). Importantly, she later proposed a ‘second generation’ of care ethics by adding a fifth element of care that proposed a broader scope of relations: relationality, or *caring with*, which adds a *plurality* to “care for citizens and to care for democracy itself” (Tronto, 2013). This aligns with philosopher Levinas’s concept of *The Third* which proposes that the ethical meeting with the Other brings you into relation with broader society. Levinas proposed that the ethical meeting renders the Other *irreducible to categorisations*, and that by acknowledging the *unknowable* in other people, it “makes possible the pluralism of society” (Levinas, 1979, p. 291) as identified in this quote from Levinas.

[T]he epiphany of the face [...] attests the presence of the third party, the whole of humanity in the eyes that look at me. (Levinas, 1979, p. 213)

Care ethics has been brought into alignment with the non-dualistic approaches of new materialism through theorists such as Care Researcher Maurice Hamington, who proposes that care and ethics are “an embodied, performative activity rather than a purely intellectual, scholarly study” (Hamington, 2012a, p. 31). Hamington’s concept of performativity will be examined throughout this thesis as aligning with practice-based research that explores *attentiveness to care* through artistic processes.

This recent interest in Care as a topic, has also introduced a developing scholarship around the concept of *Care Aesthetics* which is an emerging conversation that discusses the aesthetic qualities of care practices. Applied Theatre scholar James Thompson’s recently published book *Care Aesthetics: For Artful Care and Careful Art*, makes two main claims: He first argues that “human relations can be considered for their aesthetics” (Thompson, 2022, P. 9) and secondly “that care is an important source for ethics which can also be understood as an embodied or sensory practice” (Thompson, 2022, P. 10). In light of this newly emerging field of Care Aesthetics, I explore how the relationship between artistic practice and care, or caring, might be conceptualised. Can the arts provide care, and if so, what needs to be in place for this to occur? Just as importantly, is this relation bidirectional - can caring affect aesthetics, and if so, how? How can we understand the ethical qualities of this possibly bidirectional relationship?

New Materialisms

This research also considers a suite of perspectives that include New Materialism, Non-Representational Theory and Posthumanism which I will broadly group together under the banner “New Materialisms”.

What these various approaches have in common is a concern with the material workings of power, and a focus firmly upon social production rather than upon social construction. (Coole & Frost, 2010)

The concept of 'social production' mentioned in the quote above, proposes that identity (agency/affect) is co-produced by a relational encounter with an 'other'. This introduces the important concept of *affect* which can be understood through a complex genealogy that includes philosophers such as Spinoza, Deleuze and Guattari, the post-humanist/new materialist philosophers such as Karen Barad, Elizabeth Grosz and Rosi Braidotti, as well as philosophers such as Brian Massumi, Eve Sedgwick, Margaret Wetherell and the non-representational theorists, amongst others. While articulating a succinct definition of affect theory is 'slippery', we might define it as the marks we experience from a "world of encounters" (Gregg & Seigworth, 2010). However, numerous other definitions include:

Affect arises in the midst of in-between-ness; in the capacities to act and be acted upon.

It is the state of relation as well as the passage (and the duration of the passage).

Affect is found in those intensities that pass body to body (human, non-human, part body and otherwise).

It describes forces other than conscious knowing, active beyond emotion.

Affect is proof of the body's never less than ongoing immersion in and among the world's obstinacies and rhythms, its refusals as much as its invitations.

Affect is born in in-between-ness and resides as accumulative beside-ness.

(Gregg & Seigworth, 2010)

One central tenant of New Materialism is around the concept that:

[The affective method] takes affective encounters and bodily responses as a crucial part of knowledge production; one that can formulate new questions, research agendas, and modes of data collection and analyses (ibid.). Affective methodology takes emotions and bodily affects such as love, disgust, intensity and desire seriously because such responses and resonances expose ethical dilemmas that are part of knowledge production processes, while simultaneously offering other modes of ethics. Such methodologies are particularly essential for inclusion within the context of science and technology, which are often understood to be objective, disembodied and value free. (Mehrabi, 2018)

New Materialisms are 'material-discursive' practices that propose the inseparability between material aspects of knowledge production, such as human/non-human physical bodies and technology, and discursive practices such as language. Having critiqued the impacts of 'dualisms', the new materialists have moved beyond these to instead focus on ideas such as relationality, entanglements, ethics and responsibilities of care, proposing that ethics, ontology and epistemology are *intra-related* as an ethico-onto-epistemology (Barad, 2007, p. 90).

Post-human philosopher Rosi Braidotti further contributes to understanding the potential for socially engaged arts practice through her concept of *Affirmative Ethics* (Braidotti, 2019) in which she proposes a joyful engagement with complex and traumatic subject matter. The "affirmative" ethics of

Braidotti are central to the concerns of my socially engaged arts practice, as they propose an approach that enables me to navigate, confront, understand, and explore life in a way that makes our responsibilities of care possible to endure. Braidotti offers the philosopher Spinoza as a starting point for translating the negativity of the world (in this case - medical trauma and social exclusion) into an “affirmative” ethics. Spinoza’s *Ethics of Joy* (Spinoza & Curley, 1996) argues for confronting the pain and negativity of life in order to process it. The Australian philosopher Genevieve Lloyd interprets it as Spinoza constructing an “ethic centered not on a dour fatalism but on joy” (Lloyd, 2002, p. 83).

My ambitions for pursuing a socially engaged arts practice are to confront these difficult situations, such as working with people experiencing medical trauma, without it leading to despair. In this way, affirmative ethics can be both a method and an act of survival. In many projects I have undertaken with people experiencing trauma, there is inevitably an emotional intensity to the work, but it is also undertaken through a process that includes many moments of joy, laughter, fun and compassion, and through this I propose that the concept of affirmative ethics contributes to the ability for this method to safely uphold ethics of care.

The applied practice of new materialism within healthcare is explored in the work of Dutch ethnographer and philosopher Annemarie Mol, who in her ethnography of disease – *The Body Multiple: Ontology in Medical Practice* – aims to conceptualise disease relative to the “specific perspective of the person talking” (Mol, 2002, p. 12). As a new materialist health researcher, Mol challenges the idea of illness as a phenomenon that is solely biological, while identifying the responsibility of the researcher to consider the ethics of their own research agenda in a way that honours the ‘situatedness’ of others.

Illness Experience

Throughout this thesis, I explore topics such as “Where does illness begin and end?”. Sociologist Arthur Frank examines an aspect of this through the concept of Deep Illness which he describes as illness that the patient perceives “as lasting, as affecting virtually all life choices and decisions, and as altering identity.” (Frank, 1998, p. 21), Frank reflects on his own health experience with cancer recovery:

Whether someone remains deeply ill while in remission from cancer or while enjoying a good prognosis following successful heart surgery is a matter of that person’s subjective interpretation of her or his situation. Between two and three years after my own treatment for cancer ended, I realized I was referring to myself as someone who had had cancer, rather than someone living with cancer. I had imperceptibly moved out of deep illness, and the shift bore little relation to a medical definition of remission. (Frank, 1998, p. 21)

This question of where illness begins and ends is explored within facial nerve research which highlights disparities between patients’ and doctors’ perceptions of illness, and between medical priorities and patient experiences. Surgeons who operate on patients with facial nerve disorders evaluated 20 to 30% of patients as cured, yet the same patients experience the persistence of minor dyskinesia⁷ and did not rate themselves as cured (Ikeda et al., 2003). Similar evidence of disparity between patient experience and physician perceptions and expectations is widely discussed in research such as the report “Disfigurement in the UK”, released by the advocacy and support group Changing Faces (Changing Faces, 2017) which highlights issues relating to accessing necessary medical services.

The need to link “the practitioner’s treatment goals with patient-driven outcome goals” (Coulson et al., 2004a) has been identified as an ethical concern by researchers such as Erde and Eden in their

⁷ Involuntary movement.

paper *Ethics and the Care of Persons with Bell's Palsy* which questions when the ethical responsibility of the treating doctor ends (Erde & Eden, 1991).

To explore this issue, I look to the concept of *Empathetic Witnessing*. Arthur Frank, reflecting on the work of anthropologist Arthur Kleinman, proposes that empathic witnessing “of the patient’s and family’s stories of the illness” (Kleinman, 2017, p. 10) is “central to clinical work” (Frank, 1998, p. 22). He invokes the work of physician Rachel Naomi Remen who works:

with persons who have cancer, offering them not medical treatment but empathic attention. Kleinman advocates attending to stories as a functional part of clinical work. (Remen et al., 1985, as cited in Frank, 1998)

Whilst my own previous artistic practice could be considered a form of empathetic witnessing, there exists a responsibility that I don’t assume the role of (or be perceived as) a psychologist, counsellor, or social worker. This concern is driven by two factors, firstly because I don’t come to this research with the necessary training of those fields of practice, and secondly due to the need to manage the expectations of the participant. I achieve this by providing clarity of my aims as an artist, while articulating the difference between this research process and one that might be understood as an identified forms of therapy such as Arts Therapy (outlined later in this chapter). I am simultaneously developing methods whereby my mode of interaction doesn’t position me as the person holding all the knowledge, or as the one who is solely “in charge of” the research situation. Instead, I am attempting to create opportunities for that knowledge to be defined together.

I have argued throughout that one listens to ill people’s stories not in order to fix them by doing something “therapeutic,” but rather to honor them. (Frank, 1998, p. 35)

Theoretical Coherence

While these theoretical disciplines have been revealed as sharing certain alignments, it is important to acknowledge that contradictions exist between them. An example of this includes the theoretical relationship between New Materialist philosopher Karen Barad, and the phenomenology philosopher Emmanuel Levinas. Whilst we can see the influences of Levinas on the work of Barad, they each propose differing theories about ontology, with Levinas proposing that ontology is pre-existing, while Barad proposes that ontology is relationally constructed. I acknowledge all these theoretical positions as being useful, as part of a ‘flow towards’ the relational, ethical practices of the productive entanglement on offer within this research. By holding these differences and similarities together, I propose they have great value, which aligns with one of my proposed key features of socially engaged arts practice, the ability to hold and value contradiction as it works with different people and perspectives. Instead of seeing these contradictions as conflict, I propose that they are the valuable ‘data’ of lived experience that acknowledges the situatedness of positions.

Art as research, arts and health, socially engaged arts practice

As mentioned in the pre-face, I am not presenting a radical new interpretation of the scholarly thesis, although many people before me have made such contributions. In 1979, Lucien Clergue, a French photographer who would later become chairman of the Academy of Fine Arts in Paris, earned a PhD under the supervision of French literary theorist Roland Barthes for a “wordless dissertation”. For the first time, a body of creative work, in this case consisting of a photographic series called *Langage des Sables* (*Language of the Sands*), was recognised as a body of knowledge.

Barthes wrote:

Clergue changes the level of perception of beaches. With a mere nothing of sand he creates a giant relief, he abolishes the name-barrier: a blade of grass becomes

a tree, a trail of grains a whole chain of mountains. Thus he thwarts the perceptive and nominal prejudice, undoes and remakes identities, names, which is the very purpose of living knowledge. (Barthes, n.d.)

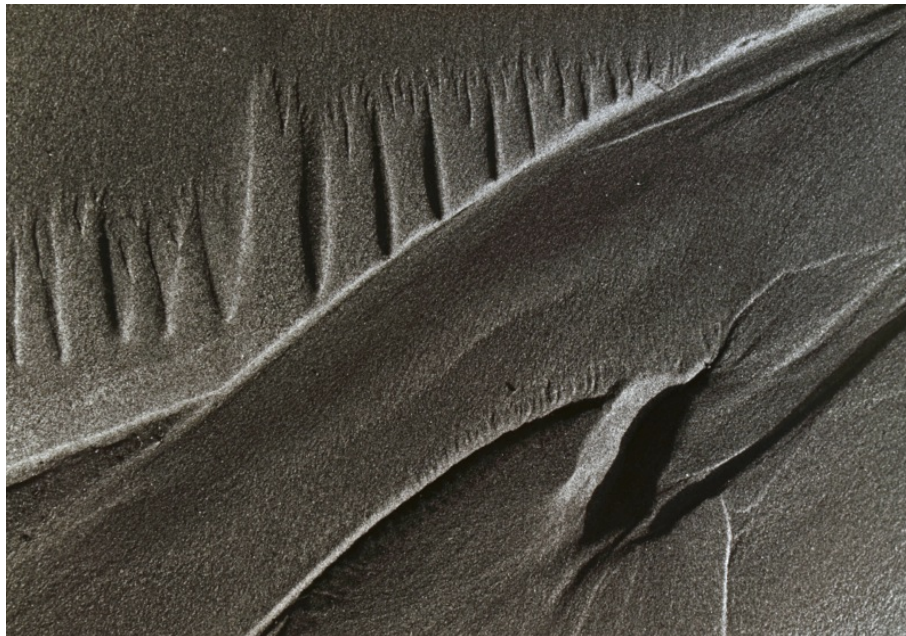


Figure 2 Lucien Clergue, from the series *Language of the Sands* (Clergue, n.d.)

While this wordless dissertation remains a unique occurrence, other artistic forms such as novels (fiction), have been accepted as PhD dissertations in disciplines such as Education and the Social Sciences. In 2005, Douglas Gosse wrote an award-winning dissertation⁸ called *Jackytar* as a fictional novel with extensive theoretical footnotes, or “hypertexts” as he called them (Jacobs, 2008). Today, a PhD earned through arts-based research typically includes both a written thesis and a body of artistic work (a model to which my doctoral research conforms).

Arts based research (ABR) is considered by many to be a qualitative research methodology (Boydell et al., 2016; Knowles & Cole, 2008; Sullivan, 2005; Walling, 2013) while some scholars argue that it is deserving of its own paradigm (Barone & Eisner, 2012; Chilton et al., 2015; McNiff, 1998; Rolling, 2013). These cross-disciplinary and arts-based research methodologies continue to gain acceptance internationally (Leavy, 2020). In the United States, associate Professor of contemporary art and theory Natalie Loveless has argued that artistic practice as research expresses qualities which are “porous and responsive”, contributing to a re-thinking about what knowledge production is considered to be (Loveless, 2012, p. 93).

In Canada, the term “research creation” refers to a type of arts-based research that the Social Sciences and Humanities Research Council (SSHRC) defines as follows:

An approach to research that combines creative and academic research practices and supports the development of knowledge and innovation through artistic expression, scholarly investigation, and experimentation. The creation process is situated within the research activity and produces critically informed work in a variety of media (art forms). Research-creation cannot be limited to the interpretation or analysis of a creator’s work, conventional works of technological development, or work that focuses on the creation of curricula. The research-

⁸ Awarded by the American Educational Research Association.

creation process and the resulting artistic work are judged according to SSHRC's established merit review criteria. (SSHRC, n.d.)

In a 2012 scoping review of 71 arts-based health research papers, Boydell et al. cited the many benefits of using (ABR) as a qualitative methodology within health contexts, arguing that ABR practitioners offer outcomes that differ from those offered by traditional research processes. This includes the potential for *embodied responses* not only from participants, but from the audience. They propose that ABR offers:

[E]nhanced engagement of participants and audiences alike, a way to enrich communication and make research accessible beyond academia and a method for generating data beyond the scope of most interview-based methods. (Boydell et al., 2012, p. 1)

However, most of the writing about ABR indicates that validation of arts-based practices is still in emergence, requiring its practitioners to continue to argue for parity within academia when measured against criteria such as perceptions of research impact, researchers' career advancement and the obtaining of research funding. Despite the advancement of these fields, this resistance is still experienced within some academic traditions.

In preparation for enrolment in my PhD, I undertook a unit of study called Advanced Qualitative Health Research at The University of Sydney. This was a coursework subject undertaken predominately by Medicine and Health students but was also available to members of the public as a professional development subject. Of the 150-200 enrolled in the subject, I seemed to be the only person who wasn't from a medical and healthcare background. In tutorials, I repeatedly witnessed students question the validity of the qualitative research papers that we discussed. "How can I trust a paper that talks about the researcher's opinion?" they would ask as they struggled to come to terms with what, as they expressed, went against everything they had learnt so far about what constitutes 'good' research. Therefore, this thesis makes claims not only about the validity of qualitative research but about the validation of open-ended artistic exploration as a legitimate and valuable form of research, acknowledging publications such as the *UNESCO Observatory Multi-Disciplinary Journal in the Arts*,⁹ which exists to nurture the maturity and acceptance of arts-based methodologies while claiming that the divides between scientific and arts-based research are no longer relevant. They proposed that one way to acknowledge the contribution of ABR, is through the adopting of a new "aesthetic intersubjective paradigm", which they suggest would allow for the multiplicity of human experiences to be explored in ways that might not be easily achieved by more traditional research approaches.

The aesthetic intersubjective paradigm refers to the intersubjective realities created and co-constructed through aesthetic – sensory and imaginal – knowledge, the investigation of which results in understanding multiple dimensions of human experience. (Chilton et al., 2015, p. 3)

While Chilton et al.'s research is informed by their backgrounds in arts-based research and art therapy, they state that their proposed *aesthetic intersubjective paradigm* isn't limited to any particular practice; instead, they propose a paradigm that allows for the diverse and *ever-expanding possibility* of what arts-based practice currently is – and could potentially become. This view is supported by scholars such as educator and author Shaun McNiff, who argues against qualitatively aligned ABR

⁹ This journal defines itself as "a clearing house of research which can be used to support advocacy processes; to improve practice; influence policy making and benefit the integration of the arts in formal and non-formal educational systems across communities, regions and countries". (Chilton et al., 2015, p. ii)

frameworks in favour of supporting the implicit qualities of artistic practice to generate different “shapes” of research (McNiff, 1998).

The innovative and critical potential of practice-based research lies in its capacity to generate personally situated knowledge and new ways of modelling and externalising such knowledge while at the same time, revealing philosophical, social and cultural contexts for the critical intervention and application of knowledge outcomes. (Barrett & Bolt, 2019, p.2)

Earlier, I shared my preference for the term socially engaged arts practice over the term arts and health. In doing so I wasn’t attempting to deny the term arts and health, instead I understand arts and health as one form that contributes to a rich network of socially engaged practices. While Lecturer in aesthetics and philosophy Vid Simoniti argues that for socially engaged art to be determined as ‘good’, it has to make a ‘real difference’ (Simoniti, 2018). It is argued one potential way that art might have real-world (and potentially measurable) impact, is through arts and health. Health researchers have actively shown that creative artistic practice has had positive impacts on patient and staff experiences in many areas, including mental health and wellbeing (Bone, Fancourt, Fluharty, et al., 2023; Bone, Fancourt, Sonke, et al., 2023), practitioner and staff morale (Staricoff & Arts Council England, 2004), clinical outcomes (Staricoff & Arts Council England, 2004), public health policy (Dow et al., 2023) and cortisol levels (Kaimal et al., 2016) to name but a few. They have also examined the benefits of arts and health in areas such as self-expression, improving carer–patient relationships, and providing insights into the patient experience. This means we have considerable evidence that confirms the multiple benefits that arise from creative arts activities in clinical care, including the capacity to provide integrated sensory, emotional, psychological, and social experiences.

Some theorists argue that one of the biggest hurdles to overcome in establishing arts and health as an accepted research field within clinical and community spaces, is the lack of unity suggested by its various titles which include “Arts and Health”, “Arts for Health”, “Arts-Health” and “Health and the Arts”, each denoting different considerations of process and power relationships. However, in this thesis I propose that the distinctive qualities of this integrated mode of engagement, and its benefits which are sometimes described as ‘transformational’ for both patients and healthcare professionals, are achieved through our ability to enable the term “arts and health” to remain flexible, while encompassing many different approaches for bringing creative practice together with health (Raw et al., 2012; White, 2009).

Australia adopted a national arts and health framework in 2014 and in 2016 NSW adopted the NSW Health and the Arts Framework. In preparation for the creation of the National Arts Health Framework, Dr Christine Putland, a consultant researcher specialising in arts, culture, public health, and wellbeing, created a background report which proposed that arts and health can be considered in terms of five different areas of practice:

- arts in healthcare design
- arts programmes (performance, exhibitions) in healthcare services
- art therapy (visual, dance, music, drama)
- arts and humanities in health professional education, and
- community-based (participatory) arts (Putland, 2012, p. 2).

Putland’s findings are supported by multiple other published models such as that proposed by Health research John Angus in the diagram below (Angus, 2002, p. 42).

Appendix 6 – Map of the art for health field

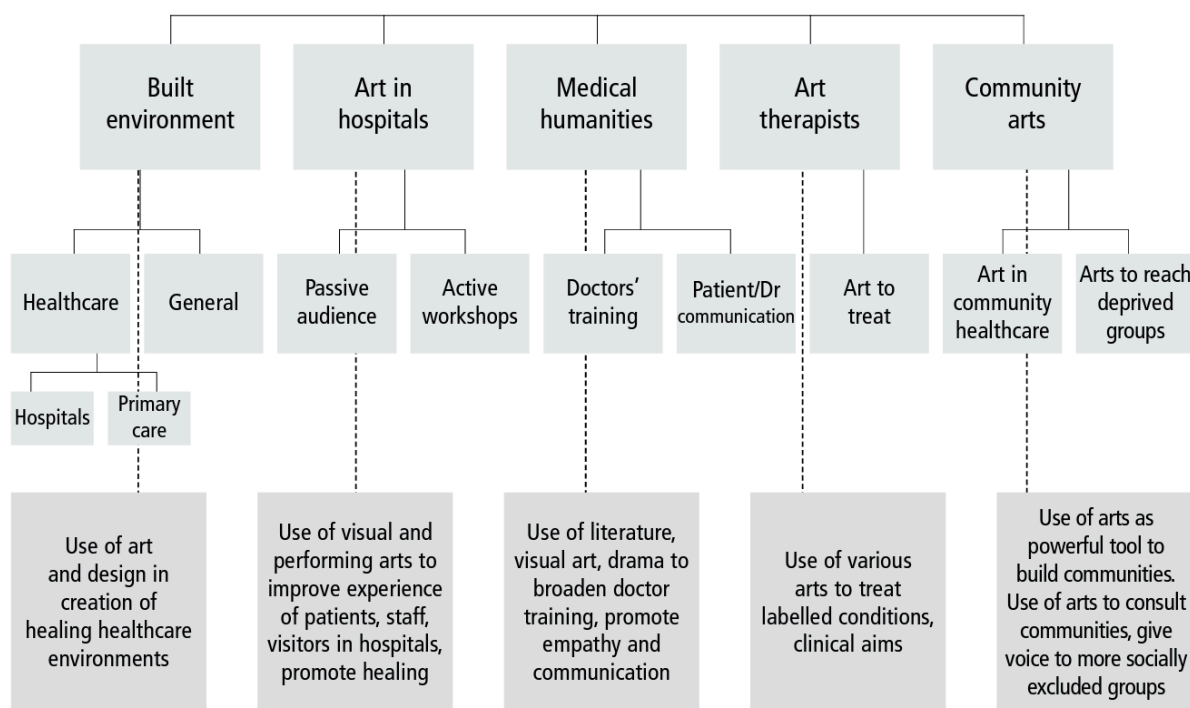


Figure 4: Map of the art for health field (Angus, 2002, p. 42)

Researchers such as Jill Sonke, Director of the Centre for the Arts in Medicine at the University of Florida, expanded on this to propose seven areas of arts and health practice:

- arts and aesthetics in the built environment
- bedside arts
- performing arts in healthcare
- caring for caregivers
- community arts for wellness
- arts therapies, and
- the arts and humanities in medical and other health provider education (Sonke et al., 2009, p. 112).

In these examples above, Putland, Merytick and Sonke all categorise Arts Therapy under the banner of Arts and Health. This is relevant to this thesis, as the question of the distinction between me as a contemporary artist and the role of an arts therapist, is one that arises from time to time. As stated earlier, one of the careful considerations that I must engage with is not to be seen as a therapist.

While the distinction between arts and health and art therapy might be negligible for some, there are many differences between the two. The term “Arts Therapy” is credited to Adrian Hill, who explored the healing property of art in his publication *Arts versus Illness* (Hill, 1945). Arts Therapy is now an established and accepted therapeutic field with its own peak bodies. The Australian, New Zealand, and Asian Creative Arts Therapy Association (ANZACATA), the peak professional association for creative arts therapies in Australia and New Zealand, defines art therapy as “an experiential psychotherapeutic approach utilising many creative modalities within a therapeutic relationship with a trained therapist” (About ANZACATA, n.d.).

Arts therapy sees patients being involved in an art-making process guided by a trained therapist to achieve specified therapeutic goals with outcomes measured via clinical evaluation (Broderick, 2011; Dileo & Bradt, 2009). The aims of an arts therapist are thus focused primarily on outcomes of therapy, rather than aesthetics. Chilton proposes that Art therapists use art-making practices as a method of self-discovery, just as arts-based researchers use art making as a method of inquiry (Chilton et al., 2015).

Whilst Arts and Health programs don't necessarily propose to create the therapeutic benefits of arts therapy, therapeutic outcomes can also be inherent in many arts and health processes, even when not defined as a part of the research design. Despite there being a substantial body of research outputs and theory development in the area of arts and health, the lack of awareness of this research base, and of art and health practices, is considered to be a major barrier in developing deeper acceptance of this field (Davies et al., 2016), while the need to develop a stronger evidence base is seen by some to be crucial (Raw et al., 2012). To this end, there have been several recent reviews that explore the existing arts and health research; this includes the outputs that I mentioned earlier, authored by the World Health Organisation (2019) and Vic Health (2020) as well as a new summary report "The Impact of Arts and Cultural Engagement on Population Health Art" published by the *Social Behavioural Research Group* (Fancourt et al., 2023)

The WHO review examined a broad range of study types that included "uncontrolled pilot studies, case studies, small-scale cross-sectional surveys, nationally representative longitudinal cohort studies, community-wide ethnographies and randomized controlled trials from diverse disciplines" as well as "psychological scales, biological markers, neuroimaging, behavioural observations, interviews and examinations of clinical records" (Fancourt & Finn, 2019, p.52). I mention this to highlight the diverse methods used in the field of arts and health whilst also acknowledging the WHO reviews analysis that arts and health research methodologies are able to draw from multiple disciplines such as:

psychology, psychiatry, epidemiology, philosophy, ecology, history, health economics, neuroscience, medicine, health, geography, public health, anthropology, and sociology, among others. (Fancourt & Finn, 2019, p.52)

The WHO identified two overall thematic areas in the arts health literature, outlined in the following diagram:

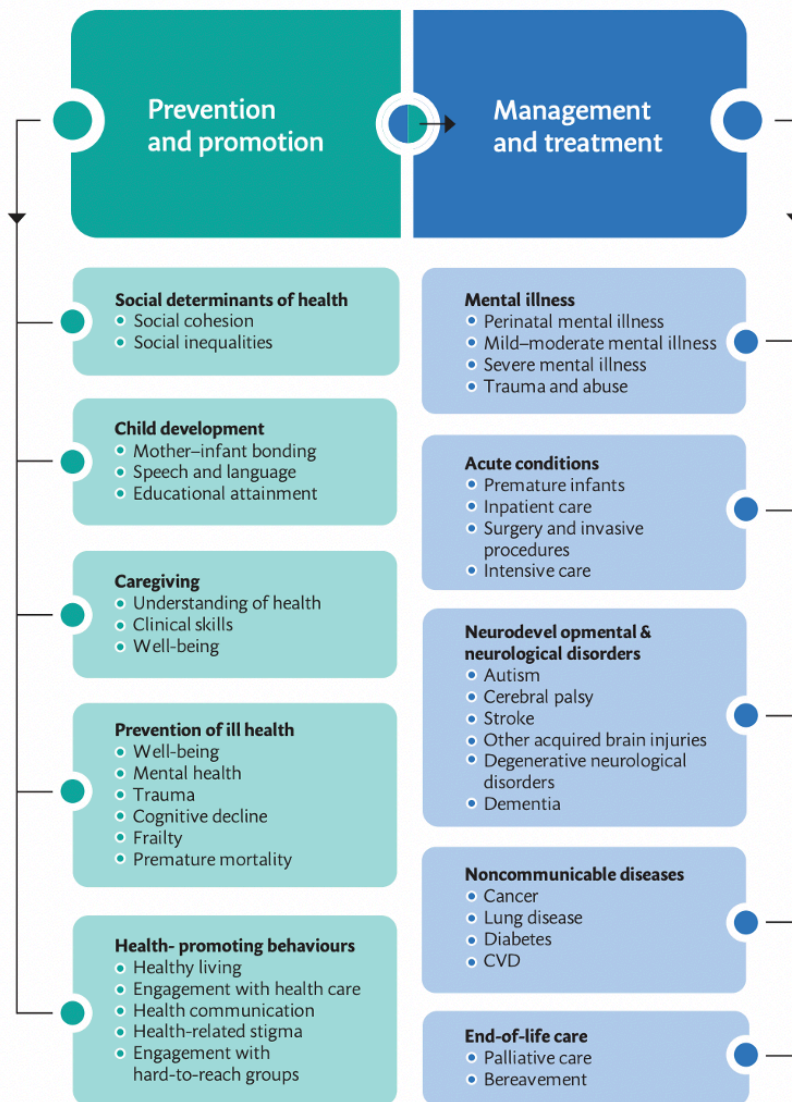


Figure 5 Thematic content for prevention and promotion and management and treatment

Source: World Health Organization, (Fancourt & Finn, 2019)

The review also identified an imbalance in art forms represented in the research, highlighting that the research is heavy with projects that involved music, dance, and visual arts, while many types of art forms, such as *engagement with digital arts, and online arts*, were under-represented in the literature. The research undertaken in this thesis addresses this by firstly not defining any particular artform in the initial research design, to ‘provoke’ the potential for allowing new, nuanced approaches to occur. This has resulted in many under-represented forms being explored in this thesis, e.g., digital arts, interactive arts and artforms involving new technologies such as electronics and 3d scanning and printing (Chapter Four).

The WHO review also detected an inherent publication bias in the literature towards positive findings and argued that “future research studies should include null findings to allow a balanced appraisal of where the arts can and where they cannot provide support to health” (Fancourt & Finn, 2019, p. 54).

It is important to note that the WHO review has also been met with some rigorous critique. Health researcher Stephen Clift and associates have examined a number of arts health reviews to challenge some of their assumptions and methods (Clift et al., 2021). Clift’s research takes issue with the WHO

review's claim that the arts are "crucial to reducing poor health and inequality", particularly around the use of the word 'crucial'. They also critique the effectiveness of the review as a tool to direct policy in the U.K as well as various criticisms of the review methods and types of evidence reviewed. Their critiques build upon the earlier critiques by researchers such as communications and media scholar Eleonora Belfiore in (Mirza, 2007). The issues that arise from these critiques that I feel are relevant to this research are included below in a table which lists their issue and my consideration of it.

Issue	Consideration
Any form of participatory activity could have an empowering effect, whether arts-based or not.	This has been a long-term consideration within my career as a socially engaged artist. In Chapter Three and 4 I present two results chapters. The first is a qualitative analysis that explores the expectations and experiences of care for patients at the facial nerve clinic. This then feeds into the second results chapter that explores artistic methods and outcomes and their impact on patients, clinical experience, and the general public. By creating this approach, I am hoping to generate a more complex analysis of the role of the artist in the health setting, beyond just a response to an enjoyable activity.
Little attention to longer-term outcomes as opposed to short-term effects.	My research is focused on working with patients during their time of medical engagement with the medical system. My outcomes are relevant to the experience of this time and aren't claiming long term impacts. I do however argue the potential for long term impacts if the right commitments to this type of artist practice as research are made. I am also aiming to make long term contributions to the development of socially engaged arts practice.
There is little attention to the artistic or aesthetic quality of cultural and arts engagements in assessing outcomes.	This has already been a repeated topic within this introductory chapter. One of the central aims within this research is to align with this critique and to offer case study, evaluation, and contribution to the development of methods that assist us to consider supporting and evaluating aesthetic and artistic practice.
A focus on the role of the arts and culture my serve as a convenient means to divert attention from the real causes of today's social problems and the tough solutions that might be needed to solve them".	Inherent in the discussion throughout this research is the impacts of social exclusion and discrimination that come with facial disfigurements as well as considerations of power and hierarchy through the considerations of barriers to care within the clinical space.

In 2020 The Victorian Health Foundation Rapid Review examined 10 systematic reviews, 4 scoping reviews, one rapid review and 41 studies.

The purpose of the review was to inform future strategic planning and investment for VicHealth's Arts Strategy (2019–2023). VicHealth's Arts Strategy has a four-year goal to promote the health and wellbeing benefits of the arts to all Victorians. (Davies & Pescud, 2020, p. 10)

The review defines Arts and Health outcomes as falling into 6 categories.

- **Mental health outcomes** e.g., increased happiness, confidence, self-esteem, resilience, relaxation, self-expression, self-reflection, and reduced stress.

- **Social health outcomes** e.g., increased social capital, networks, social connection, social cohesion, inclusion, and reduced loneliness.
- **Physical health outcomes** e.g., increased physical activity (dancing, walking, standing, performance-based movement), improved balance, blood pressure, co-ordination, flexibility, grip, heart rate, immune function, longevity, sleep, and reduced pain.
- **Economic outcomes** e.g., income, career opportunities.
- **Knowledge outcomes** e.g., increased general knowledge, business skills, communication skills, problem-solving skills, social skills, enhanced teamwork.
- **Identity outcomes** e.g., enhanced connection to self (i.e., beliefs, self-perceptions), gives life more meaning.
- **Art specific outcomes** e.g., creativity, expression, and appreciation of the aesthetic through the process of making and/or experiencing art; increased art skills, interaction with artists, creation of artworks.

The review examines biopsychosocial models of health care as an alternative to biomedical models by taking into account multiple determinants of health, highlighting biopsychosocial factors (e.g., genetics, physical health, disability), psychological factors (e.g., self-esteem, mood, attitudes), and social factors (e.g., income, education, support) influence health outcomes. The VicHealth review concludes by reflecting on the need for a ‘systems thinking approach’, stating:

A systems thinking approach calls for interventions that are multifaceted and enter the system at several levels; are focused on learning, iteration, time, and recognise the non-linearity of interactions and interconnections within a system. Future work in the area of arts-health has the potential to be enhanced with the use of systems thinking, especially where the goal is to address chronic disease prevention via healthy eating, physical activity, preventing tobacco use, preventing harm from alcohol, gender equality, social health and promoting mental wellbeing. (Davies & Pescud, 2020, p. 57)

This wealth of literature provides background context for the practice of arts and health in which I propose my contribution is as an *artist researcher*, rather than as a qualitative researcher who is using art as a method of data collection and translation. This distinction supports my earlier claim of the need to focus on artform development alongside health/social outcomes. To honour this complexity, I will henceforth use the term “artistic practice as research” or “practice-based research” rather than “arts-based research” to position myself more accurately as a *practice-ing* artist who is engaging in research scholarship in health *and* within contemporary art, rather than a qualitative researcher using methods of artistic activity within my research design.

The beneficial impact of the arts could be furthered through acknowledging and acting on the growing evidence base; promoting arts engagement at the individual, local and national levels; and supporting cross-sectoral collaboration. (Fancourt & Finn, 2019, p.ii)

I have earlier proposed that this field of arts and health sits under the banner of socially engaged arts practice and that one of the aims of this thesis is to provide contribution to the emerging theory base of socially engaged practices. To continue this process, I will now ground the reader in the relevant literature within socially engaged arts practices, to give some background to how it came to be that an artist might find themselves as part of a care team within a facial nerve clinic. I will explore the lineage of, and the major theories and arguments that underpin, the knowledge base of socially engaged arts practice generally. I will then position this within the lineage of my own arts practice.

I begin by proposing that the meaning of the term “socially engaged arts practice” is open to debate, because it is not fixed and is dependent on the context, just like life itself. Therefore, the aim of this section isn’t to define socially engaged art as such; rather, it is to identify some of its main attributes and questions, while arguing for its validity as a relevant and impactful form of artmaking and research within a Faculty of Medicine and Health. While traditionally we identify art movements in terms of art forms (e.g. painting, music, performance) or aesthetic schools (e.g. surrealism, impressionism, classical, pop), socially engaged arts practice isn’t so readily defined in this way. Instead, it is a type of practice that often moves beyond disciplinary boundaries to engage multiple art forms (Badham, 2010; Kwon, 2004; Volckmann, 2007). French curator and theorist Nicolas Bourriaud identifies that artists working in a relational/social way “are not connected together by any style, theme or iconography” (Bourriaud, 2009, p. 43). This is also highlighted within arts and health research such as the 2019 WHO review and has been identified by scholars such as Korean curator and art historian Miwon Kwon who proposes¹⁰ that this type of practice is often:

... informed by a broader range of disciplines (anthropology, sociology, literary criticism, psychology, natural and cultural histories, architecture and urbanism, computer science, political theory, philosophy). (Kwon, 2004, p. 26)

Socially engaged art practice, which is in many ways removed from the art academy’s traditional focus on form, composition, colour and so on, has the potential to generate work that is made in relationship *with* something, rather than by imposing the artist’s will *on* something. Symbolically and practically, descriptors such as “works *on* paper” or “works *on* canvas” are replaced with others that acknowledge the essential co-constituting nature of socially engaged practice, such as ‘arts *and* health’, ‘works *with* community’ and ‘works *with* the non-human’. In this way, art making isn’t merely engaging hermetically in its own lineage of art-form concerns of practice but is also engaging with a multi-layered set of ‘external’ contexts that help to define it.

Socially engaged arts practice places the artist in and of the world; it is a type of practice that has the potential to question the historic value of the art object alongside its process-driven relational value. *Who is art making for?* and *how do we acknowledge authorship?* are just some of the relevant questions within socially engaged arts practice. I expand on this by proposing that it is a type of practice that, regardless of artistic medium, is inherently or unavoidably a matter of ethics. This defining inclusion of ethics denies the seeking of a universalism in terms of artistic genre, and instead proposes that broad and diverse artistic processes might align under its banner, all within a constituency of care.

There have been many relevant discussions within art history that have helped to develop socially engaged arts practice, whether attempting to move towards an integration of art and life or moving away from it. The Romantic movement in literature, philosophy and art was one such ‘moving away’ which rejected *reason* and *logic* and instead placed value on the *emotional* and the *individual*. It made claims such as “*art for art’s sake*”, which proposed a separation of art from the concerns of the world, instead focusing on humans’ connection to nature and beauty:

Only those things that are altogether useless can be truly beautiful; anything that is useful is ugly, for it is the expression of some need, and the needs of man are base and disgusting, as his nature is weak and poor. (Gautier, 1834, p. 22)

The Professor of Philosophy Irving Singer noted that this “devotion to beauty required the subordination of any concern for the truth” (Singer, 1954, p. 347) and that the term ‘art for art’s sake’ had an agenda against didacticism”. In 1939 critic Clement Greenberg proposed that, once art for art’s

¹⁰ Kwon examination of “site based” and “socially engaged” practices are aligned.

sake gained favour, “subject matter or content becomes something to be avoided like the plague” (Greenberg, 1939, p. 5) The movement symbolised a reaction against both the aesthetic formalism of the art academy, and the servitude of art to God, to the state (or even to the revolution).

Singer writes:

Because [they] could no longer rely on the aristocracy for patronage, the artist had to turn to popular and governmental support more than ever before. This meant that he had to become either a businessman dealing with publishers or a politician dealing with bureaucrats, that he had to cater to indiscriminating tastes or hire himself out to political parties and social movements that would use him as a mere hack and polemicist. It was in protest against such employment of their talents that artists supported the banner of Art for Art's Sake. (Singer, 1954, pp. 349–350)

Many artistic movements through time have attempted to question the devotion to the concept of *art for art's sake*, even while sharing many of its characteristics. Scholars of socially engaged practice have examined the complex trajectories in art history through art movements such as the Dada, Surrealist, Fluxus, Situationist and Feminist movements, as well as how contributions made through minimalism, conceptual art and land art have all contributed to this lineage (C. Bishop, 2012). Olinde Rodrigues, who is credited with one of the first uses of the term “avant-garde” in the context of art in his 1825 essay “L'artiste, le savant et l'industriel” (The Artist, the Scientist and the Industrialist), claims that:

... the power of the arts is indeed the most immediate and fastest way to social, political and economic reform [proposing that the artist should] serve as [the people's] avant-garde. (Calinescu, 1987, p. 103)

By contrast, Professor of art history and art criticism Suzi Gablik argues:

In Western Cultures, artists aren't encouraged to be integral to the social, environmental, or spiritual life of the community. They do not train to engage in real life problems. Instead they learn to be competitive in the marketplace with their products. (Gablik, 2004, p. 12)

A rich analysis, therefore, might also consider contributions from outside the narrow view of the Western artistic canon. While the Situationists were calling for an integration of art and life in the 1950s and 1960s, indigenous cultures, for example, had long been making art that is embedded and inherent in, not autonomous from, people and place. As Indigenous curator, artist and researcher Genevieve Grieves writes:

“Art has always connected us to the Ancestral world and shared our stories and culture. In more recent times, it has recorded and shared our experiences of colonisation and been used as a political tool to demand justice and change” (Lillie et al., 2020, p. 18)

I therefore propose that the Western art canon's attempts to integrate concepts of art and life might be aided by looking outside of the art sector all together in order to define new types of collaborative potentials.

Contributions towards definitions of socially engaged arts practice include proposals that, for example “the social interaction is at some level the art” (Tate, n.d.), while others argue that art criticism must also examine “the working process, the ethical stance, conceptual basis, its process over artistic

object” (García Canclini & Frye, 2014, p. xii). Other theorists have developed these ideas to propose various concepts including *relational aesthetics* (Bourriaud, 2009), *the social turn* (C. Bishop, 2012) and *dialogical aesthetics* (Kester, 2011), which, despite disagreements among them, all speak to forms of art making that involve relationships with people and place.

In the 1990s, Bourriaud coined the term “relational aesthetics”,¹¹ which he defined as:

... an art taking as its theoretical horizon the realm of human interactions and its social context, rather than the assertion of an independent and private symbolic space. (Bourriaud, 2009, p. 14)

This concept, although situated by Bourriaud in the context of critiquing the institutional frameworks of the gallery space and the mechanisms of the art world (C. Bishop, 2012; Bourriaud, 2009), articulates arts practice as a fertile ground for conducting “social experiments” (Bourriaud, 2009, p. 9) through which inter-subjectivity becomes the central concern of artistic practice. Bourriaud believes that this practice of art making as a state of encounter establishes *micro-communities* that are collectively able to undertake artistic processes aimed at exploring *situations*. This exploration of context and place establishes a type of art making that is to be “lived through”, rather than a space to be “walked through” (Bourriaud, 2009, p. 15), creating artwork that is an outcome of time rather than of space or object. Bourriaud draws on the term ‘interstice’ from Karl Marx, to propose the term “social interstice” to suggest relational art making as something that sits outside the capitalist framework, finding its value in social relations. Like many theorists who have explored art making in the social realm, Bourriaud emphasised the expanded idea that rejects seeing the art object as a commodity in a market-orientated, overly commercialised art world; instead, he believes that “[e]ach particular artwork is a proposal to live in a shared world” (Bourriaud, 2009, p. 22).

In 2006, Professor of art history Claire Bishop added to this emerging theory base by coining the phrase “the social turn” to explore “the recent surge in artistic interest in collectivity, collaboration and direct engagement with specific social constituencies” (C. Bishop, 2005, p.178). The complex genealogy of practices that exist under the broad banner of “social art” has given rise to a range of interrelated practices, as Bishop identifies:

... this expanded field of post-studio practices currently goes under a variety of names: socially engaged art, community-based art, experimental communities, dialogic art, littoral art, interventionist art, participatory art, collaborative art, contextual art and (most recently) social practice. (Bishop, 2012, p. 1)

While Bishop supports the social agenda of these practices, she emphasises the importance of critiquing this type of work as *art*, rather than just valuing the social outcome, arguing that:

[G]ood intentions shouldn't render [relational] art immune to critical analysis. (C. Bishop, 2005, p.183)

This view is challenged by the work of Art historian Grant Kester who examines what he describes as a “remarkable profusion of contemporary art practices concerned with collective action and civic engagement” (Kester, 2011, pp. 6–7). Kester critiques these types of works under the guise of *dialogical aesthetics*, a term which emphasises the relational exchange that takes place via discourse during projects, understanding them as an:

... emergence of a body of Contemporary Art practice concerned with collaborative, and potentially emancipatory forms of dialogue and conversation. While it is

¹¹ Also see Bourriaud’s concept of altermodernism, contemporary art’s relationship to social conditions.

common for a work of art to provoke dialogue among viewers this typically occurs in response to a finished object. In these projects, conversation becomes an integral part of the work itself. It is re-framed as an active, generative process that can help us speak and imagine beyond the limits of fixed identities and official discourse. (Kester, 2011, p. 78)

One of the tensions identified by Bourriaud, Bishop and Kester is how we value, understand and critique the process and outcomes of socially engaged art practice. Do we value these works in relationship to their anchoring in an “art” context, or do we value them for their social outputs? This *relational antagonism*, as Bishop terms it, provokes practitioners, critics and theorists to focus on the “tensions between quality and equality, singular and collective authorship, and the ongoing struggle to find artistic equivalents for political positions” (C. Bishop, 2012, p. 3). Grant Kester, in his theory of dialogical aesthetics, argues that these new modes of socially engaged art making need to look to the social sciences to adapt new methods for evaluating art in the social realm (Kester, 2011, pp. 10–11). Bishop, however, argues that we need to “[d]iscuss, analyse and compare this work critically *as art*, since this is the institutional field in which it is endorsed and disseminated” (C. Bishop, 2012, pp. 12–13). Furthermore, the shift in focus from the *art object* to the *process* has provoked what Bishop calls an “ethical turn” in art criticism.

For these and other supporters of socially engaged art, the creative energy of participatory practices rehumanizes – or at least de-alienates – a society rendered numb and fragmented by the repressive instrumentality of capitalism. But the urgency of this political task has led to a situation in which such collaborative practices are automatically perceived to be equally important artistic gestures of resistance: There can be no failed, unsuccessful, unresolved, or boring works of collaborative art because all are equally essential to the task of strengthening the social bond. While I am broadly sympathetic to that ambition, I would argue that it is also crucial to discuss, analyze, and compare such work critically as art. (C. Bishop, 2006, pp. 179–180)

Bishop continues by accusing theorists such as Bourriaud of wanting to “equate aesthetic judgment with an ethico-political judgment of the relationships produced by a work of art” (Bishop, 2012, p. 3). Kester’s research, which explores the cooperative mode of civic engagement through the arts, argues that we need to examine and critique the cooperative, horizontal decision-making processes, rather than Bishop and Bourriaud’s proposal, which he accuses of highlighting the historical connection to the avant-garde and therefore privileging artistic practice over what he claims to be a new type of art movement that needs new modes of criticism. Bishop responds:

... this may explain, to some degree, why socially engaged art has been largely exempt from art criticism. Emphasis is shifted away from the disruptive specificity of a given work and onto a generalized set of moral precepts. (C. Bishop, 2005, p. 181)

What these disagreements highlight is confirmation of my assertion in the introduction to this chapter that “socially engaged arts practice” is a term whose definition (like life) is never fixed, is open for debate and is context dependent. The broad scope of projects that come under the banner of socially engaged practice range from cooperatively initiated and delivered projects of civic engagement, to projects that are a meeting between someone in a defined role as an artist and a broader community who have come together with a desire to explore an aspect of their lived experience. My intention in working in a clinical space to create both an art exhibition and a written thesis is to render myself open to critique by both medicine/health and by the arts so that we can evaluate impacts from the perspectives of all of the parties involved (Cohen-Cruz, 2016). I identify this as one of the defining

features of my artistic practice to date and a key feature of “successful” socially engaged arts practice: the ability to simultaneously speak to, and address the concerns of, different audiences, partners, and participants.

Despite many differences of opinion, the three theorists I have referred to – Bourriaud, Bishop and Kester – do agree on many aspects of socially engaged arts practice. They each speak of the turn to the *social* as being a response to several things, including modernism, the cult of the individual and neo-liberal/economic agendas. They also argue that, just as modernism was a fight against market forces, only to become one itself, so too is socially engaged arts practice prone to the danger of being taken over by the very market forces and agendas that it is reacting against.

