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***Illuminating Loss:***  
**A study of the Capacity for Artistic  
Practice to Shape Research and Care  
in the Field of Inherited Genetic Illness.**

Jacqueline Donachie

PhD

A thesis submitted in partial fulfillment of the  
requirements of the University of Northumbria at  
Newcastle for the degree of Doctor of Philosophy.

Faculty of Arts, Design and Social Sciences.

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## ABSTRACT

Contemporary art is seen as an effective way of communicating complicated science to a range of lay audiences, particularly in the context of medical research. This is the premise of 'sciart'. However this rationale can limit the cultural significance of artworks by overstating their illustrative capacity, an outcome that severely reduces the creative endeavour of the artist.

Based on the first-hand experience of an artist whose career has engaged with the opportunities afforded by 'sciart', this study seeks to address the illustration problem by exploring new methods of working across art and science that challenge representations of the inherited neuromuscular disorder myotonic dystrophy, a condition which affects one in 8000 adults in the UK. *Hazel*, a film made by the artist with the participation of eleven women affected by the condition, is placed at the centre of this as a case study. Pioneering work with the UK Myotonic Dystrophy Patient Registry facilitated recruitment, and it is this process that forms the unique contribution to knowledge of the research.

By illuminating the multiple loss experienced by families struggling with physical and social decline, this research offers a practical and theoretical image of the capacity contemporary artists have to shape research into myotonic dystrophy. The study will argue that this capacity is more ambitious than illustration, more extensive than the communication of family insights. Thus it can embrace a much-needed form of research leadership that is built upon an artist's scope to say powerful things by withholding information. In addition, the employment of feminist literature on ageing and appearance, and sociological research into the decline and isolation of affected families, helps define the particular form of leadership that can arise through extreme personal circumstances.

As pressures on services increase, cross-sector influence becomes increasingly important and this thesis and body of practical work explores the future impact of contemporary artists taking a lead in shaping research agendas in the genetic sciences.

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effortlessly moves from laboratory to airport to Tennant's bar in a long and fascinating journey that I hope will continue.

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I want to thank my family, particularly my sister Susan Craig, and my mum, Kathleen Donachie. Fifteen years ago, when I wrote that our knowledge of genetic illness was only as old as my niece Rhona, we had no idea of the extent of change that this new and growing knowledge would bring. We are all transformed by it. Susan's dignity and resilience throughout all of this is remarkable, and the fact that she has allowed me to chart some of it is to her great credit. The ambitions my parents held for all of us as we grew up was palpable, and it has been, I think, hardest of all for my mum to navigate this path.

My immediate family have put up with a lot, and so I am indebted to my husband Roddy Buchanan for steadying the ship at home and offering vital critical support and expertise, and my three sons, Archie, Duncan and James, two of whom were born during 'the making of this work'. It is one thing to grow up in an extended family that manages issues of ill health and disability, but another to have a mum who disappears for long periods to either film or write about it. Your resilience and support has impressed me at every turn. I am very proud of you all.

I have been fortunate to work with many from the dynamic, growing community of myotonic dystrophy research and care, and I hope that this research will in some way make a contribution. I am grateful to the

International Myotonic Dystrophy Consortium organising committee for allowing me to present *Hazel* at their conference in Paris in June 2015, and to the Myotonic Dystrophy Foundation, who warmly invited me to present the film at their annual family conference in Washington DC in September that year.

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Jacqueline Donachie  
Glasgow, September 2016

## **AUTHOR'S DECLARATION**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the University of Northumbria Ethics Committee, on 3<sup>rd</sup> January 2013 (reference: RE11-12-121556, Project ID: 1932).

I declare that the Word Count of this Thesis is 47,954.

Name: Jacqueline Donachie

Signature:

Date: 6<sup>th</sup> September 2016

## INTRODUCTION

### i Key themes and ideas

If you are working with a research process, the end result is not information; the end result is art.<sup>1</sup>

*'Illuminating Loss'* is an oxymoron. Yet alongside the term's grammatical ambiguity, its poetic quality reflects the ambition of this doctoral project to engage creatively with a genetic experience capable of causing much darkness. As such, *'Illuminating Loss'*, a product of research initiated sixteen years ago and continuing today, is not simply a convenient title but provides the overarching idea of the work presented here. The research described encompasses a range of methods and media that are connected by ideas and the production of art, brought together an inherited genetic condition known as myotonic dystrophy. The endeavour has been a long journey with many loops and pathways that have forced me to address why and for whom I practice as an artist, and to what purpose.

It has led to the creation of a number of new outputs in the form of an artwork, a written thesis and a unique collaboration between an artist and a clinical registry. In respect of this dialogical and collaborative dimension of *'Illuminating Loss'*, the project sits as a turning point, where research-based practice has, through process, dialogue and the production of artwork, caused a shift in how certain medical and scientific bodies consider how they see.

In demonstration of the length of this journey, I will begin with a point from the floor, following a conference presentation from my days as an artist who worked with universities, not in them:

Audience: 'There is a real transformation of things, and then it is almost denied. I would compare this panel discussion with a panel

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<sup>1</sup> Jacqueline Donachie, 'Talkin Loud and Sayin' Something – Four Perspectives on Artistic Research'. in Öberg, Johan (ed.) *Art Monitor: A Journal of Artistic Research*, Vol 4, (Gothenburg: Board for Artistic Research of the Faculty of Fine, Applied and Performing Arts of the University of Gothenburg, 2008),111.

discussion about public art twenty years ago. Somebody goes out, like yourself and does a fantastic project and sets up a whole set of new relationships beyond the gallery. Then feels obligated to go back to the studio to do their own work. But their own work is the public work. Everybody talks about change, then go back into this ghetto where they think they will find themselves. I think if you engage in what you have engaged in, when you go back to find yourself, you won't be there. The new thing is what you are doing, and what we are calling research-based practice. It is an in-between practice. Going back is not an option.<sup>2</sup>

At this point, eight years before the submission of this thesis, I held on to the idea that art production was what I did, and had always done, either alone or at times with necessary collaborators. There was honour in forging ahead as the interesting visitor. The purpose of then re-locating this practice to a more formal academic setting was initially managerial and practical; how could I access strangers to participate in the making of an artwork and how could I fund it? Four years later I begin to see what that audience member meant. If I go back now I will not be the same.

This thesis will provide a contribution to the canon of literature that exists in the field of artists-working-with-scientists and scientists-working-with-artists, which charts a unique collaborative process, presented in combination with a new artwork. This is a broad arena but one that remains artistically young; the Wellcome Trust's Sciart programme began in 1996, and from the outset discussions around the interface of two worlds have been questioned, reported and theorised, but quality of artwork has not always been at the forefront of this.<sup>3</sup>

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<sup>2</sup> Audience comment following a presentation by the author at *Talkin' Loud & Sayin' Something - Four Perspectives on Artistic Research*, a symposium organized by Johan Öberg (University of Gothenburg) as part of the 10th ELIA Biennial Conference, Gothenburg, 29 October - 1 November 2008 [<http://www.elia-artschools.org>]; *Art Monitor*, Vol 4, (2008), 110.

<sup>3</sup> For a detailed report on the scheme see: Paul Glinkowski and Professor Anne Bamford, *Insight and Exchange: An evaluation of the Wellcome Trust's Sciart programme* (London: Wellcome Trust, 2009). Particularly Chapters 3 and 5. Also an early conference: *Joseph Beuys Lectures 1996, 'Art and Science': seven lectures addressing the interface between art and science*. Presented by The Laboratory at the Ruskin School of Drawing and Fine Art. Tate Gallery Archive reference: TGA200414/7/3 Audio Arts Joseph Beuys Lectures 1996. Published 1997. <http://www.tate.org.uk/audio-arts/supplements/joseph-beuys-lectures-1996-art-and-science>

The artwork presented here will use methods beyond written academic text – of time, light and emotion – to illuminate multiple iterations of loss. These include the deep personal loss experienced by families affected by inherited genetic illness, the physical loss the condition brings, and the loss of understanding that can arise from medical research that seeks primarily to cure symptoms. The psychological trauma that can arise through such loss is a significant factor, one that requires a method beyond words to articulate; empathy and healing are important emotions to consider here, ones that certain types of art practice show a great capacity for.<sup>4</sup> This doctoral research will thus provide new knowledge in the field of art and genetics but, as quoted at the outset, its end result will not simply be to convey information or formulate answers.

My practice has, in the past decade and a half, led me into a collaborative exchange with a professor of human genetics and teams of professionals within the healthcare community. These individuals are connected specifically by *myotonic dystrophy*. This progressive condition, which symptomatically worsens as it is passed down through generations, affects many members of my immediate family - something that has been well documented in past artistic research outcomes, and which I will revisit in the context of this doctoral study in Chapter 1.<sup>5</sup>

*Myotonic dystrophy* is a form of *muscular dystrophy* (the umbrella term that refers to a whole group of disorders that cause progressive weakness in muscles) and is a complex inherited genetic condition that can cause symptoms, from mild to severe, across three generations of a family due to its extreme variability. This variability makes it a fascinating scientific subject, but causes a significant burden to individuals affected, and their families. For a straightforward description

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<sup>4</sup> See Sandra Johnston, *Beyond Reasonable Doubt: An Investigation of Doubt, Risk and Testimony Through Performance Art Processes in Relation to Systems of Legal Justice* (European Studies in Culture and Policy, Volume 13) for an investigation of performance art and trauma.

<sup>5</sup> *Strength in Numbers*, The Scotsman newspaper, April 30, 2002, 7; Mika Hannula, et al, *Artistic Research: Theories, Methods and Practices*, Gothenburg: University of Gothenberg, 2005, 125-129. John Calcutt, 'The Doctor Will See You Now', MAP Magazine, Issue 8, Winter 2007. 34-39

of the condition I turn to Peter Harper, and his definitive book *Myotonic Dystrophy, The Facts*.<sup>6</sup>

Fortunately, unlike many other medical disorders, myotonic dystrophy is a name that is reasonably easy to remember and explain. The term myotonia is used for muscle stiffness of a special kind, while dystrophy is the name for any inherited muscle disorder in which muscle shows progressive deterioration. Myotonic dystrophy combines these two features – hence its name.

It is a dominant inherited disorder that can be inherited from either a mother or a father, though the severest form – congenital myotonic dystrophy – is usually only inherited from an affected mother. It occurs when a gene has mutated in such a way that it cannot function properly, and any affected individual has a 50% chance of passing it on to their children. It is often viewed as a muscle disease, but those affected could have skeletal muscle problems, heart function abnormalities, breathing difficulties, cataracts, issues with speech and swallowing, cognitive impairment, excessive daytime sleepiness or diabetic symptoms. The variability means that some individuals could suffer from all of these symptoms, some with only a few. Many, such as diabetes or irritable bowel syndrome, are also common in the general population, and this can lead to under-diagnosis as symptoms are not always attributed to the condition by General Practitioners.<sup>7</sup>

As myotonic dystrophy is passed on, symptoms generally appear earlier, and are usually much more severe; for example a grandfather will have had very mild symptoms such as cataracts or muscle stiffness that only appear late in life, but his daughter or son will develop more significant issues with walking, swallowing, speech and breathing in adulthood. The third generation (with congenital myotonic dystrophy in particular) will have severe problems with low muscle tone, ability to walk, speak and eat and will usually have significant learning difficulties from birth. The condition is progressive with no known cure, though

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<sup>6</sup> Peter S. Harper, *Myotonic Dystrophy, The Facts* (Oxford: Oxford University Press, 2009) 3. Harper's book gives an excellent introduction to the condition, written for families and medical practitioners as a general grounding. More detailed professional information is available on a number of websites, particularly that established by the Myotonic Dystrophy Foundation ([www.mytonic.org](http://www.mytonic.org)).

<sup>7</sup> Myotonic dystrophy affects 1 in 8000 of the general population in the UK, but this is thought to be very under diagnosed. (Harper, *Myotonic Dystrophy, The Facts*, 63)

following a decade of unprecedented scientific research, a small number of clinical trials are underway.<sup>8</sup> Often, families only become aware of the condition at the birth of this third generation, as many infants are born prematurely, with breathing difficulties. This inheritance pattern, known as anticipation, can then lead to a three-generation diagnosis being made in a family within a short space of time, as described simply in my 2002 artist book *DM*.

So my dad's symptoms are appearing now that he's in his sixties, my sister and brother are developing problems in their thirties and my niece and nephew have problems all the way from childhood. Which means that three years ago we knew nothing, and now its kicking in for them all at the same time.<sup>9</sup>

As muscle weakness is the main symptom, its effects vary wildly; it can also cause some distinctive appearance related issues – premature balding in men, drooping eyelids and a 'blank' facial expression due to low muscle tone in the face. It is these shared facial characteristics that in many ways drive this study, as I seek to consider issues of inheritance and loss that particularly relate to women who have the condition, and what commonality is inherited, and what is not.

The new research, which forms the core of the present thesis, has therefore focused on locating and interviewing sisters affected by the condition, where one has the faulty gene and one does not. This situation reflects the experience of my own sister and myself, as she has myotonic dystrophy and I do not. Whilst it examines the relationship of female siblings (as opposed to mixed sex siblings or brothers), it does not, however, allude to any significant medical symptoms that are exclusive to sisters, as none have been identified other than the factor of fertility and childbirth.

As just described, myotonic dystrophy is a condition that causes a number of notable difficulties that include physical and psychological disability and a severe decline in mobility, speech and appearance.

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<sup>8</sup> A good summary of current clinical studies can be found on the Myotonic Dystrophy Foundation website: <http://www.myotonic.org/study-trial-resource-center>

<sup>9</sup> Jacqueline Donachie, *DM* (Glasgow: University of Glasgow, 2002)16.

This can lead to social isolation and a fall in economic circumstances, and a major frustration for families is the lack of awareness and understanding of the condition and the loss that it carries physically, socially and emotionally.<sup>10</sup>

It is this point that drives my research – can the artwork illuminate to others what is happening to this group (to us)? The term loss has multiple meanings, and I particularly refer to two of the dictionary definitions:

*the fact or process of losing something or someone | the state or feeling of grief when deprived of someone or something of value.*<sup>11</sup>

Given the above, my aim for this practice-led research is that it should contribute to the scientific and medical knowledge already amassed in the search for treatments and a cure through the production of high quality artwork.<sup>12</sup> However, the distinctiveness of my contribution lies in the way in which it seeks to recognise the significant impact on families, particularly women, and accounts for a number of losses that cannot easily be statistically quantified. Consequently, I begin this thesis with a research question set in response to an experience (frequently dark) shared by many, but one that has yet to be fully understood by either art, medicine or science:

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<sup>10</sup> Laberge, L., Mathieu, J., Auclair, J., Gagnon, É., Noreau, L., & Gagnon, C. (2013). Clinical, psychosocial, and central correlates of quality of life in myotonic dystrophy type 1 patients. *European Neurology*, 70(5-6), 308–315. doi:10.1159/000353991

<sup>11</sup> *Oxford Dictionaries* s.v. 'loss', accessed August 20<sup>th</sup> 2016.

<http://www.oxforddictionaries.com/definition/english/loss>

<sup>12</sup> A definition of 'high quality' within the field of fine art practice is necessary here. For the purpose of this thesis I will suggest a number of criteria that could be applied, either individually or collectively, when assessing the quality of artworks over time; whilst none are exclusive to the term 'high quality', and many artworks of quality do not secure all of these, it is a helpful start:

1. Positive peer review by recognised experts in the field – such as art critic, gallerist or museum curator.
2. Exhibition in a venue of high standing (either public, private or alternative).
3. Collection by a recognised museum, institution or significant private collection.
4. Of Influence to either individuals or groups within specific fields

- By illuminating loss, can artistic interpretation of experience shape research and care in the field of genetics?

In attempting to provide an answer to this, I aim to explore a range of topics that frame my own experience both as a member of a family affected by genetic disability, and as a professional with 20 years experience of creative practice. These topics include the (mis)representation of identity and experience through both visual art and clinical practice, and the capacity of art practice to lead.

*Illuminating Loss* therefore examines the extent to which art practice can shape thinking in the field of genetics, through employing contemporary art in specific reference to a defined group of families, practitioners and scientists. By making this new artwork through close and unique association with a medical resource – the UK Myotonic Dystrophy Patient Registry - and contact with specialist groups of scientists and clinicians who study and treat the condition, the research will seek to demonstrate the leading role of artists and contemporary art practice in offering ways of articulating, understanding and representing disability and inherited illness.<sup>13</sup> This will prioritise personal experience, a topic at the margins of genetic science. Thus, while I insist throughout on the place of my practice within the field of contemporary art, I also explore its potential for providing strong arts leadership across multi-disciplinary collaboration in the academic sector, through a small but significant transformation within a specific group from the field of genetics in how they see.

## ii A word on writing

The approach to writing in this thesis requires a word of explanation. The decision to interpose a personal, reflective writing style, (as seen

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<sup>13</sup> Groups involved are all connected via the International Myotonic Dystrophy Consortium, an international body of scientists and clinicians specialising in DM, who meet every 2 years. There are also a number of active patient and family support groups such as the Myotonic Dystrophy Foundation (<http://www.myotonic.org>), and the Myotonic Dystrophy Support Group (<http://www.myotonicdystrophysupportgroup.org>). <http://www.idmc.org>

on pages 30, 34, 38, 44 and 126, for example) that hew to the conventions of academic writing is the result of ongoing reflection on how best to ‘textualize’ ideas explored in my artistic practice.<sup>14</sup> A personal, creative writing style has formed an integral part of my practice from the earliest days of my career. It has allowed me to work through ideas and it echoes in important ways elements explored through visual representation. Writing is central to my own critical reflection on my work and has unquestionably contributed to the development of my expertise.<sup>15</sup> I would further suggest that the writing style I have developed in tandem with my artistic practice echoes some of the features Lorri Neilson attributes to ‘lyrical inquiry’: ‘liminality, ineffability, metaphorical thinking, embodied understanding, personal evocations.’<sup>16</sup> As Neilson goes on to note, however, these are precisely the methods that have ‘up to now, been undervalued or ignored in scholarly discussion’.<sup>17</sup>

In this context, ‘coming to academic writing’ posed a number of challenges for me.<sup>18</sup> Not least were the associations with ‘objective’, ‘scientific’, ‘rational’ inquiry that can appear to separate it from some of the personalized, even emotionally insightful methods often privileged

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<sup>14</sup> This term is a useful one in a discussion of the translation of ideas into visual form: ‘textualize’ - ‘to render (an oral narrative, for example) in written form, especially in a permanent rigid or authoritative form’.  
<http://www.thefreedictionary.com/textualize>  
or: ‘set down as concrete and unchanging’. <https://www.merriam-webster.com/dictionary/textualize>  
both accessed 24<sup>th</sup> April 2017.

It was first used in the 1980’s, and does not appear in the Oxford English Dictionary.

<sup>15</sup> The term places my writing at the centre of this thesis as it directly informs my art practice. Expertise: ‘expert skill or knowledge in a particular field’.  
<https://en.oxforddictionaries.com/definition/expertise>  
accessed 24<sup>th</sup> April 2016

<sup>16</sup> Lorri Neilson, chapter 8, “Lyric Enquiry” in *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, ed J. Gary Knowles and Ardra L. Cole (California: Sage, 2008), 2.

<sup>17</sup> *ibid*

<sup>18</sup> In saying ‘coming to academic writing’, there a nod to the notion of ‘coming to writing’ that was central to French feminism of the late ‘60s and early 70s (especially with thinkers like Hélène Cixous and Luce Irigaray). Cixous in particular developed theories of *écriture féminine* which were highly influential in the United States. It’s the idea of a ‘style’ of writing not *by* women, but rooted in women’s experience. She claimed some men also used it. For her, it’s defined by a sense of openness to language (it mixes theoretical writing and creative writing) and refuses the sorts of grammatical, structures/systems of other kinds of writing.

in my own training and in the visual arts more generally. Moreover, it seemed to me that part of the ‘expertise’ of the medics and scientists I was collaborating with hinged on an ability to master (understand) a disciplinary language and writing style that are traditionally theirs: as Barone and Eisner explain, ‘the clean methodological ideal is what some scholars want to achieve. Reduction of ambiguity is seen as a paramount virtue’.<sup>19</sup> Yet as these critics also insist ‘when those tools limit what is expressionable or representational, a certain price is paid for what has been omitted’.<sup>20</sup> It is this awareness of the ‘omissions’ of scientific discourse and received knowledge, coupled with a keen sense of the ambiguities and contingency experienced by those dealing with myotonic dystrophy, that persuaded me to hone my thinking on how best to develop a writing style that reflected the meeting of two very different forms of expertise.

From a theoretical point of view, my approach to writing in the current thesis has been informed by influential lines of thinking in anthropology and US feminist literary criticism that prove useful in Chapter 2. The seminal figure in late twentieth-century critical reassessment of ‘ethnography’ —anthropology’s so-called ‘objective, ‘scientific’ method of writing — is James Clifford. Beginning with his introduction to the co-edited *Writing Cultures: The Poetics and Politics of Ethnography* (Clifford and Marcus 1986), Clifford highlights the importance of beginning his reflections ‘not with participant-observation or with cultural texts [...], but with writing’.<sup>21</sup> His point is that ethnography, described by him as ‘writing reduced to method’, has for too long traded on the fact that its ‘scientific’ methods lend it authority.<sup>22</sup> Challenging that authority, for Clifford, involves championing a more inventive, less detached writing style that takes account of the subjective position of anthropologists and that acknowledges the fact that:

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<sup>19</sup> Barone and Eisner (2012), 14

<sup>20</sup> *ibid*

<sup>21</sup> Clifford, James (1986). “Partial Truth’s”, intro. *Writing Culture: The Poetics and Politics of Ethnography*, edited by James Clifford and George Marcus. (Berkeley, CA: University of California Press, 1986), 1-26.

<sup>22</sup> *ibid*

‘the poetic and the political are inseparable, that science is in, not above, historical and linguistic processes. [It] assume[s] that academic and literary genres interpenetrate and that the writing of cultural descriptions is properly experimental and ethical’.<sup>23</sup>

And whilst many will argue that the pioneering work of anthropology is more complicated than that, his contribution here is valuable.<sup>24</sup> Subsequent work by Clifford has persisted with exposing the claims to authority of ethnography and undermining the strategies it has employed historically to bolster ‘an unquestioned claim to appear as the purveyor of truth’ (Clifford 1988, 25). A further refrain of Clifford’s work is his encouragement of anthropology’s scientists to reflect on their relationship to the people/cultures they are studying. For example, in a study entitled *Routes* (1997, 61), he asks: ‘what if someone studied the culture of computer hackers [...] and in the process never “interfaced” in the flesh with a single hacker. Would the months, even years, spent on the Net be fieldwork?’ Regardless of the answer to the question posed, it is hardly a stretch to see how this reflection on observer/participant methods can be transposed to the context of scientific/medical research and artistic practice: must these researchers engage with the subjects of their inquiry? How do they do that? What are the advantages/limits of detached observation? What are the advantage/limits of personalised approaches? What insights would a collaborative approach that enables experts in different fields to come together somewhere between these two approaches provide? These are some of the questions that a focus on writing has shed light on over the course of the making of the film *Hazel*, and subsequently the more personal work *Pose Work for Sisters* (2016), that directly influence the processes outlined in Chapter 2 of this thesis, as I examine if my experience of sisterhood is fieldwork in the sense that Clifford uses.<sup>25</sup> His research is central to top anthropological debates about research undertaken through creative practices. Marcus and Fischer, for example, use his work to explore the ties between surrealism and ethnography in the early 20<sup>th</sup> Century; this demonstrates the latter’s

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<sup>23</sup> *ibid*

<sup>24</sup> See also the work of Bronislaw Malinowski (1884-1942), such as *Argonauts of the Western Pacific*, Routledge, London 1922.

<sup>25</sup> *Pose Work for Sisters*, (2015). Digital film (no sound) 8 minutes, looped. This work is discussed on Page 86 of this thesis.

particular empathy with two kinds of expertise that come into play in this thesis – that of the progressive artist and the experimental sociologist.<sup>26</sup>

Clifford's ideas on ethnographic writing have been developed in a specific political and historical context: colonisation, and post-colonisation and the role that this played in both the emergence and reshaping of anthropology — i.e. the study of 'other' cultures by the Western world — as an academic field of study in itself.<sup>27</sup> What I have retained, however, for my own purposes in this thesis are the following points: 1) the power relations that shape the 'scientific' style of writing and claims to truth used by experts; 2) the need for all 'experts' to be critically aware of this as they work with 'others' as their objects of study; 3) the value of developing more inventive styles of creative representation, including writing, that question aspects of scientific practice and illuminates those who are not always visible.

Connected to my thinking on how best to 'textualize' my ideas through writing has been a consideration: how should I approach feminist theory? As a project that places at its centre female experiences of an inherited genetic condition (whether patients or sisters of patients), the film *Hazel* (and also the larger project of which it forms a central element, *Deep in the Heart of your Brain*), is avowedly, unashamedly feminist. But as an artist-led collaboration with medical researchers, patients and their families (including me and my own family as a point of departure), my work clearly overlaps in very complex ways with multiple areas of inquiry that include genetics, social science, psychology, cultural theory and contemporary art practice. For this reason, I felt that my use of feminist theory had to be developed with my own expertise in mind. I am first and foremost an artist, and if theory

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<sup>26</sup> See: Marcus, G.E. and Fischer, M.M.J. (1986) *Anthropology as Cultural Critique: an experimental moment in the human sciences*, Chicago: University of Chicago Press, 122-125; Clifford, J. (1981) 'On Ethnographic Surrealism', *Comparative Studies in Society and History* 23, 539-564

<sup>27</sup> Clifford is a leading commentator on, and has had a sustained interest in, the problem of writing about first-hand experience. In addressing the problems of anthropological fieldwork at an experimental time in the human sciences, he could have been talking about the experimental writing styles now associated with doctoral research in art schools. In this he differs from other comparable theorists of ethnographic writing such as Clifford Geertz (1926-2006).

was to support and develop my thinking, I needed to find a way to engage with it that was respectful of my own professional position.

A helpful way into the at times impenetrable language of the type of theories I encountered is provided by African American theorist Carole Boyce Davies. Boyce Davies has written extensively about black diasporic culture and often begins with her own family's history of migration from the Caribbean to North America as an anchor for her ideas. She has a healthy, helpful suspicion of the 'authority' associated with the depersonalised language of theory and of the elevation of key figures, mostly male, to the status of 'must-quote' theoretical prophets. In opposition to this deferral to theory's 'authority', Boyce Davies has promoted a form of engagement inspired by a personal anecdote from early twentieth-century African American anthropologist, Zora Neal Hurston. Speaking of encounters with curious white tourists to her village in the southern United States, Hurston recounts how she would sometimes 'go a piece of the way' with them and engage in conversation with them at the same time.<sup>28</sup> Boyce Davies adopts and adapts this to describe her preferred relationship with theoretical discourse. For her, theory is a companion but one whose company she parts from when she feels her 'conversation' with it has gone as far as it needs to or, more importantly, when she, as a black woman, feels she is not being treated as a theoretical equal. Her approach then is one of respect for the contribution theorists can make to her own thinking, but also a cautiousness about being taken in directions where she does not want to go or that are irrelevant to her. It is also, of course an approach that is premised on an assertion of her own authority ('expertise') and the demand that her perspective be listened to, that very succinctly frames my own use of personal 'expert' experience that has brought me into direct contact with another form of professional expertise within science, as described in Chapter 1 (Science art conversations).

To adopt Boyce Davies's approach, as I do here, is not to appropriate the distinctly minority position that is hers. Rather, it is a means to reconcile how I engage with theory. 'Going piece of the way' with theorists such as Goffman and Rancière allows me to recognise the

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<sup>28</sup> <https://genius.com/Zora-neale-hurston-how-it-feels-to-be-colored-me-annotated>

ways with which my practice overlaps with multiple fields of enquiry. It is the basis on which I, as an artist with specific expertise, can engage in a mutually respectful conversation/collaboration with other experts. At times, I travel further along the road with some of these thinkers than others, simply because there is more to share and more to learn specific to my interests. At others, the conversation is brief. It must be stressed that my engagement with theory is not a questioning of depersonalised, 'objective' analysis that is underpinned by 'expert', verifiable fact: the dangers of such a tendency are all too evident in contemporary Western politics. What the 'writing' and 'theorising' of this thesis is doing is paraphrasing the well-known feminist axiom that the personal is theoretical and therefore the theoretical is necessarily personal. In my view, moving between styles of writing that recognise this and engaging theory in a way that is respectful of all expertise is the best way to reflect this.

### iii Thesis Outline

In Chapter 1, *Sciart to 'art and science'*, I introduce the platform on which the current research was built, beginning with my long-term collaborative dialogue with Darren Monckton, Professor of Human Genetics in the Institute of Molecular and Systems Biology at the University of Glasgow. I outline both the personal family circumstances and that led to our connection, the professional and academic worlds that facilitated it and the public outcomes from this period. My own position is considered, 15 years on from that first professional dialogue, and consideration is given to what role I now have within multiple sectors that include family advocacy and care, disability, science and art. Further artworks made beyond this collaborative process are also considered, as are the works of other creative practitioners such as Cathy Wilkes and Patti Smith. Through this section I seek to examine the themes and tropes that permeate my practice, and establish it as a unified activity, undivided by specific content. To this end the term 'sciart' must be examined, as it is regularly used in connection to elements of my practice. I seek to question whether it is a simple grammatical amalgamation, a funder's thematic umbrella or a genre in itself, and if any of these appropriately describe what I do.

In Chapter 2, *Hazel, a Case Study for Art and Science*, I outline the new film work that has been produced as part of this doctoral study. I will present the practice-led methodology involved, outlining the unique collaboration that facilitated its production and the subsequent exhibition and conference screenings that took place during the research period.<sup>29</sup> Reactions from these events, curated for medical and scientific professionals, will be examined, and sections of the film and the primary interviews will be considered in terms of wider academic study with which they intersect, such as feminist theory and qualitative research in social science, particularly that concerned with marginalised and vulnerable groups. Again, as I seek to illuminate loss that is both medical and personal through the film, my own connection to the fieldwork undertaken is significant, as is my professional status as an artist whose practice intersects with both families and medical professionals. The use of portraiture will arise in this section, as it is employed as a method to articulate the emotion of the particular women involved. In addition, this element of the film provides a very distinctive insight into my own circumstances as an unaffected sister that provides new directions for existing academic research in the field.

Chapter 3 examines the question of leadership, particularly in terms of art making and artists – though not exclusively related to that concerned with ‘science’ or ‘health’. Having articulated the methods and theoretical framing of my existing practice, I will then discuss arts leadership across multi-disciplinary academic research, and identify the capacity to lead of individual artists as a significant component of successful, transformational work in a range of settings both personal and professional, as described by Paul Bonaventura in relation to the Laboratory of the Ruskin School at Oxford University:

Good projects help individuals from all walks of life to reassess their activities. In the best cases the collaborations help artists to develop new work from a sound research base, but they also help academics to look at their subject in a new way.’<sup>30</sup>

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<sup>29</sup> I will use the term ‘practice-led’ throughout this thesis, as opposed to practice-based. It accurately describes the ambition I hold for the work, and my arguments toward the capacity of art practice to ‘lead’ in multiple ways.

<sup>30</sup> Paul Bonaventura, *Research in Conversation: Manuscript to Megabyte*, University of Oxford. <http://www.ox.ac.uk/research/research-in-conversation/manuscript-megabyte/paul-bonaventura>.

Artists cited will include John Latham, Beatriz da Costa and Scottish film-maker Karen Guthrie, a broad group reflecting multiple spheres of influence. Boundaries are important here, as it is not the purpose of the thesis to demonstrate the power of art as a *whole* to change the world of science as a *whole*, but rather to show the influence of a particular artistic practice within a specific group of professionals, and the potential of this practice to produce effective artworks that, through the articulation of personal experience, also offer an increased illumination of loss to wider audiences. The nature of 'process' is significant, as I seek to demonstrate the value of collaboration, of 'placement and of dialogue' in comparison to a more illustrative method, where the conveyance of wonderment, new knowledge and technological expertise, for example, become the principle expectations of the artist's role.<sup>31</sup>

#### iv Definitions of terms used

This work clearly addresses a wide and varied field, with many iterations of what can constitute 'art' and 'science'. For clarity, I will define 'art' as contemporary visual art as this is where my own practice is located. This is an important definition, as I see the work presented here as contemporary art practice, operating, at times, with references to and knowledge shared with, experts in the fields of social science, medicine and scientific research.

To reiterate this artistic context for my work, references to a range of artists and work are made, for example, Cathy Wilkes and Sharon Hayes in Chapters 1 and 3. These underline connections and continuities between my own art practice and certain of my contemporaries who reflect on care, isolation and loss using performance, sculpture and installation. Whilst these connections may appear vague in terms of content, method and display, each stems from a very real engagement with both physical and emotional loss that the artist has considered, and they have used their creative practice to

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Accessed 1st August 2016.

<sup>31</sup> Grant H. Kester, *Community and Communication in Modern Art* (California: University of California Press, 2004), 3.

articulate experience that at times, for them, defied words. That they do not stem from either the field of 'science art' or indeed from 'disability' art makes no difference to their relevance here, particularly as in most cases I have taken opportunities to engage directly with the work in a number of ways - through exhibition, and by attending public lectures and events by the artists. Through this process, intersections of practice have been evident in our shared pursuit of understanding aspects of deep loss in what is a populated field.

To define the term 'science', in a thesis that seeks to describe influence across a range of professional bodies connected to the study, treatment and care of people affected by inherited genetic illness, I will cite the open-ended, dynamic terminology outlined by Ian Hacking, and his 2006 paper 'Kinds of People', where 'living sciences' covers the specific area of genetics that is relevant here.

What sciences? The ones I shall call the human sciences, which, thus understood, include many social sciences, psychology, psychiatry and, speaking loosely, a good deal of clinical medicine. I am only pointing, for not only is my definition vague, but specific sciences should never be defined except for administrative and educational purposes. Living sciences are always crossing borders and borrowing from each other.<sup>32</sup>

More generally, a recent definition of 'science' by the Science Council provides a noteworthy intersection with aims and objectives often associated with aspects of contemporary art:

Science is the pursuit and application of knowledge and understanding of the natural and social world following a systematic methodology based on evidence.<sup>33</sup>

The Science Council, 2009

The 'pursuit and application of knowledge and understanding' at the heart of science is something that I also seek through my own art practice, the method used is where the differential lies. Yes, contemporary art can be said to pursue and apply knowledge and understanding of the natural and social world, but it does not always do

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<sup>32</sup> Ian Hacking, *Kinds of People* (London: London Review of Books, 2006), 23.

<sup>33</sup> This commended definition of science was presented by the Science Council in 2009 as an attempt to clarify what it does and for whom it works. <http://sciencecouncil.org/about-us/our-definition-of-science/>

so systematically, nor is it always based on evidence, as is perhaps shown by some of the artworks referenced in this thesis.

As an artist, I would then argue that it is not my remit to provide specific definitions for certain terms beyond those given here, and so some (science, medicine, genetics) will be used interchangeably throughout this thesis; a number of other specific medical terms will occur, including 'anticipation', and 'biographical disruption', and each of these will be explained as they arise.

A further term that arises at this point is 'sciart', a term that has been used to define a range of art practices in the last decade that in some manner intersect with scientific research or medicine. It will be dealt with in detail in Chapter 1, section 1:2

Leadership is a key term. It describes 'the action of leading a group of people or an organisation' and is important to this thesis as I aim to demonstrate the capacity of artworks to shape research and care within a very specific area of genetics, connected through an academic process.<sup>34</sup> To shape is to 'have a great influence on', an aspiration that requires a dynamic, yet considered role for an artist, and I turn here to Mika Hannula's description of research as a 'performative act'.<sup>35</sup> In this text, an early positioning of academic artistic practice in relation to other established methods, Hannula revisits Michael Feyerabend's 1970s book *Against Method* 'in which he openly provoked fellow researchers by stating that we should abandon the illusion of objective science and allow ourselves to follow the rule that anything goes'.

Seen from the other side, from within the wide walls and hopefully high ceilings of a University, artistic research is closely connected with the recent history of and developments in qualitative research. Again, its obvious 'newness' is partly a trick of perspective. There has long been a connection between certain artistic practices and, for example, practices within sociology, anthropology or practical philosophy. These connections are now being intensified since contemporary art has also entered into the university framework. But what is more important is that these interconnections are content-driven. It is very common

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<sup>34</sup> *Oxford Dictionaries* s.v. 'leadership', accessed August 20<sup>th</sup> 2016. <http://www.oxforddictionaries.com/definition/english/leadership>

<sup>35</sup> *Oxford Dictionaries* s.v. 'shape', accessed August 20<sup>th</sup> 2016. <http://www.oxforddictionaries.com/definition/english/shape>

nowadays for artists to use interview methodologies, to do fieldwork or to delve deep into archives, even if the ways they are used and what the end-results look like differ greatly from those of, say, sociology or gender studies.<sup>36</sup>

Hannula's text deftly connects the ambitions of Chapter 1 with the explicit consideration of an artwork in Chapter 2.

To be led by the work there must be some connection to the work itself – as a participant or collaborator, funder, examiner or more generally as a viewer or audience member drawn from the general public. These terms also require definition, as 'audience' cannot be singular here; the plurality of the term, like 'public', is very current in the dissection of the influence of artworks, as it is 'impact' that provides the measurement by which many are judged as a result of the requirements of funding agencies and research councils.<sup>37</sup> I am interested here in the consideration of what specific participants and key audience groups actually gain from their engagement with an artist, and if this can provide a key to assessing the 'benefits' and 'impact' of the work in meaningful ways. Naturally participants' reaction is likely to differ to that of an objective or specialist viewer, and it therefore provides a strong model for analysis in relation to art science collaborative practice, particularly those that are concerned with areas connected to healthcare, disability and wellbeing.

