(In)significant Genes

The Work of Genetic Knowledge in the Lives of People with NF1

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Dedicated to the memory of:

My father,
Jeremy Samuel John Marshall
(1963-2023)

My father-in-law,
Andrew Marc Curtis
(1955-2022)

And my participant,
Chris

Contents

Abstract

By focusing on the experiences and perspectives of those with the genetic condition NF1, the purpose of this project is to investigate Britons' thoughts on the nature and significance of genes. Genes as units of heredity are arguably central to Euro-American biomedical cosmology. However, "gene talk" is relatively rare, both in the general public and at NTUK—the London-based charity where I conducted my ethnographic research. By centring not only on participants' health narratives but also on their choices, biosocial involvements, and philosophical reflections, my aim is to understand the fluctuating relevance of genetic information in life beyond the clinic.

This thesis' primary contribution is to the anthropology of knowledge. Drawing on insights from the anthropology of genetics, I push forward by analysing situations where genetic knowledge provokes existential unease. An NF1 diagnosis not only generates medical uncertainty, it also compels my participants to think of themselves in genetic terms—that is, with what Carlos Novas and Nikolas Rose (2000) have described as a "molecular optic". In my analysis, I discuss 'temporal discipline' and a 'practice of emphasis' as tactics employed by my participants to pursue a good life. The former term concerns avoiding the temptation to anticipate the future—and future generations—based on partial genetic knowledge in the present. The latter addresses how participants 'believe in science' yet simultaneously entertain kinder truths in which they resist seeing themselves in purely evolutionary terms.

This thesis finds that genes are avoided in everyday discourse *not* because of the public's limited scientific comprehension—nor necessarily because of continuing associations with eugenics, although this plays a role—but because there exists a cultural preference for mystery. In the opinion of several of my key participants, one ought not to think too much about genes. Thus, this thesis ultimately confirms Marilyn Strathern's (1992: 171) prediction that Euro-Americans—at least my participants with NF1—value unpredictability and unknowability when considering their genetic origin.

Acknowledgements

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Finally, with love and thanks to my partner, Max. You have been my support for over a decade. I know I would not be where I am without you.

> I worried about [my daughter’s] future. When she was diagnosed with NF1, I worried about whether she would have kids. But then I think, ‘what about my [unaffected] son?’ He could have fertility problems in the future. His future partner might have infertility problems. He could be gay, and they could have hurdles if they wanted to have children. And I don’t think about that with him. So why was I thinking about this with [my daughter]? This one-year-old child, why was I thinking about her children?
>
> - Seren, mother of a young daughter with NF1

Preface

I am often asked, "why NF1?" Of the thousands of different medical conditions, including many with a known genetic component, why research this one? There are multiple answers to this question, and it is difficult to compress them into a single soundbite—try as I might to form some semblance of an elevator pitch. For the sake of transparency, and as a means of exposition, I have decided to open this thesis with a more comprehensive response. On some dry, detached level, I can argue NF1 is an interesting condition. A few years ago, during an internal Oxford assessment, I found myself accounting for my selection to a professor who wanted an analytic justification. I argued that NF1 is an unusual condition in that it troubles various binaries. I referenced the fact that there is no post-diagnostic "pre-symptomatic" (Konrad 2005: 14) time-period in NF1, but rather symptoms gradually and unpredictably increase throughout the affected person's life. I also noted that NF1 troubles the distinction made between "disease" and "difference" since many people see the condition as an inalienable part of themselves. My clinching argument was that while other conditions have some of the facets of NF1—such as unpredictability, or complex penetrance, or identified genetic origin—the confluence of these factors is unique in NF1. Despite my assessor's eventual satisfaction with this justification, looking back, I find this line of reasoning to be cold and misleading. The focus of this thesis is not NF1 but rather my participants and their reflections on NF1. Moreover, the story of how I came to this research project is more nuanced. Suffice it to say, to answer the question "why NF1", I must not only account for my genetic condition selection but also for my decision to study people with a genetic condition in the first place. As such, to begin a full explanation, I turn to 2016—when I first learnt of NF1 as a university student in Scotland.