Through the discourse of creativity, the elitist activity of art is democratised, although today this leads to business rather than to Beuys. The dehierarchising rhetoric of artists whose projects seek to facilitate creativity ends up sounding identical to government cultural policy geared towards the twin mantras of social inclusion and creative cities. Yet artistic practice has an element of critical negation and an ability to sustain contradiction that cannot be reconciled with the quantifiable imperatives of positivist economics. Artists and works of art can operate in a space of antagonism or negation vis-à-vis society, a tension that the ideological discourse of creativity reduces to a unified context and instrumentalises for more efficacious profiteering. (C. Bishop, 2012, p. 16)

Bishop speaks against the experience in the UK, arguing that New Labour’s *rhetoric* is “[r]educing art to statistical information about target audiences and performance indicators” (C. Bishop, 2005, p. 180), where the government prioritises social effect over considerations of artistic quality. These critiques of socially engaged practice, bare similarities to the critique of the WHO review of arts and health offered by Clift earlier in this chapter.

This work seeks to define socially engaged art practice as a responsive, co-constituted type of practice that is able to embrace Bourriaud’s concept of artworks to can be ‘lived’ through” (Bourriaud, 2009). Kester’s understandings of the discoveries that are possible by enacting a new type of open-ended social exchange that can create new forms of communication or identity (Kester, 2011), and Bishop’s commitment to the art not getting lost within the social/ethical (C. Bishop, 2005). By making these assertions, I begin to develop a method by which to create sensitive, respectful, and ethical engagement with the site of the SFNC.

One important consideration within socially engaged practices is this consideration of ‘site’, which I will introduce through the work of Daniel Buren. In 1973, Buren created an artwork called *Within and Beyond the Frame* which consisted of a series of banners hung in a New York gallery. The work then continued outside the gallery window, suspended across the busy street outside. The intention of the artist was to examine how the artwork changed depending on its context. The still, static, stationary viewing of the work inside the gallery contrasts with the outside portion which is animated by a different type of space. The inside component is viewed by gallery visitors with the intention of having an art experience, while the external component is engaged with the outside urban environment which has been built for the very act of living – commuters, cars, industry, pedestrians, all going about the business of their lives when they unexpectedly encounter the artwork. These different framings potentially offer different meanings, yet the artwork(s) are one and the same.





Figure 6 (a,b,c): Daniel Buren, *Within and Beyond the Frame* (1973), John Weber Gallery, New York. Photographer unknown (University of Oregon, 2015)

Even though I don't classify this work as socially engaged art, it does represent the idea of an artist making work that crawls out of the gallery space, ready to engage with the world around it, breaking free of the confines of the institution to engage with the "sites" of life.

As an initial *site* for this thesis, the Sydney Facial Nerve Clinic is a location that enabled me to observe and participate in the clinical process to consider the experiences and expectations of care in the clinical exchange. I worked with those who are engaged in this *site*, becoming part of the *site* myself, while exploring the human experience of illness alongside the educational, institutional, financial, and hierarchical barriers to care.

The *site* of my work might be the physical place of the Sydney Facial Nerve Clinic, or the healthcare system; however, I propose that it also extends to include the emotional, practical, felt, the spoken and the unspoken affective elements of the human experiences contained within. This concept can be explained further by sharing a collaborative project I undertook in 2016 with the artist Mayu Kanamori as she underwent treatment for breast cancer. This process, which created artwork during her treatment and recovery process, was documented on the blog [I Just Can't Say That Word](#). My blog entry of 16 June 2016 reads:

This is a site-specific artwork.

The site of this collaboration isn't necessarily Mayu's body.

The site of this collaboration isn't necessarily the illness itself.

The site of this collaboration isn't necessarily the hospital or medical clinics.

The site of this collaboration is in the tenuous link between present and future.

The site of this collaboration is in the complex emotional networks we build around us throughout our life.

The site of the collaboration is the struggle between power and no power, control and no control.
The site of the collaboration is in the constant negotiation that is present in daily life.
The site is both hidden and on show.

No matter how much we reveal, we are never emptied of all that we suppress (McEwan, 2016).

Theorist Miwon Kwon explores these expanded understandings by proposing that the idea of “site” is multilayered. Kwon proposes that these layers include three different perspectives - institutional, phenomenological, and discursive. Firstly, she proposes that sites have *institutional* considerations that explore the site through “social, economic and political systems” (Kwon, 2004, p. 3); secondly a site consists of *phenomenological* or experiential considerations that acknowledged the affective, emotional and memory aspects. (Kwon, 2004, p. 3); and, finally, what she calls the *discursive*¹² understanding of site, that explores the “field of knowledge, intellectual exchange or cultural debate” that belongs to a site (Kwon, 2004, p. 26). Disciplines such as Affective Geography (Pile, 2010) and Affect Theory (Massumi, 2015) all provide further investigation of these inherent qualities of place, which are all present within the complexities of the SFNC.

In addition to the concept of a ‘site’, another important consideration within socially engaged practices is one of authorship. This might include looking beyond single authorship towards distributed authorship (Rennie, 2020) or to dispensing with authorship altogether (Helguera, 2011). Curator Dominic Willsdon proposed, in relation to the work of artist Suzanne Lacy (a noted practitioner of socially engaged and participatory arts practices - which she calls “new genre public art”) that “Lacy is the author of the aesthetic, but it admits the lives of others” (Willsdon, 2017). The importance of considering and critiquing authorship is due to the potential for ill-considered practices to ‘erase’ those people who have the story to tell. Stepping into a community, or a situation, to work as an artist/researcher, involves stepping into the life of another person. Whilst some practitioners have fixed ideas about approaches to authorship, I consider it to be a fluid, context dependent conversation that relies on the co-devising of authorship agreements with participants. In my 16 years of experience working on many socially engaged projects, the desires and needs of community can vary greatly from one project to the next (or even within the same project). I can best illustrate this through the following two examples of works I have previously delivered.

Yenda Rain (2013): This project was initiated by an invitation from the residents of a town called Yenda, in regional New South Wales. Yenda was in recovery following major devastating loss through unexpected floods. During the initial stages of the project, multiple community consultations repeatedly revealed that the community of participants were excited to participate in an art led recovery process but didn’t want to be in the position of ‘the artist’. Their hope was that participation might, in some way, aide their recovery and be a chance to walk together through their story. Therefore, at their request, the agreement was that I would take the role of “the artist” who authored the works, and therefore also take on the responsibility to bring the final presentation together, in ethical engagement with them.

The Continuum (2014): This project was undertaken at Shepherd’s Park Youth Detention Facility (a youth goal in Wagga Wagga, NSW). In the initial discussion about aims, objectives and processes, there

¹² The discursive proposition is unlike the phenomenological and institutional understanding of site. In the discursive understanding, the site is not defined as a precondition. Rather, it is generated by the work. It is “discursively determined” (Kwon, 2004, p.26).

was a clear desire by the participants to collaborate and be credited as artists.¹³ In this case, we agreed that the attribution should go to the participants whom I helped facilitate to create the artwork.

At the beginning of this research project, I was frequently asked if my intention was to work with people to co-create artworks, or whether it was to make artworks ‘about’ or ‘in response to’ people in the clinic. While each of these methods can potentially be valid within a socially engaged framework, my research methodology dictated that my creative research methods would be emergent, led by the process and by my interactions with patients, including the potential that it could be different for each participant.

This topic can be a major concern when considering the presentation of artistic outcomes created through socially engaged art methods. In 2019, internationally recognised textiles artist Alice Kettle presented an exhibition titled *Thread Bearing Witness* at the Whitworth Gallery in Manchester, UK. The exhibition was the product of working with women in a refugee camp. The collaborative nature of the artistic process meant that Alice started to form the opinion that the exhibition shouldn’t appear only under her name. Instead, she felt that a new name should be created that referenced the artist and the collaborators as a group. Kettle’s concerns weren’t accepted by the gallery, however, which expressly wanted to be marketing a show by Alice Kettle, not one authored by an unknown collective.

Alice shared these concerns with me when she gave me a personal tour of the exhibition in February 2019, and later in a formal, ethically approved interview:

I wanted the show to have my name omitted but the gallery said they had never done this, and I accepted in the end that the project would have more profile if my name was attached to it. As the project was about consciousness raising, then this was important, but I still feel uncomfortable. I rationalise this as my being the representative. The gallery did a big shift through the project and accepted that the original source drawings were critical to include, and the names credited on the gallery wall. We also had dedicated events that were tailored to the groups, making sure they could come, since the gallery as a place they were welcome was another obstacle. We had to make considerable arrangements for this to take place. I also funded an artist in residence to do outreach work with communities, so the exhibition was also a way of inviting more inclusion and activities.

Kettle’s experience, while contributing to complex discussions about authorship, also speaks to the tensions that might arise when bringing socially engaged arts practices into a gallery context (Willson, 2017), where the artistic canon isn’t necessarily experienced in, or concerned with, the intricacies of the ethics of cooperative authorship. The inclusion of socially engaged practices in galleries is frequently led by public programs and the education departments of institutions, rather than by curatorial departments (C. Bishop, 2012). In view of this lack of curatorial experience with socially engaged arts practices, I suggest that a more collaborative approach between the experience base (the artist, the community and the public programs/education staff) and the curatorial staff is needed, so that curatorial practices concerned with social engagement are able to develop in alignment with complex negotiations around ideas such as ethics, and authorship, also acknowledging that the origin of the word “curator” is embedded in the concept of *care* (Art Gallery of South Australia, n.d.). In the example of *Thread Bearing Witness*, it was the artists responsiveness that enabled a way forward to address the ethics of authorship via inclusion.

¹³ This was a complex task, given that, by law, we were not permitted to use the actual names of the young people.

The socially engaged artist spends a good portion of their professional life stepping into complex, new environments. Alice Kettle, for example, stepped into the traumatic life experiences of recent refugees. These are challenging places that require the artist to repeatedly adapt to the context of others. Therefore, this research process requires time to assimilate, settle in and understand the context of the Sydney Facial Nerve Clinic and the lives contained within it, while also creating ways to enact self-care during this process.

Field note (2019):

Today was my second visit to the facial nerve clinic. When I was walking down the hallway to leave for the day, a healthcare professional, who was in a room with a patient, called me in and introduced me and my role. She then said to the patient: "Can you tell Vic what you just told me?"

The patient looked at me and said: "I want to have both of my eyes removed."

The patients and healthcare professional then looked at me, waiting for my reply, which was along the lines of: "That is a very big decision."

The patient then explained that their pathology had negative impacts on one of their eyes, which caused problems with depth perception, meaning they bump into things and have trouble navigating around spaces. Also, the "feeling" of their eyes is a constant irritation, so to counteract this, she was considering having her eyes voluntarily removed. Experiences such as these are complex things to encounter, especially for someone who is a 'foreign entity' in a space such as a medical clinic and particularly at the beginning of a project where, as a socially engaged artist, you are still understanding the complexities of the site, still potentially feeling undefined, still working out how to progress in a way that is co-constituted, still potentially seeking validation as a presence in the non-arts space, and still observing and learning the complex networks of protocols, and the pragmatic and tender processes that are enacted there.

Given that socially engaged artists have usually developed their practice on their own, without specific 'socially engaged training' and have therefore mostly generated unique approaches and practices, the lineage of my own practice as a socially engaged artist-researcher is important to acknowledge as it has an impact on this research design, delivery, analysis and output.

The artist Judy Watson has said of her work:

Art as a vehicle for invention and social change can be many things[:] it can be soft, hard, in-your-face confrontational, or subtle and discreet. I try and choose the latter approach for much of my work, a seductive beautiful exterior with a strong message like a deadly poison dart that insinuates itself into the consciousness of the viewer without them being aware of the package until it implodes and leaks its contents. (Watson & Martin-Chew, 2009)

My practice proposes a type of art making that, in the words of anthropologist Anna Tsing, encourages us to "look around rather than ahead" (Tsing, 2015, p. 22). The applied outcome of this proposed 'looking around' means that I don't enter the process with a predefined idea of what my artistic outcome will be, let alone what medium I will use. While my practice typically uses mediums such as performance, sculpture, installation, photography, video or sound, the choice of artistic outcome is generally not led by the medium; rather, it is led by a rhizomic commingling of the context with other considerations, such as the ethical encounter, the available resources, and the expectations of everyone involved. Artistic desire and ability are contributing components.

Via methods of immersion, observation and discussion, my practice is able to explore, take shape and resolve; in Baradian terms, it is affecting and being affected by the intra-action of the meeting with

the Other, acknowledging each moment as an *infinite multiplicity* (Barad, 2014, p. 167) of art-form possibilities.

There are no solutions; there is only the ongoing practice of being open and alive to each meeting, each intra-action, so that we might use our ability to respond, our responsibility, to help awaken, to breathe life into ever new possibilities for living justly. The world and its possibilities for becoming are remade in each meeting.
(Barad, 2007, p. x)

Given that I live and base my artistic practice predominantly in a regional centre, I am sometimes defined as a “regional artist” and at times I attract funding that is aligned for regionally based artistic practice. While I don’t promote myself as a regional artist, I do strongly advocate and argue for specific investment in regional arts practice, for two main reasons. Firstly, it identifies the lack of infrastructure and broader artistic networks available in regional centres. Second, it argues for the de-centralisation of knowledge, creative activity, and creative outputs beyond our city centres, broadening the contributions that can be made to our national story.

Alarmingly, this regional/urban divide extends far beyond the arts, according to the Victorian Health Foundation Rapid Review *The Arts and Creative Industries in Health Promotion*:

Australians living in rural and remote areas have poorer health and higher rates of tobacco smoking, alcohol consumption, physical inactivity, overweight/obesity, chronic disease, mortality and suicide than those who live in metropolitan areas.
(Davies & Pescud, 2020, p. 30)

Unfortunately though, The Victorian Health Rapid Review wasn’t able to identify any research that addresses arts and health issues in regional locations or that were able to provide “*insight into methods to improve arts engagement for this priority group*” (Davies & Pescud, 2020, p. 30).

When we argue nationally for the benefits that creative practice generates, we refer not only to its beneficial effect on the economy (Australia Council for the Arts, 2015), but also to its cultural impact (Davies & Pescud, 2020; Fancourt & Finn, 2019; Fielding et al., 2019). In doing so, we simultaneously identify that if we don’t invest specifically in regionally based artistic practice, then we deny opportunities for our non-capital city communities to enjoy and contribute to these diverse benefits.

Scott Rankin, creative director of Big hART, explores some of these issues in his *Platform Paper* essay, “Cultural Justice and the Right to Thrive”, arguing that everyone has a right to culture, likening it to an essential service just like health and education (S. Rankin, 2018). In 2016, Sydney Festival director Wesley Enoch was an invited speaker at the Artlands Conference held in Dubbo, New South Wales. Artlands is a biennial conference hosted by Regional Arts Australia in partnership with the state-based regional arts boards. It aims to showcase and advocate for regionally based arts practice by challenging the assumption that all art and culture comes from our capital cities. In his talk, Enoch reflected that one of the defining characteristics of regionally based arts practice seems to be its ability to connect and work with communities to create strong modes of what I refer to as socially engaged art making. This relationship between regional practice and socially engaged practices, and how these are valued and understood within the art canon, are linked themes in the history of my work, and one of the reasons why the final non-traditional output of my research, the exhibition *Face to Face: The New Normal* (explored in Chapter Four) – was exhibited in a regional gallery. In 2017, festival director and artist Lindy Hume authored a Platform Paper essay titled “The Restless Giant”, in which she proposed that regional practice in Australia, has a “benign, folksy, parochial public image” (Hume, 2017, p. 46), arguing that there is a “gap that manifests in a culturally pervasive hierarchy in which artists living and

working in regional Australia are perceived as in a junior relationship to their counterparts in mainstream metropolitan centres” (Hume, 2021, p. 67).

Relevant to this is Claire Bishop’s assertion that socially engaged practice has been largely exempt from art criticism due to an emphasis on the importance of the ethical and moral objectives of socially engaged practices (C. Bishop, 2012). However, I would offer an additional reflection. If we take Enoch’s and Hume’s reflections (and my own experience) to be true, we could propose that regional and socially engaged practice has been mostly exempt from art criticism because the mechanisms of art criticism don’t so readily engage with those things that are outside its geographic and cultural sphere. This speaks to a value system that has historically positioned both regional practice and socially engaged practices as ‘secondary’.

Prior to living in a regional New South Wales community (population 5,800), I worked and practised in Sydney (population 5.31 million). At that time, my practice was studio-based and included playing regular gigs as a live musician. My move to a regional area brought with it a slow and gradual change towards a practice that is now mostly site-based and socially engaged. This change wasn’t planned; instead, it was evoked by my immersion in a place vastly different from the major capital city that I once called home. My personal discovery during this process, was that regional living makes the supporting infrastructures of life more accessible and visible. Local Council, State and Federal members of Parliament, government departments, and other institutions and organisations that are present in the daily act of living, are all visible in the community. This enables a deeper understanding of, and connection to, some of the dependencies of life (such as food and fibre production, and water management) and the mechanisms by which these are managed and negotiated.

When living in the city, the density of population meant that I was able to construct my community of peers and friends mostly from people with a similar ideological background, or from those involved in the creative arts. Living in a predominantly like-minded community meant that I was mostly engaging with people in whom I could see some version of myself. Appropriating a term used by French sociologist Pierre Bourdieu, there was a tight fit between my habitus and the (sub)-field of arts practice in which I was immersed (Bourdieu, 2008). Since moving to a regional area I have been engaging with, and defined by, my relationships with a community of others in whom I don’t so readily see myself. Consequently, moving to a regional location has resulted in a reformulation of my artistic practice into one that is mostly socially engaged, shifting from my earlier practice which I propose was based on *me-centred subjectivity* to one based on *Other-centred subjectivity*. This shift resonates with the ethics of Emmanuel Levinas and the ethical “substitution” (as Levinas puts it) of myself for the Other.

Structure of the thesis

Summary of Chapter One

This introductory chapter, Chapter One, is an entry into the thinking, concerns, and objectives of this multidisciplinary research. It identifies the philosophical lens through which I explore my research objectives, while also acknowledging the impact that this may have on data collection and analysis. It honours the potential that comes from bringing biomedical practices into relationship with creative practices, while grounding us in the world of the facial nerve, its physiology, what it is and what it does, and what happens when it becomes paralysed. It looks at relevant medical research that explores the facial nerve.

Chapter One has also reviewed the literature about *artistic practice as research* and *non-traditional research outputs* (NTROs) to present them as valid forms of knowledge exploration and production, supporting the delivery of this written thesis alongside an exhibition of artistic works as NTRO’s. I also examined, as an extension of this, the field of arts and health in Australia and internationally, followed by a substantial review of socially engaged arts practice, examining literature that debates the

purpose, definition, intention, and ethical practice of socially engage art making, as well as positioning my own practice within its lineage.

Chapter Two

Chapter Two is the methodology chapter which outlines the various methodologies undertaken in this research, from qualitative methods to creative practice which falls under a banner of practice-based research.

Chapter Three and Four

Chapter Three and Four are presented as results chapters. Chapter Three utilises a qualitative research methodology called Interpretive Phenomenological Analysis to examine the participants expectations and experiences of care. This methodology was used to honour the 'voice' of the participants experience of facial nerve paralysis. Chapter Four then presents 15 different artistic research outcomes, analysing their impact on the clinical experience of patients, and on societal perceptions of facial difference through the public sharing in a gallery space. This Chapter relies on vignette, observation, reflection and participant response to evaluate the artistic outcomes.

Chapter Five

Chapter Five provides a conclusion which discusses the findings of this research.

Overview

This thesis aims to contribute to the growing body of knowledge within the fields of medicine, medical humanities, arts and health, and the arts, understanding these fields both separately and in relationship (Dileo & Bradt, 2009), eliciting Karen Barad's concept of *not distinct but mutually intra-acting agents*:

If we follow disciplinary habits of tracing disciplinary-defined causes through to the corresponding disciplinary-defined effects, we will miss all the crucial intra-actions among these forces that fly in the face of any specific set of disciplinary concerns.
(Barad, 2003, p. 810)

In this thesis, the centrality of ethics enables socially engaged arts processes to effectively engage with the lived experience of Others, while examining the impacts of power structures, agency, affect, access, and self-identity on the lived experience of patients and on the aesthetics of art outcomes. These ethics involve constant review while attending the clinic, presenting artwork in an exhibition, documenting the work, disseminating its results publicly, deciding what images and processes to use and deciding how deeply to discuss delicate topics.

The context for this artistic research practice is the important, and deeply personal, exploration of what life is' and 'what life might potentially be' for those experiencing medical trauma. The site of this research isn't just the physical location of the Sydney Facial Nerve Clinic; it is also the phenomenological and affective aspects of the experience, including the emotional and practical navigations that participants undergo as they negotiate their journey towards a 'new normal'.

CHAPTER TWO. METHODOLOGY

The research methods that underlie this work relied on a combination of recognised qualitative research methods alongside ‘emergent’ practice-led research methods. The aim was to explore two intersecting lines of enquiry that included - what impact an artist-researcher might have on the experience of participants with facial nerve paralysis, and how this experience might develop a ‘philosophy’ of socially engaged arts practice. To achieve these objectives, this study examines diverse theoretical foundations, including care ethics and illness narratives, as well as the ethical considerations of new materialisms and the phenomenology of Emmanuel Levinas. The overall aim of this research is to propose that socially engaged arts practice constitutes a form of care that is fundamentally grounded in ethics, and relevant for integration within a medical clinic.

Research Settings

This research was conducted in diverse settings such as The Sydney Facial Nerve Clinic, the artist studio, and the gallery/exhibition space. However, it also included considerations beyond these physical locations, including the affective and emotional experience of patients facing temporary or permanent facial paralysis. Each of these research settings are described below:

The Sydney Facial Nerve Clinic (SFNC) was introduced in Chapter One as a multidisciplinary clinic established as a place for research and treatment. It is situated inside the Chris O’Brien Lifehouse, a cancer research hospital in the inner-city Sydney suburb of Camperdown, in New South Wales (NSW) Australia. The SFNC happens in an examination room, either in person or online, where patients are examined by anywhere up to fifteen healthcare professionals of different disciplines at one time. Whilst this might sound daunting, the impact is softened by the allocation of a ‘clinic lead’ who sits with the patient to conduct the examination, while the other healthcare professionals ask questions when suitable to do so. The monthly clinic was delivered ‘face to face’ until Covid prompted it to move to an online telehealth model in 2020. It then moved to a hybrid model that alternated between telehealth and in-person clinics in 2022.

The artist studio was another research setting, one where qualitative methods were combined with emergent artistic methods. This is a setting in which I worked alone or with assistance, and where participants were invited, when appropriate, to engage in artwork creation or review/feedback of artworks.

The gallery/exhibition space was the third research setting, a place where artistic research outputs were presented and interpreted, and where ethically approved interviews were conducted with audience members and patient participants. This location also provoked consideration of the political and institutional position of socially engaged arts practice within the broader Western artistic canon. This sought to encourage a re-evaluation of the perceived hierarchies of the artworld, contributing to discourse on the value and significance of socially engaged arts practices.

In Chapter One, I explored the important concept of “site” as being more than just the ‘physical location’ in which socially engaged art practice might be undertaken. Therefore, I also acknowledge non-physical research settings such as the affective, emergent, and relational experience of patients and healthcare professionals. This means that broader concepts such as health inequality, access to treatment, barriers to care and the psychological and affective ‘symptoms’ generated through the medical experience are all a ‘setting’ in which this research takes place.

Study Design

This research utilises an approach that is constructionist rather than positivist. Constructionist approaches propose that ‘reality’ is *constructed* rather than given, as opposed to the positivist paradigm that proposes knowledge comes from one singular objective viewpoint. The research methods practiced here, which include observation, interviews, and practice-based research, are all

suitable methods that enable a constructionist methodology to flourish. These qualitative approaches are undertaken through an inductive, 'bottom up' approach, meaning that they find meaning, and develop concepts or theoretical frameworks through observation and analysis of data. This differs from the alternative 'deductive method' that propose theories first and then tests them against the data.

This research employs a mixed method approach that combines qualitative research methods alongside emergent artistic methods known as 'practice-based research' (Candy & Edmonds, 2018). Rather than operating as discrete processes, these mixed methods inform each other, leading to the development of complex research outcomes. The use of these methods was deemed appropriate as they align with the theoretical foundations of this thesis, which prioritises the emergence of the patient voice while emphasising the relationship between epistemology, ontology and ethics.

While the underlying concepts of these theoretical drivers generally align, they occasionally exhibit a 'productive opposition'. An example of this is in their relationship with modernist perspectives. On one hand, the affect-ive allegiances of new materialism have critically reconsidered the dualities, rationality, and science-focused nature of modernism. In contrast, the phenomenology of Levinas and the early years of care ethics, both originated from modernist ontologies. Therefore, the significance of this diffractive approach lies in its capacity to bridge the gap between the new materialist embrace of the 'potentials of the world' (sometimes referred to as 'speculative fictions'), and the 'long-shadow' of modernism that still casts itself across the delivery and perception of bio-medical practices. By embracing a diffractive practice, we can recognise, for instance, that while Levinas' phenomenology emerged during the modernist era, his philosophical commitment to the alterity of the 'Other' resonates towards the foundations of new materialist perspectives.

This diffractive approach allows me to navigate the perspectives and nuances of diverse theoretical traditions, enabling a more comprehensive understanding of the perspectives that exist within medical encounters. In Chapter Three, I conduct a study through a methodology called Interpretative Phenomenological Analysis (IPA), which relies on phenomenology, hermeneutics, and ideography. These will be explained in detail in chapter three, but for now, I will explain that IPA is a method which:

IPA is committed to understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people, in a particular context. (J. A. Smith et al., 2009, p. 28)

While IPA has many similarities to other qualitative research methodologies such as Thematic Analysis (Braun & Clarke, 2006, 2022), IPA's key focus on deeper engagement with a smaller sample size proposes a unique immersive research opportunity that deeply explores how people makes sense of their own lives. This reliance on a small cohort doesn't mean that IPA is only concerned with the perceptions of the individual; rather, an IPA methodology aims to examine individual experiences, to interpret patterns, commonalities, and differences among those experiences.

[IPA] does not eschew generalizations, but rather prescribes a different way of establishing those generalizations (Harré, 1979). It locates them in the particular, and hence develops them more cautiously.

As a consequence, IPA utilizes small, purposively-selected and carefully-situated samples. (J. A. Smith et al., 2009, p. 28)

IPA offers a responsive, interpretive, and emergent process that is non-linear and connected, embracing a responsive hermeneutic philosophy of interpretation, one that is dynamic and relational in nature.

Chapter Four builds on this IPA analysis with the methods of practice-based research. This method enables alternative ways for the participant and the healthcare professional to share their experiences, and alternative ways to generate and share research outcomes with the public. These methods can best be described as discursive, observational, sensory, and non-linear, facilitating an approach that gently challenges established conventions by being *inductive, generative and multiple* (Braidotti, 2019).

Practice-based-research has many similarities with methods such as creative-research-methods (Kara et al., 2020), however their fundamental difference lies in their different commitments. While creative-research-methods examine what role various creative activities can play in the research design, practice-based-methods position the researchers own artistic proficiency as a central part of the research method, recognising that artistic practice itself is a valuable form of knowledge production, and dissemination.

By incorporating IPA and practice-based research, I commit to synthesising the outputs of multiple approaches to form a complex analysis of the gap between what the healthcare world knows, and how the patient's life is experienced.

Participants

Participants for this research were selected through observation at the SFNC, or from referral from their treating healthcare practitioner. Selection was not based on any criteria apart from the treating doctor's initial assessment that the patient would be in a medical position to be able to be approached about potentially participating in the research. Therefore, participants were from a broad mix of age, gender, socio-economic background.

Sample Size

The sample size of this research study in total (both IPA and practice-based research) included 6 patient participants, 3 healthcare practitioner participants, and 24 gallery visitor participants. Information about age, gender and ethnicity was not deemed relevant to the study and was therefore not collected. There was a diversity of pathologies ranging from participants who were experiencing (potentially) temporary facial paralysis, to participants with life-long issues that revolved around complex pathologies such as brain tumours and cancer. As one of the aims of this research was to engage with a diverse range of patients who attended the facial nerve clinic, this approach of not basing the sample selection on any defining category, allowed us to engage with a random diversity of perspectives.

Recruitment Procedures

The methods used to recruit participants were either referral from healthcare professionals, direct approach at the clinic, or via email. If potential participants expressed interest, they were provided with a participant information sheet, then left to contact me at a time, and in a manner, that was convenient for them. For healthcare professionals as participants, they were first informed verbally of the research and provided with a participant information sheet to answer any queries. Participants were then given a consent form that further outlined what to expect, enabling them to indicate whether they gave their consent to be named, photographed, audio recorded, and video recorded. In the case of gallery visitor participants, a poster was created (approved by HREC) and displayed in the gallery space. This poster informed potential participants of the research study with directions of who to approach in the gallery space if they were interested in participating, before being given a participant information sheet, followed by a consent form.

Data Collection

The various data collection methods that were used, included observation, interview, creative research, and exhibition, which I will outline below.

Observation

For three years I attended the monthly facial nerve clinic and participated in consultations alongside the multidisciplinary team. At each clinic, up to 10 patients would attend, during which time I observed them and their families, their healthcare professionals, and the forms of communication that happened as part of the examination process. I observed how 'care' was enacted within the clinical space through spoken word and performative action of a type which included the "subtleties of embodiment and the nuances of communication" (Hamington, 2015).

During the observation sessions, I took free form notes as well as categorised notes with the help of a template document made in Microsoft excel. This assisted me to take notes under certain headings that included broad overviews of patient's pathologies, interesting observations, interesting comments from healthcare professionals or patients, questions that arose around medical knowledge such as anatomy, documenting interaction between patient doctor and doctor/doctor as well as any relevant notes about my own personal experience, affects, reflections. This was a 'living document' that frequently changed styles to reflect perceived needs.

Data Analysis

Data analysis was conducted in different ways for the two Results chapters. The analysis for the IPA in Chapter Three is outlined in detail within that chapter, so here I will only provide a brief overview. Following interviews, the IPA analysis process included a series of steps that involved:

1. *Data Preparation* in which interviews were transcribed by a human transcription service and then organised into a word document. This allowed for note taking to occur alongside the text (examples given in Chapter Three).
2. *Theme Development* during which I undertook a process similar to Thematic Analysis in which several close readings of the interviews allowed patterns, themes and sub themes to emerge. These themes, which were created on a case-by-case basis per participant, were then analysed together as a group, to understand connections and differences between them.
3. *Analysis* in which I analysed the themes in relation to the interview text and the theoretical frameworks that underpin this research.
4. *Reporting* through which I presented the findings

The IPA chapter sought to uncover rich insights, interpreted through iterative processes, to provide a thorough exploration of perspectives and experiences. These then contributed to the practice-led research presented in Chapter Four. As previously explained, the nature of this artistic enquiry is too diverse, emergent, and responsive to give a thorough overview here, therefore it is examined in detail in Chapter Four. For now, it can be thought of as a place where conceptual, ethical, aesthetic, and immersive 'experiments' and 'responding-s' took place.

Methodologically, my artistic processes are somewhat distinct to most arts and health studies due to the unique method of adopting an open-ended approach to artistic creation rather than using a predetermined artistic mode such as painting or song writing. In my practice, I intentionally avoid pre-conceiving of specific artform or artistic processes, and in the case of this research, I allowed artform choices to emerge from a combination of *observations*, *interviews*, and *creative experimentation*. These artistic methods were shaped by interactions with individuals from the Sydney Facial Nerve Clinic, facilitating a dynamic engagement that can be actively responsive to the expectations and experiences of participants.

As part of the practice-based research methods, an exhibition was presented as both method and outcome. This exhibition component was held over three stages including two developmental exhibitions that shared work in progress, followed by a final, major exhibition outcome which was presented as the examinable part of this research. My proposal that the exhibition should be

considered as a research method as well as an outcome is justified by the considerations that typically, an exhibition is 'constructed' by curators, gallery directors and artists who select works to represent various ideas, placing them in ways so that the ideas engage together to produce new ideas or new possibilities for ways of thinking. In this case, the exhibition was simultaneously a showing of research outputs, and an opportunity to collect data about responses to the artwork via interviews of participants.

There were two smaller developmental exhibitions that preceded the main exhibition of final works. The purpose of these was to share work-in-progress with members of the public (and participants) with the aim of allowing peoples responses and reactions to the affective qualities of the presentation, to impact the next stage development of the artworks. Development exhibition #1 took place at the 2019 Big Anxiety Festival as part of an exhibition called [The Empathy Clinic](#). The second showing of works in development was the following year, in 2020, when I was given the opportunity to share works during a research residency at The Tate Exchange, in Liverpool (UK). The Tate Exchange was a program that provided a rare opportunity to test ideas, meanings, and interactions by conducting artistic research with a large audience in an international gallery. The final exhibition outcome was called *Face to Face: The New Normal* and was presented at the Wagga Wagga Regional Art Gallery, NSW, Australia between (08/02/2022 – 22/05/2022). These three exhibition stages are examined in detail in Chapter Four.

Typically, within an artist led PhD, the final exhibition (or creative output) is presented at the end alongside a written thesis. This research, however, took a slightly different approach with the final exhibition being presented 18 months before thesis submission, thus allowing an opportunity to analyse the impacts of the exhibition through data collection via interviews with gallery visitors and participants reflections on the final artworks.

Interviews

Patient Participants

The interview process consisted of semi-structured interviews, held either in person or online (depending on COVID or geographic constraints). Typically, the interview duration would be between one - three hours each, with up to four interview sessions per participant. This significant investment of time, spent in engagement with participants, established the conditions required to create a complex and in-depth analysis of the patient experience. An initial set of questions allowed the participant to share the nuances of their story and to explore the themes they were motivated to share.

The following are some example questions:

Can you describe your condition to me in your own words?

How has your facial paralysis impacted your life the most?

What modifications have you made to your daily activities to compensate for your facial paralysis?

How was your experience at the facial nerve clinic?

How would you describe the personal experience you have had with your treating doctors?

Can you tell me what the word 'care' means to you?

What do you think are the barriers to providing 'care' in medicine?

How do you enact 'self-care'?

These questions enabled patients to discuss how they came to have facial nerve paralysis, how they have experienced the processes of treatment, what it has been like to engage with the health system, and what impacts facial nerve paralysis has had on their lives. We discussed the concept of care, what it means for them, and what they perceive as the barriers to care.

Healthcare Practitioner Participants

There were 3 healthcare professionals who were participants in this research, participating in semi-structured interviews in which they were asked questions such as:

What was it that led you into medicine in the first place?

Can you give me an overview of your career to date?

What benefits do you perceive in the interdisciplinary model of the Sydney Facial Nerve Clinic?

What are the shortcomings?

What do you think the experience is like for a patient to visit the Sydney Facial Nerve Clinic?

What does the word 'care' mean to you?

From a clinical perspective, what are the barriers to 'care'?

Given that you work in a field that is regularly exposed to trauma, how do you enact 'self-care'?

These sample questions act as a starting point to enact conversations about professional and personal connections to medicine, the multidisciplinary model, and barriers to care. Like the patient interviews, these were then used as part of the practice-led research processes in Chapter Four.

Art Gallery Participants

During this study, a decision was made to apply for ethics modifications to include the data of gallery participants to facilitate the analysis of the impacts of the artwork outputs. This approach was instigated by findings within both the published facial nerve literature (Coulson et al., 2004b; Nellis et al., 2017; Pouwels et al., 2021), and the data collected in the observation and interview phases. These relevant findings identified that patients with facial nerve paralysis have concerns regarding how they are perceived and treated by the public. Therefore, this made the final exhibition an opportunity to gather data about the impacts of the artworks and to be a catalyst for conversations about the stigma's associated with facial nerve disorders.

In the gallery, I also presented a public forum about 'care' that was attended by arts and health scholars and practitioners, general public, healthcare professionals, artists and people who work in caring roles. This forum was an 'arts funded' activity which sat adjacent to the research and is acknowledged as an influence via reflective processes but not systematically analysed and reported here.

Guiding principles

In Chapter One, I outlined some of the key themes of socially engaged arts practice. These can be thought of as guides, barometers, measures, and considerations against which creative research methods engage, 'holding to account' my artistic practice in terms of its ethics and aesthetics. Additionally, whilst undertaking the literature review component in Chapter One, I identified several research considerations that needed further scholarship, documentation, explanation, and debate to develop the fields of arts-based research, qualitative research methods and non-traditional research outputs. I have synthesised these key areas into the following categories to acknowledge them as guiding principles to my research process:

1. **Co-location:** How does my research:
 - a. Monitor what I privilege when I am placing my own research objectives (such as having an exhibition outcome) alongside the health concerns and professional clinical practice of other people?
 - b. Merge the codified languages of academia, contemporary art, the medical clinic and the human being who is experiencing illness?
2. **Ethics:** How does my research:

- a. Identify that ethics are procedural (e.g., obtaining ethics approval to conduct this research) and also situational (dependant on the situation I am engaging in) and process driven (in constant revision)?
 - b. Identify the need for ongoing ethical consideration in terms of analysing and translating data into a public form such as an art exhibition?
- 3. **Authorship:** How does my research:
 - a. Examine authorship? Do methods of engagement mean that artistic works are co-authored? What are the nuances in this negotiation, and how are they affected by different types of artistic engagement?
- 4. **Impact and Evaluation:** How does my research:
 - a. Understand how (and when) we should “measure” the impact of artistic processes and outcomes?
 - b. identify that impacts might be different across different disciplines (also see Co-location above).
- 5. **Validation:** How does my research:
 - a. Practice forms of evidence sharing such as creating, analysing and distributing documentation of processes across each partnering sector.

Human Research Ethics Approvals

It was perceived at the beginning of this research study that, due to the ‘emergent’ nature of these artistic methods, this would be a project that potentially would need to involve a number of ethics approvals and modifications. Ethical approval was therefore received from both the University of Sydney Human Research Ethics Committee (HREC) (Protocol #2019/513) and the Sydney Local Health District Ethics Review Committee (Protocol #X19-0369). Two modifications were also applied for and approved from HREC.

The application to the Sydney University Human Research Ethics Committee was the first ethics application to be submitted and approved. This permitted working with up to 1-4 doctor participants and 1-4 patient participants. Later, modifications for this were twice submitted to HREC to include gallery audience members in different gallery locations. The Sydney Local Health District Ethics Review Committee approved working with up to 20 patients and 20 healthcare professionals at the Sydney Facial Nerve Clinic, and during subsequent interviews at other locations.

The main ethical considerations within these applications included commitments to ensure patients were aware that:

- 1. declining the invitation to participate in this research would not have any negative impacts on their clinical treatment plans.
- 2. consent was to be repeatedly sought at multiple key stages of the process because interviews took place over multiple lengthy sessions.
- 3. they could withdraw from the study at any time.
- 4. they were able to approve any final artwork before public showing and could request the removal of any artwork outcome at their discretion.
- 5. they could nominate whether they wanted to be identified in the research outcomes (most participants did want to be identified).
- 6. they were able to select whether they were willing to be photographed, video recorded, and audio recorded.

In addition to these considerations were the multiple assurances that patients were kept safe, and that no harm would come to them from being involved in the research process. This included:

1. providing contact details for counselling services,
2. a clear avenue for easy withdraw from the process,
3. a clear process to speak to someone if they had any issues with me as a researcher,
4. ethical approval of the guiding semi-structured interview questions, and
5. secure storage of sensitive research material.

While the institutional ethical guidelines provided a framework to ensure participant safety, these approvals were augmented by the ethical considerations inherent in socially engaged practice. As a mixed method approach reliant on ethics, I seek to contribute a comprehensive understanding of the intricate interplay between artistic practice, care for people, and the ethics required to meet this responsibility of care.

CHAPTER THREE. RESULTS #1 EXPECTATIONS AND EXPERIENCES OF CARE

In this results chapter, I undertake an analysis that delves into the expectations and experiences of 'care' for individuals with facial nerve paralysis. As highlighted in Chapter One, 'care' holds significant interest in the medical humanities at this time, a potential indication that understanding its importance is in great need. In that Chapter, I discussed that care ethicists have largely theorised care in terms of qualities such as attentiveness, responsibility, competence, responsiveness, and relationality (Tronto, 2013). Moreover, the medical humanities, particularly in nursing, have contributed additional perspectives on care, defining concepts such as accountability, empathy, competency development and holistic service (Roland, 2014). Despite these theoretical outcomes, there remains much to learn about patient's perspectives and lived experience of care.

Throughout this chapter, I use Interpretative Phenomenological Analysis (IPA) as an approach to investigate expectations and encounters of care among participants. I propose that IPA is a suitable methodology because of its potential to expose the vibrant and nuanced perspectives and aspirations of participants, drawing on their narratives and lived experience. While the aim of this chapter is to contribute to discussions around care practices in medical settings, it also sets the scene for Chapter Four that explores the concept of care within socially engaged arts practice. Together these chapters form a complex analysis of the role of the artist within a clinical setting.

The concept of care was introduced in the original research design due to an interest in care and caring through socially engaged arts practice. However, through this responsive research process, its deeper relevance to the lived experience of participants at the Sydney Facial Nerve Clinic (SFNC) has emerged.

Methodology

IPA is a qualitative research methodology that aims to provide a thorough examination of the lived experience of people. Researchers claim that an IPA approach provides a method to "conduct this examination in a way which, as far as possible, enables that experience to be expressed in its own terms, rather than according to predefined category systems" (Smith et al., 2009, p. 30). IPA was selected as the most appropriate methodology because its goal is to accurately represent the qualia, nuance and meaning of experience, which are the elements that are frequently explored, and responded to, through art making. While I have introduced the methodology of IPA research in the previous chapter, I will now expand on the concept by discussing IPA's philosophical framework, methods for recruitment, data collection, and the process of analysis.

Philosophical framework

IPA was developed in the 1990's by Psychologist Jonathan Smith (J. A. Smith, 1996) and was originally used as a methodology in health and clinical psychology before gaining wider appeal. As its name suggests, IPA is derived from the philosophical traditions of phenomenology, which was outlined in Chapter One, but which I will recount here as being a diverse philosophical framework that explores the study of "phenomena" via the understanding of consciousness and experience. Ontologically, the goal of the IPA researcher is to explore and describe elements of 'experience' through language. This influential approach recognises that expressing experience in language is a dynamic form of construction through which we convey our thoughts, meanings and interpretations, while also recognising that meaning is constructed not only through word choice, but in *pauses, laughter, functional aspects of language, repetition, tone, degree of fluency* (J. A. Smith et al., 2009). IPA is described as always being interpretive, with the implication that, as a researcher, I bring my own experiences, expectations and biases and therefore have a responsibility to understand and acknowledge these.

IPA is also identified as an appropriate methodology to employ in this study due to its alignment with one of the main theoretic frameworks for this research, the work of phenomenological philosopher Levinas. Levinas' philosophy is an exploration of the ethics of standing 'face to face' with another

person to witness their “alterity” or otherness. One of his key propositions was that the ‘Other’ person cannot be pre-conceived by me, which is a proposal that aligns with IPA methodology, the core of which lies in its interest in the details of experience, perceptions, qualities, and the meanings these elements of experience hold for participants. Smith et al are pluralistic in their understanding of phenomenology:

There are many different emphases and interests amongst phenomenologists, but they have all tended to share a particular interest in thinking about what the experience of being human is like, in all of its various aspects, but especially in terms of the things which matter to us, and which constitute our lived world. Many phenomenologists have also been committed to thinking about how we might come to understand what our experiences of the world are like. (J. A. Smith et al., 2009, p. 13)

In this chapter, I explore the qualities, senses, states, and perceptions that participants have about their experiences of care and the meanings these experiences hold for them. Smith, Larkin, and Flowers (J. A. Smith et al., 2009) recognise that experience must be conveyed in language to the researcher, who must then interpret what the participants impart. For this reason, IPA is concerned with the idea of Hermeneutics as methodology. Hermeneutics is the philosophy of interpretation. It understands interpretations as a dynamic process between the reader and the text, to uncover meanings, intentions and understanding. The circular nature of this method of interpretation has given rise to the concept of the hermeneutic circle which proposes that interpretation doesn’t seek already establish facts, but is a dynamic, relational, and circular process of understanding between the interpreter and the information, and the part and the whole.

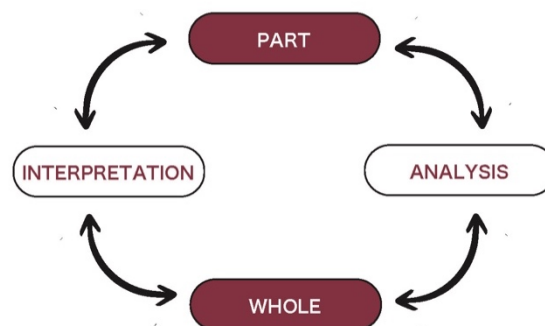


Figure 7: The Hermeneutic Circle - after Figure 2, Flowers, Smith and Larkin, 1992, p. 20

In IPA, interpretation occurs through repeated immersion in collected data, through close reading supplemented by close coding, and through the recognition and exploration of patterns of meaning in the data. While this can be done systematically, interpretation also occurs through reflexivity. Researchers interpret the experiences of their research subjects as a whole, as well as considering the systematic patterns and structures within their parts. Smith, Larkin and Flowers encourage the researcher to move back and forth between all the aspects that make up the research encounter, aiming to create a process that encourages a “dynamic, non-linear way of thinking” (J. A. Smith et al., 2009, p. 27).

IPA aspires to interpret experience and then bring these findings into relationship with theories relevant to the research. In this chapter, interpretation has been developed through cultivation of this

non-linear and dynamic way of thinking, in part because it reflects and fits with the processes used to artistically explore and respond to that experience (Chapter Four). However, interpretation has also been based on a more systematic process of pattern finding and characterisation similar to thematic analysis (Braun & Clarke, 2006, 2022). I have used reflexivity extensively, as a key form of ethical engagement in research, but also to maintain these different approaches to interpretation. My reflections have iteratively and repeatedly considered my positionality as artist and researcher, considering how I am being present within the research relationship, and scrutinising how this brings with it a responsibility to identify how my own preconceptions, biases, lived experience, expectations and motivations might impact the analysis. My reflections have also explored the other theoretical lenses I bring to interpretation, among them, New Materialist philosopher Karen Barad's concept of *intra-action*, which she proposed as a response to traditional separations between subject and object, proposing that agency is co-constituted through a "dynamism of forces" (Barad, 2007, p. 141). This too will be more visible (literally) in Chapter Four.

IPA seeks to understand the qualities and meanings of first-person experience; therefore, it is *ideographic*, meaning it is case study based. The IPA researcher is committed to deeply understanding the experience of each case in turn, because it aims to provide a 'thick' (Geertz, 2008) description of experience on a case-by-case basis. Therefore, IPA methodologies require only a small number of interviews, which are typically extensive, to provide particularly rich data, which is then used to find patterns and meanings, whether similar or competing.

In summary, IPA provided the most appropriate method philosophically because it arose from the same philosophical traditions as Levinas. Its commitment to an in-depth exploration of the individual experience that centre's the participant's agency and perspective, rather than the epistemic aims of the researcher, were also suited to my research aims/questions.

Participants, recruitment, and data collection

The sample size for this analysis is purposely small, as per IPA methods. To this end, three participants have been selected for analysis. These participants were recruited through consultation with their various treating healthcare professionals following presentation at the Sydney Facial Nerve Clinic, and in accordance with approved ethics protocols. These participants were experiencing a diverse range of pathologies, including:

Participant #1: Susan A – Recovering from Ramsey Hunt syndrome.

Participant #2: Liz C – Permanent facial paralysis following removal of brain tumour, Ongoing rehabilitation work required.