A further significant term that will be used in the thesis is 'expert cultures', used often within contemporary art to describe a practice employed by (some) artists where they seek the expertise of others in the making of their own work – be that conceptual or practical.<sup>38</sup> It is regularly used in relation to the practices that are also described as 'sciart', but through examples and argument I am placing it firmly as a term that describes a much wider range of working practice that specifically comes to the fore during the process of researching and developing artworks, and possibly less in their final execution.

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<sup>36</sup> Hannula, *Artistic Research*, 111.

<sup>37</sup> See the review of 'Pathways to Impact' by Research Councils UK. Accessed 15<sup>th</sup> March 2016 [www.rcuk.ac.uk/innovation/impacts/](http://www.rcuk.ac.uk/innovation/impacts/)

<sup>38</sup> Susan Brind (ed) *Curious: Artists' Research within Expert Culture* (Glasgow: Visual Art Projects, 1999).

Which leads, lastly, to 'collaboration'. This will be used throughout, in ways that refer to my own position as an artist whose practice relies and thrives on the input of others. However collaboration is also understood here as an 'interdisciplinary' fashion that is a necessary force driving innovative academic research that has struggled with what I would term 'Sciart Collaborative Dogma', whereby the artist is assigned the role of the interested and interesting illustrator of concepts too difficult (or dull) for the general public to grasp directly from the laboratory floor. I want to challenge this by outlining a practice that seeks to engage *with* science itself, and not with others on science's behalf. The resultant situation should be where one group has led the other by challenging what they know in order to understand better, and the aim of this thesis is to provoke this from the artist's perspective. Through the development of my own research practice as the primary example, I will identify those I seek to lead, with the aim of illustrating the significance of science as not just a collaborator, but also an audience for the work.

A number of ideas will emerge from my reflections: quality (of artworks, of experience and of 'position'); and multiplicity (in relation to a practice that operates across a range of diverse sectors, engaging through portraiture a number of stakeholders - artists, families, scientists - with the universal need for health and wellbeing. With consideration of the reach of the artworks presented, this thesis asks whether conclusions can be drawn about the articulation of ageing, beauty and loss within a given community, and whether those conclusions, through the making of a new artwork, can go on to shape thinking across a range of stakeholders (patients, scientists, families, the public). This will be caused by a shift in how these groups see and are seen, with the quiet ambition of affecting increased understanding of my own position and that of those close to me.

## CHAPTER 1

### 1.1 Sciart to ‘art and science’

There is expert knowledge, the knowledge of the professionals, and there is popular knowledge, shared by a significant part of the interested population.<sup>39</sup>

This study is based on a platform of collaborative research undertaken between 2000 and 2006 with Darren Monckton that was supported by the Wellcome Trust; phase 1 from 2000 – 2002, funded under the Sciart Research Funding Scheme, and phase 2, from 2003-2006, funded under the Sciart Production Funding Scheme.<sup>40</sup> The research resulted in a number of artworks made both collaboratively and independently, and has resulted in an on-going professional dialogue that has extended well beyond the initial funded period.

In this opening chapter I first outline this earlier work in terms of art, of science and the intersection of both. I proceed to connect it to more recent works by myself that are specific to this particular research and that were made between 2013 and 2016. Through this presentation of a number of artworks, theories and practices that relate to the diagnosis of an inherited genetic condition in my own family, and a discussion of the networks that facilitated the initial collaboration, I will describe the grounds on which the resulting Doctoral research is based. I will also establish the position of this research as leading through the production of quality artworks, in a field populated by a wide array of diverse practice gathered under this heading of ‘sciart’ collaboration.

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<sup>39</sup> Hacking, *Kinds of People*, 24.

<sup>40</sup> The Sciart funding programme was launched by the Wellcome Trust in 1996 to fund innovative partnerships between artists and scientists. See Glinkowski P, Bamford A. *Insight and Exchange: An evaluation of the Wellcome Trust’s Sciart programme*. London: Wellcome Trust; 2009. [www.wellcome.ac.uk/sciartevaluation](http://www.wellcome.ac.uk/sciartevaluation) [accessed 1 November 2009].

The role of the artist within a long-term interdisciplinary relationship is also examined in order to outline the latter's potential for leadership in academic, scientific and artistic settings. This leadership is shown to stem from professional status and also from the direct representation of personal experience. For clarity, I use the term 'sciar' to describe practices that connect two separate professional fields. At the same time, I am careful here to clarify the distinction between certain artistic methods that are commonly assembled under this heading. My aim is to question how relevant this condensed appellation is as a term; is it the meaningful intersection of two distinct disciplines in order to create a new form or is it a convenient grammatical merger? For the purpose of this thesis, I would use it as a term to describe artworks that in some way reference science – be that through a collaborative process in development or execution, or in terms of audiences that the artist seeks to address.<sup>41</sup>

The term 'expert cultures' will be key here, as I ask if many of the artworks that are cited as being 'collaborative' are in fact examples of artists making good use of the skills and knowledge of other experts – whether that be in practical, aesthetic or theoretical terms – in the production of their own work.

Thus this chapter begins to navigate the questions set out in the introduction. It examines the position of the artist in relation to science and medicine against a background of personal experience that is used to articulate, and publicly illuminate, disability and loss.

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<sup>41</sup> A detailed evaluation of the Wellcome Trust's Sciar programme which ran from 1996-2006 was published in 2009 (previous footnote), a section of which considers the introduction of the term 'Sciar', and the Trust's decision to change the scheme name to 'Arts Awards' for its relaunch in 2007: 'A number of interviewees expressed reservations about some of the associations that were perceived rapidly to have accrued to the label 'Sciar'. There was a sense that the brand had transcended its original function as the descriptor for a funding programme and had assumed much wider currency as a shorthand term (often incorrectly applied) to describe a genre of arts practice. The consequences of this were often felt to be negative. The use of the label was felt, for example, to have contributed to an unhelpful or unfair ghettoisation of arts practices that were concerned in some way with the sciences.' Pg. 29, Glinkowski P, Bamford A. 2009. [accessed 1 November 2009].

## 1.2 Diagnosis and Sciart

The initial collaboration between myself and Monckton was facilitated by a small research grant from the Wellcome Trust, awarded in 2000 under the Sciart scheme.<sup>42</sup> I had approached the Division of Molecular Genetics at the University of Glasgow with an enquiry about working together, following the diagnosis of myotonic dystrophy in my sister and her two children. The condition was subsequently diagnosed in my father, brother, and several members of our wider family.

Following the diagnosis, I sought to learn more about it in ways that would inform my own artistic practice. Key to this initial response was writing, a medium I often use as a basic research tool in my practice. Alongside more conventional academic prose, this more personal style of writing features as a key element of my thinking in the present study, and its inclusion throughout this otherwise scholarly work mirrors my introduction to the world of scientific expertise as described in the introduction. I explain its role in the following interview with Mika Hannula, referring to the condition as *DM* (also the title of the book).

...the writing I do that informs the art work is not narrative, it's more like poetry, not clearly defined instructions. A clear example is the *DM* book, addressing issues between my sister and I. It was not originally written as a text for a book, but for myself, to clarify what was going on for us at a difficult time.<sup>43</sup>

The initial funding was used to initiate a short residency in the department of Human Genetics at the University of Glasgow, followed by a research trip to the Saguenay region of Quebec in Canada in 2001. This Canadian visit was prompted by a paper by a group of Québécoise scientists that outlined the prevalence of the condition in this isolated, rural area.<sup>44</sup> The residency and this field trip, whilst having

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<sup>42</sup> For a further appraisal of this scheme see Georgina Born and Andrew Barry, 'ART-SCIENCE: From Public Understanding to Public Experiment', *Journal of Cultural Economy*, 3:1 (London: Routledge, 2010), 103-119. Accessed 26<sup>th</sup> May 2015.

<sup>43</sup> Öberg, ed. Hannula, *Talkin' Loud*, 38.

<sup>44</sup> Jean Mathieu *et al.* Myotonic dystrophy: clinical assessment of muscular disability in an isolated population with presumed homogeneous mutation. *Neurology* 42, (1992): 203-8.

no specific outcome requirement, resulted in the artist's book *DM*, cited earlier and quoted again here:

I began to work with some people who did a lot of research into the gene itself, and they gave me lots of scientific papers to read. One in particular stayed with me, about a place in Quebec, in Canada, that had an instance of the disease 10 times that of the national average – a strong 'founder effect' they said. There was also the theory that everyone who has this are descended from the same family. So if we went there, my sister and I, would we look familiar? <sup>45</sup>

Initiating that first collaborative phase, or perhaps simply making direct contacts with individuals working in this field, led to the second stage of the project where I began to look more closely at the science involved with my family's very complicated genetics.

Production funding from the Wellcome Trust facilitated this second longer, collaborative period of work, resulting, in 2005 and 2006, in the film, exhibition and book *Tomorrow Belongs to Me* that charted, through interview and film, the scientists whose research finally identified the disputed phenomenon of anticipation.<sup>46</sup> Here, the research base widened considerably. I moved away from a personally reflective period into a broad and exciting scientific discourse. My tiny, very sick niece was continuing to improve and no-one else had any particularly onerous symptoms: an elderly father whose balance wasn't great, a sister, with two young children, who got very tired in the afternoon and could no longer walk on her tiptoes, a brother whose hands froze when he gripped something tightly. Nothing unduly troubling.

They continued with their lives and I continued with mine.

On reflection, the progression of work from *DM* to *Tomorrow Belongs to Me* charts a journey of both discovery and of loss. Whilst *DM* is all about the discovery of a genetic fault within a family, *Tomorrow*

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<sup>45</sup> Jacqueline Donachie, *DM* (Glasgow: University of Glasgow, 2002), 6.

<sup>46</sup> Anticipation is the phenomenon that causes certain genetic disorders such as myotonic dystrophy to worsen as they are passed down through successive generations, often causing a three-generation manifestation in a single family. See Jacqueline Donachie and Darren Monckton, *Tomorrow Belongs to Me*, (Glasgow University, 2006), 15; Harper, *Myotonic Dystrophy the Facts*, 57-59; Höweler et al, Anticipation in Myotonic Dystrophy: fact or fiction? *Brain* 112 (1989): 779-97.

*Belongs to Me* discusses the wider scientific history that frames an individual diagnosis. Within our family the initial loss was small and the gains high; my sister's premature baby disturbed all that we knew, but as she strengthened and slowly moved out of her incubator, our confidence increased. Our knowledge was days, weeks, months old, framed by a neo natal unit and protected by knowing no-one else with the same thing. None of us knew the long game.

I suppose that you could say that our knowledge will always be as old as my niece. So by the time she finally came home from the hospital, 10 weeks old but still so very tiny, we knew that her brother also had the gene mutation. When she started to walk – slightly later than her younger cousin, and with a bit of help from physiotherapy and fiberglass splints – we had worked out that some of the other niggling things that affected my sister, brother and father could also be related to this thing.<sup>47</sup>

The work made was well received and offered a broader awareness to others (both within and beyond our immediate circle) of what was happening to one section of a close-knit family.<sup>48</sup> I had achieved what I had set out to do – to find out more about the condition that had invaded my family life. I had done this by securing access to, and dialogue with, a professional community with the capacity to teach me much more about all of it. This concept of personal understanding gained through collaborative working aligns to what artist Sharon Hayes describes in an interview in *Frieze* magazine from 2010:

I am interested in a range of collaborative practices because it is through dialogue and exchange with colleagues, friends, students and lovers that I am most able to understand myself in the world.<sup>49</sup>

### 1.3 Science art conversations

One factor in the events described above is central to this study: it was through my professional identity as an artist that I gained remarkable access to the freezers and whirring machines of human genetics research laboratories, and to conferences and scientific meetings. It

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<sup>47</sup> Donachie, *DM*, 6

<sup>48</sup> Feature article: *Strength in Numbers*, *The Scotsman*, 7

<sup>49</sup> *Sharon Hayes. Speech Acts*, interview with Roger Cook, *Frieze* (March 2010). Accessed 18<sup>th</sup> January 2016.

was not my status as a family member. Therefore it was through my art practice that I received a white coat and a name badge and the door codes to a world abounding with knowledge; a world as described by Maurice Merleau-Ponty as 'closed', in contradiction to the world of the arts, which he refers to as 'open': 'science manipulates things and gives up living in them...[it] comes face to face with the real world only at rare intervals.'<sup>50</sup>

It is thus my art practice that gained me a unique and specialist position within the closed world of science and led to the collaboration underpinning *DM* and *Tomorrow Belongs to Me*. It is my art practice that has, in turn, led to this doctoral thesis and a further investigation of both the capacity of the artist, and of the patient, within academic research.

Whilst Merleau-Ponty's description of science as an exclusive and 'closed' domain is something that has been challenged in recent years, I would argue that it has not completely disappeared.<sup>51</sup> The concept of 'closed and open' worlds continues and is tellingly illustrated in the juxtaposition of two physically adjacent institutions that are key to *Tomorrow Belongs to Me*: a University of Glasgow genetics laboratory that is difficult to access without a pass code and the same university's Hunterian Art Gallery that is freely open to all. Their proximity on the university campus where research for much of my project was carried out suggests it is worthwhile considering more closely, in further research beyond this study, these notions of 'closed and open' worlds.<sup>52</sup>

During my short residency in human genetics, I was, essentially, the 'real world'. This became apparent through many conversations in the

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<sup>50</sup> Maurice Merleau-Ponty, *The Primacy of Perception* (Northwestern University, 1964).

<sup>51</sup> One example would be the requirement of some funders to make academic research available publicly, as in the 'researchfish' initiative adopted by Research Councils UK in 2014. [www.researchfish.org](http://www.researchfish.org)  
In terms of challenges to Merleau-Ponty, see Jerome Melançon; Thinking Corporeally, Socially, and Politically: Critical Phenomenology after Merleau-Ponty and Bordieu, *Bulletin Analysis Phenomenologique*, Vol 10, 8: 312. Accessed 31<sup>st</sup> August 2016.

<sup>52</sup> Giorgio Agamben's *The Open: man and animal* is a potential starting point.

lift or cafeteria regarding why I was there: *'Oh you're an artist, how interesting... 'Where did you study? What do you paint?'* There was always an enthusiastic response from researchers whom I had come to see worked in a very similar environment to my own. Yet, when the fact that my artistic role was influenced by my family's genetics became clear, it led, at times, to uncomfortable silences, where researchers struggled to relate the person standing next to them in a lift with a sample of tissue they had sitting on their desk in the laboratory. No-one in the lab at that time had any personal knowledge of the condition. In that instant, I assumed two roles, each with a very different relationship to science.

Firstly, there was my role as an artist, where the connection I had with staff in the laboratory was co-professional, our status remarkably alike – educated beyond degree level, working hard to build a career, new mortgage, young children, mid-way through a life that held exciting possibilities. Secondly, my status as a member of an affected family, where the relationship was...

What?

Here, I struggle to find an exact term to define this relationship. Subordinate? Indebted?

Unequal.

Whilst I have regularly argued the veracity of these 'lift encounters' with the scientists whom I have now known for over a decade, they don't remember it as I did, and refute the allegations of awkwardness. They say I was mistaken.

And yet, I know how I felt. And I felt it keenly.

This conundrum of positioning is also reflective of the assertion of one or two scientists that working with an artist does not affect their research *in any way*. Is this because I cannot offer them a cure for the condition they are studying, instead representing a gap in their

knowledge (from my family's position of impairment) that their skill has yet to fill? If this is the case, the first question that must be asked is this:

Why has this no impact on their research?

Again, I will acknowledge that here I stray from accepted scholarly language to a more personal, emotional interpretation of events. It is appropriate as a method to balance my own position – as coming from a tradition that values emotional response – when faced with the objective, fact-based realities of scientific research that involves the interruption of subjective emotion. I am not saying that my emotive response trumps rational argument, simply that I seek a method to make such feelings tangible within the scientific world I encountered.

Is the distance between experience and research so great that personal experience can have no impact? Motivation is an important consideration for artists that is sometimes not identified as readily of science, though many examples exist.<sup>53</sup> This is one aspect that I seek to address thorough the production of new artworks. I return therefore to my position as a professional, to demonstrate that outcomes are not as readily defined in my world as in theirs – a world that seeks new treatments, drugs or hard data. Perhaps it is this that could account for any reluctance to acknowledge influence. As I outlined in the introduction, I seek to challenge the distance between science and representations of experience; this gap remains wide, and will remain so if collaborative science art practice leans overly toward simply illustration and explanation of complicated processes or data.<sup>54 55</sup>

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<sup>53</sup> One example of the emotional engagement of scientists and how this can drive their research can be found in James Watson's book *Double Helix: A Personal Account of the Discovery of the Structure of DNA*, (New York: Alfred A. Knopf, 1969; 2002).

<sup>54</sup> An example of I would cite of an illustration of a complicated process is *For Now We See*, (Video Installation, 2013) by artist Mariele Neudecker. The work is described as made 'in collaboration' with marine biologist Alex Rogers, at Oxford University. Rogers role was to give Neudecker 16tb of film footage of the ocean floor, already recorded by his research group using state of the art technology - it is a part of the world that we know less about than the surface of the moon. Neudecker then manipulated the footage using sound. The work was first shown at Newcastle Science Festival in 2013, then at the Wellcome Trust Gallery in London in 2015.  
<https://wellcomecollection.org/exhibitions/now-we-see>

In this case it bears repeating that the moving, talking beast that is genetic illness does not just exist in anonymous, static cell samples, but is embodied in individuals. And often those individuals have very similar aspirations to scientists, and they continue to have much to offer the world that studies them. To paraphrase Ian Hacking, rogue genes inhabit all kinds of people.

#### **1.4 Science art mirror: how scientists see**

Continuing with this theme, I would therefore then ask: can engagement with an artist, whose position in the world is by its very nature open, questioning and un-resolved prompt scientists to reflect on their own attitudes to research and care in ways that a disengaged illustration of their professional practice cannot? Could such an engagement then cause a shift from recognised representations of the relationship between illness and science that tends to present them as emotionally distant from each other? In reflecting on collaborations from a position of long-term exchange, can one artistic outcome be a challenge to how scientists see? With regard to my own work, Mika Hannula suggests it can:

Donachie's most coherent and focused research is also a very good example of research practice that can combine, in a fantastically fruitful manner, a position that brings together a highly personal point of view and motivation with a perspective of addressing the same issue via more common and general views. When put into philosophical parlance, it is about how the particular is connected to the universal, how a detail connects to the whole, and how out of something subjective meeting something objective something unique and special can emerge.<sup>55</sup>

A further example comes from the previous Donachie and Monckton research. The film *Tomorrow Belongs to Me* is based on a series of interviews with scientists and clinicians who were directly involved with the discovery of the myotonic dystrophy gene, and the inheritance

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<sup>55</sup> A compelling example of an artwork that references science very directly beyond illustration and explanation is Stephen Farthing's *Cleft Surgery and Facial Appearance* (begun in 1997), that was commissioned by the Ruskin School of Art in collaboration with Guy's and St Thomas' Hospitals Trust and supported by funding from the Wellcome Trust.

<http://www.rsa.ox.ac.uk/research/detail/stephen-farthing-cleft-surgery-and-facial-appearance1>

<sup>56</sup> Hannula, *Artistic Research*, 126.

pattern of anticipation, as seen in several genetic conditions. It concludes with a very direct quote, provided in full below, from Nancy Wexler, an American geneticist who has worked tirelessly toward firstly a test for Huntington's disease, and now a cure.<sup>57</sup> She is herself at risk of the condition, having lost her mother to the illness in 1978.

So I think we just have a massive amount to learn and I think that what's even more crucial, is that we have a huge amount to learn in terms of therapy, because even with our phenomenal sophistication about the DNA and what's happening, and the paradox is solved... We can diagnose Huntington's disease unbelievably precisely. Can we treat it? No. The treatments for myotonic dystrophy, they're sort of make-shift and organ specific, and can we treat the disease? No. What can we do for fragile X? Nothing. I think with Kennedy's disease people are trying taking the androgen receptor away; well, making you not a man doesn't necessarily cure that disease ... So I think our bag of tricks in the treatment department is very hard, we really have a huge amount to do. But the beauty is, that since we dropped our prejudices and are willing to look at anticipation, and are willing to look at expansions, and say these things actually exist and they're explicable on a molecular level, and you know, maybe there are other therapies out there, maybe they're suggesting other therapies that we really haven't thought of. Because I think that's really the point of doing all this.

You know it's fascinating, it's beautiful, it's aesthetic, it's gorgeous, but in the end... people are dying.<sup>58</sup>

As she says the words 'but in the end, people are dying', the film ends, fading to black silence. Creatively, I could not have wished for a stronger quote to end, and Monckton also immediately saw the power of Wexler's words. It brought immense impact through forcing a pause, a moment of silence to reflect on the vastness and urgency of the work still to be done, and the human consequences of this. Yet many

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<sup>57</sup> Huntington's disease is a fatal neurodegenerative genetic disorder that affects muscle co-ordination leading to mental decline and severe behavioral symptoms. Nancy Wexler's most important scientific contribution is the work she has done on Huntington's. In 1979 she learned of the world's largest family with the disease living along the shores of Lake Maracaibo, Venezuela. For 13 successive years she and her colleagues studied the disease in hundreds of patients and persons at risk. They constructed a pedigree of over 15,000 people, collecting blood samples from 3,600 people in the family. These samples led to the discovery of the Huntington's disease gene at the tip of human chromosome 4. With this knowledge, a new pre-symptomatic test was developed which can tell, for the first time, who is carrying the fatal gene and who is free, prior to the onset of symptoms. These same blood samples have also aided in the mapping of other disease genes, including those responsible for familial Alzheimer's disease, kidney cancer and two types of neurofibromatosis, manic depression and others. See Donachie and Monckton, *Tomorrow Belongs to Me*, 98-124.

<sup>58</sup> *Ibid*, 124.

researchers from the scientific and medical community questioned this ending when it was screened at an international genetics conference.<sup>59</sup> Why conclude with something so negative when so much progress has been made? Why connect failure (death) to their (successful) scientific research that has just been presented to colleagues?

One answer might be that the desire to portray scientific research as 'successful' and also therefore as 'complete' within its own field is strong, a parallel with the desire for a tangible outcome, fit for exhibition, from creative agencies and funders in the world of art. It emphasises the connection between success and quality, but also of success and fundraising. For fundraising, in science as in art, is widely used as the criteria for host institutions and peers to judge the 'success' of research.<sup>60</sup> Therefore in science - as in art - fashion, popularity and visibility can be central to what is viewed as high quality, which is reflected in, and closely linked to, to the ability to attract funding. Clearly, these notions are significant (in terms of both art and academic practice) and in the following chapter, they lead me to discuss the place of the *unseen*, domestic experience of marginalised and 'unfashionable' groups, such as ageing, disabled women. Though by no means common, this experience is at times privileged in academia through very specific research groups such as the Women's Workshop on Qualitative Family/ Household Research at Oxford Brookes University, and is also relevant to the *Hazel* research.<sup>61</sup>

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<sup>59</sup> The film was premiered as the closing event at IDMC-5 in Quebec City, Canada on 22<sup>nd</sup> October 2005, and has since been shown widely at scientific, medical and art conferences. The incident described here took place at Quebec airport, in a discussion with a group of delegates who had attended the screening and were now travelling home. These included Professor Darren Monckton, University of Glasgow and Dr David Hilton Jones, Consultant Neurologist at Radcliffe Hospital, Oxford.

<sup>60</sup> For further examples, I would cite research into autism, a condition that has seen massively increased diagnosis in the past 20 years, and that has a public profile raised by very active family associations. In the US, funding has increased annually, with grants in the field rising by around \$51 million each year. Yet this research has, as yet, achieved very little success in terms of scientific understanding of any genetic cause, or possible medical treatments. Attention is now turning to acceptance and care.

See Steve Silberman, *Neurotribes: the legacy of autism and how to think smarter about people who think differently* (London: Allen and Unwin, 2015), 13-15

<sup>61</sup> See Jane Ribbens and Rosalind Edwards, *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives* (London: Sage, 1998)

It is necessary to raise this connection of success, quality and funding when discussing the production of artworks and the capacity of artists to reflect science, with practice that presents not just a window, but also a mirror to a world that has been established as closed. Access for artists is important, as is long-term dialogue, facilitated by schemes such as the Wellcome Trust. However, so too are the terms under which these artists are engaged, the ambitions they hold, and the role they occupy. It is a combination of these that in turn will produce quality work. In particular, where the interface they facilitate provides a setting for artists to communicate directly with science, presenting a very personal motivation and a less tangible outcome that has, perhaps, been distorted by notions of fundability, quality and success.

### **1.5 Science, art and a survey of my approach**

If we are going to look at how an artist can illuminate through multiple positions that include their role, experience and position, it is also necessary to define the practice itself that extends beyond the very specific sciart dialogue. In order to do this, I look, in what follows, at further examples of my work whose connections to the *Hazel* project may not be so immediately obvious.

In addition to the Wellcome Trust funded collaboration that resulted in the film, book and exhibition *Tomorrow Belongs to Me*, what other artworks by myself can be cited to establish my broader practice as singular and distinctive in its interpretation of personal experience? Discussion of artworks that developed over the same period as the *Hazel* research (2012-2015), allows me to further contextualise the way that my 'art and science' research sits squarely within the themes and tropes of my overall artistic practice, sharing method and approach with production that also involves personal experience, and that moves between celluloid and metal, drawing and print.

A number of works made in 2014, including a series of sculptures and drawings made for both public and gallery settings, are particularly suited to this task. The works are significant in terms of scale and ambition, and of materials used; aluminium and steel, drawing and

print. They form the core of my practical work, and in introducing them here I hope to underscore a particularly productive time of analysis through production that ran in tandem with the interviews and editing of the *Hazel* study, that will be discussed in detail in the next Chapter.

Several pieces were made in response to a solo journey made around Scotland in early 2014, and to the ongoing research into my position within a family affected by disability, in particular solo exhibitions at Leamington Spa Art Gallery in 2014 and at The Gallery of Modern Art in Glasgow in 2016, where *Hazel* was exhibited publicly for the first time.<sup>62</sup> In narrating reflectively the development of these works I seek to consider if their association with difficult emotional journeys can relate to other areas of practice where almost identical materials are used. In doing so I also pose a number of questions that relate to this thesis's wider consideration of *Illuminating Loss*. I explore the themes that have emerged in this time, and the influences, both personal and social, that have impacted on the development of the works.

A large black metal box with a ramp. Immobile. Threatening. Heavy and difficult to move, the work sits on the floor of the gallery. The metal is textured checker plate, a familiar surface in industrial settings, stations and ferry ports. Sturdy, non-slip, often seen painted, usually scratched and scuffed through heavy use.

The use of a common industrial material in the work, thick aluminium checker plate, builds on earlier pieces using steel and aluminium scaffolding tubing such as *Winter Trees*, 2008 and *Winter Trees II*, 2013. The material formed the basis of several new pieces in 2014, with the gallery works shown alongside fragile drawings on paper. Through referencing ramps, a recurring thought is of their use; access for cars, vans, prams, trolleys and wheelchairs in settings that require a step or gap to be circumnavigated, avoided or conquered. These particular references to travel and navigation have been informed by another new piece from that year, an artist's book and series of mobile

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<sup>62</sup> *Keep Up: New Work by Jacqueline Donachie*. Leamington Spa Art Gallery and Museum, Leamington Spa. 16 September – 16 November 2014. *Deep in the Heart of Your Brain*, Gallery of Modern Art, Glasgow. 20 May – 13 November 2016

sculptures titled *New Weather Coming*, commissioned by the National Galleries of Scotland. As I mentioned earlier in the thesis, the book, in particular, is an example of the particularly sparse style of writing, also seen in *DM* and other artists books by myself, used to provide a reflective pause, an appraisal of my own position and thinking at a given time.<sup>63</sup> I will discuss these pieces first. I will also abandon momentarily the more rigid conventions of academic writing and allow the more reflective qualities of my writing practice to convey the thinking that informs these works, as is referred to in section ii of the introduction through a brief reference to James Clifford and his attention to the mingling of academic and non-academic styles of writing.<sup>64</sup>

The research process for *New Weather Coming* included, early in the project, a seven day journey through Scotland using public transport. This was a solo trip that began with a single flight to Lerwick in Shetland, and ended when I reached home, just outside Glasgow, a week later. I journeyed down and across the country on trains, boats and busses, with no exact plan other than to visit new or long forgotten places on routes mapped out each day. Oysters in Oban, the Kyle of Lochalsh train from Inverness, the Armadale ferry. Destinations were mainly holiday places, nothing remote or undiscovered, very much influenced by summer travels from my childhood when, as my parents did not drive, all journeys began at the local bus stop or train station.

Your mind can wander on these trips. No computer or phone was a rule, so I took notes and read books, watching from the back of the carriage as we went from one terminus to the next. The journey thus provided a very focused time of observation. I watched a lot of travellers move on and off trains, I queued with many, helped others with bags, luggage, shopping and at times had to seek assistance myself. Regular journeying experiences, heightened by being alone

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<sup>63</sup> Jacqueline Donachie, *New Weather Coming*, artist's book (Edinburgh: National Galleries of Scotland, 2014). An edition of 5000 copies distributed around transport networks in Scotland throughout summer 2014, to accompany a series of mobile sculptures sited in ferry, train and bus stations. Commissioned by National Galleries of Scotland for *GENERATION, 25 Years of Contemporary Art in Scotland*, 2014.

<sup>64</sup> Section iii, Page 20 of this thesis.

and tasked with a notepad and camera to both 'document' and 'research'.

I noticed families like my own, filling a day on a train. Busy chattering people, quiet slow people. Children. Sandwiches. Avoiding commuter routes, and commuter times, I encountered the more wistful travellers, noted relationships unfold and occasionally unravel, on journeys so different in intent and expectation than those taken by commuters. The trip resulted first in a new artist book, distributed over the course of summer 2014 on various transport routes around the country, and a family of three itinerant mobile sculptures placed at points on these routes throughout the summer, points where travellers change from one kind of transport to another, such as boat to train, or train to bus.

The title *New Weather Coming* came from a description in Kathleen Jamie's book *Findings* where she describes the ever-changing weather on the island of Orkney – a very Scottish phenomenon, to watch the rain or sun move across the sky towards you.

No Orkney weather lasts long, and you can see new weather coming a long way off.<sup>65</sup>

I read the book on my journey, and that passage recurred often, later perfectly fitting the transient, ephemeral heading I sought to describe a project that encompassed both heavy sculpture and a spare, minimal book of text and photographs.

The sculptures were built onto trailers, flat packed, with hinged metal plates, easy to tow and to assemble on site, scaled at 4, 10 and 16ft long and all able to fit within a car or bus parking bay when sited. Once installed, and wheel-locked, the trailers were left to survive alone for periods of up to two weeks, a solid green thing, robust enough to be climbed or sat upon, with just a small label indicating its status as a sculpture. The sturdy metal checker plate used was 6mm thick and powder coated a matt RAL colour (RAL 6018), the colour carefully selected to match a luminous 'super green' of grass that appeared in

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<sup>65</sup> Kathleen Jamie, *Findings* (London: Sort of Books, 2005), 7.

several of my photographs, from Shetland in the north, to the Cowal peninsula, closer to home on the Clyde coast south west of Glasgow. Again, fleeting colour, seen when the sun breaks amid a storm to momentarily illuminate a hillside patch of velvet green grass. I was interested in the convergence of the harsh materials of lorries, ferries and ramps always seen at these stations and ports with a soft, luminous element of landscape, fleetingly captured. The texture and tone of the Scottish landscape towed on a robust frame, to be glimpsed at a ferry terminal/car park/bus stop somewhere on a journey, on a day that a stranger handed you a book.

While the book was distributed freely, far and wide across the country, from some of the venues participating in GENERATION to passengers on various train, ferry and bus routes, the sculptures were transported to different locations across Scotland during the summer of 2014, positioned at points of transition or departure – places defined by what lies ahead: the next leg of the journey. Strange wordless sign-posts to journeys, or suggestive thresholds between one place and another, between work and holiday, between town and country, embodying the shift to a new place and the hopeful anticipation of the traveller.<sup>66</sup>

The artist's book is the tenth in a series I have produced intermittently since the early 1990s. These books are always conceived in relation to specific exhibitions and projects, and the distribution of them is a relevant, if changing, factor. Whilst 'art' mechanisms are mainly used, some have much wider audiences due to their own specific concerns. *DM*, cited earlier in this chapter, is now mainly distributed through the genetic research and support charities associated with myotonic dystrophy such as The Myotonic Dystrophy Foundation in the United States, and the Myotonic Dystrophy Support Group in the UK. *New Weather Coming* was always intended as a book for travellers, something to come upon in random situations, and so over the course of Summer 2014 a team of 'guides' were recruited to distribute the

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<sup>66</sup> Katrina Brown, curator's text for *New Weather Coming* leaflet, 2014.



FIGURE 1

- (i) Donachie, Jacqueline. *New Weather Coming*, 2014.  
Powder coated aluminum on trailer base, dimensions variable.  
Touring, 25<sup>th</sup> July – 15<sup>th</sup> Aug 2014, and shown installed together at Glasgow Sculpture Studios, August 2015.
- (ii) Donachie, Jacqueline. *New Weather Coming*, 2014.  
Artists book. Published by National Galleries of Scotland, Edinburgh.  
Edition of 5000 copies distributed on transport networks around Scotland in summer 2014.

books on selected rail, bus and ferry routes – usually tied to where the sculptures were located at any given point (the term *random* here is not coincidental. Its introduction points to a broader relevance that is discussed below and in the following chapter). The books were handed to individual travellers at some point in their journey, often in a transaction that involved conversation or discussion. They were never left on seats or in stations with the expectation that they would be picked up, nor were they randomly distributed in the manner of many free magazines or promotional leaflets. The content of the book is spare, a series of short text works carefully typeset in black and white, observations from my travels that may connect with the reader as they stare out of the window, electronic devices drained, during their own journey.

Two short narrative texts are also included, and at the end a series of photographs from the initial tour made in March 2014 with some information about the overall project. I enjoyed the random nature of the audience for this element of the work, wondering about where the 5000 copies distributed ended up, and the fact that it existed on several platforms: as an individual exchange, a chance encounter or later, as an edition available from participating GENERATION venues. The work also existed more widely on social media sites over that summer; the hashtag #newweathercoming was used in the book, and also via the GENERATION Twitter feed and website.<sup>67</sup>

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<sup>67</sup> Twitter account used for the project: @genartscot (live postings ended 31<sup>st</sup> December 2014).



FIGURE 2  
Donachie, Jacqueline. *New Weather Coming*. 2014.  
96 page Artist Publication, National Galleries of Scotland, Edinburgh.  
Sample page.

And so I navigate from a solo journey, to a static sculpture. A loop to connect a number of interlocking parts of life. Reflecting on this work, it's a simple line to take; a tour, water, islands, travellers, mystics, drop outs, students, carers, young families. Hills, landscapes, headphone music, boats and trains. Patti Smith via Robert Burns via Woody Guthrie via Gourock.<sup>68</sup> Ramps, trolleys, dogs. Assisted passengers, unclassified tickets, colours, textures, sunshine, darkness.

Journeys that are embodied, in sculptures and in words.

... there is a gap there, and I think that that gap is very much filled with the notion of 'participation'. And I think that 'participation' and 'communication' are some of the big things that can maybe get carers through terrible times.<sup>69</sup>

This in itself is a description of loss, and is one that continues through *Deep in the Heart of Your Brain is a Lever*, the static sculptural work referred to at the beginning of this chapter, now framed by a travelogue, a family of itinerant mobile sculptures, and an impressionistic pocket-sized book.

The title of the piece is taken from a Patti Smith lyric, from the title track of the album *Radio Ethiopia*.

Deep in the heart of your brain is a lever/  
Deep in the heart of your brain is a switch/  
Deep in the heart of your flesh you are clever/  
Oh you met your match in a bitch.<sup>70</sup>

Released in 1976, at the time this second album did not receive the acclaim of The Patti Smith Band's first seminal piece, *Horses*. Featuring poor sound quality, wandered lyrics and irregular vocals, the band and Smith herself were at their most experimental and uncompromising. Though now the album is viewed as a classic work,

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<sup>68</sup> I refer here to Woody Guthrie, and the poem *To That Man Robert Burns*, 1947 (published in anthology, Guthrie and Robert Shelton (ed), *Born to Win* (New York: Macmillan, 1953). He wrote the poem in tribute to Burns, having acquired a book of his songs and poems when stranded in Gourock with the US Merchant Navy after his ship was torpedoed during WW2.

<sup>69</sup> Jacqueline Donachie in conversation with Chris Dorsett, Leamington Spa Art Gallery, Friday Focus event, 24<sup>th</sup> October 2014.

<sup>70</sup> *Radio Ethiopia*, Patti Smith Band, Arista Records, 1975.

embodying much of the fluctuating emotions of that time, it struggled for either critical or popular acclaim at the time.

Radio Ethiopia is the name of our new record and it represents to us a naked field wherein anyone can express themselves. It's a free radio, ya know. We're the DJ's. The people are the DJ's. When we perform "Radio Ethiopia," I play guitar. I don't know how to play guitar, but I just get in a perfect rhythm and I play, I don't care.<sup>71</sup>

Yet the lyric used here, synonymous with chaos, has often spoken to me of care. Of moments found deep within, where one must go to locate the strength to complete a task. In discussing this depth one can conjure images of clambering over rocks or paddling a canoe into unknown territories, climbing mountains or swimming seas, but the darkness it presents here is domestic and suburban.