During the final year of my undergraduate degree, while increasingly interested in the anthropology of science, I became aware of the work of Adam Pearson. Adam is an English actor, presenter, and disability rights campaigner. He also has NF1. I wish I could say I encountered Adam's work through my academic studies, but the truth is my interest was piqued by a blockbuster starring Adam called *Under the Skin*. In the movie, an alien is intrigued by Adam's character's visible difference—a role for which Adam required no prosthetics. As I began investigating Adam and his disability rights advocacy, I realised this acting role was very much in keeping with his other work. Adam uses interest in his appearance to draw attention to a variety of conditions, charities, and causes. While I do not always agree with Adam's employment of somewhat controversial tactics—his shows have provocative titles, including *The Undateables*, and *Adam Pearson: Freak Show*—in my initial online exploration of his work I came to admire his wit and candour. In particular, I was struck by a cutting response given by Adam to a leading interview question. When asked by a reporter if he would consider having children "given his genes", Adam retorted, "sure, I have great genes", with a tone that added, 'thank you very much for implying otherwise'. This quip—which has subsequently been retracted—has stayed on my mind and in my academic interest for the better part of a decade.

After completing my undergraduate degree, I received the opportunity to pursue a master's in bioethics in the United States. I knew I ultimately wanted to stay in anthropology, however, I hoped exploring my interest in NF1 from another disciplinary perspective might prove useful. In hindsight, I can say this diversion did indeed help since it refined my research interests. While writing my MA thesis on genome editing, I came to realise that I was not interested in discussing biological relatedness in the abstract, but rather, I was intrigued by the significance that could be ascribed to a single gene as an isolated unit of heredity. In part, this focus was necessary for completing my master's paper: I could not discuss the ethics of germline genome editing without information on the significance of the gene in different cultural understandings. Of greater importance, however, was realising I had an anthropological interest in genetics not genomics. Even though I knew biomedical research had moved on since the advent of the Human Genome Project, and that it was more fashionable to attend to the role of complex gene interactions as well as epigenetics (Nelson 2018: 523), I was increasingly convinced that genes nevertheless continued to matter in public, everyday discourse. During my classes, I was introduced to several authors who underpinned this conviction, including but not limited to Bill McKibben (2003) and S. Matthew Liao (2017). Moreover, I was able to reflect with a little distance on my personal experiences in Britain, where Punnett squares are taught to teenagers in standardised tests; people speak of "having the gene" for certain traits; and public figures such as Adam are still quizzed on their reproductive choices in the language of genetics. Accordingly, after I finished my year in the United States, I returned to the United Kingdom interested in individual genes as substance.

I began applying for a doctoral project structured around NF1. I wanted to use people's experience with, and reflections on, this unusual genetic condition as a means to explore the significance ascribed to single genes more generally. I argued attending to NF1 as a single gene condition was sensible since it invited reflection on the scope and impact of just one gene—a means of controlling other variables if you will. I also knew this logic would allow me to continue exploring this idiosyncratic genetic condition which maintained a stronghold on my interest. In anthropological terms, I characterised my project as an investigation into the place of genes in British cosmology.[1] More generally, I located my approach within the established practice of using exceptional circumstances to shed light on broader imaginaries—that is, "as with many of the new reproductive and genetic technologies, practices that will typically only affect the lives of a few are also ideas that have to be assimilated and understood by the many" (Simpson 2000: 4). I thus entered the field with quite a settled idea of what I wanted to study.

Of course, as is the case with most ethnographic research, my project shifted to a certain degree during fieldwork. For instance, in response to my participants' hesitancy to discuss genes in certain situations, I paid increasing attention to fluctuations in the relevance of genetic information instead of concentrating solely on the content of "gene talk".[2] What is more, I was forced to make methodological adjustments after the outbreak of the Covid-19 pandemic. Yet despite these shifts, I kept the core of my project consistent. Even when opportunities arose to divert my analytic focus—such as when my participants offered rich discussion on the fragility of the National Health Service (NHS), the futility yet importance of political causes, or their experiences with managing cancer diagnoses—I knew I would ultimately be focusing my analysis on the genetic component of NF1.

My justification for maintaining this focal point is twofold. First, for a DPhil student, there is an imperative to offer something new. While many of my participants' observations were profound—and are of course included in this thesis as ethnographic detail—they pertained to established discourse on stigma and "mere difference" debates in disability studies. In other words, I would struggle to make an original theoretical contribution with this focal point alone. I ultimately chose to focus my analysis on the significance—or lack thereof—attributed to genes in order to make a novel point on the work of genetic knowledge in people's everyday lives. What is more—and this is my more significant justification—I contend this genetically-focused analysis still aligns with my participants' interests. As I will explain more fully in the body of this chapter and thesis, the existential unease provoked by thinking of oneself in genetic terms is

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[1] Please visit pages 47 – 50 for a definition and justification of my use of the term cosmology throughout this thesis.

