

# **The Art of Chronic Pain:**

## **Creating an Exhibition Proposal on Chronic Pain for a New Zealand Gallery**

**by  
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## **Abstract**

The original idea for this research came from a combination of the work that Richard Sandell has done on social inclusion in the United Kingdom, and my personal experiences with chronic pain. The aim of this research is to make known the experiences of chronic pain survivors in New Zealand and also to bring understanding about a range of invisible illnesses where chronic pain is a major symptom. Research methods used include surveys using quota sampling and content analysis, case studies, and an exhibition proposal.

People living with chronic pain make up one in five New Zealanders, meaning just over 900,000 people have this condition/disability/illness. Yet, have you heard anyone talk about it? Cancer is often spoken about, but it only effects around 20,000 New Zealanders. Mental health problems are contemporaneous but only effect approximately 582,000 people in New Zealand. However chronic pain cannot kill, or can it? Many people who have chronic pain have other co-morbid disorders such as depression. Chronic pain needs more publicity, it yearns to be spoken about and understood. People with chronic pain have said that they feel misunderstood and unheard not only by family, friends and colleagues but also by their medical professionals as well.

This research looks at whether there would be support from both the chronic pain community and healthy New Zealanders for an art exhibition about chronic pain. The exhibition would contain art produced by people with chronic pain and depict their daily lives with their condition(s). It also offers a contribution to museum studies and current practice by attending to a gap in the New Zealand literature, not even well covered by overseas literature, on this subject. It is the first dissertation to focus on pain in a museum/gallery setting in New Zealand and opens up public interaction and discussion about a taboo topic.

New Zealand museums and galleries have to have the ability to challenge preconceived opinions and ideas about chronic pain, as well as the opportunity to engage with a large and often invisible community.

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## Introduction

Imagine what it is like to lose your ability to do everything you value - an experience exacerbated by an unremitting pain that pervades your entire existence. Imagine such a life, in which not only do you receive no sympathy or empathy, but few people even believe in your predicament, and most people blame you for having it.

~David Nagel MD<sup>1</sup>

## Background

It is widely known that acute pain compels sympathetic behaviour, while those with chronic pain soon find that their complaints (which could be endless) often irritate, tire out and in the end estrange physicians, as well as family and friends. It is because of this that you do not hear us complain, see us weep, as we learn to keep the pain to ourselves. We appear normal, and yet what is distinctive about chronic pain is that others' perception of it can be harmful. To the lay person, it is difficult to understand the pathology of chronic pain and often the responses are 'you'll get over it', 'it will go away', 'you just need to do more of this', completely missing the part where it said 'chronic'.

People living with chronic pain make up one in five New Zealanders, meaning just over 900,000 people have this condition/disability/illness. Yet, have you heard anyone talk about it? Cancer is often spoken about, but it only affects around 20,000 New Zealanders. Mental health problems are also current health issues and affect approximately 582,000 people in New Zealand.<sup>2</sup> However chronic pain cannot kill – or can it? Many people who have chronic pain have other co-morbid disorders such as depression. Chronic pain needs more publicity, it yearns to be spoken about and understood. People with chronic pain have said that they feel misunderstood and unheard by not only family, friends and colleagues but their medical professionals as well.

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<sup>1</sup> David Nagel MD, *Needless Suffering: How Society Fails those with Chronic Pain*, (New Hampshire: University Press of New England, 2016), 40.

<sup>2</sup> "Quick Facts and Stats 2014," Mental Health Foundation, accessed 1 February 2016, <https://www.mentalhealth.org.nz/assets/Uploads/MHF-Quick-facts-and-stats-FINAL.pdf>.

This invisible, verbally inexpressible, and misunderstood experience begs for greater public understanding, and an exhibition could give it that. The research aim is to make known the experiences of chronic pain survivors in New Zealand and also to bring understanding about a range of invisible illnesses where chronic pain is a major symptom through an exhibition. Many overseas exhibitions of this nature focus on mental illness, as well as acute pain experiences, with the overarching theme of disability inclusion and access. As yet, few have focused solely on chronic pain, and for those which have, the main voice has been through medical professionals rather than those in the chronic pain communities.

The New Museology asks museums to generally cover three things: information, communication and integration. These ideas challenge the old museology in that information provides “value, meaning and management” to exhibits and exhibitions; in regards to communication, museums historically, and galleries more recently, have a “narrow and authoritarian approach” which does not allow for the free flow of ideas and the concept of the open forum of today’s museums; lastly, integration allows the many components of a museum/gallery to come together as one to “accomplish museum missions.”<sup>3</sup> Although galleries are not usually spaces that deal with social and political issues, as some museum spaces are, they have the potential to be more than just the spacious white walls that many present themselves to be.<sup>4</sup> Community galleries, in particular, have the ability to stand steadfast with their surrounding populace as a whole. Andrew McClellan has noted that galleries have been able to entice more of the population to visit, although it is of concern that these are just more of the same kind of visitor, whom Raymond Ryan describes as ‘egotistical.’<sup>5</sup> However, this research is not on how galleries choose to conduct their space, nor does it judge them on their visitor culture. Instead it invites galleries to consider taking on the exhibition proposal in chapter three of this dissertation.

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<sup>3</sup> Deirdre C. Stam, “The informed muse: The implications of ‘The New Museology’ for museum practice,” in *Heritage, Museums and Galleries: An Introductory Reader* edited by Gerard Corsane (Oxon: Routledge, 2005), 66.

<sup>4</sup> Christopher Whitehead, *Interpreting Art in Museums & Galleries*, (Oxon: Routledge, 2012), 33.

<sup>5</sup> Andrew McClellan in Chris Whitehead, “Visiting with suspicion: Recent perspectives on art and art museums,” in *Heritage, Museums and Galleries: An Introductory Reader* edited by Gerard Corsane (Oxon: Routledge, 2005), 91.

The objective here is to find a niche that has not been addressed before in New Zealand, to provide a research base, and to seek financial backing for a future exhibition in the hope that it opens conversational pathways between those with chronic pain and those without. It will also reveal a previously invisible community, who would be glad for some awareness, support, understanding, and inclusion to both local and national galleries and museums. My primary statement for this research is ‘chronic pain is a misunderstood and underrepresented part of society. Proposing an exhibition depicting the daily lives of New Zealanders with chronic pain may help to increase understanding and acceptance of one of the largest yet most invisible communities in New Zealand.’

### **Aims and Objectives**

The aim of this research is to make known the experiences of chronic pain survivors in New Zealand and also to bring understanding about a range of invisible illnesses where chronic pain is a major symptom. It is at the top of ‘out of the box’ thinking that has recently started to evolve overseas. Many topics of this nature focus on mental illness as well as acute pain experiences, with the overarching theme of disability and access. As yet few have focused solely on chronic pain, and for those which have the main emphasis has been through medical professionals rather than the silent or silenced chronic pain communities around the world. The objective here is to find a niche that has not been addressed up till now in New Zealand, and to provide the basis for a future exhibition in the hope that it opens conversational pathways between those with chronic pain and those without, as the latter are often blissfully unaware there is any problem.

This introduction consists of the literature review as well as the research design and methodology. Chapter one, will bring together a comparison of three exhibition case studies, while chapter two will present the data collected from the two online surveys, one by a chronic pain group and one by a control group. The focus of chapter three will be the proposal for a future exhibition.

### **About Me:**

At the age of sixteen I was diagnosed with two incurable chronic pain conditions, and within another five years I had been diagnosed with two more. This research has come



out of my personal experience with chronic pain, my interactions with the medical community, family and friends, and seeing other survivors' difficulties. I have had pain and the multiple symptoms that go along with it, since I was twelve. Four years later, the symptoms became too severe to hide from anyone any more. I did not want to be sick. I was an active child, my life was full of extracurricular activities. From music, to dance, to sport. The year of 2008 was the worst year of my life. I saw multitudes of different doctors, therapists and other health professionals, I was on a lot of different medications and supplements, I missed a lot of school and nearly failed NCEA Level 2 due to my absence. This was not the worst of it. The worst was that when the doctors could not figure things out, and the medications were not working as they were meant to, people started to believe I was making it all up. "The pain is only in your head/mind. If you just stay positive, it will go away." "You just need to get out more/do more exercise." "You must have done something to deserve this." "We will pray for you and you will be healed." These are some of the vast number of unhelpful comments I have endured over the past nine years. People mean well, but these comments soon get old. My main diagnosis is a physiological condition that is now understood to be passed down through DNA. This was not my fault, I did not ask for it, and there is currently no cure. Nine years on, and I am still learning how to cope with these conditions, such as how much I can do each day without having to recuperate for a week. This includes things that should be fun as well as household chores. New Zealand is behind in its research and treatment of chronic pain conditions and although I keep up with the latest science, those I often have to work with in the medical field, do not.

### **Why I am doing this research:**

I realised early on in my studies that if I was going to do a big research project or a thesis at some point, then I needed to be doing something that meant a lot to me, something that I had the drive to stay interested in, and something in which I had support from other people to complete the work. The topic of chronic pain ticked all those boxes for me. I introduce myself here and my connection with this topic because I am biased, I know chronic pain inside and out. I am doing this research because I am a survivor of chronic pain and I find myself in a position that could help others like me in New Zealand. The insight I have gained from studying museums, heritage and art

galleries has been able to inform me of new and exciting ways to reach different communities. Using this learning, such as new museology, I hope to be able to draw out the chronic pain community in New Zealand, start conversations, have an open forum, a safe space, and create art that speaks louder than words.

## **Literature Review**

### **Health and Museums**

There is research and development work that is currently being done on social issues in New Zealand such as the relationship between museums and prisons, museums and mental health, and museums and LGBTQ (lesbian, gay, bi, trans and queer). I am aware of this progressive research in related fields, but as yet nothing has been published. What I am proposing is offering a public space for people to come and view art about chronic pain, enter into discussions with others about chronic pain, and be at ease in a public but safe space.

Silverman claims that museums can contribute to a person's pursuit of health in five cardinal ways: Museums can encourage relaxation which can be beneficial for both a human's emotional and physiological health; museums advocate the contemplation of people's thoughts and feelings; museums stimulate education into health related topics and help in caring for oneself; museums also cover a broad range of social conditions relating to health by advocating public health.<sup>6</sup> An example of this can be seen in the traveling exhibition *Body Worlds* which was curated in 1995 by the German anatomist Gunther von Hagens. Displays include cadavers which have been processed through 'plastination', a method von Hagens came up with which "replaces body fluids with colored polymers to reveal inner structures."<sup>7</sup> Although it sounds gory, the exhibition is extremely educational to all ages and walks of life.

The University of Otago recently hosted a one day symposium called 'Art and public health: Wellbeing, social critique and communication.' The fact that this is happening solidifies the need and support for these two areas of society to come together as one.

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<sup>6</sup> Lois Silverman, *The Social Work of Museums* (New York: Routledge, 2010), 43.

<sup>7</sup> Silverman, 2010, 46.

Unfortunately it was not a free event. With a \$400 registration fee this made it impossible for me, and likely many others, to consider attending.<sup>8</sup>

### **Social Work, Inclusion and Museums**

Lois Silverman believes that museums, through communication, have the “potential to alter people's attitudes, values, knowledge, and behavior,” and when they are collectively successful, relative to a social issue, museums can operate as an agent of social change.<sup>9</sup> Silverman also says that “museums are also recognizing their ability to empower people to tackle the root causes of social circumstances like prejudice and ignorance.”<sup>10</sup> But, as Mark O'Neill has observed “museums can only be as good as their analysis of society and their awareness of the reality of people's lives.”<sup>11</sup> For chronic pain, this is a difficult task. As Dr Webster says: “pain is a cerebral experience that integrates attitudes, expectations, emotions, and stimuli. It is invisible.”<sup>12</sup> Although many people are unwilling to accept how complicated, multilayered and prevalent it is in our society, public events surrounding this issue need to be considered.

In her recent masters dissertation, Claire Baker, a New Zealand student, demonstrates that “experiences of art can be positive for people,” and through her case studies Wellington City Council's galleries are “limited by unclear policy and professionals' relatively narrow understandings of social inclusion through museums.”<sup>13</sup> Following on from this, her results suggest that the galleries included in her case studies “rely predominantly on exhibitions on ethnic cultures as a form of audience development,” which connects directly with the policies in connection with social inclusion in New

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<sup>8</sup> University of Otago, “Art and public health: Wellbeing, social critique and communication,” Summer School Symposium, 27 February 2017, accessed 25 January 2017, <http://www.otago.ac.nz/wellington/departments/publichealth/summerschool/otago623537.html>.

<sup>9</sup> Silverman, 2010, 19.

<sup>10</sup> Silverman, 2010, 24.

<sup>11</sup> Mark O'Neill, “Essentialism, adaption and justice: Towards a new epistemology of museums,” *Museum Management and Curatorship* 21 (2006): 111.

<sup>12</sup> Lynn R. Webster, M.D., *The Painful Truth: What Chronic Pain is Really Like and Why It Matters To Each of Us* (Salt Lake City, Utah: Webster Media LLC, 2015), 2.

<sup>13</sup> Claire Adele Baker, “Good Intentions: A case study of social inclusion and its evaluation in local public art galleries,” MA diss., (Wellington, NZ: Victoria University of Wellington, 2014): 2.

Zealand at this time.<sup>14</sup> New Zealand's social policies from 2015 included areas of, in no particular order, education, social inclusion, health, families, pensions, integration, safe living, and global inequalities. At this time, it was believed of New Zealand's government policies that "for the most part, [they] enable societal inclusion effectively and ensure equal opportunities."<sup>15</sup> However, in a document called 'New Zealand General Social Survey 2016: Objectives of the Civic and Cultural Participation supplement' released by Statistics New Zealand in 2014, "acceptance of diversity, social inclusion, and shared identities" has been given the highest priority, saying that "many government agencies are interested in data on acceptance of diversity, social inclusion, and shared identities to inform their work on developing strong and resilient communities."<sup>16</sup>

An additional masters dissertation written and completed by Riah King-Wall in 2016, focuses on the accessibility of museums around New Zealand and investigates how these entities are engaging with disabled communities. King-Wall discovers through questionnaires and focus groups that museums and galleries around the country are becoming increasingly aware of the range of disabilities and are instigating targeted programmes for these visitors.<sup>17</sup> This suggests that between Baker's research and King-Wall's, that museums and galleries have become more aware of other communities in their midst.

In 2001, Jocelyn Dodd and Richard Sandell examined perspectives on museums, galleries and social inclusion. According to Dodd and Sandell, museums and galleries "can enhance an individual's self-esteem, empower communities to take greater control

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<sup>14</sup> Baker, 2014, 2.

<sup>15</sup> "New Zealand Social Policies 2015," Sustainable Governance Indicators, accessed 26 April 2016, [http://www.sgi-network.org/2015/New\\_Zealand/Social\\_Policies](http://www.sgi-network.org/2015/New_Zealand/Social_Policies).

<sup>16</sup> Statistics New Zealand, "New Zealand General Social Survey 2016: Objectives of the Civic and Cultural Participation supplement," (Wellington, N.Z.: Statistics New Zealand, 2014), 12.

<sup>17</sup> Riah King-Wall, "Path to Accessibility: The current state of disability access in Aotearoa New Zealand museums," MA diss., (Wellington, NZ: Victoria University of Wellington, 2016): 68.

over their lives, challenge stereotypes and tackle intolerance.”<sup>18</sup> Although their resource is valuable in showing how these public entities can help with social inclusion, they do state that it was “both impossible and inappropriate to attempt to produce a blueprint for effective inclusion work.”<sup>19</sup> I agree with this statement. A blanket framework for social inclusion would neither be possible to develop, nor to implement. Although I have inherent personal understanding, knowledge and experience with chronic pain and can put forward proposals, theoretical concepts and suggestions in this area, I could not do it with any other condition or disability. Every condition/illness/disability comes with a unique set of symptoms and problems, and to try to come up with a universal blueprint for social inclusion to cover all of them would be absurd and bound to fail. What Dodd and Sandell do point out is that there are common misunderstandings of what social exclusion/inclusion actually means for museums and galleries.

The term ‘social inclusion’ has its roots back in 1970s France, where it was used to “describe those who fell out of the protection of the State’s social insurance.”<sup>20</sup> Since then, the term has increased in popularity and in turn its meaning has become fluid. Galleries have been critical, but one in particular is prominent. There is the belief that the idea of ‘inclusion’ is identical to ‘dumbing down’ and is “incompatible with challenging and high quality artistic practice.”<sup>21</sup> In one of Dodd and Sandell’s ‘Challenging Practices’ examples, Dr Michael Varnam, GP, is of the opinion that museums have a part to play in a multi-agency approach. He believes that more doctors need to be looking “for solutions beyond the prescription pad,” that instead, they need to position themselves within the community at large, without compartmentalising. Not

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<sup>18</sup> Jocelyn Dodd and Richard Sandell, *Including Museums: perspectives on museums, galleries and social inclusion* (Leicester: University of Leicester, 2001): 4. *See also* Richard Sandell, *Museums, Society, Inequality* (London: Routledge, 2002); Richard Sandell, *Museums, Prejudice and the Reframing of Difference* (Oxon: Routledge, 2007); Richard Sandell, Jocelyn Dodd and Rosemarie Garland-Thomson, eds., *Re-Presenting Disability: Activism and Agency in the Museum* (Abingdon, Oxon: Routledge, 2010); Richard Sandell and Eithne Nightingale, eds., *Museums, Equality and Social Justice* (Oxon: Routledge, 2012).

<sup>19</sup> Dodd and Sandell, 2001, 4.

<sup>20</sup> Dodd and Sandell, 2001, 8.

<sup>21</sup> Dodd and Sandell, 2001, 14.

one thing contributes to health issues, it is usually a range of things including employment, culture, finance, education, and the environment.<sup>22</sup>

Another part of the concept of social inclusion/exclusion is that of stigma. The term stigma has a long history. Originally a Greek word meaning a bodily mark to refer to something unusual or bad about a person's moral status. Christians have seen it as physical signs of holy grace or physical disorder.<sup>23</sup> According to Erving Goffman, society, in more modern times, believes that the "person with a stigma is not quite human," and because we assume this, "we exercise varieties of discrimination."<sup>24</sup> Similarly, Rob Kitchin believes that "disability has distinct spatialities that work to exclude and oppress disabled people."<sup>25</sup> He goes on to say that disability is not only a socially constructed concept but a spatial one as well. Another connected social construction, is the concept of the 'Other', which Edward Said covers in his book *Orientalism*, where Westerners create fictional perceptions and depictions of the East. Although this book covers racial marginalisation, it is such a well known social construction that it can be simply compared with other stigmatised communities. Coming back to disability generally, theories from psychoanalysis or social constructivism could be used to illustrate why disabled people are stigmatised and oppressed. Social constructivists, building on psychoanalytical thought, argue that "we are all unique and different and thus categories such as disability, gender and race are really misnomers."<sup>26</sup> This is a lovely thought, but in reality, society generally is yet to see it this way.

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<sup>22</sup> Dodd and Sandell, "Challenging Practices 1: Museums and the health of a community in conversation with Dr Michael Varnam, GP", In *Including Museums: perspectives on museums, galleries and social inclusion* (Leicester: University of Leicester, 2001): 77.

<sup>23</sup> Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity?* (New York: Simon & Schuster, Inc., 1963), 1.

<sup>24</sup> Goffman, 1963, 5.

<sup>25</sup> Rob Kitchin, "'Out of Place', 'Knowing One's Place': Space, power and the exclusion of disabled people," *Disability & Society* 13, no.3 (1998): 343.

<sup>26</sup> Kitchin, 1998, 344.