Participant #3: William M – Experiences permanent facial paralysis because of brain tumour removal. Still existing brain tumours also present ongoing health risks.

Generally, within biomedical research studies, these patients might be referred to as 'participants' with their name withheld as part of a process of de-identification, a protocol often used to protect the participant and to reduce the potential for bias in data analysis. In this research, however, all the participants have agreed to be named, thereby overtly acknowledging the human behind the data and behind the illness. The process, again, has been guided by the ethical approval procedures of the University of Sydney and the Sydney Local Health District. The selection of diverse pathologies of participants is intentional, acknowledging the diversity of facial nerve pathologies that are presented at the SFNC.¹⁴

¹⁴ Diversity was led purely by pathology. There was no consideration of diversity of cultural background, ability, economic position, etc. My research confirmed that there are many questions around who has access to specialised medical care. There is already extensive research around barriers to access to this type of care and of course, plenty of opportunities to further research (and impact) this area.

Interviews

The method of data collection was semi-structured interviews conducted over several meetings. The original semi-structured interview questions included:

- Can you tell me the scientific name for your condition?
- Can you describe your condition to me in your own words?
- Chronology of illness: Can you tell me when your illness was first noticed, diagnosed and treated?
- How did you first hear of the Sydney Facial Nerve Clinic at the Chris O'Brien Lifehouse in Camperdown, Sydney?
- Do you remember your feelings when you first made an appointment to attend the clinic?
- Did these feelings change the day before your appointment at the clinic?
- How did you feel as you prepared to attend your first visit at the clinic?
- How was your experience at the actual clinic, being one patient in a room of healthcare practitioners?
- How would you describe the personal experience you have had with your treating doctors?
- Have you felt that your 'voice' was heard during consultation and treatment?
- What do you think the experience is like for the healthcare practitioner that is treating patients such as yourself?
- What modifications have you made to day-to-day activity in order to adjust for your facial paralysis?
- When you look in the mirror, how do you relate to the person you see in the reflection?
- Has this changed over time since the onset of facial nerve paralysis?
- Are you affected by the language used around your medical condition? For example, if words such as 'patient' or 'disfigurement' were used, do they cause any form of emotional reaction in you?
- In a medical context, what does the word 'care' mean to you?
- What do you think are the barriers to care?
- How do you enact self-care?

These questions provided an initial opportunity to build rapport and connection between myself and the participant. This was then able to grow through a series of repeated, lengthy interviews. These interviews were conducted away from the clinic, in spaces such as the artist studio, in public spaces such as a park, as well as in a hospital ward. Due to the social distancing requirements of the COVID-19 pandemic, interviews were also conducted via Zoom and by email. They were recorded, either with a handheld portable recorder, or with a smartphone, or via the Zoom recording function. The recordings were then transcribed using a human transcription service and stored on the REDCap® (Research Electronic Data Capture) secure management system.

While questions about 'care' were directly asked in these semi-structured interviews, the reason it has been revealed as such a major theme is because conversations frequently returned to participants reflections and critiques of their experiences of it. Care is therefore presented both as a theme that originally existed in the interview questions, but one that was amplified as conversations continued.

Data analysis

Once the interviews were transcribed, they were formatted into a table in Microsoft Word that allowed space to enter analysis/notes alongside each line of interview text. Several repeated close readings of the interviews (some of which totaled over 50 pages) were then made, while making notes alongside each line of transcription. This process analysed the direct spoken words of the participants,

the language they used and the concepts they highlighted. A small example of this process is presented below.

Name	Transcription	Notes
Vic:	In your own words, what is it that you're experiencing at the moment with your face?	
Susan A:	Um, It's feeling as though one part of my face has a mind of its own (laughs) in a funny sort of way. Um, that it doesn't always do what I wanted to do, um, and it feels that half of my face is stiff, um, a little bit swollen, and sometimes it twitches when I don't expect it to twitch. Uh, the nerve muscles twitch, uh, and so sometimes when it starts twitching a lot, I realize in time I get really self-conscious, yeah, about it, yeah.	"It's feeling as though one part of my face has a mind of its own". separation and loss of control of functioning. "it doesn't always do what I want it to do" <u>referring to her own face as "it"</u> . <u>Self-consciousness, pathology affecting identity in terms of feeling uncomfortable presumably in front of others.</u> <i>She also laughs and calls it "funny"</i> . Descriptions (Stiff), Swollen, Twitches, Self-conscious. EMERGING THEMES: Joy (affirmative ethics), Exteriority of self, Pathology affecting identity, Self-Consciousness.
Vic:	Um, so that if you rest when you're feeling that twitching, does that, does that settle and back down again? Is resting an effective thing for you to do to help with what you're experiencing?	
Susan A:	Uh, yeah. So, I've discovered that resting and doing some facial massages and just to sort of one calm muscle down, um, to slow myself down-	Refers to her treatment/rehabilitation (facial massage) and also resting, have an impact on pathology (twitching) but also psychological aspect in terms of her self-consciousness that is caused by twitching. EMERGING THEMES: Modification of behaviour to manage pathology, Usefulness of rehabilitation process to impact her pathology and her psychology.
Vic:	Yeah.	
Susan A:	... to, yeah, focus on breathing and it just sort of relax a little bit, um-	
Vic:	Yeah.	
Susan A:	... yeah. I found it useful.	

The next step was to refine the long list of notes and sub-themes and categories these into themes for each participant. This is an example of the initial themes generated during this stage for one of the participants.

SUSAN A ANDREWS
Competency (care ethics)
Poor Medical Communication
Poor Medical Practice.
Poor competency (as a process of care ethics). Lack of knowledge of facial nerve issues.
Feeling let down.
Can include communication, response, knowledge of facial nerve disorder, etc.
Left to my own devices 'Nobody explained to me'
Lack of info about who to see
Lack of info about alternatives
Lack of leadership – no hand holding
Access to accessible information
Hierarchies of Pathology
Taking up too much space
Care
Barriers to care
Self-care
Time
Time as a healer - Benefits of seeing progress
Time as a barrier to care
The Illness Journey
Exteriority of Self and the social self
Self-consciousness
Mining past experiences to understand unknown feelings
Loneliness
Having to manage social interaction, even when they give benefit
Pathology affecting psychology, psychology affecting pathology
Modifying behaviours to manage pathology
Usefulness of rehabilitation to impact psychology and pathology

• Cycles of stress – Stress, twitching, stress
• Modification of routines “(the simple things you would normally take for granted) this aligns with Liz C re scar on her leg.
• Frustration
• Loss of internal strength
• Grief
• Conflict of self
• Anger /frustration/Fear
• Responsibility – her needing to feel a responsibility towards her own rehab
Information I wish I had
• Use of internet searches
• Online blogs – other experiences, hearing about others, their stories, etc.
• Feeling alone, and not right i.e., bizarre, not just an illness, but something strange.
• Having to look externally to medicine (i.e. blogs) to find needed information.

Next, I undertook an important step in IPA analysis, which is to bring the story of the individual into relationship with the other participants. For this step, I created a table of each participant’s long list of initial sub-themes to draw out correlations and differences. This hermeneutic approach of repeatedly returning to earlier processes usefully aided the development of these themes. This example is from the theme of Care.

Care:	Expectations and experiences of care		
	Participant #1	Participant #2	Participant #3
		Positives and Negatives	Through gentle sharing (intern)
	Expectations	Keeping patients informed of what is happening /details of medical interventions [Communication]	Competency as care (Diversity of Care abilities between healthcare professionals)
	Barriers	Issues of access to healthcare professionals	Barriers to care
	Self-Care	Care through explanation of procedures and repercussions	Medical education
	Lack of knowledge of facial nerve issues	Barriers to access to healthcare professionals	Insensitive communication
	Misdiagnosis	healthcare professionals focused agenda vs Patient Focused	Patients’ vs healthcare professionals needs

Care:	Expectations and experiences of care		
	Poor medical communication	Concern and follow up	Left out to dry
	Poor medical practice (skills)	Care is inclusive of praise, enthusiasm, time to talk (Beyond the bio-medical)	Feeling let down by medical care
	Poor Competency which includes communication, response, knowledge.	Different types of caring, caring not defines as one thing.	Silos of medical care
	lack of leadership (no hand holding)	Checking in is a form of minimal care, lack of follow up, no one seeing how she 'feels' about her upcoming surgery. The speech therapist would follow up with her though. Seeking her out. Humanity really what she is saying that caring for me should include caring for my humanity. Such as " <i>How are we coping</i> ".	Lack of discussion about depression
	Lack of info of who to see	Identifies that surgeons have a need for self-protection.	Insensitive communication
	Lack of alternatives	Multidisciplinary - Benefits - Susan A gave strategies to deal with communication difficulties. Needs a "go-between" who would "listen to patients". This identifies a good issue with the multidisciplinary model and should be explored later.	Care by gentle sharing of intern.
	SFNC as a delivery of competency. Multidisciplinary equals multi competencies.	She is happy with the outcome of her 'major' pathologies, but her 'secondary issues' are troubling/not addressed. Therefore, scar revision surgery was important.	"Left out to dry" by the medical system.
	Performativity of care through language used	Care - personal visits and follows up to see you were going. Makes an effort to enquire on your personal situation., including follow ups and visits.	Feeling let down my medical care
	giving patients responsibility for her own progress	Care would be a case worker to work with you to help communicate across disciplines.	Competency - A lot to say.

Care:	Expectations and experiences of care		
	care - having a gentle approach - kind thoughtful and considerate to others.	Working with me as act of self-care. Family Food	Medical education
	Feeling like a Specimen but this made fine by feeling like there was a genuine interest in me.		Communication

This process of interpretation was completed through the act of writing the following two sections. First the results section where the direct voice of the participant takes centre stage, then the discussion section that interprets the patient's voice in alignment with the various theoretical perspectives outlined in Chapter One.

Results

The narrative-rich approach taken in this results section aims to share the subjective experiences of each participant without including any interpretation or theoretical analysis. In saying that, I do acknowledge that the initial research steps of close reading, coding, and selecting themes has already enacted a type of interpretation, however, by focusing on the direct language of the participant, this section aims to, as much as is possible within a research construct, begin with an examination of the participants experience by directly sharing their voice. This includes allowing the quoted dialogue to remain in the present tense. By providing this extended opportunity for discussion with participants, I propose that this method of research enables us to contribute directly, and not just theoretically, to care-giving during the research process. In effect, this is data collection that may be interpreted as an act of care.

The world is there before any possible analysis of mine, and it would be artificial to make it the outcome of a series of syntheses which link, in the first place sensations, then aspects of the object corresponding to different perspectives, when both are nothing but products of analysis. (Merleau-Ponty, 2005, p. x-xi)

In this section, I will identify the main themes that came from the interpretative methodology outlined above. I will then share direct narrative from each participant to support my coding decisions and interpretations. I will also acknowledge from the outset that while the interpretation presented below attempts to neatly confine narrative under the boundaries of particular themes, there are many examples where the discussion would be appropriate under several thematic areas. I will occasionally discuss these crossovers where relevant, while acknowledging the readers own interpretation has the potential to make additional links between themes through their own reading. These potentials align with the hermeneutic approach that proposes a relational flow between modes of meaning making and interpretation. Following this, I will present a discussion section in which I interpret the narrative through my theoretical lenses.

The themes that have emerged through my analysis process include:

Identity	Exteriority and reconfiguration of self
PAPAP circle	Pathology affects psychology affects pathology
Time	Time as a healer, time as a barrier, time as a container of doubt
Care	Expectations and experiences of care
Hierarchies of pathology	Am I just complaining?
Communication	What's needed

Theme 1: Identity - Exteriority and reconfiguration of self.

The impact on identity that results from facial nerve paralysis have been documented in the literature shared in Chapter One and unsurprisingly arose as a topic in interviews. Hence *Identity – Exteriority and reconfiguration of self*, emerged as a key theme. This theme captures the experience of sensing the self as being exterior, not within one's own control, which is an affective impact that disrupts the patient's experience of agency. This experience arose in part from lack of physical control over parts of the face, but also from self-consciousness experienced in public and social settings. It resulted in the need to manage all social intersections, even those that were positive and beneficial. Because participants couldn't relax into the flow of interaction, part of their exteriority was the experience of loneliness. This sense of detachment from the body was accentuated by needing to mine past experiences to try to understand unknown sensations and the feelings that gave them meaning.

Susan A

In Susan A's house, there is only one mirror. It is located in the bathroom, where she uses it for personal care tasks such as combing her hair. When she looks in the mirror and sees the effect that Ramsay Hunt syndrome has had on her face, she thinks: "Who's that?"

It feels as though one part of my face has a mind of its own.

Susan A's experience speaks to a feeling of separation from self, which is supported by the physiological impacts of her facial muscles and nerves not reacting as expected. "It doesn't always do what I want it to do," she says. Her repeated references to her own face as "it" throughout the interview appear to support the assertion that feelings of separation are a major consideration for her, one where the face seems out of control. "When I get sort of enthusiastic, my face responds in a similar way, and I think 'whoa whoa'", referring to her enthusiasm triggering responses from her face which she herself can't control.

She tries (unsuccessfully) to equate the physiological symptoms with past experiences (such as previous yoga injuries), but soon realises she has "never experienced anything like this before". The unfamiliar symptoms, in combination with the poor medical attention she initially received (which will be outlined later in this chapter), led to her feeling "strange" and "bizarre", which exacerbated her feelings of loneliness. She mentions on multiple occasions that no one explained to her what Ramsay Hunt syndrome was, or warned her about the symptoms she might experience, such as poor balance and difficulty in walking. Socially, Susan A appreciated the well wishes of her friends and family. "It was like they really cared", but she developed methods of controlling and limiting social situations because, as she explained, if she herself looks in a mirror and asks "Who is this person?", then what must other people be thinking?"

If people said, "I want to come and visit," I would say: "No, don't come and visit me. I don't wanna see anybody yet."

After a while, she was able to say:

"If you wanna come, it's really nice, but please don't expect me to talk for more than 10 or 20 minutes. I'm too tired. I'm not being rude, but I have to let you know that I just get too tired."

Liz C

Liz C's experience of permanent facial paralysis followed the removal of a neuroendocrine tumour that was growing around the facial nerve. She speaks about her identify being impacted by the physical changes to her face, as well as by the restrictions that her pathology placed on her. It was the loss of her smile – "I have completely lost the winning smile I used to have" – and her perceived loss of looks that she noticed the most. Liz C was a French horn player in the Darwin Symphony Orchestra. She fell in love with the instrument at a young age. "I love[d] its rich, beautiful, but powerful, sound." Reflecting on her experience of playing the French horn, she says:

I think about playing parts of the repertoire in full "flight", like the main horn moments in Beethoven's 7th Symphony (I played this in an orchestra in Germany when I studied there), or playing the Brahms Horn Trio for one of my Uni recitals in Maastricht where I also studied horn (that part suited my abilities and tone well, so it was so enjoyable to play), or playing Mozart's 3rd Horn Concerto with orchestra at Newcastle Con. Also, [I think about] playing horn quartets busking in Bayreuth, Germany, with a killer horn group of keen students.

The injuries Liz C's facial nerve sustained during surgery to remove her brain tumour meant that she could no longer make the embouchure (mouth shape) required to play the French horn. This loss had multiple impacts on her sense of identity and on the opportunities available to her for shared experience. "A lot of my best horn moments are also wrapped up with experiences, people, places and travel." In the interviews undertaken with Liz C, she provided what might be an analogy for her personal experience; In this reflection on the difference between playing French horn and playing cello (the instrument she started learning after her facial nerve paralysis stopped her from being able to play the French horn), she said:

The cello has to submit more and blend in, whereas on horn, you can shine individually.

I propose this as an analogy for Liz C's redefining of identity, reflecting on her ability to "shine individually" before her facial nerve disorder, and that her subsequent facial nerve paralysis, like the cello, meant she had to submit (withdraw) more to "blend in". Like Susan A, Liz C places certain restrictions on how she is seen. For a long time, she avoided having her photograph taken, but have over *time* (an upcoming theme) she will now take selfies, although controlled in the sense that she only takes them from a certain angle. She admits to being uncomfortable in social situations and is nervous when she feels she is under "close scrutiny".

William M

William M was diagnosed with a brain tumour at age 12 and continues to have issues with tumours, bleeding, and permanent facial paralysis. His journey has involved life-threatening engagements with brain tumours, repeated strokes, and a medical experience that has made him very vocal about what he sees as the issues in modern medical practice. Interestingly, at the time of this research, William M was also a medical student, his illness having had multiple impacts on his enrolment.

He speaks of his major loss of independence. For example, his condition required him to live once again with his parents. He shares that he felt extremely isolated socially, to the extent that his life seemed to be on hold. Due to his facial appearance, William M experiences ongoing judgement from

both strangers and peers, including accusations of being drunk, stupid, arrogant, or aloof. When he first experienced facial nerve issues, he was in school.

[I remember] being teased by a lot of kids because, at that stage, the facial palsy was quite obvious. I found that quite difficult. My appearance gave people the opinion I was disabled and [this] impacted [on my] forming new friendships.

At the time of my interviews with William M, he says he felt:

[...] quite distant from my appearance, like my being is very separate from my physical appearance. And I think that's because I don't really associate me with having a physical appearance anymore (I recognise that that's me, but to me a person isn't their physical appearance). I think, in a sense, having avoided the mirror for so long kind of exaggerated the problem when I did look at the mirror again.

In summary, these conversations reveal that complex layers of separation from self were experienced by each participant and that these issues can be exacerbated by multiple aspects of impact that result from facial nerve paralysis. This brings the concept of identity and exteriority into direct relationship with the next theme.

Theme 2: The PAPAP Circle – Pathology effecting psychology effecting pathology

This theme highlights the intricate and cyclical relationship that exists between a patient's physical condition and their psychological well-being. The significance of this theme is particularly meaningful due to its correlation with the hermeneutic circle, which serves as a foundation for the IPA method. I have created two diagrams to give a visual representation of how the Hermeneutic circle and this PAPAP theme have similar structures.

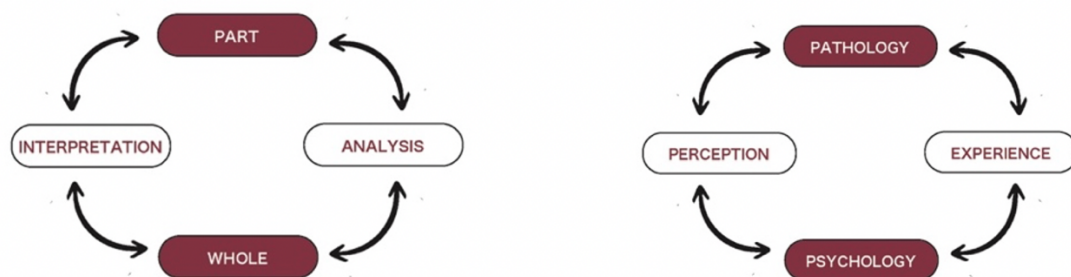


Figure 8: The Hermeneutic Circle and the PAPAP Circle

The cyclical nature of the medical experience means that there are multi-layered *impacts* and *consequences* for participants. For example, the pathology of facial nerve paralysis causes an increase in stress, which in turn causes an increase in facial twitching, which in turn causes an increase in stress and social anxiety, and on and on in a cyclical manner. These layers of consequence mean that the impacts don't stay neatly contained within this one single theme, but instead cause other impacts such as ones that effect the theme of identity. Conversely, participants also recognize that positive changes can also manifest through these negative experiences, for example by becoming intrigued by the wonder that is the human body.

Susan A

Susan A experiences uncontrollable facial twitching that causes her to become “really self-conscious”. Although the twitching occurs randomly, it is exacerbated by stress. For example, when she experiences work-related stress, Susan A feels anxious about whether the stress will cause her to start twitching, which then increases her anxiety, therefore increasing her chances of twitching. She

experiences this as a “big drama” and a “huge amount of stress”, and it has motivated her to modify her behaviour/activity/actions in multiple ways to try to avoid stressful situations. These behavioural modifications are one of Susan A’s main frustrations in managing her symptoms of Ramsay Hunt syndrome.

I felt quite depressed and quite down because, obviously, I couldn’t do things I would normally do. Doing something physical has always been good for me.

Her earlier depression, she believes, was triggered as much by the impacts of her condition on her routines, as by her facial disfigurement.

If I don’t do something physical, then I tend to go inside myself. I get too drawn in.

She describes her usual physical activity as being important to her wellbeing and as giving her a “perception of internal strength, in some ways”. Restricting her activities made her feel a loss of autonomy, complicated by the psychological impact of having to “lean on” people to get “normal things done” which was hard to process due to her loss of inner strength. Literally and figuratively, she “had to lean on Tony [her partner] to go for a walk”, which made her confront complicated psychological impacts such as having a strong sense of grief.

As a result of her visit to the SFNC, Susan A was also given rehabilitation exercises. Physiotherapy has been identified as a major contributor to the rehabilitation process of facial nerve treatment. In this case, it also had psychological outcomes, with Susan A feeling that she was able to gain “some sort of control over my face. By doing these exercises, I could participate in getting better.” This meant she didn’t just have to “wait on other people to do something” but could “be responsible for something” and “participate on my own in getting better”. The rehabilitation practice that she has learnt at the Sydney Facial Nerve Clinic has taught Susan A the importance of facial massage and of rest. She views these treatments/rehabilitation procedures as having both physiological benefits, as they reduced the physical symptoms, and psychological benefits, as they reduced the associated stress, which in turn has further reduced her physical symptoms, continuing on in a cyclical manner.

Liz C

Like Susan A, Liz C experiences a range of impacts that arise from her day-to-day engagement with the world. When she spends time looking at a screen, her eyes can become watery and sore. She experiences similar responses when looking closely at other people. This results in similar modifications of her daily activities and avoidance of certain social situations (such as having her photograph taken) which links this theme to issues raised in theme 1, identity.

However, Liz C also mentions the positive aspects of her experience. She is now taking more notice of her body, “of how amazing it is, and of what can go wrong”. She says that when she reflects on her experience, she can now positively acknowledge her own resilience, which is a positive psychological outcome. The world of medical encounters has enabled her to “meet amazing people” and to “learn a lot about surgery”. She has also taken up playing the cello, to direct her musical skills into a new instrument as a way to adapt to her “new normal”. However, she hasn’t hidden or sold her French horn, even though she is no longer able to play it. This acknowledges her poignant proposal that psychologically adapting to her “new normal” doesn’t mean she must delete her former self.

William M

If I took this glass and just dropped it on the concrete floor, that’s how it felt psychologically. I got to sit there, and I couldn’t do a single thing as I watched my entire life shatter into something that didn’t resemble, even remotely, what I had thought my life would look like. And that was [...] that was really difficult, because

there was a psychological aspect, which was something that no one could see but that I could certainly feel. And then there was the physical aspect, and that was something that everyone could see.

There were so many things affecting me at one point in time that I couldn't just sit there and say, "Oh, yeah, this is just the surgery that's causing this." I kind of had to sit there and be, like, "Well, there's the surgery and there's the emotional wellbeing and I've lost my independence." It was a whole combination.

William M talked of how emotionally draining he found the surgical interventions, such as when he received radiation therapy. The main effects of undergoing such a major procedure weren't just physical, "It was really the depression that was very, very difficult for me to deal with". Although he started to feel better over time, he realised he hadn't dealt with any of his emotional issues. Instead, he had just "swept them under the carpet".

During one of many procedures, an impactful side effect was an inability to swallow without the aid of a machine.

It was the first time in my life that I ever experienced true fear. I was terrified because I couldn't swallow. I couldn't even swallow my own saliva. So, everywhere I went, I'd have to have a vacuum sucker. I'd have to stick it in my mouth and get all the saliva, and the thought of having to do that for the rest of my life really scared me. Looking back, it's the only thing in my life that has ever really scared me or significantly scared me.

At the thought of never being able to swallow again, he says:

My heart rate went through the roof. I remember feeling really faint and I got cold sweats. I think when I say that that was the first time I've been terrified or truly scared, it was the first time I'd ever experienced that sort of response to a situation.

While the difficulties William M has faced have been described by him as being "far more difficult than dying", and despite his ongoing medical complications, he was able to feel something of a psychological shift/acceptance once he was able to swallow again "I was like, well, I better just be grateful for everything that I've got now." William M's complex journey isn't just about a spiralling within a circle of PAPAP, instead it indicated the varying degrees of intensity between complex relationships of pathology and psychology as, in this case, William M uses one of the most terrifying experiences of his life to help him to, in some way, come to terms with his pathology. While reflecting aloud on how navigating his complex medical pathology has enriched his life, William M taught me something about the anatomy of the brain, the ridges of which are called *gyri* and the grooves *sulci*:

The number of gyri I have in my brain has almost doubled in that period of four years. And this suggests that the number of neurons I have in my brain has gone up to maybe three or four-fold. And I'd wondered how much of that was related to having to relearn how to do certain things, like relearning how to walk and how to move my eyelid, move my eye again. And how much of that was related to the academic learning that I'd done as well. And that's also something that I don't think I'd have if I hadn't had this experience. It's like, if I don't wanna do something, then I won't do it. But if I love something, then I go hell for leather for it.

William M's knowledge of anatomy assisted him in seeking a positive from the impacts of the stresses of his situation. He reflects further on the positive aspects of his experience.

It's been very enriching for me to have that experience. I look at some of my colleagues who, to my knowledge, haven't been through a significant crisis, whether that's health or otherwise, and they just, they just don't get it.

In discussion of his family bonds William M also identified that responses to pathology can be positive.

It's also strengthened my relationship with my parents – my entire family, actually. Dad has certainly become a lot more emotional. I don't know if that's like a coming-of-age thing, but he is a lot more comfortable being emotional around me now and will confide in me about a lot of the difficulties he's having. It's really nice that we can just sit there as two guys sharing our feelings. It's just nice to see Dad, who grew up in like the sixties, the seventies, in that generation, [doing that].

In summary, this theme reveals that physiological and psychological impacts on patients are complex and intertwined, where closeness of family emerges from negotiating difficulty and where stress and physical symptoms affect each other, and where major physical impacts can result in increased determination, and the acceptance of a new normal doesn't have to mean the deletion of the former self.

Theme 3. Time: Time as a healer, time as a barrier, time as a container of doubt

This theme explores the complex and intricate relationship that participants have with the concept of 'time'. Their reflections on time reveal multiple considerations including time delays in accessing specialised care, timely access to treatments, time as an emotional journey (linking with the previous PAPAP theme), time as a barrier, and time as a journey of acceptance. Within the theme of 'time', the complexity of discussion ranges from the simple scheduling of an appointment to major considerations of mortality. In the context of permanent facial nerve paralysis, this includes time as a journey towards "coming to terms" with 'the new normal' - a concept that will be explored in the next chapter.

Susan A

Susan A explored time in various ways, including the impact of the time taken to maintain her treatment and tend to her various ailments.

[It] is so tedious, this whole thing – having to put tape on my eye and put gel in my eye, put drops in my eye, you know, eight times a day. [It's] taken time out of my usual [work] time.

She also referred to time as a healer. With time came physical and speech improvements, which meant she felt more comfortable.

I feel okay about seeing myself now, 'cause I know that I can use this side of my face a little bit better. I feel I can actually speak – whereas before, I couldn't get words out.

Time is enabling Susan A to learn how to better control the frustration and anger she feels when she's unable to do things, and to come to terms with the potential "new normal" that she can expect to experience. However, she said she feels she would have managed her anger/frustration better if she had known the expected timelines for treatment or recovery.

Time was also a barrier to care, with General Practitioners usually having only short available time slots. Going to the doctor can therefore feel like "being a number – get in and get out". She believes that this lack of available time from GP's inhibits the giving of care which she feels is about the little things, such as calling your patient by their first name and asking questions about their life (discussed

further in next theme section). Finally, Susan A referred to time as a place of hope for the future: she believes that she will continue to improve and, in time, be able to do the things she did in the past.

Liz C

For Liz C, time also had multiple meanings. In one way, time was an opportunity to get “used to it”, to adapt to social responses to her condition and to the “new normal”. She reflected on her perception that, within the medical process, the “busy-ness” of those providing care means there isn’t enough time to “find out what’s worrying the patient”.

Busy surgeons can't really spend a lot of time finding out about the worries and niggles a patient may have.

She also commented that time didn’t work at one speed: some impacts of facial nerve paralysis are gradual, while others are sudden. In terms of playing the French horn:

In 2014 I got what they thought was Bell's palsy, so I had a time of not being able to play. Then I got back to it. I was weaker in certain areas, but I mostly managed to still play. There were certain things I couldn't do (low notes, etc.). Then in 2017 I was supposed to play in a concert, but the tumour was found and [my doctor] said he had to do a surgical biopsy, so I couldn't do the concert. During that operation, he had to damage the facial nerve because the tumour was wrapped around it. Then I couldn't really play at all. So, I didn't do any music (apart from some guitar and singing at church). After 18 months – two years – of nothing, I started to think I should learn something else, in case it didn't come back. So, at the end of 2018 I was in Germany and a friend gave me a few cello lessons. When I got back, I started lessons in Darwin in 2019 and practised hard to try to get to a satisfying level.

Liz C’s mother told me in our one meeting that when Liz C was discharged from hospital following the final surgical procedure that brought her French horn playing to an end, she went straight to a music store and bought a cello. Liz C says:

I have found it really enjoyable. When I started, I was excited to rush home and practise. It was surprisingly satisfying very quickly and I'm still really enjoying the journey of it. It doesn't completely replace horn, because I really miss those shining moments in orchestra where my skills on horn, built up over 25 years, could really come into the light. I was good at certain things – lovely tone, picking high notes out of the air, etc. – and that was noticed by people. So, I don't have that [on cello] but my musicality can still show through cello and my teacher is very encouraging. I've got to a level where I can join in with Darwin Symphony and do what I can. With eight [cellos] or so, having one at the back who can't play all the notes is okay. And because I know the music, I know what to play and what to leave out and where we are up to. With horn you wouldn't be able to have an extra just sitting in, really – every part is an individual part and necessary. [Cellos] are all playing the same part in a group.

Finally, time is a consideration in the relationship between Liz C’s past and her hopes for the future.

My horn is in its case. It's a special instrument to me. I bought it in Germany and it's worth a bit of money. I hate the fact I may not be able to play it again, but I can't bring myself to sell it yet. I guess I still harbour some hope I could play again [...] but I know that's not realistic because of the permanent damage to the facial nerve.

William M

William M describes the incremental impacts of repeated medical intervention (“I’d had about eight MRIs in the space of a week”), which added up over time and created what he felt was an extremely heavy burden. He says he feels much older than he is:

Inside, I feel like I'm about 800 years old. I feel like I've lived a very, very long time, even though it's only been 26 years.

When William M first attended the SFNC, it was the first time in 12 years of treatment that a healthcare professional asked him how he was coping. This simple question, which took just seconds to ask, had a long-lasting impact on William M, initially causing him to cry during the clinical visit. This major moment for him, happened on my first day at the SFNC, and its impact has stayed with me. With that simple question, the flood gates were broken, relieving the pressure of experiencing 12 years of medical treatment without ever being asked how he was coping. An instant, but complex relief, it sticks with me as a memorable thing to observe.

Based on his experiences as both a patient and a medical student, William M is critical of how time issues impact on surgeons’ interactions with patients “they think they're the busiest people on the planet” and his opinion that they typically spend no more than the minimum amount of time that’s required to get through a procedure. This was a repeated concern of participants, that time constraints cause a major barrier to meaningful dialogue with treating healthcare professionals before and after major procedures.

In summary, this theme explores time as a consideration that is simultaneously a practical, emotional, and symbolic concept. Its practical components include the experience of repetition, of delays in access to treatment. Emotionally and symbolically, it is a reflection of hope, frustration, or increased burden.

Theme 4. Expectations and experiences of care

The theme of ‘care’ captures elements of what a ‘caring’ experience felt like for participants, and conversely, under what circumstances participants feel they did or didn’t experience adequate care.

Susan A

When Susan A was initially admitted to hospital during the onset of her facial nerve issues, the treatment and examination process was stressful. When she discusses this experience, she used words and expressions that signalled her dissatisfaction and frustration with the care she received and with how long it took for her doctor to “listen” to her or to “act” on what she was saying.

And, um, I was there for quite a NUMBER OF HOURS. The doctor FINALLY came to see me. Finally, she ACTUALLY looked in my ear, and then asked the same questions SO MANY TIMES without appearing to digest my answers. The doctor kept saying, “Why are you here? Why are you here?” And I’d go, “How many times do I have to say this, ma’am?” It took about four hours of her asking me why I was here.

During her five days of hospital admission, Susan A was told she was experiencing Bell’s palsy. However, when she left the hospital, her discharge papers said she had Ramsay Hunt syndrome.

So, when I was discharged after them treating my eye and getting me all the medication, they handed me a thing and then I read it and I said, “Oh, it’s Ramsay Hunt syndrome.”

This was the first time Susan A had heard of Ramsay Hunt syndrome. She asked the hospital what it was and explained that she had been told she had Bell’s palsy.

*I've never heard of it before. And I said, "I thought you told me it was Bell's palsy."
So, anyway, she said: "No, it's Ramsay Hunt syndrome." I didn't know what that was,
but everybody at the hospital kept saying to me, "You'll be fine in a couple of weeks."*

This poor communication by her doctor and the hospital meant that Susan A was discharged with no information about her condition. She didn't know what Ramsay Hunt syndrome was, what it might mean for her, what was the expected timeline of potential treatment, what was the likelihood of recovery, or even the different priorities that exist in initial treatment between Bell's palsy and Ramsey Hunt Syndrome and therefore whether she had received the correct treatment. This continuing misunderstanding contributed to her feelings of confusion, and she was also given conflicting information about the amount of medication she was meant to take, which caused her to have to return to hospital after she became so sick, she "wanted to die". Despite her negative experience in the hospital, Susan A thought the nursing staff were "wonderful". Even though she was very critical of her GP, she still conceded that, given the limited timeslots available for a GP appointment, her GP might have "had her own way of caring" although she didn't identify what that might be.

Susan A's language and method of expression seem to mimic her experience. When she is discussing her balance issues, her words mimic this imbalance: "Uh, uh, I'm, I'm." This 'lostness' and vagueness of her language potentially mimics her sense of being lost medically. Her stumbling attempt to express how the doctor responded reveals that she didn't receive or retain any information at all from the doctor and was just told to "file everything". She then articulates the rest of the doctor's words as "blah blah blah", potentially as a sign of their perceived meaninglessness or inattentiveness.

During a later follow-up visit to her GP, where she was offered no additional information about Ramsay Hunt syndrome or about specialists who might be able to help, she was told just to go away, and to come back "when you feel you need to see me". This made Susan A think, "There must be people who know more about [this condition]." Her experiences of visiting the hospital, her GP and an ophthalmologist left Susan A "feeling let down", so she started searching online for more information and came across the Sydney Facial Nerve Clinic. It is revealing to examine Susan A's different experience of care when she was able to engage with the knowledge base and skills of the multidisciplinary team at the SFNC.

*It's a little bit like being a specimen [...] but I understood that which is fine. I could
see that they were observing and also [...] there was a genuine interest in me.*

Susan A's experience of the doctor who led the clinic was that he seemed "open", like a "very likeable person" who did a good job of explaining things and "looked at me like he knew what he was looking at". This combination of perceived likeability, openness and knowledge was a marked difference from her earlier experiences.

It is important to note that Susan A's perception wasn't impacted only by the doctor's advanced knowledge of the facial nerve, but also by how he communicated the things he *didn't* know. When he proposed potential outcomes but followed up with "but I could be wrong" she didn't perceive this comment as negative. Instead, it meant that information had been shared with her about different potential outcomes, which also gave her something to track her progress against. For Susan A, the journey to the SFNC was one that shifted from her being dismissed by the medical profession to instead being acknowledged "*as a human being*" within the system.

*When I came out of the [SFNC] clinic, I went into the toilet, and I burst into tears. I
felt like it was a really positive experience, and that's why I burst into tears.*

Attending the SFNC gave Susan A a sense of optimism because it felt like she had found someone who actually “knows something about the facial nerve. They know what they’re looking at.” She reflected that a patient wants their doctor to “know what they are looking at, or at least to know how to get a patient the help they need if they don’t know what they are looking at”. Susan A wanted her doctor to “give her some sort of insight”.

Liz C

Liz C differed from Susan A in that her treatment involved several major surgeries for the removal of a brain tumour. She expressed no issues with her initial medical examination and treatment, and – in contrast to Susan A – she used very clear and defined language to share her pathology and experience. The importance of good medical communication was highlighted as a feature of providing “care”. For Liz C, this includes the doctor’s ability to explain procedures and their potential repercussions. During her multiple surgical interventions, Liz C built a trusting relationship with the surgeon, whom she liked. However, she reflected:

It sometimes takes time to figure out my agenda versus the surgeon’s agenda. He has a bigger picture of tumour recurrence and hearing and knows exactly what he has done to me internally. But I worry about repercussions for running and swimming, about the ugly scar and the lump from the last [surgery].

Liz C reflects on the differences between the ‘bigger’ issues, such as facial surgery or what was happening on the inside, and what might be seen as “secondary” issues, such as the impact of major scarring when she is out in public, running or swimming. She says there was no time allocated to discuss these aspects to assist her decision-making process, or to help her accept her situation (see also ‘time’ theme). She explains that the surgeon only spoke to her for a short amount of time, speaking very briefly about impacts, mostly focusing on the actual surgery, and that all of the decisions were made very quickly.

When she reflects on what the experience might have been like for her surgeon, Liz C comments:

I’m a body he has fixed up – nerves, thigh, eyelid, tumour, scans, etc. He notices increased and decreased weight when it affects parts he will operate on. He can see his handiwork, which must be satisfying. I’m probably an interesting case.

Liz C spoke very favourably of the allied health professionals that she engaged with at the SFNC, including the physiotherapist and speech pathologist. She felt that the physiotherapist went “above and beyond” what was expected of care, which helped her confidence as this type of care also included providing praise, enthusiasm, and time to talk. This had the effect of drawing out the emotional as well as physical impacts of her condition, which made her medical treatment feel very personal. This topic of the patient’s needs for personal care, compared to the healthcare professional’s need for detached concern, will be examined later in the discussion section of this chapter.

Liz C felt encouraged and supported by the speech pathologists, who checked her regularly after surgery. The multidisciplinary support she was offered at the SFNC meant she was able to speak with other healthcare professionals about any problems she might have been having with the process. For instance, if she needed further clarification from the surgeon but wasn’t able to raise him, she had other people she could approach to find out information. However, she thought the patient experience overall could be improved in these types of serious medical interventions if a case worker were appointed to be across all the treatments and procedures, coordinating the various communications and helping the patient to understand the totality of the health experience.

Liz C expressed the desire that care should include caring for her humanity, such as asking how she is coping or how she feels about an upcoming surgery. These elements aren't always present, she says. Finally, she reflected on self-care, which for her included:

[...] debriefing with friends and family. Taking up cello to fill the hole that stopping French horn left. Lots of swimming. Focusing on healthy food and fitness (I kind of intensified my exercise at the same time that I was diagnosed with a tumour, and someone did say to me it can be a compensation to try to get fit when other medical things are going wrong.) Focusing on the positives: enjoying the interesting journey that it has taken me on – being at the amazing Chris O'Brien Lifehouse, meeting interesting people like [my treating doctors] and yourself, having trips to Sydney which also let me see my parents regularly in that time – and reflecting on my experience through your study and exhibition, etc.

Later, I will expand more on Liz C's reflection that meeting me as an artist–researcher and participating in this research process and the final artistic outcome, was an act of self-care.

William M

William M gave a thorough and lengthy critique of the many medical professionals he has encountered. His experience has been wide-ranging, from healthcare professionals whom he “didn't like one bit” to others whose “smiles just lit up the room”. William M discussed the different personalities and care competencies of different healthcare professionals. The ‘better’ experiences were ones where the healthcare professional was ‘gentle’ and ‘caring’. In his experience, the doctors who had more personable natures also seemed to be better communicators and more willing to share information about his pathology and treatment. Others who seemed less caring “wouldn't give us much information about what was going on and what could be done”.

The healthcare professionals who made William M feel cared for were those who showed compassion, offered companionship, displayed competence and were good communicators (making him feel informed). He used language such as “I loved them” when talking about one medical practitioner, whereas he described his experience with another healthcare professional as “sour”.

During his first medical interaction in a hospital at the age of 12, while still waiting for a full diagnosis, William M was told by a nurse: “This doesn't look good.”

I was lying on my side at the time. I put my head down into the pillow and I remember crying and saying, “I don't want to die yet.”

The nurse's comment had a major impact on the entire family, with his parents becoming “very distraught”. However, William M also had pleasant experiences. During a subsequent five-day hospital stay, a pediatric intern would come and spend some time with him each day, sitting with him and reading him anatomy textbooks. This provided him with companionship, but also helped to demystify what was happening in his body.

Given William M's young age, his doctors didn't want to operate on his brain tumour. So, for the next six years, he underwent regular scans, tests, hospital visits and brain bleeds. During this time, William M felt “left out to dry by the medical system”. He says he was made to feel that his case was “too difficult, and people just didn't want to deal with it”. At the age of 18, he moved out of his parents' home and started studying Medicine at University.

Finally, William M met a doctor who was prepared to operate to remove the tumour.

I could feel the relief washing over me. And I thought at the time, “Oh, this might/will come to an end if he can take it out.”

However, when William M woke up from the operation, things weren't as expected.

Heading into the surgery, I thought it was wonderful. I thought – very naively – this would be the end of all my health problems. Um, and when I woke up, everything was completely different. I couldn't move the left side of my face. I had a strabismus¹⁵ and my left eye was turned in, so it was quite a lazy eye. I couldn't feel my right arm, or sorry, I couldn't feel temperature in my right arm. I couldn't walk properly. [It] was shit. I hadn't expected it to have that significant an impact on me.

When I asked William M whether the doctor had told him about the potential impact on his facial nerve of removing the brain tumour, he replied:

Look, I don't remember him doing so. He may have, but I certainly don't remember it. Mum and Dad don't recall it either. But we might have been quite shocked at what was going on as well.

William M's reaction was:

I didn't sign up for this. Emotionally, I got no support.

The lack of support from his doctors resulted in William M feeling an emotional loneliness around his illness, and it wasn't until he visited the Sydney Facial Nerve Clinic 12 years after his ordeal with a brain tumour began that anyone asked him how he was coping. He believes this lack of discussion of things such as depression by healthcare professionals in the general course of treating patients is a serious issue in medical care.

William M's experience identifies another core component of care, which is *competency*, and the doctor's ability/desire to, at the very least, connect the patient to people who could help with other aspects of their care, and to extend the borders of their own knowledge by working with other practitioners outside the 'silos' of medical disciplines.

For example, it was several years after William M's facial nerve was cut during the surgery to remove his brain tumour, that he was first informed by a specialist that two years is, in many ways, a cut-off period for specific treatments to aid the rehabilitation of the facial nerve. When the specialist asked William M why he had waited so long, he replied that it had never been suggested that he see a specialist or even mentioned that there was a two-year cut-off. As a result, he developed a mistrust of many health professionals.

My life was completely turned upside down and inside out. It no longer resembled something that I could recognise.

William M identifies the main barrier to care as being the disparity between the objectives of the patient and the objectives of the doctor.

I think a lot of that stems from my experience as a patient, where I've often felt that my needs are secondary to the desires of the treating doctors to do what they want to do.

A further barrier, he feels, is the medical education system itself.

¹⁵ *Strabismus* is a condition where your two eyes don't look in the same direction at the same time.

I think that, in my time at medical school, there's always been a huge emphasis on having what they call a biopsychosocial approach to patients. No one ever talks about a psychosocial approach to patients. Everyone just focuses on the biological side. So, what lifestyle measures can we do for a patient? What medication changes can we do for a patient? What surgical measures can we do for a patient? And if all of that fails, what palliative care can we give for the patient before they die? And if you look at, I'd say, a good 95 per cent of the treatments that doctors give to their patients, they just focus on those four things. Very rarely do they try and bring in a psychosocial aspect, which is arguably more important because that's what the patient lives. That is their experience [...] I think there should be a real emphasis on that in patient care. The learning in medicine is that you must be practising that by a psychosocial process, but then people aren't taught how to do that.

He further reflected that poor communication, as well as structural issues such as socio-economic status, ethnicity, gender, sex, equity, equality, climate and politics, are additional barriers to care. Given his own position as a medical student, he reflects on the 'teaching' of empathy and biopsychosocial knowledge within medical education:

Some think that you either have [empathy] or you don't. Some think it's learnt. I think it's a mixture of both. I think that, to an extent, you can learn it, but I think it's also something that needs to be experienced if you're going to be able to deal dynamically with having difficult conversations and with the rollercoaster of emotion that comes with them. I'm firmly of the opinion that, to understand empathy, students need to be put in a real clinical situation that requires it to be dealt with.

Everyone is taught a standard. I can appreciate how that must feel. And that's one of those throwaway statements that you'll hear. You do. You hear it over and over and over again. Yeah. And you also hear, "Oh, I can understand this must be difficult." And I can tell you quite confidently, as a patient, that they have no fucking idea what it's like when they're telling you, when they're breaking that news.

Which is why they can't pick up more subtle information, such as that the person mentioned they have to go home to their partner who has a disability.

As mentioned, it took until William M's first visit to the SFNC, 12 years into his treatment, for him to be asked, for the first time, how he was coping. He says this act of being asked was such a "huge relief" that he wept.

In summary, the expectations of care for patients at the SFNC were identified as including the following elements:

Connection	Being kind, careful and considerate.
Competency	Knowing your area of specialty, how healthcare professionals deal with things they don't know, and how medical education impacts this.
Communication	Knowledge translation, how healthcare professionals share and make sure information is understood including translating things they don't know.
Performativity	Language, actions, affect, embodied, witnessed

These components tell complex and connected stories of participants expectations and encounters with care. We can understand the first three components of connection, competency and communication as all being embodied through the final component of performativity.

Theme 5. Hierarchies of pathology: Am I just complaining?

Another theme that arose in the interviews was about people's perception of what I call the *hierarchies of pathology*. What this means is that patients experience feelings such as trepidation about whether their pathology was important enough to take up the clinic's time. This resulting in them thinking things such as *am I just complaining?* This had the impact of making participants question if they even deserved medical treatment, as well as causing negative impacts on their sense of identity (theme #1) and agency.

Susan A

Susan A explained the experience of preparing for her initial visit to the SFNC.

There was a little bit of trepidation about coming along, in the sense that I might be told that my condition wasn't serious enough. That I would just be told to go home, like the doctor up the road, who said just to go home and come back in a few months.

Susan A described her feeling of doubt about the "importance" of her condition; her perception that having a facial nerve disorder isn't as important as "having your leg chopped off, for example". But she further reflects that Facial nerve disorder isn't "an invisible loss", it is instead:

[...] our face with the world – we don't see people through the world with our leg or our arm. We see people through our faces. You can get a replacement for a leg.

Susan A perception of her right to seek treatment was negatively impacted by the initial medical care she received, the impacts of which continued to have effect, even once she began to receive adequate care by attending the SFNC.

Liz C

Liz C discusses "secondary" physical impacts that worry her, and which she tried to manage by modifying her behaviour and avoiding certain situations. She feels that these issues, such as a scar on her leg following surgery, weren't addressed as they weren't "major" pathology issues, and therefore the additional trauma, stress and anxiety they caused were ignored.

A surgeon will be worried about infection, but a patient may be worried about how they will look. A surgeon is happy with a healed scar, but a patient may be worried about the look of the scar. (That was me!)

William M

Unlike in Liz C and Susan A's cases, William M's ongoing major issues with brain tumours meant that he didn't question his right to be receiving treatment or the severity of his condition. However, his story is still relevant to the theme of *hierarchies of pathology*. His experience has been that a powerful hierarchy exists in terms of the needs of the doctor vs the needs of the patient. William M believes that 'care' requires this hierarchy to be replaced by a relationship between the doctor and the patient that is based on shared aims.