*Indoors, mid morning, no-one dressed. Lunch club cancelled.*

*A supermarket car park, an elderly woman struggling to fold a wheelchair into a car.*

*On a train with a teenager rhythmically banging his head on the window.*

*A woman trying to lift a fallen woman.*

*Steering an elderly man away from the bar at a funeral  
breakfast as he begins to vomit red wine gently into a  
handkerchief, the wine all he has consumed in several days.<sup>72</sup>*

Some of these times are public, but mostly they are very private, even if others are present. Many factors dictate whether these are or are not commonplace events in common places, a daily occurrence, or a dark,

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<sup>71</sup> Patti Smith, quote from: [http://dangerousminds.net/comments/radio\\_ethiopia\\_everything\\_you\\_love\\_most\\_about\\_patti](http://dangerousminds.net/comments/radio_ethiopia_everything_you_love_most_about_patti). Promotional interview for the album *Radio Ethiopia* to accompany a performance at Konserthuset, Stockholm, 3<sup>rd</sup> October 1976. Accessed 5<sup>th</sup> January 2015.

<sup>72</sup> Notes from the author, unpublished sketchbook preparatory work leading to text in *New Weather Coming* publication (illustrated on pages 45 and 47), 2014.

isolated moment that asks much of a person. They can be easy to miss, as most are small, discreet, lonely moments. There is rarely shouting, as any shouters are new and haven't yet learned to tensely and discreetly endure. They occur in many families living with disability and they require strength. The use of the term 'lever' is significant, and I cite the dictionary definition here as it very accurately describes the process of 'exerting pressure' that is often required:

*Lever.* A rigid bar resting on a pivot/ a projecting arm or handle that is moved to operate a mechanism/ a means of exerting pressure on someone to act in a certain way.<sup>73</sup>

It is the combination of fear, endurance and dignified bravery that is distinctive here, perhaps only the territory of carers, where the strain of these often long periods of time can leave a lasting mark. In the *Radio Ethiopia* track Patti Smith's voice intones darkly of a lever that I, as the artist, equates to those moments that carers, or people with disabilities have when they must go beyond the limits of what they think they physically or emotionally can do (and as described by Laura Marney in the next section of this chapter). The dark gravelly tone is appropriate, summoning strength. A cold, rough surface replicated in heavy, embossed, matt black metal.

At a much later date, long after writing and recording *Radio Ethiopia*, Patti Smith also spoke of a period of quiet endurance. At an intimate performance event in Glasgow in 2006, in the Burns Room of the Mitchell Library, she sang and talked on many subjects – her love of Robert Burns and an exhibition of her artworks at Glasgow International Festival of Visual Art having brought her to the city.<sup>74</sup> What stood out to me from this mesmerising performance was her reflection on a time spent in semi-retirement at home with her two young children in

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<sup>73</sup> Oxford Dictionaries S.V. 'lever' accessed January 8<sup>th</sup> 2015.  
<https://www.oxforddictionaries.com/definition/lever>

<sup>74</sup> Patti Smith solo exhibition at the Mitchell Library, Glasgow as part of Glasgow International Festival of Visual Art 2006 (curated by Francis McKee). April 19<sup>th</sup> – May 10<sup>th</sup> 2006. There was a live solo performance in the Burns Room at Mitchell Library on 19<sup>th</sup> April 2006. Review of exhibition: Mark Fisher, Guardian newspaper, 25<sup>th</sup> April 2006, accessed 15<sup>th</sup> January 2015.  
<http://www.theguardian.com/artanddesign/2006/apr/25/art>

Michigan in the early 1980s. This was before the sudden death of her husband, yet seemed from her portrayal that evening to have been a dark and trapped period.<sup>75</sup> Or perhaps that was my memory of the event, my experience of it at the time coloured by it being at a point when my own children, and my niece, were very young.<sup>76</sup>

The use of Patti Smith as a contextual marker in this thesis is an example of a portrayal of both loss and strength on a quotidian, domestic level. Though the lyric referenced in the artwork's title stems from a period of avant-garde performance and poetry, the words are equally relevant to scenarios closer to my experience. Much of her writing refers to ongoing, enduring loss, and is articulated most recently in the second part of her autobiography, *M Train* (described as a 'kaleidoscopic ballad about the losses dealt out by time').<sup>77</sup>

On her late husband:

"Just come back, I was thinking. You've been gone long enough. Just come back. I will stop travelling; I will wash your clothes."

And on the difficulties of ageing, particularly when one has experienced deep loss that endures:

"Everything changes. Boy grown, father dead, daughter taller than me, weeping from a bad dream. Please stay forever, I say to the things that I know."<sup>78</sup>

Closer to home, the endurance demanded of care and loss is also illustrated beautifully in a small publication by Artlink, Lothians called *This Side of Heaven*, a set of fictional short stories based on interviews

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<sup>75</sup> Smith's husband Fred 'Sonic' Smith died suddenly of a heart attack in 1994. Her brother died soon afterwards. Her writing (song and poetry) has often referred to loss, and she speaks of this in a series of interviews made when she returned to NYC from Michigan in 1996.

See: Fricke, David, 'Patti Smith: Family Life, Recent Loss and New Album 'Gone Again'. *Rolling Stone*, July 11<sup>th</sup> 1996.

<http://www.rollingstone.com/music/news/the-rolling-stone-interview-patti-smith-19960711>. Accessed 1/2/2017

also Patti Smith, *M Train* (London: Bloomsbury 2015).

<sup>76</sup> Smith has since described this as a calm and contented time for her and her family, but I maintain my response to the live event from that night.

<sup>77</sup> Michiko Kakutani, Review: *Patti Smith on All the Roads She Has Taken*, *New York Times*, 1/10/2015.

<https://www.nytimes.com/2015/10/02/books/review-m-train-patti-smith-on-all-the-roads-she-has-taken.html> Accessed 1/5/2017.

<sup>78</sup> Smith, *M Train*, 137

with carers about their adult disabled children at a time when they were leaving home.<sup>79</sup>

The only people who really understand how this feels are other parents of disabled kids and yet the job of caring often leaves parents isolated. These mums feel like a lone voice in their own particular wilderness.<sup>80</sup>

Times when inner strength is required; required to get your husband out of the house and into a car, or your adolescent, autistic son to bed, something that must be done over and over, again and again. Ordinary, unglamorous, and with no medal. A lever in your brain that at times you must apply.

A sculpture. Cold and dark and black.

*Deep in the Heart of Your Brain is a Lever* is made of powder coated, textured matt black aluminium. Cold and hard to the touch, but sleekly beautiful, the work is strong but not solid. Large enough to support several people, standing or sitting, it is hollow, with a mesh side panel that allows a peek into the darkness underneath. The ramp is hinged, and is therefore possible to lift, given enough strength. Unlike the *New Weather Coming* pieces (2014), this work is built onto a static frame, and so doesn't move. It has a strong presence, filling the gallery space.

In addition to the materials used and the depiction of loss that I have related to the work of Patti Smith, the location where I first constructed the sculpture is also relevant. Strategies of detachment and withholding are evident through my written practice (artists books) and some aspects of the works already cited, such as *New Weather Coming*, 2014; I will expand more here.

Leamington Spa Art Gallery and Museum has both a contemporary art collection and a museum section that documents the past history of the

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<sup>79</sup> Laura Marney, *This Side of Heaven*, (Edinburgh: Artlink, 2007).

Artlink (Edinburgh and the Lothians) is an organisation that commissions artists to work within or around healthcare settings. 'Our work stems from the belief that participation in the arts plays an important role in achieving social change and personal goals'. [www.artlinkedinburgh.co.uk](http://www.artlinkedinburgh.co.uk)

<sup>80</sup> Marney, *This Side of Heaven*, 14.

town as a spa and healthcare center, one of many established by the Victorians in British spa towns for the efficacy, relaxation and stimulation associated with the health giving powers of the local waters.<sup>81</sup>

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<sup>81</sup> See Jeff Watkin (ed), *The Royal Pump Rooms and the Growth of Leamington Spa* (Warwick: Warwick District Council, 2002).

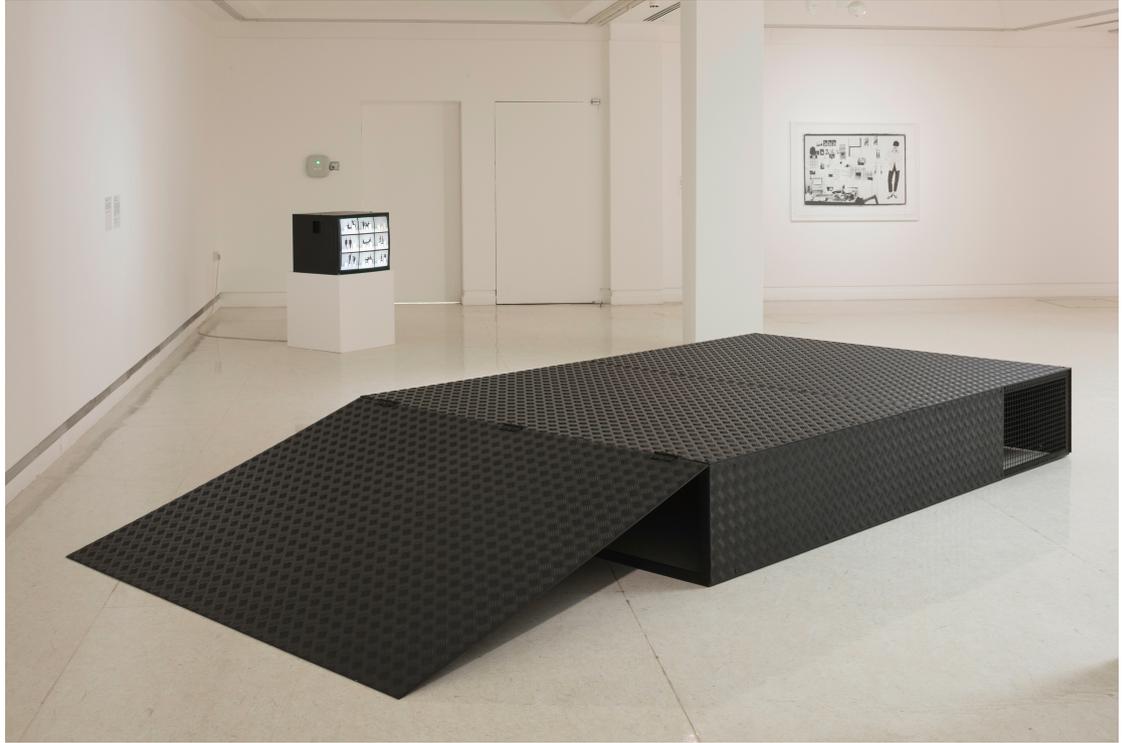


FIGURE 3

Donachie, Jacqueline. *Deep in the Heart of Your Brain is a Lever*. 2014.  
Powder coated aluminium, 3 x 2 x 0.4m.

Also in background:

*Pose Work for Sisters*, 2015

*Studio 1995*, 2015 (details Figure 7 and 8)

Installation view 'Deep in the Heart of Your Brain', Gallery of Modern Art,  
Glasgow, 2016. Photo by Ruth Clark.

The Art Gallery and Museum are housed in the former spa building itself, with the local municipal library also located on the site, built within a redevelopment of the former swimming pool. The museum shows the history of the treatment centre, with many items from its past use on display. Pulleys and harnesses from the archive collection were particularly interesting to me, along with some information boards of testimony from staff, and from patients who had been treated regularly there up until the 1980s. Though access was available, I chose not to reflect too directly on the actual collection itself. My online research into the medical and mechanical apparatus used proved fascinating, but was also evidence of how sufficient that particular archive was in telling the historic facts of the spa, in combination with the museum displays.<sup>82</sup>

More pertinent was the poignant testimony of a mother who used to bring her young children to the pool in the 1980's; her son had cerebral palsy, and she brought him and her other unaffected child to swim once a week after school. Both children loved the atmosphere there, her son benefitting from the therapeutic service available to him, mother and daughter relishing fun swimming time together whilst this took place. She spoke of how safe they all felt at these times, and how much they looked forward to them as a family. So the question to ask more than any other was where did they go when this facility closed in 1989? Was there a beautiful new therapy centre and pool available in the town? Or had the service been removed completely, to be replaced with a cultural display?

“Social histories must remain alive, and my art contributes to this. It is not historicised. People should know what they are losing.”<sup>83</sup>

My exhibition, or that of anyone else, was surely no substitute for this experience, and my purpose in making the sculpture was to present a loss that was, perhaps, brushed aside with the offer of culture. That the sculpture is there at all (and not a protest sign or an information panel) reflects a desire not to proffer information or direct questions, but to allude to something lost (to illuminate), through a measured presentation that causes viewers to consider why it is there and what

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<sup>82</sup> Warwick museums archive: <http://www.windowsonwarwickshire.org.uk>

<sup>83</sup> Jacqueline Donachie in conversation with Chris Dorsett. 14<sup>th</sup> October 2014.

decisions have been made to make it, by using their own memory and experience as a primary resource. Indicators such as title, material and a general 'sense of something' (cold and dark) are the beginning of this.

The placing of a substantial dark object, a black hole one could say, in the center of that exhibition space, alongside other artworks, becomes an artistic response to that situation. In a small local museum that was once a therapeutic swimming pool, what can a static metal sculpture invoke other than loss?

Seen later within the context of the GoMA exhibition, adjacent to the film work *Hazel*, this reference to loss again becomes evident through the use of austere, dark materials that carry a number of connotations, for experiences described by the sisters (of loss, of the need for help from others, of, at times, isolation, and of deep inner fortitude). To move it requires great strength, its cold surface offers no immediate comfort and it withholds information (what lies underneath, if anything? what is the ramp for?). It requires an effort from the viewer to consider these possibilities and relate them to personal experience. I cannot exactly stipulate what this will be.

A further example of this invocation of care, and of isolation, that I seek in objects is seen in the work of Cathy Wilkes, such as the installation *I Give You All My Money*, 2008.<sup>84</sup> The work uses mannequins, a variety of domestic objects and two supermarket checkouts whose grandiosity of scale and proportion seem wholly changed in their new location. The work resonated with me in the Turner Prize exhibition at Tate Britain, most particularly on viewing the short film made with her partner Torsten Lauschmann. One of the mannequins wears a traditional white nurse's hat with a red cross, the eyes weeping red paint. Like a lot of Wilkes' work the piece is uncompromising in its visual language, withholds information yet employs many items from everyday life to create complex narratives; other works use television sets, folding prams, cups and plates. These items are sparsely yet carefully placed,

the relationship of each considered with almost mathematical precision to create something at first domestic, but again potentially dark and melancholic.

I've used shop mannequins, and also the motif of the nurse, to try to feel what someone else feels in art... looking for yourself in a piece of art, trying to see what someone else saw. And this is to do with the separation that there is between people, and the impossibility of completely feeling what someone else feels. And I think that it is most extreme, and most human and most painful when someone is caring for someone else, or someone is nursing someone else, and trying to feel what they feel, and be a companion to them. And this might just be in friendship, or this might be in actual nursing, or it might just be in a relationship, but to try to feel what someone else feels and to accompany them in their experience of life, and in their suffering, to me is related to what I'm looking for in language as I apprehend it, coming from somewhere outside me, coming from a work of art or coming from a person, and that it acknowledges in itself the unbridgeable distance between human beings, and the vastness of their inner world.<sup>85</sup>

Wilkes also talks of a 'split' in her understanding of objects, and the impossibility, once the physical moment of production has passed, of expressing a singular personal experience through them. She dwells on events, often momentary, physical gestures repeatedly re-enacted, that connect the personal to the objects she employs, and again alludes to a deep, unsaid trauma:

I've also used the processes or the thoughts of the experience of Moses' mother, putting her baby in a basket and putting the basket in the water, and... pushing it out, and the moment when her hand is on that object, the basket and her baby, and then the moment when her fingers leave the basket; do they push the basket, or does the ebb of the water take the basket? This process of very, very deep fixation on the actual details of conscience is something that I pursue repeatedly in my work, where I might contemplate over and over again events that have happened or physical experiences of objects or of bodies, and reassess what really happened and what that physical experience has to do with the inner reality.<sup>86</sup>

Her work has been described as talismanic, and has been met, at times, with stubborn resistance; she is insistent on the value of domestic labour, of women's rights and uses her minimal works to

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<sup>85</sup> Cathy Wilkes interview, dir. Torsten Lauschmann, Tate 2008. Accessed 13<sup>th</sup> January 2015. <http://www.tate.org.uk/whats-on/tate-britain/exhibition/turner-prize-2008/artists/turner-prize-2008-artists-cathy-wilkes>

<sup>86</sup> *ibid*

explore themes such as caring for the sick, pregnancy and the loss of her father.

While we think of art in terms of active verbs, like shaping or making, Wilkes suggests that art and life might be a question of both doing and undoing. There is no such thing as careless or casual in her work. The placement of the tiniest stone marble on textile or the unfinished embroidery on a linen sampler are deliberate. But for every constructed object there is another that has reached its current state by some kind of attrition. Antique fabrics are sun-bleached, faded and distressed to the point of near dissolution. A plucked piece of heather is woody and dry. The found vessels that are such a feature of Wilkes's work in the last decade, from domestic buckets to empty jam jars, are lined with a kind of scrim, the detritus of food or clay or pigment they once held.<sup>87</sup>

This brings me to a split of what might be considered when assessing the 'impact' or 'value' of artworks, or of art making processes in relation to them that connects again to the shared territory of science and of art in relation to many things, including research and funding mechanisms. Where and from whom is value assigned? Value to me as the artist - of the personal experience of producing the work (so clearly vital for Wilkes) - and also of the finished object itself; value to the participants who take part in the making of the work; and value to the audiences that see it, as these viewers can be multiple and in many cases include the participants. These are ongoing themes that continue throughout this thesis, as I seek to describe an illumination of loss that is significant to me, and to another professional world.

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<sup>87</sup> Moira Jeffrey, Art Review – *Cathy Wilkes, Tate Liverpool*, The Scotsman 13<sup>th</sup> April 2015: <http://www.scotsman.com/lifestyle/culture/art/arts-review-cathy-wilkes-1-3743423>



FIGURE 4

Wilkes, Cathy. *I Give You All My Money*, 2008.  
Mixed media installation, dimensions variable. Installation view. The Renaissance Society at the University of Chicago, Chicago, 2012. Courtesy of The Artist and The Modern Institute/Toby Webster Ltd, Glasgow. Photo Tom Van Eynde.

## 1.6 Sciart to ‘art and science’: synopsis of a journey

In this chapter I have presented previous works that directly connect with the new research presented in this thesis. The collaborative projects *Tomorrow Belongs to Me* and *DM* were the public outputs from a period of funded research (two grants from the Wellcome Trust between 2001 and 2006) with Monckton. This resulted in a long-term professional dialogue that continues today.

However, in considering the location of this primary research – The University of Glasgow – the initial stage of my work with Monckton was described as the point at which my dual position (both artist and family member) created problematic tensions for the scientists. As a result, I had to decide if my position as a co-professional was a more fertile ground for open and frank discussion than my position as a member of a family affected by the as-yet incurable genetic condition studied within Monckton’s laboratory. The challenges outlined in the introduction are built around the idea that an artist can engage with science itself, not just mediate with the public on science’s behalf. The initial stages described above were where I learnt how science sees both patients/ families and artists.

The first of the challenges set out in the introduction – that of a consideration of how science sees itself – was then addressed, with an example from the original *Tomorrow Belongs to Me* film, where I speculated that the closing quotation by Nancy Wexler was criticised by scientists at a conference screening because of what they saw as its ‘negative’ ending. This acts as a continuum of the long-term theoretical debate according to which the world of science is ‘closed, and the world of arts is ‘open’. Can a single term (‘sciart’) encompass new works derived through collaborative research when the fields diverge like this?

The chapter then examined themes emerging through my own art practice, with particular reference to drawings, sculptural works and an artist’s book all made in 2014. An analysis of these works, and others

attendant to them, has reflected on the research topic of *Illuminating Loss* through first discussing the structure and content of these pieces, particularly the use of strict editing techniques, and references to other art forms (Smith, Wilkes) then secondly investigating the underlying influences relating to their development and the consideration of what further questions these might raise.

Whilst a brief appraisal of the concepts of loss and isolation within the work could reflect a negative or pessimistic bias, in my opinion this is not dominant. By framing pieces such as *Deep in the Heart of Your Brain is a Lever* with more publicly accessible projects such as *New Weather Coming*, which engaged a wide and diverse, *unclassified* audience of summer travellers with similarly minimal artworks constructed from harsh, industrial materials, I have raised the possibilities available for reconsidered (multiple) readings of the works. None of the themes listed here are in themselves a wholly negative term; even *loss* and *isolation* can have positive associations, and so I question whether we are more obliged to view them as such when a reference to disability is applied.

I also looked at more specifically commissioned work of my own and others. Was seeking a new consciousness the motive behind consideration of the process of 'letting go' that the parents of adult disabled children go through? Here, the writer's decision to fictionalise the experience of others becomes at once a recording of someone's (anonymous) journey, but also an opportunity to share and illuminate this journey in a targeted manner through a strategic publication. In doing so this process of sharing is lifted beyond the safe and familiar surroundings of a carer's support group, crucial as this is to its members, to a place beyond that, a place where it can have a more marked effect by offering others (social workers, wider family) a new way of considering another's experience of loss at an exceptionally difficult time. Yet, like the carer's association, or the swimming pool that is now an art gallery, many of these connective processes made through 'art' are fragile and vulnerable, susceptible to themselves being lost to us.

In the following chapter I go on to consider these and related issues in the context of the film *Hazel*, a new artwork based on a series of filmed interviews with women of varying ages. These women speak of the loss not just of physical function, but of looks and self-esteem, and the effects of that loss on their status. The question that remains is whether artwork can have influence and impact here.

## CHAPTER 2

People are disabled both by social barriers and by their bodies/  
People are disabled by society as well as by their bodies.<sup>88</sup>

### 2.1 Introducing the film *Hazel*

One of the most important qualities of researchers is the ability to listen and hear what is being said – which may not always be what is being verbalized.<sup>89</sup>

In Chapter 1 of this thesis I presented the collaborative history that underpins the research described. I also reflected critically on a number of more recent sculptural and text works that connected this earlier period with the principle time-frame of this doctoral research at the same time, as they illustrate development of the themes of strength (resilience), care and loss. In what follows, I present in detail the *Hazel* study, framed by a more theoretical examination of existing literature that pertains to research in connected fields.

By looking at scholarly research concerning embodied experience, ageing and beauty, this chapter also provides a theoretical focus to distinguish the issues and concerns that an artist can uniquely address in relation to the production of artworks, (namely the film piece *Hazel*). Although I have a long history of framing my own work with a variety of expert cultures that include several forms of academic practice, as a practitioner, formal academic scholarship is new territory for me. However it is central to this doctoral thesis to promote the capacity of artists to operate as leaders within collaborative research. In order to progress 'art and science' as a more dynamic field than straightforward interpretation or illustration allows, it is necessary to look beyond familiar systems and demonstrate where my own contemporary art practice intersects with others in related fields of academic practice. In returning the terms of *science* and *art* to two distinct entities with the

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<sup>88</sup> Tom Shakespeare and Nicholas Watson, 'The Social Model of Disability: An Outdated Ideology?' *Research in Social Science and Disability*, Vol 2 (2002): 9-28.

<sup>89</sup> Ribbens and Edwards, *Feminist Dilemmas in Qualitative Research*, 586.

potential to collide, the orchestration of this action (who is leading) comes to the fore.

A key area of interest for this research is the progression of age, as a large part of the *Hazel* study is based on interviews with women between the ages of 28 and 68. As my own practice-led research in this area began with a response to the birth of a tiny infant, then moved through to reflect on the relationship of two women, physically similar and very close in their teenage years and early 20's, a natural progression is this examination of middle age as our physicality enters a different era, and the multiple loss this entails. This development in my own thinking is also mirrored by the prevalence of scholarly research within feminist circles on the embodied experiences of women as they age.<sup>90</sup> This is no doubt in part due to the continued output of educated, motivated women radicalised in their youth during the 'second feminist wave' of the 1960s and 70s, particularly in the United States. Jankowski notes this growing critical interest in the ageing experience of women but interestingly speculates that much of the research undertaken may be limited and limiting with regard to its samples:

Despite the rapid increase in ageing populations in developed and less developed countries, whereby the number of people aged 65 and above has tripled in the last 50 years (United Nations, 2013), most appearance and body image research has focused on childhood, adolescence and early adulthood. Only limited research has examined the presence and nature of body image and related sociocultural pressures during mid to older adulthood. Furthermore, such research has tended to produce inconsistent findings and has overly focused on white older adult women.<sup>91</sup>

I concur with Jankowski but would further suggest that there is an equally significant gap in our knowledge of how ageing with a disability

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<sup>90</sup> See Frida Kerner-Furman, *Facing the Mirror: Older Women and Beauty Shop Culture* (New York: Simon and Schuster, 1997) for example or Betty Freidan, *The Fountain of Age*, (New York: Simon and Schuster, 1993) – a positive study of the decisions made by ageing Americans as they navigate their later years with energy and purpose: 'Ageing is not lost youth but a new stage of opportunity and strength'.

<sup>91</sup> Glen Jankowski *et al*, Ageing and Body Image Among Older Adults. Looking age-appropriate while growing old gracefully: A qualitative study of ageing and body image among older adults. *Journal of Health Psychology*. April 2014, 5. Accessed 13<sup>th</sup> October 2015. <http://dx.doi.org/10.1177/1359105314531468>

impacts on an individual's self-perception, particularly in relation to physical appearance and beauty. For this reason I will mainly frame my own creative research, that has resulted in the film *Hazel* and a number of other artworks, with examples taken from feminist and social science theory. I do this as I see the film, and associated primary research, as something that can contribute to this arena of research; it is a choice that reflects the importance of contemporary art to represent personal experience in ways that inform academic research *across a number of areas*, giving opportunities for cross fertilisation.

From the outset I have maintained my central role within this research process – as an artist, an advocate and a family member – and I see the issue of physical appearance as one that is under recognised in terms of ageing and disability, but one that is central to my own relationship to my sister, and, perhaps, to the relationships of others. Does the scientific and medical profession involved in myotonic dystrophy research and care consider ageing (in terms of appearance) as relevant to women? My hypothesis is that it does not, and so using these particular theoretical examples offers a framework for this research to propagate further study in particular disciplines (that are not confined to either art or science).

I will therefore begin by asking whether feminist academic study on ageing considers impairment and whether this can affect definitions and perceptions of beauty and appearance.

To examine this further I discuss Clarke and Griffin's 2008 paper '*Visible and invisible ageing: beauty works as a response to ageism*' in terms of my own research.<sup>92</sup> In doing so I introduce the scope for extending the study within a practice led framework that also includes attention to impairment. The ongoing themes of beauty, care and loss run through my exploration, and I will also consider visibility, through reference to the Women's Workshop on Qualitative Family/Household Research at Oxford Brooks University, and the concerns identified in *Feminist Dilemmas in Qualitative Research – Public Knowledge and*

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<sup>92</sup> Laura Hurd Clark and Meredith Griffin, 'Visible and invisible ageing: beauty works as a response to ageism', *Ageing and Society* Volume 28, 2008: 653-674. Accessed 13<sup>th</sup> October 2015.

*Private Lives*. Each of these Social Science publications set out to shed light on marginalised groups with low public visibility, through an investigation of ‘mundane’ domestic activity. In this way they also act as a parallel to the artworks of Wilkes, discussed in the last chapter, that reference the crossover between private experience and public outcomes, questioning the role of the researcher and the privileging of information.

Engaging with domestic experience is vital to the study of an inherited condition such as myotonic dystrophy, as affected families spend the majority of their time in such settings, often to the point of extreme isolation. This is an area that could speak more to clinical research, a field that expects, and considers, presentation of patients at medical institutions beyond the home as a primary source of knowledge. For this reason a key focus now is what ‘personal’ experience is relevant here to share?

Through appraisal of two outputs of social science research in relation to the *Hazel* interviews, I will offer a theoretical framework for my own research and suggest where it could be said to sit within an academic discourse where art, science and the humanities intersect. In turn, I identify the potential of artworks to influence and direct thinking and understanding in the ‘real’ world of treatment and care of genetic illness through discussion of key themes of strength, resilience and loss will emerge. This will be explored in tandem with another important factor – visibility, and the nature of personally driven, *random*, creative research.

I begin this section with a description of the film *Hazel* followed by the methodology underpinning its production. This artwork forms the primary output of my practice-led research and is based on a series of interviews made with female siblings where one is affected by myotonic dystrophy and one is not.

There were eleven women involved in the study, filmed individually, not together, at their homes in England and Northern Ireland in 2014 and 2015. It is relevant to detail location as it demonstrates the breadth of

participants involved – this was not a group local to me. They ranged in age from 28 to 68 years old, and apart from two cases, there had only been telephone or email contact in advance of the interview date. The sisters:

- Claire, 31 and Laura, 28, interviewed in Northern Ireland
- Sally, 32 and Lucie, 34, interviewed in Carlisle and in Lincoln
- Michelle, 36, Stephanie, 44 and Lorraine, 42, interviewed in Essex
- Louise, 52 and Rachel, 47, interviewed in Northampton and in Kent
- Jennie, 68 and Pam, 60, interviewed in Leicester (though Pam lives in Renmark, South Australia).

The women had been contacted via a letter from myself, emailed by the UK Myotonic Dystrophy Patient Registry in 2013 to each of their 500 members. The letter asked if any women who had an unaffected sister would be interested in taking part in a study that would involve filmed interviews, with sections of the footage then being used in an artwork that would be publicly screened.<sup>93</sup> My proposal had been accepted by the full Advisory Board of the Registry and successfully gained Northumbria University ethics approval prior to sending, an unusual approach for an artistic study but one that is necessary in social science when dealing with personal data.<sup>94</sup> There was a follow up letter sent by the registry (by mail) about 6 weeks later, directed to families in the North of England as response from this area had been particularly low. It was made clear from the start that content from the interviews could be exhibited publicly, that participants would be named and have

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<sup>93</sup> Appendix 2 – participant letter

<sup>66</sup>UK Myotonic Dystrophy Patient Registry is based within the John Walton Centre for Muscular Dystrophy Research at the Centre for Life in Newcastle. Over 100 people joined in 2014, and in February 2015 this total reached 500. The age of people on the registry ranges from 1 to 80 years old. Females makes up 52% of people registered, 48% males. The majority of people on the registry first experienced some DM symptoms in their adulthood. However 20% experienced symptoms before the age of 16 years old, 12% between 3 and 15 years, 8% before 3 years old. 20xxhttps://www.dm-registry.org/uk

<sup>94</sup> Northumbria University ethics submission RE11-12-121556, January 2013.

to sign a release form, and that they would therefore need to relinquish anonymity.

Over the course of the next few months I received a number of calls from individuals who wished to take part; in some cases they were unsuitable candidates (e.g. men without sisters, women with sisters who were also affected) and I was conscious of several of them hoping for attention to their condition, and personal life, that was not forthcoming elsewhere. Through a process of telephone calls and a small amount of email correspondence, suitable candidates were identified.<sup>95</sup>

Here, it is important to describe in more detail the role of the patient registries, and my relationship with the UK Myotonic Dystrophy database, and its curator, Elizabeth Wood.<sup>96</sup> Registries have become an increasingly important and recognised way for patients to become actively involved in medical research; a comprehensive, independently managed database that allows those who may be eligible for clinical trials or other specific forms of research to be contacted quickly and easily without the need to access highly regulated NHS records, held regionally, not nationally, and therefore unavailable via a single point of contact. With rare conditions such as myotonic dystrophy, recruiting patients for trials through NHS systems can be difficult and time consuming, limiting progress.

As association grows between patients, charities and the scientific community, registries are also now connected internationally, and they allow an efficient way of establishing very specific cohorts, such as those with myotonic dystrophy within a certain age bracket or sex.

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<sup>95</sup> The process of how this contact was made is worthy of note. I had given an email address and my mobile phone number on the call out communication, which naturally led to calls to this number. What I had not considered was the times that these calls may occur; as it was my personal number, these often happened in the evening when I was concerned with other family issues, or at weekends - times I felt it difficult to give the caller my full attention. The fact that this was when they were passing on very personal information to a stranger heightened the awkwardness. If I was to do a similar study again I would use an alternative telephone number with an answerphone facility. It is important, however, to keep the telephone contact option (not just email), as this was the most commonly used response method.

<sup>96</sup> Elizabeth Wood, National Curator, UK Myotonic Dystrophy Patient Registry.

Registries also facilitate a pro-active stance on the part of patients: by registering, patients are acknowledging a willingness to participate in future research. Funded by charities – in this case the Myotonic Dystrophy Support Group and Muscular Dystrophy UK, and supported by the Treat NMD Neuromuscular Network - the UK registry collates information on people with myotonic dystrophy supplied by the patients themselves and their physicians. Patients must give consent for the professionals involved in their care to provide this information. There is no data recorded of personal experience unless it connects directly to clinical symptoms, and only patients themselves, not family members, can be registered. This is a gap that I will discuss in the next section.

I have known of the registry's existence since 2012, and was very keen to try and work with the organisation as they continue to recruit families to the database, particularly whilst it was still relatively new. Having discussed my art practice with Wood at a number of conferences, she was enthusiastic about working with me and, following a meeting with her and staff at the Centre for Life in Newcastle, suggested I write a proposal for the advisory board to consider. I did this in Spring 2013, and once my proposal was accepted, the research phase was launched during a presentation by Wood at the UK Myotonic Dystrophy Support Group annual conference in Swindon in June 2013, prior to the formal call being sent out via email later that month.<sup>97</sup>

Having had close contact with the registry staff up to this point, from here it was very much left to me to manage the project. Some update emails were exchanged and Wood and myself met at the IDMC conference in San Sebastian, where I presented a poster outlining the unique process of using a clinical registry to recruit for an artistic study.<sup>98</sup> Communication was established again on completion of the film, and a screening was organised for staff at the Centre for Life in Newcastle. This is described later in this chapter.

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<sup>97</sup> Myotonic Dystrophy Support Group Annual Conference, 8<sup>th</sup> June 2013, Alexandra House Hotel and Conference Centre, Swindon. Presentation on the UK Registry, its role and purpose, by Elizabeth Wood.

<sup>98</sup> 9<sup>th</sup> International Myotonic Dystrophy Consortium Meeting, 6<sup>th</sup> – 19<sup>th</sup> October 2013, San Sebastian, Spain. Poster presentation: 'Illuminating Loss - an artistic study of siblings affected by myotonic dystrophy Type 1'. Appendix 3.

## 2.2 Hazel: a methodology

All of the affected sisters in this study are included in the UK Registry. Their unaffected sibling(s) are not listed, thus necessitating that all initial communication for the project was via the affected sister. In many, but not all cases this was a reversal of usual familial relationships; in general the sisters affected by myotonic dystrophy were significantly less proactive in managing many aspects of their lives, and were not always in regular contact with their unaffected siblings. However each seemed to think it an interesting enough proposition to invite, and encourage, their sister's participation, aware perhaps that if she did not agree to take part, then they themselves would not be eligible for the study. At times it seemed clear that this opportunity to discuss their condition 'publicly' provided an incentive different to the more mundane round of GP, physiotherapy and sleep clinic appointments for the women. The opportunity to connect with siblings was also a motivating factor in some cases.

Scheduling the interviews proved complicated, and in the end they were completed in two parts; two sisters were filmed in 2014 in Northern Ireland, the rest in early 2015 – the gap due to other personal work commitments. Throughout this time I worried about losing contact with the women, even though what details I had had been entered onto my database. The tenuous sense of responsibility that non-art participants can have for this type of research is a risk in socially engaged artistic practice, particularly when there is no significant incentive- in terms of payment or reward - for taking part.<sup>99</sup> The following extract from my filming notes suggests this caused significant anxiety at this phase of the research:

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<sup>99</sup> Further artworks to reference that have had a similar risk associated would be Roderick Buchanan's long term work with the Loyalist and Republican parading communities of Glasgow, resulting in solo exhibitions at The Gallery of Modern Art in Glasgow (*I am Here*, 2007) and *Legacy*, Imperial War Museum, London 2011. See accompanying publication 'Legacy' Roderick Buchanan, Imperial War Museum, London, 2011.

Having not made contact with anyone since the summer, I got in touch with the families again at the beginning of December to explain the reasons for the delay, ask if they were still on board (all were, delighted) and offer to send them a copy of DM (my own book) in the interim. All were very understanding. Was tough to call out of the blue (had been hanging over me since the summer) but was very good to do it – I had been putting it off, in the hope that when I did contact them it would be to schedule filming dates. Also now have email contact details for everyone I'm working with, so no more calling mobile numbers out of the blue. This is a serious consideration, as I feel it's intrusive to call folk up out of the blue to speak about something that many view as very sensitive and personal.<sup>100</sup>

By early 2015 I finally had a full schedule in place based around geographic clusters in Essex and Kent, Lincoln/Leicester/Northampton, and Carlisle/Cumbria, taking place over March – May 2015. Having email contact alleviated a lot of the stress of relying on mobile phone numbers, particularly in the case of two of the unaffected sisters, who appeared to have little or no contact with their affected siblings, and who led very busy lives. Most of the interviews had to be scheduled for weekends to accommodate the women's working hours, and all but one were done at home.

The women were filmed using Canon C100 High Definition, with one of two experienced camera operators accompanying me (Jim Rusk or Holger Mohaupt, a long-term associate who also filmed the scientists interviewed for *Tomorrow Belongs to Me*). We used a small radio microphone clipped to the participants clothing, but no additional lighting in order to keep the set-up as unobtrusive as possible. I had advised in advance that the session could take up to two hours of participant's time, and this proved to be accurate.