## Social Inequality and Diversity

While my focus is on the chronic pain community, it is necessary to take a step back and look at literature with a broader focus, such as those interested in social inclusion and exclusion generally. According to the South Dublin County Council, social inclusion is:

The process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life and enjoy a standard of living and well being that is considered normal in the society in which they live.<sup>27</sup>

Those at greater risk of social exclusion have been identified by Ireland's National Action Plan as: the older generation, ethnic minorities, disabled people, women, children and young people, travellers, and people who identify as LGBTQ.<sup>28</sup> What I would like to draw attention to is that the South Dublin County holds a Social Inclusion Week. This is something that several countries partake in, including Australia, but where is New Zealand on this issue? New Zealand is yet to organise and participate in a week dedicated to social inclusion.

## Health Care and Social Work

As Lous Heshusius states “there are many books and articles about chronic pain written by medical practitioners” but there are few that are written by chronic pain patients apart from online blogs which tend to be read only by fellow sufferers. Medical publications give a good understanding about things at a physical level though they do not tell of what “hours of pain do to a life.”<sup>29</sup> Neither do they tell of how chronic pain causes relations with other people to change, such as with family, friends, colleagues and even strangers. “The social and cultural influences of chronic pain are not often mentioned.”<sup>30</sup> It is widely known that acute pain gets the instinctive behaviours of sympathy but those of us with chronic pain soon find that our complaints (which could

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<sup>27</sup> South Dublin County Council, “Social Inclusion Week 17-24 November 2015,” accessed 4 April 2016, <http://www.sdcc.ie/services/community/social-inclusion/social-inclusion-week-17-24-november>.

<sup>28</sup> South Dublin County Council, 2015.

<sup>29</sup> Lous Heshusius et al., *Culture and Politics of Health Care Work – Inside Chronic Pain: An Intimate and Critical Account* (New York: Cornell University Press, 2009), 8.

<sup>30</sup> Heshusias et al., 2009, 8.

be endless) often irritate, tire out and in the end estrange physicians as well as family and friends. It is because of this that healthy people do not hear us complain, see us weep, as we learn to keep the pain to ourselves.<sup>31</sup> We appear normal, and yet what is distinctive about chronic pain is that others' perception of it can be harmful. To the lay person, it is difficult to understand the pathology of chronic pain and often the responses are 'you'll get over it', 'it will go away', 'you just need to do more of this', etcetera, completely missing the part where it said 'chronic'. Dr Scott Fishman, says that pain "can reconfigure the architecture of the nervous system it invades, changing the very pathways by which responses get sent to the brain in such a way as to generate more pain."<sup>32</sup> "This invisible, inexpressible, and misunderstood experience begs for greater public understanding" and an art exhibition could give it that.<sup>33</sup>

### **Pain Studies**

Through the available literature, it becomes quite apparent that 'pain', particularly of the chronic nature, is misunderstood and misrepresented within today's society. It is also far more prevalent than people seem to think. Adding these aspects together, it shows that more needs to be done for this fast-growing, invisible community. What is also specified throughout the literature, is that talking about it and using words is not enough, as this does not engage others or offer a sensory understanding or connection. The word 'pain' is a label that adheres to a range of ailments from scraped knees and headaches, to phantom limbs, and kidney stones. "The adjective 'painful' is so broad that it can be applied to a toothache as easily as to a boil, a burst appendix, and a birth."<sup>34</sup> Words are not sufficient enough in themselves to describe, show, or aid in visualising the daily strength and suffering of those with chronic pain, and this is where art can do its part. As Joanna Burke explains: pain creates communities. People have always

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<sup>31</sup> Heshusius et al., 2009, 9.

<sup>32</sup> Heshusius et al., 2009, 19.

<sup>33</sup> Heshusius et al., 2009, 17.

<sup>34</sup> Joanna Bourke, *The Story of Pain: From Prayer to Painkillers* (Oxford: Oxford University Press, 2014), 1.



struggled to render the sensations, emotions, and beliefs associated with pain-events into words.<sup>35</sup> “Words are never enough.”<sup>36</sup>

Chronic pain is described best by Dr Lynn Webster as being “an unbidden guest, humanity's shadow companion down through the ages. It is an interloper, a despoiler of dreams, a thief. Pain can affect anyone, young or old, male or female, rich or poor. No one is immune.”<sup>37</sup> These facts make this subject a growing issue in society. A collaborative effort from both chronic pain survivors and museum/art gallery professionals could bring about a change in the perceptions and stigmas associated with chronic pain.

People with chronic pain often get treated similarly to people who are slowly dying. People often know not what to say, nor how to act, and this is a societal problem. Society today is desensitised against death. People see death all the time, on the news, in movies, in video games, and we feel nothing, we learn nothing. And when it is a family member or a friend we learn that we do not know what to say or how to act. Death is an essential part of being a human being, we live and we die, it requires us to “develop means of coping with it”.<sup>38</sup> Some people believe that humans struggle to care for the sick and dying because it reminds them of their own ability to die or get sick, and since the “development of medicine, sanitation and improved diets [...] death can be now pushed back into the darker corners of our minds” hidden away in hospitals, care facilities, and people’s homes.<sup>39</sup> The sick makes sickness real, and the dying makes death real. The solitude that exists today around both these ‘communities’ is not just harmful for the ill parties, but for all. By this I mean that isolation can cause those who are sick and/or dying to receive diagnoses of co-morbid conditions such as depression, which in turn causes them to give up on life. And on the other hand, the healthy keep on being ignorant and continue to live in a fairyland where death does not exist.<sup>40</sup> An exhibition telling these stories of treatment, not just by the medical community, but by

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<sup>35</sup> Bourke, 2014, 46.

<sup>36</sup> Bourke, 2014, 159.

<sup>37</sup> Webster, 2015, 1.

<sup>38</sup> Chris Shilling, *The Body and Social Theory* (London: SAGE Publications Ltd, 1993), 175.

<sup>39</sup> Shilling, 1993, 190.

<sup>40</sup> Shilling, 1993, 190-196.

our friends, family and colleagues would not just be an awakening to those who treat us this way, but also a safe space to educate those whom we hold dear.

Unfortunately for those with chronic pain, there is no future different from chronic pain. At this stage there is no-one, no physician of any sort, who can promise a cure. In general, doctors during their many years of training have had but a few hours of pain-management training which for the most part involves learning about drugs. As I and many other people with chronic pain have found, the “willingness to find out what can be done about it [... can] vary considerably among doctors.”<sup>41</sup> Even pain clinics and their specialists are included in this observation as there is a marked difference in treatment depending on who runs the clinics. The issue with chronic pain is that its existence is not striking and often cannot be seen at all by the naked eye, or even the trained and assisted eye. According to Dr Scott Fishman, the chief of Pain Medicine at the Davis Medical Centre at the University of California, there is a public health crisis surrounding those with under-treated chronic pain. Those with it, need care, and doctors who are ill-skilled to handle us are being put on the ‘frontlines’.<sup>42</sup> Not only would this exhibition centre around the twenty percent of the population in New Zealand with chronic pain and their daily struggle, but it would also highlight the training, or lack thereof, about chronic pain management in the medical sciences through forums and talks.<sup>43</sup>

## Art and Pain

I believe that ill people need to be able to tell their stories in a safe environment where others can learn, engage, and understand their world, and this applies particularly to the chronic pain community. It would also be a chance for those with chronic pain “to construct new maps and new perceptions of their relationships with the world.”<sup>44</sup> In *Enduring Creation: Art, Pain and Fortitude* by Nigel Spivey, Elaine Scarry has noted

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<sup>41</sup> Heshusius et al., 2009, 48.

<sup>42</sup> Heshusius et al., 2009, 144.

<sup>43</sup> Nicola Swain and Matthew Johnson, “Chronic Pain in New Zealand: a community sample,” *The New Zealand Medical Journal* 127, no.1388 (2014): abstract summary.

<sup>44</sup> Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), 3.

inadequacies of the English language when it comes to describing pain; she concludes that “pain's 'resistance to language' is not accidental, but 'essential to what it is'.” Those who suffer from migraines, arthritis, chest pain and the like, tend to believe that those who have never had their type of pain can [not] ever imagine its quality of painfulness; the pain is verbally inexpressible.”<sup>45</sup> This is where art comes in - it is a medium that can express understanding and empathy, where words fail. As stated by Pascual Nieves, it is “the art of pain [which inevitably] comes from a witness, i.e., a doctor, an ex-patient or an onlooker sympathetic with the pain of the other.”<sup>46</sup> But in respect to the chronic pain sufferers in New Zealand and to this research project, I wish the art of pain to come from the survivors themselves, therefore presenting to the public a first person perspective of the nature of chronic pain and the lives of those living with it.

An impressive historical example of the kind of art exhibition I would like to propose is that of Frida Kahlo. Kahlo was a self taught artist and she used this skill to create surreal art in order to make her pain and anguish tangible. These were recurrent themes in her works and she described her paintings as “the most frank expression of [herself].”<sup>47</sup> Many of her works “depict her physical suffering: her bleeding, broken, and weeping body”. ‘The Broken Column’ is a good example of this.<sup>48</sup> It is one of her best known oil paintings and it encapsulates the pain community’s agonies. Hayden Herrera has observed that the pain in the painting is made vivid by the nails driven into Kahlo’s naked body. Kahlo “stares straight ahead with dignity. Tears dot her cheeks, but her features refuse to cry. An immense and barren plain in the background conveys physical and emotional suffering.”<sup>49</sup> For those in chronic pain this is exactly what life is like. Friends and family are supportive at first but they do not entirely understand the word ‘chronic,’ even if they want to, they envision you getting better one day soon and when you don’t, they get bored with you. Sick people are boring. And soon enough

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<sup>45</sup> Nigel Spivey, *Enduring Creation: Art, Pain and Fortitude* (London: Thames & Hudson Ltd, 2001), 96.

<sup>46</sup> Pascual Nieves eds., *Witness to Pain: Essays on the Translation of Pain into Art* (Bern, Switzerland: Peter Lang AG, 2005), 8.

<sup>47</sup> Hayden Herrera quoted in Manuel Martínez-Lavín et al., “Fibromyalgia in Frida Kahlo’s life and art” *Arthritis & Rheumatism* 43, no. 3 (2000): 708.

<sup>48</sup> Valmantas Budrys, “Frida Kahlo’s neurological deficits and her art” *Progress in Brain Research* 203 (2013): 242.

<sup>49</sup> Herrera in Manuel Martínez-Lavín et al., 2000, 708.

people begin to disappear, leaving a barren social plain around you, which in turn can lead to emotional issues on top of the physical ones you already have. Valmantas Budrys asserts, that Kahlo's "paintings and drawings are like medical case reports," meaning that they read perfectly well to the naked eye.<sup>50</sup> Just by looking at her art, the viewer can understand her state of mind, her pain and suffering, her life and her history.

Kahlo turned to art to give her life meaning, and to give her suffering a voice when she could not express it herself. Related to the Frida Kahlo example is art therapy in hospitals and medical care. It is a well-researched area and patients show significant improvement through the use of this therapy.<sup>51</sup>

By offering a chance for people to create something that shows how their life has been affected by chronic pain to those in the wider population, there is the chance for some general understanding around the lives of chronic pain sufferers as well as a change in how these people are treated by their loved ones, the medical community, educators, and the public in general. The people involved in the potential exhibition may or may not find that producing their piece of art is therapeutic. This research will not be focusing on this aspect any more, other than saying that the art will be used as a communication tool, and from there therapy may occur when a safe space and open empathetic ears, eyes and minds come together. This research will also not be documenting artists or artworks, but focusing more on the social use for which art is put.

There has been a longstanding connection between art galleries and academia, where only those who understand art can view, converse on and be in the space. This ideal has been changing recently, with art galleries working with their communities, and offering free entry to the public space, though museums have been quicker to take up the lead. The response has been positive, and as Carol Duncan has noted, a kind of ritual plays out. The art gallery is the stage, and the ritual is both social and personal. Socially

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<sup>50</sup> Budrys, 2013, 242.

<sup>51</sup> Gil Bar-Sela et al., "Art therapy improved depression and influenced fatigue levels in cancer patients on chemotherapy" *Psycho-Oncology* 16, no.11 (2007): 980-984.; Nancy Nainis et al., "Relieving Symptoms in Cancer: Innovative Use of Art Therapy" *Journal of Pain and Symptom Management* 31, no.2 (2006): 162-169.; Helen B. Landgarten, *Clinical Art Therapy: A Comprehensive Guide* (New York: Routledge, 1981).; Lois H. Silverman, "The therapeutic potential of museums as pathways to inclusion" in *Museum, Society, Inequality* edited by Richard Sandell (London: Routledge, 2002).

people are able to share the response to the art with other people, and personally, they have an individual choice to be in that public space.<sup>52</sup>

### **Medical Studies and Pain Exhibitions**

An example of an exhibition pertaining to chronic pain is called ‘Pain INSights’ which was at Guy’s Hospital in London from November 2011 to January 2012. The King’s College group called the London Pain Consortium offered a series of art workshops which “blended the perceptions of people with chronic pain and researchers’ less intimate experiences to create poetry, dance and visuals.”<sup>53</sup> They wished to increase the understanding of what people with chronic pain experience, to generate an interest into the research of the mechanisms of pain, as well as increase researchers’ awareness of the effects of chronic pain conditions. An example pertaining to another physical disability is called *Sight Unseen: International Photography by Blind Artists*. This exhibition “explores the idea that blind people can often see in ways that sighted people cannot.”<sup>54</sup> In the exhibition they use a technology called 3DPhotoWorks which creates 3D tactile versions of the photographs, and “touch-activated sensors provide audio information about the images.”<sup>55</sup> The exhibition hoped to not only disperse ideas about people with vision loss, but also to get people to start questioning the limitations imposed by sight. I would like to compare these two examples of exhibitions on disability against each other then show how in this my proposal will differ. *Pain INSights* was run by medical personnel and researchers with the chronic pain patients being their subordinates, whereas *Sight Unseen* used blind artists’ photographs to create an exhibition for both sighted and unsighted people. Although *Pain INSights* has the right subject content, it is *Sight Unseen* that is more similar to my research, as it works

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<sup>52</sup> Carol Duncan, “The art museum as ritual,” in *Heritage, Museums and Galleries: An Introductory Reader* edited by Gerard Corsane, (Oxon: Routledge, 2005), 78.

<sup>53</sup> Wellcome Trust, “Doctor, it hurts... all the time: The London Pain Consortium,” accessed 3 April 2016, <http://www.wellcome.ac.uk/Funding/Public-engagement/Engagement-with-your-research/Support-and-resources/Patient-groups/WTP051844.htm>.

<sup>54</sup> Canadian Museum for Human Rights, “Sight Unseen: International Photography by Blind Artists,” accessed 11 July 2016, <https://humanrights.ca/exhibit/sight-unseen>.

<sup>55</sup> Canadian Museum for Human Rights, accessed 11 July 2016, <https://humanrights.ca/exhibit/sight-unseen>.

with the people and their artwork for a greater cause, it does not use them as objects to compare to medical professionals' perceptions. In chapter one, there is further discussion and a comparison of three exhibitions pertaining to pain.

### **Summary**

The literature review has presented many areas of interest, all of which could end up being research projects on their own. This research is situated in a small gap between social inclusion and art galleries. As mentioned previously, art galleries are often elitist and have a particular type of visitor, although some institutions are changing this focus. With many types of research projects there is a need to pigeon-hole the type of research. It has been suggested that this work could be seen as social work or community work. I am dealing with a social issue, but at the same time I will be working with a specific community to make it happen. At this stage I do not want to define what category it is intended to occupy as this may detract from what it could turn out to be. In the end it could be defined as being both social and community work, but it could also end up being neither.

There are museums which exist that specialise in health, life sciences, and biomedical sciences, however these usually attract a very specific audience. The proposal for this future project will be presented in such a way that a large proportion of the general public will see the exhibition, therefore it will align itself with a community gallery.

### **Research Design**

My overall general approach is through action research. I want to change something, and this research project is laying the ground work so that the change can happen in the future.

### **Action Research**

Action research is used when the research sets out to not only understand issues in everyday practice but to solve and change these problems. Although this research is very much theoretical, it is the precursor to a practical event, aimed at dealing with a

real-world problem – giving voice to chronic pain sufferers. Action research is also a cyclical process.<sup>56</sup> The theoretical research will inform practice and the practice (in the future) will refine the theory, in a continuously repeating cycle. Action research is generally small in scale, which makes it a good strategy to use for this dissertation. The advantage of this process is that the research will not be held back by the rigidity of a method, however the disadvantage of this, is that the research may appear to be driven in a disorderly manner.

I will also be using a mixture of both quantitative and qualitative data, the quantitative will give me numbers of interest in certain areas, whereas the qualitative will give me thoughts, feelings and ideas.

### **Mixed Methods**

Using a mix of case studies and quantitative data means that I can receive a well-rounded viewpoint of thoughts and events behind the representations of chronic pain in New Zealand and abroad, as well as how much need or desire there is for an exhibition focused on the experiences of those with chronic pain. The advantages of quantitative data includes richness and detail, a tolerance of ambiguity and contradictions, the prospect of alternative explanations and the fact that the data and analysis are usually ‘grounded’. The disadvantages are that the data is less representative, the interpretation is bound up with the ‘self’ of the researcher with the possibility of decontextualising the meaning and the danger of oversimplifying the explanation. The analysis will also take longer.<sup>57</sup>

### **Research Methods**

My sources of data will be primary and secondary research of written material, and photographic examples of chronic pain art. Written material will include the literature review (above), case studies and the online surveys. Another method, and the main method for this dissertation will be a proposal for an exhibition. The exhibition can be

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<sup>56</sup> Martyn Denscombe, *The Good Research Guide: For small-scale social research projects* 4th ed. (Berkshire, England: Open University Press, 2010), 126.

<sup>57</sup> Denscombe, 2010, 304-305.

seen as a method to support the research as well as the goal after the research is completed. The instruments used in data collection and analysis will include a computer with Excel, and the Qualtrics software to put the survey online as well as code and analyse the survey data.

## **Surveys**

The first survey was to gauge what interest there is in the chronic pain community about participating in an exhibition. The second survey was to gauge understanding from a control group about chronic pain. Both surveys were put online, and were posted to multiple online support groups through social media and via email. This method is appropriate, in particular social media, as I wish to reach a large number of respondents throughout New Zealand, and the questions will be straightforward with a simple answering capability.<sup>58</sup>

## **Quota Sampling**

This type of sampling technique is non-probability 'quota' sampling. A particular sample size was chosen to gauge interest, around the 100 respondent mark, which I anticipated achieving. However I kept in mind that "the original sample may not equal the number of responses that are finally obtained which can be used in the research."<sup>59</sup> This type of sampling can be seen as having limited quality due to having no sampling form and because of the lack of a true representation of the population it will be a biased sample. Though, because the survey's job was to gauge interest in participation in a chronic pain exhibition, I only needed to receive a broad understanding and overview, so I could use the results to make suggestions about the need for an exhibition on this topic. The advantages of surveys included the ability to collect both quantitative data and qualitative data, a focus on empirical data, wide and inclusive coverage, as well as cost and time efficiency. Disadvantages however included the tendency to focus on data rather than theory, lack of details and depth of the data, and the possibility of a low

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<sup>58</sup> Denscombe, 2010, 156.