[2] By "gene talk", I refer to articulations on the nature and significance of genes. Duden and Samerski define gene talk as "the intrusion of the term [gene] into common parlance", especially the "encroachment of 'genes' into personal deliberation [including] the very perception of the self" (2008: 161).

understudied, and regrettably so. When my participants negotiate the relevance of genetic information to their lives, they are enacting a creative and profound resistance to eugenic logic. It is my role and privilege as an anthropologist to point out this innovation. So, while I cannot say my participants are interlocutors or co-theorists—since I am the one deciding the analytic direction of this write-up—their thoughts and theorisations are nevertheless the crux of this thesis.

In summation, in response to the question “why NF1”, I can say that I by chance learned of a distinctive health condition, and through it became interested in the significance that can be ascribed to genes. At the close of this preface, I wish to add that in hindsight, no-matter my original justifications, I am glad to have researched NF1 if only because it has introduced me to wonderful people—many of whom I now consider dear friends. My participants cannot be reduced to their NF1. They are diverse people, each with their own stories and struggles and joys. My key participant, Stewart, remarked to me recently, “you could study a hundred people with NF1 and get a hundred different takes on it.” My aim, and achievement, has not been to paint a unified picture of life with NF1 in the United Kingdom but to appreciate that my participants—through their experiences of NF1—have had exceptional cause to introspect on their genetic situation. If I could sum up the findings I have accessed through their wisdom—that is, the backbone of this thesis—it would be this: that it is possible to understand and respect biomedicine without letting genetics define how you think about yourself and others. Genes can simultaneously be respected as the seminal substance of all organic life and eschewed as utterly irrelevant to a kind worldview. My participants choose—with much consideration and deliberation—which facts matter beyond the clinic.

Introduction

Outline of Chapter

This introductory chapter is broken down into three parts. The first is dedicated to exposition. I begin by detailing the clinical facts of NF1, including the condition's symptoms, inheritance patterns, case frequency, and prognosis. I then offer a research outline, which traces my transition from online data collection during the outbreak of the Covid-19 pandemic, to in-person participant observation towards the end of my fieldwork period. Included within this overview is a cursory introduction to my seven key participants: Stewart, Tara, Jamie, Chris, Sven, Amy, and Sharon. This leads into a broad brushstrokes account of life with NF1 in the United Kingdom. Necessary to this account is a description of the current state of the National Health Service (NHS), as well as other forms of support available to people affected by neurofibromatosis. I close this section with a description of Nerve Tumours UK (NTUK), the charity which assisted in my participant recruitment, and which subsequently became a locus of analysis in and of itself.

The second section of this introduction is dedicated to making plain my research contribution. Included at the outset of this section is a comprehensive summary of my central argument. I go on to outline the content of the various chapters of this thesis, and detail how the findings of each contribute to the overall story of this thesis. Also included within this section is a review of existing literature. I discuss the merits and limitations of various anthropological and sociological works, before suggesting how this project fills a research gap by attending to the fluctuating relevance of genes. At the close of this section, I explain my anthropological approach to further unpack the novelty and necessity of this project.

The third section of this introductory chapter presents figures on demographics, explains research techniques, and discusses other facets of my method and methodology. Included at the end of this section is an ethnographic portrait of my key participant, Stewart. My intention is both to illustrate the depth I achieved during my ethnographic interviews, and to introduce Stewart as my main participant. Even among my seven key participants, Stewart was exceptional. His experiences, philosophical reflections and idiosyncrasies form the backbone of this project, and as such, this introduction closes with his illness narrative.