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<sup>100</sup> Filming notes, December 2014

Throughout the filming I kept a narrative notebook, and some extracts from this are included in this thesis ('Filming notes'). More extensive extracts are not appropriate however, as, other than the descriptions of airports, car hire and Premier Inn accommodation, much of it is concerned with the private situation of the women involved that is not included in the interviews, and I do not see this as something I have been given their permission to discuss.<sup>101</sup>

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<sup>101</sup> One important point to note here would be my reassurance at having not visited the women alone. This is something that was raised in the risk assessment required for university ethics approval that I had noted and, whilst unlikely for me as I needed a camera operator, it would not have been exceptional for me to visit the women alone, in advance. In most cases the atmosphere was welcoming, if perhaps terse – I was asking them to discuss something very personal. However in one or two cases I would not have felt safe had I been alone due to the threatening attitude of others in the household.



FIGURE 5

Filming of interview for *Hazel*, on location in Northern Ireland, 7<sup>th</sup> February 2014

On completion of the interviews, the next stage was to edit. There was over 8 hours of footage, which in the first instance I had transcribed into a document of 70,000 words. The decisions made in the editing process form a central feature of the artwork, and are discussed at length in the coming chapters; the final film is 9 minutes in duration.

The opening and closing scenes were shot with my sister at Glasgow Sculpture Studios, and the film was edited with Mohaupt, who, as already mentioned, also filmed and edited *Tomorrow Belongs to Me* in 2003/ 2004. This abstract filmic section, discussed later, was made with a particular purpose in mind, of offering a 'pause' to the talking head scenario of the main film. This device parallels what had been done with the black and white rostrum camera shot of laboratory gels that was first used in *Tomorrow Belongs to Me*, in keeping with my desire to make a work that reflected on this first piece in both format and content.

The final work, the film *Hazel*, can be shown in two ways: a single screen conference/ cinema version, where a split screen format is employed, or a three-channel video installation for gallery exhibition. In the latter, two monitors are suspended side by side at eye level, showing each sister on the full screen, and the sequence that begins and ends the film is projected.

In both formatting scenarios the film is bookended by a blurred opening shot, inky black with some faint light beyond, which extends as the camera moves out to an almost discernable human shape. A clear, distinctive voice speaks:

I look nothing like my sister. If my sister walked in here now and sat down next to me, you would not even think that we were related. We are completely different. I'm slightly shorter than she is; a little bit heavier than she is; different colour hair... We're just so different. The only thing that is alike with us is the fact that we both have blue eyes.

The edit then moves on to each set of sisters, shown full face (as the scientists were in *Tomorrow Belong to Me*), and side by side. Sisters. Each pair has the same format; one sister speaks, the other does not - instead, she stares at the camera in silence. The sister who speaks is the sister who has myotonic dystrophy, the sister who is silent is the one who does not. In a single case there are two affected sisters, one unaffected – in this instance the unaffected sister, Lorraine, is on screen twice, paired separately with each of her siblings.

Concluding the piece, after the last pair of women are seen, the monitors return to black and the surround sound picks up a female voice, as at the start:

I find it very difficult to describe my sister...<sup>102</sup>

The blurry image reappears on the wall, then expands to become two women walking along a corridor, arms linked. They have their backs to the camera, and walk slowly away, chatting quietly. One of the women has a different gait; she walks awkwardly, her leg bending slightly outward and buckling at each step. At one point she stumbles. This aside, the two women are physically very similar, both tall and slim, wearing dark clothing.

This is my sister and I. That information is not offered; you do not need to know it. Perhaps, as Sharon Hayes says, I used myself so that I did not have to 'cast another body'.<sup>103</sup> Perhaps.

My intention was to show two women who are the same, but different.

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<sup>102</sup> Audio extract from *Hazel* (from interview with Rachel).

<sup>103</sup> Sharon Hayes in conversation with Dr. Dominic Patterson, Yudowitz Lecture Theatre, The University of Glasgow, 17 November 2014. *Primer* event organised by the Common Guild.

<https://www.thecommonguild.org.uk/programme/event/primer-sharon-hayes>

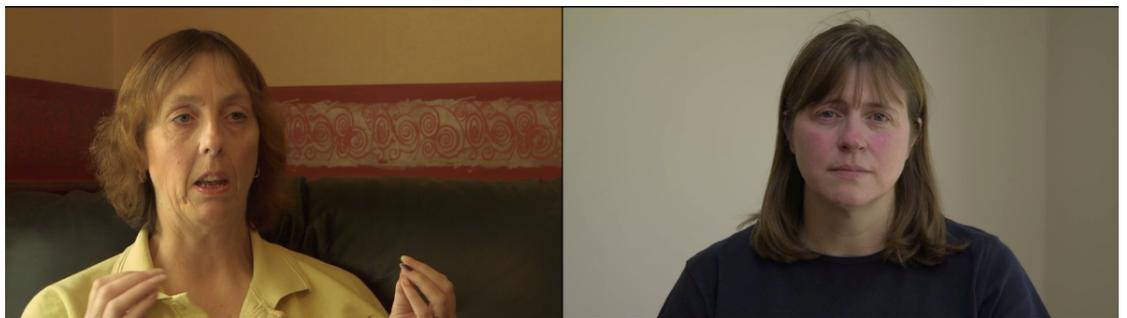


FIGURE 6

- (i). Donachie, Jacqueline. *Hazel*, 2016. Installation view 'Deep in the Heart of Your Brain', Gallery of Modern Art, Glasgow, 2016. Photo by Ruth Clark.
- (ii) Donachie, Jacqueline. *Hazel*. 2015. Still from HD video, single screen version.

### 2.3 Hazel: questions and answers

Some questions immediately arise from this description of the work.

On content:

- Why sisters?
- Why split screen of the sisters?
- Why is the unaffected sister silent?

On format:

- Why are the sisters on monitors and the 'walking footage' projected?
- Why is the camera shot so closely framed on the faces?
- Why video? Why HD?

I will begin to answer them here.

*Why sisters?* I chose sisters as I have a sister. I am a sister.

But I also have a brother who has the condition, why did I not film him and seek siblings of either sex? Several came forward from the first call by the Registry, and the experience of an unaffected sister who has a brother with myotonic dystrophy would also have mirrored my own.

There are two main reasons for this. Firstly, I am closer to my sister and we are physically very alike. I have always been closer to her, most evidently in my teens when I revered her clothes, her music, and her freedom. Although wildly gothic, she was also eminently sensible, always the one with a tidy room and the knowledge to make chicken soup. There is a loss recorded in the film that is my own; a loss of youth, as our relationship now is different.

Secondly, the relationship between sisters is particular whether close or not, and I wanted to chart not just the progression of myotonic dystrophy, but also the progression of age in closely related women. Each section of the film discusses a significant factor of life: appearance, fertility, employment, aspirations, and the format of the piece offers a very clear, unadorned image of the women facially. Across these two elements – speech and physiognomy – my first

ambition was to create a portrait of loss that described both my sister and myself. By using two related women I was able to provide a familial comparison, and therefore perhaps more clearly offer an illustration of what has changed, and what has been lost between us. A consideration of these two strands - of family similarity (or dissimilarity) and clinical, symptomatic similarity – was what initiated my very first contact with geneticists over a decade ago, and it persists through this work in the very direct use of portraiture using a time-based, moving image format and closely framed faces. In elucidating one half of this doctoral project (the film *Hazel*) with the other (this thesis) my decision to focus here on issues relating to appearance, ageing and beauty are relevant, as that is what has, and continues to, define a great deal of my relationship with my sister, particularly that which I have portrayed through my art practice.<sup>104</sup>

It was also prevalent within the *Hazel* interviews. Every woman I interviewed at some point defined herself in relation to her sister through a description of appearance. For example, Rachel says (of her sister Louise): ‘She’s a little bit heavier than me’, and Sally, describing her sister Lucie says: ‘Well, my sister doesn't look much like me at all. My sister is very thin. She's basically got the figure of a supermodel where it's really abnormally thin – but that's just the way she's born, really. So, she's abnormally thin; she's very pretty; she's got roughly the same colour hair as me – maybe a bit lighter or a bit darker because she does tend to dye it a bit.’

Some are used in the film, some are not, edited using artistic methods of detachment (from the primary research data) and withholding (of information in the form of the words of the unaffected sisters, but not their visual appearance) to present an artwork that offers a portal to further questioning.

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<sup>104</sup> see Donachie, *DM*, (2002) artists book; Donachie, *Studio 1995* (2014) digital print 110 x 180cm; *Pose Work for Sisters* (2014), digital video;.Hannula, Mika and Öberg, Johan (ed). *Talkin' Loud and Sayin' Somethin: Four Perspectives on Artistic Research*, (art: *El Mal* by the author); Art Monitor, Gothenburg: University of Gothenburg, (2008), 37-40.

The film also speaks to ideas of change and movement, and when seen in an exhibition context it is also looped, offering a further allusion to a less fixed cycle of ageing for sisters, where accepted patterns are disturbed and *biographical disruption*, a term mentioned in the introduction, can arise. Further discussion of this term follows shortly; here it describes a mis-match of physical decline that is a significant part of the loss I seek to portray: a younger sister carefully taking the arm of and steadying a woman only three years her senior.

Within this context, the silence of the unaffected women becomes a significant element of the work, particularly in relation to specific audience groups and collaborators from science and medicine. Clinicians rarely see unaffected adult siblings; they see unaffected parents of pediatric patients, or unaffected partners of adult patients at clinics, but not so often individuals of a similar age and genetic background who do not have the condition. This presentation of unseen family, of contextualising the patient beyond symptomatic evidence, is discussed later in the chapter, where the agency of silence, and of knowledge, both given and denied, becomes a critical factor in the reading of the work.

In this thesis I draw on sociological and feminist engagements with appearance and ageing.<sup>105</sup> At 47, I am ageing. My sister is too, at 50. But we are ageing differently, she far more rapidly than me. Not mentally, or in fashion, taste or style, but physically. I help her up stairs and into cars in a way that I did for our late father just a few years ago. Occasionally I have to pick her up when she falls; something I don't yet do for our mother (who is 74). I had not reckoned on the bizarre world of *biographical disruption* when disability first descended on my family. The term is a significant one, yet relatively new in scientific discourse. My first encounter with *biographical disruption* was at the 2016 IDMC-10 meeting in Paris, though published literature described it in terms of other conditions before this.<sup>106</sup> It has arisen through the prevalence of

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<sup>105</sup> Clarke and Griffin. *Visible and Invisible Ageing*, 653-674.

Joan Chrisler. 'Leaks, Lumps and Lines: Stigma and Women's Bodies', *Psychology of Women Quarterly* 35 (2) (2011): 202-214.

<sup>106</sup> Kori A Ladonna *et al*, 'Biographical disruption: shedding light on myotonic dystrophy type 1 and reproduction' (Presentation at IDMC-10, Paris, 8-12<sup>th</sup>

families where the expected order of 'care' is distorted through an inherited genetic condition that gets markedly worse, with an earlier age of onset, as it is passed down through generations. It is touched on in *DM*:

It grows and repeats itself throughout your lifetime, and the severity of the symptoms multiply as it passes through generations. The type that my niece got from my sister is worse than the type that my sister got from my dad. The age of onset of symptoms gets steadily younger, although you can only inherit the congenital form, like my niece has, from your mother. So my dad's symptoms are appearing now that he's in his sixties, my sister and brother are developing problems in their thirties and my niece and nephew have problems all the way from childhood. Which means that three years ago we knew nothing, and now it's kicking in for them all at the same time.<sup>107</sup>

Therefore I have used other women in this study, and in this thesis have referred to feminist literature, to portray a broad range of female experience connected by a single genetic factor. In doing so I seek to illuminate the loss that affects each of us differently, with certain specifically shared aspects that most directly connect to appearance – whether that be facial deterioration, or the consideration of when, if at all, an affected sister becomes more recognised for her disability than her familial characteristics. The artistic submission that forms 50% of this doctoral research is centered on the use of a number of female participants to define an experience and a position that is unquestionably my own.

Put simply, this work is a portrait. It is a portrait of the ineffable loss of my sister.

In making *Hazel* through a series of filmed interviews, I was constructing a portrait. The process of conducting the interviews provided testimony from an under represented group with whom I share a particular experience, and the opportunity to use the words of others to describe ineffable loss. From these larger interviews, a short extract was taken, that touched on the following:

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June 2015); J Reeve *et al*, 'Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer'. (2010) *Health*, London: 178–195.

<sup>107</sup>Donachie, *DM*, 2002.

- Appearance (*I can tell that my face has dropped*)
- Fertility (*...the diagnosis is the reason why I don't have a family now, at 31*)
- Inheritance (*We're not sure if it came from my dad's mum or my dad's dad*)
- Family relationships (*She just says she'll take me out in my wheelchair, because my mum and dad, they wont do that*)
- Premature death (*...so we were quite a large family really... today there are just three*)
- Aspirations (*I wish I was a bit cleverer than I am*)

Whilst I will draw on theories from social science later in this chapter, art provides alternative references, particularly with the use of the words of others to describe very personal loss. Sharon Hayes, in the *Love Address* works, provides a comparison that I will go on to discuss shortly, but first, let me return to the more formal aspects of the work and the questions asked earlier:

1. *Why split screen of the sisters?*
2. *Why is the unaffected sister silent?*
3. *Why video? Why HD?*

When I initiated the interviews, making contact was a fragile process of sporadic communication by telephone and email. From the outset I had had an idea of what kind of film I would make, but this did not extend much beyond a visual description of 'talking heads like the scientists film'. I had not envisioned what the women would actually say, nor the experience of actually meeting them.

In then visiting strangers in their homes, I felt intrusive, glad of my small camera and single operator. In framing the shot, I chose to exclude everything but the women's faces, as their domestic situations varied so widely, from expansive luxury to squalid, as did their attire. I did not want this to become a feature of the piece, and it was not something

that ethically I thought I could include, having not mentioned this as a reason for filming them at home.<sup>108</sup>

Practically, having travelled far and gained access to strangers' living rooms and personal lives, I tried to cover all bases – I would not be going back again within the context of this research as even, if time allowed, funding did not. Therefore, in addition to a formal interview, I felt it would be valuable to also film the women not speaking, silently looking ahead in a more formal portrait style. We did this at the end of the interview, asking each to look into the camera to reflect on the very private conversation we had just had as we left them alone in the room for five minutes.

Though this footage was intended as back-up, the decision to use the silent portrait alongside the words of the affected sister was, in the end, visceral. Restrictions of time and the demand to fashion an exhibition and conference quality film from over eight hours of footage were the starting points for a strict editing process. Through this, I decided to avoid the more emotive aspects of the interviews – death of infant children, private grief, infertility, social exclusion – as a means to present something more measured and considered, just as decisions made with metal and paint dictate my sculptural practice. I intended the film to be an every-woman depiction of the ubiquity of loss across a range of issues, from appearance to mobility, that connects as much to my life as to the affected sisters and aspires to avoid the 'misery lit' trap that audiences can be rapidly inured to when dealing with portrayals of disability. There are no children in the film, and the women depicted speak calmly, shown in detail, larger than life.

Installed in the gallery, the work is therefore both filmic and arresting, presented as two large portrait faces side by side. The combination of a close head shot and an HD camera magnified everything about the women's physiognomy – broken veins, wrinkles, pores, make up

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<sup>108</sup> This is also why I have chosen to only use edited extracts from the narrative notebook I maintained during and after the filming period; whilst fascinating, it was also very descriptive of each woman's personal domestic setting, and I felt the issues to which those parts gave rise were not within the scope of this particular study for which I had asked their permission.

(where worn). It is both fascinating and intrusive, to the point that it troubled me when I saw it on a large screen for the first time (up to the installation it was only viewed on a laptop monitor or conference projector screen). One sister has dandruff on a black t-shirt. I wish I had brushed it away before we began recording. The lighting is domestic, and therefore at times yellow and unflattering on film – it was cumbersome enough invading the women’s homes with a camera operator in tow. thus I decided to work without additional lights, and the budget did not extend to a studio location where cinematography could have been more expertly employed.

The split screen provided a device to examine both women simultaneously; if both spoke, the viewer is drawn each time to the face of the speaker. Having a silent figure was designed to push understanding away from simply listening to words.

The manner of speech is also relevant. Not all of the dialogue is clear; though all of the women are articulate. Over and over in the longer interviews each of the affected women voiced their frustration at not being heard, or understood – whether that be by their families or the medical profession. In this iteration of the research it seemed right to have the unaffected sisters sit and listen, to deliberately silence them.

*Why are the sisters on monitors and the ‘walking footage’ projected?*

The filmic sections that open and close the film provide a device to interrupt the talking head format when the film is looped, and an introduction and conclusion that provides balance when shown singly. Too much interview becomes a documentary, and I wanted to reflect the style used in *Tomorrow Belongs to Me*, where black and white rostrum camera footage of a gel was used to provide a mid-point pause between the scientists talking on screen. Using my own body and that of my sister Susan allowed me to present a more physical portrait of what, at times, the women discussed, depicting similarity as well as difference. In the gallery installation, projecting this image separately to the monitors provided a difference of scale that again, offered a pause

by physically moving the viewer to look away from the monitor screen and onto the adjacent wall.

The single screen version of *Hazel* was premiered at the International Myotonic Dystrophy Consortium Meeting (IDMC-10) in Paris, on 12<sup>th</sup> June 2015, a decade after *Tomorrow Belongs to Me* had been shown to the same group in Quebec (cited earlier, in the introduction of this thesis).<sup>109</sup> It was the closing event of a five-day international genetics conference with over 350 delegates attending; I gave a 20 minute introductory presentation and then the film was shown. Reaction was not what I had expected - initially quiet, followed by applause. Many of the scientists who had been aware of my work for over a decade seemed moved, though this was not what I had set out to do. Was it the normality of the women featured that had perturbed them? A long-term family association colleague, whose adult daughter has the condition, described it as 'a very private experience'.<sup>110</sup>

Following the conference, delegates were sent a short questionnaire via Survey Monkey, to gauge some more specific reaction to the piece. In response to the question 'How did watching the film *Hazel* affect your understanding of myotonic dystrophy and how it impacts the lives of families, including unaffected relatives?' There were 12 responses, including:

'The film gave me a much better understanding of the challenges of living with the disease, and the impact of the disease on families. Seeing the two siblings was visually striking and a very effective way to communicate.'<sup>111</sup>

'A lot, as a molecular biologist I didn't have much idea about the social issues of affected people.'<sup>112</sup>

'Watching the film reinforced the wide range of impacts of the condition on both the individual and their family and in particular the challenges facing siblings whose life trajectories evolve down very

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<sup>109</sup> 5<sup>th</sup> International Myotonic Dystrophy Consortium Meeting (IDMC-5), Quebec. 19<sup>th</sup>–22<sup>nd</sup> October 2005.

<http://www.idmc.org/documents/idmc5/IDMC-5-program.pdf>;

10<sup>th</sup> International Myotonic Dystrophy Consortium Meeting (IDMC-10), Campus des Cordeliers, Paris. 8-12<sup>th</sup> June 2015.

<sup>110</sup> Don Mackenzie, Director of the Marigold Foundation, Canada. From filming notes, June 2015.

<sup>111</sup> Conference survey response to Question 3, 19/8/2015

<sup>112</sup> *ibid*, 31/7/2015

different pathways.’<sup>113</sup>

‘It made me appreciate the day to day struggle; it’s not something that gets better like a headache or backache.’<sup>114</sup>

The multi-screen installation version of the work was first exhibited as part of a larger solo exhibition at the Gallery of Modern Art in Glasgow, which opened on 19<sup>th</sup> May 2016.<sup>115</sup> Critic Moira Jeffrey provided the following appraisal:

Deep in the Heart of your Brain is a show about family, about ageing, about love and lineage, about the best of circumstances and some of the hardest.<sup>116</sup>

I will digress here to mention briefly two further works in the exhibition that arise from the *Hazel* research, *Pose Work for Sisters* (2015) and *Studio 1996* (2015). The concept for both came from consideration of the work of Bruce McLean – a hunch that I should look again at his early photographic and performance work including *Pose Work for Plinths* (1971).<sup>117</sup> McLean’s work is often seen as ironic, however it is both his sharp sense of art being ‘in the world at large’ and his perceptive use of performance, props and staging that are relevant here.<sup>118</sup>

It connects in ways that are complex, various, and essentially unpredictable the natural and the social aspects of human existence.<sup>119</sup>

I find the use of both the term and the action of *posing*, employed throughout McLean’s practice, compelling, and this key work from the 1970’s provides a clear exemplar. In one sense it is a peculiarly Glaswegian understanding of the word that cleaves directly to one

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<sup>113</sup> *ibid*, 30/7/2015

<sup>114</sup> *ibid*, 30/7/2015

<sup>115</sup> Donachie, *Deep in the Heart of Your Brain*, Gallery of Modern Art, Glasgow.

<sup>116</sup> Moira Jeffrey, Art Review. Scotsman newspaper, 28<sup>th</sup> May 2016  
<http://www.scotsman.com/lifestyle/culture/art/art-review-jacqueline-donachie-duncan-marquiss-1-4139711>

<sup>117</sup> This hunch was also prompted by the recalling of a bar lunch with McLean, whilst teaching together at Edinburgh College of Art in the late 1990’s, where I was accused of posing because of my (fashionable) dungarees, and the fact I did not drink beer (both due to an unannounced pregnancy).

<sup>118</sup> Mel Gooding, *Bruce McLean* (Oxford: Phaidon, 1990). 31

<sup>119</sup> *ibid*

particular dictionary definition of *pose* - to 'behave affectedly in order to impress others'; in another it is an allusion to Ernest Goffman, cited later in this thesis, and his description of 'performance in the everyday world of social interaction' that is also explored in Mel Gooding's description of McLean's band *Nice Style*.<sup>120 121</sup>

The staged format of the original photograph and its playful, spirited images of a young man awkwardly posing, mimicking statue shapes in a staged setting (on white plinths against a white background) brought to mind an early set of photographs taken with my sister Susan, when she was pregnant with her first child in 1995. This was well before any diagnosis of genetic illness, and at a time when I was producing a number of staged, studio style portraits of myself that were exhibited in diptych form, each with a short written piece.<sup>122</sup> The decision to capture a moment when our physical similarity began to separate (due to her expanding size) was at that time purely opportunistic, as it sat well with a number of portrait/ text works I had been producing, and struck me as an appropriate moment for a wry, humorous text. The value of them as a recording of a significant point *before our knowledge began* was only to arise as I embarked on this research years later, and considered how best to present our (again) differing physicality in terms of an illumination of loss.

As it is mainly in movement, and not physical shape, that we now differ, film was an appropriate medium for this piece, and a studio session was organised with three plinths and a white backdrop (again with Holger Mohaupt filming). I asked Susan to dress in black (as McLean had done in the original), though beyond that the action was very simply choreographed: walk into the frame, sit/ stand on the plinth, hold

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<sup>120</sup> <https://en.oxforddictionaries.com/definition/pose>. Accessed 15th March 2017.

<sup>121</sup> *Nice Style, the World's First Pose Band* was a performance group established by Bruce Mclean in 1972 that created a number of live events between 1972 and 1975. See Gooding, *Bruce McLean*, 63-83; 'Nice Style: The Art of Pose.' The term 'affected' – used in relation to McLean's posing in its 'pretentious' sense, is also worthy of note. It is so appropriate to the youthful selves of my sister and I, yet now takes a central role in this thesis with a new contextual marker in relation to inherited genetic illness.

<sup>122</sup> These works include: *Jackie & Another Tall Story About Love, Money and Art*, 1994; black and white photocopy (diptych), each 180 x 90cm on paper. See *Shift* exhibition catalogue, De Appel 1994.

the pose for around 5 seconds, stand up, walk out of the frame. I decided against studio lighting, and so we also had to work quickly to make best use of daylight; it was a spontaneous, uncomplicated session measured mainly by what Susan could and could not physically manage.<sup>123</sup> Each pose was photographed as well as filmed, but it was the moving image footage of us walking in and out of the frame and holding a series of bizarre and impromptu positions that was the most compelling. The setting of plinths against a white background and the grid of multiple poses a deliberate reference to McLean, and the looped repetition of the piece rendering a simple, rhythmic rise and fall to the work that offers an additional portrait of both similarity and loss to that seen in *Hazel*. Two tall, slim middle aged women wearing black, walking, sitting and standing. Posing. When static, little separates us, but in moving on and off the plinths there are subtle differences in gait, posture and ability that speak of inheritance in many forms. It brings to mind the opening line of *DM*: 'All my life I've been told how much I look like my sister.'<sup>124</sup>

While seeking out the original photograph on which this work was based I came across a black and white photograph from my studio taken in 1995. This shows a number of my 'posed pieces' in contact sheet form on the wall, including those taken with my sister, together with a full size single portrait of myself from the same series. At that time my obsession was in being tall, a confident riff on the assumptions of too much height made in the (not tall) West of Scotland, also mentioned in *DM*.<sup>125</sup> This seems almost too poignant now; the moment 'before our knowledge began' captured for vastly different reasons. Exhibited as a new print (*Studio, 1995*) it provided a subtle framing for *Pose Work for Sisters* in indicating this early body of work, the use of black and white photography and contact sheets, and a striking image of a young woman posing.<sup>126</sup> All of us change.

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<sup>123</sup> An early edit contained a small number of poses where Susan stumbled or was unable to stand up. She requested that these were not used in the finished work.

<sup>124</sup> Donachie, *DM*, 5.

<sup>125</sup> 'And she's a few centimetres shorter than me, which for tall girls in the inherently stocky West of Scotland is a big deal.' Donachie, *DM*, 7.

<sup>126</sup> Jacqueline Donachie, *Studio, 1995*. Digital print, 2015.



FIGURE 7

Donachie, Jacqueline. *Pose Work for Sisters*. 2016.  
Single screen digital film, no sound. 8 minutes, looped. Edition of 4  
(collection of Glasgow Museums). Shows film still image.



FIGURE 8

Donachie, Jacqueline. *Studio 1996*, 2016.  
Digital print on Somerset paper, 1100 x 1800 mm. Edition of 10  
(collection of Glasgow Museums).

## 2.4 Hazel: whose voice is heard?

Having described the work in detail, I will now move on to the theoretical framework it inhabits. When dealing with marginalised and vulnerable groups, and with people affected by a significant disability, the process of 'dialogic practice' as defined by Kester is relevant, in that it offers the means for participants to establish a voice.<sup>127</sup> This is similar to aspects of feminist practice that I will go on to describe, but Kester's reference is worth mentioning as it continues to connect the research to contemporary art.

This voice is not necessarily the 'voice' as is used in terms of community based arts.<sup>128</sup> Nor as is current within NHS practices with 'Voices' training for patients and families, as the artist remains the editor and author of the work at all times.<sup>129</sup> Is it possible to distinguish between these types of activity by saying that one is professionally and creatively led by others *for* the benefit of patients, and others, and that the other is professionally and creatively led *by* patients perhaps, but not exclusively, for others? Through involving an artist initiating a participatory process where personal reflection is recorded, a platform for dialogue is established between the artist and participant that manages to archive and share broad aspects of their lives, not just their medical condition.

In discussing, then, a contemporary art practice that involves engagement with individuals and their families over a period of time, there is naturally an intersection with qualitative research methods within social science, particularly auto-ethnography, and so it is here that I will continue.

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<sup>127</sup> Kester, *Community and Communication in Modern Art*, 2004:

<sup>128</sup> Marijke Steedman (ed) and Grant Kester, *Gallery as Community: Art, Education, Politics* (London: Whitechapel Gallery, 2011); Petra Kuppers, *Disability Culture and Community Performance: find a strange and twisted shape* (London: Palgrave Macmillan, 2011)

<sup>129</sup> Voices Scotland is a programme of workshops and support for patients and carers, together with advice and facilitation for NHS managers and clinicians, aimed at helping patients to become effectively involved in improving healthcare services. It was established by the Scottish Health Council in 2005 and evaluated in 2014.  
[www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org)

In the Introduction I referred to the work of James Clifford, and his late twentieth-century critical re-assessment of 'ethnography' in the field of anthropology. Clifford's thinking has also prompted me to give some consideration to the relevance of the closely related practice (to his thinking and to my work on myotonic dystrophy) of auto-ethnography. Unlike depersonalised writing styles, auto-ethnographic writing asks its 'readers to feel the truth of stories and to become co-participants, engaging the storyline morally, emotionally, aesthetically, and intellectually'.<sup>130</sup> An example of this type of approach is Shahram Khosravi's 2001 text, *'Illegal' Traveller: An Auto-ethnography of Borders*. In the foreword, Khosravi explains that his study, developed from a PhD thesis, is the outgrowth of my 'own embodied experiences of borders [...], my astonish[ment] at how my informants' experiences overlapped, confirmed, completed, and recalled my own experiences of borders'.<sup>131</sup> He goes on to note the value of 'thinking poetically' whereby 'one does not focus either on one's own subjectivity or on the objectivity of the world, but on what emerges from the space between'.<sup>132</sup> It is precisely here, I would argue, in the space between personal experience and objective, detached knowledge that I would situate this practice.

Within the field of auto-ethnography in social science, Deborah Reed-Danahay states *'By exploring a particular life, I hope to understand a way of life'*.<sup>133</sup> As has been said, my own position within the study, as a family member, gives me specialist knowledge that is shared with the individuals involved, and directly connecting the personal to the cultural is an accepted practice within visual arts.<sup>134</sup> It is therefore well placed to

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<sup>130</sup> Ellis and Bochner, 2000, 745

<sup>131</sup> Shahram Khosravi, *'Illegal' Traveller: An Auto-ethnography of Borders*, Basingstoke: Palgrave Macmillan, 2001. 5

<sup>132</sup> *ibid*, 6

<sup>133</sup> Deborah Reed-Danahay is a cultural anthropologist, currently Jean Monnay Chair in Cultural Anthropology at the University of Buffalo. A key early publication is *Auto/ethnography: Rewriting the Self and the Social*, (Oxford: Berg Publishers, 1997).

<sup>134</sup> Again, this is very well developed in feminist art practice. See for example the work of Maud Sulter, Jo Spence and others. A substantial archive is available at Glasgow Women's Library: <http://womenslibrary.org.uk> See also Sharon Hayes, whose work is referenced in this thesis, in particular the recent piece *'In My Little Corner of the World Anyone Would Love You'*

take on a stronger leadership role when examining, for example, the role that art practice can play in facilitating experience to filter more deeply into medication and healthcare. You could say that life and narrative are inextricably linked, therefore narrative is both *about* living and part of it. Therefore the particular of whose stories are being told in the *Hazel* study is critical in framing my own experience, something made clear in my decision to only use female siblings in the piece. As social scientists Carolynn Ellis and Mel Bochner say, as far back as 2000: *Whose narrative? Whose stories get told, and by whom and for what purpose?*<sup>135</sup>

This relates to the issue to advocacy, and feminist literature provides much evidence of the difficulties of undertaking deeply personal qualitative research. I will turn again to *Feminist Dilemmas in Qualitative Research – Public Knowledge and Private Lives* by Jane Ribbens and Rosalind Edwards.<sup>136</sup> The book is a compilation of examples of the difficulties faced by researchers in the realm of very personal domestic practice such as childbirth, lone parenting and qualitative studies involving children. The editors are clear on the importance of observing the minutiae of family life, and begin by establishing its position as a direct challenge to existing conventions:

There is a danger that the voices of particular groups, or particular forms of knowledge, may be drowned out, systematically silenced or misunderstood as research and researchers engage with dominant academic and public concerns and discourses.<sup>137</sup>

They state that in order to avoid being driven toward only conventional understandings that reshape women's voices, academic research has to counteract this by listening to, documenting and asking about the simple and the mundane. Within sociology, and feminist discourse in particular, scholarly writing warns us of the dangers of being drawn

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2016, which 'examines the ways in which political discourse is formed and political identities constructed through individual acts of writing and reading'. <https://www.thecommonguild.org.uk/programme/exhibition/in-my-little-corner-of-the-world-anyone-would-love-you-lv1q>

<sup>135</sup> Norman K. Denzin and Yvonne Lincoln (eds), *Handbook of Qualitative Research*, (New York: Sage, 2000): 749. Carolyn Ellis (University of South Florida) is a qualitative researcher often seen as the originator of 'auto-ethnography', which she defines as: "research, writing, story, and method that connect the autobiographical and personal to the cultural, social, and political"

<sup>136</sup> Ribbens and Edwards, *Feminist Dilemmas*, 2008.

<sup>137</sup> *Ibid*, 2.

overly to conventional understandings that can re-shape marginalised voices and experience if dominant public and academic concerns are repeatedly prioritised.<sup>138</sup> The writers state that this threat should be countered by a dissection of everyday domestic activities in the lives of women, and give a number of examples from the Centre for Family and Household Research.<sup>139</sup> The work of the centre echoed my own thinking as I undertook this doctoral research; I too seek to re-shape through my practice, in a reverse of what the writers here identify as a problem – dominant voices reshaping the experience of marginalised groups. This compilation of studies, presented in a purely narrative written form, is limited to participants directly available to the researchers (as recruited via a snowballing technique through their own networks and locales).<sup>140</sup> Yet despite being also restricted by geographic spread and the existing networks of the authors, it still provides a useful companion to my own research in terms of method – the use of small scale interviews conducted at home to inform more formal academic study.

The interviews with the sisters in the *Hazel* research recognise the importance of considering private, domestic experience of inherited disability by asking these particular women to speak frankly about their own lives. As outlined in Chapter 2, it is a very specific group I have chosen to interview – women between the approximate ages of 30 and 70. This was due to the similarity of sister's affected/ unaffected by myotonic dystrophy (like my sister and I), and with the visibility of progressive female ageing, both in general and within the specific world of genetic research. There is no scientific evidence of a difference in the manifestation of the condition in men and in women other than in terms of fertility and reproduction, and the use of a sister, as opposed to a male sibling, stems from my own personal concerns at the outset

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<sup>138</sup> Smith, 1987; Griffin and Smith, 1987 and DeVault, 1990, 1994.

<sup>139</sup> The Women's Workshop on Qualitative Family/ Household Research was established in 1987 and is based within the School of Social Sciences and Law at Oxford Brookes University.

<sup>140</sup> Whilst it could be said that the cohort for the *Hazel* study was also limited, the fact that the sisters were located throughout the UK (with one in Australia), had a variety of backgrounds and educational experiences, were different ages and had professional lives of a wide range, would imply that apart from sharing the experience of an inherited genetic condition, this would not be accurate.

of the research.

The women in *Hazel* are not the poster-girls of disability, nor even for their own genetic condition. Their stories are not as commonly told as that of families with severely affected children, or healthy parents who have lost their teenage sons to Duchenne muscular dystrophy.<sup>141</sup>

These are much more ordinary and mundane experiences of quiet, often childless women living through slow physical deterioration that is resulting in not just wheelchairs and premature death, but in hair loss, collapsed facial muscles and low income employment. And whilst much of their testimony in the full interview is highly emotional, particularly when discussing infertility or the loss of infant children, there is a calm in their considered personal reflection, something which I sought to capture in the edited film that extends the research focus beyond a simple retelling of bad luck or collating of statistical data.

## **2.5 *Hazel* and beauty**

Appearance is central to the portrait format of the film, and so I will now turn to current research that examines how ageing women are seen. *Visible and Invisible Ageing: Beauty Works as a Response to Ageism* is a quantitative study, cited earlier, of over 40 Canadian women aged between 50 and 70 that looks at their attitudes to ageing, particularly in relation to appearance. It recognises that discrimination against women is prevalent, and that it increases as women age. Many participants feel invisible, and discuss their beauty treatments – which can be anything from eyeliner to full cosmetic surgery – in relation to making themselves ‘more visible’ to society in general. The authors are critical of current attitudes to older women within their own society (academic, north American), and have initiated the study to enhance their hypothesis of appearance related discrimination.

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<sup>141</sup> Duchenne is a form of muscular dystrophy that affects only boys, and is diagnosed in infancy. It causes severe muscle degeneration, and those affected rarely live beyond their late teens.  
<http://www.muscular dystrophyuk.org/about-muscle-wasting-conditions/duchenne-muscular-dystrophy/>

...ageism is rooted in an insidious societal obsession with youthfulness and the results in the assigning of social value, resources and opportunities based on actual and perceived chronological age.<sup>142</sup>

The sampling in Clarke and Griffin's study results offer little surprise, the outcome reflecting the personal beauty habits of any general office, workplace, class, church or society with large groups of women over the age of 50. The majority use hair dye and make-up, a small number also use more extreme methods such as plastic surgery and professional treatments (all expensive, invasive procedures not easily done at home), and a further small number use no products or treatments at all. What it does not say is how many of these women began wearing makeup in their teens and early twenties, and how many have only just begun with these 'beauty works' since reaching their senior years. What is lifelong personal habit, and what has been adopted later in life to counter a stigmatising society, for example?

A more informative, qualitative analysis of why women actually use treatments, based on their own personal experience, is found in Frida Kerner-Furman's book *Older Women and Beauty Shop Culture* connecting as it does the action of having beauty treatments with a physical location (the shop), and a shared collective experience that encompasses individual narratives, including why and when they began to attend to their appearance in this way.<sup>143</sup> The reasons are so deeply embedded in culture, migration, perception of worth and position in familial/ professional relationships in addition to simple enhanced physical appearance, that a simple quantitative analysis chart seems inappropriate and unrepresentative. Further analysis of effective and appropriate ways of undertaking research with groups of older women is set out in several studies – again, Ribbens and Edwards 1998 publication proves valuable, particularly Parr (*Theoretical Voices and Women's Own Voices: The Stories of Mature Women Students*).<sup>144</sup> Offering a parallel to my own study is also Mauthner (*Bringing Silent Voices into a Public Discourse: Researching Accounts of Sister Relationships*).<sup>145</sup>

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<sup>142</sup> Clarke and Griffin, *Visible and Invisible Ageing*, 655.