<sup>59</sup> Denscombe, 2010, 41.



response rate to the surveys, though as explained above, I believed the advantages of this type of social research outweighed the disadvantages.<sup>60</sup>

## Content Analysis

To analyse the qualitative data collected from the surveys, content analysis was used. “It is used as a way of quantifying [...] text. Political scientists might use it to study the transcripts of speeches, educationists to study the content of children’s books, and historians to study statesmen’s correspondence.” The answers to the qualitative questions were read multiple times to see whether there were repeated ideas within the text. There were particular words and phrases that came up throughout the answers given to the questions. Relevant categories of ‘key words’ and ‘key phrases’ were developed to analyse the data more thoroughly. These categories were coded and the frequency with which these categories occurred were tallied. From this, graphs were made to show and explain these occurrences.<sup>61</sup>

## Case Studies

The three exhibitions which have been chosen are: *Pain Less* from the Science Museum in London, *Pain Exhibit*, an online exhibition, and *The Art of Pain* from the University of South Australia. The reason these three case studies have been chosen is because they are the only exhibitions in recent years pertaining to pain that I have found, meaning there is no real choice, but all three are still intrinsically interesting.<sup>62</sup> The case studies will be studied and analysed more closely in chapter two.

1. *Pain Less* from the Science Museum in London focused on getting rid of pain through medications.<sup>63</sup>
2. *Pain Exhibit*, which is an online ongoing exhibition, focuses specifically on pain art for use as a resource to communicate with others. The art is created by artists with

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<sup>60</sup> Denscombe, 2010, 48-50.

<sup>61</sup> Denscombe, 2010, 281-282.

<sup>62</sup> Denscombe, 2010, 59.

<sup>63</sup> The Science Museum, “Pain Less,” accessed 22 March 2016, <https://painlessexhibition.wordpress.com/>.

chronic pain, and art from this site has been used on the covers of peer reviewed medical journals on pain.<sup>64</sup>

3. *The Art of Pain* from the University of South Australia focused on contemporary pain research and its implications.<sup>65</sup>

Case studies generally focus on one, or a few, instances of a particular phenomenon with a “view to providing an in-depth account of events, relationships, experiences or processes occurring in those particular instances.” In this instance all three exhibitions exhibit pain in particular ways, and specific attention will be paid to what processes were involved to get to the end product, what relationships were forged in those processes, and comparisons will be made between the three. Identifying what is missing from these past exhibitions will be explained, along with describing how the exhibition proposal will differ.<sup>66</sup> The advantages of case studies is that while focusing on just a few examples, I can analyse intricacies in the complex social situations that come with an exhibition. With case studies, the researcher has little or no control over events, and in this case the exhibitions have already closed. Also, case studies fit well when the research is small in scale.<sup>67</sup> The disadvantages include criticisms to do with the plausibility of generalisations made by me, the researcher, so both differences and similarities must be demonstrated between each case. Case studies can be seen as yielding ‘soft’ data, showing processes rather than “measurable end products,” but in this case, the dissertation is analysing processes and producing a working framework for an exhibition on chronic pain, so this disadvantage may work out to be an advantage. Another disadvantage may be contacting the people who worked on the exhibitions, and accessing the processes behind each of the exhibitions.

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<sup>64</sup> Collen, Mark. et al., “PAIN Exhibit,” accessed 22 March 2016, <http://painexhibit.org/en/>.

<sup>65</sup> Australian Network for Art and Technology, “The Art of Pain,” accessed 22 March 2016, <http://www.anat.org.au/the-art-of-pain/> 20-30 July 2015.

<sup>66</sup> Denscombe, 2010, 55.

<sup>67</sup> Denscombe, 2010, 62.

## Exhibitions

Exhibitions are often used as a method or a tool to get from a to b, to get a message across, to start conversations or to give voice to communities. Some examples include: the exhibition *Small scale, big change* which featured architects addressing the functional requirements of their designs and aiming to have a broad positive effect on the communities they worked in.<sup>68</sup> An example of an exhibition on art and social change was at the gallery Te Tuhi last year, called *Art and Social Change Research Project: Delhi Residency*. It examined whether a potential long term collaboration between artists seeking social change and social entrepreneurs could be feasible, or desirable, as a way to have lasting effects in communities.<sup>69</sup> Some examples of arts for social development include *Arts for Social Development Exhibition Workshop* at the Swedish Institute at Athens which brought together NGOs and voluntary organisations using arts and creativity as a working method to support and help immigrants, refugees, and other minority groups with their integration, learning, mental and social change.<sup>70</sup> Additionally, *Disobedient Objects* at the Victoria & Albert Museum focused on exploring objects of art and design from around the world that have been created by grassroots social movements as tools of social change.<sup>71</sup> An example of using an exhibition as a tool of social change can be seen in Mathilde Bertrand's research article on an exhibition from 1983 called *Belfast Exposed*. The objective of the exhibition was not about the art of photography, it was about people having representation.<sup>72</sup> The exhibition proposal for this research is the medium for the message.

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<sup>68</sup> MOMA, "Small Scale, Big Change: New Architectures of Social Engagement", accessed 27 September 2016, <http://www.moma.org/interactives/exhibitions/2010/smallscalebigchange/about.html>.

<sup>69</sup> Mercedes Vicente, "Art and Social Change Research Project: Delhi Residency", Te Tuhi April – July 2014, accessed 27 September 2016, <http://www.tetuhi.org.nz/whats-on/exhibitiondetails.php?id=145>.

<sup>70</sup> European Union National Institutes for Culture, "Arts for Social Development - Workshop Exhibition", accessed 27 September 2016, <http://www.eunic-online.eu/?q=content/arts-social-development-workshop-exhibition>.

<sup>71</sup> Artlyst, "New V&A Museum Exhibition Explores Social Change Through Art And Design", accessed 27 September 2016, <http://www.artlyst.com/articles/new-va-museum-exhibition-explores-social-change-through-art-and-design>.

<sup>72</sup> Mathilde Bertrand, "'A Tool for Social Change': Community Photography at Belfast Exposed", accessed 27 September 2016, <https://lisa.revues.org/8770>.

Benefits of using an exhibition as a public forum for chronic pain include: the possibility of reaching people who would not normally be accessible; opportunities to raise the status and image of different conditions where chronic pain is the main symptom; and the ability to pass on wide ranging, and specific information to the public through a variety of visual formats. Disadvantages of using an exhibition as a public forum for chronic pain include: Exhibitions need resources and funding to be produced; they must be actively promoted; they require careful planning in advance; they must be held at an all-accessible venue; they need sick/vulnerable members to be involved in the process which could cause their health to go downhill.<sup>73</sup> The exhibition proposal can be found in chapter three.

The subject of this research may be a deterrent because for some people the topic of 'chronic pain' is taboo and sensitive.<sup>74</sup> It could also cause people more pain than they are already in. It is possible that because the questionnaires were on the internet that the older, non tech-savvy population may have been missed out. Non-responses, however, were not a big issue for the surveys and they were not targeting specific demographics.<sup>75</sup>

## Summary

This chapter has laid out the current literature, the research design, and research methodologies which will inform this dissertation. The literature review has combined theories from and including pain studies, art and pain, health care and social work, medical studies and pain exhibitions, health and museums, social work, inclusion and museums, as well as social inequality and diversity.

The research design and methodology lays out the preparations and preliminary measures to this research, and the following chapters work through the research phase and the potential answers to the issues discussed in this chapter. Chapter two details the

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<sup>73</sup> "Exhibitions", Involving People – Scottish Health on the Web, accessed 28th September 2016, <http://www.sehd.scot.nhs.uk/involvingpeople/methodologies/individualmethodologies/exhibitions.htm>.

<sup>74</sup> Denscombe, 2010, 19.

<sup>75</sup> Roger B. Fillingim, et al., "Sex, Gender, and Pain: A Review of Recent Clinical and Experimental Findings" *J Pain* 10, no. 5 (2009): 447-485.

findings of the surveys as well as comparing and contrasting three case studies, showing the gap that needs to be addressed. Chapter three presents an exhibition proposal that could address this gap.

## Chapter 1 - Background and Case Study Analysis

Pain doesn't show up on a body scan and can't be measured in a test. As a result, many chronic pain sufferers turn to art, opting to paint, draw or sculpt images in an effort to depict their pain.

~Tara Parker-Pope<sup>1</sup>

This chapter looks at a comparison between three exhibitions with a focus on pain. The next chapter looks at the results from the two surveys which were conducted online and through email. The information from this chapter will lay the ground work for the final chapter where an exhibition will be proposed. The chapter is arranged in the following order: the case studies will be outlined, one by one, starting with *Pain Less*, *PAIN Exhibit*, and ending with *The Art of Pain*; then the case studies will be comparatively analysed.

### 1. Pain Less – The Future of Relief: Nov 2012 – Aug 2013

Pain Less was an exhibition at the Science Museum in London which investigated the future of pain relief. In the year 2012, close to 6 billion painkillers were sold in the United Kingdom, and it's likely those figures have gone up. The main way pain is treated in western societies is with drugs, and this has not changed in decades. The exhibition questioned whether there is a better way to control pain – especially for those whom pain is an ongoing issue, which is one in five people in the United Kingdom, a similar proportion to New Zealand.<sup>2</sup> Pain Less explored pain through a range of stories from a range of people who deal with pain every day – from those with missing limbs to those with no pain at all. “Pain Less aimed to introduce visitors to the latest pain research through personal stories, scientific discovery, fascinating objects, films and even games.”<sup>3</sup>

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<sup>1</sup> Tara Parker-Pope, “Pain as an Art Form,” *The New York Times*, 22 April 2008, accessed 22 March 2016, [http://well.blogs.nytimes.com/2008/04/22/pain-as-an-art-form/?\\_r=0](http://well.blogs.nytimes.com/2008/04/22/pain-as-an-art-form/?_r=0).

<sup>2</sup> “Pain Less,” Science Museum, accessed 21 October 2016, [http://www.sciencemuseum.org.uk/visitmuseum/plan\\_your\\_visit/exhibitions/painless](http://www.sciencemuseum.org.uk/visitmuseum/plan_your_visit/exhibitions/painless).

<sup>3</sup> “Pain Less,” Science Museum, accessed 21 October 2016.

To start this project off, the Pain Less exhibition team worked with a group of adults who live with pain, which shaped their approach to the exhibition. They then brought top researchers to give talks about pain, anaesthesia and consciousness to the group of adults with pain. There was some comparison of what the participants had experienced and what the researchers had found in their work. Other questions that were asked for this exhibition pertained to the experts in the field of science, how they are working to create the ideal pain relief, whether or not we really feel no pain when under anaesthesia and how this affects us, how different emotions can affect how we feel pain, and how our own DNA can be decoded to see how it works in our bodies.



*Figure 1 and 2:* These are two images from within the exhibition *Pain Less*. The first shows the layout of the four people and types of pain focused on, and the second shows a close up of one of those sections. © The Board of Trustees of the Science Museum.

*Pain Less* made short films to accompany the exhibition where they followed four different people from around the United Kingdom, plus one longer film. The films are called ‘Pain in the brain,’ ‘Pain killers,’ ‘Painfully unaware,’ ‘Virtually painless,’ and the longer one, ‘Fragmented Lines: revisualising pain,’ with the first four being available online via the Pain Less blog and through the Science Museum’s youtube channel. ‘Pain in the brain’ is about how our moods and expectations can affect our experiences of pain. ‘Pain killers’ is about the few people who cannot feel any pain at all, and how scientists have found that this is due to a genetic mutation in their DNA that means that no pain signals ever reach the brain. They question whether this rare condition could be the answer to the perfect pain killer.

‘Painfully unaware’ is about how anaesthesia works and how much pain a person really experiences under the influence of anaesthesia. ‘Virtually painless’ is about the condition phantom limb pain, which over sixty percent of amputees have, and is used as an example of chronic pain in the exhibition. In this exhibition, chronic pain is described as being “a condition which continues to baffle doctors and cause immense distress amongst those who suffer from it.”<sup>4</sup> ‘Fragmented Lines: revisualising pain’ is an overview of the exhibition as a whole and was co-created with five adults who live in pain. The focuses of the film include: the connection between the body and brain, how nerves act as pain transmitters, how emotions can affect pain and vice versa, and how pain is an ongoing experience.<sup>5</sup> There were also corresponding blogs posted with each of these short films, under the same titles, to the *Pain Less* wordpress blog.

Another general theme the exhibition focused on was the distinctive ways in which people experience pain and how each person copes with it. Numerous contributors also articulated optimism that “improved scientific understanding and medicine would lead to better pain relief in future.”<sup>6</sup>

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<sup>4</sup> “Virtually Painless,” Pain Less Exhibition, accessed 21 October 2016, <https://painlessexhibition.wordpress.com/start-here/virtually-painless/>.

<sup>5</sup> “Uncovering the personal experience of pain,” Pain Less Exhibition, accessed 21 October 2016, <https://painlessexhibition.wordpress.com/2012/11/19/uncovering-the-personal-experience-of-pain/>.

<sup>6</sup> “Uncovering the personal experience of pain,” <https://painlessexhibition.wordpress.com/2012/11/19/uncovering-the-personal-experience-of-pain/>.





Figure 3: This image is from the *Pain Less* blog and tells a one sentence introduction of each of the people in the exhibition and their story with pain. © The Board of Trustees of the Science Museum.

In order to make the exhibition relevant to other age groups, the Pain Less exhibition team not only worked with adults, but also with children. Children aged thirteen and fourteen collaborated on a game with game engineers from ‘Thought Den’ – a digital studio which creates educational experiences for a range of mediums. The game was included in the exhibition, titled ‘Ouch,’ where the player of the game has to protect the brain from pain, kill the pain with treatments and choose which treatments will kill the pain. It is still available on the Science Museum’s website.<sup>7</sup>

## 2. PAIN Exhibit: 2005 – Ongoing

*PAIN Exhibit* is an online, ongoing exhibition created by Mark Collen. The story goes that Mark was an outside sales person prior to hurting his back and that changed everything for him. His injury forced him to change his vocation from sales person to a patient advocate and an independent scholar, and Mark began to advocate for people

<sup>7</sup> “Ouch,” Science Museum, accessed 21 October 2016, [http://www.sciencemuseum.org.uk/online\\_science/games/ouch](http://www.sciencemuseum.org.uk/online_science/games/ouch).

with chronic pain. He now has a Bachelor's in Agronomy but is self-taught in Law and Medicine. He serves on the editorial board of the *Journal of Pain & Palliative Care Pharmacotherapy* and functions as the journal's cover editor. He also peer-reviews manuscripts for a number of other journals and has developed an intervention for people with chronic pain and illness.<sup>8</sup> He has also written a journal article which appears in the *Journal of Pain & Palliative Care Pharmacotherapy* in 2005 about his own experience with chronic pain and his realisation that "art was the most effective way to describe his pain experience to others and the resulting development of the pain visual arts exhibit PainExhibit.com."<sup>9</sup>

The start of *PAIN Exhibit* came in 1997 when, during a suicidal episode, Mark began to create a piece of art which reflected what he was experiencing. Within a day, he had completed the mixed media piece and he called it 'Chronic Pain.'<sup>10</sup> When Mark's friends and family saw the art piece, it was then that they finally understood what he had been experiencing with chronic pain. The artwork 'Chronic Pain' was the formative art piece which led to the foundation of *PAIN Exhibit*. Mark pondered whether others had also resorted to creating art to speak for their pain. He imagined an "educational, art exhibit with art from across the world whose focus was on communicating the pain experience."<sup>11</sup> The exhibition was set up under the California Assembly of Local Art Agencies (CALAA), which is a non-profit organisation that provides representation in San Francisco.

The mission for the exhibition *PAIN Exhibit* is "to educate healthcare providers and the public about chronic pain through art; and to give a voice to the many who suffer in abject silence." Essentially it is something that I see as being the mission for my proposed exhibition, but in my case, limiting it to New Zealand society. However, *PAIN Exhibit* actually focuses on artists with chronic pain, or people with chronic pain who already engage with art. The way Mark publicised the exhibition and his need for artworks was by designing a flier (see above) and requesting pain-related websites to

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<sup>8</sup> Email correspondence with Mark Collen, 20 September 2016.

<sup>9</sup> Mark Collen, "Life of Pain, Life of Pleasure: Pain from the Patient's Perspective – The Evolution of the PAIN Exhibit," *Journal of Pain & Palliative Care Pharmacotherapy* 19, no.4 (2005): 45.

<sup>10</sup> Mark Collen, (2005), 51.

<sup>11</sup> Mark Collen (2005), 52.

post it, as well as mailing the fliers all over the world to pain doctors, nurses, psychologists, and art therapists. Within six months he had received five-hundred art images on different media. Mark introduced *PAIN Exhibit* as an online, visual-arts exhibit instead of a touring exhibition due to funding constraints – of which there were three: It is cheaper to create a virtual art exhibition rather than tour a live show; there is generally a good portion of the world which has access to the internet and therefore can access the exhibition; and, it was easy to “distribute digital images of exhibit art for medical and health educators to use.”<sup>12</sup>



Figure 4: This image is the submission form and call for art flyer for Mark Collen's PAIN Exhibit.<sup>13</sup>

<sup>12</sup> Mark Collen (2005), 52.

<sup>13</sup> In email conversation with Mark Collen, 21 October 2016.



Figure 5: Some of the *Journal of Pain & Palliative Care Pharmacotherapy* covers.



Figure 6: The different galleries within *PAIN Exhibit*.

The exhibition was launched online in early March 2004, and during the first year of it being live online, the exhibition was visited by around 15,000 people from ninety different countries around the world. People are encouraged to use the art, whether they are medical doctors, educators, or people in pain, and there is no fee to access and download the artworks. From 2005 onwards, the *Journal of Pain & Palliative Care Pharmacotherapy* has had an artwork from *PAIN Exhibit* on its cover.



*Figure 7: An example of 3D sculpture submission to the PAIN Exhibit. This work is by Deborah Ann and is called 'Pain without words'. The artist's statement says: "I have peripheral neuropathy and find it impossible to describe having feet as dead and as heavy as rocks while so sensitive that touch causes sharp pain, so I created this piece as a way of showing people what this is like. It also helps me put the pain outside of my body so it doesn't consume my mind."*<sup>14</sup> The work is made with paper machè, clay, cardboard, glass, wire and spray paint. PAIN Exhibit, Inc. © 2017. All Rights Reserved. [www.PainExhibit.org](http://www.PainExhibit.org)

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<sup>14</sup> Deborah Ann, "Pain without words," accessed 8 October 2016, <http://painexhibit.org/en/galleries/pain-visualized/>.





*Figure 8: An example of a digital art submission to the PAIN Exhibit. This work is by Katherine Stock and is called 'Self Portrait'. The artist's statement says: "The person in the picture is me. I tried to portray the feeling of chronic pain, how I feel like my body is being eaten by acid and disintegrating. The mask is the happy face I have to put on for the world. The darkness is where I am mentally. The bright lights are painful to me, but must be endured for the sake of my public image."*<sup>15</sup> The work is digital art with photo manipulation. PAIN Exhibit, Inc. © 2017. All Rights Reserved. [www.PainExhibit.org](http://www.PainExhibit.org)

### 3. The Art of Pain: 20-30 July 2015

*The Art of Pain* was a collaboration exhibited by the Australian Network for Art and Technology (ANAT), Pain Network (Adelaide), and the Bob Hawke Prime Ministerial Centre at the University of South Australia for ten days in July 2015. It coincided with Australia's National Pain Week, with its' focus being on discussing contemporary pain research and its implications.<sup>16</sup>

Supporting the exhibition were three public programmes including a keynote address focusing on low-back pain and whiplash by Professor Michele Sterling in conversation with Professor Lorimer Moseley; an exhibition performance called 'Somatic Drifts' by

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<sup>15</sup> Katherine Stock, "Self Portrait," accessed 9 December 2016, <http://painexhibit.org/en/galleries/portraits-of-pain/>.

<sup>16</sup> "The Art of Pain," Australian Network for Art and Technology, accessed 21 October 2016, <http://www.anat.org.au/the-art-of-pain/>.

Cat Jones and Melissa Hunt; two panel discussions on ‘morphine and mindfulness – same room, different windows?’ with Professor Mark Hutchinson, Dr Tim Semple and Georgie Davidson, and ‘Playing tricks with the mind – Illusion and its affect’ with Valeria Bellan, Cat Jones and Eugenie Lee.