William M talked of having to navigate the psychological aspects of surgeons not explaining the potential negative outcomes of procedures (such as permanent damage of the facial nerve), and not being able to discuss with his medical caregiver his shock when this became an actual outcome. Therefore, closure couldn't happen because it never seemed appropriate to raise, with his surgeon, the question of whether the specialist had adequately explained this possible outcome.

In summary, this theme concerned patients' perception of hierarchies and burdens that lead them to question entitlement to care, even resulting to them having to do their own doctoring, on their own behalf. It showed how this feeling is often caused or exacerbated by initial care received and past experiences as well.

Theme 6. Communication: What's needed

This theme explored participants' experiences of access to information. On one hand, participants reported that issues around poor clinical communication meant that they could feel unprepared for major procedures or miss vital information which could potentially have major impacts on the prospects of recovery and psychological prepared-ness. On the other, participants discussed how they looked to alternative, self-directed sources for information, self-sourcing information such as stories about lived experience from other patients.

Susan A

I just kept thinking, "It's the 21st century. There's gotta be people out here who know something about the facial nerve."

Susan A was eager to use the internet to find "layperson knowledge" and "accessible information" about the facial nerve written in non-academic/medical textbook language. The lack of information she received from her GP and the hospital, including lack of acknowledgement and lack of information, made her feel alone. "Nobody I spoke to had ever heard of Ramsay Hunt syndrome." So, for Susan A, the internet became an essential source of information, as well as a conduit for connection with others who experienced similar pathologies and who could potentially provide the solace and understanding she found lacking in her medical caregivers before she attended the Sydney Facial Nerve Clinic.

Despite most of the online content being from overseas, blogs written by other people with Ramsay Hunt syndrome helped Susan A understand "what I might experience", and "what others had experienced", and how she might progress through the "day-to-day stuff". For example, she learnt that her condition might cause her to get soap in her eyes more easily when washing her hair and found tips on how to manage this. Information she found online helped her to have a better understanding of what was, and wasn't known about Ramsay Hunt syndrome:

I would have liked to be told what those known, and those unknown things were. And I think in some ways that's what I was trying to look for when I was looking up, you know, that Ramsay Hunt, like what, what is it? And what is it meant to look like? And how does someone look? Or how does it affect someone? And, you know, uh, what are the symptoms meant to be? What is it that you are meant to be feeling, you know?

Reading people's blogs was "like a personal diary of their experience, so I could actually see that someone's experience was very different from someone else's" revealing that even if someone's pathology was about the facial nerve, but different, she still found it to be "very helpful". This included finding shared information such as photos, personal accounts, and stories of returning to work as well as discussions on topics such as how they were treated by other people, and how they coped with depression. Susan A repeatedly described these issues as the "other stuff" that she says needs to be attended to by healthcare practitioners when enacting care for a facial nerve patient.

Susan A commented: "It seems like the whole idea of sharing information with patients is missing in some ways." She says that more information is needed for the person "to understand what could or might happen" because if this type of information was more readily available, then patients wouldn't be left wondering why things are happening to them, "or whether you were the only person having this experience, or whether it would be permanent" she says.

Susan A felt that, before she attended the SFNC, it had been up to her as the patient to “do the job of the doctor”, which she did by going online to investigate her options, to educate herself about the symptoms she could expect, to share in the experience of others and to feel less alone.

Liz C

The internet was an important resource for Liz C, helping her to locate the information that she felt was missing throughout her care journey. The things she searched for included factsheets with information about surgeries and different types of tumours, general information about the facial nerve, details about staying in hospital and the different procedures she might encounter. Liz C thought her doctor should have had this information already on hand to enable scenarios along the line of “You’re having this surgery. Here are some factsheets about preparation and recovery, etc.” She was so eager for this type of information that she would have “gobbled up anything I was given to read”. She was not given details and accurate information about the different types of surgery, or their effects and pros and cons which would empower her to make more informed decisions, instead she relied on following the wishes of the surgeon, which suggest that the long shadow of bio-medical practices that positions the doctor as the one with all the knowledge, who will therefore make all the decisions, is still part of the mottled patina of the health experience. She reflects that trying to find out any more information is “completely left to your own muddling research. It’s not like there are any factsheets handed out. I had to try to locate factsheets from other hospitals to get an idea and hope it was sort of the same.”

Another treasure that Liz C searched for online was access to personal narratives/discussions and other patients’ journeys: “I also wanted to talk to people who had had the surgery, but I do realise it is such a personal journey and everyone’s case is different” but she believes that the facial nerve clinic has the potential to facilitate this kind of connection. This happened in a small way during Covid-19, when the SFNC shifted to an online clinic and the waiting room, on Zoom, became a place to, in some way, connect with other patients. “It was an interesting experience doing the facial clinic. It was nice to wait in the ‘waiting room’ with others and have a chat about people’s situation. I hadn’t spoken to anyone before and found out different stories, so that was nice.”

Liz C also turned to online chat groups for people experiencing facial nerve paralysis. There are several options for these on platforms such as Facebook, providing opportunity for a user lead support and information exchange system.

“Now I’m on the facial paralysis Facebook group, but it’s nearly overwhelmingly members across America and UK. I’d prefer just an Australian site. There’s nothing from Australia and not enough on the facial nerve clinic. From America I found YouTube videos of a lady who had a tumour removed and she was being interviewed by the doctors about her experience of the process and care. But she didn’t have my exact situation. Then on UK sites I find excellent explanations of the cross facial nerve graft surgery and impact, plus videos for facial massages. Eventually I joined the Facebook site for facial palsy sufferers, which is mostly American based.”

Finally, Liz C concluded that she wished there was more information about the SFNC online.

William M

As has been expressed throughout this first part of the chapter, William M’s experience was one of ‘missing information’ which he took on as his responsibility.

I feel like I should have read more about what was happening, what people did after brain surgery, what services they needed access to – [I should have] just read forums

or information pamphlets, things like that. And I should have known that if something was wrong with my eye, [I should] go and see an ophthalmologist. I mean, I can't cry helplessness all day. I think it just gets to a point where it's like, you just need to shut up and do it.

William M repeatedly reports that his experience was riddled with poor medical communication, lack of information, and a sense that he needed to direct his own medical care, which is a complex undertaking given the multiplicity of issues that he faces. His experience at the SFNC was positive in that it addressed some of his concerns and enabled him to make some much-needed “change”. It also made him imagine that the SFNC could potentially be a clinic that had a strong focus on “after care”, one that transitioned from being a “clinic of medical treatment” to being a “clinic of wellbeing” – a national network that shifted the focus from medical treatment to allied health and included social workers and psychologists.

In summary, patients experiencing facial nerve disorder expressed their reliance on the internet to seek information about their condition due to factors including the perceived lack of information they have received from the healthcare professional, a desire to connect with people with similar pathologies/experiences, to find out more information, share stories, and to combat feelings of isolation. Used in this way, the internet become (and has the potential to be) a tool for providing practical information, social opportunities and perhaps even a sense of hope.

Discussion – Care-ful caring

Having shared the results of the IPA in a manner that allows the voice of the patient to take centre stage, I will now interpret these finding in this discussion section through the lenses of my theoretical frameworks of the phenomenology of Emmanuel Levinas, new materialisms, illness narratives, and care ethics.

The results of this study identified several important themes, including:

1. IDENTITY: Exteriority and reconfiguration of self
2. THE PAPAP CIRCLE: Pathology affects psychology affects pathology
3. TIME: Time as a healer, time as a barrier, time as a container of doubt
4. CARE: Expectations and experiences of care
5. HIERARCHIES OF PATHOLOGY: Am I just complaining? and
6. COMMUNICATION: What's needed.

Through careful interpretation, it becomes clear that these themes are not isolated, but rather interconnected and overlapping. Consequently, they present an opportunity for further analysis to reveal new insights and discoveries. A prime example of this interconnectedness can be found in the participant discussions around the concept of ‘time’. For example, discussion about the temporality of illness revealed a recurring observation; that concerns about issues of time (theme #3), generally impacted the type of care patients received (theme #4). Additionally, the frequently repeated perception that surgeons don't have enough ‘time’ to adequately address patients concerns about expectations of upcoming procedures, or to thoroughly delve into their concerns and questions or by rushing through their appointments, means that the concerns of time (theme #3), impacted their experience of care (theme #4) as well as their perception of the hierarchies of pathology (theme #5). In this section I extend the interpretive analysis of the phenomena of care by exploring these connections in ways theoretically informed by new materialist and relational ethics perspectives.

The interconnectedness between these themes highlights the intricacies, depth, significance, and entangled nature of the care-giving experience, as patients grapple with complex experiences, such as not knowing the person they see in the mirror, or not knowing what treatment options they have. This reveals that poor medical care can not only have negative impacts on the treatment plans of

patients but can also threaten their identity. Conversely, 'well performed' care can diminish identity issues/exteriority issues by making patients feel 'seen', giving them the sense that they can access the support they need and simultaneously access their own agency. When care is car-ing in this way, patients experience a positive self-reinforcing cycle in which improved physical health leads to, and is in turn augmented further by, improved psychological wellbeing that strengthens their threatened identity and perception of their right to receive treatment.

The concept of 'performance' or 'performativity' of care is prominent throughout the result section above and is highlighted in the components of care within theme #4. In this context, the word "performance" doesn't propose an insincere act, or a disingenuous artifice. Instead, I use the concept of performativity as it has developed within 'postmodern' scholarship. This has its roots in anthropology where performativity is defined as a 'speech act' (Austin, 1975) which details the impact of speech 'doing something' rather than just 'saying something'. For example, when a doctor informs the patient of their diagnoses, it is a speech act that constitutes an action which has consequences that significantly impact the patient's life, altering their reality. The philosopher Judith Butler proposes that a speech act of this nature "produces the phenomena that it regulates and constrains". In this sense, the 'performativity' of medical knowledge and attentiveness can result in defining a patient solely by their illness, confining them to a bio-medically imposed identity.

The idea that care is "performed" in this embodied manner, is a topic that emerged in the identified themes above, in both its presence and its absence, and aligns with my own attention to the attentiveness to affect that is present in my own artistic processes. This analytic interpretation of these interviews fits with the theoretical framework proposed by Maurice Hamington, a care ethics scholar who bridges the gap between care ethics and new materialism through his anti-dualistic approach to care. Hamington explores the importance of 'performance' to care ethics. He describes this performance as an 'action', a "witnessed event" performed by an "embodied human being" (Hamington & Rosenow, 2019, p. 15). Hamington proposes that in a medical context, "the body is viewed not only as a repository of tacit knowledge regarding how to convey care, but also a resource for imaginative empathy than can improve patient relations" (Hamington, 2012, p. 52).

In the early stages of this research, attending the SFNC, I was immersed in conversations laden with precise medical language; words that were foreign to me with my lack of medical training. However, I was able to develop some level of understanding by observing the embodied performativity of the healthcare practitioners. Their intentions of professionalism, care, skill, and enquiry were palpable and evident through their actions. These embodied performative actions were "witnessed" by me, an important element of performativity discussed by Hamington.

While Hamington argues that clinician's technical language and diagnosis provides an important, albeit limited, notion of care that does not account for the robust notion of caring described by feminist theorists" (Hamington, 2012, p. 53), the response of participants in this research, revealed that technical proficiency displayed through the doctors speech act, coupled with their embodied actions, did indeed contribute to a beneficial level of care. Additionally, participants were adversely affected when speech acts were not accompanied by an embodied performance of care.

An important aspect of nurturing embodied performativity aligns with the aims of the IPA approach and the phenomenology of Emmanuel Levinas by caring for participants without imposing predefined research assumptions. Importantly, this study does not claim to fully comprehend, or know the participants or their experiences, which is acknowledged by the potential for multiple explorations of the entanglements between themes. Whilst the new materialist philosophers that contribute to this research might propose that the agency of the other person is co-constituted in our interaction, Levinas instead proposes that the agency of the other is contained within 'them', and my

responsibilities towards them concerns the ethics of me not ‘colonising’ the other person with pre-conceptions. My process adopts a genuine engagement with the entanglements of diffractive practices, accepting multiple theoretical positions as a ‘flow’ of ontology, and understanding these complex relationships as a form of perpetual ‘becoming’ (Deleuze & Guattari, 1987).

Exteriority is a theme presented in analysis above, and is a phenomenon that is raised by Emmanuel Levinas in his publication *Totality and Infinity: An Essay on Exteriority* (1979). Levinas’s ‘exteriority’ refers to the concept that the “Other” always remains outside of ‘us’ (Levinas, 1979, p. 49). This is a foundational principle for Levinas’s concept that the “Other” is only definable on their own terms, and in-fact is ultimately unknowable to us (an exteriority). By presenting the theme of identity and exteriority (theme #1) in this way, I am proposing a synthesis, via Levinas, that the pathology of facial nerve paralysis can render the patient with a sense that they themselves are an ‘Other’ that is unknowable to themselves, and that all of these themes, through their interconnectedness, can impact the embedding of this exteriority.

The theoretical frameworks used in this thesis all explore various concepts of ethics. While the semi-structured interviews did not explicitly raise questions of ethics, their resultant critiques of medical ‘care’ fit closely with issues raised within the literature, for example within *care ethics*. This begins with the core recognition that to *care* for someone is to have an ethical relationship with them. In some ways, these participants all provided conceptions of care that closely align with Tronto’s original approach, as set out in her four elements of care (Tronto, 1993) which were *attentiveness, responsibility, competence, and responsiveness*. While the field of care ethics arose as a binary opposition to accepted ethical theories of the time, it was Tronto’s fifth element of care, *relationality*, which she added in 2013 as part of a *second wave of care ethics*, that points care ethics more towards the other relational theories within this research. The inclusion, by Tronto, of ‘relationality’ enabled the development of her argument to include a broader purpose for care ethics beyond the intimate relation, into relationship with much larger concepts such as democracy, economics, and in this case, health care. This, therefore, confers in the direction of Levinas who proposes, as discussed in Chapter 1, that acknowledging the Other is *irreducible to categorisations*, “makes the pluralism of society possible”. (Levinas, 1979, p. 57)

[T]he epiphany of the face [...] attests the presence of the third party, the whole of humanity in the eyes that look at me. (Levinas, 1998, p. 213).

The underlying ‘pluralism’ that encourages the emergent and relational nature of this research is expressed in these interviews. It reflects a desire for a medical experience that is *relational – a joint journey*; in the words of new materialist philosopher Karen Barad, an *intra-action*, which she defines as a “mutual constitution of entangled agencies” (Barad, 2007, p. 33). As evident from the interview extracts, the realising of this type of ‘relational care’ is far from straightforward. Instead, it necessitates navigating complex and emergent affective states, as well as confronting real and perceived barriers to care. These findings align with current conceptualisations of care within health, as set out in Chapter One, mostly authored by nursing scholars attempting to distil the essential features, factors or dimensions of care (Leininger, 1981; Roland, 2014). By the standards of Roland and Leininger, patients experiencing facial nerve disorder often find that their general treatment is of a *low* standard of care: Their care lacked accountability (in fact, patients felt that asking questions was illegitimate) and it lacked empathy, as evidenced by the absence of queries about how they were coping.

Within this study, we encounter patients who have complex relationships with the concept of ‘time’. This is further exacerbated by long and varied processes of *waiting*. Long waits for specialist appointments, clinic dates, tests, results, more tests and more appointments, are experienced alongside another type of waiting that confronts concepts such as explorations of self, facing of

mortality, avoidance, and depression. Anthropologist and zoologist Peter D. Dwyer proposed that the *waiting* can be defined into two experiences - *situational waiting* and *existential waiting* (Dwyer, 2009, p. 18).¹⁶ He describes situational waiting as a type of waiting that is 'of the world' – a commonplace, procedural waiting that is always in context with its surroundings and expectations, such as waiting for a bus or waiting for an appointment. Existential waiting, on the other hand, is defined as an embodied experience, such as when outcomes revolve around an "uncertain future" (Dwyer, 2009, p. 19). Dwyer also suggests that there is "no fixed line that separates situational and existential waiting" (Dwyer, 2009, p. 25).

Within this waiting, lies multiple potentials- from recovery to deterioration, during which time it can feel like life is on hold or that time is moving on without your being involved in it. The impact of poor communication, of missed opportunities, or of extra time needed to search for potential treatments, is a major obstacle for, and a source of criticism from, patients experiencing facial nerve disorder. This includes the risk of missing out on time-sensitive treatments (such as two years for nerve rehabilitation). However, as with most themes within this study, we see that there is at least something of another side to this, in that time is also an emotional enabler for navigation towards the 'new normal', providing 'space' to come to terms with pathology and to navigate the symptoms and complications that arise in day-to-day living.

The experience of time is further examined in medical literature which identifies that extended wait times for patients can result in negative clinical outcomes (Moscelli et al., 2016; Reichert & Jacobs, 2018; S. Su et al., 2016), as well as the impacts of time on pathologies such as mental health recovery (Deegan, 1988) and cancer (Martino & Freda, 2016). Martino and Freda studied the experiences of "time" for women experiencing treatment for breast cancer and identified it as a "parenthesis":

[...] a time suspended and removed from the natural flow of time: "I lived the dark period of chemotherapy for more than a month, a month removed from life; you are dead, not alive." The clear separation between the patient's life before and after the diagnosis is the most prominent; it represents a suspended period of life in expectation of healing or death. (Martino & Freda, 2016, p. 627)

Within the mottled patina of the health experience, we can envision the patient with facial nerve paralysis as a body that is actively participating and waiting to react in some way (Andrews, 2018, p. 126), a body that is participating in the potentials of time.

This chapter identifies that the lack of general knowledge and competency within the medical community beyond the SFNC, is a major issue for patients, especially when there *are* important timeline requirements, such as the improvements that come from receiving corticosteroids steroids within 72 hours of the onset of Bell's palsy (Vargish & Schumann, 2008) or when there is a two-year timeline for the rehabilitation of facial nerves before they succumb to atrophy and motor endplate fibrosis (Morgan, Stuart & Byrne, 2004).

Accessing the specialised services of the SFNC provided a remedy for some of the deficiencies in care experienced by participants. As quoted earlier, one participant (S.A), eloquently reflected that being able to access the SFNC felt like being re-connected to their own humanity. This arose from various factors such as her exposure to competency, effective clinical communication, and the performative aspects of medical care. Attending the clinic not only provided her with previously missing information, but also gave her an understanding of treatment plans, and potential timelines. In enacting medical care, however, it isn't just the 'known' elements that provide value; there is equal

¹⁶ Dwyer developed these classifications from the work of Professor of philosophy Lars Svendsen, who explored them in his book *The Philosophy of Boredom* (2005).

value in understanding how to articulate the potentials of the unknown. Combined, these elements contributed to enacting a type of care that was more in sync with her own expectation of care; a care that included being kind, careful and considerate. Despite not understanding a lot of the healthcare practitioner's medical language, she explained that it gave her confidence that he had expertise in the field. This indicates that the performativity of medical knowledge/care, expressed through clinical language, is simultaneously a form of medical communication and a performing of care through perceived competency, including a competency to be able to relate what the doctor 'doesn't know'. This highlights a vast difference between the patients experience of being given wrong or misleading information before attending the SFNC, and their subsequent experience of being cared for through the potentials of various treatment plans.

While it is widely acknowledged that the quality of medical 'care' and treatment wait times effects patients negatively, this chapter explores a deeper and more nuanced consideration of what these impacts mean. The profound effects on patients have far reaching implications for issues of identity and hence exteriority, *and* hence the capacity to manage pathology. The majority of patients, therefore, find themselves questioning their sense of what they are entitled to, and how much space they are entitled to take up within the healthcare system. Susan A, for instance, offered that the feelings which she developed during her initial medical encounters, still persisted at the SFNC, however, the performative nature of care that she experienced there, helped to alleviate them. Therefore, this study reveals the pervasive nature of negative medical interactions and recognises their potential to impact how, and if, a person might seek access to medical care. It raises the question of whether someone with a different personality might have chosen not to visit the SFNC at all after feeling "dismissed" by their GP? This acknowledgement underscores the fact that people's anxieties regarding the significance of their condition aren't solely generated internally but are shaped by past medical experiences.

Doctors are seeing so many different people with so many different ailments, I suppose. I [...] it's just that [...] I just feel like it is [...] there's just [...] you're just another one, if you know what I mean. Just another person.

These results highlight that by attending the SFNC, which brings together a multidisciplinary team to deliver health outcomes, the opportunities for the patients' expectations of care to be met, are increased. However, like many things, the positive experiences of the SFNC don't mean it is completely free of the perceived constraints of biomedical practice such as the separation of subjectivity and objectivity, the perception of hierarchies of pathologies, time constraints of healthcare professionals and the needs of the doctor vs the needs of the patient. Conversely, participants also looked for the 'good' in their situation, such as Liz C's poignant acceptance that psychologically adapting to her "new normal" doesn't mean she must delete her former self, alongside her considerations about future potentials for the SFNC which include the potential for the SFNC to be a wellness clinic, rather than a medical clinic, where provision of multidisciplinary care could be guided by a case manager – someone with knowledge of relevant treatments and procedures, who can assist patients in their encounters with various specialists, guiding them through the components of their treatment plan. Participants also identified the potential for internet-based resources to assist them to further their knowledge and to fill in the gaps.

This chapter has effectively displayed the multiplicity and connected-ness of impacts experienced by patients with facial nerve paralysis, making space for the direct words of the participants, and my interpretation of them. I have attempted to be clear about my own position within this study by identifying my multiple theoretical lenses and my interest in the ability of socially engaged arts practice to navigate these complex topics. By dedicating extended time for interviews and discussions with study participants, I have created a safe and supportive space to share their story, explore their concerns and find a voice within their medical experience.

Drawing on the finding of this study, it is evident that the methodology of IPA not only enables us to contribute theoretically, but also directly, to the act of caregiving. Here the data collection process itself, becomes an act of care, which is confirmed by the participant Liz C who shares her view that deciding to participate in this research was, for her, an act of self-care.

The findings of this chapter, now serve as the foundation for the next chapter, which examines practice-based research methods and outputs. Together, these chapters form a complex examination of what contribution an artist might make to the clinical experience of patients who experience facial nerve disorder.

CHAPTER FOUR. RESULTS #2 FACE TO FACE: THE NEW NORMAL

I begin this chapter by revisiting the pre-face at the beginning of this thesis. As an artist-researcher enrolled in a Faculty of Medicine and Health, I encounter the diverse disciplinary traditions and assumptions that are considered to be the most impactful ways to generate, translate and present research within each field. As previously expressed, I don't seek to be subsumed into any particular 'version' of research, nor am I trying to purposefully agitate against any particular tradition. Rather, I approach this process in a manner that aligns with my philosophical frameworks, and therefore I proceed with a process of relationality and emergence. One outcome of this is the presentation of two 'results' chapters. The first of these took a traditional approach by using a well-established qualitative research method, Interpretative Phenomenological Analysis (IPA). In this chapter however, I aim to share how the information interpreted in Chapter Three, also gave rise to a series of artistic outputs that support one of the claims of this thesis - that socially engaged practice is also a practice of care. I present these creative methods and outputs as a type of affect-ive research method that values, responds to, and generates affect-ive responses, motivations, and outcomes.

By examining the creation, presentation, and analysis of the 15 artworks that were made through engagement with patients and healthcare professionals at the Sydney Facial Nerve Clinic (SFNC), I will show how artistic-practice-as-research has the potential to be an impactful method of care within the crucial and complex environments of the medical experience. By doing this, my claims are sixfold:

1. That the inclusion of an artist in a medical clinic can result in improved clinical outcomes for patients.
2. That inclusion of an artist in a medical clinic can result in artistic outcomes that also engage with professional artistic concerns.
3. That the 'care-ful' sharing of artworks that explore trauma, can have a positive benefit for both patients and the public.
4. That the sharing of these works publicly in a gallery space can enact important conversations about difference, trauma, and social acceptance.
5. That we don't have to remove 'art' concerns from the arts and health (or socially engaged) method, for it to have social good.
6. That we can infiltrate the visual arts sector by bringing a complex socially engaged art outcome into a gallery space.

To achieve this, I will continue to call upon my core theoretical frameworks of Levinas, new materialisms, illness experience and care ethics/aesthetics to attend to the components of care that were identified (Chapter Three) as:

Connection	Being kind, careful and considerate
Competency	Knowing your area of specialty, how healthcare professionals deal with things they don't know, and how medical education impacts this.
Clinical Communication	Knowledge translation, how healthcare professionals share and make sure information is understood including translating things they don't know.
Performativity	Language, actions, affect

Following this introduction, I will present a brief methods section that outlines the broad processes taken to create each artwork, including sharing details about studio development time and a series of public presentations. I will then present a combined results and discussion section. The purpose of combining these sections is firstly a practical decision, as presenting 15 individual artworks could potentially become unwieldy if separated. Secondly, it is a conceptual decision to tackle the information through a more 'embedded' interpretive process. This is the opposite approach than was

taken in Chapter Three. Therefore, as I present each artwork, I will also do the job of presenting a comprehensive interpretation of each work, which will include an analysis of responses from participants including patients, healthcare professionals, and general public (audience members). I will then finish this chapter with a conclusion section, outlining my findings of art making as an affective research method to then arrive at the findings chapter which will bring this thesis to conclusion by presenting its main findings and claims.

Method

This method section provides an outline of the various stages of studio development and showing of works in development. It outlines how the foundations of these artworks arose from multiple sources including the interviews in Chapter Three, observations at the clinic, and additional patient and healthcare professional interview material. In the early stages of this work, I was repeatedly asked if my intention was to work with people to co-create artworks, or to make artworks 'about' or 'in response to' people in the clinic. While each of these methods can be valid within a socially engaged framework, my methodology dictated that creative research methods would be emergent, relational, and led by interactions. This included the potential that approaches might vary from patient to patient.

This building of creative relationships with each participant was a complex journey. Even to propose to someone in a facial nerve clinic that they might benefit from an open-ended experience with an artist, isn't a straightforward undertaking. There were many questions to answer, and given the emergent nature of these methods, answers weren't always ready and waiting. Importantly, people in the clinic might be experiencing a type of trauma that didn't leave them with space to include something so seemingly out of the ordinary as this, but we discovered that the majority of people that were approached about this research, felt intrigued enough to continue, believing that their treatment plan could accommodate such a proposed artistic connection.

In the building of these relationships, issues can arise around topics such as 'authorship'. As discussed in Chapter One, these negotiations require complex considerations. Therefore, I asked myself: Should I facilitate patients to make their own artwork about their own experience? Or should I be using my skills as a professional artist to make work that emerges from our discussions and sharing of experience? After engaging in discussions with patients at the start of this process, it was agreed that the best way forward would be for me to make the artworks while engaging with them as participants. Some patients found the prospect of authoring artworks daunting and felt limited in their capacity to develop these new types of skills while undergoing treatment and its associated stressors, but they also wanted to be involved and were intrigued by the prospects of such a unique proposal. Therefore, it was jointly agreed that the most productive way forward involved undertaking a series of interviews that enabled me to respond to their experience through artwork creation while using my *competency* as an artist, acknowledging competency as one of the defining characteristics of care identified in Chapter Three.

Whilst the theories of socially engaged arts practice hold different views about decisions on authorship (as explored earlier), in my version of practice this decision is always context dependent and decided on together. Sometimes the context dictates that the project should be about access and participation for participants in the active making of the work, and sometimes it should be a social exchange that results in a professional artist making informed ethical artistic decisions that produce work in relationship to those exchanges. Either way, I propose that these processes can all be an act of care.

The decision to have a lead artist (in this case me) deliver the final artworks, does not mean that the voice of the patient is silenced. Instead, the decision has been made in consultation with them and the artistic outcomes all honour their experience. Some participants appear directly in artworks, some have written their own text for the labels in the exhibition as a direct sharing of their voice, and

everyone was credited with their contribution with an acknowledgement of the sensitive and complicated nature of this work.

One way to consider it is that once a patient attends the multidisciplinary SFNC, they meet with a number of health care professionals with different skill sets. They will then go on to work with the healthcare professionals that have the skill set necessary for their needs. In some cases, I was able to provide my own set of skills to potentially meet those needs. This means that through contemporary art, I contribute to the clinical care of patients.

The interviews that were used to create these artworks included 6 interviews conducted with patients, 3 interviews conducted with healthcare professionals, 24 Interviews conducted with members of the public who viewed the artworks, and through monthly observation at the SFNC. To develop these artworks, I held two “development” residencies at the Rex Cramphorn Performance Research Studio at the University of Sydney, NSW, Australia, each of 2-weeks duration (working 7 days per week). This was an important time to experiment, fail, succeed, and to feel emotional responses to different ideas. During these residency sessions, I invited in healthcare professionals, patients, and families to explore different creative potentials. I also used the space to invite in other artists and to film, record and make final aspects of various artworks.



Figure 9: Residency at Rex Cramphorn Performance Research Studio



Figure 10: Working with The House That Dan Built choir for the MRI Choir artwork

I also conducted many periods of development in my own artist studio where I continued to make, explore and experiment in a continued responsive process throughout the research period.

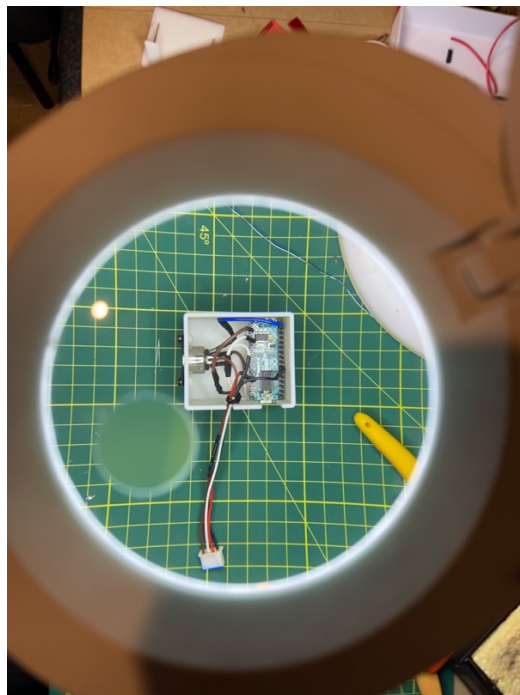


Figure 11: Early version of Lachrymal Vase electronics

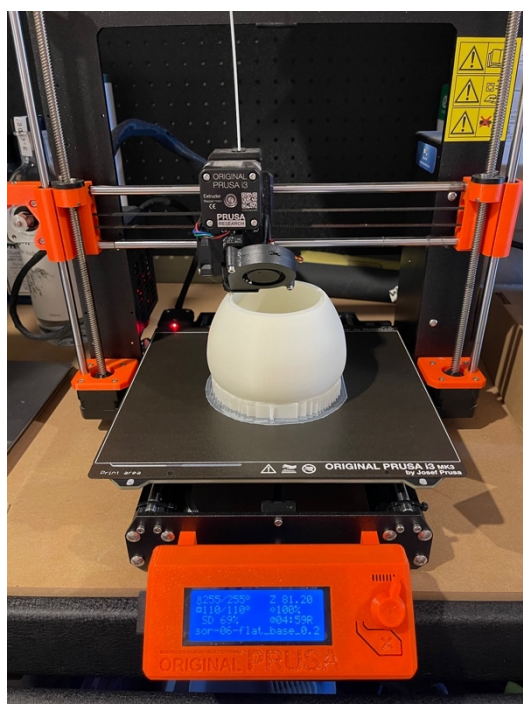


Figure 12: 3-D printing of Lachrymal Vase

As part of the development process, I conducted two showings of work to the public, which I will share here in the methods section, as I consider them to be part of the methods that led to the development of the final exhibition that will be the focus of the majority of this chapter. In 2019 I presented one artwork, titled [If They Spend The Time To Get To Know Me](#) as part of a group exhibition called [The Empathy Lab](#), presented as part of [The Big Anxiety Festival](#). This enabled me to test out ideas for this work, in the relative ‘safety’ of a group exhibition and resulted in me making major changes that led to one of the final artworks called *William*, which will be presented in this chapter.

The second showing of works in development was the following year, in 2020, when I was given the opportunity to share works during a research residency at The Tate Exchange, in Liverpool (UK). The Tate Exchange was a program that provided a rare opportunity to test ideas, meanings, and interactions by conducting artistic research with a large audience in an international gallery. The ethos of The Tate Exchange aligns with the ethos of this thesis, in that it identifies the social potential of art making. From the Tate [website](#):

Tate Exchange is a space and programme at Tate Modern and Tate Liverpool where we ask, “How can art make a difference to people's lives and society?”

We do this with the public and with over eighty Associates, from across the UK and the world, and across the arts, education, health and wellbeing and community development, to collaboratively produce a programme that explores the impact of art on individuals, communities, and societies. Each year we explore a theme and work with a Lead Artist to spark debate and engage with issues that matter today.

The Tate Exchange program is positioned within the central gallery, where it is surrounded by the permanent exhibition highlighting major key works from the British National Collection. To place this field of socially engaged arts practice in such a central position in relation to a more traditional art-historical context, is to enact one of the aims of this thesis: to embed socially engaged arts practice within the larger art canon.

The residency was an opportunity to collect data by presenting six artworks – some finished, some still in development, and some made in the gallery space in collaboration with gallery visitors – these allowed opportunities for engagement and interaction and assisted visitors to understand that this type of socially engaged art making is a *process-dependent* practice. One of my challenges was therefore to develop methods that were able to reveal this process to the gallery visitor. As one participant responded:

I did see a good Turner exhibition a couple of years ago ... [T]hey had cases and cases of his sketchbook work, and I think that's what I'm seeing of yours. I'm seeing your "sketchbooks" and all the things that you're developing. I think it really helps people [...] to engage with the art.

The Tate Exchange presentation was an opportunity not only to see how visitors engaged with the work, but to test processes for bringing site-based, process-based artworks, made specifically from clinical experiences, into a gallery setting without losing any of the unique relevancy of site that gives them depth and integrity. Questions such as, *how do I not lose the emotional intensity of the participant experience when I am bringing work into the clean white walled space of the gallery?* And, *if I am successful at doing this, how do I keep the audience safe and cared for?*, are queries that identify just some of the challenges involved in this task of sharing socially engaged outcomes.

The process undertaken at the Tate Exchange, enabled me to explore ways to share the importance of 'process' without relying on didactic displays of background information.

... I think sometimes the artists forget that you need to communicate the core idea, [...] your starting place about the facial distortion. And I can see it flying off in different directions, but I think this is well explained, which ... it has to be ...[S]ometimes we forget that. But it's that fine balance between over-explaining and being completely opaque. And I think there's a lot of artists that can be too opaque.
(Gallery Visitor/Participant, Tate Liverpool)

Tate Liverpool attracts a diverse audience. The first people to enter the space when we opened to the public were a group of 12 young men (18–25 years old) from Vietnam who had all experienced major trauma. They were accompanied by two trauma counsellors. We engaged in the work together and talked about the intention and their responses. With limited language in common, we communicated mostly through translation, gestures, and body language and via the artworks. The young men were followed by primary school groups, high school groups, bridging programs that provided pathways for young people to access a college education, university students of all types, tourists, locals, art lovers, people from across the cultural and socioeconomic spectrums, and visitors who travelled to The Tate specifically to engage with the work, having read about it online. Through this process we were able to (successfully) test whether the work could communicate across different cultures, backgrounds, and diverse lived experiences.

Over 10,000 people viewed the works in development at Tate Liverpool, many of whom were observed as they interacted with the work. Of these, 512 people had their faces three dimensionally (3-D) scanned for an unfolding *Wire Mesh Scan* artwork that explored image, facial geometry, and aesthetics, and over 50 visitors had their faces 3d scanned to create another installation that grew over time on the wall of the gallery. In addition, 23 people undertook ethically approved interviews about their experience of the exhibition. These interviews were semi-structured, exploring reactions to the artworks, knowledge of and reactions to the concepts of art and health, perceptions of difference, perceptions of self and knowledge of the facial nerve. These will be shared throughout this

chapter alongside observations and interviews from the outcomes presented at the final exhibition back in Australia.

[O]ur understanding of what our own faces look like is a collage that we've built [...] from other people's reactions to our face. (Participant, Tate Liverpool)

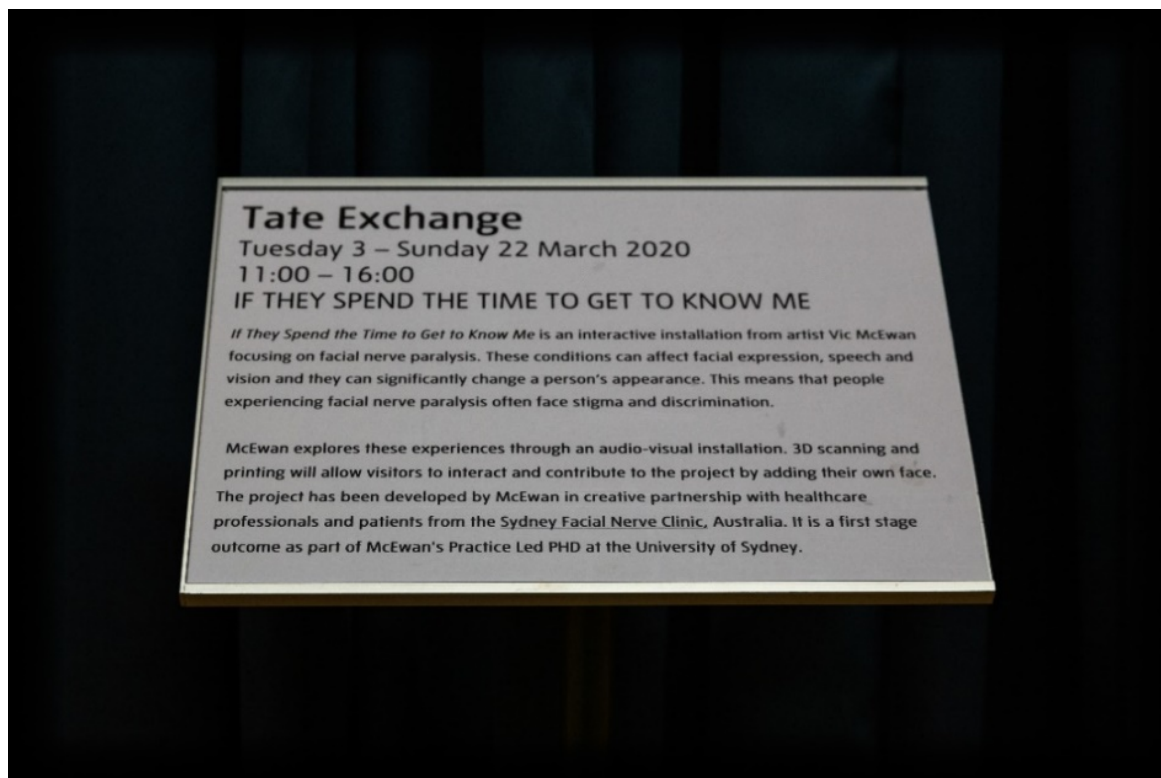


Figure 13 Sign outside the Tate exhibition

Results and Discussion

In this section, the 15 artworks that were presented in the final examinable exhibition will be described and analysed. I begin with a justification of the decision to present the final NTRO's in a gallery space when the history of my socially engaged arts practice and its outcomes reveals a working method that is typically drawn towards art making that is *of place* and often presented in spaces that aren't 'controlled' in the way we might think of a gallery or theatre as being controlled. The places of my past practice include rivers, mountains, rice mills, hospitals and travelling stock routes, working with people, fog, clouds, water, and dirt. These places aren't blank canvases waiting for meaning to be placed onto them; instead, they are full of (often contested) histories, uncontrollable weather elements and complex bureaucracies – all with relationships to living, breathing communities. These locations can also feel far from the eye of the artistic/research canon.¹⁷

Therefore, it would be fitting to ask why a research output from a PhD enrolled in Medicine and Health would present a final outcome in a gallery space, as opposed to within the clinic itself or within any other type of public (or private) space associated with the medical experience? I made this decision for three reasons. First, I was attempting to address the large body of literature, and my own findings, about the social stigma that came from presenting to the world with facial difference. By presenting work in a gallery, to a large general audience, I intended to share information about the facial nerve,

¹⁷ For example, when applying for a scholarship to undertake this PhD, the criteria for recognising non-traditional research outputs included that they had to be shown in a city based (not regional) gallery. This criteria has since been removed.

but also, to initiate conversations and reflections about responses to facial difference, social exclusion, and exposure to complex realities. Secondly, I wanted to create an opportunity for patients to engage with a public sharing of work about their pathology and psychology, to understand what value it might have for them, and thirdly, it was my intention to present work in a gallery space, to provoke conversations about the artistic value of this type of making.

The final artworks were exhibited between 5th February and 22nd March 2022 at the Wagga Wagga Regional Art Gallery (NSW, Australia) in an exhibition titled *Face to Face: The New Normal*.¹⁸ The text at the entrance to the exhibition read:

Face to Face: The New Normal is a major exhibition by Vic McEwan developed during three years of creative research exploring medical science and contemporary arts practice. While being in residence at the Sydney Facial Nerve Service, Vic has worked on the front lines of clinical treatment with patients experiencing facial nerve paralysis, examining what impact a contemporary artist might have within the clinical environment.

This visceral exploration has been developed through observation, collaboration, and direct sharing of experiences to create both intimate and large-scale interactive installations using sound, sculpture, photography, projection, performance, 3-D scanning and 3-D printing.

The exhibition highlights the potential for medical science and the arts to come together to nurture the human dimensions of illness and trauma, while exploring issues of identity and the self through the human face.

Face to Face: The New Normal is an outcome of Vic McEwan's PhD, which he is undertaking at the University of Sydney. He is the first artist to be accepted into the Faculty of Medicine and Health, working under the supervision of Dr Susan Coulson (Health Sciences), Dr Claire Hooker (Medical Humanities) and Dr Paul Dwyer (Performance Studies).

Exhibition label from Wagga Wagga Art Gallery

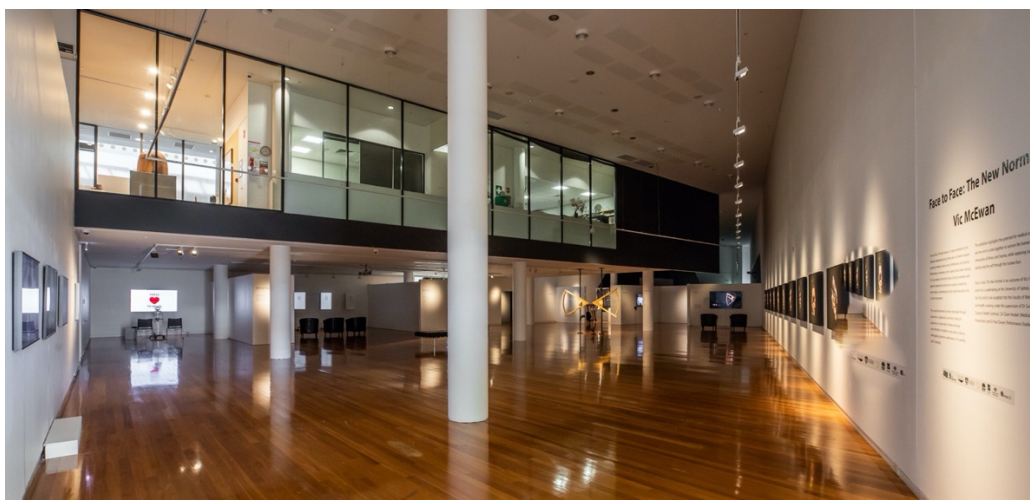


Figure 14: Wagga Wagga Gallery main space

¹⁸ Exhibition catalogue is attached as Appendix 1.

The first part of the title, “Face to Face”, refers to the French philosopher Emmanuel Levinas. As outlined in Chapter One, Levinas’ ethical concerns included the primary responsibility to meet the Other “face to face”. The second part of the exhibition title, “The New Normal” originates from two sources. The first source was an interview I undertook with a healthcare professional from the Sydney Facial Nerve Clinic who declared: “I think we need to define ‘normality’ based on the pathology.” By this, he meant that healthcare professionals need to work with patients who are not going to return to what had been their “normal” life before their illness, to assist them to adapt to what he terms “a new normal”. Here, he identifies the healthcare professional’s responsibility as guiding the patient, through treatment, to a place where they perceive their quality of life in *the new normal* as “acceptable” or possibly “good”. He identified two barriers to this, firstly that “some people, for some reason, cannot accept the new normal” or that the “healthcare professional has failed to translate information that provides comfort around the new normal”.

The healthcare professional identified the clinical process as being a series of “skillsets” that include *diagnosis, treatment* and *breaking bad news*, as well as the skill of *bringing patients to the new normal in a way that means they don’t feel abandoned*. However, he conceded that bringing patients to the new normal in this way isn’t always valued – or even identified – in the clinical process.

The healthcare professional reflected on his earlier years spent working as a registrar and being taught that an oncologist’s responsibility isn’t just to treat cancer; they must also not let the patient lose hope. He identified this as being ‘subtle work’ while referring to the task of breaking bad news to patients as an ‘art form’ that some healthcare professionals practice well, and others practice poorly. In this context, including “The New Normal” in the title hints at the potential of artistic practice to contribute towards the patient journey.

The second source of the exhibition subtitle references the social impacts of presenting to the world with a paralysed face. The title examines the etymology of the word ‘normal’ through the analysis of Lennard J. Davis, a Professor of English and a disabilities advocate. Davis argues that until the mid-1800s the word ‘normal’ had meant ‘perpendicular’: “the carpenter’s square, called a ‘norm’” (Davis, 2006, p. 2). Previously, he argues, the word “ideal” was instead used as a standard that was deemed to be unobtainable by humans, as it was linked to the gods.

The central point here is that in a culture with an ideal form of the body, all members of the population are below the ideal ... One can never have an ideal body. And there is no social pressure, we would imagine, that populations have bodies that conform to the ideal. (Davis, 2006, p. 2)

Davis identifies that it was the French statistician Adolphe Quetelet who developed an approach of estimating the *average* of human attributes (physical and moral) which resulting in the term ‘normal’ becoming “paradoxically a kind of ideal” (Davis, 2006, p. 2). He quotes Quetelet:

... deviations more or less great from the mean have constituted (for artists) ugliness in body as well as vice in morals and a state of sickness with regard to the constitution. (Davis, 2006, p. 2)

Through the development of the concept of ‘average’, the word ‘ideal’, which had been previously defined as something unobtainable by humans, was replaced by the term “normal”. As a result, the “notion of physical beauty as an exceptional ideal becomes transformed into beauty as an average” (Davis, 2006, p. 2).

The concept of a norm, unlike that of an ideal, implies that the majority of the population must or should somehow be part of the norm. The norm pins down that

majority of the population that falls under the arch of the standard bell-shaped curve. This curve, the graph of an exponential function, that was known variously as the astronomer's "error law," the "normal distribution," the "Gaussian density function," or simply "the bell curve," became in its own way a symbol of the tyranny of the norm. Any bell curve will always have at its extremities those characteristics that deviate from the norm. So, with the concept of the norm comes the concept of deviations or extremes. When we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants. This, as we have seen, is in contrast to societies with the concept of an ideal, in which all people have a non-ideal status. ...

An important consequence of the idea of the norm is that it divides the total population into standard and nonstandard subpopulations. The next step in conceiving of the population as norm and non-norm is for the state to attempt to norm the nonstandard – the aim of eugenics. Of course, such an activity is profoundly paradoxical since the inviolable rule of statistics is that all phenomena will always conform to a bell curve. So norming the non-normal is an activity as problematic as untying the Gordian knot. (Davis, 2006, p. 3)

While there is a large body of scholarship that explores concepts of 'normal', I don't offer a synthesis of those ideas here, instead, my aim is to present Davis's work as one of the inspirations for the subtitle of this exhibition, acknowledging that his reflections on the transformation from 'ideal' to 'normal' identifies negative implications for self-image making, a major issue in the experience of patients with facial nerve paralysis.

Artworks

The artworks in *Face to Face: The New Normal* can be thought of in three groupings.