<sup>143</sup> Kerner-Furman, *Older Women and Beauty Shop Culture*, 1997.

<sup>144</sup> Ribbens and Edwards, *Feminist Dilemmas*, 87-102.

<sup>145</sup> *ibid.* 39-57.

In Clarke and Griffin, however, I would note that on close reading many of the references to the visibility of ageing women are made in relation to 'dating' situations where the respondents are single. However, the conclusion here that women in society are rendered invisible by their age is perhaps questionable given that examples are mainly confined to competitive dating situations, where the women feel they get no attention if there is 'a tall, long legged blonde in the room'. An inclusion of other situations – women only, or women dominant groupings for example, or workplace and family settings, would be of interest and detract from the feeling that women are only concerned with being visible to potential sexual partners. What of other sexualities and ethnicities, for example? There is minimal attention to ongoing health issues and their associated effects. Taking account of issues such as general health associated with old age or disability (degenerative or otherwise) could extend the study.

Indeed broader study by the research team, published in the article *Failing Bodies, Body Image and Multiple Chronic Conditions in Later Life*, 2008, attempts to redress some of these earlier shortcomings.<sup>146</sup> Using another small cohort (10 women and 10 men), this study does consider issues of impairment in relation to chronic illness and ageing, producing testimony very similar to that of the (younger) women in the *Hazel* research who were dealing with similar symptoms. Again, though, several references are made in relation to 'attractiveness to potential partners':

Well, the Parkinson's shows. You know, everybody can see that. Whereas some of the other things no one can see. So that's changed my image now. I do look old. I feel old... And the shaking is . . . when people see that, they see age in you... I don't feel the same way at all about attracting anybody... A fellow doesn't want an invalid.<sup>147</sup>

Whilst I have found this paper to be of value to my own research, I remain critical of the limited nature of their study cohort involved; although it is a limitation they have clearly acknowledged, by recruiting

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<sup>146</sup> Laura Hurd Clarke and Meredith Griffin, and The PACC Research Team. 'Failing Bodies: Body Image and Multiple Chronic Conditions in Later Life' *Qualitative Health Research*, August 2008, 18: 1084-1095.

<sup>147</sup> Clarke and Griffin (female participant, aged 77) 2008: 1088

mainly Caucasian, educated women for interview (36 of the 44 women studied were educated to degree level or beyond) – Clarke and Griffin have produced a study of how women age by interviewing many (older) women involved in academia and therefore very like themselves.<sup>148</sup>

In this criticism, however, there is also a distinct intersection with the *Hazel* study. The results here are also of personally gleaned testimony gathered through dialogue with others with whom I share a significant life experience, though they are drawn from a wider social, geographic and economically diverse background. Elements of recruitment, in parts, reflect snowballing techniques used in qualitative research – one of the families was known to me through my work with the UK Myotonic Dystrophy Support Group, and all have in some way intersected with my own experience of myotonic dystrophy, though as an artist my overall methods of research and my ambitions for an eloquent and compelling outcome are different to that of social science. Crucially I seek broad audiences for this research beyond academia - audiences with varying backgrounds of skill and experience to connect to the work and inform their understanding of something very personal made public, including a clearly defined audience taken directly from professionals and families dealing with genetic illness.

## **2.6 *Hazel* and stigma (two faces on a screen)**

The word stigma applies to any mark or attribute that sets some people apart from others because it conveys the information that those people have a defect of body or character that spoils their social identity.<sup>149</sup>

I have mentioned that the issue of facial deterioration is significant to this research, particularly in relation to women affected by disability. The way in which the changes brought about by illness can begin to identify one person as intellectually or emotionally inferior to another, and how these perceived changes to physical and psychological ability can have a profound and long term affect on self esteem for the affected sister. When *seen* in parallel with someone of a similar

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<sup>148</sup> see footnote 113 for a note on cohort similarities in the *Hazel* research.

<sup>149</sup> Ernest Goffman, *Notes on the Management of Spoiled Identity* (New York: Simon and Schuster, 1963).

physical and genetic background who is also beginning to deal with the ageing process in terms of physical appearance, in a society filled with mediated images of what a woman in her 40's, 50's and 60's *should* look like, can we see something new through this illumination of loss? And is this loss purely physical? Parallels of experience, education and financial status between each sibling set in the *Hazel* study would certainly indicate a loss of status as well as physical appearance and ability that could be associated with recognised forms of stigma.

As a primary concern is ageing, the study, whilst small in scale, offers unique data on how women with an impairment, and their siblings, approach this life stage when they have a genetic condition that will accelerate many aspects of functional loss associated with old age; mobility, ability to walk and climb stairs, dressing, eating, swallowing. The dominant thinking in popular culture is that old equals impairment, but *biographical disruption* caused by genetic illness is an increasingly recognised phenomenon, and so a depiction of age – in a new format – challenges established thought by both prompting questions, and offering new knowledge based on the words and appearance of the women. As a primary question is age: which sibling is older? How does the condition affect established family hierarchies? At specialist screenings of *Hazel*, the issue of age was a dominant theme in discussions, and the speculation over older/younger sibling relationship did not always correspond to fact. '*All of the women who were affected looked older*' was one comment from the specialist screenings (which was not the case).<sup>150</sup>

Difficulty in establishing the age of the sisters could be attributed to the perception that women with myotonic dystrophy can have fewer wrinkles and appear younger looking than unaffected women their own age – a statement based, I must acknowledge, on wide anecdotal evidence and the authors own experience – and is not the reaction to *Hazel* quoted above. It is known that the condition causes weak muscle function and tone, and so the women's own genetic systems replicate

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<sup>150</sup> Screening of *Hazel* to an invited audience at the University of Glasgow, 25<sup>th</sup> November 2015. Details in Appendix 4.

anti-ageing cosmetic beauty treatments such as Botox.<sup>151</sup> However this cosmetic observation does not carry through to genetic fact: women with myotonic dystrophy have a reduced life expectancy, the average lifespan is 54 years.<sup>152</sup> Several of the unaffected sisters mentioned this in the interviews, though none of the affected sisters raised it when asked to consider ageing.

Nobody can say – it may be that she will live to the age of seventy and have some disabilities, or it may be that she won't. The thing that I worry about most is that she'll die before my mum.<sup>153</sup>

The use of a visual image of the women is central, and at this point it is timely to return to practice. Once again it bears repeating that the current research has resulted in finished artworks where decisions are made with content and format that distinguish them from the conventions of social science and medical research. I have used this example only because there is a clear intersection in terms of methodology and content, but the outcomes are clearly distinct. In its final presentation, the film *Hazel* uses a split screen format that simultaneously shows the faces of both sisters as a method to illuminate difference and similarity in a depiction of loss. I will cite one example, Louise and Rachel, where Louise, who has myotonic dystrophy, describes the changes to her appearance as she moves into her fifties:

With my appearance (my physical appearance) I know that my face has dropped – especially my eyelids. They are a bit hooded and also, I can sort of pull them and they look a bit strange. My mouth is sloping down, so a smile is sort of straight. I know that I've got a lot of lines as well... But I know it's definitely my face that's actually dropped. I can tell my features have actually changed. It's all going down. I used to have a chin, and now I'm sort of all neck – if that makes any sense.<sup>154</sup>

This section is paired on screen with footage of her unaffected sister Rachel staring at the camera, silent. She looks upset, but says nothing. Filmed at the end of a very long and at times emotional interview where we discussed the loss of her mother, her sister's life now and the disability that increasingly is causing her older sister to physically fail,

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<sup>151</sup> Botox is a cosmetic procedure where neurotoxin proteins are injected into the face to reduce muscle activity associated with frown lines.

<sup>152</sup> Life expectancy with DM: Harper, *Myotonic Dystrophy: The Facts*, 54.

<sup>153</sup> Interview with Lucie, 15<sup>th</sup> March 2015.

<sup>154</sup> Interview with Louise, 14<sup>th</sup> March 2015.

Rachel's silent face provides a stark contrast to Louise animatedly describing her physically deteriorating features. Rachel's face shows no sign of disability and little of ageing, yet it is etched with loss. She looks bereft. In the interview prior to the silent filming we talked of children not had, and the end of a genetic pattern that will result in no more myotonic dystrophy in their family line; her disabled sister leads a busy life and barely mentioned the fact that she hadn't had children, or for what reason, in her own interview. Rachel, on the other hand, is much more distressed by the joint prospect of her sister's worsening condition and her own old age as a childless woman.

To know that my sister is going to have to go through everything that we both watched my mum go through; to *know* that she's going to have to do it, and she's so far away ... [*Upset*] Because she knows what's coming, and I think that must be awful to know that this is what's going to happen, and how it's going to be and I don't know if she thinks about that; does she look back on my mum and think that this is what she's going to have to go through as well or does she just blank it out and think there's no point in thinking about it and worrying about it and waiting for it to happen? I don't know.

Ageing. I try not to think about it. I do wonder what it's going to be like not having any children or ... [*breaks off, upset*] And I've got to that point now where I think, "Will I end up in a home? Will I be able to stay here? Have I lived more years than I've got left to live?" which I never thought about in my thirties but since I got past forty-five I think, "Oh, have I got another forty-five years to go? That's ninety. Do I really want to get to ninety?"

I do think about Alzheimer's and dementia – is that something that's on the cards for me or my husband, and if it is, how am I going to cope or how is he going to cope? <sup>155</sup>

This compelling portrait of a woman dealing with loss on a highly emotive level was achieved through the process of making the artwork; I had interviewed her at length on film, then asked her to remain in the room alone and look into the camera for five minutes, as a method to discreetly record the emotion held there. This is the footage used.

Thus despite the powerful testimony used in the concluding film work of this doctoral research, I have chosen to leave Rachel silent. To exclude her words. This point is significant. Whilst I cannot say with certainty what someone from an alternative academic discipline would do with this material, it would perhaps be unlikely to leave out so much

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<sup>155</sup>Interview with Rachel, 15<sup>th</sup> May 2015.

testimonial evidence in a final presentation. On the contrary, the skill of editing, of assessing the importance of the unsaid and the meaning that viewers will take from this, is one that is hard learned by artists. It requires the experience of placing themselves both centrally to a work of art (as its producer) yet maintaining at the same time a subjective view that is capable of making something that, as Wilkes describes, 'acknowledges in itself the unbridgeable distance between human beings, and the vastness of their inner world'.<sup>156</sup> It is through this practice-based expertise that we begin to see an illumination of the loss felt by each of the sisters.

Whilst both Rachel and Louise's quotations contain testimony of the kind recorded by social scientists in studies such as those cited here by Clarke and Griffin or Kerner -Furman, it provides another view of what that genetic inheritance has meant to these women beyond current academic discourse on ageing. It also acts as an addition to the Clarke and Griffin research as it introduces a discussion of appearance and ageing to that of impairment and accelerated ageing.<sup>157</sup>

In the field of social science research, using examples such as the Clarke and Griffin study cited here, most data is gathered in the form of questionnaires. These statistical accounts, whilst necessary in terms of quantitative evaluation, cannot fully describe the physicality of those involved, something which becomes crucial where a study is linked to the stigma of physical disability, and the associated loss of movement, physical appearance and consequently self-esteem that begins to onset for the women in middle age.

Several of the sisters now require walking aids, and have had to deal with degenerative physical changes at an early age; one woman, Stephanie, has lost her hair (at 44) and requires a wheelchair; another, Louise, is now reliant on a walking stick to get around at age 52. Here, she gives a very clear description of the effects of myotonic dystrophy

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<sup>156</sup> Cathy Wilkes interview, Tate, 2008.

<sup>157</sup> There will be a publication by Glasgow Museums in summer 2017 that will contain the full interviews with each sister, together with documentation of the exhibition *Deep in the Heart of Your Brain* and a commissioned fiction essay, loosely based on the interviews, by writer Nicola White.

on both her facial appearance and her mobility in addition to the excerpt used in the film:

I find that I have to keep myself looking younger. I'm using a slightly heavier day cream - but I like to wear make-up every day to go to work because I think I look better with it. It takes ages to look this bad – but I don't wear make-up over the weekends and I do, sometimes, change my hair colour. Being an Avon Lady, I can sort of get the stuff, and I do have a perm. My hair looks a bit better with a perm. I try and keep myself as good-looking as possible.

I think with my age – I'm gradually fitting into my face and I think, with my age as well, the disability with the walking is actually fitting with my age. I'm catching up. Sometimes people say I'm older than I am. I think, as I'm getting older, I'm catching up with how sort of dodderly I am – if that makes any sense.<sup>158</sup>

That many older women suffer prejudice is sadly true and Clarke and Griffin's study rightly focuses on this by looking specifically at prejudice based on appearance.<sup>159</sup>

...social invisibility arises from the acquisition of visible signs of ageing and compels women to make their chronological ages imperceptible through the use of beauty work.<sup>160</sup>

Invisibility is also discussed by Freidan in relation to print media, and discrimination is implied (it being just one aspect of stigma) by Harriet Deacon in her analysis of stigma associated with HIV/AIDS in Southern Africa.<sup>161</sup> There are many examples of 'negative effects' of stigma, and in Deacon's list they read like a compilation of issues experienced daily by those living with impairment:

Deacon (2006) noted that discrimination is only one negative effect of stigma. Others include status loss, internalisation, and failure to take advantage of social, economical and healthcare opportunities because of expected stigma. Therefore, negative stereotypes, prejudice, and

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<sup>158</sup> Interview with Louise, 14<sup>th</sup> March 2015.

<sup>159</sup> Another study of ageing and appearance from University of West of England in Bristol (Janowski, 2014) looks at a broader range of participants in a qualitative survey, in an effort to enhance this; there, researchers contacted a wide group of both male and female participants as the researchers recognized the limits of Clarke and Griffin. This study was for males and females aged 65 – 92, and through dedicated recruitment to represent a more culturally diverse range of the population (in the West of England), had a far wider demographic in terms of race and background. The study was conducted using group discussion methods recognised within social science.

<sup>160</sup> Clarke and Griffin, *Visible and Invisible Ageing*, 245.

<sup>161</sup> Freidan, *The Fountain of Age*, 35-38; Harriet Deacon et al, *Understanding HIV/AIDS Stigma, a Theoretical and Methodological Analysis* (Cape Town: HSRC Press, 2005), 15.

discrimination may rob people of important life opportunities that are essential for achieving life goals.<sup>162</sup>

Even in a brief summation, we see that the scope of scholarly text where women's ageing is central ranges widely, from the stigma of the ageing female body and its associated physical attributes ('menstruating, fat and old'), deemed unattractive and threatening by wider society, to philosophy as far back as Simone de Beauvoir's comments that ageing is 'carefully passed over in silence, and that is why this silence has to be shattered'.<sup>163</sup> These quotes evidence the fact that ageing women can be ignored and become unseen. As a society we also wish to 'not see' the disabled. So the position of ageing, disabled women in society is marginalised on two counts.

Powerful people can also protect themselves from the types of threats discussed earlier by distancing themselves from stigmatized individuals, bodily substances, and biological processes; by objectifying the stigmatized groups and thinking of them less as individuals and more as objects to be derided, admired, or manipulated; by discriminating against stigmatized individuals in social and employment settings in order to minimize their contact with those individuals; and by setting and enforcing cultural rules that require individuals to control, eliminate, or hide their stigmatized marks from public view.<sup>164</sup>

The notion of a mark or attribute 'setting some people apart from others' as described by Goffman, is relevant here.<sup>165</sup> As the women in the film *Hazel* discuss their changing physical abilities and appearance, they are set apart from their unaffected sisters through knowledge the viewer holds of their genetic inheritance, and also by the chosen format on screen that shows sisters who are simultaneously visible, yet clearly separate. Set apart, yet connected by a blood relationship that is known to the viewer, as it is made clear in the exhibition information/ pre screening presentation that the women are sisters. Thus we have possession of additional information that tells us about the women and their relationship to each other, and as we watch the film it is clear from

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<sup>162</sup> Anna Azulai, *Journal of Social Work Values and Ethics*, Volume 11, Number 2 (2014), Association of Social Work Boards (ASWB).

<sup>163</sup> Chrisler, *Leaks, Lumps and Lines*, 7; Simone De Beauvoir, *The Second Sex* (Penguin, 1972).

<sup>164</sup> Chrisler, *Leaks, Lumps and Lines*, 7.

<sup>165</sup> Ernest Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (New York: Simon and Schuster, 1963)

those that speak that they are talking about the effect of the gene on their lives.

My interest is not in further discussion around stigma, ageing and disability, however, but in how my own artistic research can offer a new interpretation of loss, in particular if directed toward specific audience groups.

## **2.7 Hazel: specialist screenings**

To this end I presented *Hazel* at a number of specialist screening events held in Newcastle and Glasgow.<sup>166</sup> Here, many medical staff questioned the format and split screen method of presentation, and were particularly vocal regarding the complex ways that information (about the artwork and the sisters) is both withheld and provided in a contemporary art setting. Cathy Watt, a highly experienced Genetic Nurse Specialist:

Cathy: Surely for people not from a clinical background, not with any understanding of the condition, basically they'd be looking at two heads talking. And apart from the first lady describing what had gone wrong with her, would they see someone with a genetic condition?

JD: You'd have to ask people who don't know [the symptoms]. I knew as soon as every single woman opened the door to me that they had myotonic dystrophy. I knew.

Cathy: But you know what you're looking for.

JD: But that's my take as an artist, in presenting something that's personal to me. It's not a conference paper. So we don't know the answer to that - if you walked in and looked at the film would you think, oh, there's something funny going on with all of them?<sup>167</sup>

Louise Hastings, a genetic nurse specialist in Newcastle, wrote about her frustration at not hearing the unaffected sister

Thank you for showing us your piece of work. I am a Nurse Specialist that runs yearly assessment clinics for DM1. I see approx. 8-9 patients and their families monthly with varying severity of symptoms. One of the most striking features of DM1 is the cognitive deficit leading to their lack of awareness and apathy. They also find it difficult to

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<sup>166</sup> These screenings are detailed in Appendix 4.

<sup>167</sup> Cathy Watt, Principle Genetic Counselor, West of Scotland Genetics Service, at a post screening discussion at Glasgow University on 25<sup>th</sup> November 2015.

express themselves and to listen to advice. This can cause frustration and relationship difficulties with family members.

I have to be honest and say that I was disappointed with the content of your film. I think the concept was good but I think you missed the chance to see the contrast between what the patient thinks and their family member. It would have been useful to hear the opinion of the sibling.<sup>168</sup>

Dr Mark Hamilton, another clinician present at the Glasgow University screening, who sees patients with myotonic dystrophy every day, reinforces the power of the ‘unknown’ unaffected sister with his own analysis:

I think one of the main things I took from Hazel was an insight into how dystrophy can impact the identity of an individual. As clinicians, we’re trained to look for the typical signs - such as facial weakness, droopy eyelids, even aspects of personality - that we associate with the disease. It is all too easy then to fall into the trap of defining the person by their illness; “another myotonic”. The effect of the silent sister - a range of different women from the general population - reminds us that the affected sisters are equally diverse, and encourages us to look beyond the superficial similarities of the disease and to see the individual.<sup>169</sup>

Dr. Sarah Cumming, a scientist in the molecular genetics laboratory at Glasgow University, wrote this in response:

I work in a molecular genetics laboratory at the University of Glasgow. We receive large numbers of DNA samples from patients with myotonic dystrophy type 1 (DM1) and I spend a lot of my time studying the changes in the DNA that cause the disease in these patients. Sometimes we are sent DNA samples that have not given a clear positive or negative result in the diagnostic test in the NHS genetics lab. I have often carried out an experiment in the lab that gives the answer, often that they have an unusual form of DM1. Usually, I am pleased to have come up with an answer, thinking the clinician and the patient will both be relieved to know for certain. I have not often given much thought to everybody else in the immediate and extended family, and how the diagnosis might affect them.

It is remarkably easy to drift into a state of mind that sees the DNA samples as no more than an interesting puzzle, as something to get excited about when I find something unexpected. It is always useful to be forced out of that comfortable illusion. For those of us in the lab who work on myotonic dystrophy, we sometimes attend patient support group meetings or research days for families with muscular dystrophy. The chance to meet patients and families helps to remind us why our work is so important. The film “Hazel” and the rest of the work in the “Deep in the Heart of Your Brain” exhibition at GoMA in

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<sup>168</sup> Louise Hastings, Nurse Specialist in Neuromuscular Genetics, John Walton Muscular Dystrophy Research Centre, Newcastle upon Tyne, in an email to the author on 31<sup>st</sup> January 2015.

<sup>169</sup> Dr. Mark Hamilton, Clinical Geneticist, West of Scotland Genetics Services. Interviewed 20<sup>th</sup> March 2016.

Glasgow has made me think about things in a slightly different way, as I considered the feelings of the whole family, not just the patient. Watching the changing emotions on the unaffected sisters' faces made me think about my own sister, who lives a long way away. The time pressures of both our work and my family mean we don't speak often enough, but our common history means we still understand each other so well and fall very easily back into a very comfortable and loving relationship when we do get to meet. Both the film and the art works made me think more about the shared experiences, common memories and love in any family, regardless of how life works out.<sup>170</sup>

An alternative view was given by Dr Cheryl Longman, consultant clinical geneticist for all families in central Scotland:

Seeing Hazel led me to explore my own thoughts about people with myotonic dystrophy and other genetic conditions. To me, all the people on the left side of the screen (the affected people) merged into one, very similar, person with myotonic dystrophy. I saw them as having much more in common with each other than they did with their unaffected sibling on the right. The people on the right, however, I saw as a series of individuals. My expectation was that other medical professionals would see the same thing. I was surprised that most doctors I spoke to did not see that, but found the family similarities most striking. I have reflected on that since and realised that perhaps I see the disease rather than the individual. Being more aware of this during consultations has I think been helpful in shaping my ongoing practice.<sup>171</sup>

From these comments, another series of questions arise.

- Which sister do you look at?
- Do they seem alike?

As viewers try to identify a family resemblance, do they, like Dr Longman, also seek similarities in the women who speak, the women who share a disability? Do they also look alike? For the sisters who have myotonic dystrophy, how does looking at the film and seeing other women who have their condition (some with marked facial characteristics, some with none) make them feel? Do they see a 'genetic resemblance'?

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<sup>170</sup> Dr. Sarah Cumming, Research Associate, Institute of Molecular, Cell and Systems Biology, The University of Glasgow.  
Interview by email, March 2017

<sup>171</sup> Dr. Cheryl Longman, Consultant Clinical Geneticist, West of Scotland Genetics Service, Queen Elizabeth University Hospital, Glasgow. Interview by email 21<sup>st</sup> March 2017.

In addition to privileged knowledge that was highlighted in feedback from the professional screening of the work, there was also some discussion around the format of the film:

It's the contrast with the silent side. You're always looking for reactions and an interplay between the two. That's what resonated. It's that moment of looking at both, and having both there.<sup>172</sup>

This returns me to the question I have asked from the outset of this research in 2001, and at the start of this section; where is the tipping point when someone stops looking like their family and begins to look like their disability?<sup>173</sup> In considering this, I would suggest that *Hazel* has presented something to the general public, and to specific audience groups, both professional and lay, that asks them to consider their understanding of sibling relationships, ageing and disability, of similarity and difference, and of loss. The artwork therefore does not answer the question above, but establishes it as subjective.

It was only on final editing of the piece that these associations emerged, as I sought a method to distil several hours of interview into a format that conveyed some of my confused emotions around my own family. Themes of beauty and resilience remain central; each woman represents some or all of these through personal testimony and reinforces the attributes deemed necessary to address loss, whether consciously or unconsciously employed. In clinical terms, the visibility is therefore with the patient, and not the sibling, as that is what is 'known' to science.

Using my own terms, my sister and I look like each other, but my sister also looks like an illness.

This work has contributed to existing knowledge of stigmatisation, of *virtual social identity*, and *actual social identity*, as described by Ernest

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<sup>172</sup> Dr. Bob Ballantyne, Clinical Geneticist, West of Scotland Genetics Services at a post screening discussion at Glasgow University on 25<sup>th</sup> November 2015.

<sup>173</sup> I use the term 'disability' as description of the difference between family members and acknowledge that this use of the term could be problematic, as several of the sisters, including my own, do not see themselves as 'disabled'. However to say 'has the gene' does not describe a physical separation, as it is possible to have myotonic dystrophy and display only very mild symptoms as it is a degenerative condition where the physical affects worsen over time. See Harper, *Myotonic Dystrophy, The Facts*, 15-16.

Goffman in his 1963 publication *Notes on the Management of Spoiled Identity*, through the placing of three elements (artist, patient, scientist) in a discussion that involves both difference and similarity.<sup>174</sup> In the work I assume the role of the 'wise normal', but, as Goffman describes, this position is interchangeable depending on circumstances; in my case a positioning that involves multiple roles of professional, academic, advocate and care giver. Each of these positionings can be stigmatised through associations with a 'non-normal' family.

Extending this further in relation to academic practice, Joan Chrisler's paper from 2011, whilst dealing with very specific feminist theory on weight and bodily excretions, and the stigmatisation of women via their own physical make-up, also cites the roles available to women within academic research. She extends a call to academics and professionals to eradicate stigma by positioning ourselves, then others, in supportive situations that offer a protective force. She asks that we protect ourselves as we seek to re-educate others, and that we question how women are compared. It is notable that this call should come from within academia, and fortifies the argument that the creation of research led artworks that redefine women in this field is both relevant and necessary.

It is our job, as therapists, researchers, and educators to help women to situate themselves in empowering ingroups (sic) and adopt identities that protect them from oppressive messages about our bodies and ourselves. It is possible to redefine the standards of comparison, but we have to start now. Furthermore, we have to realize that not all feminists are already enlightened about stigma and women's bodies; rather, we have work to do with ourselves as well.<sup>175</sup>

This has never been more important, as the disabled and impaired population are increasingly stigmatised by government and society. Several studies confirm this, and news reports and journalistic articles list daily examples of benefit restructuring, of extreme discrimination and violence, and police crime statistics now acknowledge how under-

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<sup>174</sup> Ernest Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (New York: Simon and Schuster, 1963), 2.

<sup>175</sup> Chrisler, *Leaks, Lumps and Lines*, 9.

reported crimes against the disabled population are.<sup>176</sup>

I see this first hand from the employment history of my family, from families I have met through charities that support them, and now through the interviews with this group of women. Referring back to the *Hazel* film and interviews, I quote Sally: ‘...I wish I was a bit cleverer than I am because that has affected my life – getting a good job or getting good grades – so I wish I was a bit cleverer.

In almost every case employment history, lack of attainment in education and low wages when in work are clear. By recording the thoughts of sisters affected by myotonic dystrophy, in a manner that is both personal and empathetic, similar to the Ribbens and Edwards work on non-disabled families, the interviews that form part of the wider study lay a strong foundation for continued research to shed light on terrain inhabited by many, whilst the artwork that forms 50% of this submission forms a singular artistic response in the form of a portrait of something very private - the loss of my sister.

## 2.8 Hazel and expertise

Observing the position of the affected sibling within their family, and

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<sup>176</sup> see UK Home Office – Corcoran, Lader and Smith. Hate Crime, England and Wales, 2014/15. Published by Open Government Licence, Crown copyright 2015.

This paper notes 5% of ‘Hate Crimes’ are against those identifying as disabled, yet also states that this figure should be higher: ‘The survey suggests a higher proportion of hate crimes are for the religion, sexual orientation and disability hate crime strands than is found in the police recorded crime figures. For disability hate crimes, for example, this fits the pattern that some respondents in the CSEW might be answering the question based upon their perceived vulnerability. For example, a burglary victim with a disability may have felt that this was a factor that made them a vulnerable target, but it does not necessarily follow that the offender targeted the individual due to a hatred of their disability’.

In 2014-15, 177 charges were reported with an aggravation of prejudice relating to disability, 20% more than in 2013-14. There is a broad consensus however that this type of crime continues to be under reported compared to other forms of hate crime. Both Police Scotland and COPFS are engaged in a variety of activities aimed at increasing the level of awareness, especially amongst disability communities, that hate crime is unacceptable and should not be tolerated. Hate Crime in Scotland 2014/2015. Crown Office and Procurator Fiscal Service, Edinburgh, 2015: 3-4  
Accessed 20<sup>th</sup> February 2016.

<http://www.copfs.gov.uk/images/HateCrimeinScotland2014-15>

considering the visibility and the stigmatisation of disabled populations within wider society, brings into focus the position of science and the medical profession in relation to those they treat and research, where the dominant relationship is of the doctor leading the patient and the scientist directing the research. Within these existing hierarchies, does this positioning have capacity to shift, by acknowledging that the information the patient holds is necessary and of use to those that research them? In one sense, we could say that this is an example of 'expert culture', as the families are the experts in many aspects of a multi-systemic condition, and hold knowledge – whether that be in their brains, bodies or genetic structure – of something which the professional medical world seeks answers to. To ignore this is at the peril of medical advancement, as was indicated in my discussion of the earlier film *Tomorrow Belongs to Me*, which charted the journey that certain individuals took to prove the scientific phenomenon of *anticipation*, something that was recognised but unexplained by families in the face of 'knowledgeable' scientific opposition. As Dr. Mark Hamilton said, on reflecting on the film several years later:

The section "tell me about your father" is particularly poignant and important, I think. This reminds us that good science involves seeking truth by making observations as they are, even if they don't appear to make sense, rather than trying to contort our observations into pre-conceived models. It makes me think of a quote we were told at medical school, from Sir William Osler; "Listen to your patient, he is telling you the diagnosis."<sup>177</sup>

This leads directly to the concept of expert culture as a means to connect artistic research with the clinical work mentioned here. Expert culture is a term used in several academic disciplines such as social science, science and technology and cultural studies. It is a more recent term used in relation to contemporary art practice to categorise a method of working that is widely employed, and a type of art making that is integral to the practice of many artists who seek out expertise beyond their own knowledge and understanding. An excellent example of this is the practice of Christine Borland, in works such as *From Life*, that explored the provenance of a human skeleton, purchased via the internet, through the expertise of a number of experts in fields ranging

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<sup>177</sup> Dr. Mark Hamilton, from interview by email, 20<sup>th</sup> March 2016.

from forensic reconstruction to pathology and criminology.<sup>178</sup> It is often used in relation to the term 'collaboration', though as I have argued, I see them as being distinct. Instead, I would say 'expert culture' can be applied when considering who references whom in the development of good practice, and as recognition of the value of knowledge transfer and shared understanding across many sectors. Pavel Büchler describes this well here:

...it is the way in which integration brings to the surface the specificity of individuals, as a source of all exceptions to every professional rule, which makes professional cultures permeable and makes other peoples trades the places to find out and learn from one another who we are and how what we do could also be done differently.<sup>179</sup>

Within the world of medical research, the opportunity for shared forums for patients, scientist and physicians is not as common as it is for groups within the arts that have an association or common purpose to discuss. The weakest of these communication channels within myotonic dystrophy research had traditionally been that existing between scientists and patients. This could be explained by the fact that science deals with cells and samples, whereas patients are living entities that do not exist in laboratories. Thus the convention is that patients see physicians, and physicians and scientists working in a specialised field communicate with each other through professional journals and conferences. Through this research I seek to address this aspect of the triangular relationship, as many in this field now do using methods outwith contemporary art, to strengthen the communication link between scientists and families through artworks that seek to present data and experience differently.

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<sup>178</sup> Christine Borland, *From Life*, 1994, Installation. First shown at Tramway, Glasgow, 1994. Exhibition publication, *Christine Borland: From Life*, (Glasgow: Tramway, 1994).

<sup>179</sup> Pavel Büchler, 'Other People's Culture', in *Curious: Artists Research within Expert Culture*, ed. Susan Brind (Visual Art Projects, 1999), 47.

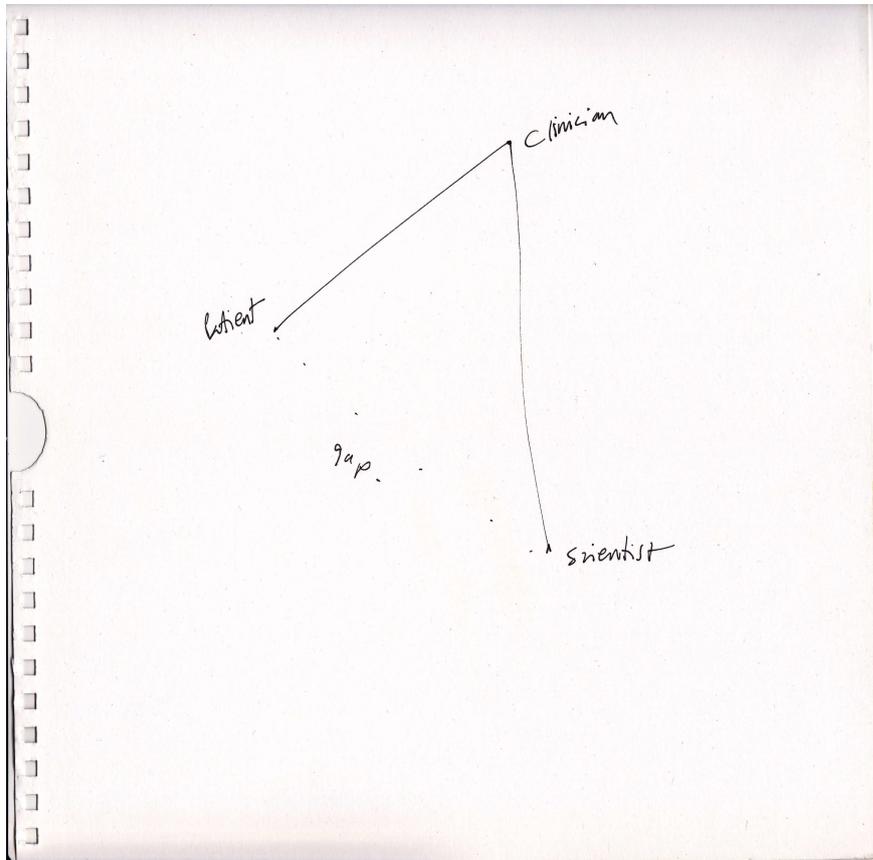


FIGURE 9  
Donachie, Jacqueline. *Medicine, Family, Science*. 2016.  
Drawing, ink on paper, 22 x 27cm.  
Courtesy of the artist.

In 2003, in Glasgow, I spoke at the first joint formal session of scientists, clinicians and families in the international myotonic dystrophy research sector – individuals associated either through their professional practice or family inheritance<sup>180</sup>. I had been invited to speak about the initial Wellcome Trust funded research with Monckton that had resulted in the artists book *DM*.<sup>181</sup> In the lecture theatre that afternoon there were scientists who had spent an entire career studying the genetic code and inheritance pattern of the condition, yet had never seen a living person who suffered from it until that point. This joint conference session began to address an ongoing problem of the disconnect of laboratory to hospital to home, a weighty discussion that is beyond the scope of this research. What is most pertinent here is my function within the meeting - an artist talking about a collaboration with a scientist, as described in Chapter 1. My family status was not my primary position, although it was that experience that had given me the impetus to contact the Division of Molecular Genetics in the first place. But it was as an artist seeking a collaborative dialogue, and the opportunity to apply for Wellcome Trust funding, that led to the university meetings, the research trip to Quebec, and the publication of *DM*, that in turn led to the platform presentation in Glasgow that finally seemed to offer something that was of equal value to all involved.

These shared forums, which now happen regularly within the myotonic dystrophy community and elsewhere in the rare disease network, are a significant step forward in the development of research and care.<sup>182</sup> Having now been to several, the most important thing I recognise is this: that they are most effective when there is input beyond the first hand, personal experience of families. These families rightly seek specific solutions to their very own individual problems from the

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<sup>180</sup> 4<sup>th</sup> International Myotonic Dystrophy Consortium Meeting (IDMC-04) was held at the University of Glasgow from 10<sup>th</sup> – 12<sup>th</sup> April 2003. The session cited was a joint one organised with the UK Myotonic Dystrophy Support Group (MDSG), the patient and family support group established by Margaret Bowler in Nottingham in 1990 <http://www.myotonicdystrophysupportgroup.org>

<sup>181</sup> Wellcome Trust Sci-Art Award, 2001. *DM*, artists book (University of Glasgow, 2002).

<sup>182</sup> Since the meeting in Glasgow, there have been shared conference sessions at the IDMC meetings in Quebec (2005), Milan (2007), Wurzburg (2009), Florida (2011), San Sebastian (2013) and Paris (2015); they are now a fixed part of the conference schedule. Scientific and medical practitioners also attend family support group conferences held by MDSG each year.

eminent physicians attending, as it is rare for them to have access to a professional with expert (or indeed any) knowledge of the condition. But this situation can lead to a long, long session that lurches from heartbreaking loss to unruly emotions concerning drug distribution and postcodes, entwined with advanced technical information of the structure of DNA that is beyond the understanding of many.<sup>183</sup>

Within this milieu I have presented artworks – films made in response to my own experience as a family member affected by the condition – that have provided an alternative view. Not instructive or informative, nor overly emotive, but perhaps more a provocation. These works are not universally loved by the audience, something that was demonstrated earlier by the reaction of many scientists to *Tomorrow Belongs to Me* for its ending, and the frustration by some at the silence of the unaffected sisters in *Hazel*. It is explicit that this stems from my profession as a contemporary artist with broad experience of socially engaged practice over a number of years, and not simply from my position as a family member with a story to tell of sick relatives. Throughout my career I have honed a range of editing methods in relation to materials that produce many things, a number of which were discussed in Chapter 1: dark minimal sculptures, sparsely written artists books and public artworks that often disappear. I deliberately eliminate elements to produce art that seeks a more complex relationship with the viewer, asking toil from both sides with no offer of immediate reward, that produces a different engagement than the offering of information, sympathy or charity.