For Eugenie Lee, chronic pain has been a personal experience. Through her experience, she decided to turn her pain into an art form. The pain was extremely consuming and Eugenie could not think of doing anything else. Art, for her, was a natural progression. She represents herself in most of her artworks – lonely, frightening and confined – no one understood what she was going through, and she could not find the words to describe it. In Eugenie’s early twenties she was diagnosed with Endometriosis, and the diagnosis gave her a sense of control.

The artwork she selected for *The Art of Pain* exhibition is a piece Eugenie made in 2012 which combines an objective clinical method with the subjective experience of pain. Two white filing cabinets with multiple drawers face each other, depicting the order that the medical community tries to fit the pain experience into. Within the filing cabinet is a roll of rotating barbed wire which is the visual manifestation of Eugenie’s pain. Metaphors used in the McGill Pain Questionnaire are throughout the artwork. The questionnaire, a measuring tool for a patients’ clinical pain assessment and used by pain clinics throughout the world.<sup>17</sup> Eugenie is the only one involved with this exhibition and the public programmes who has an experience with chronic pain, or was open about having that experience. However, since having a hysterectomy in 2014, she believes she has started to forget the experiences she went through, now that she is not in chronic pain. She feels her art will change in the future because of this. Professor Lorimer Moseley says that it is a profound experience to learn anything new about the lived experience of pain. Scientists want to better understand the twenty percent of humans who have some sort of disabling pain, and Eugenie Lee’s artwork did that.<sup>18</sup>

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<sup>17</sup> Eugenie Lee, “McGill Pain Questionnaire 2012,” page 16, accessed 25 October 2016, <http://eugenielee.com/wp-content/uploads/sites/27/2013/09/McGill-Pain-Questionnaire.pdf>.

<sup>18</sup> ABC Radio National, “The Art of Pain: rendering the invisible visible,” accessed 25 October 2016, [http://mpegmedia.abc.net.au/rn/podcast/2015/07/lms\\_20150721\\_0920.mp3](http://mpegmedia.abc.net.au/rn/podcast/2015/07/lms_20150721_0920.mp3).



Figure 9: This is Eugenie Lee's artwork from the *The Art of Pain* exhibition called 'McGill Pain Questionnaire' (detail) 2012. Image provided by the Australian Network for Art & Technology.



Figure 10: This is the other artwork in *The Art of Pain* exhibition, called 'Somatic Drifts'. It is by Cat Jones (design and performance), and Melissa Hunt (sound design). This installation was "a sensory, one-to-one artwork [...] and accumulative audio-visual installation" where participants were able to explore body fluidity through touch and illusions. Image provided by the Australian Network for Art & Technology.<sup>19</sup>

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<sup>19</sup> Australian Network for Art and Technology, "The Art of Pain – Somatic Drifts," accessed 9 December 2016, <http://www.anat.org.au/the-art-of-pain-somatic-drifts/>.



### **Analysis of Case Studies:**

There are some evident differences between these three exhibitions, and a clear gap which I wish to address. *Pain Less* took the focus group approach. They had a group of people with chronic pain, a group of pain specialists, and a group of children to help with the project. *PAIN Exhibit* opened its arms to everyone. Anyone could participate if they wanted to by sending in their artwork. *The Art of Pain* used people they already knew, their two artists in the exhibition had been fellows with ANAT previously, and one of the professors who spoke, lectures at the University of South Australia.<sup>20</sup> The gap I have just mentioned is that there has not been an exhibition in a physical space where a community of chronic pain survivors have taken the helm and directed the storyline. Mark Collen's *PAIN Exhibit* comes close, but it is run by one man and is a virtual exhibition. This exhibition would be a community effort driven by those with chronic pain, with the medical community being brought in as a supporting resource for some of the public programmes. This is the opposite of the *Pain Less* exhibition. Here the exhibition team brought in focus groups of people in chronic pain and focus groups of medical scientists and compared the experiences to the science. There will be no comparisons made between pain experience and the science on pain in my proposed exhibition. The *Pain Less* exhibition was relatively conventional for a large museum whereas *PAIN Exhibit* was a personal initiative, and *The Art of Pain* more of a series of public programmes. The idea by Mark Collen and his *PAIN Exhibit* is key to my concept, and can be seen in depth in chapter three.

Within *The Art of Pain* exhibition there was an interlocking loop of science and art illuminating and instructing each other. This is quite an important rationale for my research but will be used slightly differently. In ANAT's exhibition, the medical professionals had a clear upper hand in the programming, in my research the medical professionals will be involved, but on a small scale, with the main focus being on the different experiences of New Zealanders with chronic pain.

Pain is subjective, and each person will get the opportunity to tell their story through their chosen medium. For those who cannot contribute a piece of art for whatever reason, there will be ways they can be involved. For instance, they can be part of the

community art exhibit of pairs of shoes to account for those who are too physically unwell to participate, or they can be involved in the online offer of the exhibition.<sup>21</sup>

These three exhibitions have given an overview of what is currently being offered to the public in the museum sector on the topic of pain. Their differences have shown gaps, which in the next chapter the exhibition proposal intends to address. The fact that there have been only a few exhibitions pertaining to pain around the world suggests that there needs to be more recognition and drive behind it so that it can become an acceptable topic of conversation. This way, fewer people will suffer in silence but instead have the opportunity to thrive in their community and society. The next chapter will cover the results collected from the online surveys.

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<sup>21</sup> Bristol Post, “100 pairs of shoes used to make poignant protest on ME research in Bristol city centre,” accessed 11 November 2016, <http://www.bristolpost.co.uk/100-pairs-of-shoes-make-silent-protest-on-me-research-in-bristol-city-centre/story-29755005-detail/story.html>

## Chapter 2 – Survey Results

Chronic pain [...] is long-term pain in one or more areas of the body. The pain itself is the problem – rather than being a symptom or indicator of something else that can be healed.

~Survey Respondent <sup>1</sup>

The last chapter discussed a comparison between three exhibitions which all related to pain in some way. It showed how people had chosen to present and lay out their exhibitions. Where *PAIN Exhibit* was set up as an educational resource, *The Art of Pain* was quite purely an artistic academic exercise, and *Pain Less* about enticing all ages to consider the different types, causes and cures of pain.

The outline for this chapter is as follows: firstly, quantitative answers to the chronic pain survey will be laid out with graphs and the ways that this data helps support the need for an exhibition will be discussed, key themes from the qualitative answers will be examined, and what makes up the outlying data will be deliberated; secondly, the same will be done with the control group survey results; thirdly, there will be a short description of the concept development of the exhibition proposal; and lastly, an analysis of the findings from the survey data collected will be recapitulated.

I decided to survey other New Zealanders with chronic pain to gain a stronger argument and to confirm my suspicions around the understanding of chronic pain in New Zealand. I soon realised after collecting the data from this survey that I also needed to question a control group of healthy New Zealanders to get a fuller picture of how a public exhibition would help the awareness of chronic pain. The surveys were set up with both simple binary (yes/no), and open-ended answer type questions. I received one-hundred responses from the chronic pain community within four days, and the same number from the control group within six days.

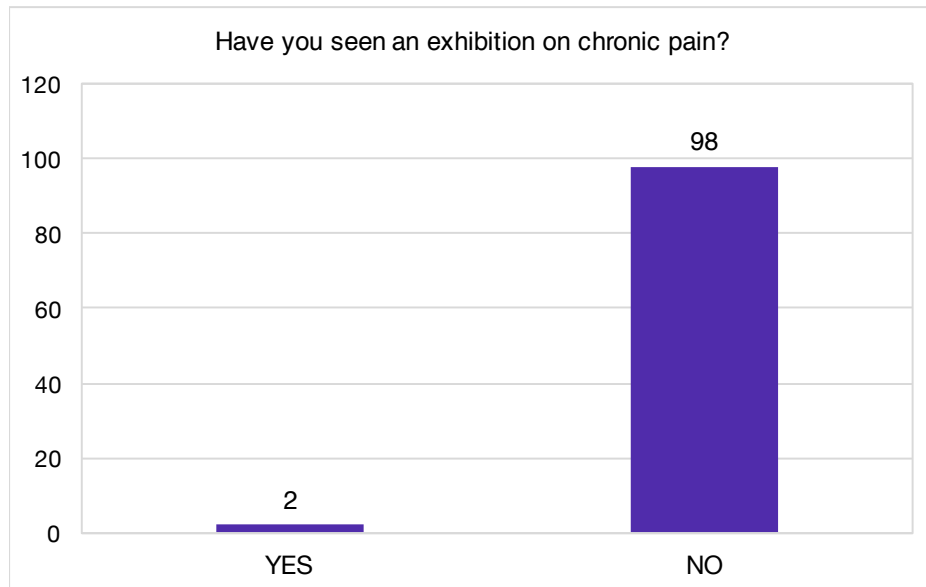
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<sup>1</sup> Survey Respondent, Chronic Pain Example, Control Group Survey.

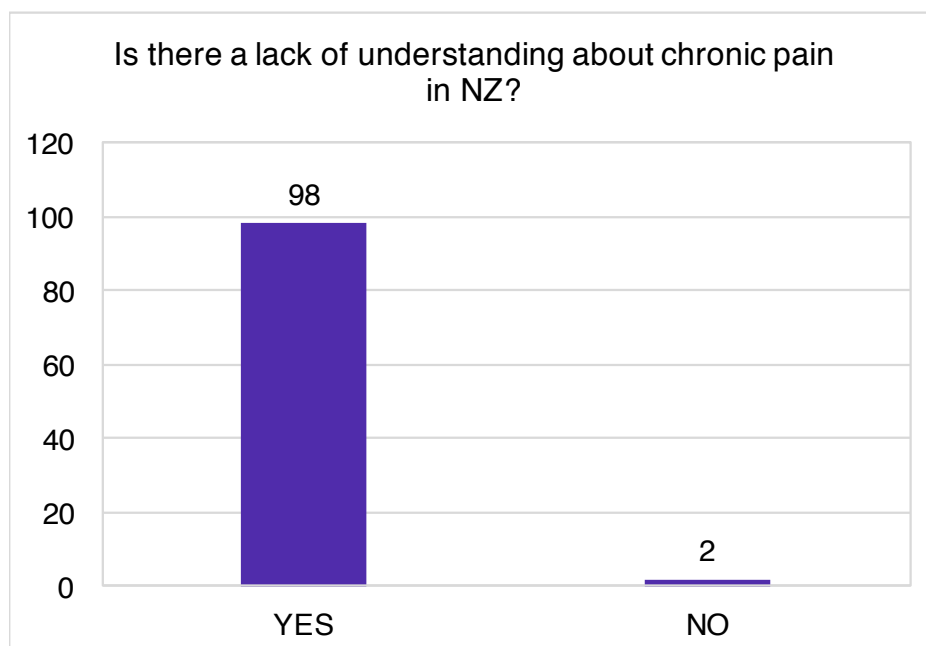
### The Chronic Pain Community:

Quantitative answers:

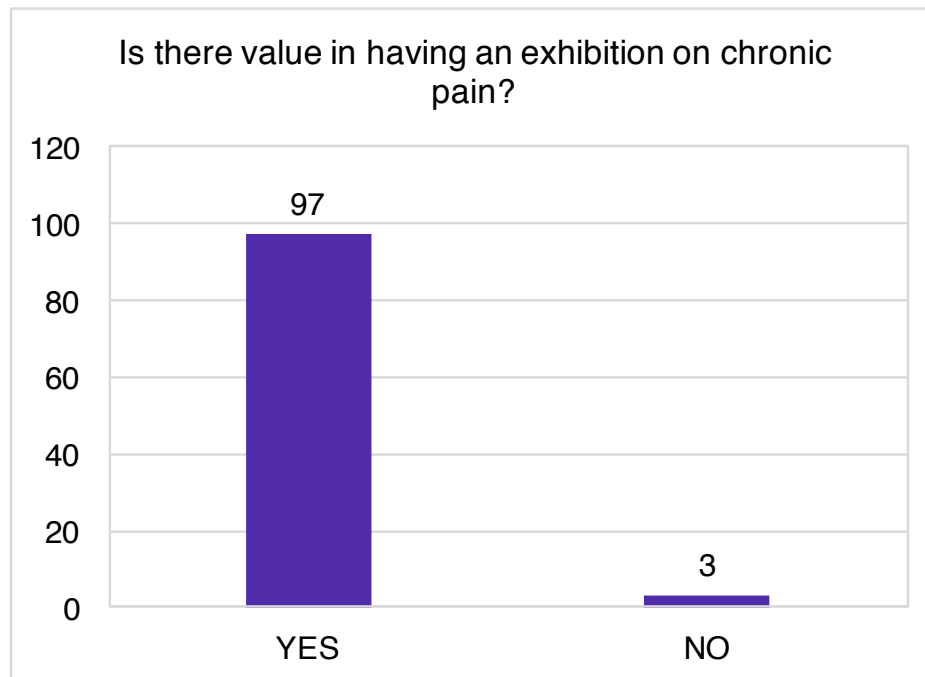
98 out of 100 people said they had never been to or seen an exhibition on chronic pain. Of the two that had seen one, one was in Manchester, United Kingdom and one was in Auckland, New Zealand. (*Figure 11*).



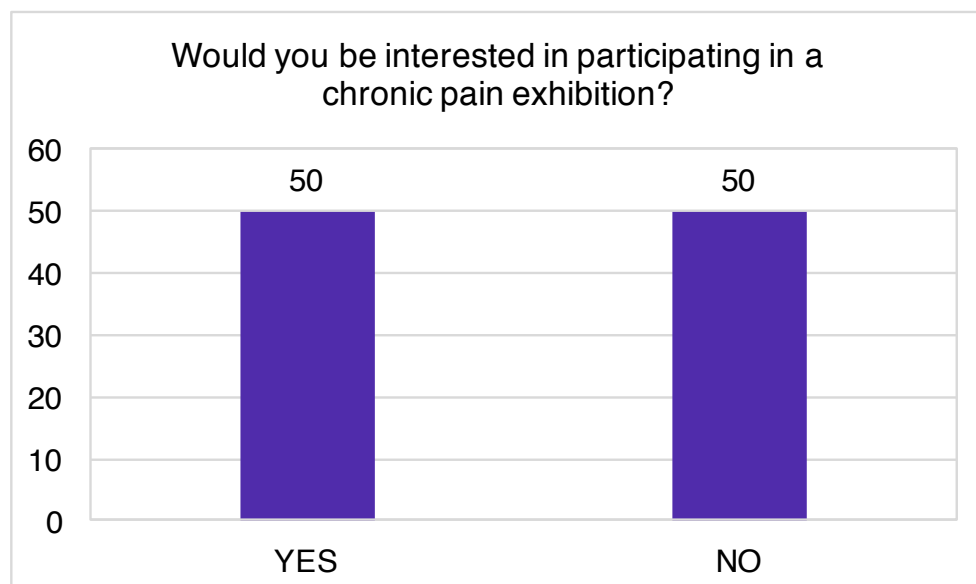
98 out of 100 people said they thought there was a lack of understanding and/or conversations about chronic pain in New Zealand. (*Figure 12*).



97 out of 100 people said that there is value in having an exhibition produced by people with chronic pain, depicting their daily lives with chronic pain. (*Figure 13*).



50 out of 100 people said that they would be interested in participating, by submitting an artistic creation of their own making – showing their personal experience with chronic pain – which may lead to an exhibition on chronic pain in a New Zealand gallery. (*Figure 14*).



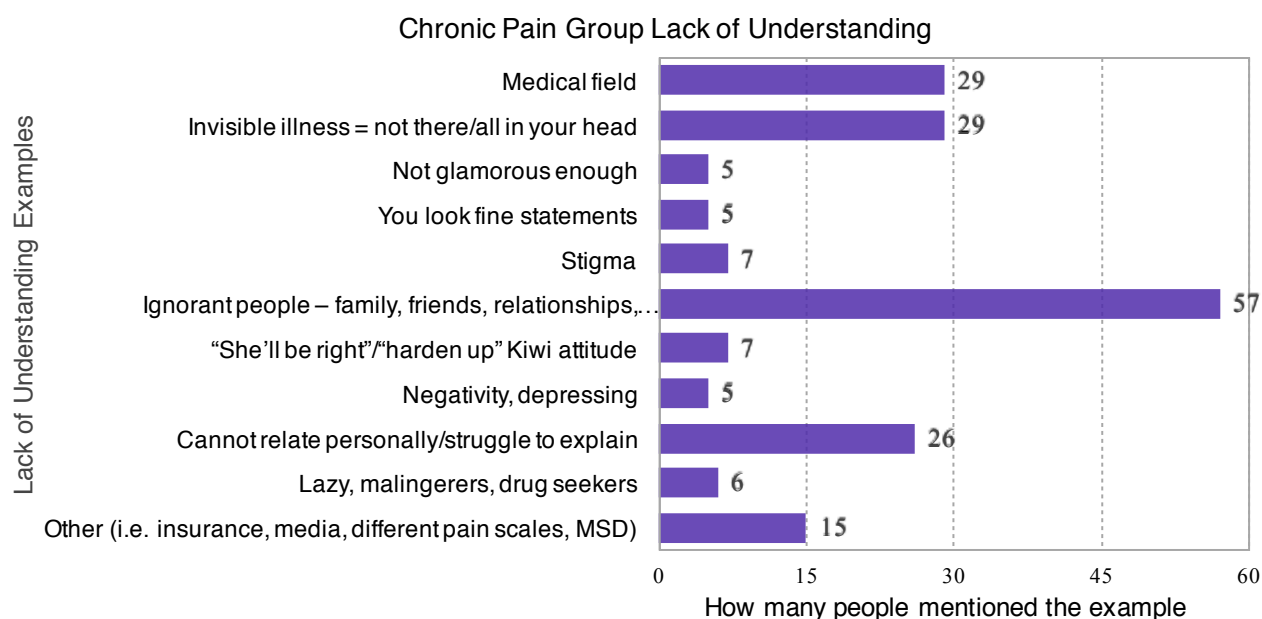
Outliers:

There were no outliers for the fourth qualitative question as there was a 50/50 split. One possible explanation for this result is as half the population with chronic pain being too

unwell to participate, whereas some people did not believe they had an artistic bone in their body so although they said no, they may in future be part of the exhibition but in a different way.