- Grouping #1: Seven artworks that explore the patient experience, the healthcare professional's experience, and the facial nerve itself.
- Grouping #2: Three artworks that explore, more explicitly, the implication of the artwork viewer, to the meaning of the exhibition.
- Grouping #3: Five artworks that more directly share ideas of socially engaged arts practice and processes.

Each of these artworks are presented as Non-Traditional Research Outputs (NTRO's), so we can think of them, each, as the equivalent of a published paper or manuscript, supporting the idea that artistic outcomes can be a form of knowledge production, dissemination, and analysis. I will proceed by presenting each of the 15 artworks, their background process and presentation, including discussions about responses and impacts. In Appendix One, I have included the exhibition catalogue, and a narrated documentation video can be viewed [here](#).

Artwork Grouping #1

Artwork #1: William

Video, audio; 5mins 32sec

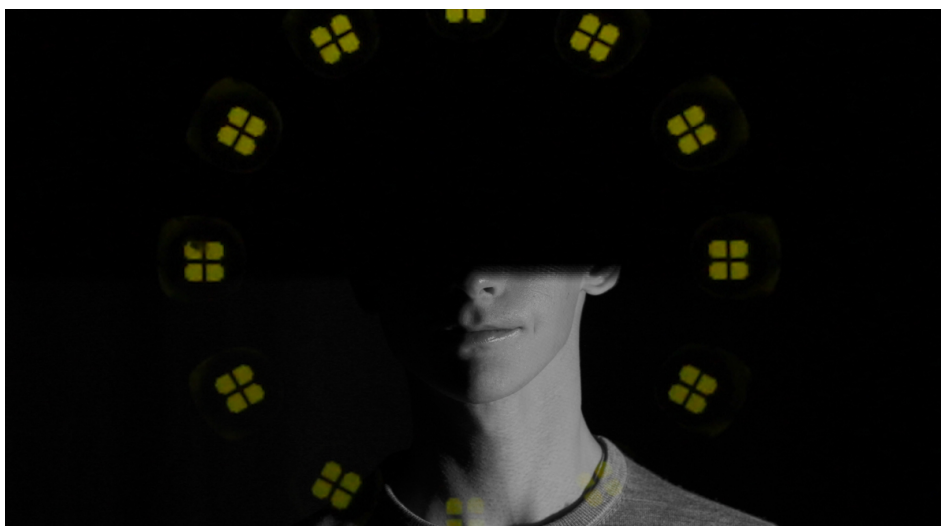


Figure 15: Screenshot taken from 'William' video artwork

People look at me and see [that] one half of my face works, but all they focus on is the half that doesn't work. I feel like if people spend the time to get to know me, they get to experience what I am truly like as a person.

Background

This first-person narrative shares one patient's experience of facial nerve paralysis, exploring how he is treated by others and how he processes such responses. The intention of this artwork was to share William's story in a way that evoked sensory stimulation that reflected medical procedures. To provide a sense of the specimen like nature of medical treatment, but with enough artistic reprieve to soften the spotlight of observation and to share proposed characteristics of illness - being fixed but floating, untethered yet weighed down.

To assist the reader of this thesis to ground themselves in the experience of this patient, and as an attempt to "'show' and 'animate' the push of the world; to convey it in ways which reflect as much as possible its physicality, energy and intensity" (Andrews, 2018, p. 3), I will begin the analysis by asking the reader to visit [here](#) to view the artwork.

Process/Making

The video was filmed as William underwent a process of 3-D scanning. It employs flashing lights (a part of the 3-D scanning process) as an artistic element which he referred to as being reminiscent of having an MRI scan, a process he has undertaken more than 40 times. The artwork, with its duration of 5mins 32secs, was crafted from over four hours of interviews, during which time the patient had an extended opportunity (typically unavailable in the clinic) to talk about some of the difficult aspects of facial paralysis (Ogden et al., 2004; Ohtaki et al., 2003).

In the creation/editing of the artwork, I was confronted by artistic decisions about how I presented William. Should I use imagery that emphasised his paralysis, putting the medical condition visually at the center of the video? or should I emphasise his words and his story? This question, about the potential power of the artist to manipulate outcomes towards emotional gain, shock value, or an extension of 'othering', is one I have had to confront many times in my artistic practice. The potential for personal narratives to be manipulated for the author's gain is a discussion that also exists within practices such as Verbatim Theatre (Martin, 2006; Reinelt, 2009).

Installation

This work was installed in a large room, with the video projected in a large wall with the sound amplified in the space.



Figure 16: Installation shot of 'William' video artwork

Response and Discussion

The philosopher Levinas discussed the importance of language to the *witnessing* of the Other. Meeting the Other through their language, he claims, allows us to meet the 'concept' of William rather than just the representation of him (Levinas, 1987). These words that William speaks in this video, could have simply been shared in the IPA method of the last chapter, but by sharing them in a large immersive video artwork, it allowed the activation of multiple senses through which to 'hear' William. The message that William conveys in this artwork, aligns with the literature that examines the impacts of social exclusion experienced as a result of facial nerve paralysis (Ishii et al., 2012; Lansdown, 1997). Given that the main theme of his narrative explores how he is treated by others, an intention was to place William's work in a public context to enable others to be exposed to, and grapple with, his observations.

Instead of taking an artistic/aesthetic approach that was confronting, I made the choice to create something that was slow and meditative, focussing on the psychological experience rather than the physiological aspect. One gallery visitor remarked:

I think overall the video is quite soothing and gentle and yet they are talking about something quite visceral ... I think that that style and the way [it] was approached ... probably enabled you to see the person underneath it more because it was different than my expectations, because it was gentle and quieter.

And another:

[I was] waiting for a clinical demonstration of William's paralysis, and by not being focused on it, the video makes you realise that you are looking for it.

This approach provoked participants to realise that they were “searching” for the paralysis, and once they realised this, it caused them to reflect on their own responses to facial difference¹⁹. As a result, this provoked many participants to discuss their own inclination to judge people with facial difference, to turn away, or how they experienced the ethical quandary of “not wanting to stare, yet not wanting to look away”. This further provoked many participants to examine their fear about upsetting people, and not knowing how to address someone with obvious facial difference. One participant reflected on this as a learnt cultural response, where we are trained by society to “turn away from difference” and “not to stare”, believing it was also a “self-preservation thing” as people don’t want to confront something that could also happen to them. This artwork enabled a meeting with the paralysed face of the Other, but it also caused viewers to confront their own vulnerability, and to question their own responses:

You should question your gut and question where that came from and what's causing you to feel like that and analyse that and reflect. I think it's a hard listen, really. It's a hard watch and a hard listen.

This response highlights an important potential for artistic outcomes that draws in the viewer while making them connect and reflect on themselves. By engaging the viewer in a way that is meaningful about themselves as well as another person, I aim to set up the conditions for the artworks to have the potential for multiple impacts. This work had the impact of provoking viewers of the artwork to not only empathise with William but to explore their own responses to facial difference.

It's a human condition. That's who we are. That's what we do. And we're sort of almost modelled genetically to pick up these facial cues or to make instant judgements about people. And I suppose it goes back to a sort of survive or fight or flight instinct where we have to make value judgments straight away.

We have a field of meaning for what [a] look means. And if you're not in control of those looks, you're in a minefield of communication ... but why do we? What's the factor operating that makes us pull away? Because there's something about our need for communication that gets stopped when we don't recognize the face in front of us as fully functional, if you like. [It's a] fear of the unknown.

It is unfortunate that people won't look him in the eye, but that's totally a failure on everyone else's part.

Despite receiving many responses of this nature, I am cautious about claiming that these artworks result in ‘social change’. Even though many participants reflected on their need to change the way they respond to people with facial disfigurement, I cannot claim that they will continue with these thoughts and make any actual change. What I do claim as an outcome of this research, however, is that by making and presenting work in this way, I am presenting the ‘conditions for social change’ rather than directly claiming the change itself. I will expand on this theory of *conditions for social change* in the next chapter.

¹⁹ (Canadian facial difference charity, About Face, define facial difference as a condition where someone’s appearance “from the neck or above, has been affected by a congenital (from birth), acquired (after birth), or episodic (comes and goes) condition or syndrome.” (About Face, n.d.).

This method of artistic research output allows us to foreground “powerful storytelling to create emotional openings and move readers to feel something, rather than just think about it” (Vannini, 2015, p. 8).

When the subjective voice (spoken or written) is absent – as it typically is in medical representations – it is difficult to see past the visual record of injury, disfigurement, or disease. Conversely, personal narratives are often used [...] to humanize images of trauma, and to counteract or compensate for the objectifying and “othering”. (Biernoff, 2017, p. 14)

In the previous chapter, two of the participants - Liz C and Susan A - expressed the desire to find stories of others who had experienced facial nerve disorder. They both watched this video artwork and expressed how it impacted and was beneficial for them. Susan A said:

[When] William started talking about his personal feelings about his face, I sensed my heart was beating louder and, my breathing got faster. I noticed I was doing shallow breathing.

I understood him, know how he feels, because I've had similar feelings. When he was talking about acceptance, I feel like I've gone through that too.

Liz C thought “William’s story was very positive”. Watching the video was also a positive experience for her family who took the opportunity to ask Liz C questions about her own experience and whether it matched William’s. Liz C later reflected on how seeing the entire exhibition could have a positive impact for the family members of patients to help them understand what someone might be going through.

Relationships and encounters between people are another core concern of this research. Humanities scholar Professor Jennifer McMahon has proposed that “we think and feel in virtue of concepts internalized through interactions with our communities” (McMahon, 2014, p. 1). This is reflected in the response from multiple participants, which I will summarise with the quote below:

So, it's that interchange of me meeting William on the street. The burden on him is to look what I consider to be normal for me to treat him normally ... That sort of pressure to conform because we'll only react to you in a way we know how if you conform to our expectations of you. That's exactly what's happening with William M.

This identification of societal ‘flaws’ is continued in one participant’s shared story about his sister, who he describes as having a face that naturally rests in a position that other people think makes her look angry. As a result of this response from her community, she explored having surgery to change her face but was deterred by the fact that the doctor would have to break her jaw during the operation. The participant reflected on “the idea [that] to correct people's interpretation you might have to break your own face”.

The response to this video work was very reflective and positive, with people commenting on William’s strength of character, on how charming, intelligent, and handsome he is. From this you might conclude that William was granted the wish he articulated in the video: that people see him for who he truly is, through his reflections and through his story but ultimately, and positively, through his physical appearance as well.

Artwork #2: The Face That Your Face Feels

Series of ten photographic prints; 869mm x 1214mm

Background

Taking its name from a patient's response to seeing these artworks for the first time, *The Face That Your Face Feels* is a series of ten images made in collaboration with facial nerve physiotherapist Dr Susan Coulson and two participants who had experienced a facial nerve disorder. This research reveals that avoidance of having your photograph taken is a common behaviour for those experiencing facial nerve paralysis. Participants commonly talk about their fear of being photographed, perceiving that they fall below the bell curve of 'normal'. These observations reveal that the fear of photographs broadly lies in four categories: *fear of major family events*; *sadness caused by not documenting family relationships*; *fears around social media*; and *avoidance of casual photographs*. The following are just some examples of each of these sourced from observation during the 4 years of attendance at the SFNC

Fear of major family events

Example: A patient with facial nerve disorder, spoke of the fear of their children getting married as they would "ruin their wedding photos". The children were both under six years of age, yet the fear of this future photograph was so great, it was a trigger for expressing great emotional distress.

Sadness about not having family photographs

Example: An elderly patient who was expressing acceptance of their "new normal", articulated very clearly, without signs of obvious emotional distress, that they had accepted that their face was how it was and that they didn't want to undergo further treatment or surgeries. The one time their apparent acceptance broke down and they displayed great emotion was when they said they avoided being photographed but regretted not having any photographs of themselves with her grandchild. "If I don't have any photos with my grandchildren," they said in a later discussion, "I fear that when I die, I will be erased from their memory."

Fears around social media

Example: S was a young patient in their early twenties whose social life formed a major part of their identity. In the clinic, they expressed great sorrow at how their face looked when they smiled; however, all the healthcare professionals responded that their smile, from their perspective, looked very good. They then pulled out her phone, showing social media posts of them and their friends on a night out, and said: "I know, but it doesn't look good on Instagram." The importance of representation via social media for someone of that generation meant that it was of great concern for that patient's perceptions of self-identity (Gündüz, 2017).

Avoidance of casual or work photos

People commonly expressed frustration about regularly having to avoid having their photograph taken in social or other situations. One participant, a primary school teacher, experienced facial nerve paralysis following the removal of a brain tumour. After a number of years, they returned to teaching, where they found the experience and the negative comments from students painful. Reading an online blog (from the United Kingdom) written by a patient who was also a school teacher with facial nerve paralysis facial, helped this person to navigate their own experience, indicating the value of sharing facial nerve experiences. In one clinic visit, this person explained that they had refused to be in school photographs ever since the facial nerve paralysis occurred; however, after many years, they finally felt comfortable enough to agree to be included in a photograph.

The complexities of impact that result from the avoidance of photographs described above, reinforce issues of identity, exteriority and erasure that were highlighted in Chapter Three and therefore create a meaningful exploration to be had through practice led research.

Process/making

The intention of this photographic artwork is to highlight the relationship of care that happens between the healthcare professional and the patient. Honouring the complexity of how the clinical outcome is so tied up with the immediacy of the patient's identity, these photographic artworks were created through a three-step process. First, I created a photographic portrait of a male and a female patient, a delicate negotiation in itself. I then used a video projector to project their portraits onto the hands of one of their treating healthcare professionals, Dr Susan Coulson. The next step was to re-photograph Dr Coulson's hands as the video projected portrait fell onto them. The resulting images were then printed as large photographic works on A0-sized paper. These artworks have not undergone any computer manipulation. Instead, the 'manipulation' and composition of the image is created by the relationship between the faces of the patients and the hands of the healthcare professional. To me, these images evoke the aesthetics of painting to tell the story of the intimate professional relationship that happens between a doctor and a patient.

The process of making these works reveals numerous ethical considerations. The first of these was about what type of photographic portrait to project onto the healthcare professional's hands. Initially, we used an image where the patient was smiling, which had the result that their facial disfigurement was exaggerated, foregrounding 'disfigurement' as the focus of the image. If we suspend any ethical concern for a moment, what the resulting images revealed to me, as an artist, was something inspiring, as if the process was uncovering something new in my artistic practice. But I also understood deeply that there was something so unsettling about the images, that while we could look at them with the joy of discovery of artistic outcomes/process, it was also clear that the images couldn't be used publicly, or even be shown to the patient.

In a second attempt, we began with a neutral facial expression, with the muscles relaxed in a resting position. This was much more successful, retaining the 'artistic excitement' of the first attempt while also addressing its ethical concerns. However, there was still substantial care needed to ensure these images didn't highlight disfigurement, rather than reconsider it. This supports two of the claims made in Chapter One. Firstly, that socially engaged arts practice is the meeting of ethics and aesthetics, and secondly, in relation to the emerging field of care aesthetics, that it is not just the fact that 'care' has an aesthetic component, but that the act of care through the arts, also impacts the aesthetics of artmaking itself. During the process of showing these final images to one of the participants, I was careful to present the works in a particular order, starting with the least confronting, or least abstracted images, and allowing the patient to talk about each one before moving on to the next. These considerations of care are a repeated process of my practice, and are present in many conversations, agreements, experiments, and outcomes.

As mentioned, one of the artistic discoveries that emerged, was the 'painterly' quality of the images. This has been a thread running through my artistic practice for many years, through projects such as [*Haunting*](#) and [*Shadows and Consequences*](#), where I have been considering photography and projection as a type of painting with light. In the presentation of this work, I emphasised the painterly qualities through the selection of a particular photographic paper, and the choices made around framing of the images, which I saw as a continuation of the art-making process rather than a separate step of preparation for installation.



Figure 17: Test prints (A4 size)

The paper used was an extremely delicate, completely matte (non-gloss) paper called Hahnemühle Photo Rag (308 gsm). I chose it because it wouldn't pick up any reflection from the room or the lighting, allowing the images to be viewed in an undisturbed way, as if suspended in space, a void, a hovering. This choice of paper was coupled with a type of framing that is more commonly used to frame paintings: a black shadow box with no glass.

The decision not to use glass was so that the room itself didn't introduce any reflections, leaving nothing between the viewer and the work so that the image could be experienced through the textural, almost velvet quality of the matte paper. This meant that the artworks were fragile – able to be damaged by just the touch of a hand on their surface. Susan A, the participant in half of these images, commented on this photographic paper choice: "It's touchable,²⁰ soft to look at and the image of my face is cushioned by this softness."

Installation

The risks associated with framing, transporting, and installing such delicate work were worth taking for the aesthetic/conceptual effect of the final presentation, which was ten large, framed images on a long wall, where the only reflections were those of the artworks being reflected on the shiny floorboards underneath.

²⁰ Appears touchable – invites touch (although you can't)



Figure 18: Installation photograph, Wagga Wagga Art Gallery

Field note (2022):

In the gallery space, the viewer seems to be drawn into the images, frequently led by a curiosity to figure out what's going on. Drawn in by wonder and curiosity, which then 'traps' them in the image, and the choice of whether to engage is withdrawn. In the time of my PhD, what has been running parallel is a thread of artistic consideration withing my practice, about how to draw people in with wonder, in order to then 'trap' them in the artwork. The way that they then engage with the work is their own choice, but the creation of ways to draw people in is an important consideration. This is also a reminder, and an important part of my artistic practice, that ideas such as whimsy, imagination and play are an important part of navigating trauma. Often when I am working with patients on difficult topics, there is also a lot of joy, combined with the tears shed in our process together.



Figure 19: (a) & (b) Artwork examples from The Face that Your face feels

Results and Discussion

One of the major outcomes from this work, is the potential for it to facilitate an opportunity for conversations about carer–patient relationships while also revealing new ways for the patient to communicate their experience. Susan A, the participant who appears in five of these artworks, said of them:

These images are how I feel, getting pulled in all these different directions. That's how I feel sometimes, not quite all gelling up together, if you know what I mean. I feel like I've got my cheek, my forehead, my mouth, and then the right side of my face, and then somehow, they've got to all sort of connect [laughs].

If you can imagine, it's almost like being a puppet, the strings are being pulled tighter on one side and they're going upwards, they're being pulled up, but I want to pull them down. I'm being pulled in all these different directions internally. It reminds me of a string, or tightness around the face, sort of squished in, tight, taut, squeezed in and pushed.

While the interview data reveals this work's potential to enable new ways for the patient to share their symptoms and discuss their patient experience, the viewing of these images in a gallery setting reveals potential impacts for wider audiences. As one gallery visitor shared:

I was driving to Wagga from Canberra today, and the whole way in the car I was worrying about my dad who is having spinal surgery today. I have been thinking things such as: "What if the surgeon slips, or sneezes, and causes him damage. Spinal surgery is such a delicate thing, anything could go wrong. I've been so worried about it, but after spending time with these images, I now feel consoled, it allowed me to think about the relationship that my dad has with the doctor and how important this is. I don't feel as worried.

As I listen to this gallery visitor talk about their response, and the relief it brings them, I understand this as one example of how sharing this work can impact the lives of viewers in unexpected ways. This acknowledges the potential for socially engaged art outcomes to have impact beyond their direct place of research. By presenting these artworks in an art gallery, where visitors can enter, engage, and depart on their own terms, there is potential for the work to resonate with viewers in meaningful ways that lie beyond considerations of the facial nerve, and beyond research concerns. I propose, therefore, that making artwork in this way is also about a shared humanity, the Levinas-ian "third" (Levinas, 1979) and the "caring with" of Tronto (Tronto, 2013). In a gentle way, it is about care, solidarity, and recognition, both within and outside of the clinic environment.

The exhibition was reviewed by Penny Grist, a curator from the National Portrait Gallery, Canberra, Australia (full review in appendix 2). About this artwork in particular, she wrote:

A series of ten photographic portraits, *The Face That Your Face Feels* (2021), ran along the gallery's longest wall. On approach, the immediate visual parallels flashed into my mind: Albert Tucker's cubist series of *Cratered Heads* or Francis Bacon's blurred, distorted portraits. But this immediately dissipated. These portraits clearly didn't depict altered perception or psychological states, but instead told a story: a story of closeness. McEwan projected photographic portraits of patients' faces onto the hands of Dr Susan Coulson, one of their treating healthcare professionals, and rephotographed them. At a distance the faces were more distinct. Up close, it was the creases, lines and shapes of the fingers that dominated. As one of the sitters,

Susan A Andrews, noted of the portraits: ‘These images are how I feel, getting pulled in all these different directions.’ To me, each work in this series offered three layers of meaning: a visual simile for medical care in the holding of expertise that holds someone’s future; a narrative of the strange intimacy of this human relationship; and an evocation of the experience of being treated. In this way these portraits captured three dimensions of feeling. (Grist, 2022)

This artwork prompts us to consider the relationships of medical care by sharing “three dimensions of feeling”, as Curator Penny Grist puts it. What I discovered through the process was the potential for it to offer up new modes for patients to communicate how/what they are experiencing. It also confirmed for me that socially engaged arts practice is indeed a meeting of aesthetics and ethics, and that the experience of enacting ethical care has the potential to impact aesthetic processes. The artwork impacted people lives beyond the clinical site or subject matter, through encountering others with their own set of concerns.

Artwork #3: Wire Mesh: Portraits, Landscapes and Wildflowers

Three-channel video; 10mins 52sec

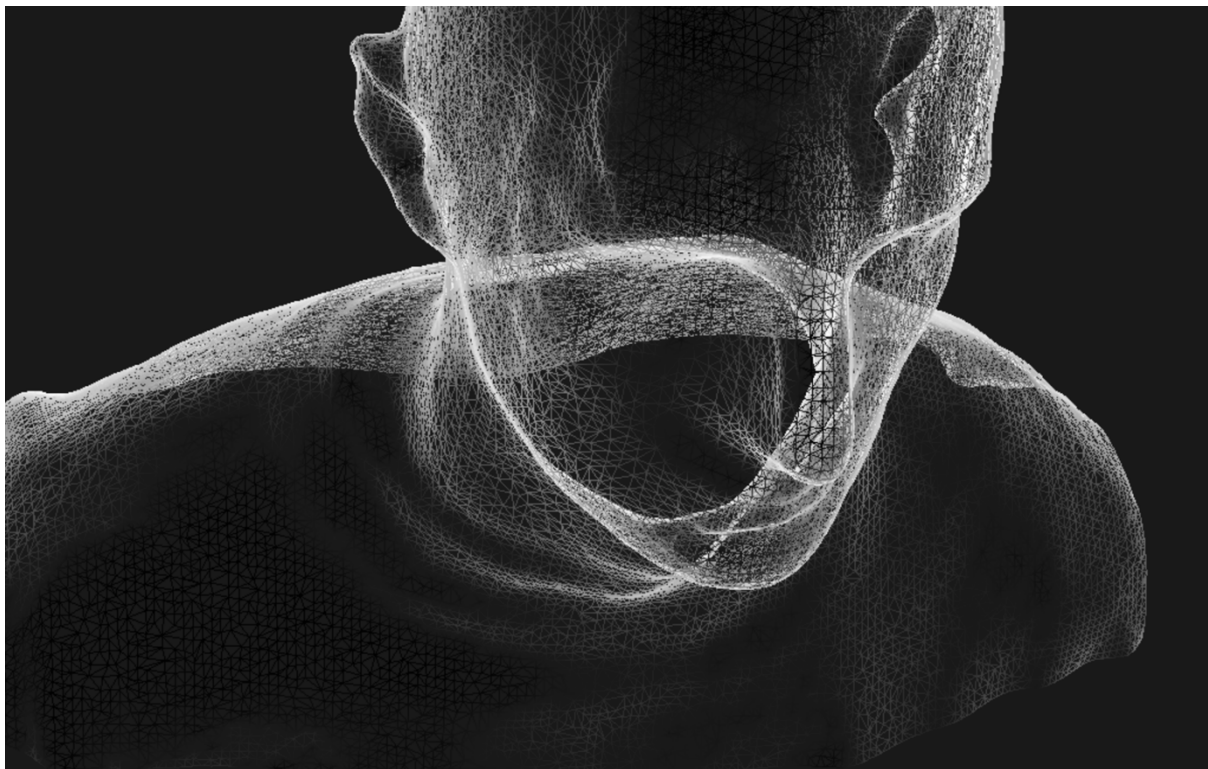


Figure 20: Artwork example

Background

This artwork is a series of over 500 images that were created using 3-D scanning technology. The images show the face as a wire mesh, a geometry, a series of connected vertices without any identifying “texture”. The aim of the work is to consider what is *revealed* (or *concealed*) in portraiture. These images, as an aesthetic experience, present a series of “nearly abstractions”, where they at times resemble other forms such as landscapes and flowers.



Figure 21: Artwork example

Process/Making

These images were created by using a 3-D scanner to scan people in order to obtain the “wire mesh” data, or the ‘geometry’ of their scans. These were then edited in video editing software to create a series of 3 videos that were shown together.

Installation

The works were installed on 3 separate screens with no sound, each playing their respective video (all of which were at different lengths, which meant that the sequence of videos was evolving throughout the day).



Figure 22: Installation photograph

Results and Discussion

This form of presenting portraiture as a wire mesh of data points on a geometric grid, potentially runs the risk of reducing the portrait sitter to a series of objective mathematical points along a series of planes, or what philosophers such as Donna Haraway and Thomas Nagel might call a “view from nowhere” (Haraway, 1988; Nagel, 1989). Their perspective of this ‘view’ is derived from their examination of objective and subjective viewpoints arguing that situated objectivity has the potential to be a form of reduction that creates a ‘view from nowhere’.

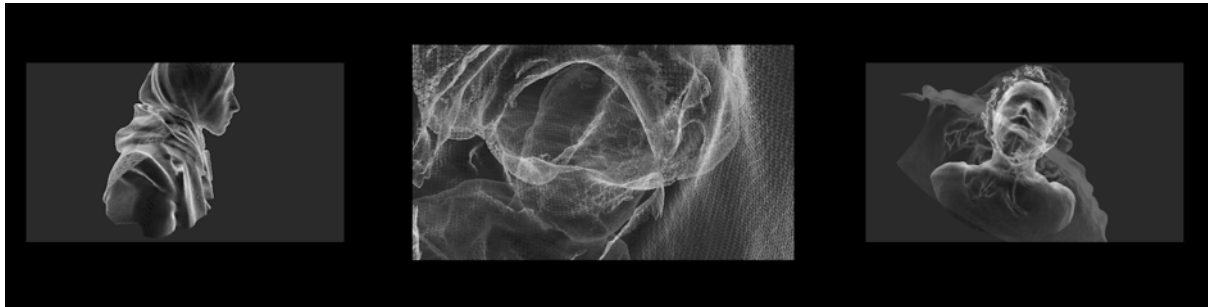


Figure 23: Mock-up #1 of 3 screen artwork

Through a process of aesthetic consideration, the risk of creating a solely objective view from the gathering of mathematical points is overcome by an aesthetic process that honours a type of “digital materiality” such as that proposed by Media Studies scholar Christiane Paul. Paul’s work “explores the evolution of materiality in the context of art and digital technologies” while examining the potential for the “materiality” (or neo-materiality, as Paul proposes) of digital processes to “mirror and reflect us back to ourselves” (Paul, 2015, p.1).

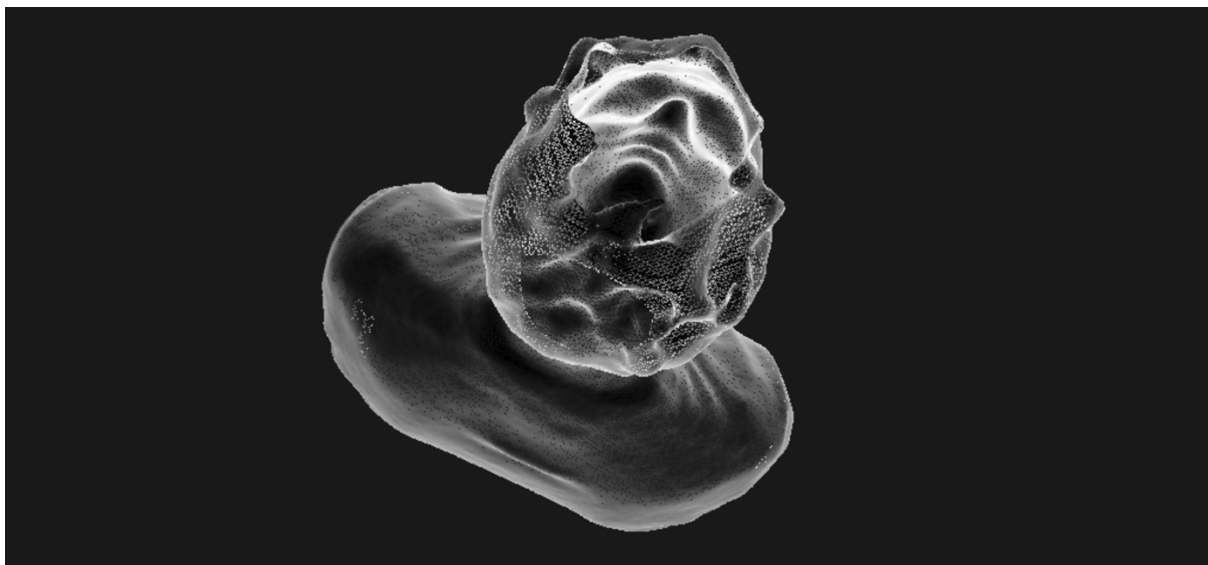


Figure 24: Artwork example

This consideration of the potential materiality of digital processes, leads me to propose that instead of the mathematic geometric data of these wire mesh images leading us to an objectifying ‘view from nowhere’, they actually reveal a ‘view from everywhere’ as proposed by philosopher Merleau-Ponty. Merleau-Ponty argues that modern art has the potential to reveal “the structure of the visual world in which not all objects are attended to at one time from one point of view[;] instead our perceived world is structured by a plurality of overlapping perspectives, within which different aspects are somehow seen together, as aspects of one world” (Merleau-Ponty, 2009, p. 19)

The completed object is translucent, being shot through from all sides by an infinite number of present scrutinies which intersect in its depths, leaving nothing hidden.
(Merleau-Ponty, 2005, p. 79)

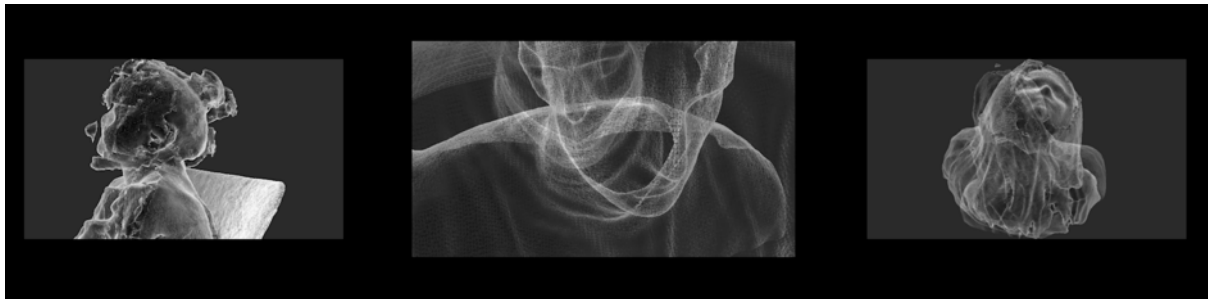


Figure 25: Mock-up #2 of 3 screen artwork

This artwork explores the human face as intimate, localised, points of mathematical data to consider Levinas's reflection of the "Other" as a "site", rather than a "container" (Levinas, 1979). This *aesthetic meander* through multiple overlayed perspectives, reveal suggestions of images such as landscapes, wildflowers and geometric abstractions, acknowledging the multiplicity of the corporeal "patient", who is frequently singularly defined by the many perspectives of medicine (Mol, 2002). In this work, I am questioning the impacts on self-identify, alongside the question of *who and what* gets to define the *new normal*.

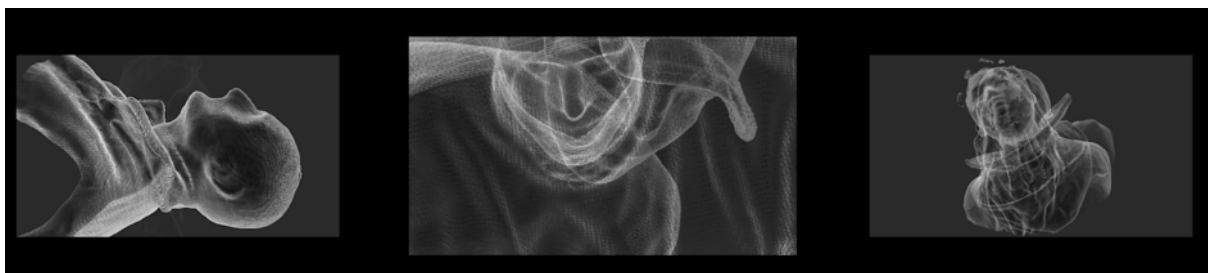


Figure 26: Mock-up #3 of 3 screen artwork

This was a three-screen video work, watch a video of each screen at the following links. A mockup. Up of the three screens can be viewed [here](#).

Artwork 4: The Unravelling French horn, audio

Background

As earlier identified, facial nerve paralysis can cause practical issues such as when eating or drinking, or even when trying to smile or to close the eye. Additionally, concerns can arise that are specific to the individual, such as when a professional French horn player experiences facial nerve paralysis and is unable to achieve the required embouchure (mouth shape) required to play the instrument. When this occurs, a lifetime of musical training and playing can unravel as it does when musicians experience focal dystonia (involuntary muscle movements) in the lip region (Altenmüller & Jabusch, 2010).

This artwork, in the form of an unravelled French horn, was made in response to, and in consultation with, a participant called Liz C, whose interviews were part of the Interpretative Phenomenological Analysis in Chapter Three. Liz C lost the use of her facial nerve following surgery in 2020 to remove a head and neck tumour. The procedure required the surgeon to cut the facial nerve and at the same time, cut the life-long relationship that Liz C had with the French horn. Realising how meaningful this must have been for her, I asked what it was that had first sparked her interest in the French horn. Liz C replied:

The sound and hearing orchestras for the first time – I remember going to hear the Brandenburg Orchestra live in Sydney and I loved it. I was maybe in year 12. It is known for being mellow, rich and golden-sounding when playing melodies of the romantic orchestral repertoire – but it can be as brassy as a trombone and Wagnerian but also light and flexible like the woodwinds in chamber music. I love its rich, beautiful but powerful sound.

Process/Making

This French horn is made up of over 13 feet of brass tubing, and the idea of this artwork was to ‘unravel’ a French horn as a symbol of Liz C’s experience. To achieve this, I worked with a brass instrument repair technician Edwin Diefes (pictured) to ‘unravel’ a French horn. Edwin opened his Sydney-based shop afterhours approximately once a week for a month, at which time we would work together to figure out how to go about the task of unravelling. It is intricate work, which may be described as a different type of surgery that was happening with the intention to hopefully have a positive impact for Liz C.



Figure 27: Edwin Diefes holding an un-ravelling French horn



Figure 28: Edwin Diefes trying to 'play' an unravelled French horn

Installation

The final work installed in the gallery included a speaker fitted into the mouthpiece at the bottom of the French horn, this speaker quietly played a recording of Liz C playing the cello. The sound of this travelled through the tubing of the unraveled French horn and was heard through the 'bell' of the horn at the top. The volume was quite low, so it was an unexpected discovery for the viewer to realise that the sound of the cello was emanating from the French horn bell.

The Unravelling was suspended from the ceiling with discreet fishing wire. It was a complex installation task to get the horn to sit in a suspended way as intended, this required the fabulous skills of the gallery curator Drew Hallyday who drew on his well-developed installation skills to encourage the French horn to hang in such a way.



Figure 29: Installation of French horn

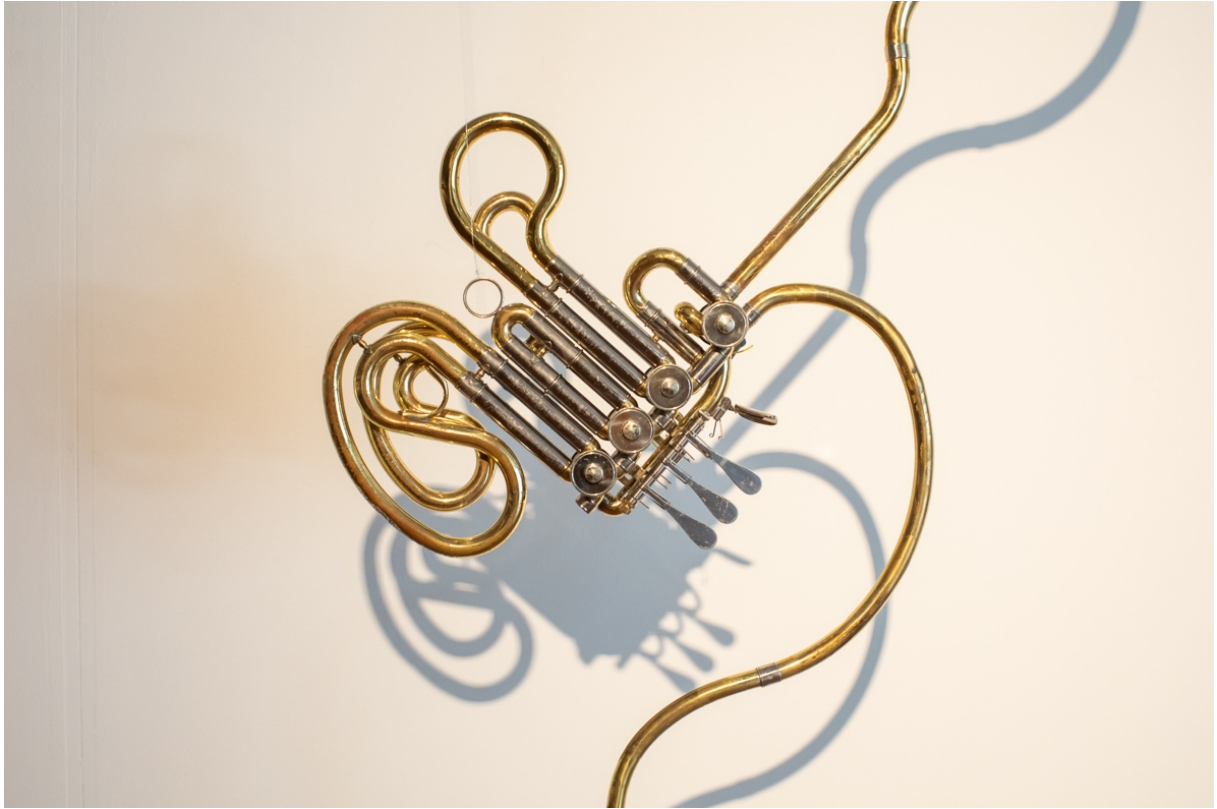


Figure 30: Artwork detail #1



Figure 31: Artwork detail #2



Figure 32: The Unravelling installation photograph

Results and discussion

The Unravelling was made to show that the loss of identity that comes with facial nerve paralysis can be multilayered – in this case, caused by the loss of a lifetime relationship with the French horn that included years spent living and travelling overseas in pursuit of education and playing experiences:

[A] lot of my best [French] horn moments are also wrapped up with experiences, people, places and travel.

The ending of her ability to play, was a gradual process, as Liz C explains.

It was a bit of a gradual stop-and-start progression to not being able to play. In 2014 I got what they thought was Bell's palsy so I had a time of not being able to play. Then I got back to it but was weaker in certain areas, but I mostly managed to still play. There were certain things I couldn't do (low notes, etc.). Then in 2017 I was supposed to play in a concert but the tumour was found. [My doctor] said he had to do a surgical biopsy, so I couldn't do the concert. During that operation he had to damage the facial nerve because the tumour was wrapped around it – then I couldn't really play at all. So I didn't do any music (apart from some guitar and singing at church).

My horn is in its case – it's a special instrument to me. I bought it in Germany and it's worth a bit of money. I hate the fact I may not be able to play it again, but I can't bring myself to sell it yet. I guess I still harbour some hope I could play again ... but I know that's not realistic because of the permanent damage to the facial nerve.

Following this, Liz C decided to learn to play the cello:

After 18 months to two years of nothing, I started to think I should learn something else in case it didn't come back. So, at the end of 2018 I was in Germany and a friend gave me a few cello lessons. When I got back, I started lessons in Darwin from 2019 and worked hard practising to try to get to a satisfying level. In 2020 I had the surgery to completely remove the tumour and that cut the facial nerve so that really was the end of playing horn.

[The cello] doesn't completely replace horn because I really miss those shining moments in orchestra where my skills on horn, built up over 25 years, could really come into the light. I was good at certain things and that was noticed by people (lovely tone, picking high notes out of the air, etc.). So, I don't have that ... but my musicality can still show through cello and my teacher is very encouraging.

For me, hearing the cello being played through the horn in this artwork is like the new coming out of the old, an amalgamation of my experiences. It brings my horn-playing and cello-playing experiences together even though for me, they don't both exist at the same time. I miss playing the horn, I grieve the loss ... but I love playing the cello and I would not have that if I was still playing horn. My horn-playing identity is still part of me but I'm also bit by bit becoming a cello player and seeing myself as such. I'm moving into a new identity which incorporates the new and the old. The facial palsy has been the catalyst for this new state I find myself in.

My observation in the gallery was that visitors were initially drawn to this artwork by its quirkiness, by the aesthetics of the shape of the unravelled French horn. They were then drawn in further by the sound of the cello emanating from the bell of the French horn. Their subsequent reading of the text panel, which explains the patient's story, completed that stage of 'drawing in' the viewer to the deeper dimensions of the artwork. This occurred firstly through engagement with *abstraction* (the French horn form), then *surprise* (upon hearing the softly played cello), and then *personal story* (the sharing of the patient's words on the artwork label).

Liz C travelled thousands of kilometres from Darwin in the Northern Territory, to view the exhibition in Wagga Wagga NSW with her elderly parents and her brother's family - seven people in total. I left them alone to view it together, so they could navigate it as a family without the pressure of having to respond to me as the artist-researcher. When we met later that afternoon, Liz C talked about how beneficial it was to view, not just her work, but the entire exhibition; particularly to see/hear the stories of other patients. Her parents were also impacted by seeing the work, and hearing about the process. The previous year, I had asked Liz C if she was happy for me to email her a series of question about her relationship with the French horn. She agreed, and within a couple of days, had replied with a set of thorough answers, also informing me that she had sent the questions, and her answers, to her parents:

I think Mum felt guilty or bad that she hadn't asked those questions of me. She said I seemed to be doing fine so she didn't think it was affecting me that much and they didn't think to ask. I didn't think my answers were over-emotional so it was interesting to me that the responses seemed to make her sad and she felt my loss. But they were glad to receive it.

I hadn't previously considered that a potential outcome of this project would directly impact the extended family of participants, but Liz C further explained that it initiated a request from her mother for a family zoom meeting to talk about Liz C's experience. At the Wagga Wagga art gallery, I had the opportunity to meet her family, and when I was introduced to her father, he thanked me for helping

him to understand more about his daughters' experience. Liz C herself described her participation in this process as a form of "self-care" that was therapeutic. Moreover, it opened conversations within her family about her illness, and empowered her parents to feel they had permission to ask questions.

Reflecting on a previous encounter at the SFNC, I recall being present when healthcare professionals were discussing Liz C's case. I shared with them the work I was doing around the French horn, but my concerns were disregarded, with a comment that Liz C was now playing the cello, so her musical needs were being met. I mention this, not to criticise the SFNC, but rather to acknowledge the potential that comes from having an artist working in an open-ended way, as part of a multidisciplinary care team. By following artistic hunches, and intuitive leads, but most importantly, by listening, responsively, to the voice of the patient while surgeons and other carers were doing the business of their disciplines, this artistic collaboration initiated a valuable contribution to the clinical journey of the patient, one that might have otherwise been overlooked.

Artwork #5: Dr Glen Croxson

Audio, 3-D scanning and printing, reel-to-reel tape machine, metal arms, microphone stands; dimensions variable

Health professionals obviously aren't exempt from the same biases and stigmas that everyone has. (gallery viewer)

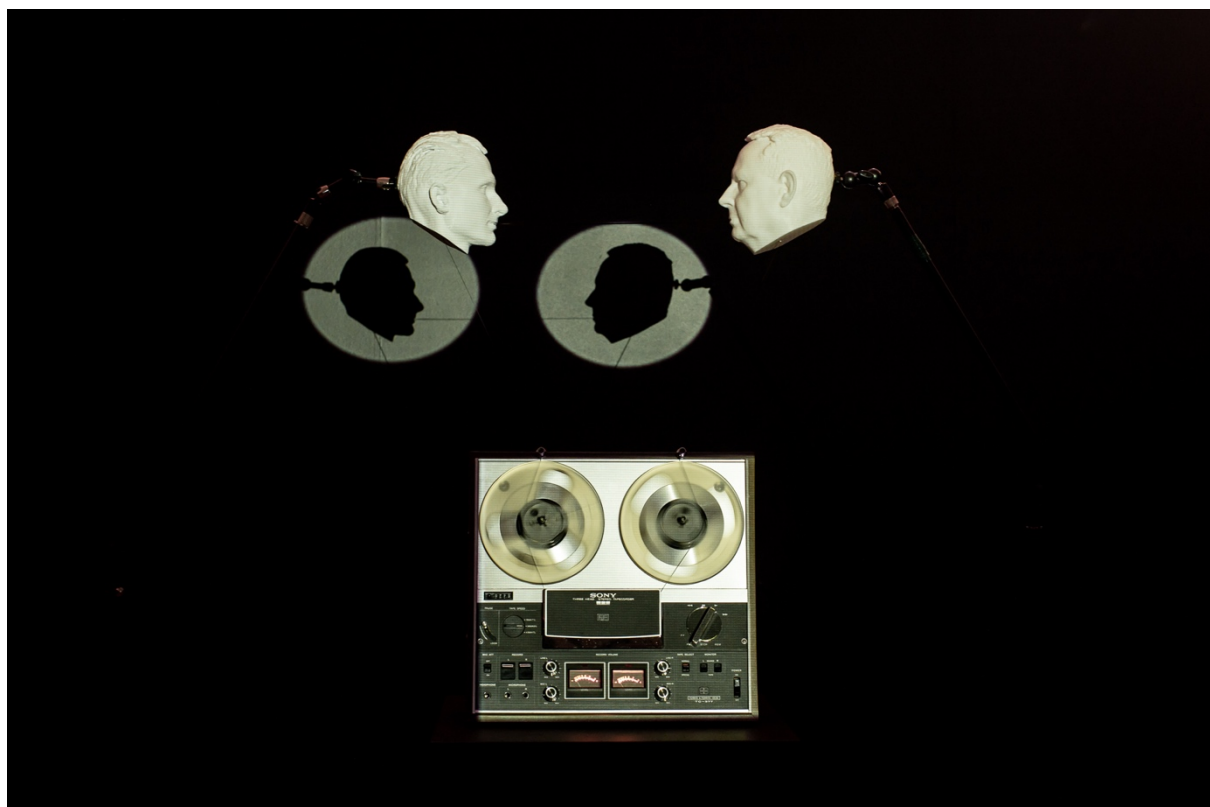


Figure 33: Dr Glen Croxson installation photograph

Background

At the time of this research, Dr Glen Croxson was a recently retired neurotologist, an ear, nose, and throat doctor who specialises in surgery related to tumours of the ear, facial nerve, and base of the skull. One of Australia's leading facial nerve surgeons and a founding member of the Sydney Facial Nerve Clinic, he was regularly called on to work on complex cases of facial paralysis and disfigurement. I have been told that Dr Croxson's reputation was based on his meticulous attention to detail and his compassion for resolving the delicacies of facial fragility.