Section 1: Exposition

Neurofibromatosis Type 1 (NF1)

Neurofibromatosis type 1, often abbreviated to “NF1”, is a single gene condition. All humans have an NF1 gene: it encodes the production of the protein neurofibromin, which is found throughout the body. When there is a mutation anywhere along someone’s NF1 gene, and this mutation is significant enough to disrupt protein-coding, this results in the individual *having* the condition “NF1”. Half of neurofibromatosis cases are inherited through an affected parent. It is an autosomal dominant condition—meaning if one parent has the condition, there is a 50:50 chance they will pass the condition on to each child. The other half of cases arise through a spontaneous mutation, whereby the individual is the first in their family to have NF1. Owing to the fact the NF1 gene is the longest gene in the human genome, mutations in this region are relatively frequent. Neurofibromatosis type 1 is among the most common single-gene conditions. Affecting around one in 3,000 births worldwide, NF1 is more prevalent than cystic fibrosis and Huntington’s disease combined (Rozario 2007; Carrieri 2011; Ratner & Miller 2015; Carrieri et al. 2016; The US National Library of Medicine 2018).

Haunted by its mis-association with “the Elephant man”,[3] NF1 is often underdiagnosed and frequently misunderstood. The most obvious symptom of the condition is benign tumour growth throughout the body. Small lumps called neurofibromas can develop on and under the skin. They are frequently pea sized and flesh coloured. Some people with NF1 have a few of these lumps, others have hundreds. Larger growths involving multiple nerves are known as plexiform neurofibromas (Carrieri et al. 2016). These ‘plexiforms’, as they are often termed, can cause more pronounced visible differences, especially if they affect the face. Several of my participants disclosed to me that when they explain NF1 to someone new, they warn, “don’t Google it!” Their reasoning for this caution is that images on the internet may be frightening and misleading. While some people do live with a visible difference due to their NF1, others have only the less obvious manifestations of the condition. In addition to tissue growth, people with NF1 characteristically present with numerous pigmented

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[3] The American anthropologist Joan Ablon writes, "Although the rediagnosis was made in 1986 [that Joseph Merrick, “the Elephant Man”, had Proteus syndrome and not NF1], NF1 is still often associated with the Elephant Man in the media… One informant angrily talked about this outdated [mis-association]" (Ablon 1995: 1488). Despite Ablon’s caution—that the mis-association between Joseph Merrick and NF1 continues to hurt people with neurofibromatosis (1995)—I have decided to mention this association to contextualise my participants’ experiences. One of my participants, Chris, utilised Joseph Merrick in his work presentations to explain NF1. He reflected, “I know it’s wrong to use the Elephant Man, but it’s easy. Visual descriptions help. The only other visual example I could use would be Adam Pearson, and I’d feel worse using him.”

birthmarks known as café-au-lait marks. This hyperpigmentation is a part of the diagnostic criteria for NF1 since possessing more than six large café-au-lait marks is a strong indication of the presence of NF1. Bone abnormalities, unusual freckling, short stature, and a proportionally large head may also be seen in people with NF1. Apart from these cosmetic symptoms, NF1 can also cause cognitive differences. There is a higher frequency of dyslexia, autism, dyspraxia and other neurodivergences among people with NF1 (Ratner and Miller 2015).[4] In summary, although the cause of the condition is limited to a change in one gene, neurofibromatosis type 1 manifests as a "multi-system disorder" (Ratner and Miller 2015).

For many people, and for all but two of my research participants, NF1 concerns morbidity not mortality. In the United Kingdom, the life expectancy for people with NF1 is roughly comparable to that of an unaffected individual. To give a regional example, in the northeast of England in the 2010s, women with NF1 had a life expectancy of 71.5 years, compared to 79.5 years for unaffected women (Evans, O'Hara, Wilding et al. 2011). Furthermore, NF1 can be so mild it is estimated that fifty percent of people with NF1 do not know they have the condition. Only with the birth of an affected child do many parents come to be diagnosed through cascade testing (Ablon 1999: 4). In my initial exploration of online NF1 communities, I found people on NF1 forums were reluctant to compare their condition with other, supposedly more severe, genetic "diseases". One online forum user commented that, "comparing NF and Down's syndrome makes no sense, like comparing a paper cut and an amputation. Down [sic] is a chromosomic abnormality with an extra chromosome, which means 200 extra genes" (Neurofibromatosis Network User 2018). Owing to its oftentimes mild symptomology and localised underlying genetic component, many see NF1 as a mere difference or simple nuisance—with medical uncertainty and societal stigma causing greater distress than any given symptom.