Qualitative answers:

Lack of Understanding: (Figure 15)

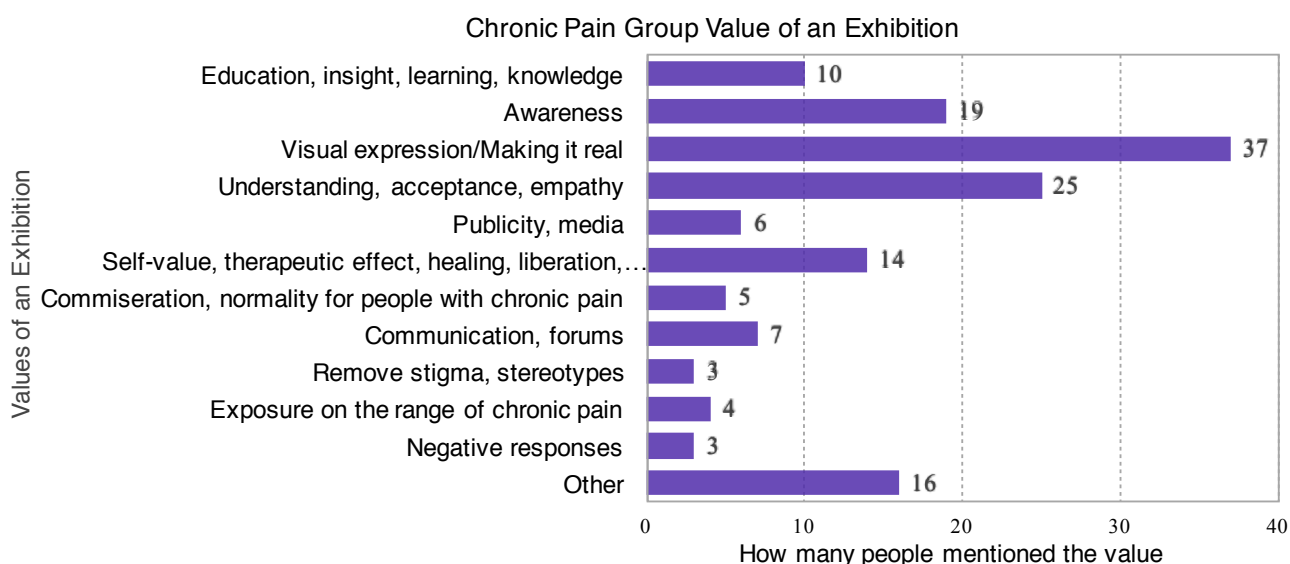


- 57 out of 100 people mentioned ignorant people as a source of lack of understanding, these included family, friends, significant others, employers, and coworkers.
- 29 out of 100 people mentioned that the lack of understanding came from the medical field.
- 29 out of 100 people said the due to chronic pain often being an invisible illness, people did not believe the pain was actually there or that it was all in their heads (i.e. mental illness).
- 26 out of 100 people said that due to others not being able to relate personally to the chronic pain experience and people with chronic pain having difficulty explaining it, this led to lack of understanding.

Outliers – Lack of Understanding:

15 out of 100 people mentioned a reason that was not repeated by any other participant and these are grouped under ‘other’.

Qualitative answers – Value of an Exhibition: (*Figure 16*)

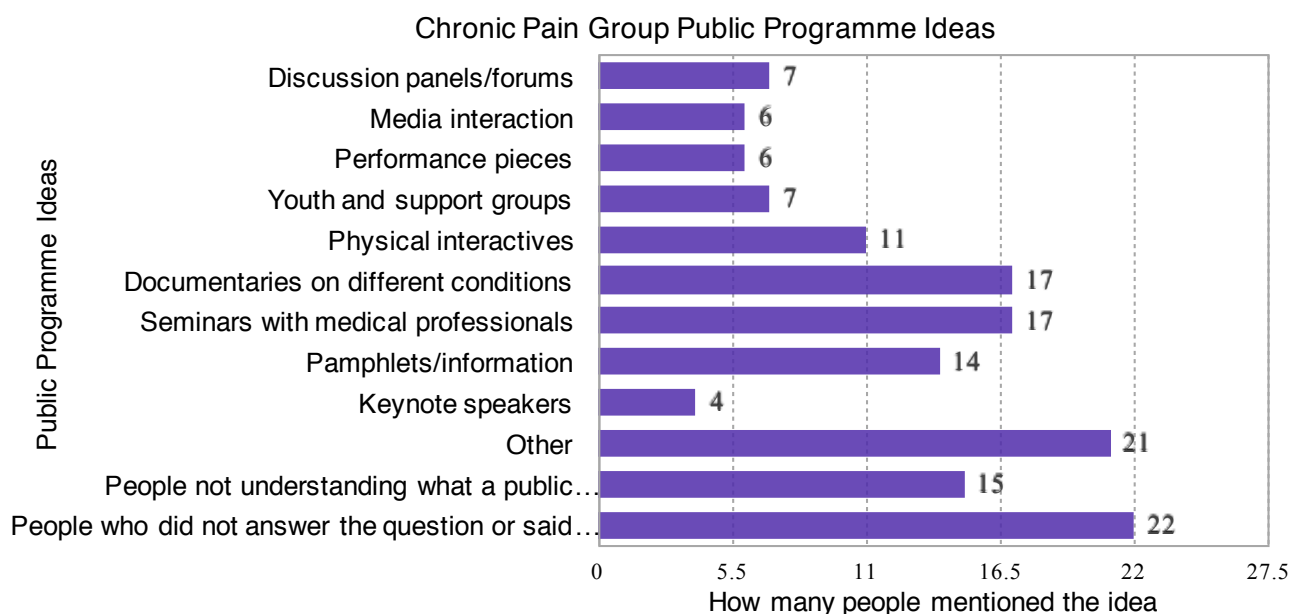


- 37 out of 100 people mentioned that the value of having an exhibition would be its visual nature and the fact it would help to make chronic pain more real.
- 25 out of 100 people believe that understanding, acceptance and empathy are likely to come out of having an exhibition on chronic pain.
- 19 out of 100 people believe that awareness would go along with having a public exhibition on chronic pain.
- 14 out of 100 people believe that there will be a self-value, therapeutic, healing, liberating effect for those who participate in the exhibition and those who create artworks will receive recognition.
- 10 out of 100 people believe that education, insight, learning and knowledge will come out of having an exhibition on chronic pain.

### Outliers – Value of an Exhibition:

- Ideas under ‘other’ had only one participant mentioning them, which is why they are grouped together.
- 3 out of 100 people gave me negative responses to the value of an exhibition.

### Qualitative answers – Public Programme Ideas: (Figure 17)



- 17 out of 100 people requested documentaries of people with different conditions be made and be played in the exhibition.
- 17 out of 100 people requested seminars with medical professionals who understand chronic pain.
- 14 out of 100 people requested take-away pamphlets and information sheets on different chronic pain conditions to be available at the exhibition.
- 11 out of 100 people requested there be physical interactives as part of the exhibition (e.g. weighted suits).

### Outliers – Public Programme Ideas

- 21 out of 100 people mentioned ideas which no one else mentioned.
- 22 people did not answer the question or replied with ‘not sure’.

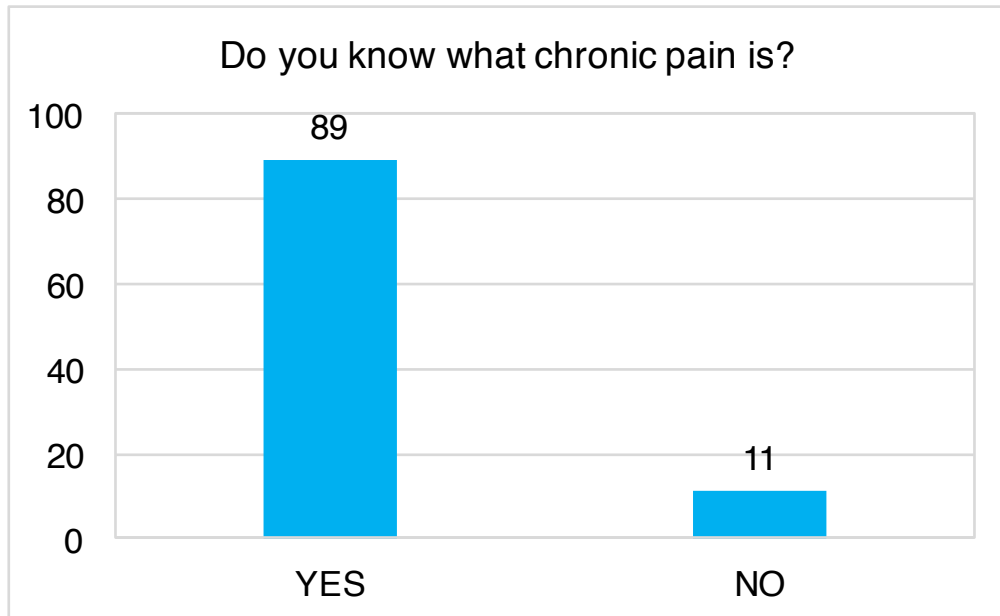


- 15 people replied but appeared unsure about what a public programme actually is.

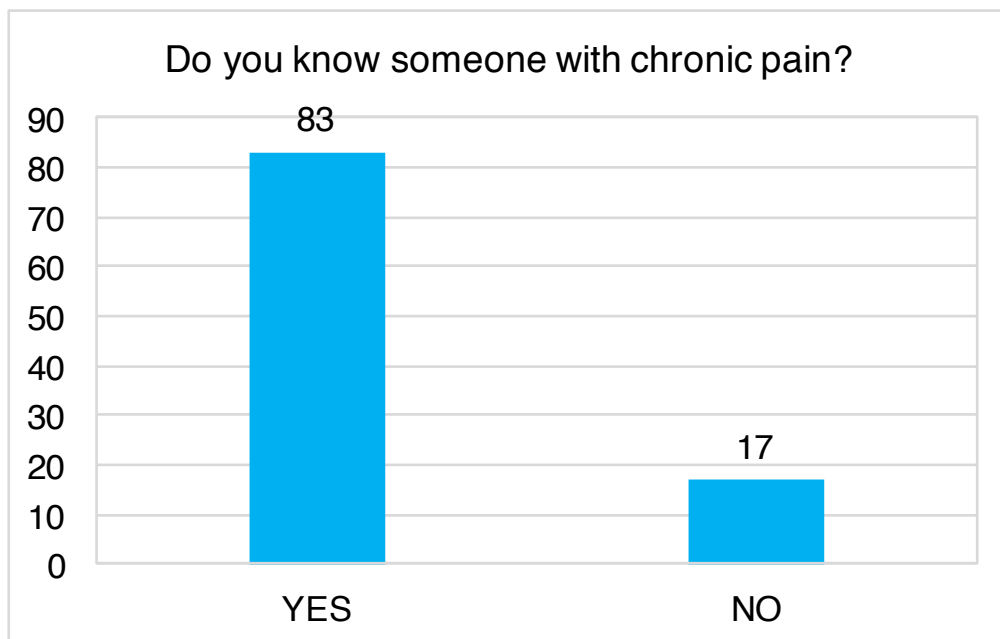
### The Control Group

Quantitative answers:

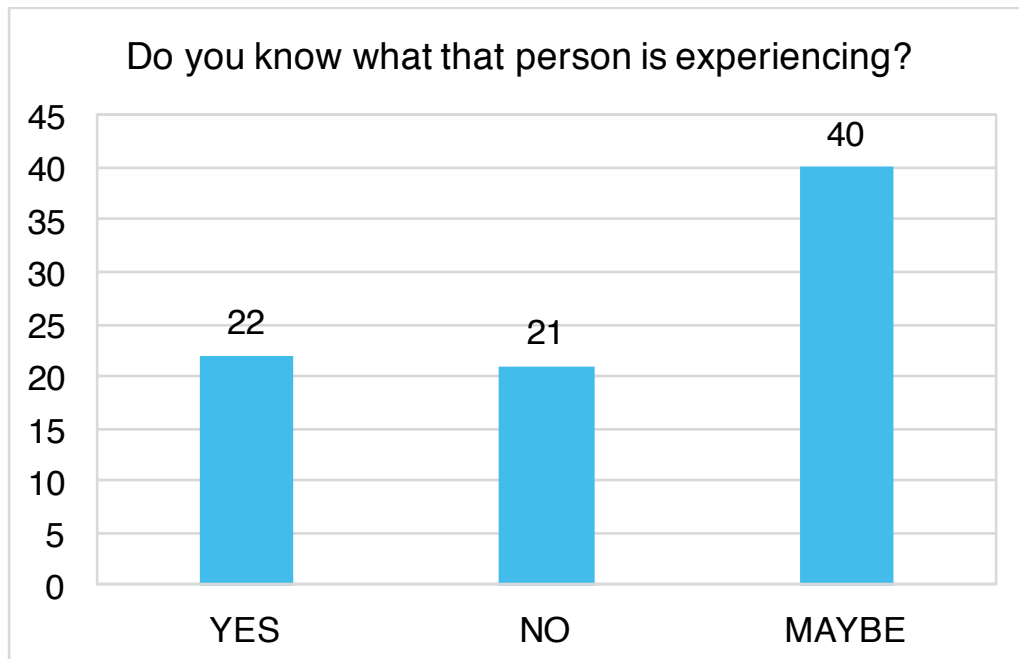
89 out of 100 people said they knew what chronic pain was. (*Figure 18*)



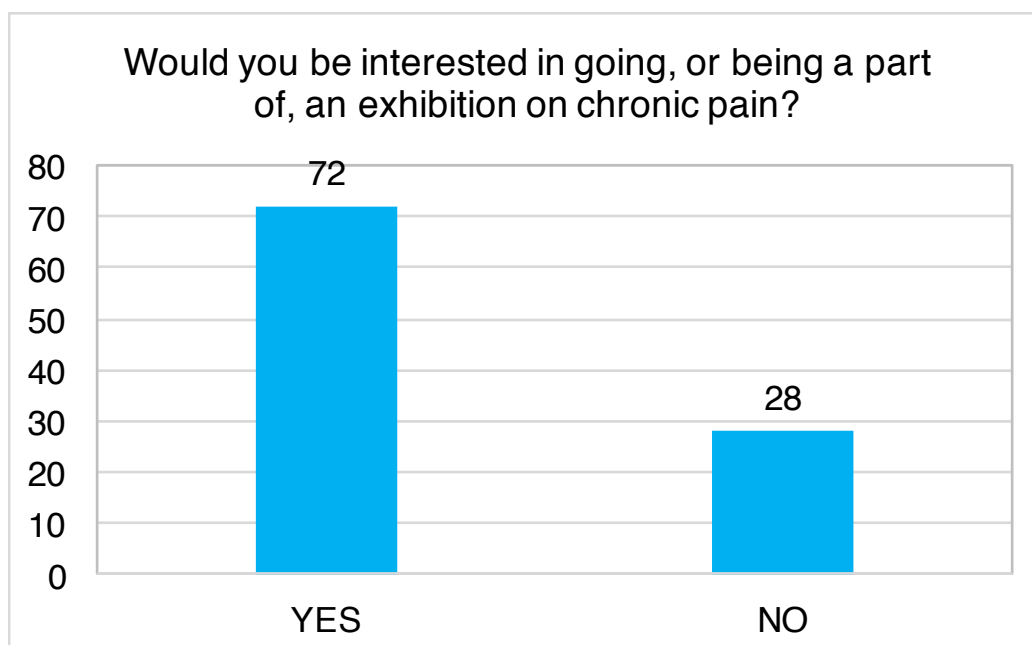
83 out of 100 people said they knew someone with chronic pain. (*Figure 19*)



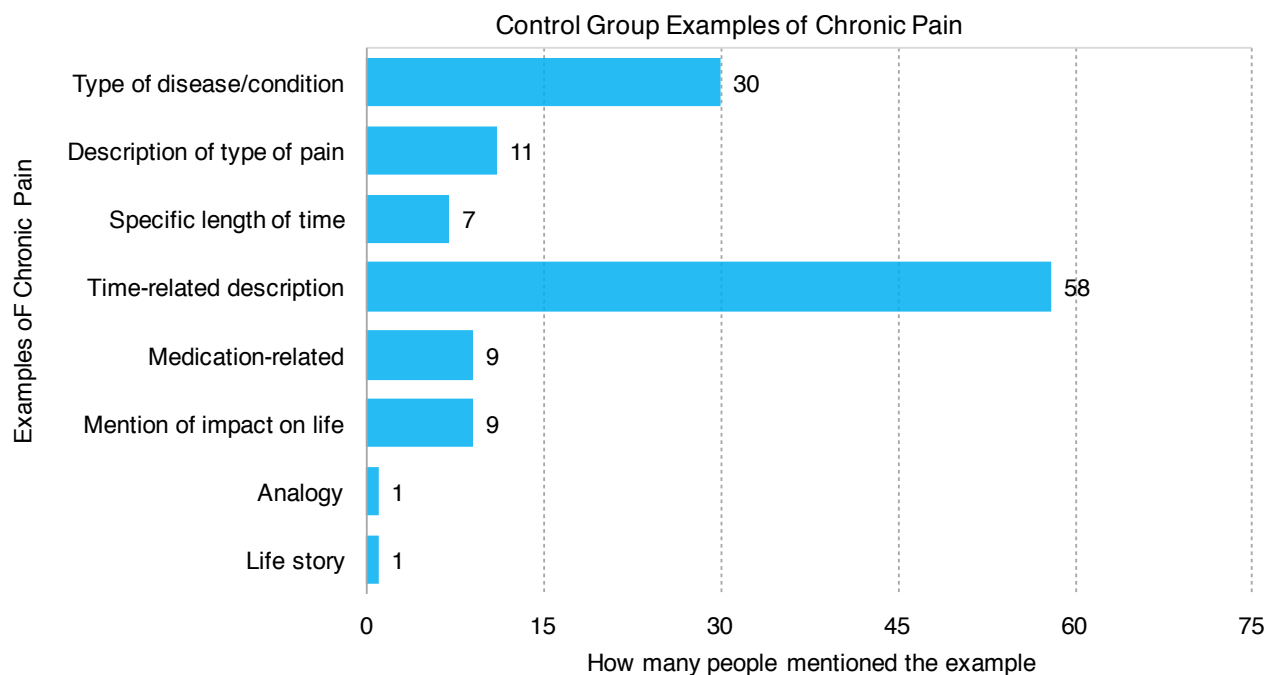
40 out of 83 people said they might know what that person is experiencing with their chronic pain. (Figure 20)



72 out of 100 people said they would be interested in going to, or being a part of, an exhibition on chronic pain. (Figure 21)



### Qualitative answers – Chronic Pain Examples: (Figure 22)



- 58 out of 89 people described pain with a time-related description (e.g. ongoing, permanent, continuous).
- 30 out of 89 people described pain as being a type of disease or condition and listed different types.
- 11 out of 89 people described the type of pain chronic pain can be (e.g. stabbing, aching).

### Analysis of Survey Results

Interestingly, the most common comment about chronic pain by the control group was that chronic pain is an ongoing, permanent or continuous condition. However, it also happens to be one of the main complaints from the chronic pain group, that healthy people do not seem to understand that the word ‘chronic’ means ongoing. However, it is possible that the people surveyed in the control group are biased towards knowing about chronic pain, and therefore are not an exact sample of New Zealand society. As well as this, people may theoretically understand that chronic pain is ‘ongoing’ but when put into practice and talking to someone with chronic pain, they may still have trouble understanding the limitations of it.

There were some very eloquent answers to some of the qualitative questions asked, while others were straight to the point. The question ‘Can you give some examples of what chronic pain is?’ Fifty-eight people mentioned that there had to be some sort of persistent pain going on to be chronic. The most articulate answer was this one:

Chronic pain is a constant barrage of hurt over one's body. On better days all the pain is dull, like when the orchestra music is playing softly in the background of a movie you are watching. Sometimes the pain is very loud, like when the orchestra plays for those highly emotional, climatic [sic] parts of the movie and at other times, one or two instruments play louder than the rest it seems like it might be a solo part but the orchestra is all there still, they never go away.<sup>2</sup>

This explanation is a very good one as it not only uses descriptive words, but also effectively utilises an extended metaphor.

In response to whether there is a lack of conversations in, or understanding of, chronic pain in New Zealand, ninety-eight out of one-hundred people in the chronic pain group said there was. Within these, there were some responses that should not only be reduced to a bar graph but also be quoted. One respondent commented that:

It seems to be yet another subject like mental health. Where, if people can't see the physical effects of an illness, then it's all in your head. We are made to feel like we are just lazy and can't be bothered doing anything, even if we look like we are in pain. [...] There's a stigma that goes with invisible illnesses.<sup>3</sup>

Another respondent said: “People are very quick to judge because of little understanding. In majority of cases, chronic pain can not been seen by others and unless experienced personally, people do not have an understanding of what someone with chronic pain goes through.”<sup>4</sup> Following on from the invisibility of chronic pain, one respondent commented: “It is often invisible and people can[not] relate to what they can't see. Also being chronic, it goes on and on, and it gets boring for people. There is no 'novelty' value to onlookers. And sympathy runs out quickly.”<sup>5</sup>

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<sup>2</sup> Survey Respondent, Chronic Pain Example, Control Group Survey.