Process/Making

During our nearly three hours of interviews, Dr Croxson reflected on his career – its challenges as well as its impact. For this exhibition, I edited together a segment of the audio in which Dr Croxson explores what the idea of care means to a person with his experience, and the changes he has seen within medicine during his lifetime. I created a 3d scan of Dr Croxson head alongside a scan of the participant William M who was featured in artwork #1. I then 3-D printed these to create a kinetic sound installation work.



Figure 34: Dr Glen Croxson artwork in development

The portion of the audio, recorded during an interview with Dr Glen Croxson, that was used in the artwork, was as follows:

One of the largest barriers to care is effective communication. Care can be anything from reassuring a patient, right through to managing a patient who you have diagnosed and revealing to them your knowledge and [your] insight into what that tumour represents for them and their family and their life. Educating them up to a point where they can make informed decisions, and then implementing skills which you have honed and learned over years to be able to make a significant change to their life.

Thirty years ago, 40 years ago, it was: Hand your problem over to me. I know best. I'll take care of it, and I'll give you back what's left of your life. You know, the ability to be able to communicate with empathy and insightfulness [is something] that, I think, [is] important.

I have honed specific surgical talents, which led to me objectifying patients with physical disorders to the detriment, I'm sure, of being able to, uh, fully assess and deal with the patient's emotional response to their disorder. I think the objective path of what I do has a practical use to the patient; but subjectively, I feel that, with

facial nerve disorders, I skate along and try and minimise that as a way of basically being able to <pauses> cope.

It's a mechanism which allows me to stick, with some degree of certainty, to those things I can do, without actually having to take on the full emotional impact of a facial nerve disorder, which is extraordinarily devastating. If you give the patient information and power to make decisions, to a degree subjectivity and objectivity becomes a thing of the past, as it becomes an agreement between the patient and the doctor as to what is important to them, and what is most important as far as care goes.

Installation

This artwork consists of the 2 x 3-D printed heads mounted above an old-fashioned reel to reel tape player. The tape was “diverted” so that its path of travel went through the mouth of the doctor, to the patient. Amplified in the space was the sound of Dr Croxson, talking about aspects of his experience. In the gallery, this work was positioned close to the *William* video mentioned earlier (Artwork #1). My aim in placing these experiences of the doctor and the patient in a relationship with each other was to speak to the personal journeys of the patient and the doctor. Multiple visitors to the exhibition referred to the success of placing these works together, so that they experienced them one after the other – both separate and in relationship.

It was good to see that after William. William was all about his subjective experience and this is 'objective' and it's something that many of the doctors I know will still battle against, because their medical training is still heavily in that mode and then they're told to do something completely different and engage with patients or clients or whatever you're calling them, customers in some cases (terrible). And you have to be so many things already to be a doctor ... so much that is expected of you, to be all of these things to all of these people and to know exactly what's wrong with them and not to fuck it up, that's very hard.

Response and Discussion

This installation provides an opportunity for visitors to reflect upon their own medical experiences and to engage in conversations about what people expect of their healthcare professionals, how much they expect them to take on, while also reflecting on their own experiences with medical communication. As one gallery visitor participant commented:

Well, his profession's realization over the years that they've started to see people as human beings rather than as a problem to be solved or an object coming mechanically, that's only a fraction of it. And that's just the tip of the iceberg, really. William M talked about the black void behind the face. And I think they [the medical profession] are only just realizing that, actually they have to delve into that black void as well as the physical face. I felt what he was saying is important, because you do need to discuss with a patient what's going to happen next and give them options, especially if it's going to affect the rest of their life.

And from another:

A lot of the time people go in for their hospital appointment and their biggest problem is actually their emotional concerns ... and it's kind of the job of the doctor now to help to give certainty and help to kind of emotionally console people as well. It's definitely an evolving field. It used to be just, you'd treat a set of symptoms and

then it was you treat a patient, and now you're treating the person. Trying to move it away from just treating a syndrome to talking about an actual human being.

This artwork triggered multiple art gallery participants to talk about their past experiences with medical treatment, while relating encounters that have made them feel 'helpless' due to poor communication between themselves and their healthcare practitioners. However, engaging with this artwork also provoked conversations that acknowledged the "change" towards more person-centred care that Dr Glen Croxson is talking about. Additionally, participants acknowledged the complexity that comes with caring for both the physiological and the psychological wellbeing of a patient.

This work provided medical professionals the chance to reflect on their own understanding of patient–doctor relationships and of the personal impacts that arise from professional practice. One art gallery participant, a doctor, talked about trust.

Communication is just a transactional analysis where you're talking about different ego states. And so, if you start dropping down into that ego state, then you're not going to feel effective, and you get a communication barrier. So, there's an emotional aspect to it and a personal aspect, but there's also communication and professionalism to it as well.

You do find yourself sliding into that and losing focus of who the whole person is. And I don't know if some of that is coping, because you do have to have a certain amount of resilience. And the only way you can do that is to distance it somehow. But then if you get to a point where you're distancing yourself so much that you can't see the person behind the diagnosis, I think you're in big trouble. And I think you touching those bits resonated quite a lot. It is that thing of being separate in some way, but not indifferent. It is trying to get that right, isn't it? I mean I guess the job of the doctor is to deal with the presenting problem, which as you said is what's clinically wrong. But the presenting problem isn't always the most important.

Treating the person as a whole. They're not their facial palsy.

This artwork introduced the voice of the surgeon exploring thoughts about objectivity, the doctor patient relationship and care. In multiple other healthcare professional interviews conducted in this research, participants shared that they had no real practice of self-care to balance the trauma that they are exposed to. One doctor participant from the SFNC responded:

I guess if I'm being brutally honest, I think I don't receive it as a trauma. And why is that? I don't know. Certainly, in medicine you're taught that, "Okay, move on to the next patient." You don't have time to go and speak to somebody. You don't have time to go and get counselling because you've got the next patient to see. I guess you internalize it and how that comes out, I don't know. Honestly, I just don't, I don't know the answer. I don't know, because I guess I've never gone outside of me to observe what I actually do. How do I deal with it? I don't know the answer.

Much scholarship within philosophy, sociology and medical humanities explores how a medical professional manages the practical and emotional aspects of patient encounters. In 1963, Leif and Fox further developed the idea of *detached concern* (Osler, 1910), meaning:

The empathic physician is sufficiently detached or objective in his attitude toward the patient to exercise sound medical judgment and keep his equanimity, yet he also

has enough concern for the patient to give him sensitive, understanding care (Lief & Fox, 1963)

Professor of Bioethics and Medical Humanities, Dr Jodi Halpern explores this concept further:

Physicians recognize that emotions influence healing. Yet many physicians impose the norm of detachment upon themselves in part because they believe emotions seriously threaten objectivity, and further, that detachment is the best way to maintain or regain objectivity. They are influenced by the philosophical view that emotions have no cognitive value, a view derived from rationalist philosophers like Descartes and Kant. This view is no longer generally accepted, however, as current philosophers see emotions as playing a cognitive role. (Halpern, 2011).

Tseng further explored the ideas of Halpern in her research project that explored the process of learning detached concern in medical education through cadaver dissection in which she proposed that:

Medical cadaver dissection training is considered both a tool of anatomy, or surgical training, but also as a device of training for students confronting emotional difficulties of practice. (Tseng & Lin, 2016).

On participant medical student in Tseng's research referred to the cadaver dissection in the following terms:

At first, we may have viewed it as a person. Cut by cut, every one of us became a little bit benumbed, cutting while murmuring, 'Oh, it's just an organ, organ, and organ.' When dissection progressed to the eye, we said, 'Oh, an eye.' But after dissecting it into smaller fragments, we told ourselves, 'He is just made up of tissues.' We gradually stopped projecting our emotions. (Participant #2) (Tseng & Lin, 2016).

In the extended interview with Dr Glen Croxson, he talks about compensating for this necessary detachment by making sure he is surrounded by people who can give patients the emotional support that he is unable to. Since Hippocrates, we have been identifying these complexities that arise in care-based professions:

"The physician "sees terrible sights, touches unpleasant things, and the misfortunes of others bring a harvest of sorrows that are pecuniary his". (Smith, 1994)

This research asks, In an overburdened health care system, is it even possible for the surgeon to manage the various types of care that patient need? and to bear witness to the components that might be missing? Particularly when this particular work at the SFNC is to do with the human face that is so often the *perceived* centre of our identity. As one student mention in Wei-Ting and Ya-Ping's study of detached concern, the head, face, and hands can be the most confronting for a healthcare professional, as they are perceived as being the most human. (Tseng & Lin, 2016)

This artwork could be seen as a moment of self-care for a healthcare professional. It is a rare opportunity to hear the voice of a healthcare professional in quiet and reflective consideration of their career as a provider of care. As an act of empathetic witnessing, this work acknowledges the humanity of the doctor alongside that of the patient, in consideration of the complexities of care management.

Artwork #6: Facial Nerve Harp

Wood, guitar pegs and strings, 3-D scanning and printing, contact microphone, audio interface, pre-amp, computer; dimensions variable

Background

Facial Nerve Harp is an interactive installation, an educational tool, and a musical instrument. In its artistic representation of the facial nerve, it has a conceptual aim of 'giving voice' to a part of the body that could be considered as dormant, or as having 'no voice' when paralysed. As an educational tool, it shows the anatomy of the facial nerve while facilitating a meaningful and interactive exploration of the face, facial paralysis, and facial difference.

Process/Making

These harps were constructed as a wooden frame with the 3-D printed face of a facial nerve participant attached. The five musical strings of the harp emerge from the approximate anatomic location on the printed face of the stylomastoid foramen where the extracranial facial nerves align.

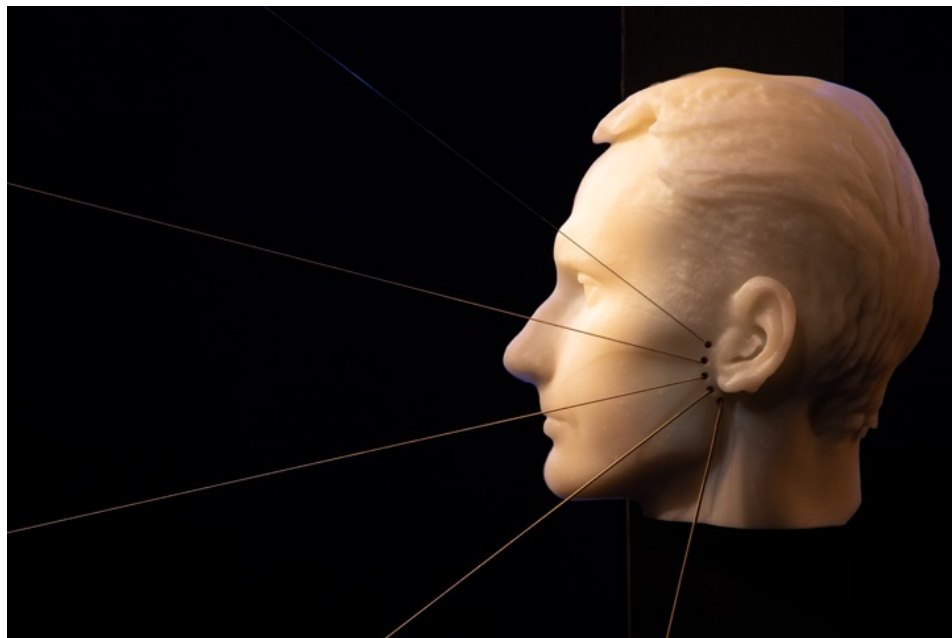


Figure 35: Facial Nerve Harp detail

From there, they are stretched across the frame in an anatomical approximation of the position of the five branches (temporal, zygomatic, buccal, marginal mandibular and cervical) of the extracranial portion of the facial nerve. It is damage to these nerves that have resulted in the pathologies for all of the patients I have worked with.

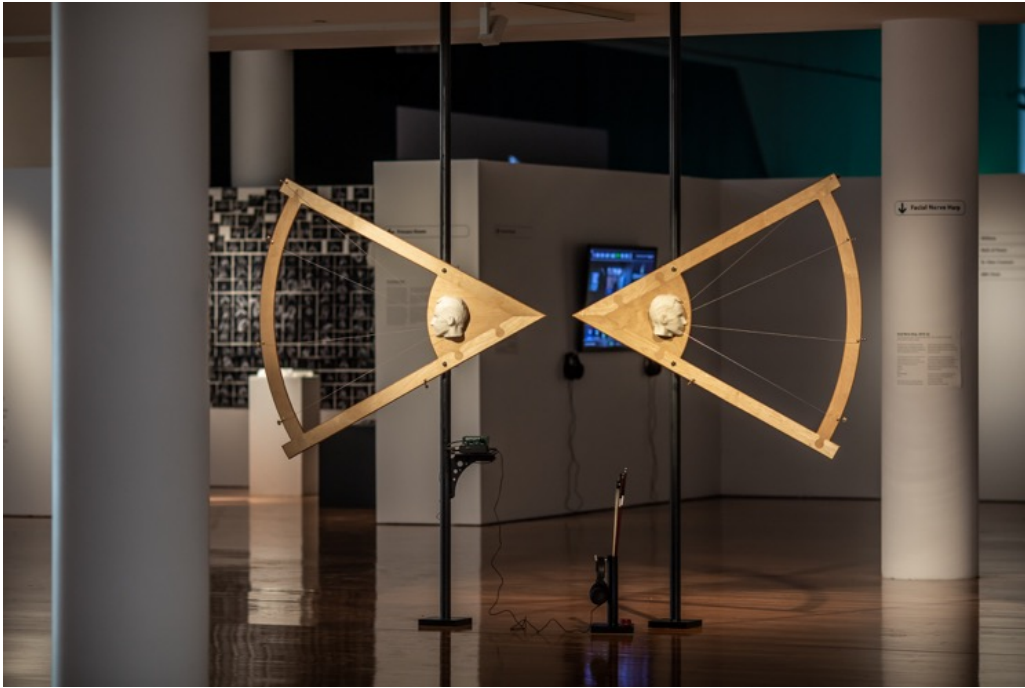


Figure 36: Facial Nerve Harp installation photograph



Figure 37: Facial Nerve Harp detail

Installation

In the gallery space, the harps are interactive, people are allowed to play them with their fingers or with a bow. There are headphones for people to wear while playing the harp, although it can also be heard acoustically in the space. The sound in the headphones is an immersive one, with slight treatment of the sound which is picked up from a contact microphone placed on the wooden frame of the harp.

No prior musical experience is required to be able to explore the facial nerve harp in a satisfying way. It is something that creates meaning through its interaction with people of all skill levels. It is curiosity that makes it truly resonate.



Figure 38: Facial Nerve Harp being played in the gallery

Results and Discussion

I discovered through the presentation of this work that the harps provided, for the majority of people, their first opportunity to learn about the facial nerve.

I had never thought about [the facial nerve] before. It seems so fragile. (Gallery participant)

Art gallery participants reflected on how this manner of presentation provided an opportunity for deeper learning and the potential for information retention to be increased through an engaged, interactive, and novel process.

I will not forget playing the facial harp because the resonance in what was happening is just so interesting to me and such a sensory experience. I will actually remember this more [than printed information]. I've been going through the patient journey myself, [and] by the third or fourth page of your pamphlet, you're just like: "Oh, yeah." It's far better to have fewer, simpler words if you're trying to make a point. [Illness] is a real sensory thing. If you get given a pamphlet, it's all information, information, information.

This observation that illness is a “sensory thing”, is an invitation to propose that using multiple senses (such as via artworks or artistic processes) might be a meaningful way to care for patients, and to translate information while providing opportunities for reflection on the human experience (Serres, 2016) therefore it is an invitation to consider the potential of these types of immersive artworks to contribute to the care provision in the medical journey. Another participant remarked on this by sharing that when they engage in medical treatment, they can feel:

I'm interested, but it's not soaking into my brain. But when it's [like this installation] it's like, "Oh, okay" because you're actually making people do it, and it's about them and their bodies, [it] makes them click, using themselves as an example.

Other participants commented on the multisensory experience of the work, and how this added to the richness of the shared story. Creating an artwork such as this, means that Information was able to be received through many senses including touch (through the interactivity of the artwork) and hearing, not just vision:

I can feel it in me, where the memories are flying. You have all these connections to other things ... This is the sense in which you experience the world. What is the world to me, except the things that I can experience through the senses I've got?

Multiple researchers have explored the role of the arts in knowledge translation (Banner et al., 2019; Boydell et al., 2012; Dew & Boydell, 2017; Kothari & Wathen, 2017) and the 'qualia' of medical experience (*Ethics and the Arts*, 2014; Hooker et al., 2022) while artists have also been exploring these concerns. For example, Eugene Lee created her installation [McGill Pain Questionnaire](#) (Lee, n.d.) as an immersive opportunity to express her pain experience and her response to the clinical pain measure authored by McGill. Lee describes that her work is an opportunity to:

... speak the 'truth' of one's lived experience in a way no words could ever replace and are as valid a way of communicating as any scientific pain measurement tool, if not better.

Eugene's artwork is an example of artistic practice as a form of knowledge production, just as this exhibition is an examinable component of this research. Importantly, this includes the consideration, touched upon by McGill, that this new knowledge can be generated in methods that are sensory, that don't contain words. This raises many questions, identified during this research, such as how to convey the importance of a look that I am given by a participant after they engage in an artwork, when that look reveals so much that is unspoken. Or how do I value and interpret the way that they hold their breath as if suspended, or stare at the ground mid-sentence. How do I convey the suspension that occurs as a participant gives voice to the facial nerve by playing the facial nerve harp with their eyes closed, lost in their interaction with the artwork and the connection to human experience that the work is trying to convey. Sometimes words can break that suspension, which is why I believe that the value of artistic works as NTRO's is such an important co-contributor to knowledge.

Central to my artistic practice is the use of sound as an artistic medium. There are multiple instances of sound as an act of care within these exhibition outcomes, and this is the first artwork that I present here that explores this concept. Participants referred to these connections between the sound and the experiences of patients, sometimes as a sonic metaphor for the pain and trauma:

You could spend all day doing that, couldn't you, creating your music? But for me, when I was doing it, it was also representing some of the background pain and noise you get from facial nerves – or from any sort of pain.

It was like this background constant noise that people sometimes carry with them.

The themes are not relaxing; they're quite brutal. [But] the rhythm is [relaxing].

A comment like this could be taken as a negative, but that is not the intention with which the participant conveyed their response. Instead, they were talking about the complexity of engaging with something that kept them suspended, not just in a fanciful soundscape of imagination, but in one that grounded them in the intention of the artwork, which was the experience of the facial nerve patient.

Facial Nerve Harp is an interactive way to learn about what the facial nerve is. The responses identified that through an artwork of this nature, we can provide sensory and immersive experiences that aid in the emotional and practical exploration of these topics. As an installation it facilitates a "sensory"

learning experience, which participants propose is an impactful way to retain medical information (Bleakley, 2015, 2020). It also creates an embodied experience, where the gallery user is activated to engage while making immersive tones.

The thing that struck me with the facial harp is that it reminded me of other work that is emotionally important to me. And that's what we go to art for, to use the [art]piece as a way to make connections across different pieces of your life. And I think also, too, being reminded that the body is kind of – in and of itself – an instrument. You kind of play yourself, in that sense.

I will end this section by sharing a field note taken from an observation in the gallery:

Field note (2022):

An elderly man sits playing with the facial nerve harp in the Wagga Wagga Art Gallery. A conversation begins between him and Natalie Power, the 'cultural mediator' who is in the gallery to talk to people about their experience. The man's phone rings, he looks at it and excuses himself, saying it was his son who is in the Ukraine, and he must answer it. At this time, the war in the Ukraine has just begun. All indications are that it is a time of confusion and worry for the man.

He answered the phone and said "Son, please listen to this" then he placed the headphones on his phone and played the facial nerve harp for his son in the Ukraine. He was then left in private to continue his conversation.

This art installation, which aims to teach people about the facial nerve while having an embodied and immersive experience, began its life in consideration of the intimate thin fibers that form the facial nerve, and ended up being played as a greeting from a worried father to a son all the way back in the homeland, in a nation at the beginning of war. This speaks to the potential for this type of work to continue its intention of care beyond the immediacy of the medical clinic by enacting rich outcomes as it is shared and engaged with by audience in a variety of different locations and contexts. Care is the condition that we are creating through these works, acknowledging that their output of care isn't just bound to the subject of the facial nerve.

Artwork #7: Wall of Faces and MRI Choir, 2021

3-D scanning and printing; dimensions variable; video, audio; 5mins 45sec

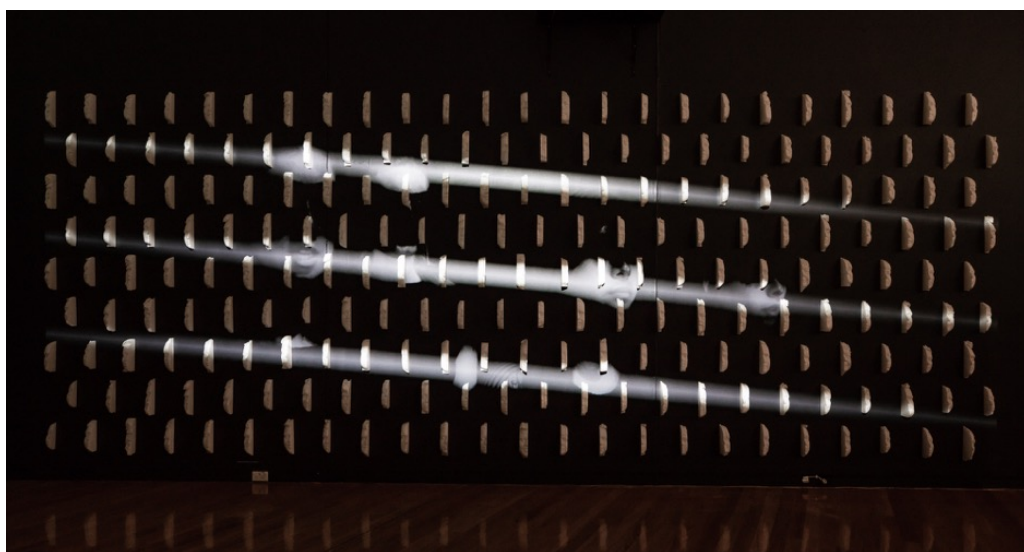


Figure 39: Wall of Faces with MRI Choir installation photograph

Background

This wall of faces presents a diverse range of people: refugees, people with learning disability, trauma survivors, schoolchildren, elders, families, tourists, etc.

Process/Making

During my residency at Tate Liverpool in March 2020, visitors were invited into the Tate Exchange gallery to participate in activating, creating, or sitting for artworks while sharing their lived experience. Participants were scanned with a 3-D scanner, and their faces were 3d printed in the gallery space. During the residency period there emerged a 'wall of faces' that shared the story of encounter, of diversity, and the face's ability to convey emotion, even in a context of digital and material reproduction.

Installation

Over 250 printed faces installed on a black wall with video projection overlay.



Figure 40: Faces ready for installation

Results and discussion

Whilst undertaking this process, participants engaged in conversation about how they view their own face, revealing that you don't have to be a patient suffering from facial nerve disorder to feel uncomfortable with how you present to the world. Creating and exhibiting this work was another example of bringing the gallery visitor deeper into the artwork by exploring the considerations of 'self' that we encounter when we consider the life of the Other.

In the final exhibition, the Wall of Faces installation was overlaid with a video work that I call *MRI Choir*. This was a collaboration with singers from The House that Dan Built, an all-female choir directed by artist Danielle O’Keefe. In this work, I directed them to sing in duet with the soft, hidden, almost human-like tones that are buried within the cacophony of the MRI scanner. This video provides an opportunity for a unique collaboration that softens/humanises the technology of medical machinery that is used in clinical settings, and sets the scene for future artistic research that explores the negative impacts of the loud volume of sounds emitted from the MRI scanner (this is a topic that has been explored in a [previous research project](#) of mine). The MRI Choir video work, with an added contextualising introduction, can be viewed [here](#).



Figure 41: Wall of Faces detail

The wall of faces speaks to the diversity of people. In planning, a decision was made to remove the colour from each 3-D printed face for practical reasons. It is virtually impossible to represent the vast array of skin tones that exist in society, as Pantone’s research has identified that over 138 different skin tones exist worldwide. The limited range of available 3-D printing filament would not allow for an accurate portrayal of this diversity. Therefore, the decision to present the faces without colour was a practical one, however it highlighted that even with the absence of colour, through a clinical white, we can still see and connect with the individual emotions and expressions of the face before us. As you look at the 3-D printed faces shown in the photograph above, they continue to project humanness, compassion, and warmth. These faces transcend the intricacies of the 3-D scanning process, their conversion into ‘data’ as geometric points, the subsequent 3-D printing, and then their eventual exhibition on the gallery wall. What persists is a humanness that cannot be erased by these reductions. This parallels with a proposal present in this thesis, that artistic practice can work together with biomedical practice to nurture emotional expression and diversity, even through a field of clinical white.

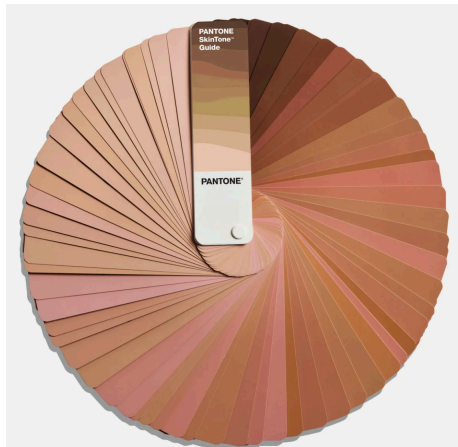


Figure 42: Pantone skin tone guide (Pantone, n.d.).

Artwork Grouping #2

The artworks presented above as grouping #1 all explored some aspect of the experience of facial nerve pathology and perceptions of the face. Although the interpretation of these works involved multiple instances of the relationship of the viewer that arises when engaging with artworks about another person's life, grouping #2 are more explicitly about the viewer.

In the context of this exhibition, the gallery viewer is confronted with ideas of trauma, responsibility, illness, treatment, recovery, and non-recovery. Visitors frequently referred to the exhibition as complex and hard-hitting, with two participants referring to its 'brutality'. However, they all, without exception, discussed how these subjects, even ones described as a 'brutality', were rendered with a love and care that enabled the viewer to engage with them in a safe way. From my perspective, this 'love and care' that gallery visitors have identified, is created through the care that is taken in making and then presenting each artwork and then expanded by the exhibition layout and the design which includes this second grouping of artworks, which provide a type of *dwelling*.

The phenomenologist Emmanuel Levinas proposed this theory of *dwelling* in his examination of ethics. One argument that can be made against Levinas's work is the perception that in his philosophy there is the proposition that 'I' am to be totally subsumed by the "Other". However, Levinas clearly states in his theory that I (or my ego) still exist within his proposed substitution of *being-for-the-Other* (Levinas, 1998, p. 103).

Levinas argues that 'I' am compelled by *responsibility* when I meet the *face* of the "Other" but he also argues that 'I' might turn away from this responsibility. Levinas proposes that this ethical "responsibility" to meet the "Other", is an asymmetrical ethical relation as the "Other" is not compelled to act with the same responsibility towards me. Levinas's proposes that I can find a way to endure both the "responsibility" and the "asymmetry" of this ethics, through his concept of *The Dwelling*, which is a place for this ego; a place for recollection, a place to re-gather in the safety of "me" to then enable me to be able to stand face-to-face with the "Other" with a sense of "hospitality" towards them. As Levinas describes it, the dwelling is:

... a recollection, a coming to oneself, a retreat home with oneself as in a land of refuge, which answers to a hospitality, an expectancy, a human welcome. (Levinas, 1979, p. 156)

How I understand *the dwelling* in Levinas's philosophy is that it doesn't refer to an actual location, or home, but instead to a form of embodied consciousness which might be within my practice, or within my process, or within my family, or home, or within a space in a gallery or an artwork. This concept of *the dwelling* allows me to have a process to explore (or recover from) my experiences of caregiving,

making them possible to endure, so when I face the “Other” again, I can meet my responsibility, and their potential, asymmetry with *hospitality*.

By providing a *dwelling* for the gallery visitor, it allows me the opportunity to share the depth of this work in a way that doesn’t hide away from the trauma, but also addresses my responsibility to keep viewers safe and supported enough for them to be able to sit with complex topics that potentially have relationship with their own lives. My artistic research methods come with their own bias that believes that artistic work made with those who are experiencing trauma, often needs to convey these traumatic complexities rather than just conveying lighter feelings of hope and calm. I believe this is an ethical responsibility to honour the complexity of the experience.

The following three artworks which make up grouping #2, are presented to provide a moment of reprise, a place for *dwelling*, away from the responsibility of the ethical meeting with the “Other”. They are moments for self-reflection and for (some type of) rest.

Artwork #8: Bio-Medical Composing Machine

Video, audio, medical sensors, electronics; dimensions variable



Figure 43: Logo from Bio-Medical Composing Machine

Background

This interactive artwork invites audience to connect to medical sensors that measure heart rate, temperature, and blood oxygen levels. This ‘medical data’ is then used to trigger sounds that are responsive to any changes in any of these readings, creating a live, real-time composition ‘written’ by the body’s own medical data. This artwork transforms this common process, the ‘taking of vital signs’, to reconsider it as a personal, embodied, musical experience that sonifies and personifies. The intention is that, instead of the mere ‘taking’ of vital signs, the user is also ‘given’ something through their body’s own information and their sense of inquisitiveness and wonder as they listen to, and draw connections between, their body/surroundings and the composition they hear. The *Bio-Medical Composing Machine* is a gallery installation of an imagined piece of medical equipment that gathers data in a way that is an embodied evoking of the senses.

Process/Making

This artwork was created by using medical sensors that were able to be programmed via Arduino as the starting point to develop a standalone machine. I then designed methods by which we could convert the gathered medical data, which consisted of a series of numbers, into midi data that could be used to trigger various sounds. The Bio-Medical Composing Machine was made to resemble a piece of medical machinery rather than taking on a fanciful or poetic form. Instead, the poetics were contained within the headphones and the sounds that the user would hear in response to their medical data.

Installation

When the gallery visitor sat down at the machine, they were invited to press a heart-shaped button that played an instructional video explaining how to proceed. Watch instructional video [here](#). The user then put on the headphones and connected the sensors, then they sat and listened. While this installation provided an opportunity for immersion for the gallery visitor, it also aimed to consider the Bio-Medical Composing Machine's potential application in an actual clinical space.



Figure 44: Bio-Medical Composing Machine installation photograph

Response and discussion

People expressed curiosity about being sonically connected to their medical data, and they frequently tried to 'take control of' the sounds they were hearing. When they tried to control them by trying to raise their heart rate for example, they could hear the change in their 'composition'; they then felt connected to the fact that the music was made from something that was a part of them.

It's being translated into music [...] you rarely think of your heartbeat and the sound of your breathing, but then to have it translated into sound was extraordinary [...] I did try holding my breath to adjust my blood oxygen levels and then it slowed down [...] it was just amazing. I [...] wish I could take a clip home.

Participants speculated about the bio-medical composing machine's potential in areas such as dementia care, or as a form of anxiety relief, providing opportunities for further avenues of research.

It might help your brain calm down. I think music in terms of helping people with mental health, sleeping disorders, whatever, is amazing and it is something that helps. I just think it's so cool.

It also provided reflection for those working in the medical profession. A visiting anesthetist also commented on the device's potential for working with teenagers.

If you're relaxed and you have a feeling of relaxation, then they [veins] tend to dilate because it's part of your fight or flight. So, if you're about to fight something, all of your blood goes to your vital organs so that you can run like the clappers. But if you're just sitting calmly, then your blood vessels relax and then they expand [making it easier for taking blood, etc.].

Machines like the composing machine [...] would be a fantastic way, a practical way of using medical practice, but in a way that [it] is an empathetic machine.

Teenagers are great, [...] you can get them to do a lot of stuff with their physiology. So when you're putting all of the monitoring on them for an anaesthetic, you can get them to do things like imagine that you're on a roller coaster and it's going really, really high. Their heart rates go up. And you see it. They're the ideal age group for [...] embodying what they're thinking.

As one patient reflected:

[The device] could be good for something like white coat hypertension ... my blood pressure shoots up about 25 points when I take it in the doctor's surgery.

Positive enthusiasm was reflected in the response from many users, who conjured up different potentials for the machine in stress reduction and connection to medical pathology. The Bio-Medical composing machine shows that there is a real role for acknowledging the body as a site of wonder, even when it is a site of medical care.

I find things like this always make me think about: has my ability to discuss my experience in my body or my medical history expanded in some way? Were they altered? ... I love the idea of being able to turn it into music.

The artwork also acknowledges the “body” in its gathering of medical data, which as one participant remarked, reminded them that:

the body is kind of, in-and-of-itself, an instrument. Hearing isn't something that we, in a physical sense, do passively ... You kind of play yourself in that sense.

It's another great way of [thinking] how amazing our human body is.

And another:

It sort of humanizes and personifies something that otherwise would not have a voice. And it's just raw data and raw science so to speak. And that's pretty cool.

One participant remarked: “It’s like someone’s talking about me and I’m just listening to what they say.”

Field note (2019):

A primary school group, perhaps year 4 (ten-years-old), visited the exhibition today and the students spent a lot of time engaging with all the work. I spent my time at the bio-medical composing machine, explaining it to the students and helping them to experience it (by connecting sensors, and explaining what they are hearing). The kids appear to love it, but given time limitation, they only got to spend about one minute each connected to its sensors. The last student to try it sat there for ten minutes, with her eyes shut, completely still. A teacher runs up to me and whispers, “She is a hyperactive child.

I've never seen her sit calmly in the last four years I've known her." The girl opens her eyes and takes off the headphones. I ask her, "How was it?" She replies with a calm, gentle smile: "It's just so relaxing. It's brilliant."

The heart rate, temperature and blood oxygen levels are all part of the autonomic nervous system which undertakes many of the body's involuntary tasks such as breathing and regulating heart rate and temperature. It is a system that is in constant dialogue with other parts of the body, as well as with the environment around us.

As a type of *biofeedback* (Schwartz & Olson, 1995), the Bio-Medical Composing Machine creates new ways for patients to connect to the transfer of information. Australian artist George Khut who has investigated visual and sonic "biofeedback" in clinical settings as a major part of his practice, describes the potential for interactive artworks of this nature to explore

the concept that nothing is being done to the participant – that it is the participant themselves who is influencing the behaviours in question via the quality of their engagement/being. (Khut, 2006, p. 19)

The Bio-Medical Composing Machine presents the "medicalised body" as being full of wonder and proposes that not only is the body connected to the world around it, but it *is* the world around it. In this sense, the artwork is taking up Merleau-Ponty's conception of the "lived body".

'Our own body is in the world as the heart is in the organism; it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system'. (Merleau-Ponty, 2005, p. 203)

Instead of reducing the individual to a numerical value that then defines health/ill-health, this artwork provides an opportunity to measure and gather, as bio-medical concerns require, while also providing an opportunity for personal connection beyond just the numbers of measurement. One participant described this type of 'number' reduction as "translating your corporeal sense into a set of numbers". Another participant commented that when he lived in the United States, his cholesterol was measured as 111, whereas when he lived in the United Kingdom it is 3.9 – entirely different numbers that apparently have the same meaning. He reflected on the machine's ability to "translate" this information into music, which held a greater meaning for him personally.

My intention with the *Bio-Medical Composing Machine* was to create an artwork that provides future research opportunities. The Bio-Medical Composing Machine contributes to this field of study with its potential to create a mobile clinical device that reimagines a common and simple medical data collection process. It is a work that reveals a sense of poetic wonder, acknowledging the importance that whimsy and imagination play in artistic navigation of issues of trauma, illness and recovery.

Within my artistic practice, I have explored this theme of what I call *the unlocking of the poetics of functional infrastructure* multiple times in my artistic practice. From the "bringing to life" of silos and machinery in regional farming communities (see photo) to the "playing" of a hospital bed as a musical instrument within a demolished hospital site (see Artwork #15 later in this chapter).



Figure 45: "Playing" a pivot irrigation system at Artlands Festival (Dubbo 2016)

In the case of *Bio-Medical Composing Machine*, my exploration of medical data is also attempting to provide the future benefit of creating an artwork that is at home in the day-to-day clinical experience as a moment of surprise and wonder, as well as a potential for anxiety reduction and human embodiment.

By presenting this artwork in a gallery setting, I am taking the opportunity to examine things such as user response, stability of the device, identification of any maintenance issues and potential refinements, with the intention of exploring what role a device like this might have in a clinical setting. In the three-month exhibition period, the Bio-Medical Composing Machine was very stable, the only issue was when an over-enthusiastic group of adults started arguing over who was next and started grabbing and pulling at the device trying to grab it from each other, resulting in a custom-made cable being ripped apart and needing to be remade. I don't envisage it would encounter this type of behaviour in a medical clinic.

Beyond these practical concerns, the Bio-Medical composing machine holds many intentions. Firstly, it responds to the *exteriority* that patients expressed in Theme #1 of the preceding IPA chapter by directly connecting the humanness, the 'body' of the patient, into a deep relationship through imagination and wonder. It provokes consideration about what use it could have in a clinical space as an operationalised piece of equipment that 'gave something back' while the 'taking' of vital signs occurs. It also sparked an important question that this research project raises, and the easiest way for me to relate that question, is through sharing an experience from the gallery.

During a quiet moment in the gallery, a visitor came into the space and interacted with the Bio-Medical composing machine. This visitor was in the early stages of receiving chemotherapy for a type of cancer. Before they used the device, we had some conversation about how the chemo, which was new to them, was 'feeling'. They then sat with the bio-medical composing machine on their own for over 20 minutes with the headphones on, eyes closed for most of the time, listening to the composition of their body in which the impacts of chemotherapy were present. As they took the headphones off and stood up, I approached them. They looked at me for a while, maybe 10 seconds, without saying anything, they then shared that they had experienced a deep embodied experience. However, the thing that conveyed the most information to me was the look in their eyes as they stared at me for the ten seconds before talking, because this look said so much about the intensity of their experience. When I looked in their eyes, I saw within them, a traversing across time, simultaneously in the past, present, and future. Their eyes alone shared stories about the connection the person had just had to their own body, to their own experience, to their own disease. The look in their eyes has stayed with me until now as I write this thesis, and it causes me to question how we find ways to share and

evaluate such experience within a paradigm of 'research'? How do we value these things that often arise through artistic processes and outcomes? How do we 'feel' an embodied experience as knowledge, and value this type of observing, and this type of 'being with' as a research output? How do I convey the importance of an experience of staring into someone's eyes for 10 seconds that I 'feel' said just as much as the words contained in these pages? How do I convey it, so it is valued, and how do I not forget it? If we cannot find space within research to value a stare, a goosebump, a suspended breath, then at least my consolation is that at the very least, I can keep it with me as one of the special privileges that we receive when we approach relational encounters with a deep commitment of listening, and care.

Artwork #9: Lachrymal Vase

3-D printing, electronics; **205mm x 105mm x 105mm**

Background:

A lachrymal vase is a 'vessel' that is thought to have been used, historically (over 3000 years old), by people in mourning to collect the tears they cried while grieving (de Laet & Dani, 1994). The reason for wanting to bring the 'idea' of a historical artifact that nurtured the experience of grief, into relationship with the facial nerve paralysis experience, was to acknowledge the process of grief that patients encounter on their journey towards trying to accept the 'new normal'. Additionally, it was provoked by observing patients become embarrassed when they cried during the clinical encounter. This work, therefore, honours the crying of tears, acknowledging my observation that when people cry in the clinic, the most common phrase they say is "I'm sorry".

Process/Making:

This artwork was created through a process of computer aided design, 3-D printing, electronics, and computer programming. The design of the vase underwent several iterations, before settling on its organic shape that in some ways resembles a tear (it was actually modelled on a 'maraca' that I had in my studio). I then utilised a type of sensor that is used in automatic windscreen wiper systems, to act as the tear drop sensor. Utilising an Arduino computer processor and associated computer programming, this process enabled me to trigger any audio file from the sensing of liquid on the sensor that was built into the top of the lachrymal vase.



Figure 46: Lachrymal Vase detail

Installation

In the exhibition this lachrymal vase was installed in a dark, quiet, and reflective area of the gallery, in a room of its own (providing a sense of privacy). Sitting on a white plinth, and lit with a single light, the artwork was presented as an interactive sculptural form which could be activated when/if a gallery visitor cried a tear that landed on the top portion of the vase. When this happened, an electronic sensor triggered a sound to play- a voice which told the visitor that they are loved. Knowing that it would not be frequently triggered (if at all) there were room notes that explained to the visitor what the work was/did. These room notes are available in the exhibition catalogue in Appendix 1.



Figure 47: Lachrymal Vase installation photograph

Although the intention was that a ‘cryer’ would be met with a voice telling them they were loved, I did attend the gallery one day and replace the voice with a recording of a [song that was sung](#) at the funeral of a family member of mine. For a few days, the sound that was triggered by a tear falling on the vase, was a song that explored my own navigation of grief. This had the outcome, from my perspective, of keeping the artwork alive and still in development, even while being presented to the public as a final outcome. It was the installation of the entire exhibition that provoked in me a need to ‘alter’ the work for a few days to acknowledge something that the work had triggered in me.

Response and discussion

I don't provide any user response data from the installation of this artwork. Anecdotally I know that it was triggered several times by people who cried a tear on it. I received an email from one person telling me that they visited the work and cried on it, triggering the sound. I also heard from gallery staff about conversations with people who also interacted with the work in this way.

Rather than collected response data, this artwork is considered by me as being an offering in which visitors didn't need to directly cry on the vase itself but could just read the room label and to think about the way we do, or do not, make space for the emotional aspects of complex topics in our life. It is also a way to make space for these types of conversations.

My aim with this artwork was to 'pay attention' to the importance of the teardrop and therefore, of the importance of acknowledging the emotional aspect of health. One of the beliefs that underpin my entire socially engaged arts career has been the belief that, in general, 'people' do a poor job of dealing with the emotional aspects of trauma in a way that is embedded and responsive. Therefore, I would propose that this has been a lifelong area of interest within my work.

This work was made to create moments that acknowledge the emotional journey of medical care, and of life in general. It offers the idea that a tear shouldn't be something to be apologised for, but instead revered as the materiality of our emotional experience. Tears could therefore be conceptualised as a call to action from the *components of care* that were interpreted in the previous chapter. The very presence of tears invites human connection, but so often creates barriers to it.

Observations within the clinic revealed not only discomfort from the crying patient, but from some healthcare professionals as well. One surgeon responded that when they witness a patient cry, they just don't take it on board, feeling that what they can offer to the patient is their knowledge about the internal structure of the face, and various methods of intervention, but not necessarily the skills to cope with the emotional aspects. Another surgeon responded that "very early in my career, it was confronting, and you would almost take it personally. You'd almost feel, "Oh my God, what have I done? What have I done to make you burst into tears?" And I guess what I've learned is that...it's not a negative thing. There is some positivity in the fact that that patient is actually open enough to actually feel that they can be emotional." Within medical education itself, researchers have identified that crying within medical school is seen as a weakness, which can cause bullying (Wagner et al., 1997). Arlie Hochschild explored the concept of emotional labour at work and defined the theory of 'display rules' in the workplace (not to be confused with Ekman's Display Rules). In Hochschild's version, she proposes, that display rules govern how we may display emotion in the workplace, which has relevance to the clinical journey in relation to patients' perception that unspoken display rules restrict them from expressing the full gamut of the emotions they experience. The potential here, Hochschild proposes, is for the individual to feel "wrongness".

Wrongness refers to a discrepancy between "what I do feel and think" and "what I should feel and think". (Hochschild, 2012, p. 75).

This work was about correcting the 'wrongness' while attending to the "other stuff"²¹ that participants mentioned in Chapter Three. This other stuff refers to the concerns of the patients that aren't just biomedical. I propose that the new materialist philosophers offer an opportunity to think about tears as an embodied and affective expression of the patient's experience. In this artwork, tears are presented as the materiality that gives emotion physical form while bringing emotion outside of the body. By acknowledging this materiality, we can generate potential to navigate the contours of human experience.

²¹ The title of this thesis.

Artwork #10: The Crying Room

Video, water, MDF, chime bars, electronics, 3-D scans and prints; dimensions variable

Background

While viewing this entire exhibition, the gallery visitor encounters the stories of the patient, the doctor, and the artist. As they navigate these stories, they become implicated in and impacted by them. While one purpose of this exhibition might be to place an ethical obligation on the viewer, it doesn't aim to create a burden, or to harm them. *The Crying Room* is therefore a place for reflection – an offer of a Levinas-ian *dwelling* for the gallery visitor. This artwork continued on from ideas explored in the lachrymal vase artwork that considered the impact of the emotional experience in clinical settings, and our tendency to hide and apologise for our emotional responses. This artwork invites the gallery visitor to dwell in quiet contemplation of their own experience

Process/Making:

This artwork was an elaborate combination of water, electronics, valves, projectors, and chime bars. It involved creating a system that would trigger, randomly, a series of video projections and then align the triggering with water droplet/tears at the exact moment that the video projected tear reached the bottom. Therefore, the system used an array of custom-made electronics and computer programming.

Installation

In this room, five white canvases are adorned with five white 3-D printed faces. At random times, the canvases are illuminated with white light before a video-projected, red 'teardrop' cries from the eye of the face and falls down the canvas. When the projected teardrop image reaches the bottom of the canvas, it triggers a hidden solenoid valve which replaces the projected tear with a real, three-dimensional, liquid 'teardrop' that then lands on a chime bar beneath it, creating a soft, meditative tone. These tones play randomly throughout the day, a composition made by tears.



Figure 48: The Crying Room installation photograph



Figure 49: The Crying Room detail #1



Figure 50: The Crying Room detail #2

Response and discussion

Like the lachrymal vase, the intention of this work wasn't to collect participant responses. Instead, it was an offer, a dwelling (Levinas, 1979, p. 152) in which people could sit and rest and potentially, think. During the development of this work, a decision was made not to amplify the sound of the chime bars when the soft water droplet (tear) lands on them. This meant that the sound was soft and delicate enough to be just audible. Unexpectedly, gallery visitors responded to the subtlety of the chime bar tones and how they mixed with other sounds from the exhibition, including the gentle sounds of the cello from the *Unravelling* artwork, the voice of the William video playing across the space, the sounds from people playing the facial nerve harp, and the general sounds of the space itself. I propose that what these participants were referring to, was new modes of interpretation via the additional composing that was happening through the relational nature of the sonic characteristics of all of the artworks combined. Occasionally, if the gallery was very busy or noisy, the chime bars might be barely audible at all, which was an intended metaphor for the implication of time and *other business* resulting in us not "hearing" the tones that emanate from the emotional experience. This intention was amplified by the relationship that this artwork created with the art institution during the showing of this work, which I will share via a field note.

Field note (2022):

Grrrr. Today, again!! I had to respond to the failure of the gallery to provide the maintenance that the Crying Room requires. Despite multiple meetings with gallery staff about the need for three - five minutes of daily maintenance to nurture the exhibit, these simple tasks have been repeatedly forgotten. This failure of maintenance has multiple consequences. Sometimes the installation runs out of water, so no teardrop can fall. Sometimes the gallery fails to empty the chime bars after they fill with water, which meant the sound becomes muted and therefore doesn't "chime". This is a continual frustration and a major issue.

This, however, provides the opportunity to draw parallels between institutional indifference/failings about the value of tears and emotional expression, and the failings of the gallery to maintain the work

resulting in the tears falling silent. I experienced frustration from the gallery's lack of 'care' for this work, but also, I was able to identify a pattern of which staff worked on which days, and who would tend to the crying room, and I could therefore predict when the work would and wouldn't be cared for. I will further explore the implications of this in the following chapter.

In general, this artwork was presented as a response to a Levinasian ethic around the recuperation on offer within a *dwelling* that enables us to gather the ability to meet our ethical obligation towards the "Other".

Artwork Grouping #3

This final grouping of artworks consists of works that reveal something of the process of socially engaged practices and collaboration.

Artwork #11 Artwork Removed

Lights, text; dimensions variable

Background

I will share the background intention of this work by sharing the text that was installed on the wall as part of the work.