It is from this position (an artist who uses the withholding of information as a technique of detachment) that the film *Hazel*, and the earlier *Tomorrow Belongs to Me* stem. It has brought reaction to the films from professional interest groups and the interview participants themselves that is not universal acclaim on first viewing. Does this demonstrate that longevity is also a worthy consideration? Certainly, artworks are not

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<sup>183</sup> Moves to address this have ranged from requesting that questions are tabled in advance to enable themed grouping, clear instruction for experts on the tone of their presentations, and more dynamic chairing.

dependent on facts. The knowledge of the viewer can, and undoubtedly will, change over time, but the work itself remains immutable. It is this that differentiates subjective and creative engagements with lived experience from documentation, illustration and fact. In the words of Wood:

So often things are presented for academic or promotional reasons. “*Hazel*” provided a very real, unfiltered view into the lives of these sisters. On reflection the film has made me consider how the medium of film and art in general can be used to make scientific research more accessible, but also to provide an insight into others’ lives in a non-clinical way. Furthermore it has allowed me to consider the wider scope and reach the registry could have by collaborating with people from other fields.<sup>184</sup>

## **2.9 Writing about *Hazel*: a synopsis**

The issue of ageing and loss are central to the unfolding debate in this thesis, and in this chapter I have examined in more detail the significance of the artwork *Hazel* in relation to existing scholarly work that intersects with these themes, with particular reference to feminist literature and qualitative methods of social science research. I began with an appraisal of the making and presenting of the piece, giving a description of the unique recruitment process that involved several partner agencies such as the UK Myotonic Dystrophy Patient Registry and the Centre for Life in Newcastle. I then went on to outline how the work was presented within both conference and gallery contexts, briefly describing each situation.

A stated ambition for the research is to move beyond artworks that are simply illustrative or explanatory through the production of work that has employed unique collaboration with a clinical agency and primary field-work involving a group of disabled women and their sisters. Technique of interview and selection of participants is therefore pertinent. My decision to seek out women representative of all generations in adulthood to portray ageing was significant, as it parallels my own position within the work; the narrative of the body of

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<sup>184</sup> Elizabeth Wood, Curator of UK Myotonic Dystrophy Patient Registry. Interviewed by email, 18th March 2016.

work presented in this thesis began with the diagnosis of the condition in my sister when she was in her late 20's. As we enter our 50's, what sets ageing apart from the effects of disability in a portrait of two women, once physically alike?

Attitudes to ageing and beauty were discussed through an examination of the Clarke and Griffin paper from 2008, *Visible and invisible ageing: beauty works as a response to ageism* and associated academic writing, particularly in the field of feminist research.<sup>185</sup> I contextualised the interviews I made with eleven women affected by inherited disability with the Clarke and Griffin cohort, to demonstrate the scope of this research across a range of sectors, not just contemporary art practice. In doing so, I identified a gap in the parameters of that particular study that could benefit from an expansion to include participants with impairment, particularly where there is acceleration of the already established symptoms of ageing through inherited conditions. The issue of *biographical disruption*, the stigmatisation of older women, and a comparison with the treatment of the disabled in general, shows clear connections here with the writing of Joan Chrisler and others.

In addition to recruitment of participants and the interview process, visibility and stigma were both significant in the format of the final work through decisions made in the editing process. This was examined with particular reference to one set of siblings, Louise and Rachel, and the decision to leave the unaffected sisters mute in the film was established as key to the work's impact. Whilst the opportunity to use the spoken interview of each woman was available, I decided to instead use the silent footage of the unaffected sister's face, shown on screen beside her (speaking) sister, as a means to demonstrate both the similarity and difference of the women, and to portray the particular invisibility and loss that each described.

A significant part of this research has been the desire to speak directly to science and medicine through the art works produced. To that end a number of professional screening events were held in Glasgow and

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<sup>185</sup> Clarke and Griffin, *Visible and Invisible Ageing*, 653-674.

Newcastle for clinical and scientific research teams.<sup>186</sup> Reactions to the film were described, particularly comments on the use of silence in the work, and on knowledge both known and denied through privileging of information. Whilst this purpose remains dominant, through the examination of parallel literature from other fields my own desire to portray the loss of my sister though this work also becomes evident.

Lastly the employment of the term 'expert culture' provided a fitting connection between this artistic practice and medical research. The significance of who holds power in relationships within the world of inherited genetic disability (even the relatively small world of the myotonic dystrophy community) is significant, as laboratory based science moves closer to treatments and therapies, and drug companies become involved. My argument here is that the patient and family community is also the 'expert culture' whose voice should be heard, challenging accepted notions of treatment, of normality and of value. If the patient is recognised as having the capacities of an expert – someone with somatic knowledge that is of use to the scientific community – and this is demonstrated through the production of quality artworks made by an artist who is recognised as an expert in their own field of contemporary art, can this be of benefit to those communities, and therefore provide a platform for discussing (promoting) the direct leadership role of certain artists within collaborative academic practice?

How this is articulated is the challenge. It is the role of the artist, as the leader in the research and editor of the work, that is key to how this particular knowledge is presented.

The artwork *Hazel* offers effective ways to facilitate this by illuminating aspects of the condition, as they are experienced by siblings. This is achieved in new ways that, in terms of celluloid, are distinct from a documentary monologue of symptomatic deterioration, illness and decline, or films made by charities for fundraising purposes. In addition, this thesis acknowledges parallels with qualitative social science research, particularly in identifying and preserving (recording)

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<sup>186</sup> See Appendix 4 for details.

marginalised domestic experience within an academic context – in this case the experience of a group of women who are often invisible to society through their inherited disability, their gender and their age.<sup>187</sup> The film extends this, contributing new knowledge, through examining the recording and presentation of individual experience to portray an ineffable, personal thing: the loss of a sister.

By describing the issue of agency underpinning this practice, particularly the experience and reaction of the women involved, and the discussions with professionals from scientific and medical backgrounds who attended two curated screening events, I was then able to consider the significance of the use of silence in the final artwork, and the capacity it has to both frustrate and illuminate, as unique contributions to conventional methods of academic research.

Thus the positioning of myself as a professional within this community has given me a singular platform from which to undertake research, and in the next chapter I will go on to examine this. Central to this is my own status. I have begun to establish as significant, and multiple, as a family member, an advocate and an artist. By defining my artistic position with reference to works by other artists that employ auto-ethnography and collaboration as a process to navigate and articulate significant loss, can this practice also be seen to lead? Through an interrogation of what compels artists to make public very private situations, I ask if this process helps to establish a position of leadership that is denied to many dealing with the stigma of long term illness and impairment, and demonstrate the potential for artists (this artist) to challenge those who exercise power in relation to marginalised and vulnerable groups. The responses of those professionals (e.g. clinical geneticists Dr. Cheryl Longman and Dr. Mark Hamilton, and scientist Dr. Sarah Cumming) used in this Chapter indicate an approach to patients and their work that seems to have been shaped by their engagement with the artwork, both in terms of its method of editing and its mode of display.

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<sup>187</sup> There is no statistical difference in sibling sexes inheriting myotonic dystrophy, as described in Chapter 1. My use of sister | sister here stems only from my own specific position as a female with a sister who has the condition.

## CHAPTER 3

### 3.1 Leadership and collaboration.

In the previous chapter I framed the *Hazel* research in terms of scholarly work in the field of social science, and gave reactions to the film from various professionals (scientists, genetic consultants and nurse specialists) involved in medical and scientific research connected by myotonic dystrophy. I proposed that the work had the capacity to 'illuminate loss' in relation to certain clinical, social and emotional aspects of the condition. In this chapter I discuss further practice-led collaborative working that has the capacity to transform thinking by offering new articulations of loss. To support this discussion I cite examples of criticism and also of good practice in art science collaborations such as through the use of a public experiment, as that undertaken by Beatriz da Costa and scientists at UCI in Los Angeles. Considering the importance of the capacities of artists within research, I also give an example of auto-ethnographic film making by artist Karen Guthrie, and further extend the references to contemporary art by citing the work of Sharon Hayes, who employs the use of 'voice' within her practice to describe very personal emotional states.

Continuing with the theme of public research involving private experience, as introduced in Chapter 2 through the work of Jane Ribbens and Rosalind Edwards and the Woman's Workshop on Qualitative Family/ Household Research at Oxford Brooks University, specific examples from work concerning sisters and pregnancy and childbirth raise problems of locating the researcher in the practice that are topical to his study, where there is shared experience between myself and the participants.<sup>188</sup> I will continue to examine this with a deeper dissection of the role of the artist in this current research practice, and give further consideration to the capacity of leadership as was initially identified in Chapter 2. Critical attention to the question of collaborative working is key to this, as I continue to examine an artistic

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<sup>188</sup>Melanie Mauthner, 'Bringing Silent Voices into a Public Discourse'; Tina Miller, 'Shifting Layers of Professional, Lay and Personal Narratives'; in Ribbens and Edwards, *Feminist Dilemmas*, 39-57 and 58-71.

research model that inhabits the realm of 'sciart' collaboration whilst seeking to challenge what is recognised as acceptable motive, outcome and value to this contested field. At the same time I will establish my own position, and ask whether quality art practice can transform personal crisis into leadership and empowerment.

...all work of quality has influence, but it is important to distinguish influence from leading, and highlight transformation as different from influence.<sup>189</sup>

### 3.2 Leadership and 'the random'

If they want to be efficient, the artists and philosophers should be aware of their action's limitations.<sup>190</sup>

In the previous chapter I described the possibilities of art as a means to both challenge understanding and illuminate the experience of women affected by inherited disability. I also gave examples of the importance of creative, practice-led research within collaborative working. Within this setting, the position of the artist is significant, and it is therefore important to establish the role of leadership in this context. J.K. Tanke's interpretation of Jacques Rancière's position on the artist and the spectator is a good place to begin. Here, Tanke considers the French philosopher's understanding of the relevance of art functioning actively on the political stage:

While Rancière's work is by no means polemical, it works against these two positions in order to clear the ground for possible interventions. That is, his work attempts to cultivate a theoretical position that will allow us to understand how art can be active on the political stage rather than simply lament the failures of aesthetic and political collaboration throughout the twentieth century. One should hear in his emphasis on possibility the repudiation of all discourses that turn art into the dressing for some type of wound, just as one should understand titles such as "The Emancipated Spectator" as indicative of the positive features that he locates within contemporary viewership - despite all that we know about spectacle, commodification, domination, and the narcissism of the gaze.<sup>191</sup>

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<sup>189</sup> Anne Douglas and Chris Fremantle, *Artist as Leader Research Report* (Aberdeen: Robert Gordon University, 2009), AHRC funded research, 35.

<sup>190</sup> Jacques Rancière, via Daniela Labra, 'S-L-O-W' in *Slow Prototype*, ed. Brett Bloom and Nuno Sacramento (Aberdeenshire: Scottish Sculpture Workshop, 2015), 80.

<sup>191</sup> Joseph K. Tanke, 'Why Rancière now?' *The Journal of Aesthetic Education*, Volume 44, Number 2, Summer 2010, 1-17

For Tanke, then, via Rancière, artworks cannot function as sticking plaster. But some do have a role to play, and as they evolve as an important part of our society in ways that refer to looking and seeing, visibility and perception, and establishing and maintaining the necessity to *notice well*, they demonstrate the power to illuminate, and of the artist to lead. It is what they lead that becomes more relevant for my own purpose here.

In the context of this research, which involves a very personal investigation of disability and ageing, the question is extended to ask whether a dialogic practice can operate in medical situations without the audience being drawn into the pitfall of either sympathy for or aversion to the cause in question, as outlined by Kester below. As there are an increasing number of artists working in areas involving medicine, healthcare, and disability, as well as those examining ethics and technology, the issues of sympathy and therapy are important to consider here.

If the specific social issue or community that the work addresses is seen as laudable or sympathetic (the AIDS crisis, struggles against racism, homelessness, etc), then the work itself is seen as successful by sheer contiguity. By the same token, criticism of these works is often constrained by fear that one will be seen as disparaging the issue or community involved.<sup>192</sup>

Many artists engage with political and contextual themes in their work, but, as Rancière directs, it is important to remember the limits to the range and transformational qualities of this in 'global terms'; it will not change the world. The importance of the dialogue, as opposed to the sympathy, shock or wonderment value of the works background - the scientist's imagery or the participants' given situation - is what is important to me here. This emphasis on dialogue stands in opposition to what is described as 'information art' by Kester, but also aligns itself to what Jacques Rancière notes as a reaction to the current international biennale circuit, whereby overwhelmingly powerful and topical issues are used as thematic exhibition concepts. Issues such 'war' or 'the environment' are applied, and the artworks shown are often

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<sup>192</sup> Kester, *Conversation Pieces*, 11.

given as an authoritative reflection on the state of the world - 'an awareness of the hidden reality and a feeling of guilt about the denied reality'.<sup>193</sup>

I agree with this to an extent, but feel a caveat must be introduced: within distinct, circumscribed communities (such as families, or medical specialists, for example), the relevance of work can change, given the smaller, but more influential, cohorts involved. And even though the overall possibility of grand social change is limited, as Rancière describes, such directed works, and the artists who make them, can be important. The latter's potential importance stems from their ability to step outside the established boundaries of art making and art viewing to connect with alternative groups of both 'real' and highly specialised, professional people – scientists, molecular biologist, clinical geneticists, nurses and care workers, for example – who do not share the intellectualised discourse around art theory but are highly knowledgeable in an alternative, connected field. These groups will use their own acumen to process what the artist has done when they impinged on their world.<sup>194</sup>

Specifically, in the case of *Hazel*, a great deal of discourse related to the work's reception has centred on the 'unaffected sister'. There has been a strong desire to know more about her, as she seemed – by appearance – different to the affected sisters that the clinicians in particular are used to seeing; in some ways even the idea of them has become an object of curiosity. At the curated screenings of the film in Newcastle and Glasgow, the clinical teams appeared at times to de-pathologise their patients for the first time, to see them as women who had a life beyond their symptoms, as described here by Dr. Mark Hamilton:

The effect of the silent sister - a range of different women from the general population - reminds us that the affected sisters are equally diverse, and encourages us to look beyond the superficial similarities

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<sup>193</sup> Jacques Rancière, *The Emancipated Spectator*, (London: Verso, 2011), 27.

<sup>194</sup> Examples included in thesis would be the teams at UCL who worked on PidgeonBlog (environmental science) and the relationship that Karen Guthrie established with the UK Stroke Association to distribute her film *The Closer We Get*.

of the disease and to see the individual.

On a related note, I was also surprised to hear affected women talk about how aspects of their appearance, or their performance in social situations bother them. These are things we tend not to ask about in clinic, and as a result I had never really considered how affected people feel about these issues. Certainly I think this has made me much more mindful of identity issues in my approach to people with myotonic dystrophy.<sup>195</sup>

The hierarchical nature of relationships within medicine continue. However, the transformative power of art does not always have to exist in a top-down scenario of emancipation, where artists only engage directly with vulnerable or excluded communities to affect immediate, short term social change through community arts or therapy. They can also exist in an intellectually equal environment where knowledge and experience are re-presented using high levels of expertise from an alternative field.

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### 3.3 Leadership and the Artists Placement Group

In investigating this further, I am going to go back, not forward in time, and turn to the Artists Placement Group, and their work in the 1970s that dealt with the role of artists in society. I feel that it is this theory of artists in practice that better suits my ambitions within what I have now established as the 'art and science' arena.

The Artists Placement Group (APG) proposed that organisations, from government to industry, have artists 'placed' within all forms of their planning constructs.<sup>196</sup> Crucially, the artist was to have no brief and there was to be no demand for an outcome (the 'open brief') – a reversal of assumed relationships between artists and business/industry.

End products were normally paramount in the sense that a sculptor worked in a metal factory in order to produce a metal sculpture. Subsequently APG perceived that an artist placement in industry could

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<sup>195</sup> Dr. Mark Hamilton, interview by email, 20<sup>th</sup> March 2016.

<sup>196</sup> APG was established as a charitable trust in 1966 by John Latham and Barbara Steveni; other artists involved were Jeffrey Shaw, Barry Flanagan, Stuart Brisley, David Hall and Ian MacDonald Munro.

be much more ambitious: it could be longer term and more like a university fellowship.<sup>197</sup>

A notable example of this was John Latham's placement at the Scottish Office in Edinburgh. Whilst there, in the Planning department, he worked to designate 5 shale bings in Longniddry as monumental works of public art (Five Sisters), following a period of investigation considering derelict land near Edinburgh.<sup>198</sup> And whilst his work around urban regeneration in the Glasgow area did not come fully to fruition during his placement, subsequent developments a decade later that led to the city becoming European City of Culture stemmed from a recognition of the value that art and culture could play as a means to stimulate post-industrial regeneration.<sup>199</sup>

So whilst radical in thought it was not without success; government institutions such as the Scottish Office just mentioned, but also the London Health Board and the Department of the Environment each had artist's placements. In a resulting official memo, the Civil Service encouraged all departments to involve artists in their planning activities, so highly did it regard the value of the process:

Artists, arguably, have the ability to comprehend and synthesize these broader interrelations because they are not limited by the technical expertise required by each specific area and can thus more easily view them as interrelated parts of a larger whole.

Such knowledge is less concerned with the internal operations of an individual discipline than with a topographic ability to assess interconnections among various disciplines at a given time.<sup>200</sup>

This radical process was later adapted by other arts bodies, for example Arts Council of England, to become 'artists in residence'

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<sup>197</sup> See John A. Walker, *John Latham, Incidental Person* (London, Middlesex University Press), 98.

<sup>198</sup> Latham's placement at the Scottish Office is discussed in detail by Craig Richardson in his article '*John Latham: Incidental Person*', *Map* No.11, 2007, accessed 13<sup>th</sup> March 2016.

<http://mapmagazine.co.uk/8787/john-latham-incident-person/>

His proposals are well documented and resulted in a series of works being purchased by the Tate, including '*Derelict Land Art: Five Sisters*', blockboard panel, photographs (by Rita Donagh), glass jar with shale, 1976. See also exhibition publication from *John Latham: A World View*, (London: Serpentine Gallery), 2017.

<sup>199</sup> Walker, *John Latham*, 134.

<sup>200</sup> Kester, *Conversation Pieces*, 67.

positions, something David Harding criticised by saying it both 'suppressed' and 'diminished' the process.<sup>201</sup> It is perhaps this transition from 'placed' artist to 'artist in residence' that has shifted the artists position from that of co-professional and 'direct participant', with a remit to consider the long view of organisations, to that of an observer. With this observer status the desire is for a creative individual to offer new depictions for the wider world of current and past internal practices or a practitioner from one art form to collaborate with another (a relevant example here is artist Martin Boyce's role with Scottish Ballet).<sup>202</sup> This is not in itself bad practice (Boyce's resulting work on sets and stage design was highly acclaimed). However across the fields of science, medicine and artistic research there is also the possibility of some thing or things much more able to affect change in the future:

It is clearly not sufficient to say that any collaborative or conversational encounter constitutes a work of art. What is at stake in these projects is not dialogue per se but the extent to which the artist is able to catalyse emancipatory insights *through* dialogue.<sup>203</sup>

John Latham's theory of the 'open brief' was in opposition to established market-driven processes that were only concerned with monetary wealth and short-term capital accumulation.<sup>204</sup> Organisations mired in this were making reactive, firefighting plans, and therefore had difficulties in seeing (or perhaps acknowledging) the long-term implications of their actions. In much the same way that Principle Investigators composing interdisciplinary research bids within universities become aware of a 'public engagement' box to be ticked. A durational model is able to be critical of this practice, and artists, as Latham argued, are skilled in 'durational and imaginative thinking' - as has been proven with ongoing successful collaborations such as that with the Department of the Environment, and with my own long term engagement with Monckton.

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<sup>201</sup> David Harding from Malcolm Dickson (ed.) *Art with People* (Sunderland, England: AN Publications, 1995).

<sup>202</sup> Martin Boyce, set design for Martin Lawrence's production *Run for It*, for Dance GB (Scottish Ballet, Welsh National Ballet, English National Ballet), as part of the Cultural Olympiad 2012.

<sup>203</sup> Kester, *Conversation Pieces*, 69.

<sup>204</sup> Kester, *Conversation Pieces*, 62.

### 3.4 Leadership and the scope to challenge

The above criticism of research funding in contemporary academic contexts is not an incidental swipe. Nor is it in any way evidence of ill will towards researchers in other fields. Instead, by raising this point concerning the perfunctory way in which certain research practices and funders can approach the involvement of artists, my aim is to advance the argument beyond my simple binary equation of artist (good) and funders (bad) through the artwork. The criticism of 'research leadership' within academia can, in some ways, stem from how funding is distributed and assessed, together with a difficulty around terminology that goes back to a discomfort at the suitability of the term *sciant*, with its association with illustration and explanation that was outlined earlier.

It is interesting to note that within current UK academic contexts, for which I use the RCUK Pathways to Impact guidelines as a representative example, 'impact' is described in terms of who will *benefit* from the research, and not solely in terms of who will be *influenced*. What is notable is the use, again, of the (subjective) term 'quality'; how will this be measured, and on whose terms?

Through Pathways to Impact we want to encourage you to explore, from the outset and throughout the life of the project and beyond, who could potentially benefit from your research and what you can do to help make this happen.<sup>205</sup>

In terms of art production, benefit can be established across a range of stakeholders and is calibrated across a range of subjects. The artist can benefit by the supported creation of new work; through public display, both the wider public and specific interest groups can benefit by seeing it; and by gaining deeper insight as a result of their increased understanding of the topic involved, or by finding located somewhere within the artwork a moment of shared experience that offers (among other things) solace, support or joy (that may be used now, or at a later point of difficulty). The audience can benefit in a deeper, more holistic

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<sup>205</sup> Research Councils UK Pathways to Impact guidelines; <http://www.rcuk.ac.uk/innovation/impacts/> accessed 9<sup>th</sup> March 2016

way through both empathy (with the artist) and, perhaps, an increased connection to and understanding of their own situation. Through this process audiences can emerge with new knowledge, whether that be of experiences old or new, or issues public or private, with the potential to be transformed (and at times empowered), by the experience.

Leadership remains central. It is a quality that must be defined as a unique attribute that is manifest in a range of ways, but that in terms of this artistic research, can be described using Latham's terminology of 'a kind of person'.<sup>206</sup>

Using this example of the Artists Placement Group, transformation through artistic leadership will therefore lie in the concept of the 'incidental person', a person with no specific brief, as described by John Latham and defined by Rancière here (see 3.2 above) and in Chapters 2 (expert cultures) and 3 (agency).<sup>207</sup>

### **3.5 Collaboration or leadership?**

Having introduced the concept of leadership, and its relevance to my position as an artist with a long-term engagement with another professional group, I wish to return to the distinctive methodology employed in the *Hazel* research, with reference to the concept of 'randomness' that was introduced in Chapter 1 (1.6).

As an engagement with others in both research and practice has long been integral to my artistic practice, a new, specific question emerges from this research that must be defined if the work is to be used as a demonstration of leadership within academic collaboration:

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<sup>206</sup> A useful publication exploring this idea is the 2009 Artist as Leader research report, by Dr Anne Douglas and Chris Fremantle. The research has developed through a partnership between four organisations drawing together the academic, professional arts and business support and training sectors: On the Edge Research (OTE); Performing Arts Labs (PAL); Cultural Enterprise Office, Scotland (CEO) and The Scottish Leadership Foundation (SLF). Conclusion: 'cultural leadership should be about more than simply well-run cultural organisations. It should include an understanding of the capacity and value of artists leading through practice.' Douglas and Fremantle, 39.

<sup>207</sup> Richardson, 'John Latham: Incidental Person', 98.

Is *Hazel* a collaborative work? Whilst *Hazel* provides an exemplary example in a discussion of collaborative practice, in that it sits as one product of an ongoing, decade-long example of dialogue between an artist and a scientist that has achieved recognition from both camps, I would deny creative input to anyone but myself, as the artist, to this particular outcome. There are other works that emerged from this period that I would identify as being collaborative, for example the film and book *Tomorrow Belongs to Me*. However, I see this film, in its immediate production, as inhabiting a different space that requires more thought to identify.

As *Hazel* could not have been made without the direct involvement of a number of individuals and organisations, the answer, in part, is 'yes'. Conversely, it is also 'no', as I have maintained sole artistic directorship of the eventual outcome, whereas with *Tomorrow Belongs to Me* editorship was shared equally with Monckton. Instead, I would argue that it is one of a number of results born of a long-term professional collaboration in which my capabilities and capacities have evolved as a result of a number of factors. These include my own personal circumstances, and a greater understanding of how the research culture within academia operates.

The taxonomy of reality, of living with impairment and issues of care could be said to mirror that of scientific research's relationship to artistic practice in that each is both useful and necessary to the other, even though terms of value may not appear equal. Principle Investigators grappling with daunting research bids that require either an impact statement or public engagement strategy of a 'thing' that is hard to effectively communicate widely using the established language of their field are encouraged to look more widely. The process becomes an equation of cause and effect. Established research cultures want the fields of medical science, and indeed the conditions they seek to treat, to be as visible as possible. Therefore those who work in professions that produce high levels of visually communicative material (namely artists) are frequently approached for help. But if this help is only included at a late stage (following a pattern already familiar with architects and developers in relation to public art strategies) the results

are often very limiting. The outcome in this case is that we can lose the opportunity to produce something new and create effective change, instead maintaining the existing hierarchies that relegate the artist's role to that of illustrator, as aptly described by Born and Barry in their 2010 paper *ART-SCIENCE: From Public Understanding to Public Experiment*:

Whether motivated by accountability or innovation, in the trajectories of UK art-science that we have sketched, interdisciplinarity is uniformly conceived in the terms of what we have called the service-subordination mode, auguring hierarchical relations in which art is enrolled in the service of science.<sup>208</sup>

In using this model, the artist requires specialist knowledge from the world of science. They seek out the skill set required and badger for access, absorbing the new knowledge and distilling it into their artworks, with perhaps a credit to the scientists for their help (for scientist read any expert culture; engineer, linguist, historian, for example, or architect, archaeologist or mathematician). Both are transactions between professionals seeking to further their own practice, and both can result in success. We like to call this process collaboration, particularly within academia, as it is a currently fashionable term that connects to significant funding opportunities, an area promoted highly by research councils and government. Thus, in a very blunt summation, the art world enjoys feeling smarter, the scientific world enjoys feeling more visible. But is it collaboration?

Just because you work on something does not mean you are in collaboration. It depends on what point you come in. You may be a mere participant.<sup>209</sup>

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<sup>208</sup> Georgina Born and Andrew Barry, 'ART-SCIENCE: From Public Understanding to Public Experiment'. *Journal of Cultural Economy*, 3:1 (2010): 103-119 <http://dx.doi.org/10.1080/17530351003617610> For an example of a more illustrative science/ art project see Footnote 54, Pg 37 (Neudecker and Rogers) or *Going Viral* exhibition, Glasgow Science Centre (2012) <https://blogs.glowscotland.org.uk/glowblogs/CreativityPortalAdmin/2012/08/23/going-viral-at-glasgow-science-centre-innovative-art-and-science-exhibition/>; I acknowledge that this is just one model of research based art practice and that other exist.

<sup>209</sup> Christian Nerf, 'Notes on Collaboration,' in *Slow Prototype*, ed. Brett Bloom and Nuno Sacramento (Aberdeenshire: Scottish Sculpture Workshop, 2015), 107.

When we fail to reach a point where the skill sets are acknowledged as equal, where each gains from the other and moves forward, together, to output this new thing – and by new thing I would say this can be anything from a cup of coffee to a 90 minute feature film to an academic publication or a set of data – we languish in a world known well to families living with disability, whereby we accept mediocre, explanatory outcomes as they are the best that can be achieved given the time and resources available. The artists are participants in the study but they do not direct it; those with impairments are living their lives but they are not in control of them.

Are there any good examples of ‘collaborative’ work? Here I would like to cite a more dynamic and equal, positive collaboration across disciplines in science and art that was made in 2008, and outlined in the paper by Georgina Born and Andrew Barry in the 2010 *ART-SCIENCE* article just mentioned. In it they chart the recent history of ‘art and science’ working stemming from CP Snow’s 1959 lectures on the Two Cultures, that outlined the need for further collaboration at a time when, as he saw it, the two fields did not communicate, and had not done for the best part of the 20<sup>th</sup> Century. Snow’s call was from a political standpoint, and he went on to become a minister of technology in Harold Wilson’s 1970s Labour government as he was concerned with a lack of knowledge around technology in the arts. Many initiatives since have addressed this, though my discussion here is not with them.

Born and Barry are concerned with three logics of accountability, innovation and ontology, and seek examples of collaborative practice where outcome requirements and methodology are different from established practice. These outcomes should be celebrated as providing access to new data, and give rise to the concept of the Public Experiment that can lead to Scientific Gains (sic), often by using less substantial and systematic methods to achieve them, and where randomness is a significant factor: ‘[The project] points to a distinction between the provision of public information and the practice of a public experiment’.<sup>210</sup>

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<sup>210</sup> Born and Barry, *ART-SCIENCE*, 113.

Born and Barry address the difficulties of categorising the scientific benefits of artistic collaboration away from the notion of recorded spectacle or wonderment, or generic public engagement that I have also acknowledged in Chapter 1 of this thesis.

In these developments, art that is in dialogue with science is conceived primarily as a means by which the (absent) public for science can be interpolated: science is understood as complete, and as needing only to be communicated or applied, while art provides the means through which the public can be assembled and mobilized on behalf of science.<sup>211</sup>

They cite the work of artist Beatriz da Costa as an example of good practice, and the collaborative project she developed with fellow academics at UCI in Los Angeles called *Pigeonblog* (2006-2008). The crux of this artistic process was that by offering a different way to record pollution data - through attaching a measuring device to pigeons that was developed by the artist - the work could produce new scientific gains. It was successful because this method of data collection bypassed standardised testing as it used the concept of a 'public experiment'. Conceived as a visual/ performance public artwork as much as a scientific experiment, it subsequently addressed a gap in how pollution data was previously gathered through a singular, random element (the pigeons flight path) that meant they flew across more economically deprived areas, that had far higher levels of pollution than were recorded through existing methods. This in turn offered an opportunity for local people to both engage with the process of collection, but also, latterly, the results of the research and the relevance of it to their lives.<sup>212</sup>

In the case of *Hazel*, the opportunity to conduct a small study with a group of women recruited from a clinical registry produced new data by way of another public experiment that would not have been gathered if done through regular academic or NHS channels. This sense of almost random opportunism becomes clear when compared with a new study, *The DM-1 Neuro Study* by the University of Glasgow/ NHS West of

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<sup>211</sup> Born and Barry, *ART-SCIENCE*, 1.

<sup>212</sup> Further information on the artist Beatriz da Costa (1974-2012), and the *Pigeonblog* project available at: <http://bdacosta.net>

Scotland Genetics Service, that also seeks to catalogue symptomatic and lifestyle issues of people with myotonic dystrophy, to compare with their genetic changes over time.<sup>213</sup> This research has taken over two years to move to a stage where clinical staff can begin to recruit patients and through this tangle of ethical and procedural form filling, necessary for accountability and transparency within medical research, clear differences emerge. Whilst the West of Scotland Genetics Service study will produce hard, scientifically credible data over a period of 5 years, my study has produced ‘softer’ evidence. But this evidence can also be directed toward research through both its content and reaction to its public display, and in the quiet shaping of the thinking of medical and scientific professionals that was outlined earlier in section 2.7. This in turn *may* lead to pathways to improved care that come directly from the engagement of an artist, an acknowledged ‘expert’, with multiple groups: clinical teams, scientists and families, whilst at the same time certainly producing something capable of engaging a much wider public with deeply personal issues associated with themes of ageing, loss and resilience (universal themes not exclusively held by the world of inherited genetic illness). This ability (of artists) to step in and circumvent established channels for their own research purposes is a useful tool in questioning existing social, academic and medical methods.

### **3.6 Collaboration and recruitment**

In terms of my own practice, and also that of others concerned with genetics, health and wellbeing, the collaboration with a patient registry has thus been established as an important factor. Registries provide a method to collate details of individuals from a clinically connected group who are willing to participate in a range of studies, which can be accessed independently of the medical research establishment.<sup>214</sup> The

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<sup>213</sup> ‘Structural CNS changes, neuropsychological impairment and sleep disorder in myotonic dystrophy type 1: a genotype-phenotype study’. Led by Dr. Mark Hamilton. See more at: <http://www.hra.nhs.uk/news/research-summaries/dm1-neuro/#sthash.0nLmgSXF.dpuf>

<sup>214</sup> The advisory board of the registry, whether creative or otherwise, must approve all research proposals, but this is a far more direct and efficient process than seeking NHS approval for a study.

potential to use these (non NHS) databases more creatively is therefore significant to research as it removes the demands of NHS Ethics approval, and connects the researcher more directly with an organisation that has regular communication with families nationwide.

Their reach has limits though, and the ambition for what they might go on to do can be seen through comparison with another significant area of academic practice - the role of oral history archives as a method of gathering personal detail and reflective testimony of patients and their families for further study. This method remains underused in medical research; the registry used for the *Hazel* study collates only clinical data, plus personal details such as name, gender, age, and contact details of the affected individual. By signing up, individuals are acknowledging their willingness to participate in 'research' but what that entails is not expanded upon, and no further personal data is gathered at the time. As the scale and reach of registries continues to expand, much more use could be made of the potential to record personal experience through this established channel.

But why would we do this? Again, I turn to feminist academia, where the value of such qualitative data is well demonstrated in recent studies: a current example would be the Steinem Project undertaken at Smith College in the United States by Dr. Joyce Follet, to articulate publicly, again, the history of women of colour campaigning for reproductive rights. This particular research was begun using the existing archives at Smith that include oral histories of the 'second wave' feminist movement in the US in the 1960s and 70s, to specifically confront the misappropriation of the *Black Lives Matter* campaign by right-wing activists, and legislators, as an anti-abortion tactic. These groups cite *Black Lives Matter* as a reason why young, poorly educated black women should continue with unwanted pregnancies to defy 'feminist, pro-choice white women' who were telling them that it was their right to terminate should they choose to do so.<sup>215</sup>

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<sup>215</sup> <https://www.smith.edu/library/libs/ssc/staff-follet.html>  
see also Christine Assefa, 'All Lives Matter Act is a Blatant Attack on Black Female Bodies in Missouri', *Feminist Wire*, (January 2016).  
<http://www.thefeministwire.com/2016/01/all-lives-matter-act-is-a-blatant-attack-on-black-female-bodies-in-missouri/> accessed 9<sup>th</sup> February 2016.

There is a powerful case, therefore, for more in-depth collation of lifestyle-related qualitative data in the field of genetics that can be employed over time for a number of reasons: to restate existing knowledge of social, emotional and physical circumstances when challenged by dominant thinking, to remind us of debate on all levels of the human condition and to arm ourselves for battles yet to be fought.<sup>216</sup>

### 3.7 Collaboration and methodology

The function and status of the artist is important, as outlined in the section before, through the Artist as Leader research. But so to, clearly, is the quality of the artworks produced, particularly when those artworks deal with deep personal experience, a situation described by artist Jo Spence, on her diagnosis of cancer:

I realised with horror that my body was not made of photographic paper, nor was it an image or an idea or psychic structure... it was made of blood, bones and tissue.<sup>217</sup>

There is an interesting theoretical tension in my position in the study, a position that whilst unique, can align with other artists and film-makers who have chosen to use their own lives very directly in creative practice (see Chapter 1 for a discussion of the work of musician and artist Patti Smith, for example). To expand on this further, I will compare my own experience with a very recent example of work by another artist who has used her personal position within a family group to navigate long term emotional trauma through creative practice.

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<sup>216</sup> I would cite here the current, radical restructuring of Social Security benefits for the disabled by the current Conservative government (2015 – 2017) in the UK as a key example of future use. The long-term impact of these cuts is not yet known, and so it is important to collect personal testimony of the effects of the changes as they are happening, in ways that are separate to journalism and media coverage. An extension of the *Hazel* study would be to investigate facilitating other family groupings, not just sisters, to record their own experience for an archive stored by the registry. This will remain as proof of what is happening in households at this time, for future use by others across creative practice and academic research.

<sup>217</sup> Jo Spence, *Putting Myself in the Picture: a Political, Personal and Photographic Autobiography*, (London: Camden Press, 1986), 152.

The film *The Closer We Get* charts the decline of Karen Guthrie's mother after a severe stroke, through her own experience of returning home to their small, coastal home-town to care for her.<sup>218</sup> Guthrie is the writer and director, but also a prominent presence on screen as she is filmed caring and cooking, in addition to speaking to (interviewing) her parents and siblings. She is also the mainstay of her family at this time; organising the household in collaboration with her siblings and touchingly re-acquainting herself with her father, a dominant, eccentric presence on screen who returns to the family home after 20 years of separation.

It is her voice that narrates the film, reflecting on footage that was mainly filmed in her mother's home following the stroke – a period of time that stretched across four years, from 2011 until 2014 - but also including formal, on-camera interviews and archive footage. In a post screening discussion, Guthrie said that the process of filming (and later editing the film after her mother's death) 'kept her together' during a time that was filled with emotional challenges.<sup>219</sup> Having cameras around the house made her feel more in control of a distressing situation that she often struggled to speak about, providing something to 'deal with' beyond the domestic. Is this the same for me? What do I achieve by seeking out the sisters of women who share my sister's disability? Is making this work my shield against a family with whom I don't often communicate effectively?