<sup>3</sup> Survey Respondent, Lack of Understanding Explanation, Chronic Pain Group Survey. The following footnotes are from the same survey question.

<sup>4</sup> Survey Respondent.

<sup>5</sup> Survey Respondent

In reply to whether there is any value in having an exhibition on chronic pain, one chronic pain respondent compared this proposal of an exhibition to the ‘It’s not ok’ campaign, commenting that it is trying to encourage people to communicate before things go wrong.<sup>6</sup> Another respondent mentioned, as has been shown through the case studies earlier in this chapter, that this has been done overseas and the respondent has “been an interested viewer from afar [...] but being able to see it in person would be a more visceral experience for the individual. Furthermore, with appropriate publicity, such an exhibition could encourage everyone to talk about chronic pain and their own experience with it.”<sup>7</sup>

Responding to what sorts of activities or public programmes people would like to accompany an exhibition such as this, the main suggestions included documentaries, seminars, pamphlets, and physical interactives. An example of a physical interactive can be seen with this response: “Something that [...] shows what its like trying to move when in pain. The public could interact with something and say push it hard, but it only moves a little, and slowly. To show the effort expended to do every day simple things.”<sup>8</sup>

### Proposal Concept Development

The original development of the research derived from my wish to give back to a community that has given me support in the past. I researched ways of bringing awareness to chronic pain whilst at the same time connecting the topic to museum studies. Next I bought a book about producing museum exhibitions called *Creating Exhibitions: Collaboration in the Planning, Development, and Design of Innovative Experiences* by Polly McKenna-Cress and Janet A. Kamien.<sup>9</sup> This book contained a lot of helpful ideas, diagrams and thoughts which culminated in my proposal being under way. From here I consulted Rebecca Rice (Curator Historical New Zealand Art), and one of my advisors, in how Te Papa Tongarewa conducts their exhibition proposals.

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<sup>6</sup> Survey Respondent, Value of an Exhibition Explanation, Chronic Pain Group Survey. The following footnotes are from the same survey question.

<sup>7</sup> Survey Respondent.

<sup>8</sup> Survey Respondent, Public Programme Examples, Chronic Pain Group Survey.

<sup>9</sup> Polly McKenna-Cress and Janet A. Kamien, *Creating Exhibitions: Collaboration in the Planning, Development, and Design of Innovative Experiences* (New Jersey: John Wiley & Sons, Inc, 2013).

This directed me to what could be included and discussed in a proposal. I also looked at galleries' 'call for art' and researched what they looked for in their proposal submissions. The culmination of these things led to the proposal which can be found in chapter three.

### **Summary**

The results above, although biased, show that there is significant support for an exhibition depicting the daily lives of those with chronic pain in New Zealand. This was concluded by asking two-hundred participants their understanding on chronic pain, and whether they see value in having an exhibition to visually illuminate the daily issues that come with living in chronic pain. Fifty out of one-hundred people surveyed in the chronic pain community said they would participate by creating an artwork depicting their daily lives. And seventy-two out of one-hundred people surveyed in the control group said they would be interested in going, or being a part of an exhibition about chronic pain.

The surveys conducted show a small snapshot of the chronic pain community and the non-chronic pain community in New Zealand, their experiences, their thoughts and their values. The next chapter will be a proposal for a potential future exhibition depicting the daily lives of those who live with chronic pain in New Zealand.

## Chapter 3 - Exhibition Proposal

By manipulating our threshold of pain and enacting it out as a groan, a song, a painting or other model that is then witnessed by another person, we may reestablish identity within our bodies. Pain results in an identity crisis, while the enactment of pain redefines existence.

~Dana Milstein.<sup>1</sup>

### Project Aims:

This final chapter blends the responses from the surveys discussed in chapter two, and the theory examined in chapter one. It attends to the main method of this research, the exhibition proposal, and gives an example for what has been shown to be an idea supported by both the chronic pain and non-chronic pain communities surveyed. This proposal lends itself to a collection of possibilities, none of which are set in stone, but which rather give multiple potential options to be included in such an exhibition if one were to go ahead. It offers a refreshingly different way of addressing the exhibitory gap that has been identified in the last chapter. This exhibition would be driven by the chronic pain community, with the medical community used as a resource for workshops and forums. Art media submissions would be sent in from the chronic pain community and would make up a large portion of the exhibition. These people do not need to be artists to submit an artwork.

### Executive Summary:

1. The proposed exhibition is titled *The Art of Chronic Pain: Stories of our daily lives*.
2. It is an exhibition which tells first-hand stories and depicts the daily lives of New Zealanders with chronic pain through a variety of media submitted by survivors.
3. This would be the first major exhibition on this topic in New Zealand.
4. It will include a programme of public events as well as a web-based/social media component.
5. The exhibition aims to explore the daily experiences of a large invisible community and draw attention to the current issues and research surrounding chronic pain.

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<sup>1</sup> Dana Milstein, "Pain is a Preposition," in *Witness to Pain: Essays on the Translation of Pain into Art* edited by Pascual Nieves (Bern, Switzerland: Peter Lang AG, 2005), 79.

6. The exhibition offers an opportunity for a community-run space to open its arms to another community in need and to build a network of support and understanding.

### **Proposal Objectives:**

The specific objectives of this proposal include:

1. To bring together New Zealanders with chronic pain through a range of art media.
2. To visualise an often invisible condition, using art media depicting the daily lives of New Zealanders with chronic pain to bring their experiences to light and promote awareness and understanding from the general public.
3. To consider someone else's life and walk in their shoes.
4. To learn something new and explore how to be accepting and supportive of others.
5. To utilise a gallery-based exhibition, public programmes and web-based social media interaction to engage a wide range of people.
6. To explore how pain can affect every part of someone's life.

### **Short Summary of Exhibition:**

'The Art of Pain' is about experiencing someone else's life through a range of media. It is about opportunities for stepping into someone else's shoes for a small amount of time in order to learn about other peoples' difficulties with daily life. It is to educate those who are yet to understand, to open eyes, minds and hearts.

### **Detailed Summary of Exhibition:**

One in five people have some level of chronic pain, and it has been described as being the largest public health issue we currently have.<sup>2</sup> This exhibition would showcase the daily lives of New Zealanders with chronic pain through a variety of media, as well as offering workshops with specialists and forums on different topics relating to chronic pain and the management of it, documentaries and takeaway pamphlets on a range of conditions. It would interlock itself with the international chronic pain awareness month

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<sup>2</sup> Nagel, 2016, 9.



of September to raise its awareness and would continue to remain open as long as funding permits.

### **Proposed Gallery Space:**

The space would need to have disability access, and be in an easy-to-navigate area, with all facilities being on one floor or otherwise easily accessible. The area would need to accommodate multi-media artworks as well as a place to hold public programmes. Some potential places include the Thistle Hall Community Venue on Cuba Street. This venue would be fitting due to its open gallery/exhibition space, a meeting room, toilets, and lifts to the second level which includes a kitchen and hall space both of which would be good for public programmes and activities. The venue itself is an independent arts and cultural community venue, and is funded and partially owned by the Wellington City Council.<sup>3</sup>

Alternatively, the Expressions Whirinaki Arts and Entertainment Centre, a charitable trust which seeks to “engage, enrich, inspire and connect people with art, culture, recreation and heritage.”<sup>4</sup> They have multiple venues for hire, of which the Rotary Foyer and the Gillies Group Theatre are good matches for accessibility, layout and size, along with their exhibition space.

The ROAR! Gallery is a not-for-profit exhibition space on Vivian Street in Wellington, and is connected to Pablos Art Studios. Their ethos for taking on exhibitions is that the art has to tell a story. Your story, either about your life, experience, vision, perspective, and/or spiritual/cultural inspirations.<sup>5</sup> They would take all types of art, such as paintings, 3D works, multi-media, and sculptures which would fit in with the call for art media for this project.

The Toi Pōneke Arts Centre and Gallery’s vision is to strengthen arts within Wellington by supplying a setting that “supports innovation and encourages artists to work together

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<sup>3</sup> Thistle Hall Community Venue, “About Thistle Hall,” accessed 19 November 2016, <http://www.thistlehall.org.nz/about-thistle-hall>.

<sup>4</sup> Expressions Whirinaki Arts and Entertainment Centre, “About Expressions,” accessed 19 November 2016, <http://www.expressions.org.nz/about-expressions/>.

<sup>5</sup> ROAR! Gallery, “Exhibit at ROAR! Gallery,” accessed 19 November 2016, <https://roargallery.org.nz/pages/exhibiti-at-roar-gallery>.

and connect people to the creative community.”<sup>6</sup> They are a wheelchair accessible building as well as having a hub which can be used as a casual meeting place, or for public programmes. At this stage only spaces in Wellington areas have been considered as this is where I am currently residing.

### **Function and Purpose of the Gallery:**

Collection items would be created specifically for this exhibition by New Zealanders living with chronic pain. Displays would be short-term and interchangeable. For example, artworks would be changed out for other artworks depending on the size of the exhibition, how many artworks are collected, and how long the exhibition is open for. Those who submit artwork to the exhibition would be given an option to have their piece available for sale or not. General visitors, who may not necessarily be motivated by a research need, would have the opportunity to experience something new, engage with collection items and learn about something that affects twenty percent of the New Zealand population.

### **Qualities of the Gallery Experience:**

The exhibition would be educationally interesting and would draw attention to targeted audiences. It would be reflective of the diversity of art media as well as the people with chronic pain and their range of symptoms. The exhibition would be mindful of opportunities and possible synergies with national and international events, such as Chronic Pain Awareness Month, which is in September every year. There would also be possibilities for nurturing new relationships with a previously unrepresented community of people in New Zealand.

### **Key Material on which this proposal is based:**

This proposal is based on future submissions to the exhibition. Participants would be asked to produce a piece of work (in any medium) depicting chronic pain and how it

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<sup>6</sup> Toi Pōneke Arts Centre, “About Toi Pōneke,” accessed 19 November 2016, <http://wellington.govt.nz/services/community-and-culture/arts/toi-poneke-arts-centre/about-toi-poneke>.

affects their lives, describing in a short sentence a little bit about their artwork. Those who are in too much pain to draw, paint or write may do something intangible such as a recording of sounds, phrases or words, or could get someone else to produce a suitable piece of artwork for them. There would also be a documentary playing with short stories of people's lives - people wanting to be involved with this would send in a one to two minute clip of themselves describing what it is like to be them and to have their condition(s). The assortment of clips gathered would be cut into a looped file, and played continuously within the exhibition. Having real art media that are connected to real stories can have a genuine influence on visitors and can endow a lasting impression.<sup>7</sup>

### **Key Ideas and Concepts to Convey in this Exhibition:**

The main idea to convey is awareness about chronic pain in New Zealand in a visual way. Chronic pain is often an invisible illness, meaning that the chronic pain community often look well to other people. The exhibition would offer the chance for other people to understand how coming to harsh conclusions about the way we live our lives is not the best way to communicate with the chronic pain community, for example, disabled carpark use, which has recently been in the media. Although many people with chronic pain look able-bodied, looks can be deceiving. Passive aggressive notes left on window shields and angry confrontations are not the answer. Instead, a mutually beneficial approach would be to start up a friendly conversation, asking why these sorts of supports are needed. People are generally quite open if asked in an appropriate manner. Opening up the causeway to two-way conversations would allow both those with, and those without chronic pain, to have a free conversation about something that is so often swept under the carpet. There is a reason many of us in the chronic pain community do not speak about it. Chronic pain is a traumatic experience which is also often invisible. It is a common feeling amongst chronic pain sufferers that we are unsupported wherever we go. Everyone is sick of hearing us complain (family, friends, medical personnel), but have you ever taken a moment to think about what it would be like to be in our shoes? This exhibition hopes to start that experience off.

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<sup>7</sup> McKenna-Cross and Kamien, 2013, 136.

## **Topics and subtopics**

Topics and subtopics would be dependent on the art media sent in from the chronic pain community. The main topic would be about chronic pain, whereas subtopics could include fatigue, depression, digestion issues, anxiety, hearing/sight problems, difficulties communicating with friends, family and the medical community, among other things. The exhibition could be ordered by symptom. Those who focus on pain, fatigue, depression, or other related symptoms could be grouped together. The exhibition could also be by illness. For example, putting all those depicting life with Lupus together, and those with chronic pain from injuries together. The exhibition may also be ordered by the type of medium used, for example, all works on paper are together, and all 3D artworks are together. However, this would be decided closer to the time of opening, when a substantial number of artworks have been collected. The organisation of the exhibition may even depend on the physical space, as item order and content will have to be arranged in a way that compliments, rather than obstructs, the space.

## **Targeted and Potential Audiences:**

There are three main target audiences for this exhibition. The first audience would be the chronic pain community. It would be a chance to publicly support and meet each other and bring awareness to a range of disabilities, illnesses and injuries. The second audience would be the friends/family/support-people of those with chronic pain. There are some who are lucky enough to have people who accept us as we are, but some of us are not. It would be an opportunity to connect and network. It would be an educational experience as well as a way to meet other people in the same boat.

The third target audience is the medical community. Although they were not consulted for this proposal, they are an integral part of our lives (whether we like it or not). Unfortunately, doctors and other healthcare professionals often find themselves at a loss with patients with chronic pain. They do not know how to help due to their lack of training around chronic illnesses. At most they spend a couple of hours on pain management in their entire degree, and for much of this the focus is on the common drugs that are used which only help some people. Their presence in a neutral platform

would be good, as it would have the potential to open up the possibility of discussion between survivors and practitioners – a platform that is often quite forced in real life. Chronic pain patients often find they need to see their doctors regularly, either for repeat prescriptions, new symptoms or check-ups completely unrelated to their chronic pain, but practitioners often shy away from people in chronic pain and put them in their ‘too hard’ basket.

Potential audiences for this exhibition includes the general public; people who have just been made aware that they know someone with chronic pain; people who have just walked off the street to get out of the weather; people who are curious and enjoy learning; people who have an interest in medical conditions; people who are empathetic; people who enjoy art; people who enjoy aesthetic and/or engaging experiences. Another potential audience includes children and young adults. Chronic pain in young people is unusual but it does occur. A specific public programme would be in place to entice both children and teenagers to come along to the exhibition.

### **Visitor Experience Objectives:**

Visitors may:

1. Encounter a range of experiences of how chronic pain affects daily life.
2. Gain insight into how they can help and support their friends, family, colleagues, and employees who have chronic pain.
3. Learn about the vast-reaching impact of chronic pain on people’s lives and feel compassion towards this community.
4. Network with each other to strengthen friendships and support within both the chronic pain and carers communities.
5. Be given the opportunity to talk in an open forum about specific topics pertaining to chronic pain.
6. Engage with physical interactives in order to fully appreciate what someone with chronic pain deals with on a daily basis (e.g. a simulation involving wearing a weighted suit while trying to complete simple household tasks. This would give the

experience of extreme fatigue and muscle heaviness that comes with having chronic pain).

7. Learn about a range of conditions which cause chronic pain, as well as take away pamphlets with information on different conditions if they want to.
8. Reflect on the history and current research on chronic pain conditions.
9. Understand and admire the range of art media made specifically for the exhibition.

### **Knowledge and Learning**

As there are many different styles of learning. Ideally these styles would all be represented in the exhibition. Multiple different factors need to be taken into consideration to make the exhibition a memorable, useful and educational experience. Exhibition text must allow for those for whom the world of chronic pain is second nature, as well as for those who have never considered it before. For example, labels would use accessible language, make a point and be as brief as possible. It is important to tell the story without putting an entire essay on the wall. The writing style would be pyramidal. The most crucial information would be at the top, the information that's not so crucial would be next, and so on. Layering the information in this way caters for three types of people, which Helen Hales, the VERVE Project Curator and Engagement Officer at Pitt Rivers Museum, calls the paddlers, swimmers and divers.<sup>8</sup>

Other influences can be the visitors' prior knowledge, motivations, and interest in the topic and content, the architecture of the space, the quality of the exhibition, and any interactions with staff in the exhibition. According to Howard Gardner, there are eight different styles of learning: Linguistic, naturalistic, musical, logical/mathematical, spatial, body/kinaesthetic, intrapersonal, and interpersonal.<sup>9</sup> The linguistic learner processes information and expresses themselves through words, they generally enjoy drama and writing. The naturalistic learner best acquires skills when they can see patterns in nature, and therefore enjoy being outside. The musical learner thinks in sounds. They often learn best through chronological thinking or step-by-step techniques.

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<sup>8</sup> Helen Hales, "Writing effective museum text," accessed 19 November 2016, <http://www.slideshare.net/HelenHales/writing-effective-museum-text-8243677>.

<sup>9</sup> Howard Gardner, *Intelligence Reframed: Multiple Intelligences for the 21st Century* (New York: Basic Books, 1999).

The logical learner enjoys numbers and abstract visuals, and quantifying things. The spatial learner likes maps, graphs, charts. They tend to replace words with colours and images and cannot cope with large amounts of text. The kinaesthetic learner like to learn best doing something physical, and enjoy hands-on experiences. The intrapersonal learner is solitary - they like to work and study by themselves. Lastly, the interpersonal learner acquires knowledge best when they have interactions other people. They do well in group tasks and are good at reading others.<sup>10</sup>

Preferably, the exhibition would provide for all eight learning styles, but this may be constrained by time and funding. The invitation for a range of different types of art, such as poetry, works on paper, sculpture, and sound installations, should mean that these different types of learning would be addressed.

### **Public Programming, Activities and Formal Learning**

The public programmes would be diverse in order to appeal to the range of key audiences: the chronic pain community, friends and relatives of the chronic pain community, the medical community, and the general public.

There would be one or more pre-exhibition local focus group workshopping opportunities for groups of ten people with chronic pain to share ideas amongst themselves about the exhibition. Having this number of people would be enough for a range of opinions without including so many people as to leave some feeling unable to speak up. One workshop example would be getting an art tutor in to work with those who do not feel capable producing something for the exhibition by themselves. They would be guided by the tutor as well as have the chance to do a group artwork rather than an individual one.

There would be a two minute composite documentary where each person has two minutes to tell their life story with chronic pain. These would be pre-recorded with someone asking specific questions and they would play on a looped repeat within the ensuing exhibition.

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<sup>10</sup> Nayomi Chibana, "The 8 Learning Styles: Which One Works for You?," Visual Learning Centre, accessed 20 November 2016, <http://blog.visme.co/8-learning-styles/>.

There would be forums, panel discussions and workshops with medical practitioners, WINZ, medical research companies and people with chronic pain in a 'safe space'. Each forum would have a topic of discussion so there is some structure to each talk. Areas of focus include: a workshop on alternative remedies, support workshops for friends/family, and an open floor Q&A session.

Information evenings about specific illnesses/disabilities featuring speakers with these conditions. Each Friday or Saturday evening while the exhibition is open, a speaker or speakers would give a presentation about their condition to the public. Maybe relevant artwork could be prerecorded (photo/video) and cycle through during the presentation, projected on a screen(s), or displayed on a video screen(s).

Within the exhibition there would be a study and resource area where there would be books, informational videos, website links, and pamphlets available to take away. Hand-outs are useful for providing more information and provide visitors with a reminder of the exhibition and their visit. Catalogues/magazines/publications can be used and are useful to extend the reach and depth of the exhibition, while websites can be consulted by people anticipating a visit, or those looking for help after their visit. Of note, the pamphlets would be produced from the experience of chronic pain survivors with some additional information from the medical community. The pamphlets would prioritise the survivors' experiences and their own suggestions about support and management.