This work acknowledges that within any arts practice that is "socially engaged", there is a complex engagement with people as they undergo, in this case, traumatic life experiences. Given the delicate process of making work of this nature, I keep open the potential that a patient, a doctor, or a family member might change their mind about the public showing of an artwork of a deeply personal nature. Exhibition delivery timelines don't always coincide with medical timelines or timelines of personal grief.

This artwork acknowledges the constant state of negotiation that exists when working within the context of the lived experience of other people. Artistic practices that are socially engaged include a complex negotiation of care, ethics and artform.

Process/Making

The 'made' part of this artwork consisted of vinyl lettering that was professionally printed, and two standard gallery lights.

Installation

The artwork text, above, was installed on a gallery wall in vinyl lettering beneath a space on which two gallery lights illuminated where an artwork "might" have been.



Figure 51: Artwork Removed installation photograph

Response and discussion

This deceptively simple work, which aimed to share some of the complexities of socially engaged arts practices, became a surprisingly rich addition to the gallery space. I was frequently able to observe people having in-depth conversations about things such as grief and time. The success of this work, from my perspective, lies in its ability to share the complexities of working in this way, while also initiating deep and personal conversations among gallery visitors. It acknowledges an important consideration within socially engaged arts practice, about how we manage the competing priorities of different needs and perspectives.

Artwork #12: Self-Portrait

Puzzle; 534mm x 739mm

Background

There are many reasons someone might undertake a PhD. For some it is part of an academic trajectory towards employment or promotion, part of an expected process of professional development. For me, it was an opportunity to question my practice and to make sense of the work that I do. I have done this by placing myself in deep alignment with another discipline to explore the potential impacts of contemporary art practice (which I think of as a 'life practice'). It has been an attempt to understand myself by putting my practice 'on the line' by engaging in the complex, life altering experiences of other people, while trying to navigate the demands of different disciplines.

Process/Making

The artwork consists of a custom-made, all-white jigsaw puzzle that has been painstakingly assembled (with no identifying marking to assist) and framed. It has (eventually) been assembled, all except for one final piece.

When I placed the custom order for a white jigsaw puzzle to be made, I received a call from the owner of the company telling me that there was some sort of mistake as my order was accompanied by a picture that was just all white. When I told him that that was what I wanted printed, he replied “but you won’t be able to put it back together”. I convinced him that this was indeed what I wanted, and he agreed to make it.



Figure 52: (a) & (b) Preparing jigsaw

Once I received it, I realised what a task it was going to be. To assist, I attempted to make contact with the Australian Jigsaw Puzzle Association for assistance but received no reply. I also discovered that there were competitive jigsaw puzzle competitions and people were crowned as jigsaw puzzle champions. I tried to contact one of these ‘champions’ but again, received no reply.

So, I was left to my own devices, and time, (theme #1). Once I neared completion, I decided to not place the last piece, denying completion, and leaving the jigsaw in a constant state of becoming. During the framing process, I had it framed with red backing paper to highlight the missing piece.



Figure 53: Self Portrait installation photograph

Installation

The installation of this work was a standard hang of a framed work.

Response and discussion

In the earlier stages of my socially engaged art career, there were times where I was concerned with the potential for my practice to lose itself to the demands/concerns/wishes of other people. With time and experience, I have overcome this concern and am motivated to undertake this PhD to satisfy a need to be able to articulate myself better in order to build this type of practice (for myself and for others). This self-portrait therefore reflects on my 16 years of socially engaged arts practice by acknowledging that the co-constituting nature of engaging with people, place and circumstance is a foundational component of my work. It acknowledges the importance of allowing processes and outcomes to emerge from the experience while honouring the potential for exchange, nuance, new ideas and learning. This artwork acknowledges that the role of the “artist–researcher” is a relational process where the artist isn’t positioned as a detached researcher whose job is to sit and observe the Other. Instead, the research process undertaken in *Face to Face: The New Normal* positions the artist–researcher as both impacting and being impacted by the experience of research exchange.

Professor Mary Jane Jacob (School of the Art Institute of Chicago) has reflected on the work of American philosopher John Dewey (1859–1952), who, she proposed, believed that “social art practices” were a *“holistic practice, not a style taken on, but a way of working that emerges from one’s life’s interests and needs, one’s observations and actions”* (Sholette et al., 2018, p. 7).

In this artwork, the Levinas’s concept that the Other is ultimately unknowable, is linked to my own question of whether I might, by living a socially engaged art practice, make myself knowable to myself.

Artwork #13: Duet

Video, audio; 6mins 27sec

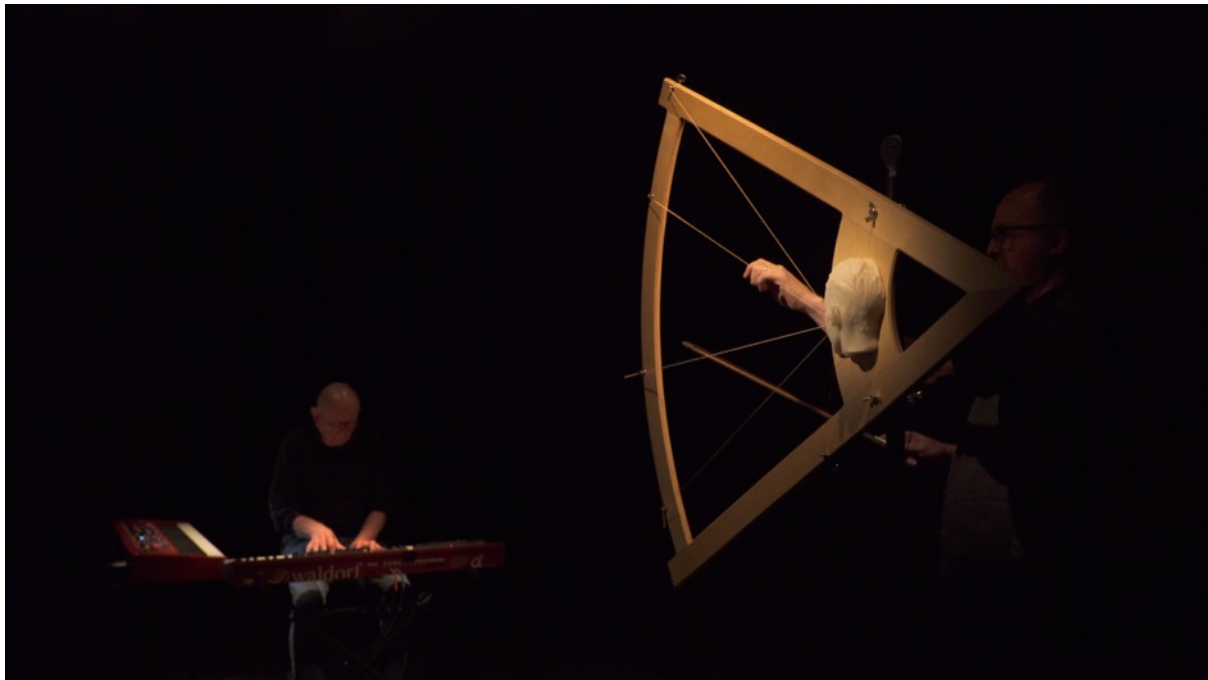


Figure 54: Screen shot from video artwork Duet

Background

This video and sound artwork is a live improvised performance featuring myself playing the Facial Nerve Harp in duet with the legendary ARIA Award winning Australian musician Chris Abrahams (The Necks, n.d.)

Process/making

To create this artwork, Chris Abrahams and I met on a scheduled day in the Rex Cramphorn Research Studio at the University of Sydney, where I had assembled a filmmaker and a lighting designer. We agreed that we would make this recording by doing a series of improvisations together (we recorded 10 improvisations in total). By creating these compositions via improvisation, we are creating an outcome that is generated by responsiveness, listening and being very aware of each other.

Installation

In the gallery space, this video work was installed on a screen, with headphones and seating for people while watching/listening.

Response and discussion

As artists, Chris Abrahams and I came together to explore our artforms, while considering the human experiences that underlie the development of the work in this exhibition. This was an attempt to make an artwork that has impact for patients and gallery visitors, but I also wanted to explore the potential for this type of process to inspire other artists to create more new work as a way to expand the process of care through art making. Instead of providing further analysis of this work, I will instead share the video of it [here](#) so you can consider it to be a soundtrack to this thesis.

Artwork #14: Hospital Rubble

Video, audio; 13mins 57sec

Background

Between 2014 and 2018, I travelled to the UK twice a year to work at Alder Hey Children's Hospital, where I undertook a project that explored the sonic landscape of that hospital space. The project responded to numerous medical research papers that highlighted the impacts of noise levels in hospitals which included increases both in length of hospital stay and in medication. During the project, there was major construction of a new hospital next door to the old one. This video and sound work, which was improvised in the rubble of the old hospital as it was being demolished, honours the histories of that place – the lives saved, the lives lost.

Process/Making

After undertaking a very lengthy process of approvals through construction companies, I assembled a team of three additional people (2 camera people and one production assistant) to spend, what ended up being, 2 days filming in the rubble of the 'in the process of being demolished' hospital. To create this, I undertook a series of live, performed, improvisations that were filmed in one take each to facilitate minimal editing later. By working in this way, I am trying to capture the performance onsite to honour the intricacies of that experience, rather than later *fully* editing a composition together.

I created the work by placing a contact microphone on a hospital bed and playing the bed live with a cello bow. The contact microphone picks up the sound contained within the material of the bed, rather than airborne sound.

Installation

This work was presented as a video work on a screen, with 2 pairs of headphones. It would have worked very well as a large immersive installation in a darkened room, but the gallery infrastructure didn't allow for this type of installation.



Figure 55: Installation photograph of Hospital Rubble artwork

Response and discussion

By drawing sounds out of this hospital bed, I was attempting to activate the voices held within its material structure, exploring the poetics contained within practical and functional objects and places.

The work honours not only the human experience of illness, but the human experience of living. “I could hear my entire career in the sound that you managed to play from that hospital bed,” said a senior intensive care doctor at Alder Hey Children’s Hospital.

I included this work in the exhibition to acknowledge the lineage of my artistic practice that has led me to be undertaking this PhD. Like the previous artwork, I offer no further interpretation, just an opportunity to view/listen to the artwork [here](#).

Artwork #15: Process Room

Various studio objects; dimensions variable

This final piece wasn’t an artwork as such, so I won’t present it in the previous layout of background, proceed/making, installation, response, and discussion. Instead, I will explain that it was a room that I created so that I could have a space to work during the exhibition, observing visitors, and writing. It also provided an opportunity to share some of the elements that went into the making of this exhibition and was therefore full of tests, background information, failed experiments, etc. At the entrance to the room, the description read:

The artist’s studio is a fusion of debris, inspiration, frustration and experimentation; a haven where failure might be understood for its potential. It is a place of small and large visions, of thoughts and investigations that might not be visible directly in the final artworks yet are deeply relevant to and entwined within them. It is a place that contains various speeds, expansions and contractions of time, contradictions, and stuff – always lots of stuff!

Having a history of making work that is “site-specific” and delivered in non-arts settings, I often collaborate with people and places with the aim of enabling the resulting works to be active and in development, even when sharing them with an audience. This can be at odds with the expectations of gallery-based exhibitions, where the public viewing is centred around the finished work. Typically, when a gallery-based exhibition is over, the work either goes back to a storeroom in the artist’s studio or is purchased to hang on a wall in a private collection or to be displayed by an institution or held in a collection room.

This process room is shared to help articulate the idea that, although many of the artworks in this exhibition seem fixed and final, I am still attempting to maintain them in an open state that might change over time.



Figure 56: Installation photograph of Process Room

Conclusion

In summary, these practice-as-research methods and outcomes have demonstrated their capacity to elicit affective and responsive processes for patients, families, healthcare professionals, and audience members. These findings provide compelling evidence to support the proposition that integrating artistic processes into the structured space of the medical clinic holds immense potential. By integrating creative approaches, I have successfully attended to the core components of care that were identified in Chapter Three. These were:

Connection	Being kind, careful and considerate
Competency	Knowing your area of specialty, how healthcare professionals deal with things they don't know, and how medical education impacts this.
Clinical Communication	Knowledge translation, how healthcare professionals share and make sure information is understood including translating things they don't know.
Performativity	Language, actions, affect

To support this claim that integrating a contemporary artistic practice within a clinical environment significantly enriches the care experience, I have addressed each of these components of care under their four sub-headings.

Connection

Patients identified the desire to participate in a medical experience that was relational, with qualities that included kindness, being careful, and consideration. Through socially engaged arts practice, I was able to provide multiple ways in which to enact modes of connection for participants. To begin with, these artworks were created through interactions that was based on kindness and care, providing the opportunity for patients to participate in multiple and lengthy engagements to explore their story, to try to understand and share their experience, and to be heard.

The initial inspiration to create an exhibition as the final artistic outcome, arose in response to the literature, observations, and interviews that all spoke of the social stigma's associated with facial nerve paralysis and my assumption that a gallery exhibition and development showings could generate large audience numbers which could increase the aims of facilitating conversation, to make people be 'seen' despite their difference, and to create the conditions where social change could *potentially* be encouraged by 'confronting' people with difficult subject matter, but in a way that kept them cared for and without harm.

In Chapter Three, patients expressed the desire to hear the stories of other patients and this exhibition successfully provided that much needed opportunity. In doing so, it demonstrated the potential for artistic practice to meaningfully engage with the clinical experience. By creating multi-sensory, and immersive platforms for (direct or abstract) storytelling, this exhibition enabled patients and the general public, to engage with (and potentially understand?), their own unique journey. When the exteriority that the patient feels isn't just an exteriority of self, but of the world, then this sharing of multisensory story via exhibition becomes an important tool in the re-grounding of self.

The exhibition, as a platform for shared experience, provided meaningful experiences for those that engaged with the artworks. Susan A identified that watching the video artwork made with William M provoked the psychological benefits that arise from feeling connected to a shared experience, while also causing her heart rate to increase and breathing to become rapid and shallow. This confirms the theme identified in Chapter Three, the PAPAP Circle which highlighted the connections between pathology and psychology, while provoking a new question; *what type of composition would have been generated if we had attached Susan A to the Bio-Medical Composing Machine before, during and after her viewing of William M's video?*

Additionally, we see the multiple benefits that arise from the sharing of stories in the response from Liz C's family, who discussed the value of seeing the exhibition, and the greater understanding it afforded them of their daughter's experience. Poetically, we also see this 'coming together' of families through the father who played the facial nerve harp for his son in Ukraine. All of these experiences paint a picture of the positive potential of *connection* that has been delivered through this research process.

Competency

My proficiency as an artist, developed through a long career in making work that explores the complex reality of other people, plays a pivotal role in my ability to engage in the type of delicate work that is encountered at the SFNC. The lengthy and prolific nature of my practice has facilitated me to develop the skills to instigate ethically appropriate creative methods that 'honour' the patient experience, while also creating complex and unique artworks. The decision for me to create these artworks, to be their author, was a decision jointly arrived at with participants. The benefits of this aligns with research by Mulligan and Smith (Mulligan & Smith, 2010) that examines the benefits that arise from having a designated 'lead artist' on community engaged artistic projects. This chapter confirms that this research has been able to offer participants the fundamental component of care: competency.

Communication

There are two ways to consider this in terms of the arts as research paradigm. The most obvious is in the way that these relationships are established and nurtured through trust, empathy, mutual understanding (Parker et al., 2013). The second is in the role that the artworks themselves play in communicating stories to a broader audience. When a patient with facial nerve paralysis experiences social prejudice due to their disfigurement, their medical concern is no longer their own, but involves all of society. The artworks therefore communicated these stories to the general public through art exhibitions, publication, and review. By doing so, they made conversations about the face and about how we respond to difference, central to the experience.

Further evidence of the communication potential of this work includes concepts found in artworks such as the Facial Nerve Harp. The Facial Nerve harp can be considered to be a tool of education that teaches people what the facial nerve is, and about its anatomy. Making the artwork interactive, so that people could "play" the facial nerve with a cello bow, meant that an immersive experience was created in which people could have a different type of learning experience than if they were given a "pamphlet" that explained the facial nerve. Most visitors to the exhibition admitted they had no prior knowledge of the facial nerve, or of its importance, despite the centrality of our face in forming our

identity, and social navigation of the world. Therefore, this exhibition was an opportunity to learn, not only about the facial nerve, but also about the physical and psychological impacts on patients experiencing its paralysis. As one participant said, “Illness is a real sensory thing” identifying the potential for sensory, interactive artworks to aid the translation of medical knowledge, provide opportunities for patient education, and for emotional navigation through the ‘lived body’.

Performativity

Susan A, one of the participants identified in Chapter Three, referred to the sense of ‘care’ she felt from the language used by healthcare professionals in the clinic, and the way they performed their examination. However, she also discussed the performativity, or the embodied action of care, that was missing from her health encounters. This embodied performativity was able to be addressed in the artistic experiments outlined in this chapter, in the gentle explorations of affect, and in the way complex topics were addressed. Showing and sharing artistic experiments allowed space to talk through their meanings and the ‘feelings’ they generate. This aligns with the conceptualisation of performativity that was set out in Chapter 3, particularly around the embodied nature of the care performance as expressed by care researcher Mark Hamington which aligns the care ethics of scholarship outlined in Chapter 1, with the various new materialist practices that I also outlined in that chapter. It does this by providing a non-dualistic approach to the understanding of processes of care.

Additionally, this has been enacted through a performativity of care that also honours the *materiality* of emotional experience through the creation of artworks such as the two works that involved tears, Lachrymal Vase and The Crying Room. The act of responding to the material output of emotion, the tear, that is so often silenced in the medical encounter, and undertaking a performative action of embodied care directed towards it, further aligns the ideas of care ethics with the material-discursive position of the new materialists. This idea of a tangible materiality through the teardrop, was expanded in the artworks *Wire Mesh: Portraits, Landscaped and Wildflowers* and the work *Wall of Faces*, both of which talk of a type of digitally mediated materiality that is navigated to explore complex ideas of portraiture and identity.

By exploring concepts such as materiality, affect and performativity, this Chapter has identified new ways for the patient to share their experience and their symptoms, which in turn has the potential to reveal important clinical information. This research has provided sensory and immersive experiences that aid in the emotional exploration of Quality of Life (QOL) and treatment concerns, while having positive impact on the general public’s attitude towards people with facial difference. It has generated educational tools about the facial nerve, while providing opportunity for empathetic witnessing and making contributions to the emerging theory base of socially engaged arts practice.

By presenting artistic outcomes as forms of knowledge production, we are able to augment traditional forms of research and knowledge by showing how:

humans consciously shape the immediate, physical and sensory in life, and how these things in turn shape the human experience often less-than-fully consciously. In other words, how immediate, physical and sensory non-representational processes (i.e. the forming and performing of life) overflow and interplay with conscious personal, social, political, economic and institutional representational processes (i.e. what more clearly comes into view), and together how they both contribute to power, significance and meaning in life. (Andrews, 2018, p. 3)

One of the original aims of this research was to have impact on the art world as much as on the human experience of patients, healthcare professionals, and audience members. This impact can be demonstrated by a review that the exhibition received from National Portrait Gallery of Australia

curator, Penny Grist, for their publication *About Face* (Grist, 2022). In this review, Grist identified the contribution that this work makes to the artistic form of portraiture.

The empathy and ethos of care underpinning McEwan's approach was profoundly realised in Face to Face: The New Normal. McEwan's research supervisors, Hooker and Coulson, both emphasise the collaboration, trust and respect he built with patients and healthcare professionals during his residency. He disrupts the pandemic-era cliché referenced in the exhibition title by making it feel like a hopeful challenge – there is no normal, just unique individual humans with skin and flesh within which our nerves nestle. While the exhibition at Wagga Wagga is over, keep a lookout for more of McEwan's ground-breaking work. I found in this exhibition a reason to seek a fundamental shift in the values and definitions of portraiture away from representing what we look like and closer to representing how we relate to each other and simply how life feels.

The entire review is attached in appendix 1 and offers further consideration about what the value of this work might be from an art perspective, a topic that will be discussed further in the next/final, chapter. By creating work in this way, I have shown that enacting care through artmaking doesn't just deliver an aesthetic experience, but it instead generates considered and relational ethics that impacts the experience of patients and public, while also impacting the aesthetics of the art outcomes themselves. By bringing together concepts such as **Materiality**, **Affect** and **Performativity**, as this chapter has done, we can create a type of **MAP** by which to navigate the contours of human experience and which contributes to my claim that socially engaged arts practice is the meeting of ethics and aesthetics. This has the potential to re-evaluate what we could mean by patient-centred care, as one participant proposed:

Working with patients like this could form part of a treatment package for the future.

CHAPTER FIVE. DISCUSSION

The previous two chapters openly shared the outcomes and the intricacies of the last four years of research experience. In this concluding chapter I discuss how these results address the two pivotal research question that lie at its core: Q1 How can my role as an art practice-based researcher enhance the experience of care for individuals affected by facial nerve disorder. Q2 In what ways can I contribute to the development of the fields of arts and health and socially engaged arts practice. This thesis, and the research processes it reports, have come to understand that the answers to these questions are entangled.

Through an analysis of the empirical, philosophical, and creative inquiries that this thesis brings together, I propose that the answers lie in how we understand, and perform, what it means to “attend to the other”. Philosophically, an early finding of this research was that my socially engaged arts practice was aligned with, and expressive of, the ethical theories of Levinas. Levinas’ emphasis on a particular form of responsibility - to attend to the ‘Other’ in a way which he calls “face-to-face” (Levinas, 1979) – articulates the ethical commitment of this practice. Levinas provided me with the opportunity to define the shift from a studio based practiced to a socially engaged practice, as a shift from a me-centered-subjectivity to an other-centered subjectivity, thus incorporating the ‘Other’ into the realm of art. This encouraged me to translate Levinasian philosophy into an applied ethic that became a guide for this thesis. In this scenario, studio-based practice isn’t subsumed, but remains crucial as a form of Levinasian dwelling, where one can not only rest from the ethical obligation, but continue to build competency, which I have shown addresses one of the components of care identified by participants.

Empirically, this thesis showed that patient experiences of (health)care often fell short of delivering the fundamental components of caregiving because it often dismissed what participants referred to as “the other stuff” - the impacts of scarring, fears and doubts, depression, anxiety, and other forms of emotional distress. The SFNC embodied varying degrees of these components of care-ing, particularly, but not limited to, the component of competency, as found in the Interpretative Phenomenological Analysis (IPA) of Chapter 3. Because of this, the SFNC has had significant impact on improving patient experiences and generating positive healthcare outcomes. Nonetheless patients continue to experience that the norms of bio-medical practices negatively impact them, even when they begin to feel more cared for. In this context, competency within a Levinasian framework could refer to the requirements that are needed to meet the demand that is placed on us when we recognise the ‘alterity’ of the other. While Levinas doesn’t directly discuss competency, it can be interpreted that competency to address this ethical responsibility is required, while only possible through an entangled enactment of multiple considerations, such as with the other three components of care identified in Chapter Three (connection, communication and performativity).

Through analysis of the research data, this thesis bears witness to the discursive structures that continue to frame the world in ways that are dichotomous and opposing - doctor/patient, knower/known, active/passive. This limits, or in some contexts removes, the capacity for Levinasian response-ability. The creative outputs discussed in Chapter Four addressed the need for the relationality that participants identified was missing from many of their medical experiences, including the need for their stories to be heard, for conversations about “the other stuff” to happen, and to hear the stories of other patients. The exhibition enabled this positive and sought-after relationality for both participants and their families. Utilising Tronto’s version of care ethics (Tronto, 2013), which she extended beyond application solely to intimate relationships, formulating the ethics of relationality as intrinsically political and relevant to the wider social sphere, this research brought the intimate suffering of the patient into direct relationship with society by presenting themes of exclusion, discrimination, and facial difference. The structure of the exhibition aimed to ensure that the gallery visitor was cared for, while being exposed to Levinasian responsibility through the direct

stories of facial nerve patients. Stories that told of a need for joint relational humanity as an act of care.

In what follows, I synthesis the thesis findings through a series of reflections on care as concept and phenomenon. I begin with reflections on what care might mean *to the socially engaged artist*, as well as to those with whom they work. This forms a parallel with the engagements with care *for clinicians* which were subtly present in this thesis (eg, in Chapter Four), rejecting the disembodied and unlocated positioning of the physician in biomedical discourse (Hooker, 2015; Pedersen, 2008) - the *view from nowhere* as explored in Chapter Four (Haraway, 1988).

Embodied practice of care:

In Chapter Three, one of the research findings revealed that participants seek an embodied form of care giving that is not wholly present in their medical experiences. The findings in Chapters Three and Four further confirm that socially engaged arts practice can deliver a type of embodied care that makes a positive and unique contribution to the experience of the facial nerve patient that has the potential to satisfy these care aims.

In Chapter Four I shared the observation and reflection that during the exhibition, the gallery, who held responsibility for the care of the artworks, were mostly unable to provide the very minimal care that was required for one artwork called *The Crying Room*. The task of refilling water when required, clearing water from the chime bars, and then re-aligning them, which required 4-5 minutes of time per day, was frequently omitted. In effect, this rendered the crying tears of the participant, silent or muted – mimicking some of the participants criticisms of bio-medical care. This lack of care for the artwork, as a metaphor for the care that isn't provided in the medical encounter, instigated a period of observation by me, where I was able to identify that adequate care of the artwork aligned with the rosters of certain staff members. What I observed was that when staff members 'embodied' this need for care into their daily routine, then the work was attended to without any apparent negative time impacts for the staff member. When staff members maintained this care as a separate 'task' that they had to try to 'fit into' their busy schedule, then it was held as an exteriority that was often missed. Fittingly, participants discussed the perceived impacts of time on the healthcare practitioner, which were described as causing a juggle between "patient needs v's doctors needs". Embodied practices of care were shown in the gallery to contradict the proposal that time in itself is a barrier to care. This touches on critiques that discuss the need for embodied empathy/care within medical education and practice, rather than 'slotting' in moments in which to "do empathy". This critique exists in the literature (Hooker, 2015; Marshall & Hooker, 2016) and within the data interpreted in Chapter Three. Further, one healthcare practitioner participant positively reflected that their 'care' for patients was directed by a 'script' that they had developed from observing other clinicians over the years. This thesis questions what happens when the uniqueness of the 'Other' goes 'off script'? Does care then become an exteriority that is missed?

The findings of this thesis lead me to propose one answer to the question of how a socially engaged artist can contribute to patient care. I propose that practices of care, delivered through relational arts practice, nurture the 'Other' through an embodied process, rather than as an additional task. The uniqueness of the 'Other' is therefore supported by a process that is reflective and agile, while being self-reflective enough to identify when it is, and when it isn't, meeting its own ethical responsibility. In this way an embodied, socially engaged arts practice is presented as a significant provider of care.

Acceptance and Validation

Can a socially engaged artist contribute to patient care, when not delivering a tested clinical treatment? As this research progressed, one of its achievements emerged in the responses of the healthcare professionals at the SFNC, one of whom reflected that initially they thought they had misheard the proposal: "If there are only so many seats in the room, why would we give one to you?".

This sentiment was common amongst those interviewed, provoking me to reflect that healthcare professionals would rarely have had cause to think about the potential impact of the arts in the world of the facial nerve, particularly when their work unfolds within environments which are *controlled* as an act of care. As discussed in Chapter One, ‘arts’ and ‘health’ are discursively positioned as very different fields, therefore, this research was designed to bridge this perceived gap by uncovering the potential for collaborative approaches to patient care. An outcome of this thesis is that it highlights the importance of *acceptance and validation* in the establishment of a project such as this, identifying that there are complexities involved in navigating the initial doubts and hesitation surrounding the presence of an artist in a typically non-arts space. While I understand the initial response received at the SFNC as being reasonable, I also acknowledge that types of resistance – even outright hostility – are frequently encountered by artists when entering new types of non-arts work settings. Healthcare is one such setting, one that has received extensive attention as the ‘arts and health’ sector has expanded.

Levinas provides us with one way to consider this through his concept of the asymmetrical ethical relation in which he proposes that the actions of the Other cannot be equated with our own ethical responsibility, otherwise we would be predetermining the experience of the Other to match our own experience. This is a helpful consideration when confronting hesitation and doubt when entering a non-arts space as a socially engaged artist. Levinas explains this further in published interview in which Philosopher Philippe Nemo asks whether the ethical relation was two-directional: *If I am responsible for the Other, is the Other also responsible for me?* He responded:

One of the fundamental themes of Totality and Infinity about which we have not yet spoken is that the intersubjective relation is a non-symmetrical relation. In this sense, I am responsible for the Other without waiting for reciprocity ... Reciprocity is his affair. It is precisely insofar as the relationship between the Other and me is not reciprocal that I am subjection to the Other; and I am "subject" essentially in this sense. It is I who support all. You know that sentence in Dostoyevsky: "We are all guilty of all and for all men before all, and I more than the others." This is not owing to such or such a guilt which is really mine, or to offenses that I would have committed; but because I am responsible for a total responsibility, which answers for all the others and for all in the others, even for their responsibility. The 'I' always has one responsibility more than all the others. (Levinas & Nemo, 1985, pp. 98–99)

Levinasian asymmetry can help to understand hesitations and scepticisms in these new fields, but importantly, can urge us to note that actual hostility around the presence of an artist is a workplace issue. Given that most socially engaged practitioners are freelance, independent artists not affiliated with institutions, there isn’t necessarily a “duty of care” to look after or provide resources for their welfare, yet there are high expectations placed on them to nurture communities that are experiencing unique and complex situations.

By navigating the understandable beginnings of hesitation and doubt, this research provided ways for healthcare practitioners to be exposed to the potentials of artistic practice as a method of care, evidenced by one of several responses received from healthcare professionals at the SFNC: "I can only do so much for the patient, but you have the potential to have some impact". This highlights the benefits that can come from respectful exposure to these unique methods.

Scale of Impact

Differentiating between, understandable hesitations and antagonistic responses, steps the socially engaged artist towards creating the conditions which they need to work effectively and productively with continual openness. I identify this openness as being a required condition to meet the ethical

responsibility that Levinas suggests, and that artistic practice also demands. This enables the socially engaged artist to be responsive enough to hear/see/feel/observe the nuances of engagement that enable outcomes to address various scales of impact. From the microscopic and fibrous facial nerve that sits delicately, but strongly, just under the skin, to society wide considerations of exclusion, erasure, and barriers to care. Within the exhibition (Chapter Four) the scales of impact that have been impacted through this research, range from the tiny, personal materiality of the teardrop examined in the work *The Lachrymal Vase*, to the immensity of trauma that is encountered when we hear of a patient talking about loss, suffering, discrimination, and exclusion, even to the immensity of war through the *Facial Nerve Harp* being played by a worried father to his son in the Ukraine.

While health outcomes of individual patients are a central concern of this thesis, they are entwined with considerations for developing the field of socially engaged art making itself. I use the term socially engaged arts practice rather than arts and health because, although this proposed *responsibility* of care is predominantly directed towards the individual, it is also a responsibility towards the social, towards wider society. Levinas argues that once we turn to the *face* of the Other, we also turn to the face of society, which he refers to as “the third” (Levinas, 1979, p. 213) This notion has applied relevance to this research, as I make myself present to the broader implications of my work beyond the individual patient, beyond my individual practice, and beyond the present time frame. I am cognisant, within this work, of the proposal that looking into the face of the individual (meeting their subjectivity) is also an act of looking into the face of society, and as such has broader implications.

The field of 'arts and health' has been critiqued by Clift and Mirza (Clift et al., 2021; Mirza, 2007), among others (Williams, 2022), because of the potential for the arts to become ‘co-opted’ by biomedicine: turned into a resource to palliate suffering, rather than used to make visible, and challenge, the systems and structures that generate that suffering. Arts are meaningful for health, contend Clift and Mirza, when they highlight wider society issues. By connecting the intimacy of the health experience with its broader social shaping and implications, this research addresses Clift and Mirza’s critique that arts and health research generally ignores these broader, foundational, issues. Simultaneously, and similarly, this research make visible what was learned from interviews: that patients struggle with competing priorities between ‘the patient need vs doctors need’, an issue that can be partly addressed by understanding, and taking seriously, patients’ expectations of care.

Competency through studio-based practice

Chapter Three identified that *competency* was a core component of expected care. Chapter Four then revealed that this was not the preserve of clinicians alone, it was also present (delivered and valued) through the quality of the artistic processes and outputs delivered in Chapter Four. In arguing for the value of socially engaged practice, I do not propose an uncritical reversal (Plumwood, 2003) where I undermine the value of a studio-based practice in favour of a socially engaged practice. In fact, this research has revealed that studio-based practice is an integral part of socially engaged practice, addressing various issues inherent in debates surrounding the integration of artistic practice with these sites of life (Badham, 2010). While recognising the potential for socially engaged arts practice to redefine the very concept of what the ‘studio’ might mean in this context, I also offer reflection on the implication of maintaining a studio-based practice. The studio is a place where artistic competency is honed, where the artistic component of the skills necessary for collaboration in socially engaged practices, are practiced, tested, learned and re-learned. By recognising studio-based practice as an important component of socially engaged practices, we can recognise that the act of caring is itself an artistic endeavour that yields artistic outcomes, facilitated by artistic competencies.

Bella Freud, daughter of the portrait artist Lucien Freud, recalls a childhood occasion when she witnessed her father having lunch with the artist Francis Bacon. She observed the two friends sharing a meal while engaged in a passionate discussion about painting. She describes her childlike wonder at witnessing this conversation, which was conducted with an intensity unlike any other she had ever

experienced “It was like they had cut open a body and were examining the insides of it” (Freud, 2021). This thesis considers its outputs to simultaneously be an act of care and an act of art, acknowledging that it has historically been assumed within the Western art canon, that artistic rigour or intensity, such as that shared by Bella Freud, cannot exist in tandem with art practices that are considered as community art or socially engaged art. This research recognises that co-locating artistic, ethical and health competencies within a clinic, can address complex life challenges, while also being consumed with an intense passion for artistic exploration. This proposal counters the *dilution of artistic practice through instrumentalisation* that was discussed in Chapter One, seeking instead to acknowledge the competency of socially engaged arts practice to define a new position that fosters both the health outcome and the artistic process/outcome in recognition of this type of competency as a component of care.

Connection through positive hesitancy

The recognition of competency, however, has the potential to generate differences in power. The competency of a clinician easily becomes a disempowering form of epistemic authority (Popowicz, 2021), hence the crucial importance of the second component of ‘care’, as experienced/expected by patients (Chapter Three), as ‘connection’. But what kind of connection? The act of connection between myself as an artist researcher, and the participants in my study, provided a unique opportunity to explore the medical experience in a way that honours the voice of their stories. Whilst connection is an essential component of care within the artist-researcher paradigm, Clift argues that this connection can arise from any activity that allows the patient to engage with another interested person, and therefore it is not exclusive to artistic practice (Clift et al., 2021). This thesis agrees with Clift’s assertion, acknowledging that so much of this work is about a shared humanity that is grounded in relationships. As a socially engaged artist, my role is to contribute to the complexity of these relationships by facilitating multi-sensory connections (artworks) that are infused with kindness and care-fulness.

These immersive artistic outcomes create distinct benefits that differ from, but complement, those of bio-medical practice. The unexpected and novel nature of the artist/patient relationship lacks pre-conceived notions about authority (who is in charge) and knowledge dominance (who is the holder of the knowledge). I would go further to argue that it is not only the patient who is undergoing a new and complex navigation, but that the socially engaged art practitioner in the process of immersing themselves into the ‘site’, can feel undefined as well. Because this is a young field of practice and its conventions aren’t established, this can potentially generate a positive contribution to the artist/patient relationship, allowing it to progress with all parties feeling a ‘positive hesitancy’ that naturally aligns with Levinasian responsibility. This undefined relationship, has the potential to progress in a non-linear way that is simultaneously moving forward, retreating, pausing, stepping sideways, diagonally, remaining hidden, becoming revealed, and even shining with joyful exuberance, all while navigating traumatic realities.

One defining characteristic of this ‘positive hesitancy’ lies in its vulnerability. In this, it is almost the opposite of the way a doctor is positioned in relation to a patient. As a socially engaged artist, I encounter various vulnerabilities, both within myself, and in my collaborators. Levinas, again, is relevant here in his assertion that the ethical responsibility to the “other” is provoked by their revelation of vulnerability, which I respond to with the vulnerability of my own responsibility. Through this study, I reveal findings about the value of vulnerability held front and center as part of the research design: vulnerability as method, entwined with shared humanity. This proved to be a valuable approach in response to the persisting dualisms of bio-medical practice and in the way that it enabled conversations that encouraged the discovery of new ways to provide care, explore artistic ideas and define methods/approaches.

Communication that stops erasure

This positive hesitancy enhances communication, the third component of care identified in Chapter Three. Through an open and responsive form of communication, methods of socially engaged practice, provided the conditions under which patients were sufficiently cared for in order to communicate their experiences to me. During my field work, patients regularly discussed how their facial paralysis resulted in a loss of self-esteem and had caused them to socially isolate themselves. The types of comments I would hear included:

I just don't try to smile anymore.

If we fix this [pointing to eye] and that [pointing to mouth], then I am 70 per cent a human being.

I just want to be able to say my name properly.

I'm scared of my kids growing up and getting married. I am going to ruin their wedding photos.

I feel like people speak down to me because of my facial paralysis.

These comments reveal that the physiological impacts of facial nerve paralysis cause major psychological impacts as outlined in Chapter Three and identified in the literature (Coulson et al., 2004b; Pouwels et al., 2016). If the best that someone can hope for is that medical intervention might make them a percentage of a human being (70%), it speaks to a type of impact that is hard to fathom as an 'outside' researcher yet is a central part of the daily journey for many patients experiencing facial nerve disorder, and their healthcare providers. Further discussions with facial nerve participants, speak of a fear of being "erased". Erased from life due to social isolation or erased from the memory of loved ones due to avoiding having photos taken at key memory making events. These 'erasures' result from social stigma, from deep immersion into a type of *waiting* that includes confrontations with identity and mortality, and the potential erasure that comes from not recognising who stands before you in the mirror.

Patients experiencing facial nerve disorder frequently reveal that the various forms of "Other-ing" and discrimination that occur as a result of facial difference range from small and unintended gestures, such as a stare that lingers longer than it should, to more extreme examples of prejudice, systemic biases and exclusion. We can also see these forms of bias within traditional modes of art making through formalised concepts such as symmetry and beauty. Charles Darwin identified this when he looked to art to further his study of facial expression, concluding:

I had hoped to derive much aid from the great masters of painting and sculpture, who are such close observers, but with a few exceptions, have not thus profited. The reason, no doubt, is that in works of art, beauty is the chief object; and strongly contracted facial muscles destroy beauty. (Darwin, 1872)

This thesis presents socially engaged arts practice as a welcoming space that acknowledges the experience of the person with facial nerve paralysis – a non-erasure. That so much of the development of socially engaged arts practice has happened away from the institutions of art, means that it has been able to develop outside of many of the narrow views that we often encounter in the Western art canon. In doing this, socially engaged arts practice makes space for an emergent type of *communication* that I claim can be inherent in these types of practices if we develop them in a responsive and ethical manner. This claim isn't steeped in idealism, but instead in a type of *responsibility* that Levinas claims is present when we meet the 'Other' face-to-face.

The tie with the Other is knotted only as responsibility, this moreover, whether accepted or refused, whether knowing or not knowing how to assume it, whether able or unable to do something concrete for the Other. (Levinas & Nemo, 1985, pp. 95, 97)

Additionally, by delivering the results in Chapter Three via a process of Interpretative Phenomenological Analysis (IPA) I have enacted a process of care through data collection, by giving substantial time and space to the patient to explore and share their story, acknowledging the relationship that is formulated during this data collection by providing a results section that focusses separately on the patients voice, before a discussion that clearly outlines my interpretation of those conversations.

Performativity with the Unknown

This study suggests that both bio-medical practice and socially engaged arts practice can work together to provide enhanced care for patients. Firstly, the technical performativity of competency through language and examination is identified as having the potential to deliver some aspects of care, as acknowledge by theorists such as Mark Hamington, and participants in Chapter Three. The embodied 'care' that is offered through socially engaged arts practice provides a complex addition of care-giving that acknowledges the participant is experiencing a state of 'unknowingness', placing value on a performed contribution of care that nurtures this complex experience. I argue that while bio-medical practice, at a minimum, focuses on solving biomedical concerns and eliminating the 'unknowns' of illness, the embodied performativity of socially engaged arts practice has the potential to engage deeply *with* the experience of 'not knowing'. The 'unknowingness' that the patient experiences is acknowledged here as being a complex 'site' with which this research is undertaken. It also aligns with the theoretical foundation of Levinas, who claims that the "Other" is unknowable.

What this thesis proposes is that socially engaged art practice has the potential to address the four components of care identified in Chapter Three, when delivered in a manner that engages with the materiality, affect, and performativity of human medical experience. This concept of creating a MAP (Materiality, Affect, Performativity) is introduced in Chapter Four as a framework through which practitioners can engage with the complexities of human experience via a creative examination of the body's relationship to the tangible and intangible aspects of materiality, the emotional and psychological dimensions of illness, and the performative, witnessed, aspects of human impact and expression.

Caring for artists, caring for community

The exhibition featured artworks that drew the clinician into view as a vulnerable participant, one deserving of care. However, one of the underlying concerns that hasn't yet received enough attention, in practice or in this thesis, is the 'crucial' proposal that if we increasingly call on artists to work in areas such as arts and health, or in other fields such as creative recovery, we should be asking ourselves: *How do we care for the artists who are caring for our communities?* Eleonora Belfiore, Professor of Communication and Media Studies at Loughborough University published a review into the "hidden cost of socially engaged labour" in the United Kingdom. In this work, she argues that the "environments of contemporary arts funding point to a clear moral failure of cultural policy" in terms of the shortfalls in provisions within funding to properly support the person who is engaged as a socially engaged arts practitioner. She referred to these as the "'hidden costs' that socially engaged artists shoulder". She proposed that:

... funders are able to essentially neglect meaningful care (both during and after completion of the project) for the groups involved in the arts activities because artists are willing – due to their beliefs and a strong ethical and political drive in their practice – to carry out those duties without pay, specialist training or support. (Belfiore, 2021, p. 61)

The instability of the arts sector is compounded by the unique terrain of socially engaged arts practice, where artists are immersed in the 'often-traumatic' lives of other people:

Evidence shows that precariousness, informality and the demand for flexibility characterises this type of work, with significant psychological impacts. (Belfiore, 2021, p. 63)

I argue throughout this thesis that ethics is a central concern of socially engaged arts practice; however, it isn't a central concern of arts education (Gablik, 2004), where very few opportunities are made available within art schools to learn about socially engaged practices. So, this begs the questions, how do we equip artists who are caring for our communities with the skills required to make good decisions for others and for themselves? As they walk the fine line between collaboration and colonisation, how do they ethically engage, how do they recover from mistakes, how do they articulate what they need to articulate without fear that they "won't get the next gig"? and how do they not become overburdened with the burdens of others. As do doctors, artists must also ask, how do they not hurt people? This thesis doesn't provide the solution to caring for artists, but it identifies and contributes to the conversation.

Undertaking this research at the SFNC was an opportunity to examine many of these questions by ethically devising methods of working that were safe, and co-led by the knowledges at the SFNC. By providing evidence for, reflections about, and a case study to examine these working methods, this thesis aims to identify the needs of artist, particularly when there is pressure on them to create social change.

Conditions for change

So, what does change if an artist is embedded in a healthcare space? Does, or should, healthcare change? Do patients recover? The ambition to generate social change is normalised in discourse about socially engaged arts practice (ICASC, n.d.; University of Auckland, n.d.) and has been confirmed anecdotally in numerous conversations with socially engaged artists over many years. Artists commonly experience a sense of responsibility about creating beneficial types of social change. I, myself, have experienced this in the past, but I now recognise that holding the expectation for social change, at all, but especially while severely under resourced, is a potentially damaging situation for the artist. This concern perhaps resonates with Clift (2021) and Mirza's (2007) position that the arts are not "crucial", to which I suggest that what is 'crucial' isn't necessarily art, but 'change'; particularly in terms of the implicit discursive norms of biomedicine that position doctors and patients in ways that help erase and disempower. Nonetheless, I also contend that art can help facilitate this change, acknowledging that the first step to creating change, is to create the conditions in which this change can occur.

As a finding from this thesis, I propose that the responsibility of socially engaged arts practice isn't to deliver direct social change as such, but rather, to create *the conditions in which social change can occur*. I have been influenced in this more modest claim for the role of art by Levinas, who proposed that metaphysical desire cannot be fulfilled, as it is a desire directed toward an "absolute other" who remains unknowable. Levinas argues that claiming the fulfilment of this desire is a 'deception of satisfaction' (Levinas, 1979, p. 33). In parallel, my finding is that rather than the unfulfillable desire to achieve actual social change, my form of ethically grounded, socially engaged arts practice attempts to create the conditions in which social change can occur. In this research, I am creating a condition where an artist is integrated into a medical clinic, I am creating a condition where conversations around discrimination and judgement occur between people because of the artwork, and I am providing these as an example for others to consider, potentially inspiring others to also establish conditions for change, however small (Balfour, 2009). The potential for artistic processes to navigate non-linear pathways through which they can indeed provide beneficial change. (Fancourt et al., 2021; Warran et al., 2022) are not denied in this proposal, instead I am arguing for a 'care' to be taken with artists, who from their position within an under resourced arts sector, are charged with the task of delivering this change.

Diffraction Practices

I began this thesis with a clear commitment to diffractive practice. As the chapters progress, this work of Levinas has come to the fore. This could provoke a decision to return to Chapter One and edit the text in such a way as to bring the spotlight off the 4 diffractive practices of Levinas, care, illness experience and new materialisms, and to focus on this thesis through a Levinasian exploration. However, I don't think this would do the diffractive practice of this thesis, justice. It is through an examination of these diverse theoretical traditions that I have been able to understand the relevance of Levinas. Despite the new materialist's proposal that agency is co-constituted emergently, rather than being pre-existing, or their focus on discursive material practices in relationship with the non-human world, I have been able to rely upon Levinas to practically align this research with the new materialist's core claim that ethics, ontology and epistemology are combined. In particular, it has strengthened my commitment to Rosi Braidotti's claim for an Affirmative Ethics (Braidotti, 2023), which I have expressed in multiple ways throughout this thesis. Similarly, I have been able to understand that the attentiveness, responsibility, competence, responsiveness, and relationality of Trontos' Care ethics (Tronto, 2013) are operationalised through a commitment to the complexities required in Levinasian responsibility. Additionally, it is through understanding the importance of Illness Narratives that I have undertaken the methods of both Chapter Three and Chapter Four which also align with Levinas's claim that the alterity of the 'Other' is revealed through their expression (Levinas, 1979). Therefore, the diffraction remains, despite who or what might be taking the focus at certain points of the journey.

Conclusion

You the reader cannot see it, but I originally began this closing section with a quote from post qualitative researcher Elizabeth St Pierre: "The Post Qualitative researcher must live the theories" (St. Pierre, 2018). This quote has stayed with me from the beginning, inscribed amongst the copious notes that shaped the development phase of this thesis. Throughout the last four years, I have repeatedly added this quote to the text, only to remove it in subsequent drafts. I had come to accept that it would remain outside of the main body of this text, consigned to a document titled 'Important other bits.docx' which I created to store the many notes and comments I needed to eliminate in order to refine my thesis for submission. For this final chapter, this quote became a starting point to embark on a process (recommended by St Pierre), wherein writing becomes a method of enquiry. Much like I used artistic processes as a method of enquiry within this research.

As I placed the quote onto the page, I came to realise that I had been misinterpreting it all along, believing it to say "The Post Qualitative researcher must live *their* [own] theories". This misreading spoke to the weighty responsibility I feel in delivering this research, because it is an act of entangling my own socially engaged arts practice within the lives of individuals experiencing a traumatic medical journey. By misinterpreting that single word, I was led to construct my own theoretical positions. This misinterpretation turned out to be, not an error, but an opportunity: to reconsider the original quote from a new perspective, a Deleuzian form of 'becoming', as St Pierre might position it.