The sense of loss that I discussed with some of the unaffected sisters is something that I have never discussed with my own family.<sup>220</sup>

The use of multiple auto-ethnographic methods to interpret my own lived experience in the course of this research has caused images from my past to illuminate more recent events. I think of dark times in the recent history of my own family, and my position as an artist amidst

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<sup>218</sup> *The Closer We Get*, 2015. Written and directed by Karen Guthrie, produced by Karen Guthrie and Nina Pope, edited by Alice Powell. 87 minutes.

Distributed by Somewhere Films. <http://thecloserweget.com>

<sup>219</sup> Screening and discussion with the director. Scottish Mental Health Arts and Film Festival, CCA Glasgow, 19<sup>th</sup> October 2015.

<sup>220</sup> Donachie, filming notes, October 2015.

that, and return to older images from childhood of my great grandmother, bedridden in her hundredth year, with distinctive flat combed white hair and straight fringe - a hairstyle that we all hated, done by my eccentric great aunt using kitchen scissors. Decades later, it was the haircut that my mother administered to my father in his final years. I think of him, in a geriatric ward on his seventy-fourth birthday. Cake and tension in a hospital side room. A man who spent his life in blazers and polished shoes now wearing pale blue jogging trousers and a nappy, as an awkward assemblage of old women and grumpy teenagers (mine) toast his 'health' in Earl Grey tea and Irn Bru. This scene is almost exactly like a Mother's Day celebration in Guthrie's film, her mum a shrunken, paralysed figure surrounded by gregarious family members eating her cake. In developing my film *Hazel*, I considered similarly positioning myself on camera at the centre of domestic events within my wider family, particularly in that last year of my father's life.

If honest, I would have struggled to work like that. Not the caring, but the filming. I like to remain outside. I am a bigger personality than many in my family but not that big. If I take out a camera everyone expects to see what I have filmed or photographed, make a big deal of it. I can't be an anonymous snapper with them and at that point I had no confidence to put myself at the center of anything.<sup>221</sup>

The 'after-life' of artworks is significant here. *The Closer We Get* has achieved notable success on the documentary film circuit – winning Best International Documentary Feature at the Hot Docs Film Festival in Toronto in 2015 and numerous other prizes, but it also has another life that extends beyond this established celluloid network. From the outset it was supported by agencies working with survivors of stroke, and through funding from the Big Lottery *Awards for All*, the filmmakers have been able to offer a wide range of more intimate screening and discussion events throughout Scotland to people affected by stroke, under the project *See Beyond Stroke*.<sup>222</sup> There is a shorter version of the film available for these screenings, and the film-makers attend the sessions with health professionals:

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<sup>221</sup> Donachie, filming notes, October 2015

<sup>222</sup> *The Closer We Get* outreach project *See Beyond Stroke*; <http://thecloserweget.com/see-beyond-stroke-outreach-campaign>

The stories of people with stroke and their families are unique, often very moving and challenging and uplifting in equal measure. No two stories are the same, and no two families cope in the same way. However, listening to and talking about these stories can provide an insight into the lives of people with stroke which can be immensely valuable to others in a similar situation, either personally or professionally.<sup>223</sup>

This combination of characteristics – creative film making, auto-ethnographic study, long-term engagement with specific interest groups beyond established art audiences – connects Guthrie’s film with my own practice, and I would say that both have demonstrated the importance of personal leadership through extreme circumstances, and of high quality outputs in this difficult arena. In assessing the position of the artist within collaborative practice, a role has been established where they have the power to both introduce and withhold information, making private worlds public and vice versa, that is separate to science and medicine, where all information is seen as an addition to knowledge. When dealing with highly emotive situations, this can be a significant feature that is not confined to medicine.

Can personal experience be employed in less direct, autobiographical ways? It is important to remember here that it is artworks that this thesis is concerned with, and that though many crossovers exist to connected fields across academic research such as social science and medicine, my language remains that of contemporary art as a medium to communicate concepts that are important to me to these other worlds. In thinking of this, and of my motivation to undertake the *Hazel* research as a means to seek an alternative voice for my own experience, reinforcement comes through the work of another artist whose politically engaged practice exists very much in the realm of contemporary art, yet demonstrates the value of the alternative voice and acts as a conjunction between Guthrie’s film and the *Hazel* research.

Using the concept of the artist’s voice in her work, Sharon Hayes employs numerous layering techniques in her spoken word and filmic performances that address feelings of frustration and impotency at

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<sup>223</sup> *ibid.* Phillipa Tyrrell, Professor of Stroke Medicine, University of Manchester

certain political situations. In the *Love Address* works Hayes speaks the words of others in a scripted, mannered fashion that indicates she is speaking personally, from the heart. It is clear, though, that she is not acting (her term is *re-speaking*).<sup>224</sup>

There are parallels in the assumption of roles, and also her reason for undertaking these performance works, made in the early 2000's, with the *Hazel* research. Hayes describes feeling powerless at certain points in her life, and of using art methods and performance interventions to give voice to this position of weakness. This is particularly resonant in one of the *Love Address* performances, *Everything Else Has Failed! Don't You Think Its Time For Love*, where Hayes performs a prepared script standing outside the Bank of Switzerland in downtown Manhattan.<sup>225</sup> The text is in the form of a letter to an unnamed individual, on the surface very much addressing a lover. In describing her performances she says she speaks as '*an unnamed 'I' to an unnamed 'You'*', adopting a very considered approach to roles within her work.

The text performed reads as an utterly beguiling, poetic plea to a former lover, yet is interspersed with memories of recent anti-war protest and their futility at that time, as the US fought a second Iraq war.

My dear lover, I need to speak to you my love, of your life and of mine, of sweet things that have turned to bitterness and bitterness that has turned to joy...

We were so in love that day and we really thought things could change

What holds me to this microphone is you.<sup>226</sup>

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<sup>224</sup> Examples of these works include: *I March in The Parade of Liberty, But as Long As I Love You I'm Not Free*, (2008). *Revolutionary Love: I am Your Worst Fear, I am Your Best Fantasy*, (2008). All at <http://shaze.info/>

<sup>225</sup> *Everything Else Has Failed! Don't You Think It's Time for Love?* Performance, (2007).

<sup>226</sup> *ibid* (extract from performed text).



FIGURE 10

- (i) Hayes, Sharon. *Everything Else Has Failed! Don't You Think It's Time for Love?* 2007. Spraypaint on Paper, 45 x 60cm. Courtesy of The Artist and Andrea Rosen Gallery, New York.
- (ii) Hayes, Sharon. *Everything Else Has Failed! Don't You Think It's Time for Love?* 2007. Photograph from performance for *25 Years Later: Welcome to Art in General*, United Bank of Switzerland, New York. September 17-21, 2007. Courtesy of The Artist and Andrea Rosen Gallery, New York.

Whilst not shouted, the text is spoken through a microphone as a loud plea to passers by, close to the style of evangelical Christian preachers seen in city centres, yet more plaintive. Some people stop, some walk by. She looks vulnerable, standing there with a portable speaker and microphone – small in stature, dressed in what she has described as ‘dyke temp’ style, the awkward office clothing of someone who is uncomfortable in both business wear or overtly feminine clothing.

Thus Hayes is publicly positioned on the street, small and awkwardly dressed in clumpy shoes and ill-fitting dark trousers, appealing to passers by. She has spoken of the protection of the learned script – assuming this very public position made her vulnerable, but by using the words of others to speak to strangers she created a barrier between herself and the street passing by (the words are taken from love letters of varied historic provenance such as Oscar Wilde’s to his lover Bosie).

On the surface the text is an address of a lover and sounds very personal, but really it is an attempt to talk about power from a place of powerlessness.

The love letter works actually arose from research for ‘In the Near Future’. I found an image at some point in the process, of a whole sea of people sitting in between two buildings at UC Berkley. There was this guy in the foreground, sitting cross legged with a sign propped on his leg that said, ‘Everything else has failed, don’t you think its time for love?’. I found myself thinking a lot about this question. What did it mean? It was 2007. I was depressed and despondent and felt very much that everything has failed. It was the very end of the Bush years, the US was deep into the ongoing war against Iraq and it felt like there was no meaningful way for a group of people to stand on the street and have any power. There was also a way in which I felt it wasn’t possible to talk about the war in a salient manner publicly.

So the first love address was an attempt to talk, in public, about the war.<sup>227</sup>

Here, Hayes appears to address concerns that are not central to the issues that dominate my research. And yet she helps me illuminate a juncture between public and private worlds at the moment it is bridged by an art practice. Just as Patti Smith surpasses a world dominated by caring for young children, so Hayes moves beyond the position of powerlessness (particularly in relation to the political policies of her

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<sup>227</sup> Sharon Hayes interview with Bret Schneider, November 1<sup>st</sup> 2010 from <https://howmoving.wordpress.com/2010/11/01/interview-sharonhayes/> accessed 19<sup>th</sup> January 2016.

country) that fills her life. Both resonate with the words used by Wilkes in Chapter 3 ... 'The unbridgeable distance between human beings, and the vastness of their inner world'.<sup>228</sup> These examples frame *Hazel* with a sensibility that I associate with the transformative voicing of weakness. They are not directly involved in the issues that arise when artists and scientists respond to the experience of disability. However they do function as investigatory markers for my own reflections on my own personal experience as a non-disabled woman seeking to convey the effects of my family's genetic condition to contemporary audiences. I have watched Smith and Hayes perform/ speak in public and know first-hand that the communicative power they summon works (bridges Wilkes' 'unbridgeable distance') in the socio-cultural context in which I operate as an artist. And so the question of how this inner world is made public is at the heart of the current research, as I seek to illuminate a very distinct loss that affects many. The scope of both the *Hazel* research, and the earlier *Tomorrow Belongs to Me*, to also challenge and lead those who exercise power and manage knowledge within a very specific area [concerning marginalised and vulnerable groups and their relationship to the science that researches them] further extends the capacity of the artist: the latter can contribute new knowledge to an existing field through the very particular language of contemporary art.

### **3.8 Collaborative methods and emotions**

Having looked in detail at the use of private personal trauma in the making of art and film works, and having compared my experience of loss with that of Guthrie, and her depiction of the decline and death of her mother following a severe stroke, it is interesting to return to the initial fieldwork, and to question both the role of the researcher and the agency of the participants within that research. As social science methods were employed in certain elements of the recruitment and interview process, it is here that I will begin.

There are several studies in Ribbens and Edwards, in particular that of Mauthner, *Silent Voices into a Public Discourse: Researching Accounts*

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<sup>228</sup> Cathy Wilkes interview, Tate 2008.

of *Sister Relationships*, and Miller, *Shifting Layers of Professional, Lay and Personal Narratives: Longitudinal Childbirth Research*, that connect with my own experience of interviewing the sisters.<sup>229</sup> Both authors reflect on their position within the research, and how their personal life, and the manner in which it was employed in their relationships with participants, and at what points, affected the quality of their interviews.

For example, in discussing childbirth with women both ante and post natally, Miller decides to not mention her own experiences of labour while interviewing women during their pregnancy, concluding that:

I have decided that informing women antenatally of the potential pain of childbirth is not part of my role as a researcher.<sup>230</sup>

On the dilemma of interviewing a group of women about their relationship with their sisters, Mauthner comments:

Gradually, I felt the emotional exhaustion of listening to the women's stories and eventually, in the middle of fieldwork, I puzzled over how I, as a researcher and sister, was going to locate myself and my personal experience in the research.<sup>231</sup>

I also chose to withhold information when interviewing the sisters. I acknowledged that my family had the condition, and that my sister was quite badly affected but I felt unable to discuss her recent decline with any of the women, and did not discuss my own (healthy) children at all, feeling it inappropriate when many of the participants were sharing their experiences of miscarriage, stillbirth and infertility. In all but one case, I also had a higher knowledge of current developments in medical research. This process of simultaneously withholding and privileging information is reflected in the final outcome of the project (the artwork) but I could not say if it enhanced or hindered the actual interviews. I certainly felt that it put the sisters more at ease with inviting me into their homes to know that we shared knowledge and experience of the subject for interview, but the assessment of the longevity of the actual recorded testimony will have to arise from its future use as a resource

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<sup>229</sup> Ribbens and Edwards, *Feminist Dilemmas*, 39-57 and 58-71.

<sup>230</sup> *ibid*, 62.

<sup>231</sup> *ibid* 49.

for others (as discussed earlier using the example of the Black Lives Matter/Smith University archival research, see 2.6).

Tina Miller raises the point of the limits of longitudinal research via the ‘imposed timescales of PhD research’.<sup>232</sup> My own research journey would endorse this; given a longer timescale (and further funding) I would have arranged a second interview with the women, particularly in the cases of the unaffected sisters, as the conversations raised a number of complex issues that they had not considered for a long time, that could offer further insight given an opportunity to follow up. In this extract from my filming diary I wonder if they would have agreed. The questions I am asking myself here demonstrate the ethical dilemma of pursuing a second invasion of the interviewee’s private worlds:

As with Lucie, I feel my visit with Rachel brought a multitude of emotions to the fore in someone who is usually very private. Her husband could see we had been having an intense conversation and that his wife was upset. Was he implicated in the childless life? As soon as he came back with the dog I felt like an intruder in their home, the bad fairy bringing more dark tidings. I think they were both glad to see us go.<sup>233</sup>

I relate this to another set of family interviews I was involved in at the Myotonic Dystrophy Foundation annual family conference in Florida in 2007, where several families said later that they were left utterly drained, at times overwhelmed, by the interview. These anxious reflections shed an uncomfortable light on both past and future situations within my research.<sup>234</sup> Certainly repeat visits would have changed the reach and scope of Hazel, but no follow-up interview or survey was ethically feasible following my experience at the Florida conference. Although I have no way of estimating how much additional research material might have been gathered, or how much Hazel might have changed, nevertheless it is important to note here that this filming cul-de-sac was a defining feature of the practical project.

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<sup>232</sup> *ibid* 60.

<sup>233</sup> Donachie filming notes, May 2015.

<sup>234</sup> MDF Family Conference, Clearwater Beach, Florida, 2007. Interviews were conducted with a range of families about their experiences of living with myotonic dystrophy. Edited versions of these are available on the charity’s website <http://myotonic.org/connect/family-stories>

In addition to illuminating the complexities of conducting primary research with individuals with whom you share a common experience, both of these scenarios make a case for research based artistic practice of this nature originating from the university establishment. Universities can be seen as excellent hosts for the development of socially engaged art practice as they offer a recognised platform for artists, as opposed to the position of 'freelance artist', that is valuable when dealing with external, non-art bodies, and essential when dealing with vulnerable groups or individuals and their guardians. Secondly, the nature and structure of academic research imposes restrictions on personal contact with participants through their ethics procedures, which require a review of several issues in advance of the work beginning – safety of researcher, for example (a very worthwhile consideration I found), but also the use of data and the potential emotional impact on participants of taking part in the research. Consideration of this is not always a requirement for freelance artists who seek to employ the personal lives of others in their (public) outputs, and is therefore reliant on Codes of Conduct established by organisations who either commission, fund or display the work.<sup>235</sup> Whilst this may seem contradictory to earlier discussions concerning research funding and the role of the artist, it is not. Rather, it is an acknowledgement that given the right circumstances – parity of status and funding, effective leadership and a high level of expertise – there is great potential for further creative research within the academic arena.

Projects that are privately (or self) funded require no formal ethical framework beyond the moral judgment of the artist and host institution on exhibiting the work. This is self-regulated within sectors on the occasion of their public presentation, but is little policed (or unregulated) at the earlier stages of artistic research and production. In terms of visual art practice this can allow for controversial,

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<sup>235</sup> Funders such as Creative Scotland issue strict guidelines for 'Equalities and Diversity' to all their funded organisations, updated in 2015, though these are not specific regarding the ethics of working with others. ([http://www.creativescotland.com/\\_\\_data/assets/pdf\\_file/0003/26778/Equalities-Information-Sheet-2014-15-v1-1.pdf](http://www.creativescotland.com/__data/assets/pdf_file/0003/26778/Equalities-Information-Sheet-2014-15-v1-1.pdf)). Their funding agreements state that Open Funded clients must 'complete the project in such a way that is not, in our reasonable opinion, derogatory, offensive, inflammatory or obscene'. Item 2.1.7 of CS funding agreement, issued 2015.

groundbreaking artworks to be made and exhibited that are on the edge of the decency/ morality (of their time) that at times go on to change our thinking, for good or ill. Where participants and practitioner(s) are all fully aware of what they are taking part in, the process would seem to hold no long term implications, however there can be highly negative effects on any vulnerable participants involved.<sup>236</sup>

This is clearly a vast area of work that is not within the realm of this specific research, but it is important to recognise it. In engaging directly with individuals and their own lived experience, all parties have the capacity to make personal experience very public, and this can give rise to situations of both risk and bad practice that must be acknowledged.<sup>237</sup> Some questions that arise directly from this lead to an exploration of how the artists' advocacy translated into agency for those included in the research. Has this been demonstrated? Was it ever intended?

It would be fair to say that most of the sisters involved in the *Hazel* study were underwhelmed by the eventual artwork, perhaps as a general reflection of their relationship with research, or perhaps more tellingly as a reflection on their relationship with contemporary art.

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<sup>236</sup> Examples I would give here are Vito Acconci's *Seed Bed* performance at Sonnabend Gallery in New York in 1971: <http://www.moma.org/collection/works/109933>, and the work *Blind Date* by artist John Duncan that was presented by Dr. Francis McKee at the symposium *Death Animations* (Baltic, Gateshead, 19<sup>th</sup> October 2012). [https://en.wikipedia.org/wiki/John\\_Duncan\\_\(artist\)](https://en.wikipedia.org/wiki/John_Duncan_(artist)) <http://balticplus.uk/death-animations-symposium-10-dr-francis-mckee-c22282/>

<sup>237</sup> The artist Phil Collins has acknowledged the problematic nature of this process, where he considers the impact of reality television making public personal experience, and the raised expectations and ultimate disappointment this can facilitate in participants:

A new work conceived for the Turner Prize examines the relationship between the production of art and its wider social context by recognising and utilising the mechanism of the Turner Prize itself as a media spectacle. 'Over the course of the exhibition, a fully functioning office, Shady Lane Productions 2006, will research and organise a set of projects exploring the influence that the camera exerts on the behavior it seeks to record, beginning with a British episode of the *Return of the Real*'. Tate Gallery, 2006.

Responses ranged from attempts at critically constructive comments (*'I think the film was good but I would have been interested to hear from the siblings not affected by the condition'*) to complete disengagement (some did not even take up the link to view the final film although everybody involved approved the content of their own interview that was to be used).<sup>238</sup> My feeling is that the lack of enthusiasm had a lot to do with a perception of what is expected of a film. A familiar 'screen' presentation was not possible using my single camera, non-studio technique: as a result the women did not look like TV personalities simply because they were on a TV screen. Furthermore, there may have been a degree of 'research fatigue' experienced by each affected sister – anyone with this condition is continually providing medical experts with symptom-related knowledge. Thus, in relation to the use of feedback comments, there was a lack of follow-through. Repeated emails and telephone calls elicited no response from six of the women. However, even if there had been funding to make further visits, the momentum of my project was not, I increasingly realised, built around this kind of feedback.

People with genetic disabilities are asked a lot of questions, relating to many aspects of their life, beginning from the point when their condition is diagnosed and continuing throughout their lives. Questions of lifestyle and symptoms for healthcare provision at annual or 6 monthly genetic clinic appointments; questions from GP's, physiotherapists and speech therapists; questions for the provision of benefits such as Disability Living Allowance (PIP), and Jobseekers Allowance for the unemployed; questions from council officials when they seek a Blue Badge and designated parking space at their home, and, if they have children who share their condition, innumerable questions regarding all of the above, and more, about their family as well as themselves. They give answers, often and willingly, and recite their narratives of loss with deliberate and pragmatic accuracy. Sometimes these answers result in a direct improvement in their care, and possibly an improvement in their health and wellbeing, but more often than not the results are fed into a database that collects many details, but returns little by way of bespoke

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<sup>238</sup> Email to the author, 19<sup>th</sup> October 2015.

understanding of their own specific problems. What is required are answers that will categorise and fit the symptoms that they have with the boxes available to the questionnaire, a very generic, and often binary process that does not reflect individual experience. And whilst I felt that my study would in some way address this by recording a long and personal interview, I had not perhaps fully considered that the outcome expectations of the women might be beyond what was produced using the language and mechanisms of contemporary art. The longevity of the artwork, the impact of its simple presentation, the opportunity for myself and others to present it in a wide variety of situations - creative, medical and political – all of these may build toward something that has a more long-term influence, but I acknowledge that it is not mainstream television. As a result, I came to realise that the creative value of hunches and intuitions, so embedded in the training and development of an artist's career, were important drivers for the final resolution of the *Hazel* project.

The use of silence in the film is the element most commonly cited for comment by both professional (medical and scientific) audiences, and by the participants and family members. As outlined, feedback can be negative - why can we not hear the unaffected sisters?<sup>239</sup> What it is important to remember here is my reasons for undertaking this research. As has been outlined already in terms of my own work and also the wider realm of 'art and science' practice, motive is important; I did not seek to explain or illustrate anything to professional worlds or the general public, but to present a personal view of an experience which connected myself and my family to their specialism in ways that could potentially challenge their working methods. Embarking on the initial study, there were dual aims of identifying women 'like me' - in their capacity as unaffected sisters - but also to give voice and visibility to those women who have myotonic dystrophy and its associated symptoms, like my sister. During the interviews several of the women

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<sup>239</sup> Refer to section 2.6, for a range of audience comments both negative and positive. Further notes from the comments book in the GoMA exhibition included: '*Very interesting. I had very much of a fellow feeling with one of the sisters, Sally;*' '*I appreciate your video, but I would have preferred to see the silent sisters who couldn't speak and express their feelings and emotions. I think that a dialogue between the sisters would be better for the public.*'

spoke of the problems they have being understood, as weakening of facial muscles has affected their speech. Sally:

I know my speech isn't perfect. I can't hear it myself, but when I hear myself back on a tape, I can tell. Some people find it hard sometimes to understand a word I'm saying. Also, when I try and tell people things, sometimes I go about it the long way round and they get sick of listening before you get to the point.<sup>240</sup>

Many of the unaffected sisters spoke of the way they felt their sisters could manage their health better, and voiced concern at what their futures might hold – as said in the quote from Rachel earlier in this chapter, and in this quote from Sally's sister Lucie, that also shows deep frustration:

She's meant to do things like physio to keep herself healthy. She had pneumonia recently and she was in hospital and the nurses were saying to her, "You've got to get up and you've got to do a walk once a day" – and she wouldn't do it; she wouldn't do it – and I still get frustrated and I still want to say, "For God's sake, Sally. You've got a child now. You've got responsibility to just get off your butt and do some physio and try and be more healthy. You've also got responsibility to us because we're the ones who's going to have to sit here watching you deteriorate and potentially die at the end of the day. Do something about it! Save yourself! There are things you can do."<sup>241</sup>

As the artist, I defend my use of silence; if both women are speaking, a conversation is implied that denies the power of the face itself. The viewer has an instant, non visual relationship presented that prompts them to compare one woman directly to another through their physiology. I don't feel that a conversation is representative of the sisters, or what I sought to convey with the work. Thus it was the decision to omit the unaffected women's spoken words that was the primary consideration in the editing process, a decision ultimately informed by my art practice. That the silence at times engenders frustration is an outcome that over time may have greater impact than each of the sisters vocalising their own position. The curiosity for the unaffected sisters that the film provoked amongst professional audience groups is an example of the potency of knowledge both presented and denied by an artist.

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<sup>240</sup> Interview with Sally, 1<sup>st</sup> March 2015.

<sup>241</sup> Interview with Lucie, 16<sup>th</sup> March 2015.

Thus the use of portraiture is distinctive and essential, setting it apart from 'lived experience' documentary formats already in existence in the medical research arena.<sup>242</sup> It offers a stillness beyond written, painted or photographic renderings of... and then I pause.

Renderings of what? Is it the role of the unaffected sister? And therefore is it simply a portrait of normal? Or of luck? As I don't recognise that as a description of me, I would have to say no. For me, it is a portrait of loss.

Therefore the advocacy goes beyond the participant's own experience, and whilst it is important to consider, it is the agency of the scientists and practitioners who see the film and read the interviews that is most relevant at this juncture. Will it be their actions (in reconsidering how they view the women attending their clinics, perhaps) that provide the most dynamic and impactful results of the research? Or will it be the role of families and the wider public in accepting and understanding the differences that disability presents, establishing new knowledge as they move through the world? I acknowledge that frustration at being presented with silence affects some audience groups, and some of the participants involved, and recognise this as a direct outcome of the artistic nature of this research that mirrors well the frustration of not being heard that the affected sisters encounter every day through the withholding of information.

### **3.9 Collaboration, leadership and vulnerability**

In working at this intersection of creativity, personal experience and loss, it is pertinent to again mention vulnerability. There is an ongoing debate around the visibility of impairment, and how it is represented in the media that extends to the expectation of artworks in this field to create either technicolour superheroes or despondent victims through interpretations of personal experience, as has already happened with

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<sup>242</sup> See patient testimony film clips recorded by Treat NMD, accessed 15<sup>th</sup> November 2013.

<https://www.youtube.com/user/TREATNMD/videos>

sport. Neither case is common. This applies to those who have a disability, but also, I would argue, to family members ~~directly involved in care~~; these family members can also be stigmatised, as was mentioned in Chapter 2, but they (we) do not fit a singular category any more than their (our) disabled siblings. We are not all the same, and should not be represented as such.

I share the stance of Shakespeare and Watson in their criticism of 'the social model of disability' where it echoes feminist theory. Radical thought denies any disparity between a 'normal' body and an impaired one, just as feminism has at times denied any difference between the male and the female.

In properly rejecting the causal role of the body in explaining oppression, disabled radicals have followed their feminist precursors in denying difference entirely.<sup>243</sup>

I know, and see others recognise, that this cannot be the case. Sometimes things don't work and need fixed. Tom Shakespeare has written of this at length; the vulnerable, impaired body that at times needs repair.<sup>244</sup> Thus, at times we need to retreat and help our bodies and minds heal – a process that with genetic illness applies to carers and unaffected family as well as the affected individuals. We take time to support failing relatives, which then entails leave from work, a promotion not applied for, a grant deadline missed:

I have removed myself from shortlistings, declined to attend certain interviews when even the act of scheduling that interview was unachievable at that time. How could I take on the commission in question if I couldn't fit around interview times?<sup>245</sup>

So a job is lost, income is unearned. Economic slide is inevitable, lack of care for appearance a likely daily slip. It is this same circumstance that let me allow my father, a proud, handsome man who had always taken the most meticulous care of his appearance, to have his kitchen scissor haircut and supermarket-bought jogging trousers at the end of

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<sup>243</sup> Shakespeare and Watson, *The Social Model of Disability*, 14.

<sup>244</sup> Tom Shakespeare and Mairian Corker (eds.), *Disability and Postmodernity: Embodying Disability Theory* (London: Continuum, 2002). Tom Shakespeare, 'Losing the plot? Medical and activist discourses of contemporary genetics and disability', *Sociology of Health and Illness*, 21:5 (1999).

<sup>245</sup> Donachie, filming notes, April 2014.

his life. It was a manageable solution for my mother that I didn't have the time to challenge, nor she the energy to address more effectively. Nobody asked my father.

This identification of the impact of inherited disability on wider family networks is described in several myotonic dystrophy studies.<sup>246</sup> It was also outlined in the *Tomorrow Belongs to Me* publication in an interview with Nancy Wexler, a family member at risk of Huntington disease who has become a celebrated, pioneering researcher and advocate for inherited disease treatments.<sup>247</sup> She established clinics in Venezuela in the 1970s and 1980s, working with communities with extremely high incidences of Huntington's to collect blood and sperm samples that would ultimately be used to establish a test for the condition, and identify the gene that had killed her mother. The Venezuelan families would always describe the disease as affecting 'everyone':

...they said 'everyone inherits it, but only certain people get sick' and psychologically that's really true because everybody within a family with any genetic disease inherits it. The people who are healthy, the parents who don't have a genetic risk themselves, but they have sick husbands or wives or children, and so everybody inherits it.<sup>248</sup>

This too is a trauma. Unaffected siblings, parents, spouses and carers will all show the impact of the gene on their lives. The unaffected women in the *Hazel* study have experienced deep loss through their sister's diagnosis and ultimately failing health, and they attempt to articulate this in the interviews. That some moved far away is also, in a sense, a loss, as they do not see their sister regularly; why they moved

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<sup>246</sup> L. Laberge *et al* (2013). 'Clinical, psychosocial, and central correlates of quality of life in myotonic dystrophy type 1 patients.' *European Neurology*, 70(5-6), 308–315. doi:10.1159/000353991

M. Hermans, *et al* (2013). 'Fatigue and daytime sleepiness scale in myotonic dystrophy type 1. *Muscle & Nerve*, 47(1), 89–95. doi:10.1002/mus.23478

M. Minis, *et al.* (2010). 'Employment status of patients with neuromuscular diseases in relation to personal factors, fatigue and health status: a secondary analysis.' *Journal of Rehabilitation Medicine : Official Journal of the UEMS European Board of Physical and Rehabilitation Medicine*, 42(1), 60–65. doi:10.2340/16501977-0482

<sup>247</sup> Donachie and Monckton, *Tomorrow Belongs to Me*, 98–124. Nancy Wexler, her father and her sister Alice established the Hereditary Disease Foundation in the USA in 1968, following the diagnosis of her mother with Huntington's disease (from which she died in 1978).

<sup>248</sup> Donachie and Monckton, *Tomorrow Belongs to Me*, 105.

in the first place isn't always explained. In most cases it would not have been as a direct result of the diagnosis of their sisters as many did not know about it until they reached adulthood. But perhaps there was some ineffable thing that drove them to leave, an unidentified lacunae in family life and circumstance that they set out to fill. Again, I speculate, but within the remit of this research it is a necessary tool.

Are there any clues to this in the staring, silent faces seen in the film? As 'normal', do the women share more in common with professional and lay audiences? Or do they also look different to what we expect? This is a question I have returned to many times in terms of my own personal situation, and one that conversations had during the interviews did not fully answer. In considering this, the artwork of the artwork becomes my attempt to describe this.

### **3.10 Collaboration and leadership: a synopsis**

In this chapter I have set out to address a range of questions that arise from the production and screening of the artwork *Hazel*. By citing scholarly work that reflects on the processes involved, particularly the implications of making private experience public, and through reference to similar, but distinct artworks that have used auto-ethnographic methods of research coupled with creative, filmic practice, I have also considered my own position within the research as an artist and family member, questioning if it extends to a leading role.

Firstly, there was a consideration of collaborative research methods, and a discussion of if the *Hazel* research sits within this genre, particularly in terms of previous interdisciplinary research by myself and Monckton, made between 2002 and 2006, from which the study emerged. Stating 'I thought it up and I made it' challenged accepted interdisciplinary practice, but by recognising that I could not have made the work without the knowledge, resources and skills of others (different to me, but co-professionals) nor without the participation of others (the same as me, but not professionals), it was impossible to give a clear answer. Certainly, collaborative processes were integral to its making,

through the connection with other expert cultures during the research period that included the sisters themselves.

This led to an appraisal of the criteria for value in collaboration involving science and artists that recognised time, parity of funding and position of the artist as key factors in any project. Success lies with the capacity of artists, which is not exclusively concerned with either the production of artifacts, or the provision of reference or resource material on a given theme, but instead through an ongoing process of gaining and sharing knowledge and experience in continuous dialogue with others that requires leadership.

I further explored the issue of collaborative working practice within science and art, citing examples of criticism and also of good practice through the use of public experiment, as demonstrated by Beatriz da Costa and academics at UCL in Los Angeles; this introduced the concept of 'random' used several times in the chapter, the term arising from the ability of artists to circumvent established research methods in other sectors with strategies that are derived from a much more personal engagement with an issue, and much less hampered by the restrictions of conventional academic research.

Public working as a method to investigate very personal, private issues was examined, and I continued to look at this in both practical and theoretical terms. The Douglas and Freemantle study has established three scenarios to aid the definition of the role of the artist as leader, one of which was the production of high quality artworks; my own position within the field, as outlined in the thesis introduction, was also examined in the context of other artworks. Firstly, *The Closer We Get* made by Guthrie in 2015, that used biographical experience of personal family trauma as the centre of a long-term creative study that positioned the artist as a leader within both her professional and private worlds, as she emerged as a protective force to fight vulnerability and become empowered in the face of severe physical and emotional challenge. The work of artist Sharon Hayes was also mentioned, in particular her use of performance as a means to address her personal desolation and impotence in the face of political events she could not

control. Through a process of re-speaking the words of others she creates poignant, emotive works that address many of the themes in this thesis – loss, trauma and power.

The difficulties of working with primary research material so closely connected to my own personal experience were contextualised through examples of feminist theory that examine minute and mundane aspects of domestic life. These indicated that the location of the researcher was key, and I established that my own position was multiple and varied; I act as a leader within the myotonic dystrophy community and the family that I advocate for, but simultaneously hold a professional role as an artist. However, neither the initial research, nor the artworks investigating in detail my relationship with my sister would have emerged from my position solely as a family member affected by illness, yet it was this that provided the initial momentum to begin the research more than a decade ago. Thus my position is defined by my professional status as an artist, but is enhanced, and can at times be stigmatised, and complicated, by my position as a family member.

Returning to my own practice, I questioned if this advocacy had resulted in agency for the women who took part in the *Hazel* study. By considering discussions following specialist screenings, and the reaction of the sisters (some negative, mostly missing) I recognised that factors such as fatigue with medical questioning and detachment from contemporary art methods of display versus entertainment television, for example, could lead to disappointment in the final mode of presentation on screen. This disappointment also translated at times into some frustration at professional screenings as described in section 6.2; a reaction that was in part due to the unusual position for scientists and medical practitioners of being denied information through my decision to only use the words of the affected sisters in the artwork, leaving the unaffected sisters - the category of which they had little existing knowledge - silent.

I ended the chapter by examining the vulnerability of the affected sisters in the *Hazel* research, particularly in terms of social science

research and gave examples of disability research that intersected with feminism and the demands of ageing, impaired bodies.

The editing and denial evidenced in the film seems significant to me, as it establishes the potential value of one aspect of 'art and science' collaboration if directed at specific professional groups, and suggests a form of 'best practice' that should, and could, be adopted more widely if pressure on final outputs was reduced in favour of process and the role of individuals. Throughout the chapter there are references to the position and voice of the artist within the research, ending with a return to my original reasons for the study, questioning if the use of 'other sisters' is to reflect on my relationship with my own.

Thus in questioning what benefit there was in researching and making this particular work (an illumination of loss), a picture emerges that shows a transformative process that can be connected to both families and professionals in the field through the use of portraiture, public experiment and unique collaborative working.

## CONCLUSION

### Towards an illumination of loss

This thesis poses a fundamental question

- *By illuminating loss can artistic interpretation of experience shape research and care in the field of genetics?*

In addition to this overarching concern, the study further identifies two key areas of research:

- *The (mis)representation of identity and experience through both visual art and clinical practice*
- *Art practice as leadership*

The practice-led research is based on a series of filmed interviews with 11 women – all sets of sisters, where one has myotonic dystrophy, and one does not. The resulting artwork, the film *Hazel*, was made through a unique collaboration with a clinical patient registry that facilitated recruitment for this creative study. This is something that has not been done before and forms the new contribution to knowledge of this research. Issues raised by the process of both locating and interviewing women, women with whom I share a significant life experience (a sister affected by the same genetic condition), caused a substantial shift in the research framework, leading to a complex discourse around the personal loss associated with ageing, familial relationships and genetic illness.

In response to the initial question I found that the illumination of loss could be described in a number of ways. This loss was neither singular, nor straightforward: it involved a more general loss associated with inherited genetic disability (physical, emotional and social) but this was combined with acute personal experience of deeply emotive issues. As a result, the articulation of my own personal loss is deeply embedded in the research. It is also notable that this non-physical loss was not

readily acknowledged by science as significant. This was evident in the case of the 'unaffected sister' specifically. The final output of the research, a film work that projected the faces of the participants, used a mechanical yet ethereal method of illumination to provide a distinctive depiction of the complexity of loss that is at once physical and something 'other', something less tangible.

### **Synopsis of Key Points**

At the outset of the thesis I examined the capacitive function of the artist within a long-term interdisciplinary professional relationship, and reflected on earlier collaboration prompted at first by the diagnosis of a genetic condition in my own family. In reference to an artist book from 2002, *DM*, two phrases are quoted that in many ways offer an alternative narrative to the more scientific and scholarly consideration of issues that informs much of the research presented here: 'I suppose you could say that our knowledge will always be as old as my niece' and 'If we went there, my sister and I, would we look familiar?' This alternative narrative was rooted in experiences, thought processes and feelings that were intensely personal to me as a sister, daughter and aunt but that were also shaped profoundly by my professional identity as an artist. The former shaped the emotive response, the latter the particular style of writing, the methods of 'practice' employed.