There would be one or more tactile experiences within the exhibition called 'Two minutes in our shoes', where people can see how it feels to experience one of our symptoms. Some examples include: 2kg weights around major joints and walk around for two minutes like that or wear a weighted suit and try to do normal household tasks. As explained earlier, this would give the experience of the extreme fatigue and muscle heaviness that comes with having chronic pain. Another example would be having migraine simulation glasses, which show the aura and visual effect of having a migraine. Although not everyone with migraines experience this symptom it would be worthwhile if someone understands it even a little bit more.

Other public programmes include an Art Day for youth, where children and teenagers are asked to depict how they envisage pain. This could become educational, in that there could be a discussion to clarify the difference between acute and chronic pain. It would be open to all ages, and sessions would probably be grouped by age.



Pain is often understood a lot better if people can visually see it, so extreme make up sessions could be a way of doing this. The pain would be painted on by a local artist. For example, the artist paints one half of a person with fiery muscles and icy bones. This depicts a couple of the different types of pain people experience. The other half of the person remains without makeup, showing the invisible factor of chronic pain.

For all the people who cannot take part in the exhibition, either by sending in art or being onsite helping out, but who nevertheless would have liked to be involved in some way could contribute to an art exhibit of pairs of shoes, sent in by survivors, which would be included in the exhibition.<sup>11</sup>

### **Exhibition Experience:**

Each public programme has been designed to engage one or more of the target audiences. This exhibition is not only about visually expressing the daily lives of those living with chronic pain, it is also about making the experience an engaging and interactive experience. This would be through the multimedia in the exhibition, along with workshops and forums. The exhibition is also devised to encourage visitors to take things (such as pamphlets) away with them, as well as to learn more for themselves for their ongoing enlightenment once the exhibition concludes.

### **Key Stakeholders and External Groups requiring specific engagement:**

The medical community would be a key external group to include in this exhibition, in particular for the public programmes. These groups could include The Ministry of Health and therefore the Health and Disability Commissioner and the Office for Disability Issues, as well as the Ministry for Social Development. In relation to this, university and polytechnic engagement particularly from medical, dental and physiotherapy students and their professors/lecturers would be key. These are the people training as the new general practitioners, nurses, specialists and other medical personnel, and those training them. Achieving a degree of understanding and perhaps even a constructive change leading to some inclusion in their course work of

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<sup>11</sup> Bristol Post, "100 pairs of shoes used to make poignant protest on ME research in Bristol city centre".

information about types of chronic pain, together with its possible causes and treatment possibilities including both standard medical and alternative remedies, would be a great accomplishment.

Attached to this, involving District Health Boards and their respective pain clinics would be advantageous, as would be using the pain clinics' noticeboards as a way of reaching a greater range of people with chronic pain. Groups in relation to pain could include the New Zealand Pain Society, Arthritis New Zealand, Kids Health, and Pain Management & Rehabilitation Services (PainRelief.co.nz). These are types of groups that people go to for help, education and understanding about pain. Mobility Parking New Zealand, CCS Disability Action, Inclusive NZ, and Enable New Zealand offer a range of support for non-specific disabilities and conditions.

Other groups and entities that could be involved either in attending the exhibition or public programmes or being a part of the activities include The Royal New Zealand College of General Practitioners, the Southern Cross Healthcare Group, the New Zealand Medical Journal, the Best Practice Advocacy Centre New Zealand (BpacNZ), Work and Income (WINZ), Ministry of Business, Innovation and Employment (MBIE), Green Cross Health, TedX, and Arts Access Aotearoa. These organisations could be interested in participating, attending or supporting the exhibition.

Until mid-2015, there was a social change campaign run by the Ministry for Social Development called 'Think Differently'. Its main drive was "to encourage and support a fundamental shift in attitudes and behaviour towards disabled people."<sup>12</sup> Apart from funding projects that wished to make a difference, they also offered a toolkit called the 'Social Change Toolkit' which was developed to help change-makers in their projects with templates, tools and tips.<sup>13</sup> Think Differently was clearly a success, and if something similar happens again this exhibition proposal would be submitted to them.

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<sup>12</sup> Think Differently, accessed 12 November 2016, <http://www.thinkdifferently.org.nz/>.

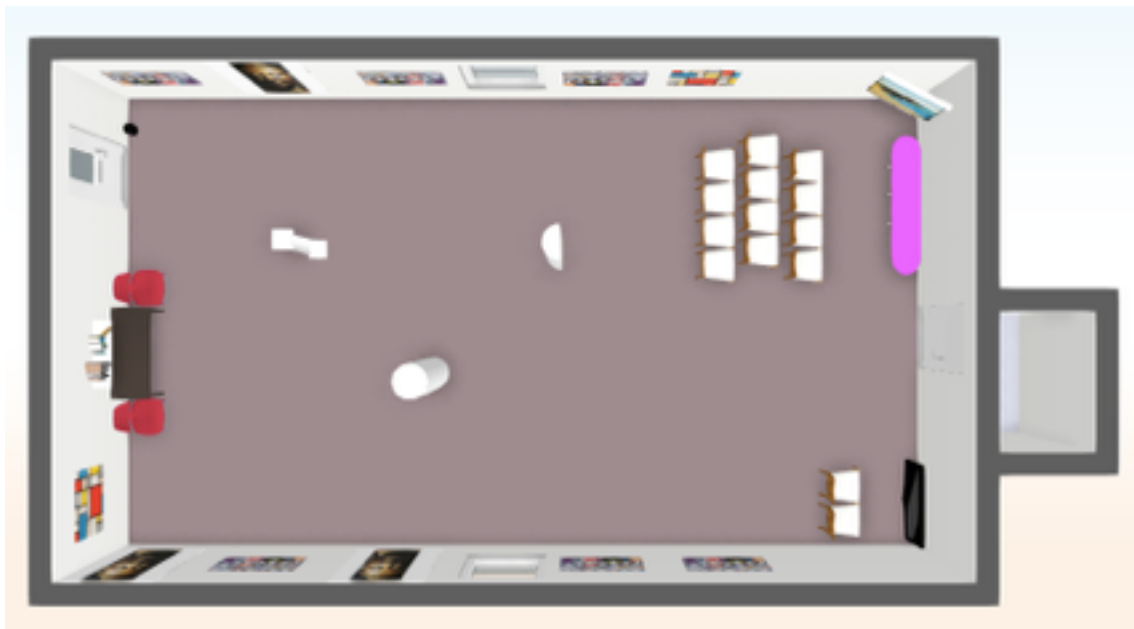
<sup>13</sup> Thinking Differently, "Getting Funded," accessed 12 November 2016, <http://www.thinkdifferently.org.nz/getting-funded>.

### Visitor Comfort:

Chairs would be scattered throughout the exhibition for those who need frequent rests. The chairs would be comfortable, and easy to get into and out of. Water for hydration would be made available for free. During workshops, forums and other public programmes, pillows and blankets would be made available for those who need them.

### The Physical Space:

1. The show will feel spacious without feeling empty. Visitors will be able to move around at ease and in their own way (the show will not force a direction for visitors to go).
2. The bird's eye floor plan below (*Figure 23*) shows a possible layout including the following details: the exhibition being contained on one floor along with toilet facilities; 3D artworks are in the middle of the room with sufficient space to move comfortably and safely around them; works on paper/canvas etc are on the walls of the space; there is an area dedicated to the forums/talks, a corner with a tv screen for the looped documentary, plus random seating for those who tire quickly, and an information desk at the entrance/exit.



### **The Online Offer:**

Several online platforms would be used to both advertise and track the process of the project and exhibition. Use of Facebook, Twitter, and Wordpress are anticipated to be the most suitable current media. A Facebook page and a Twitter account would be created to cover the two main social media platforms, and a Wordpress blog would be used so that people can follow the progress pre-, during, and post exhibition. This is similar to how the Science Museum conducted their pain exhibition 'Pain Less', (see chapter two). Facebook will be used in the build up to the exhibition to promote it online to establish interest. It will include key dates, times, and addresses, as well as posting reminders about the public programmes. Twitter will be used to bring light to and discuss themes within the exhibition. There will be a topic chosen each week the exhibition is open.

### **Exhibition Management and Collaborations:**

Depending on how much funding is able to be sourced for this exhibition, the staff involved would either be paid or be volunteers or most likely a mix of both paid key personnel supported by many volunteers. This exhibition could include consultation from museums, individuals, or organisations in particular aspects of the exhibition development, public programming, and staffing. Support would be acknowledged in the opening of the exhibition with gifts where funding permits, as well as being listed on any of the advertising and media interactions.

### **Labels and Signage:**

Labels and signage would be in large, easy-to-read formats. Those with chronic pain, often also have issues with their eyes and eyesight. Subtitles would be used in the looped documentary for those with hearing problems.

### **Funding and Sponsorship**

When it comes to funding and sponsorship, as well as stakeholders, questions must be asked, such as how suitable are they? Is there a synergy between the project and the

company/ies? Could the project attract potential clients to a particular sponsor? Do I want this project to be associated with the company/ies? Does the purpose of my project match the fund's interests and guidelines? Is the project budget realistic? The initial approach once these questions have been pondered would be to write a letter to the potential funders asking whether their current funds and interests would allow for a positive consideration of this project application. The letters would cover the purpose of the project, information about and qualifications of those involved in the project, any issues and problems the project would address, the period of time that funds would be needed, and an estimated overall budget.

Potential sponsors and funders for this project include the Lottery Grants Board of which the Lottery Community fund would be well suited - "funding is available for projects, activities, resources or services that have a community or social service focus, and which help connect communities, improve well-being and the quality of people's lives."<sup>14</sup> GivUs (Generosity) is a community group funding scheme and offers access to over 1200 grants and schemes for communities and groups. They can assist with operational costs and project based resources among other things.<sup>15</sup> They also have an individual scholarships and awards scheme called GiveMe. The Lions Foundation's grants are given to a "diverse range of charitable causes in the areas of health, education, sports and community (which includes arts, culture, heritage and environment)," which indicates that the Lions Foundation aligns itself with this proposal.<sup>16</sup> AMP Scholarships is another option for funding, as they offer more than "\$2 million to help over 180 everyday Kiwis achieve their dreams" every year.<sup>17</sup> There are four scholarships that can be applied for, National, People's Choice, Study Start, and AMP People Scholarships. Of these, the National Scholarship worth up to \$10,000 and the People's Choice Scholarship would be of interest for this proposal. An additional source of funding could be from Boosted which is run by The Arts Foundation and

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<sup>14</sup> Lottery Grants, "Lottery Community," accessed 19 November 2016, <http://www.communitymatters.govt.nz/Funding-and-grants---Lottery-grants---Lottery-Community>.

<sup>15</sup> Generosity New Zealand, "givUS," accessed 19 November 2016, <http://generosity.org.nz/giv-us/>.

<sup>16</sup> The Lions Foundation, "Funding Q & A's," accessed 19 November 2016, <http://www.lionfoundation.org.nz/applying-for-funding/useful-tips/>.

<sup>17</sup> AMP Services Ltd, "About AMP Scholarships," accessed 19 November 2016, <https://www.amp.co.nz/scholarships/about/about>.

powered by Westpac bank. Boosted says that “everyone needs art... But most art needs money!” Boosted removes the barriers between artists and backers.<sup>18</sup>

Entry to the exhibition would be free, but koha would be available for those who can and/or want to give money.

### **Marketing and Communications:**

The Purple Awareness Ribbon for chronic pain would be used to market the exhibition. Purple is internationally recognised as the ribbon colour for chronic pain. The exhibition would be marketed in a way that entices non-chronic-pain people to come and take a look. It would be personal, and ask personal rhetorical questions about their knowledge of chronic pain, as well as offering support for those with chronic pain if they come too. Marketing for the exhibition would be through local and national newspapers, social media networks (i.e. Facebook, Twitter, Wordpress), flyers at universities and district health board pain clinics, radio, and by word-of-mouth, so that anyone and everyone has an opportunity to come. Purple ribbons could be sold at the exhibition.

### **Exhibition Merchandise and Publications:**

For those who send in works, there would be the option for them to put their work up for sale or not. They would also have the option of having their art media design screen-printed onto t-shirts and mugs etcetera, from the sale of which the artist would get a percentage. Books on chronic pain would be for sale.

### **Proposal Budget:**

The budget cannot be set at this time as it would depend entirely on the funding and sponsorship granted, and this could be influenced to some extent by the number of artworks received for the exhibition. Expenses to keep in mind include:

1. Exhibition personnel: curator, designer, display technician/installer, marketer, and visitor/programme hosts

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<sup>18</sup> Boosted, “About Boosted,” accessed 19 November 2016, <https://www.boosted.org.nz/about>.

2. Other contractors: printing, graphic design, audio-visual production and presentation, electrician
3. Materials needed: display items (cases, podiums etc), construction materials (wood, paint etc), signage and advertising, opening event (invitations, food and drinks)
4. Marketing: flyers, radio time, newspaper articles, ribbons.

Income would include koha donations, sponsorship and merchandise sales.

### **Evaluation Methods and Exhibition Success:**

This proposal has been what some would call front end evaluation. It has detailed a development of early ideas for an exhibition on chronic pain and has laid out the key goals, layouts of a potential space, and possible stakeholders. All of this has been progressively developed from the information collected from two surveys completed by a control group and a group with chronic pain, which were discussed in depth in the previous chapter. Formative evaluation of this exhibition proposal will happen when there is a more concrete timeline, the exhibition space is decided on, and people definitely interested in helping the exhibition get off the ground.

Success will be judged partly by observing people going away with an enthusiasm and open-mindedness to support their friends, family, colleagues and/or employees with chronic pain. Further, there may be interest from other gallery spaces in hosting the exhibition elsewhere or developing their own similar exhibition. Media interest in covering the exhibition and peoples' stories would indicate a positive outcome, as well as large numbers attending the public programmes. To evaluate the success of the exhibition methodically there would be a visitor feedback survey. These would be available online, as well as in paper form at the exit to the exhibition. A visitor book for anecdotal comments would also be at the exhibition.

## Conclusion

This dissertation started by laying out my personal experience, bias on this topic and the key statement for this research in the introduction, which was: *Chronic pain is a misunderstood and underrepresented part of society. Proposing an exhibition depicting the daily lives of New Zealanders with chronic pain may help to increase understanding and acceptance of one of the largest and most invisible communities in New Zealand.* This statement has been supported by all four chapters. The introduction situated the topic in the literature available, and showed how the chronic pain community can be brought into the realm of social inclusion in relation to museums/galleries, as well as providing the research methodologies. Chapter one offered a comparison of three exhibitions from around the world where the exhibition topic was pain, and it identified a gap in the ways the exhibitions were run, advertised, who was involved, and what communities they were representing and targeting. In chapter two, the results of two online surveys were analysed, and they strongly suggested that there is the support and need for an exhibition on chronic pain in New Zealand. Finally, in chapter three, a possible format of the proposed exhibition I envisage happening, was presented.

I hope you as the reader, can see the potential behind bringing more awareness to this topic through the use of art and a community gallery space. The further this message reaches, the more likely the daily lives of those with chronic pain will change for the better. Today, many are treated by doctors and practitioners who do not know what they are doing, or even worse, pretend to know what they are doing when they actually have little or no knowledge. And, on a daily basis people with chronic pain are turned away from specialists, who they have a right to see, due to funding cuts from the government. The only way forward is to go privately, though this is an option only financially available to a few. Amid many of the current issues in the community are how and what our young medical professionals are being taught about chronic pain, and where the government is providing funding. Through bringing a public awareness to the plight of one in five New Zealanders, there is the hope of changing the situation for the better.

In the Introduction, the literature outlined how museums and galleries are working towards social inclusion. Silverman believes that these public entities can be agents of social change by altering attitudes, however, as O'Neill comments, museums can only help the situation if they are aware of the realities of peoples lives. In Baker's masters



dissertation she outlines that museums and galleries are limited in their ability to help due to their staff's narrow understandings of what social inclusion actually is, and instead focus on ethnic cultures as their contribution to change. King-Wall suggests that museums and galleries in New Zealand are becoming more aware of disabled communities and are tailoring specific programmes for these groups. Heshusias et al. says that people's perceptions can be harmful, and what better way to change public comprehension than a public exhibition. Dodd and Sandell have both in theory and in practice, proved that museums and galleries can challenge stereotypes and tackle intolerance.

In summary, Australia, United Kingdom and the United States of America have already had exhibitions where the focus was pain or even chronic pain (see chapter one). It is time for New Zealand to stand up for their people and publicly recognise a community that consists of one in five New Zealanders. Creating an exhibition to explore the diversity of the daily lives of those with chronic pain would empower this community, as well as bring awareness and understanding through visual representations of pain to the public. This research contributes to the field of museum studies by presenting an opportunity to museum and gallery staff to learn about and reflect upon an invisible community in New Zealand. It also suggests that although there are audiences interested in going to an exhibition on chronic pain, museums and galleries in New Zealand are yet to present an exhibition on this topic.

To conclude this research, I would like to provide New Zealand galleries and museums with some recommendations and suggestions.

1. If your gallery is not totally accessible (both inside with available seating/lifts, and outside with ramps at the main entrance) then you are not catering to your audience – not all illnesses/conditions/disabilities are visible to the naked eye.
  - If you are interested in being more accessible there is a company that can help you get started called 'Be. Accessible'.<sup>1</sup>
2. Galleries need to be aware of the community they are in, who makes up that community, and look for ways of bringing them in to the space.

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<sup>1</sup> "Be. Welcome," Be. Accessible, accessed 19 January 2017, <http://www.beaccessible.org.nz/be-welcome>.

- A broad way of finding this out is to look at Statistics New Zealand's 2013 census which can offer quick statistics on your area.<sup>2</sup>
3. Galleries should strive to build connections and bridges with all people visiting their gallery as well as work with local museums on social inclusion techniques with all staff, not just front-of-house workers.
    - An easy way of doing this is writing up an exit survey for your visitors to complete either online, or on paper before they leave. This is your chance to ask your audience what they would like to see from you.
    - Working with local museums strengthens not only cultural and social bonds, but professional ones too.
    - It is important that curators and those involved in creating exhibitions and designing spaces are just as knowledgeable about their visitors as the front-of-house staff.
  4. Please do understand that describing art is not 'dumbing it down'.
    - For instance, how would you describe visual art to a blind person? You would most likely reflect on an experience or tell a story which in turn conjures up an image of understanding. Now describe it like that to the rest of us.
  5. Any further studies in this area of research should obtain data from a much larger sample of people in order to get a fuller picture and understanding. It could also ask people what type of chronic pain they have in order to see the distribution of what type of chronic pain is affecting people the most/least.

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<sup>2</sup> "2013 Census," Statistics New Zealand, accessed 19 January 2017, <http://www.stats.govt.nz/Census/2013-census.aspx>.