This does, however, give me pause to 'think through' the imperfections inherent in research. These imperfections diffract the imperfections inherent in human exchange, and as this thesis examines, the imperfections inherent in the very act of caregiving. The thesis has nurtured these imperfections into new understandings, presenting findings that reveal that socially engaged arts practice produces multiple benefits because it is fundamentally grounded in Levinasian relational ethics, and its varied diffractive entanglements. As a result, when conducted in this manner, socially engaged art practice benefits those who engage with it, by enacting a unique form of care, while creating the conditions for more response-able being-in-the-world. In the healthcare context, this care was responsive to suffering caused in part by experiences of being devalued or excluded, both in terms of society and

within healthcare practice. It subsequently provided the conditions under which these experiences might change or be challenged. Methodologically, this thesis has shown that socially engaged arts practice pursued with a Levinasian ethic is characterised by open ended, and interpretive inquiry, artistic competency acquired from studio practice, and forms of connection that centre the concerns of an 'Other'.

I propose that the conditions for change that this thesis suggest, can be established by ethically response-able socially engaged arts practices that provide: (1) a context for simultaneous engagement with multiple and hugely divergent experiences (e.g., that of someone experiencing medical trauma, and their clinician), (2) a context for simultaneously receiving the multiplicity of perspectives that are present when working in partnership with non-arts partners, (3) a perspectivism that actively holds a positive space for opposing viewpoints, contradictions, differences, the unknown, fears and anxieties, and (4) the grounding of these capacities to engage in multiple ways, with the intensities and excitements of contemporary art development and practice, and (5) An acknowledgement that the need for 'care' is universal, in this case, as a consideration for the patient, their families, healthcare professionals, audience and the socially engaged artist as well.

Instead of viewing multiple experiences and perspectives as barriers to change, contemporary socially engaged arts practice enables them to be positioned as having ethical, epistemological, and ontological value. By understanding my *responsibility* alongside Barad's concept that ontology, epistemology, and ethics are inseparable (Barad, 2007, p.409), I provide an artistic research process that attempts to "live" these theoretical proposals because, in the words of British philosopher Gillian Rose:

... the other too is distraught and searching for political community – the other is also bounded and vulnerable, enraged and invested, isolated and interrelated.
(Rose, 1996, p. 37)

It is through these elements that socially engaged arts practice can nurture our "sense of attachment and connection to a shared world" (Braidotti, 2013, p. 193). Revealing that: "[e]ntanglements are relations of obligation," and hence our ethical debt towards the Other is interwoven into the fabric of the world (Barad, 2010, p. 265). By creating artworks using multiple art forms, I have provided sensory and immersive experiences that aid in the emotional exploration of medical trauma and identity while making theoretical positions alive and 'actionable'.

Limitations and future research

I have identified two limitations that impacted this research:

At the beginning of this research, the Sydney Facial Nerve Clinic was an in-person clinic only. The Covid-19 pandemic had the impact of firstly stopping the clinic from proceeding for a while, but then returning as an online model before eventually moving to a hybrid model that alternated monthly. While the online model had many benefits, particularly around access for people across the country, it was a very different experience for an artist-researcher who was still quite new to the process, still navigating ways to position and articulate myself. Therefore, this move to an online model resulted in barriers being created in terms of experiencing (in person) the various intensities that are possible from sitting in close proximity to a patient while they are being examined. It also impacted my building of relationships with clinicians and the bigger clinical experience.

My next limitation was the decision that I made to hold the final exhibition in a regional gallery. Despite the Sydney Facial Nerve Clinic being open to patients from around Australia, the fact is that all of the healthcare professionals and the majority of the patients, come from Sydney. This decision to hold it in a regional gallery limited attendance opportunities. However, there is currently discussion about additionally bringing the exhibition to Sydney and Brisbane.

Future

The process of this research resulted in many strands of investigation that could have been investigated further, meaning there are many future possibilities that are either in process, or at the very least, possible next steps. The Bio-Medical Composing machine is one such future potential for further research to test its efficacy within a clinical space. I have also received external arts funding to further develop ideas in this thesis, into a series of papers titled the “Peep Papers” that propose a philosophy of socially engaged arts practice to an arts audience.

There is also potential to deliver future outcomes that address the concerns of patients identified in this research. For example, patients repeatedly indicated they relied heavily on the internet to find information about what was happening to them. This reliance developed for several reasons, including that they felt that their doctor hadn’t given them enough information; they felt a need to connect to others who had had a similar experience, to learn what might happen to them; and they wanted to feel less alone. Their research was an opportunity to understand what was missing from their treatment as a facial nerve patient and to get an idea of what they could hope for in the future.

This research was an opportunity to understand what was present, and what was missing from the treatment of patients, and a large part of this was *information*. This has meant a heavy reliance of online resources. Therefore one potential future aim is the creation of a webpage, created in collaboration with me as an artist and facial nerve healthcare professionals and patients, to address a number of these aims. A webpage that used online artwork to help convey information and experience through a multidisciplinary approach, I claim, would enable us to provide relevant information that assists the biomedical journey, while having the artistic integrity that supports the affective, phenomenological and emotional journey, while gently allowing us to create a community of pathology.

Whilst there are numerous possibilities for expanding research in this area, immediate steps following submission of this thesis will involve producing a series of academic papers for publication. These papers aim to make ongoing contribution to both the domains of health and the arts.

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APPENDICIES

Appendix 1: Exhibition catalogue

The exhibition catalogue provides a detail of each artwork along with short essays by two of my supervisors Dr Claire Hooker and Dr Susan Coulson. It was available in hardcopy in the gallery shop and was given to participants as a record of their participation. A link to an online copy is available [here](#).

Appendix 2: Review, National Portrait Gallery

The NTRO of this research were reviewed by National Portrait Gallery of Australia curator Penny Grist. This review is available to read [here](#).

Appendix 3: Lindy Hume Opening Speech for Face to Face: The New Normal exhibition.

Lindy Hume is one of Australia's leading directors, acknowledged internationally for fresh interpretations of a wide variety of repertoire, and for progressive artistic leadership of international festivals including 2017-2023) Ten Days on the Island Festival, Sydney Festival (2010-2012) and Perth International Arts Festival (2004-2007). She has been Artistic Director of West Australian Opera (1992-96), Victoria State Opera and then OzOpera (1996-2001), and most recently Opera Queensland 2012-2017.

As a director, she has created more than 50 major opera productions across Australasia. In Europe she has directed productions including *La bohème* (Deutsche Staatsoper in Berlin), which was telecast live throughout Europe. She made her American debut with *The Barber of Seville* at Houston Grand Opera; and in recent years she has directed new productions for Seattle Opera, San Diego Opera, Leipzig Opera, Royal Opera Stockholm, New Zealand Opera, Pinchgut Opera, West Australian Opera, Opera Queensland and in 2021, Welsh National Opera.

She has been instrumental in redefining the role of major festivals to support and commission socially engaged arts practice.

Dr Lindy Hume AO
February 19th 2022
Opening of Face to Face: The New Normal, Vic McEwan
Wagga Regional Gallery

I'm visiting tonight from *pataway* Burnie in the in the NW of *lutruwita* Tasmania, whose traditional custodians are *palawa/pakana*. I pay respect to Wiradjuri elders past present and emerging and recognise Wiradjuri cultural heritage and continuing connection with the land and rivers of this place.

INTERSECTIONS

In Dr Clare Hooker's excellent article in the front of the catalogue for this exhibition, she notes that Vic McEwan's *Face to Face* sits at the intersection of two fields: 'Medical Humanities' and 'Arts and Health'. And indeed, as we can see it does so, meticulously, and elegantly. A second (also excellent) article by Dr Susan Coulson talks about the intersection between Facial Nerve Rehabilitation and Contemporary Artistic Practice, and this exhibition is a powerful exploration of that site of connection. I urge you to read both articles and their insights into Vic's work. Drs Hooker and Coulson have both walked alongside Vic in his PhD research and in the creation of these works over several years and know these intersections intimately.

But I've just arrived in Wagga today and, like many here, tonight is my first opportunity to explore the works around us. I've been intrigued about this rich new body of work for a while. And it seems to me that we could riff on this theme of intersections for far longer.

For a start, Vic brings to each work his deep human empathy and exceptionally meticulous technical proficiency and fluency across a range of digital modes, a confluence between rivers that do not always flow together in my experience. But what draws me to Vic's work is that there's always an unpredictable, ephemeral element – a concept from left-field, something surprising, emotional, often joyful or eccentric that elevates the art beyond research, that drives the work and brings it home to audiences. Something about the ingenious amalgam of French horn and cello, or a digital twist on a lachrymal vase, or a Bio Medical Composing Machine makes us smile. In his beautiful National Museum of Australia exhibition *Haunting* – which he brought to the *pataway* Burnie last year as part

of Ten Days on the Island in 2021, he animated museum objects with fog, mist, smoke and water, and was described evocatively by George Main as ‘a collaboration with a river’.

Serious as his research is, there’s always something of the mad Professor and the vaudeville showman in play in Vic’s genius inventions. The musician/ performer in him always seems to burst through. Even the most difficult subjects have a performative element, handled with careful judgement and elan. I vividly recall the stunned silence at some regional arts conference (Dubbo?) when he played a recording he had created in a highly reverberant subterranean tunnel. It was a work created in collaboration with a terminally ill teenager in the UK. Echoing through eternity, it seemed, was the beating of her fragile, failing young heart. It was deeply moving, epic and unforgettable, and I have greatly valued our conversations since then, most recently in *lutruwita* Tasmania. We had planned a deep engagement with Vic and the Burnie community over 2020. Covid got in the way of that. Instead he led conversations with local artists and in the decaying Willow Court colonial asylum in New Norfolk outside Hobart, we installed his achingly poetic Alder Hey video and sound work, performed and filmed over two days in the rubble of a half-demolished children’s hospital.

Whether it’s a solo work like the Alder Hey piece, or a deeply collaborative work like his *Specimen* series with regional landscapes and communities in NSW and Victoria, or this exhibition, Vic’s practice has a generosity that inspires trust. It’s about ‘us’, not about ‘him’. He deploys the wonderfully stretchy concept of distributed creativity, globally ubiquitous since Covid and Zoom. It’s a familiar concept for artists in regional and remote places for decades and the way of the future. Distributed creativity is articulated (Glaveanu) as the ‘We-paradigm’: *Unlike the I-paradigm, taking the individual as the primary focus of creative expression, the We-paradigm highlights the relational, distributed quality of what it means to act creatively in and on the world.*

This kind of generous, deeply collaborative work that connects Vic with regional communities or patients, or doctors, or families, or universities or landscapes, may be framed by the old-fashioned concept of the Covenant, recently re-explored by Rabbi Jonathan Sacks, who says simply: *Covenant is about what we have in common despite our differences. It speaks to us as active citizens sharing collective responsibility.* (Sacks 2020) In the context of arts practice, the concept speaks to a deeper sense of mutuality and trust flowing between artist and community. There are strong synergies between covenantal creativity and covenantal politics...*bound by a sense of shared belonging and collective responsibility.* This is exactly what Vic is doing here. I see active citizenship in this exhibition.

And empathy, of course: ‘*the ability to understand and share in another person’s feelings and experiences.*’ Empathy what we as a community most need in these confusing, trying times. And here art is especially helpful. I’ve heard the arts described as the ‘empathy gymnasium’, strengthening those muscles and setting off neurological responses that become pathways to more empathetic, compassionate behaviours, those that the British educator Ken Robinson suggests are ‘*the cultural glue that holds us together as communities*’.

But compassion and empathy are active, not passive, concepts. That’s why I love this quote from Olivia Laing (2020) who stresses that art is no ‘magic bullet’ for those seeking a kinder world:

Empathy is not something that happens to us when we read Dickens. It’s work. What art does is provide material with which to think: new registers, new spaces. After that, friend, it’s up to you.

So that’s the challenge that Vic’s exhibition *Face to Face* sets us. The subjects Vic chooses are not easy. They are often difficult, often painful. Over his three years of creative research in residence at the Sydney Facial Nerve Service, Vic has been examining what impact a contemporary artist might have

within the clinical environment. By exploring the potential for (as he writes) *'medical science and the arts to come together to nurture the human dimensions of illness and trauma, exploring issues of identity and the self through the human face'*, by creating these works, his research is a form of empathy in action. Here at Wagga Wagga Gallery, Vic has transferred the challenge of these works to us - the audience - to feel and respond to their impact. The insights, concepts and understandings of these artworks have a deep effect on us – and then what? How do we take these ideas and emotions and new knowledge forward into our lives and communities? To paraphrase Olivia Lang, he has *provided us with material with which to think: new registers, new spaces*. It's up to us now.

Lindy Hume

Appendix 4: PhD CV: Presentations, papers, residencies, exhibitions

Research Outcomes

Exhibition

The Big Anxiety Festival: (UNSW) is Australia's largest festival that explores mental health issues and practices in Australia

Outcome: "If They Spend the Time to Get to Know Me" was a video installation presented as part of the Empathy Lab between 27th Sept – 16th Nov 2019 at the University of NSW Gallery.

Webpage Link: <https://www.thebiganxiety.org/events/vic-mcewan/>

Published Review: (need to locate link)

TATE Liverpool: Public presentation of outcomes in development from Sydney Facial Nerve Clinic at the Tate Liverpool, a major international art institution.

Outcome: "If They Spend the Time to Get to Know Me" an expanded presentation of 8 artistic works created in collaboration with patients from the Sydney Facial Nerve Clinic.

Wagga Wagga Art Gallery: Feb – April 2022: Presentation of major PhD research outcome.

Outcome: "Face to Face: The New Normal" – Presentation of 15 artistic research outcomes.

Webpage Link: <https://waggaartgallery.com.au/whats-on/past-exhibitions/exhibitions-2022/face-to-face-the-new-normal>

Published Reviews: <https://www.portrait.gov.au/aboutface/2022/08/facing-the-feeling>
<https://arichlife.com.au/face-to-face-the-new-normal-by-vic-mckewan/>

Presentations

Oct 19 - Presentation - The Inaugural Sydney Facial Nerve Symposium

Oct 19 – Invited Presentation - Sydney Ideas - Arts, Health, and Healing

Aug 20 – Invited Presentation - The Create Centre: How-to walk-through walls: reimagining health and healthcare through the arts

April 21 – Poster Presentation - World Physiotherapy Congress 2021

June 21 – Invited Keynote - Culture, Health, and Wellbeing Conference (International)

Oct 21 – Invited Keynote - Enhancing Practice Conference, Wollongong.

Nov 21 – Presentation - Chris O'Brien Lifehouse Research Symposium

Apr 22 – Invited Presentation - [Expanding Health Humanities](#) - Canberra University

Apr 22 – Two Presentations - 14th International Facial Nerve Symposium (Sth Korea)

May 22 - [The Caring Effect](#) - Research outcome - Forum <blurb> and Link

Appendix 5: Industry Publication

Behind the Smile: [3d Technologies used in art practice led research into Facial Nerve Paralysis](#)

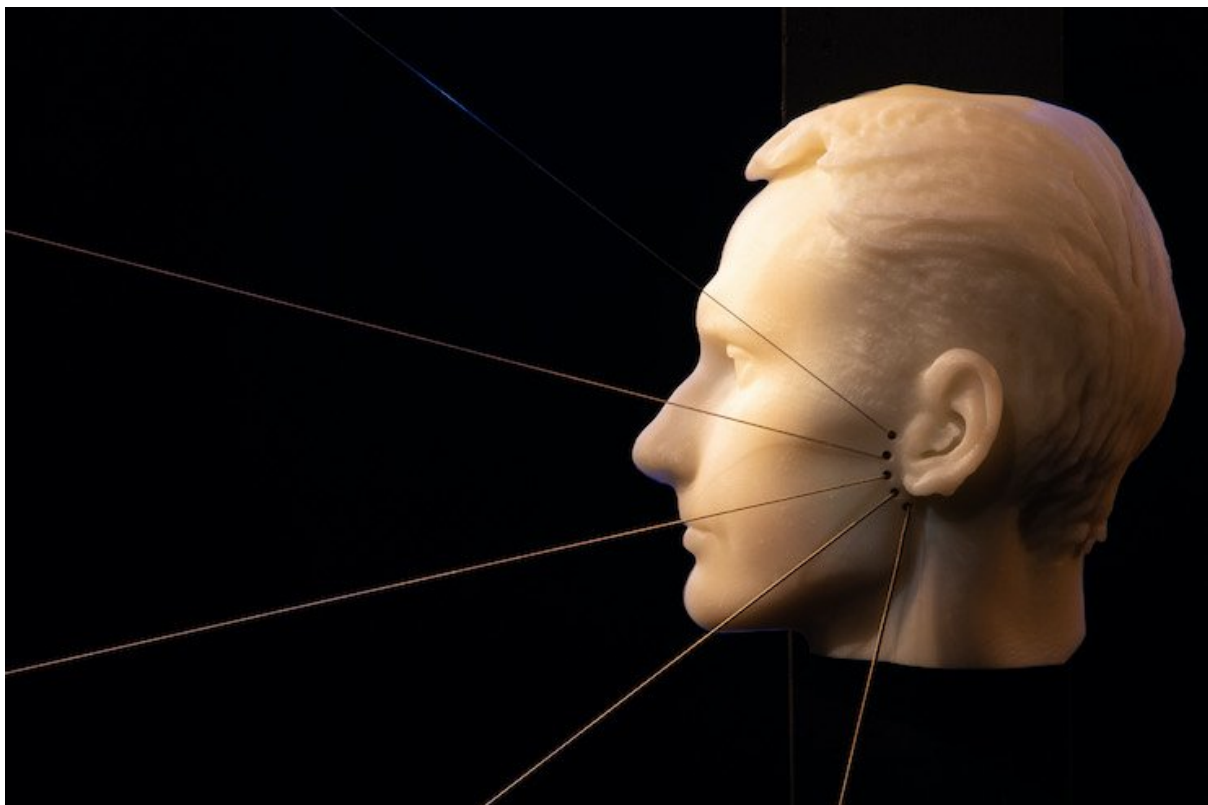
“I guess there was a feeling of inadequacy, I always felt inadequate as a person. I think that’s very human, just very, unashamedly human. Where I used to see something wrong with that, I don’t think there’s anything wrong with that anymore.”

The voice is William M’s (*pictured above*) and overlays pictures of his profile as a 3D scanning device flashes across an obscured face, half of which doesn't work. It remains still when he smiles or grimaces, laughs or cries. William M’s face cannot absolutely communicate the things he’s feeling, or react to the things he sees, but he can talk.

He opened up on his experiences as one living with facial nerve paralysis in a series of interviews with [contemporary artist and researcher Vic McEwan](#), who in 2019 embarked on a project to not just tell the stories of those affected by the disability, but allow a small number of them to explore their medical condition in a new way.

In March, hundreds of visitors to the **Tate Liverpool museum** in the UK heard William M’s story. It was the first component of an interactive exhibit titled, ‘[If They Spend the Time to Get to Know Me](#)’ - a line lifted from William M’s interview and a display that featured a 3D printed replica of his face.

Getting to know William M, his experiences and the condition that affects 1.5% of people at some point in their lives, was part of McEwan’s aim. He had teamed up with the **Sydney Facial Nerve Clinic** in his native Australia, observing the treatment given to patients, before opening up a dialogue to understand more about the emotional and physical experiences and then getting creative. Performative art, visual pieces and video work have all been strings to the McEwan bow as his work continues.



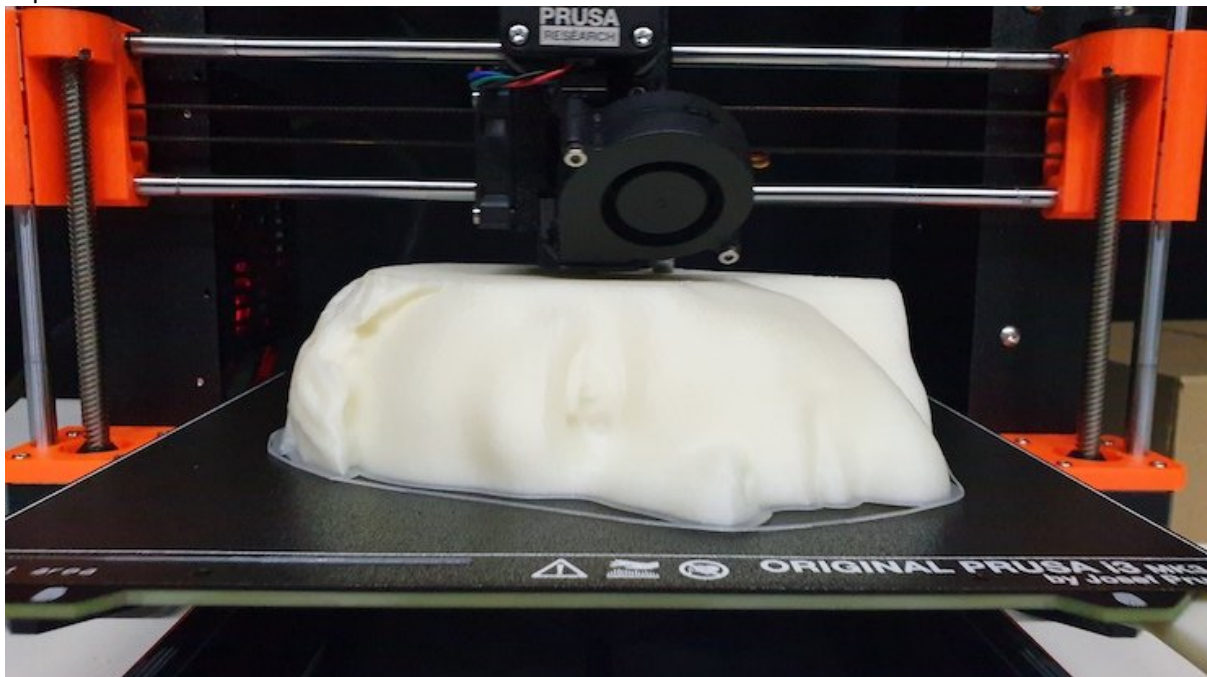
Facial nerve harp.

Becoming the first contemporary artist to be accepted into the [Department of Medicine and Health at the University of Sydney](#), McEwan is one in an emerging field of arts practice-led PhD researchers looking to use art to enable 'knowledge production'. What this entails is everything you'd expect of a traditional thesis – being transparent with the methodologies, articulating the background of the field and detailing important considerations like, for example, the anatomy of the face – while also presenting a body of work through exhibitions, which will also be examined.

"Embodied knowledge," McEwan calls it. "So much rich information, and what a more standard researcher might call data, has been drawn from that experience at the Tate."

McEwan's goal is to explore the effects of facial nerve paralysis in a deeper way. While acknowledging the science of the condition – that when damaged or inflamed the face's five nerve branches can lose function and reduce the ability for brows, eyelids, cheeks and lips to move – McEwan has sought to determine the impact those inabilities have on the person. "What an astonishing thing to think about," was his immediate reaction upon learning that some Sydney Facial Nerve Clinic patients couldn't express their happiness through a smile. What an astonishing thing to have to live with, he would learn.

Expand



Facial nerve paralysis - A participant's face being printed on a Prusa machine.

"I was hearing people talk about themselves feeling disembodied from their own face," McEwan tells TCT, "like their face isn't a part of them because it doesn't move anymore. They don't smile; they feel an emotional sense of happiness, but they look at their face in the mirror and their face isn't showing happiness. People would talk about not knowing their face and so one of the ways that they are dealing with their illness is in understanding them separate from their face."

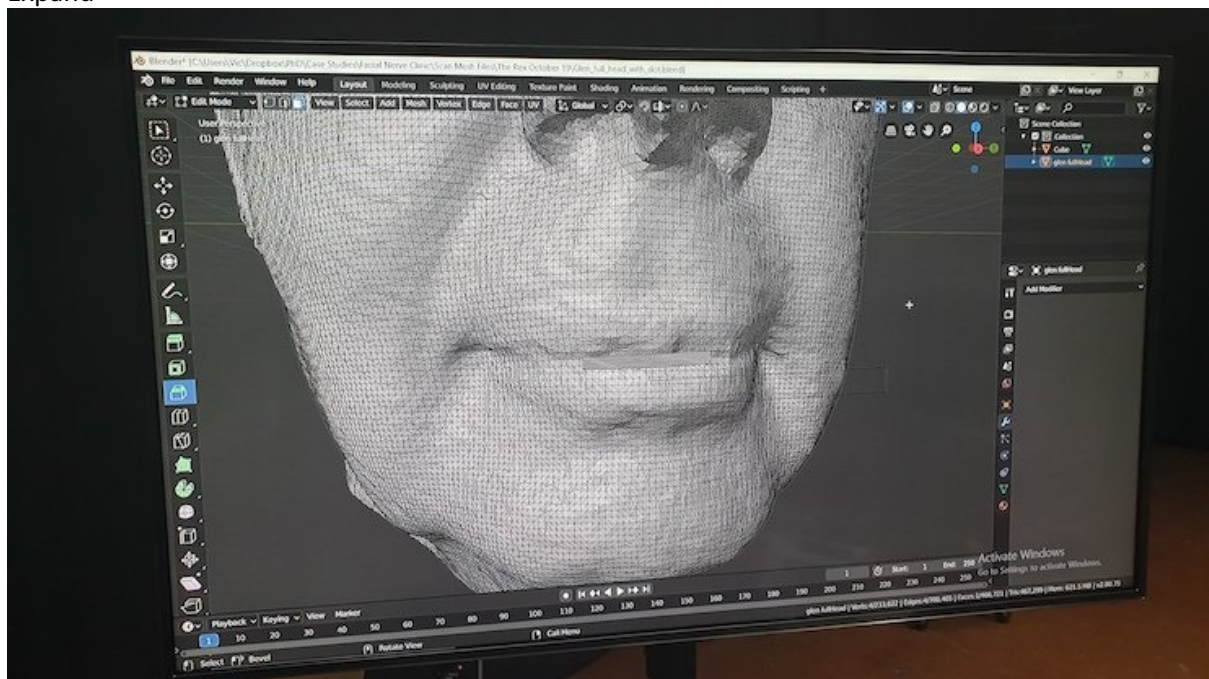
"Other people speak about more horrific things; ashamed of it. A lady was speaking about being in fear of when her kids grow up and she has to go to their weddings and school graduations, that she's going to ruin those events for their kids. She's thinking, 'if I place myself in the world, it's a negative thing, not just for me, but for the people I love.'"

Despite some early hesitance around incorporating technology into a project that is exploring the emotional aspect of how people live with facial nerve paralysis, McEwan had the idea to leverage 3D scanning and 3D printing technology in a way that might help the patients reconnect with their faces. Recreating an exact replica of the patient's faces digitally with Artec 3D scanning technology and physically with the 3D print – and allow them to follow the process, see the 3D imagery, hold the print in their hands and respond to the technology's output in the presence of McEwan – enabled McEwan to create several different artworks that were exhibited at the Tate.

"I was completely surprised by the whole process of scanning and printing. It's a craft, it's very tactile, it's not just about G code and computer files and putting that data into a printer, there are so many nuances to how that happens," McEwan says. "What I was surprised about is the human isn't removed from it. The patients I work with are very much in their scans, they're there in their final 3D printed objects that we make and then they're there in the artworks that we make out of those 3D printed objects."

At the Tate, **Artec's** Eva 3D scanning device and **Prusa's** i3 mk3 extrusion printers were used to create a facial nerve harp and a wall of faces. The facial nerve harp is a musical instrument based on the scans and prints of a patient's face, with the five branches that come out of the temporal bone and spread across the face, representing a harp's strings, able to yield a melody. McEwan says it 'gives a voice' to the part of the faces that no longer works. Meanwhile, the wall of faces was made up of patients and visitors alike, with 3D prints being continuously added to display throughout the exhibition thanks to the two Prusa machines working overnight at the Tate.

Expand



Modelling inside the Artec Studio software. Facial nerve

Modelling inside the Artec Studio software.

"It's been a really rich exploration of scanning and printing," McEwan says. "We're starting to find all these artistic outcomes from every step, particularly in the Artec [Studio] software. Visually, some of the ways you can view those images, as they're being captured and after they've been captured, are really beautiful; there's poetry to some of them, they are quite visually stunning. And to scan

somebody's face who experiences facial difference, somebody who struggles with their profile or the spotlight being put on them, and then [for them] to stop and look at the images they see, they see [them] as being beautiful.

"By seeing that beauty of the way those images look in a computer before we've even done anything with the scan, I witness patients have a real wonder about their face. They're not having a fear about their face, they're having a wonder and that allows them to enter into their face again, rather than step away from it."

While McEwan's artwork and thesis intends to explore the emotional and physical impact of facial nerve paralysis, to educate and raise awareness of the condition too, the process of replicating patients' faces and the raw, personal discussions around it, have been somewhat therapeutic for many of the subjects of McEwan's study.

As the flashes cease, the full face of William M finally appears against a dark backdrop, his eyes blinking not exactly in tandem and while his mouth raises only half a smile, his eyes convey a complete one.

He continues: "Emotions don't have to be a physical manifestation as much as they're a metaphysical manifestation. I can be happy without outwardly projecting that. I don't need a physical vessel to be happy and I'm quite content with my face at the moment. I'm becoming more accepting of it and it's because I feel intrinsically very, very happy with who I am as a person."

Appendix 6: Forbes Magazine

See How This Artist Turned Research Into Art

Jennifer Kite-Powell

Senior Contributor

[See How This Artist Turned Research into Art](#)

Vic McEwan, an artistic director, and a Ph.D. candidate, started using scanning technology to research patients suffering from facial paralysis and believed his research would lead to a better understanding of the condition.

But, what he found instead, was that the digital images from the scans had an emotional quality that told a patient's story without words.

McEwan's research comes from Sydney at the Facial Nerve Clinic, where he observes clinical engagement and works one-to-one with staff and patients. It took one-year for McEwan to transform his research into an interactive installation, [If they spend the time to get to know me](#), at [Tate Liverpool Museum](#).

The interactive installation lets visitors scan their faces in 3D using an [Artec Eva](#). Due to Covid-19, Tate Liverpool is temporarily closed, but McEwan's installation will run for three weeks when the museum reopens.

McEwan's work at the Tate Liverpool is a combination of finished artistic work made in collaboration with doctors and patients, as well as new work being developed in the space. He wants to bring more awareness and acceptance to facial paralysis by showing the similarities between scans of those with the condition and those without it.

McEwan transformed the gallery space at Tate Liverpool into a working artistic laboratory.

"I have been scanning people using an Artec Eva 3D scanner and then 3D printing them to create a large installation that grows each day within the space," said McEwan. "I also interview visitors about their response to the artworks, how they respond to people with a facial difference, and how they experience their place in the world."

McEwan is both an artist and a researcher. He is a Ph.D. candidate in the Faculty of Medicine and Health at the University of Sydney in Australia. His acceptance in the program is the first time a contemporary artist was accepted into the program.

McEwan believes his interdisciplinary approach allows him to deliver a practice-led Ph.D. which results in both a written thesis and meaningful exhibition. By doing this, he positions contemporary art as a form of knowledge production that contributes to the process of care for people undergoing facial nerve paralysis.

"Facial nerve paralysis is a condition that causes major physical as well as the psychological and emotional impact for patients. Research shows that people with facial nerve paralysis experience depression at rates up to five times higher than the general population," said McEwan.

McEwan says that medically, the field has identified the importance of multidisciplinary approaches, which have typically included ear nose and throat specialists, head and neck surgeons, plastic surgeons, physiotherapists, speech pathologists, psychologists, and now, artists.

"What's central to this research, beyond the practical, physical treatments that might be possible, is the stigma associated with facial nerve paralysis," said McEwan. "This research understands the importance of exploring the emotional experience of patients while also presenting contemporary and conceptual work in galleries as artworks as well as tools for sensitive navigation and education."

McEwan calls his work 'socially engaged art practice.

"Over the last 20 years, I have explored many difficult and complex themes through contemporary art practice. Some examples include working with traumatized communities following major flood devastation [...] and exploring complex water management issues with diverse community members," added McEwan.

McEwan was introduced to the condition of facial nerve paralysis by [Dr. Susan Coulson](#), a founding member of the [Sydney Facial Nerve Clinic](#).

"What struck me most when I first met Dr. Coulson was that she believed people who experience facial nerve paralysis have difficulty expressing emotion on their faces. When you take a moment to consider what that means, not being able to smile, I was immediately fascinated about how people explore this personally, and how it affects their acceptance by others in the world," said McEwan.

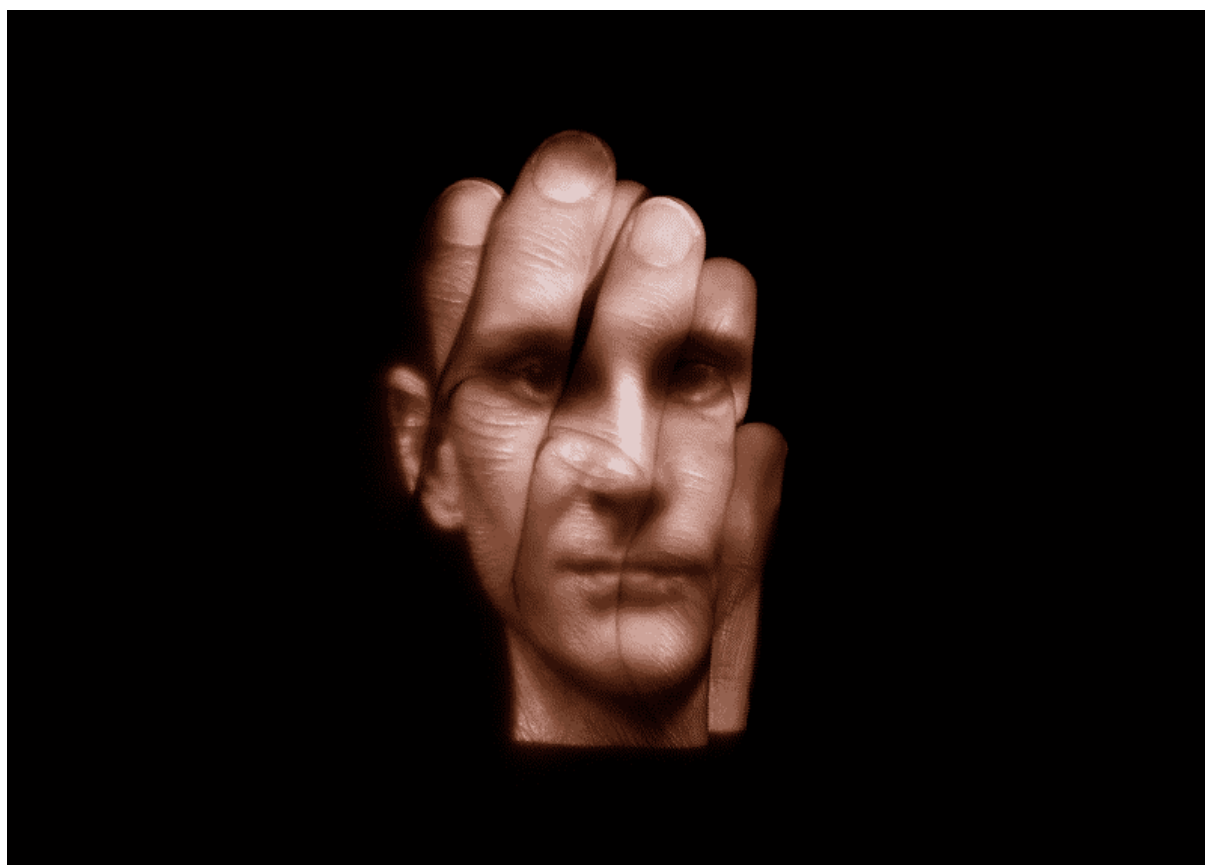
"The installation has several aims, which include an educational role in teaching people about the facial nerve while exploring the experience of those who present themselves to the world with a facial difference," said McEwan. "The art asks people to (re)consider their responses, and it argues for the inclusion of artistic practice within non-arts settings such as medicine while giving voice to the emotional lived experience of patients."

"Through this project, we explore human identity, empathy, and difference," says McEwan.

Appendix 7: A Rich Life

Until 8 May, Wagga Wagga Art Gallery is presenting 'Face to Face: The New Normal' by Vic McEwan. McEwan is an interdisciplinary artist whose artistic practice participates in and reveals the possibilities of "the active role that the arts sector can play in reimagining a better world."

Art can be many things. It can be beautiful, illuminating, provocative, powerful, confronting, poetic, and so much more. Across all its forms art traverses a broad range of stories and ideas about the world we live in and how we perceive one and other, bringing endless stories, imaginings, viewpoints and explorations to our attention.



The Face That Your Face Feels, William M, 2021. Courtesy the artist and Wagga Wagga Art Gallery, New South Wales

Working primarily with sound, video, photography, installation and performance, and with a particular interest in the creation of site-specific art activations, McEwan often engages with medical science and health service professionals, including hospitals and specialist doctors, and their patients.

McEwan explores the complexities and challenges that people face whose lives are affected by ongoing health conditions both physically and emotionally, and in terms of stigma and social acceptance or non-acceptance.

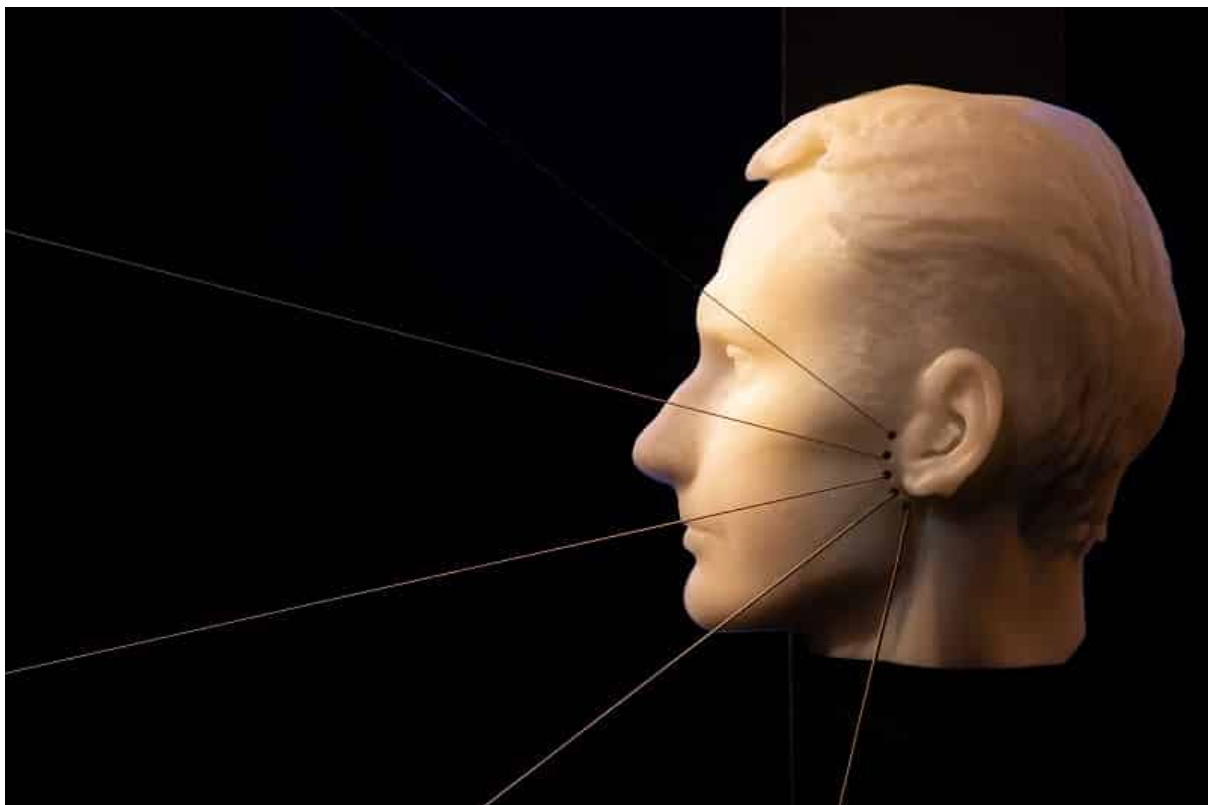
'Face to Face: The New Normal' presents the artistic outcome of McEwan's creative research project developed during a three-year residency at the Sydney Facial Nerve Service (SFNS), which examines the human experience of identity in the face of trauma and ill health through the explorations of our most obvious characterisation, the face, while also looking at "what impact a contemporary artist might have within the clinical environment."

SFNS is a specialised multidisciplinary clinic offering expert care for patients with facial paralysis, nerve injury or facial palsy. The organisation takes a collaborative and holistic approach to ensure improved

outcomes for their patients. It offers expertise in plastic and reconstructive surgery, head and neck cancer, ear nose and throat surgery, neurosurgery, and rehabilitation.

And as the first artist to be invited into the Faculty of Medicine and Health at the University of Sydney, McEwan's research project forms part of his ongoing PhD, supervised by Dr Susan Coulson (Health Sciences), Dr Claire Hooker (Medical Humanities) and Dr Paul Dwyer (Performance Studies).

Through his observations and collaborative interactions with specialist practitioners and their patients in the clinical setting at SFNS, McEwan has created an extraordinary body of work revealing a range of issues, which reflect on the experiences of patients living with illness and trauma, and how they are perceived by others, with large-scale interactive installations incorporating sound, sculpture, photography, projection and performance, and the innovative mediums of 3-D scanning and 3-D printing.



Vic McEwan, *Facial Nerve harp (detail)*, 2021. Courtesy the artist and Wagga Wagga Art Gallery, New South Wales

One example of McEwan's interactive works can be seen in Facial Nerve harp (detail) (2021), an unconventionally designed instrument where the "Strings are roughly in the position of the five branches of your facial nerve as it crosses the face, which lay dormant in somebody who doesn't have operation of these facial nerves..."

So, this is a method of giving voice to those nerves. It's something that someone can come and engage with, they can learn about the facial nerve and its five branches, whilst they can play this instrument and engage and be immersed in the sound that they create into action with the facial nerve," the artist explains in the video presentation of 'The Create Centre (USYD) Forum 2020 – "How to walk through walls: reimagining health and healthcare through the arts.'" This recording and an extensive list of interviews, reviews, talks and presentations, are available at www.vicmcewan.com.

The exhibition includes a series of photographic artworks titled *The Face That Your Face Feels*, 2021. Working closely with SFNS patients – William M Maish and Susan A Andrews, and Dr Susan Coulson, McEwan has created ten portraits of Maish and Andrews faces projected onto Dr Coulson's hands. Belonging to the nervous system, our nerves are highly complex electrical transmitters sending messages through the body.

Damaged nerves play to a range of peculiar behaviours, such as pushing and pulling, vibrating and pulsating, under and on the surface of skin causing both visual and sensorial activity and pain. These portraits emanate a deep sense of doctor to patient care and seek to bring understanding to the physical, emotional and medical experiences of people living with facial nerve damage. "It's almost like being a puppet, the strings are being pulled tighter on one side and they're going upwards, they're being pulled up, but I want to pull them down. I'm being pulled in all these different directions internally," explains Andrews.



Installation view, *Face to Face: The New Normal* in Wagga Wagga Art Gallery, 2022. Courtesy the artist and Wagga Wagga Art Gallery, new South Wales

McEwan is also Artistic Director of The Cad Factory, which he co-founded and runs with his wife, artist Sarah McEwan. The Cad Factory is an artist-led organisation inspired to create an international program of immersive and experimental works guided by authentic exchange, ethical principles, people and place. McEwan is the curator of the *Tamworth Textiles Triennial*, a three-year travelling exhibition, and in 2023 will be showcasing photographic and video works in a touring exhibition titled *Haunting* beginning at The National Museum of Australia.

Appendix 8: ArtsHub Article

In March 2023, Vic McEwan wrote an article for arts industry website, ArtsHub. This article explored responsibilities of care using this research project as a case study. Read the article [here](#).

Appendix 9: Realtime Arts Review of Bix Anxiety exhibition

Realtime is an Australian arts publication that reviewed The Empathy Clinic, in which the first, early, 'work in development' was shown as part of the Big Anxiety Festival. The review of the exhibition is [here](#).

Appendix 10: Gallery comment sheets

On the following four pages are comments left by audience in the gallery comments book. These comments have not formed part of the analysis within this thesis but are provided here as additional information.

VISITOR COMMENTS

Date	Name	Where are you from?	What did you think?
19/4	Anta	Cornwall	Great
19/4	Trisha	Sydney	So amazing!
20/4	Millie + Jodi	Wagga Sydney	really interesting - very touching. I hope this helped patient healing wonderful - found interesting with the wagga flower - also can say great
20	Geg Clarkson	Melbourne	loved it! very interesting.
20/4	Becky + Lisa	Wagga Wagga	
20/4	Jane and family	Sydney	Much appreciated for the art works and research behind. I was deeply touched by the last artwork "unravelling". Thank you.
29/4	David & Family	Sydney	LOVELY EXHIBIT WITH ENLIGHTENING INTERACTIVE FEATURES.
11/5	Marianne	Sydney	FASCINATING WORK PRESENTED WITH CARE INTEREST + A WILD, BEAUTIFUL IMMERSION!
13/5	COINHER	SYDNEY	SAME JOUBNET DIFFERENT ROADS BT
13/5	L. DEERING	MELBOURNE	FANTASTIC ✓✓✓

200

Date	Name	Where are you from?	What did you think?
12.4.22	ARTHUR ABRAHAMSON	Sydney	is I was watching his PhD I would award the Engle- Score prize to him for demonstration of originality, original thought and ability to bring it all together - not forgetting Campbell's
	Louis	Sydney	I love this place !!
	D'Agostini family	Port Lincoln	You have an amazing talent I love it.
	Gerold	Singapore	very interesting, love exploring.
	ay D		
	Sumiko	Melbourne	It was a very nice and beautiful place! Thank you!
	Walter Wilson	Singapore	fascinating
	Sophie	Sydney	thank you, I could investigate this installation for many many hours
17/04	Nikita Shelton	Brisbane	was a very interesting experience. Thank you!
19/04	Tina	Sydney	we need more of this. Thanks!

VISITOR COMMENTS

Date	Name	Where are you from?	What did you think?
10/4/22	Eleanor	Abelaide	amazing.
19/4	Anne	Adelaide	Very poignant and lovely.
19/4	Doreen	Sydney	So interesting. Another world away from mine / my work.
22/4/22			
23/4	Karen	Melbourne	Beautiful concept intriguing.
22/4	FARRAH	WAGGA ²	EXCEPTIONAL <3
	FINNA	Melbourne	It is beautiful
24/4	GABZ	CENTRAL COST	all around me are familiar faces worn out places
24/4	Ava	Narrandera	Very amazing grate work Q1
24/4	airah	Narrandera	cool work bit scary but still
24/4	Sarah	Wagga ²	Fantastic work! Would visit again!

VISITOR COMMENTS

Date	Name	Where are you from?	What did you think?
	Peter Gilby	Edinburgh Scotland	Fascinating combination of sounds & the visual arts - stimulating.
	Barbara Kruger-Davis	Narrandera	Thank you - enjoyed making my own music - fascinating/absorbing
	Christie Robertson	new to Wagga	very personal felt poured into your world
	Peter Scott	old school Wagga	pretty cool 😊
	Dasha Linnik	gold coast	creaky
	Louis Davis	Wagga Wagga	Love the intersection of ART/science/music & the abstract nature of sound.
	Judy Tan	Singapore	Very unique art pieces! Thank you!
	Brett Williams	Wagga	Wow, your work truly touched my heart, thank you so much!
	Kathy Higgs	Melbourne	Thoroughly enjoyable great interactions
	Hannah	Sydney	A bit weird!!

Love the intersection of ART/science/music & the abstract nature of sound.