Through this particular reflection, I established that it was my profession as an artist, and not my status as a member of a family affected by disability, that gained me access to a new world often described as 'closed'. This brought the realisation that access and leadership is something that is often denied to those affected first-hand by illness, even within professional communities. I began to ask if a more influential, leading position had been gained in other ways through my creative practice? Was I listened to (heard) more as an artist than a family member? Within the genetics laboratory of Glasgow University I embodied something that I felt made scientists uncomfortable – their lack of knowledge and inability to arrest a fatal

genetic inheritance pattern, a factor that temporarily but visibly interrupted their vast research arena.<sup>249</sup>

This gap in knowledge and understanding has become a central theme of the thesis, as it corresponds to a very measured form of art making that my practice employs. It underpins my interest in the intersection of the pursuit of knowledge, and the possibilities of learning enhanced by denial – something that is described by Jacques Rancière as *'the knowledge of ignorance'* that could lead to a shift in the way that science views families affected by impairment.<sup>250</sup>

Can art practice challenge this gap? I am firmly convinced that it can, and begin with the example of Nancy Wexler's quote used to end the film work *Tomorrow Belongs to Me*. Wexler's insight brought such anger from conference delegates at its premier screening at the International Myotonic Dystrophy Conference in Quebec in 2005. My inclusion of her words, which directly challenge established thought on success, is directly linked to the position of the artist and of the scientist in relation to their own research ambitions and outcomes, something that is dealt with again in Chapter 3, where the role of leadership is examined in detail. The significance of how science views itself, and others, is therefore central to the outcomes of the research. In relation to this issue, the term 'sciart' is used at the outset of Chapter 1, in reference to the funding framework that facilitated the initial period of collaborative working with Monckton. However, the term is positioned from this first stage as problematic both in terms of artworks grouped under this widely used umbrella heading, and also in the dominant methodology associated with it, that is to say of artists illustrating or explaining the work of others from the field of science, or of artists 'making' science or scientists 'making' art – as I make clear, both understandings of 'sciart' are problematic for me as a practitioner. Again in Chapter 3, this questioning of success criteria that is tied to outcomes and not process is directly associated with a rejection of the

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<sup>249</sup> There is no possible way to substantiate this as the assessment was based on multiple small, undocumented incidents. However I have discussed this openly many times in public lectures with Monckton, and it has never been challenged.

<sup>250</sup> Rancière, *The Emancipated Spectator*, 9.

'sciart' term in relation to my own practice and that of others who seek to make artworks that respond, in leading ways, to a wide range of socially apposite issues through process and dialogue as well as high quality artwork. In my case, as an artist whose practice intersects with science (at times), the term 'art and science' is a more appropriate description.

Through this thesis, the examination of the term 'expert cultures', where it intersects with science and medicine, and the separation of practice that is defined by this mainly in relation to 'collaborative' funding, has led me to understand that 'sciart' has become a wearied, easy label for any art practice that requires the input of others from the vast world of science. Often this is a simple transaction of specialist knowledge exchange (or gathering) that informs much contemporary art practice, and that 'science' is simply one term of reference that can be substituted by many others (engineering, music or sport, for example). I conclude that we cannot accurately describe 'sciart' as a 'type' of art, as termed by the original Wellcome Trust scheme, for example. Rather, it is one of a range of methods employed by artists in the production of their own work.

In Chapter 1 other works made by myself during the same period as the *Hazel* research are presented to provide further insight into the ways in which my 'art and science' work sits squarely within my practice as a whole. By referring to these works deemed 'not art and science', particularly sculpture and artist's books, I highlight the ways in which my practice more generally is informed and shaped by an interconnected method and approach. This detailed but necessary survey of practice that reflected on the use of writing, observation and editing used, as I said in Chapter 1, to '*navigate from a solo journey to a static sculpture*' introduced the concepts of minimalism, sparseness and editing that went on to inform the concluding artwork of the research (the film *Hazel*). The sculpture *Deep in the Heart of Your Brain is a Lever*, the writing and performance of Smith, and the artworks of Wilkes are all alluded to in order to highlight an interpretation of the hidden depths required of individuals when pushed beyond recognised limits, often through actions daily, mundane and

domestic. For me, at the time of making these works, there was a distinct purpose to consider and explore troubling events through embodying particular moments in physical objects. The employment of references to music and literature, particularly by Smith and Jamie, sought to enhance this purpose. In a related way this also connects to my decision, (in this chapter and throughout the thesis) to interpose my own more personal style of writing between the sustained examples of more 'scientific' academic writing. On the one hand, the former style of writing constitutes a long-term feature of my own practice that I wish to highlight. However, in the context of the research presented here, the inclusion of examples of personal writing from artist's books and diaries also mirrors my desire as an artist to negotiate a terrain between the 'rigorous', 'expert' skills of an objective professional and the more subjective, unquantifiable experience/expertise of those directly affected by disability and loss (including myself). Consideration of installations by Cathy Wilkes and her working processes also contributed to this recurring preoccupation, particularly the latter's affecting reflection on the role of conscience in relation to reality. Citing the moment that the hand of Moses' mother separates from her baby as an event that demanded deep consideration, spoke clearly of embodied thought.

Chapter 2 of the thesis then examined in detail the new artwork that forms 50% of this submission, the film *Hazel*. The recruitment of the female sibling participants through a unique collaboration with the UK Myotonic Dystrophy Patient Registry, the first time that this clinical network has been used to recruit for a creative study in the field of contemporary art, has formed the contribution to knowledge of my research. The managerial and emotional aspects of this process are detailed, as are my thoughts as I embarked on a period of primary research with individuals whose personal experience so closely mirrored my own.

A series of specific questions on the format and content of *Hazel* were addressed – the use of a single camera, and filming in participant's homes using a very close shot to eliminate background and personal

domestic situation. I also consider the decision to use only sisters, raising the issue of visibility of middle-aged women in general, and also, in particular, their status within genetics that has been informed by personal experience and by academic research in other related fields. In this section I also discussed briefly a further two works in the exhibition: *Deep in the Heart of Your Brain* (where *Hazel* was first shown in a gallery setting) and *Pose Work for Sisters* and *Studio 1995* (both 2016). These stem from a set of photographs made with my sister over 20 years ago, and use performance and photography in addition to film to record specific actions that relate to the ongoing concern of similarity and difference in siblings.

The significance of whose voice is heard within academia is then considered, and is summarised here through an appraisal of qualitative research methods used in social science, particularly those concerned with feminist research and stigma.<sup>251</sup> The importance of domestic research that references marginalised voices within academia was emphasised, and I conclude that this study enhances the field through participant selection (middle aged, disabled women, often with no children) – a group that even within the world of myotonic dystrophy can often be ignored as a result of the inheritance pattern of the condition. Where children are also born with the gene, they are affected much more severely due to the phenomenon of *anticipation* described in *Tomorrow Belongs to Me*, and in Chapter 2 I introduce the resultant situation of *biographical disruption* as an area that requires further study – an example here is where mildly affected grandparents take on the task of raising severely disabled grandchildren when the mother's health deteriorates rapidly in middle age, or women are faced with the mobility issues, deterioration and stigmatisation of the elderly before their parents.

In this chapter, visibility and voice are shown to connect directly to appearance, and to the way in which ageing women are viewed by society. I go on to refer to the study of Clarke and Griffin and others on the beauty treatments of older women, concluding that the *Hazel*

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<sup>251</sup> Ribbens and Edwards, *Feminist Dilemmas*; Chrisler, *Leaks, Lumps and Lines*.

research offers an addition to works such as these as it extends the arena to encompasses accelerated ageing that comes as a result of genetic disability.

### **Hazel: Issues of Reception, Collaboration, Influence**

The decision to use only the voices of the affected sisters, leaving the unaffected women silent, was the most significant element of the work, a decision informed by my wider practice that employs strict editing to provoke a deep engagement with artworks as described in Chapter 1.

The reactions of doctors and health professionals at a series of curated professional screenings in Newcastle and Glasgow is outlined in the thesis. I describe the frustration of a few at what they are not told or given access to (i.e. the words of the unaffected sisters), their discomfort and also their fascination. Through the reaction of some to the denial of knowledge, I am satisfied that, for me, a connection is made to the position of the affected sisters when they say that no-one hears or understands them. The use of portraiture also returned me to the original question – when does someone stop looking like their family and begin to look like their condition?

Here I would say that expert cultures – a terminology often used in contemporary art - is a better description of a collaborative working method such as mine. The patient is an expert, the artist is an expert, the scientist is an expert; all of us cited here are expert. But has my work offered new insight to this populated field? I believe that it has: critical response to *Hazel* and my own observations of the way in which professionals and families responded to it support my view.<sup>252</sup> My research broadens what the scientist sees. It introduces the unaffected sister to highlight a gap in their knowledge that demonstrates that not all is as it first seems. My work also questions in constructive ways the assumed hierarchies of knowledge and experience, that was first outlined in *Tomorrow Belongs to Me*, through the families' description

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<sup>252</sup> For example Moira Jeffrey, Scotsman, 28<sup>th</sup> May 2016.

of inheritance that did not fit the scientific pattern that had been established.<sup>253</sup>

In doing this I reinforce the argument that both the patient and the artist are expert within a field that is dominated by science, as they embody information that science does not have. Patients hold invaluable knowledge in their brains, bodies and experience, and artists do so in their skill at highlighting the minutiae of human emotion through strict editing. Seeking truth through observation is what I did with *Hazel*. I presented the sisters as they are.

In relation to the theme of *Illuminating Loss*, in Chapter 3 I return again to the work of other artists who have presented new articulations of loss through the use of personal experience in creative practice. Karen Guthrie's candid exploration of family dynamics in the face of illness, the film *The Closer We Get*, and the poignant, plaintive *Love Address* performance works of artist Sharon Hayes that confront political and emotional frustration, are used both to frame my own feelings, and as a demonstration of the power of making a private inner world public. Again it is interesting here that both examples result in some way in celluloid depictions that employ illumination to articulate loss – *The Closer We Get* is a feature length film shown in cinemas and broadcast on television and Hayes work exists as filmed documentation of a live performance.

### **Final Thoughts and Ways Forward**

Throughout this thesis I have referred to the making of artworks that connect personal experience of loss with clinical practice and scientific research. I see this process as a collaborative, looping journey that I would argue has been led by art. Many routes have taken my practice through a significant period of both knowledge gathering and knowledge exchange that has led both camps to know new things, and resulted in a number of artworks that illuminated some things and hinted at others.

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<sup>253</sup> Donachie and Monckton, *Tomorrow Belongs to Me* (Grant Sutherland interview, 71; Christian Höweler interview, 173).

By presenting the final research outcome as an artwork in combination with a written thesis, this new public articulation of personal loss has resulted in a range of reactions from a number of audiences. These have encompassed disappointment, frustration, and some contemplation from a specific group of professionals (scientists, geneticists and genetic nurse specialists) as they consider their patients' own identity and experience, and the potential impact of their research and clinical practice on the lives of others. I do not claim that my research has changed the world of science. Nonetheless, through the presentation of a new artwork made using a unique collaborative process, I believe my research has begun to shape the thinking of this core group of physicians and scientists as outlined in section 2:7. I am also confident that it has influenced the ambitions and outlook of the administration of a clinical registry as they consider how they might better capture the lived experience of families affected by genetic illness, as demonstrated by the quotation from the Registry Curator Elizabeth Wood on Page 117. In all of this, I have examined the enormous potential of contemporary art as a means to lead this process.

My directness in accusing scientists of fear of my familial connection to their research has tempered in the years since the first collaboration began. My search for artistic brilliance to arise from a fairly miserable diagnosis of those close to me was akin to families whose lives are changed by the onset of incurable illness and then go on to skydive or run marathons or bake cakes to raise money for research into the disease. It offers an outlet for grief and anger and allows family and friends to feel empowered by actually doing something.

Therefore it is with some pride that I say that my work contributes to the literatures in the field of visual art practice, scientific research and medicine that have been presented in this thesis. It concludes a long-term interdisciplinary collaboration with Monckton, and demonstrates the advantage of such enduring intellectual engagement through the production of a high quality artwork. At the same time, this output challenges the genre known as 'sciart' (both as an art-form and as

terminology), by clearly showing that illustration and explanation cannot be assumed as the only role of art within interdisciplinary research. This assumption is common within both academic and artistic practice. In my view, it can be explained by the emphasis on tangible outcomes and the desire to secure funding, which can have a detrimental effect on longitudinal processes where the eventual outcome need not be collaborative. What the present work has shown is that the production of high quality art is central to any dialogue that concerns science and art, just as it is to dialogues that concern 'politics and art' or 'music and art'. It is the research process itself that remains collaborative in these cases. This then establishes the position of the artist as significant, and through the written thesis my findings enhance existing work surrounding leadership and the role of the artist.<sup>254</sup> My consideration of women in the age range of late twenties to late sixties brought an intersection with social science research in the field of beauty, ageing and domestic experience, and caused a reflection on the relevance, and limits, of this work. Academic writing on middle age shows a lack of consideration of the impact of accelerated ageing brought on by degenerative disabilities such as myotonic dystrophy, something that could add much to existing studies on appearance, ageing and stigma with further research.

The new knowledge presented through the *Hazel* study promotes the value of high quality artist-led research where it intersects with clinical practice (through ongoing dialogue between professionals and families, and also a very direct collaboration with a patient registry). It highlights the importance of the role of the artist (as leading) and shows that this capacity is defined by high quality output, the process of engagement and by the 'type' of artist involved (or the type of experience they bring to the table). This is not a universal artist. Difficult personal experience can be translated into effective, powerful works, and in doing this the artist can assume a leading position on a number of levels, both personal and professional. This is significant in an arena where stigma and social exclusion is prevalent, and more commonly leads to a loss of status and power.

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<sup>254</sup> For example, Bergit Arends and Davina Thackara, *Conversations in Art and Science*, (London: Wellcome Trust 2003).

My work is relevant to a number of bodies and individuals. It is relevant to research councils and funders, as they can benefit from further examples of successful practice that values the role of process as equal to outcomes. It is of importance to medical and scientific professionals who are challenged by this unique articulation of lived experience that questions their assumptions of patients and encourages them to identify each participant as an individual, not a genetic condition. It is also relevant to the world of contemporary art, both within and beyond academia, as a demonstration of the fact that high quality artistic outcomes, exhibited in mainstream, centrally located institutions, can deal directly with unfashionable and unattractive impairment, and that socially isolated and vulnerable communities must remain a visible part of our creative world.

Why? Now more than ever the lived experience of marginalised groups (such as ageing women, ageing disabled women and families affected by multi-generational disability) must be noted as essential to our understanding of the human condition and academia's role within this is vital. Visibility is important, and the use of very public forums (a contemporary art exhibition and presentation at scientific and medical conferences) for a work that articulately describes personal loss through the thoughts and faces of women often rendered invisible by modern visual culture and medicine, is a powerful example of the effectiveness of art in approaching stigma. This knowledge will equip a defined group within science to better understand the impact of their research on families, embolden registries to work more with artists and demonstrate to funders the positive impact of long term engagement with artists that is not driven by pressure on pre-determined results.

These findings could also be of interest to funders and research faculty at universities, prompting them to examine the methods used to compile bids. There is potential value here also for scientist dealing with human genetic research, and clinicians dealing with patients affected by an inherited illness, as they reconsider how they view each individual. Curators of other registries, for conditions such as multiple sclerosis or Huntington's, for example, could also benefit from my

research in seeking to recruit more creative studies through new pathways. These new pathways will require leaders, and again here I return to the concept of a particular kind of artist to do so (the 'incidental person' as introduced by John Latham in the late 1970s).<sup>255</sup> In the thesis I note the potential concern here for too much invasion of an individual's privacy by artists, but suggest this could be managed by strict ethical procedures (as those adhered to in this study) and the increased engagement of artists within academia, where ethics procedures exist at a higher level than in the 'freelance' art world, and training is available. If managed correctly this is already something I see as being of benefit to socially isolated individuals living with myotonic dystrophy.

The limits of my study did not allow for issues related to the agency of participants to be clearly explored. Further investigation could more fully address the impact to patients of being involved with filmed, creative research concerned with lived experience. This could consider, for example, if a more pro-active, patient led voice was possible (using established public forums such as YouTube in addition to exhibitions and conferences). I would envisage such a development as using artists' professional expertise on camera technique and presentation. This would allow for a more long term, interview-based study that allowed both patients and families/carers to become more engaged with a high quality public outcome that manifests itself differently to that made here (by this artist), whilst at the same time contributing to an archive of personal experience (digital and written) that is available to other researchers over time. Through this the position of patients and families as forming an expert culture can be reinforced.

My reflection on the questions of writing and engagement with theory that I raise at the beginning of this thesis are ongoing. This is because I believe that the growing demands on artists to 'professionalise', through third-level accreditation of their skills and 'expertise', require that more is done to support this transition into the rigours of academic critical reflection. Questioning the traditions of an established field is a

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<sup>255</sup> Richardson, 'John Latham: Incidental Person', 1.

vital part of opening it up to new practitioners. A creative, lyrical, personalised form of writing must surely have a place in a field that sees itself as becoming more inclusive.

This draws me to the final conclusion that there remains scope for further artworks of mine that are a direct result of the process of interviewing the sisters in *Hazel*. These would be based on a genuine desire to draw on the knowledge and skills of others in the pursuit of something new, but, as stated, this does not sit under a 'sciart' heading. There is also scope for this interdisciplinary research process to provide new data, in the form of the primary interview set, which will be of benefit to others across multiple academic disciplines.

A final word: this research has highlighted for me the importance of maintaining at all times my position as an artist and ensuring that I keep in sight the 'expertise' that I bring to bear in the contexts in which I work. Certainly, the processes that inform my practice are built upon exceptional collaborative dialogue with many expert cultures. These have richly informed my practice. However, qualifying my outcomes as 'collaborative' is inaccurate; my work is singular and unique and in the end provides a distinctive illumination of loss.

'Is the artist going to solve problems?'

'No, the artist is going to show us problems we didn't know were there.'<sup>256</sup>

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<sup>256</sup> Ibid.

## **Appendix 1**

Email sent to all members of the UK Myotonic Dystrophy Patient Registry, with attached letter from the author. Sent 4<sup>th</sup> June 2013.



Re: Project involving families with Myotonic Dystrophy.

Dear

In line with the consent you gave when you signed up to the Myotonic Dystrophy Registry, we are contacting you to inform you of an upcoming research project being carried out by Jacqueline Donachie an artist completing her PhD at Northumbria University. Approval of the project has been granted by the necessary ethics board.

Attached is a letter from Jacqueline Donachie explaining her work and what will be involved in her project. The letter also explains the criteria for taking part; Jacqueline would like to work with families containing an affected and unaffected sibling. Her contact details are also in the attached letter. If, after reading this information, you would be interested in taking part in this project then please contact Jacqueline directly. We will not forward your personal details to Jacqueline.

Please be aware that this letter is for information only and does not necessarily imply that the Myotonic Dystrophy Registry endorses this project; the Myotonic Dystrophy Registry is not responsible for this project. We would also like to point out that this letter does not guarantee that you will participate in this study. The decision to include any particular individual in this study is the responsibility of Jacqueline Donachie.

Yours sincerely,

Libby Wood

UK Myotonic Dystrophy Registry Curator

UK Myotonic Dystrophy Patient Registry  
MRC Centre for Neuromuscular Diseases at Newcastle  
Institute of Genetic Medicine  
Newcastle University  
International Centre for Life  
NE1 3BZ  
04/06/2013

### **Could you help me make a new artwork?**

I am an artist currently working on a PhD at Northumbria University in Newcastle. I have a particular interest in myotonic dystrophy as several members of my own family have the condition. My PhD will be called *Illuminating Loss*, and through it I want to explore the extent to which art works can challenge representations of experience in the fields of genetics and disability.

I have previously worked alongside scientist Prof Darren Monckton and in In 2002 I produced a small book entitled DM that reflected on the experiences of my family as we learnt about myotonic dystrophy after a congenitally affected child was born.

For this study, I would like to speak to siblings where one has the myotonic dystrophy gene and one does not, and I am particularly keen to speak to sisters. The aim of the project would be to make a short film, based on the stories of a group of siblings of varying ages (from teens to senior citizens) that would be screened at an exhibition in Newcastle, and also then hopefully shown at conferences and other public events in the UK. Clips from the film may also be available online.

If, following an informal discussion, you would like to take part in the first stage of this project, I would then arrange a further interview with you. This interview would be recorded (very informally), and would happen at a location convenient for you – most likely your home. None of the recorded material would be used publicly without your full permission. Further interviews may take place if you are comfortable with the process.

If you would be interested in speaking to me further about this I would be delighted to hear from you. My contact details are listed below. I will be at the MDSG conference in Wiltshire on Saturday 8<sup>th</sup> June and would be happy to discuss the project there with anyone who is interested.

**Jacqueline Donachie**

**The Woon Studio, Baltic 39  
School of Arts and Social Sciences  
Northumbria University,  
Newcastle**

**Tel: 07811447865**

**Email: [info@jacquelinesdonachie.co.uk](mailto:info@jacquelinesdonachie.co.uk)**

**Website: [jacquelinesdonachie.co.uk](http://jacquelinesdonachie.co.uk)**

## **Appendix 2**

Participant Information Sheet and signed Release Forms, authorising public use of interview content.



**Illuminating Loss/ Sisters affected by Myotonic Dystrophy**  
**PhD Research study by Jacqueline Donachie**

**Participant Information Sheet**

The study you have agreed to take part in is provisionally titled *Illuminating Loss*; through it I want to explore the extent to which art works can challenge representations of experience in the fields of genetics and disability. I am particularly interested in representations of myotonic dystrophy, as several members of my own family have the condition.

The aim of the project is to make a short film, based on the stories of a group of female siblings of varying ages (from teens to senior citizens) where one has the myotonic dystrophy gene and one does not. The film will come from a series of filmed interviews, one with each sister, and on completion will be screened at an exhibition in the UK, and also then hopefully shown at conferences and other public events.

You have agreed to take part in an interview which will be recorded (very informally) as part of this research, and I will show you any footage I may later wish to include in the final edited work. None of the recorded material would be used publicly without your full permission.

**Jacqueline Donachie**

**Northumbria University**  
**School of Arts and Social Science**  
**Newcastle Upon Tyne, NE1 8ST**

**T: 0191 227 3162**  
**T: 07811447865 (Jackie)**

**Email: [info@jacqueline-donachie.co.uk](mailto:info@jacqueline-donachie.co.uk)**  
**Website: [jacqueline-donachie.co.uk](http://jacqueline-donachie.co.uk)**



**RELEASE FORM**

This agreement relates to the photographs and associated websites/social media to be produced by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions.

- (1) Jacqueline Donachie has the right to edit or abridge the Photograph, reference to Photograph in this Release includes any and all edited or abridged versions made by the Company.
- (2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) provisionally entitled "Illuminating Loss".
- (3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking their out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor

Signed .....  
 Print Name: LOUISE CHARLES  
 Address:   
 Date Signed: 14-3-15

For and on behalf of Jacqueline Donachie

*Louise Charles*

**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**

PROGRAMME TITLE: Illuminating Loss/  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
- 2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
- 3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED ..... DATE: 14-3-15

To be accompanied by (1) Participant Consent Form and (2) Information Sheet



RELEASE FORM

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(3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
(4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
(5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
(6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed: [Signature]
Print Name: JACQUELINE DONACHIE
Address: [Redacted]
Date Signed: 15/03/15

For and on behalf of Jacqueline Donachie

NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION CONTRIBUTOR RELEASE FORM

PROGRAMME TITLE: Illuminating Loss/ Interviews with sisters affected by Myotonic Dystrophy PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material, including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED: [Signature] DATE: 15/03/15

To be accompanied by (1) Participant Consent Form and (2) Information Sheet

*Lucie Barbour*

**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**

PROGRAMME TITLE: **Eliminating Loss/  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie**

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED ..... DATE **16.3.15** .....

To be accompanied by (1) Participant Consent Form and (2) Information Sheet.



**RELEASE FORM**

This agreement relates to the photographs and associated websites/social media to be provided by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions:

- (1) Jacqueline Donachie has the right to edit or abridge the Photograph. References to Photograph in this Release includes any and all edited or abridged versions made by the Company.
- (2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) provisionally entitled **Eliminating Loss**.
- (3) Jacqueline Donachie has the right to screen and broadcast the photograph in an online website / social media (which may include other recordings and material).
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed  .....

Print Name **Jacqueline Donachie** .....

Address **16.3.15** .....

Date Signed **16.3.15** .....

For and on behalf of Jacqueline Donachie

**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**



PROGRAMME TITLE: Illuminating Less:  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR: Sally Cartwright

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED: S. Cartwright DATE: 01-08-15

To be accompanied by (1) Participant Consent Form and (2) Information Sheet

**RELEASE FORM**

This agreement relates to the **photographs and associated webbased social media** to be produced by **Jacqueline Donachie** and for the potential use of the below named Contributor's material.

I hereby agree to allow **Jacqueline Donachie** to record (the "Recording") of me on to a digital file on the following terms and conditions:

- (1) **Jacqueline Donachie** has the right to edit or abridge the **Photograph**. Reference to Photographs in this Release includes any and all edited or abridged versions made by the Company.
- (2) **Jacqueline Donachie** has the right to print, screen and broadcast the **Photograph** (which may include other recordings and material) provisionally entitled **Illuminating Less**.
- (3) **Jacqueline Donachie** has the right to screen and broadcast the **photograph** into an online website / social media (which may include other recordings and material)
- (4) **Jacqueline Donachie** owns and shall own all rights, title and interest (including copyright) in the **Photograph**.
- (5) **Jacqueline Donachie** agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
- (6) I acknowledge that **Jacqueline Donachie** is not obliged to use the **photograph**.

Agreed and accepted by the Contributor:

Signed: S. Cartwright  
Print Name: SALLY CARTWRIGHT  
Address: 81 Hickory Grove

Date Sign:

For and on behalf of **Jacqueline Donachie**

Signed: J. Donachie  
Print Name: JACQUELINE DONACHIE



**RELEASE FORM**

This agreement relates to the photographs and associated websites/social media to be produced by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions:

- (1) Jacqueline Donachie has the right to edit or abridge the Photograph. Reference to Photograph in this Release includes any and all edited or abridged versions made by the Company.
- (2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) privately, non-commercially and on an illuminating basis.
- (3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed: R Z Mallett  
 Print Name: RACHEL MALLETT  
 Address:   
 Date Signed: 16-5-15

For and on behalf of Jacqueline Donachie

*Rachel Mallett cont.*

**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION CONTRIBUTOR RELEASE FORM**

PROGRAMME TITLE: Illuminating Loss/ Interviews with sisters affected by Myotonic Dystrophy PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
- 2. I hereby irrevocably and unconditionally waive a way so called "moral rights" in respect of my contribution.
- 3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED R Z Mallett DATE 16-5-15

To be accompanied by (1) Participant Consent Form and (2) Information Sheet



**RELEASE FORM**

This agreement relates to the photographs and associated websites/social media to be produced by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions:

- (1) Jacqueline Donachie has the right to edit or abridge the Photograph, Recording or Photograph in this Release includes any and all edited or abridged versions made by the Company.
- (2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) provisionally (initially) Illuminating Loss.
- (3) Jacqueline Donachie has the right to screen and broadcast the photograph into an entire website / social media (which may include other recordings and material)
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and name, neither misrepresenting the Contributor's words nor taking them out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed  
Print Name  
Address

*Handwritten signature*  
[Redacted area]

Date signed

For use on behalf of Jacqueline Donachie

*South Australia/  
Leicester.*

*Fain Hurley*

**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**

PROGRAMME TITLE: Illuminating Loss/  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
- 2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
- 3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED *Fain Hurley* DATE *24.9.2015*

To be accompanied by (1) Participant Consent Form and (2) Information Sheet



RELEASE FORM

This agreement relates to the photographs and associated websites/ social media in the production of the film 'Illuminating Loss' produced by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me in a digital file on the following terms and conditions:

- (1) Jacqueline Donachie has the right to edit or abridge the Photograph. Revisions to the Photograph in this Release includes any and all effect or abridged versions made by the Company.
(2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) professionally entitled 'Illuminating Loss'.
(3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
(4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
(5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
(6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor

Signed L Sadler

Print Name: L SADLER

Address

Date

File and on behalf of Jacqueline Donachie

NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION CONTRIBUTOR RELEASE FORM

PROGRAMME TITLE: Illuminating Loss/ Interviews with sisters affected by Myotonic Dystrophy PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company and this assignment shall operate to the extent necessary as a present assignment of future copyright. I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

SIGNED L Sadler DATE 17-3-2018

To be accompanied by (1) Participant Consent Form and (2) Information Sheet





RELEASE FORM

This agreement relates to the photographs and associated websites/ social media to be produced by Jacqueline Donachie and for the potential use of the below named Contributor's material.

I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions:

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- (3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed ..... *Clare Graham* .....  
Print Name: ..... CLARE GRAHAM .....



**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**

PROGRAMME TITLE: Illuminating Loss/  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

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- 2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
- 3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.

*J. D.*



**NORTHUMBRIA UNIVERSITY MEDIA PRODUCTION  
CONTRIBUTOR RELEASE FORM**

**RELEASE FORM**

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I hereby agree to allow Jacqueline Donachie to record (the "Recording") of me on to a digital file on the following terms and conditions:

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- (2) Jacqueline Donachie has the right to print, screen and broadcast the Photograph (which may include other recordings and material) provisionally entitled Illuminating Loss.
- (3) Jacqueline Donachie has the right to screen and broadcast the photograph into an online website / social media (which may include other recordings and material)
- (4) Jacqueline Donachie owns and shall own all rights, title and interest (including copyright) in the Photograph.
- (5) Jacqueline Donachie agrees to retain the integrity of the Contributor's image and voice, neither misrepresenting the interviewee's words nor taking them out of context.
- (6) I acknowledge that Jacqueline Donachie is not obliged to use the photograph.

Agreed and accepted by the Contributor:

Signed ..... *Jacqueline Donachie* .....  
Print Name: ..... *Jacqueline Donachie* .....



PROGRAMME TITLE: *Illuminating Loss/  
Interviews with sisters affected by Myotonic Dystrophy  
PhD Research, Jacqueline Donachie*

NAME OF CONTRIBUTOR:

In consideration of Northumbria University ("the Company") agreeing that I contribute to and participate in the Programme, the nature and content of which has been fully explained to me, I hereby consent to the filming and recording of my contribution and my participation in the Programme, and the use of this contribution (including any personal material including photographs supplied by me) in whole or in part or not at all, subject to the terms and conditions specified below.

- 1. I hereby agree that the copyright (if any) and all other right title and interest in and in respect of my contribution shall vest in and is hereby assigned to the Company (and this assignment shall operate to the extent necessary as a present assignment of future copyright). I irrevocably grant the Company all rights and consents or waive the same so as to permit the use throughout the world of my contribution or any part(s) thereof in perpetuity by all means and in all media, for the purposes explained in the accompanying information sheet.
- 2. I hereby irrevocably and unconditionally waive any so called "moral rights" in respect of my contribution.
- 3. I warrant that the content of my contribution shall to the best of my knowledge and belief be true and shall not contain anything intended to bring the Company into disrepute. I will promptly notify the Company of any information that might call into question the integrity of the Programme.



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**Could you help me make a new artwork?**

I am an artist currently working on a PhD at Northumbria University in Newcastle. I have a particular interest in myotonic dystrophy as several members of my own family have the condition. My PhD will be called *Illuminating Loss*, and through it I want to explore the extent to which art works can challenge representations of experience in the fields of genetics and disability.

I have previously worked alongside scientist Prof Darren Monkton and in 2002 I produced a small book entitled *DM* that reflected on the experiences of my family as we learnt about myotonic dystrophy after a congenitally affected child was born.

For this study, I would like to speak to siblings where one has the myotonic dystrophy gene and one does not, and I am particularly keen to speak to sisters. The aim of the project would be to make a short film, based on the stories of a group of siblings of varying ages (from teens to senior citizens) that would be screened at an exhibit on in Newcastle, and also then hopefully shown at conferences and other public events in the UK. Clips from the film may also be available online.

If, following an informal discussion, you would like to take part in the first stage of this project, I would then arrange a further interview with you. This interview would be recorded (very informally), and would happen at a location convenient for you – most likely your home. None of the recorded material would be used publicly without your full permission. Further interviews may take place if you are comfortable with the process.

If you would be interested in speaking to me further about this I would be delighted to hear from you. My contact details are listed below. I will be at the MDSG conference in Wiltshire on Saturday 8<sup>th</sup> June and would be happy to discuss the project there with anyone who is interested.

**Jacqueline Donachie**  
The Woon Studio, Baltic 39  
School of Arts and Social Sciences  
Northumbria University,  
Newcastle  
Tel: 07811447865  
Email: [info@jacquelinedonachie.co.uk](mailto:info@jacquelinedonachie.co.uk)  
Website: [jacquelinedonachie.co.uk](http://jacquelinedonachie.co.uk)



**northumbria**  
UNIVERSITY

**Illuminating Loss/ Sisters affected by Myotonic Dystrophy  
PhD Research study by Jacqueline Donachie**

**Participant Information Sheet**

The study you have agreed to take part in is provisionally titled *Illuminating Loss*; through it I want to explore the extent to which art works can challenge representations of experience in the fields of genetics and disability. I am particularly interested in representations of myotonic dystrophy, as several members of my own family have the condition.

The aim of the project is to make a short film, based on the stories of a group of female siblings of varying ages (from teens to senior citizens) where one has the myotonic dystrophy gene and one does not. The film will come from a series of filmed interviews, one with each sister, and on completion will be screened at an exhibition in the UK, and also then hopefully shown at conferences and other public events.

You have agreed to take part in an interview which will be recorded (very informally) as part of this research, and I will show you any footage I may later wish to include in the final edited work. None of the recorded material would be used publicly without your full permission.

**Jacqueline Donachie**  
Northumbria University  
School of Arts and Social Science  
Newcastle Upon Tyne, NE1 8ST  
T: 0191 227 3152  
T: 07811447865 (Jackie)  
Email: [info@jacquelinedonachie.co.uk](mailto:info@jacquelinedonachie.co.uk)  
Website: [jacquelinedonachie.co.uk](http://jacquelinedonachie.co.uk)

### **Appendix 3**

*Illuminating Loss: recruitment for an artistic study of siblings affected by myotonic dystrophy type 1.*

Poster presented at 9th International Myotonic Dystrophy Consortium Meeting, Kursal Conference Centre, San Sebastian, Spain.

16 – 20<sup>th</sup> October 2013.

# illuminating Loss

an artistic study of siblings affected by myotonic dystrophy Type 1.

Jacqueline Donachie

Northumbria University, Newcastle upon Tyne, UK



BALTIC 39

## Introduction

*illuminating Loss* is practice-based doctoral research led by artist Jacqueline Donachie in collaboration with the **Centre for Life, Newcastle**

Through a series of film-based installations *illuminating Loss* challenges representations of genetic dysfunction in the fields of genetics, social science and contemporary art. Based on a series of filmed interviews, *illuminating Loss* explores the changing attitudes of sisters (one affected with DM, the other unaffected) in terms of their physical and emotional wellbeing, and in a wider context of ageing.

Due for completion in 2015 *illuminating Loss* will be one of the first outcomes of **Baltic 39**, a new, collaborative contemporary art research institute at Northumbria University.

## Methodology

*illuminating Loss* explores an interdisciplinary methodology grounded in contemporary art practice and sociology. Drawing from autoethnographic traditions the doctoral research adopts ethnographic and **narrative approaches** to the collection of data: participant observation, interview and video.

## Recruitment

Participants have been recruited through the **UK Myotonic Dystrophy Patient Registry** based at the Centre for Life, also in Newcastle, and the **Myotonic Dystrophy Support Group**.

Currently the participant group is composed of 14 pairs of sisters (late teens – early 60s) who have agreed to be interviewed and filmed.

The project builds on an earlier collaborative film and book project (*Tomorrow Belongs to Me*, 2005/6) between Jacqueline Donachie and Professor Darren Monckton at the University of Glasgow, and the small artists book, *DM* (Donachie, 2002). The method of using patient networks to recruit for a creative/ artistic study is new, but offers great potential for the use of Registries for creative and social studies, as well as scientific and clinical research.

## Questions

- How does an artistic or social study that is concerned with personal narrative (story-telling) affect not just audiences, but those that agree to participate?
- By finding new mechanisms for life stories to be recorded and heard, can artworks offer new ways of illustrating and understanding the effects of DM, leading to new strands of research and more effective care pathways?
- Can artists envisage simple models for the sharing of personal stories that are both productive and beneficial to the wellbeing of patients and their families, and illuminating to the scientific community?



## APPENDIX 3

## **Appendix 4**

Details of screenings and discussion events with specialist audiences in 2015.

#### APPENDIX 4

*Hazel* was presented to a number of specialist audiences in 2015 as part of this research.

1. 10<sup>th</sup> International Myotonic Dystrophy Consortium Meeting (IDMC-10)  
12<sup>th</sup> June  
Campus des Cordeliers, Paris. 8-12<sup>th</sup> June 2015.  
Screening and presentation was the conference closing event.

The IDMC is the leading disease specific conference for myotonic dystrophy. The screening was to a mixed international audience of scientists, clinicians and some families all connected with research and care in this field. This conference has taken place every two years since 1997, when there were 80 delegates. Attendance in 2015 was over 240.

<http://www.idmc10.org>

2. Myotonic Dystrophy Foundation Annual Conference  
Washington DC, USA.  
18<sup>th</sup> September 2015  
Presentation and screening (conference opening event).

Mixed audience mainly of families and clinicians associated with the US family support group.

<http://www.myotonic.org/2015conference>

3. University of Glasgow, Gilmorehill Cinema  
25<sup>th</sup> November 2015

Screening of *Tomorrow Belongs to Me*, (Donachie and Monckton, 2006) and *Hazel* to an invited audience of researchers (PhD students, post-Doctoral staff and research fellows) from the Department of Molecular Genetics at the University of Glasgow and staff from the West of Scotland Genetics Service, Queen Elizabeth University Hospital, Glasgow (consultant clinical geneticists, GP's and genetic nurse Specialists). Attendance 45.

4. John Walton Muscular Dystrophy Research Centre,  
Centre for Life, Newcastle upon Tyne  
15<sup>th</sup> December 2015

Screening and presentation to invited audience of staff from the Centre including NHS clinical genetics teams who care for families in the North East of England, research scientists from the University of Newcastle and staff from the Myotonic Dystrophy Patient Registry.

Attendance 58.

<http://newcastle-muscle.org>

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