## Appendix

### Survey Questions for Chronic Pain group:

1. Do you have chronic pain as a main symptom of an illness/disability/injury? Yes/No.
  - *If answered 'no', respondent gets screened out of questionnaire and thanked for their time.*
2. Have you ever been to an exhibition that talked about chronic pain? Yes/No.
  - *If answered 'yes', respondent is further questioned where/which museum/art gallery this exhibition was.*
3. Do you think there is a lack of understanding and/or conversations about chronic pain in New Zealand? Yes/No. Please explain.
  - *Respondents are asked to explain their answer.*
4. Is there any value in having a public exhibition of art produced by people with chronic pain, showing their experiences with it? Yes/No. Please explain.
  - *Respondents are asked to explain their answer.*
5. Would you be interested in participating, by submitting an artistic creation of your own making, showing your personal experience with chronic pain, which may lead to an exhibition on chronic pain in a New Zealand gallery? Yes/No.
  - *After submission, respondents are thanked for their time.*

### Survey Questions for Control group:

1. I agree that I have read and understood the information sheet. Yes/No.
  - *If answered 'no', respondent gets screened out of questionnaire and thanked for their time.*
2. Have you got chronic pain? Yes/No.
  - *If answered 'yes', respondent gets screened out of questionnaire and thanked for their time.*
3. Are you aware of what chronic pain is? Yes/No.
  - *If answered 'no', respondent skips next question.*
4. Can you give some examples of what chronic pain is?
  - *Multi-line answer capability.*
5. Do you know someone who has chronic pain? Yes/No

- *If answered 'no, respondent skips next question.*
- 6. Do you understand their experiences with chronic pain? Yes/No/Maybe
- 7. Would you be interested in going to, or being part of, an exhibition depicting the daily lives of New Zealanders with chronic pain? Yes/No
- *After submission, respondents are thanked for their time.*

## Bibliography

### **Books**

- Boddice, Rob. *Pain and Emotion in Modern History*. Hampshire, England: Palsgrave Macmillan, 2014.
- Bourke, Joanna. *The Story of Pain: From Prayer to Painkillers*. Oxford, U.K.: Oxford University Press, 2014.
- Denscombe, Martyn. *The Good Research Guide: For small-scale social research projects*. 4th ed. Berkshire, England: Open University Press, 2010.
- Dickson-Swift, Virginia, Erica Lyn James and Pranee Liamputtong. *Undertaking Sensitive Research in the Health and Social Science: Managing Boundaries, Emotions and Risks*. Cambridge: Cambridge University Press, 2008.
- Dodd, Jocelyn and Richard Sandell. *Including Museums: perspectives on museums, galleries and social inclusion*. Leicester: University of Leicester, 2001.
- Dodd, Jocelyn, and Ceri Jones. *Mind, body, spirit: How museums impact health and wellbeing*. Leicester, U.K.: Research Centre for Museums and Galleries (RCMG), 2014.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.
- Gardner, Howard. *Intelligence Reframed: Multiple Intelligences for the 21st Century*. New York: Basic Books, 1999.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc., 1963.
- Heshusias, Lous, Scott M. Fishman and David B. Morris. *Culture and Politics of Health Care Work: Inside Chronic Pain – An Intimate and Critical Account*. New York: Cornell University Press, 2009.
- Landgarten, Helen B. *Clinical Art Therapy: A Comprehensive Guide*. New York: Routledge, 1981.
- McKenna-Cress, Polly and Janet A. Kamien. *Creating Exhibitions: Collaboration in the Planning, Development, and Design of Innovative Experiences*. New Jersey: John Wiley & Sons, Inc., 2013.

- Moscoco, Javier. *Pain: A Cultural History*. New York: Palgrave Macmillan, 2012.
- Montalk, Stephanie de. *How Does It Hurt?* Wellington, N.Z.: Victoria University Press, 2014.
- Nagel, David. MD. *Needless Suffering: How Society Fails those with Chronic Pain*. New Hampshire: University Press of New England, 2016.
- Nieves, Pascual. *Witness to Pain: Essays on the Translation of Pain Into Art*. Bern, Switzerland: Peter Lang AG, 2005.
- Sandell, Richard. *Museums, Society, Inequality*. London: Routledge, 2002.
- . *Museums, Prejudice and the Reframing of Difference*. Oxon: Routledge, 2007.
- Sandell, Richard, Jocelyn Dodd and Rosemarie Garland-Thomson, eds. *Re-Presenting Disability: Activism and Agency in the Museum*. Abingdon, Oxon: Routledge, 2010.
- Sandell, Richard and Eithne Nightingale, eds. *Museums, Equality and Social Justice*. Oxon: Routledge, 2012.
- Shilling, Chris. *The Body and Social Theory*. London: SAGE Publications Ltd, 1993.
- Silverman, Lois H. *The Social Work of Museums*. Oxon: Routledge, 2010.
- Spivey, Nigel. *Enduring Creation: Art, Pain and Fortitude*. London: Thames & Hudson Ltd., 2001.
- Thernstrom, Melanie. *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing and the Science of Suffering*. New York: Farrar, Straus and Giroux, 2010.
- Watson, Sheila, ed. *Museums and their communities*. New York: Routledge, 2007.
- Webster, Lynn R. M.D. *The Painful Truth: What Chronic Pain Is Really Like and Why It Matters to Each of Us*. Salt Lake City, Utah: Webster Media LLC, 2015.
- Whitehead, Christopher. *Interpreting Art in Museums & Galleries*. Oxon: Routledge, 2012.
- Wilson, Peter, et al. *Clinical Pain Management: Chronic Pain*. 2d ed. London: Hodder & Stoughton Limited, 2008.

### **Chapters in Edited Collections**

- Budrys, Valmantas. "Frida Kahlo's neurological deficits and her art." In *Progress in Brain Research*, vol. 203, edited by Bettina Studer and Stefan Knecht, 241-254. Amsterdam: Elsevier B.V., 2013.
- Duncan, Carol. "The art museum as ritual." In *Heritage, Museums and Galleries: An Introductory Reader*, edited by Gerard Corsane, 78-88. Oxon: Routledge, 2005.
- Karakas, Scott L. "Expressions of Chronic Pain and Suffering in Western Art." In *Maldynia: Multidisciplinary Perspectives on the Illness of Chronic Pain*, edited by James Giordano, 87-102. Florida: CFC Press, Taylor & Francis Group, 2011.
- Milstein, Dana. "Pain is a Preposition." In *Witness to Pain: Essays on the Translation of Pain into Art*, edited by Pascual Nieves, 77-98. Bern, Switzerland: Peter Lang AG, 2005.
- Nightingale, Eithne. "Afterword: The Continuing Struggle for Diversity and Equality." In *The International Handbooks of Museum Studies: Museum Practice*, vol. 2, edited by Conal McCarthy, 599-611. Chichester, U.K.: John Wiley & Sons, Ltd., 2015.
- Silverman, Lois H. "The therapeutic potential of museums as pathways to inclusion." In *Museum, Society, Inequality*, edited by Richard Sandell, 69-83. London: Routledge, 2002.
- Stam, Deirdre C. "The informed muse: The implications of 'The New Museology' for museum practice." In *Heritage, Museums and Galleries: An Introductory Reader*, edited by Gerard Corsane, 54-70. Oxon: Routledge, 2005.
- Whitehead, Chris. "Visiting with suspicion: Recent perspectives on art and art museums." In *Heritage, Museums and Galleries: An Introductory Reader*, edited by Gerard Corsane, 89-101. Oxon: Routledge, 2005.

### **Journal Articles**

- Bar-Sela, Gil. "Art therapy improved depression and influenced fatigue levels in cancer patients on chemotherapy." *Psycho-Oncology* 16, no. 11 (2007): 980-984.

- Bose, Joerg. "Images of Trauma: Pain, Recognition, and Disavowal in the Works of Frida Kahlo and Francis Bacon." *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry* 33, no. 1 (2005): 51-70.
- Budrys, Valmantas. "Frida Kahlo's neurological deficits and her art." *Progress in Brain Research* 203 (2013): 241-254.
- Collen, Mark. "Life of Pain, Life of Pleasure: Pain from the Patient's Perspective – The Evolution of the PAIN Exhibit." *Journal of Pain & Palliative Care Pharmacotherapy* 19, no. 4 (2005): 45-52.
- Dominick, Clare, Fiona Blyth and Michael Nicholas. "Patterns of chronic pain in the New Zealand Population." *The New Zealand Medical Journal* 124, no. 1337 (2011): 63-76.
- Fillingim, Roger B., et al. "Sex, Gender, and Pain: A Review of Recent Clinical and Experimental Findings." *J Pain* 10, no. 5 (2009): 447–485.
- Hide, Louise. "Dialogue with pain: How and when we give meaning to bodily pain." *Wellcome History* no. 53 (2014): 2-3.
- Kitchin, Rob. "'Out of Place', 'Knowing One's Place': Space, power and the exclusion of disabled people." *Disability & Society* 13, no. 3 (1998): 343-356.
- Lynch, Bernadette T. and Samuel J. M. M. Alberti. "Legacies of Prejudice: racism, co-production and radical trust in the museum." *Museum Management and Curatorship* 25, no. 1 (2010): 13-35.
- Nainis, Nancy, et al. "Relieving Symptoms in Cancer: Innovative Use of Art Therapy." *Journal of Pain and Symptom Management* 31, no.2 (2006): 162-169.
- O'Neill, Mark. "Essentialism, adaption and justice: Toward a new epistemology of museums." *Museum Management and Curatorship* 21 (2006): 95-116.
- Martínez-Lavín, Manuel, et al. "Concise Communication: Fibromyalgia in Frida Kahlo's life and art." *Arthritis & Rheumatism* 43, no. 3 (2000): 708-709.
- Sandell, Richard. "Museums as Agents of Social Inclusion." *Museum Management and Curatorship* 17, no. 4 (1998): 401-418.
- . "Social inclusion, the museum and the dynamics of sectoral change." *Museums and Society* 1, no. 1 (2003): 45-62.



- Swain, Nicola, and Matthew Johnson. "Chronic Pain in New Zealand: a community sample." *The New Zealand Medical Journal* 127, no. 1388 (2014): abstract summary.
- Watts, Jacqueline H. "Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics." *Medical Sociology Online* 3, no. 2 (2008): 3-14.

### **Reports**

- Creative City Network of Canada and Canada Council for the Arts. "Making the Case for Culture: Arts and Positive Change in Communities." Vancouver, Canada: Creative City Network of Canada, 2005.
- Jermyn, Helen. "The Art of Inclusion." United Kingdom: England Arts Council, July 2004.
- Office of Policy and Analysis. "The Making of Exhibitions: Purpose, Structure, Roles and Process." Washington, D.C.: Smithsonian Institution, October 2002.
- Statistics New Zealand. "New Zealand General Social Survey 2016: Objectives of the Civic and Cultural Participation supplement." Wellington, N.Z.: Statistics New Zealand, 2014.

### **Theses and Unpublished Sources**

- Baines, Penelope. "Non-Core Business? An Examination of University Art Galleries in Aotearoa New Zealand." MA thesis. Victoria University of Wellington, 2015.
- Baker, Claire Adele. "Good intentions: A case study of social inclusion and its evaluation in local public art galleries." MA diss. Victoria University of Wellington, 2014.
- Email correspondence between Mark Collen and Melissa Wells, 20 September 2016.
- Email correspondence between Mark Collen and Melissa Wells, 21 October 2016.
- King-Wall, Riah. "Path to Accessibility: The current state of disability access in Aotearoa New Zealand museums." MA diss. Victoria University of Wellington 2016.

Mhando Nyangila, Jacob. "Museums and community involvement: A case study of community collaborative initiatives - National." Museums of Kenya." Conference paper. INTERCOM, 2006.

### **Websites**

ABC Radio National. "The Art of Pain: rendering the invisible visible." Accessed 25 October 2016, [http://mpegmedia.abc.net.au/rn/podcast/2015/07/lms\\_20150721\\_0920.mp3](http://mpegmedia.abc.net.au/rn/podcast/2015/07/lms_20150721_0920.mp3).

AMP Services Ltd. "About AMP Scholarships." Accessed 19 November 2016, <https://www.amp.co.nz/scholarships/about/about>.

Ann, Deborah. "Pain without words." Accessed 8 October 2016, <http://painexhibit.org/en/galleries/pain-visualized/>.

Artlyst. "New V&A Museum Exhibition Explores Social Change Through Art And Design." Accessed 27 September 2016, <http://www.artlyst.com/articles/new-va-museum-exhibition-explores-social-change-through-art-and-design>.

Australian Network for Art and Technology. "The Art of Pain." Exhibition, University of South Australia, 20-30 July 2015, accessed 22 March 2016, <http://www.anat.org.au/the-art-of-pain/>.

Australian Network for Art and Technology. "The Art of Pain – Somatic Drifts." Accessed 9 December 2016, <http://www.anat.org.au/the-art-of-pain-somatic-drifts/>.

Be. Accessible. "Be. Welcome." Accessed 19 January 2017, <http://www.beaccessible.org.nz/be-welcome>.

Bertrand, Mathilde. ""A Tool for Social Change": Community Photography at Belfast Exposed." Accessed 27 September 2016, <https://lisa.revues.org/8770>.

Boosted. "About Boosted." Accessed 19 November 2016, <https://www.boosted.org.nz/about>.

Bristol Post. "100 pairs of shoes used to make poignant protest on ME research in Bristol city centre." Accessed 11 November 2016, <http://www.bristolpost.co.uk/100-pairs-of-shoes-make-silent-protest-on-me-research-in-bristol-city-centre/story-29755005-detail/story.html>

- Canadian Museum for Human Rights. "Sight Unseen: International Photography by Blind Artists." Exhibition, 20 February - 18 September 2016, accessed 11 July 2016, <https://humanrights.ca/exhibit/sight-unseen>.
- Chibana, Nayomi. "The 8 Learning Styles: Which One Works for You?" Visual Learning Centre. Accessed 20 November 2016, <http://blog.visme.co/8-learning-styles/>.
- Collen, Mark, James Gregory and Elizabeth Heim. "PAIN Exhibit." Online exhibition, accessed 22 March 2016, <http://painexhibit.org/en/>.
- Blakemore, Paul and Laura Dannequin. "Hardy Animal." Documentary. Filmed 2014, accessed 10 July 2016, <https://vimeo.com/87581056>.
- Davis, Jonathan. "UPLIFT Connect." Media Channel. 17 July 2015, accessed 31 July 2016, <http://upliftconnect.com/opposite-addiction-connection/>.
- European Union National Institutes for Culture. "Arts for Social Development - Workshop Exhibition." Accessed 27 September 2016, <http://www.eunic-online.eu/?q=content/arts-social-development-workshop-exhibition>.
- "Exhibitions." Involving People – Scottish Health on the Web. Accessed 28th September 2016, <http://www.sehd.scot.nhs.uk/involvingpeople/methodologies/individualmethodologies/exhibitions.htm>.
- Expressions Whirinaki Arts and Entertainment Centre. "About Expressions." Accessed 19 November 2016, <http://www.expressions.org.nz/about-expressions/>.
- Generosity New Zealand. "GivUS." Accessed 19 November 2016, <http://generosity.org.nz/giv-us/>.
- Hales, Helen. "Writing effective museum text." Accessed 19 November 2016. <http://www.slideshare.net/HelenHales/writing-effective-museum-text-8243677>.
- Lee, Eugenie. "McGill Pain Questionnaire 2012." Accessed 25 October 2016, <http://eugenielee.com/wp-content/uploads/sites/27/2013/09/McGill-Pain-Questionnaire.pdf>.
- The Lions Foundation. "Funding Q & A's." Accessed 19 November 2016, <http://www.lionfoundation.org.nz/applying-for-funding/useful-tips/>.

- “London Brain Project: Exploring brain sciences through the arts.” London Brain Project, accessed 10 July 2016, <http://www.londonbrainproject.com/>.
- Lottery Grants. “Lottery Community.” Accessed 19 November 2016, <http://www.communitymatters.govt.nz/Funding-and-grants---Lottery-grants---Lottery-Community>.
- Mental Health Foundation. “Quick Facts and Stats 2014.” Accessed 1 February 2016, <https://www.mentalhealth.org.nz/assets/Uploads/MHF-Quick-facts-and-stats-FINAL.pdf>.
- MOMA. “Small Scale, Big Change: New Architectures of Social Engagement.” Museum of Modern Art. Accessed 27 September 2016, <http://www.moma.org/interactives/exhibitions/2010/smallscalebigchange/about.html>.
- “New Zealand Social Policies 2015.” Sustainable Governance Indicators. Accessed 26 April 2016, [http://www.sgi-network.org/2015/New\\_Zealand/Social\\_Policies](http://www.sgi-network.org/2015/New_Zealand/Social_Policies).
- “Ouch.” The Science Museum. Accessed 21 October 2016, [http://www.sciencemuseum.org.uk/online\\_science/games/ouch](http://www.sciencemuseum.org.uk/online_science/games/ouch).
- Parker-Pope, Tara. “Pain as an Art Form.” The New York Times. 22 April 2008, accessed 22 March 2016, [http://well.blogs.nytimes.com/2008/04/22/pain-as-an-art-form/?\\_r=0](http://well.blogs.nytimes.com/2008/04/22/pain-as-an-art-form/?_r=0).
- “Pain Less.” The Science Museum. Accessed 21 October 2016, [http://www.sciencemuseum.org.uk/visitmuseum/plan\\_your\\_visit/exhibitions/painless](http://www.sciencemuseum.org.uk/visitmuseum/plan_your_visit/exhibitions/painless).
- The Pain Research Forum. “RELIEF: Pain Research News, Insights and Ideas.” Accessed 26 June 2016, <http://relief.news/home/>.
- ROAR! Gallery. “Exhibit at ROAR! Gallery.” Accessed 19 November 2016, <https://roargallery.org.nz/pages/exhibiti-at-roar-gallery>.
- The Science Museum. “Pain Less Blog.” Exhibition Nov 2012 – Aug 2013. Accessed 22 March 2016, <https://painlessexhibition.wordpress.com/>.
- South Dublin County Council. “Social Inclusion Week 17-24 November 2015.” Accessed 4 April 2016, <http://www.sdcc.ie/services/community/social-inclusion/social-inclusion-week-17-24-november/>.

- Statistics New Zealand. "2013 Census." Accessed 19 January 2017, <http://www.stats.govt.nz/Census/2013-census.aspx>.
- Stock, Katherine. "Self-Portrait." Accessed 9 December 2016, <http://painexhibit.org/en/galleries/portraits-of-pain/>.
- Think Differently. Accessed 12 November 2016, <http://www.thinkdifferently.org.nz/>.
- . "Getting Funded." Accessed 12 November 2016, <http://www.thinkdifferently.org.nz/getting-funded>.
- Thistle Hall Community Venue. "About Thistle Hall." Accessed 19 November 2016, <http://www.thistlehall.org.nz/about-thistle-hall>.
- Toi Pōneke Arts Centre. "About Toi Pōneke." Accessed 19 November 2016, <http://wellington.govt.nz/services/community-and-culture/arts/toi-poneke-arts-centre/about-toi-poneke>.
- "Uncovering the personal experience of pain." Pain Less Exhibition. Accessed 21 October 2016, <https://painlessexhibition.wordpress.com/2012/11/19/uncovering-the-personal-experience-of-pain/>.
- "Art and public health: Wellbeing, social critique and communication." University of Otago. Summer School Symposium, 27 February 2017. Accessed 25 January 2017, <http://www.otago.ac.nz/wellington/departments/publichealth/summerschool/otago623537.html>.
- Vicente, Mercedes. "Art and Social Change Research Project: Delhi Residency." Te Tuhi April–July 2014, accessed 27 September 2016, <http://www.tetuhi.org.nz/whats-on/exhibitiondetails.php?id=145>.
- "Virtually Painless." Pain Less Exhibition. Accessed 21 October 2016, <https://painlessexhibition.wordpress.com/start-here/virtually-painless/>.
- Walsh, John. "Sickening, gruelling or frightful: how doctors measure pain." *The Guardian*, accessed 1 February 2017, <https://www.theguardian.com/science/2017/jan/25/how-doctors-measure-pain>.
- Wellcome Trust. "Doctor, it hurts... all the time: The London Pain Consortium." Blog post, accessed 3 April 2016, <http://www.wellcome.ac.uk/Funding/Public->

engagement/Engagement-with-your-research/Support-and-resources/Patient-groups/WTP051844.htm.

———. “Pain: Passion, compassion, sensibility. A Wellcome Trust exhibition at the Science Museum.” 13 February - 20 June 2004, accessed 22 March 2016, <http://www.wellcome.ac.uk/en/pain/exhibition.html>.