Be that as it may, for many others, NF1 results in serious and even life-threatening complications. NF1 is classified as a cancer predisposition syndrome. People with the condition have a higher lifetime risk of certain cancers, including but not limited to breast cancer, gliomas, and sarcomas (Reynolds 2021). A particularly aggressive cancer associated with NF1 is a malignant peripheral nerve sheath tumour (MPNST)—which claimed the life of my participant, Chris, shortly after the completion of my fieldwork. It is also important to note that even non-cancerous NF1 tumours can

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[4] I want to highlight that most people with NF1 are within the 'normal range of intelligence'—but I am reluctant to endorse such statistical rhetoric given its historic associations with eugenics. Suffice to say, although NF1 affects the brain, it rarely causes profound mental disability.

cause significant problems. Many people with NF1 struggle with pain, sleep disturbances, itchy skin, epilepsy, and visual disturbances. So, while most of my research participants identify themselves as being mildly affected—and prefer the term genetic condition to genetic disease—I must stress that NF1 can still be difficult if not deadly. The anthropologist Santi Rozario put it well when she wrote that, "NF1 is often not severely disabling, but [it] can have a dramatic effect on the life of those who are born with it" (Rozario 2007: 552).

Each case of NF1 is unique. Even within the same family, even among identical twins with the same genome, there can be vastly different presentations. Consider again Adam Pearson. This actor—whom I introduced in the preface of this chapter, and whom I should clarify is not one of my research participants—shares his genes with his identical twin brother, Neil. Yet despite what one would expect, the two have markedly different presentations. Whereas Adam has noticeable tumour growth on his face, Neil is visibly unaffected but experiences more pronounced neurological complications. This variability evidences the fact that there is little known correlation between genotype and phenotype in NF1. That is, even in siblings who inherit the same 'spelling mistake' in their genetic code, their symptoms may well differ in number, nature, and timing. One of my participants, Zoe, uses the helpful analogy of a pinball machine when describing the varied presentation of NF1. Just as every different game of pinball produces different ricochets, no two people with NF1 have the same symptomology:

> When I talk to people about NF1, I talk to them and describe it as almost a pinball system. Along the side [of the pinball machine] you've got optic [nerve gliomas], you've got tumours, you've got café au lait marks, ADHD, you've got all of these different things, and there's tons of them. And you pull your ball, and it pings, and you got no idea where it's gonna go and what it's gonna hit. The ball might go straight through the middle, and you get nothing at all. Or it might hit every single [symptom] on the way, or just a couple.

Zoe's pinball analogy also alludes to the characteristic unpredictability of NF1. People with NF1 do not know which symptoms will arise during their life. In the condition, tumour growth and other complications can rapidly accelerate at any time without provocation or warning. As such, affected people cannot know when they are fully symptomatic. To complicate matters further, because NF1 symptoms are numerous and ambiguous, it can be difficult to distinguish symptoms from unrelated ailments, the effects of aging, or the simple idiosyncrasy of an individual's body. NF1 has been dubbed the "condition without parameters" for this reason (Carrieri et al. 2016). In summation, people with NF1 live everyday lives with a liminal prognosis that problematises how they define themselves and the degree of their illness.

Research Outline

The initial plan for this project was to conduct participant observation at various NF1 charity events in the United States. I anticipated leaving Oxford in the summer of 2020 to conduct fieldwork in Naperville, a suburb of Chicago. From there I would attend weekly community events run by a local NF charity, and later accompany young people to NF1 summer camps in other parts of the country. Inevitably, with the onset of the Covid-19 pandemic in the spring of 2020, these fieldwork plans dissolved. Not only were international borders closed, but domestic lockdowns[5] in the United Kingdom meant just as I was scheduled to embark on fieldwork, I found myself physically stuck at home in Cambridgeshire. During the summer of 2020, I began scoping the possibility of conducting fieldwork remotely. I considered interviewing Americans online. However, it became apparent that translating a physical project into an online investigation would be complex—not least because sourcing online participants from a specific geographic location, such as Naperville, would be difficult to reverse engineer. I looked into the possibility of conducting research in a virtual environment. Again, this plan did not appear to be feasible: I could not find a sufficiently attended NF1 platform to justify conducting an immersive ethnography in a digital landscape. Finally, and only with the looming threat of becoming an armchair anthropologist, did I eventually turn my sights to anthropology 'at home' in the United Kingdom. It was with this decision that my luck finally changed. No sooner had I begun investigating local NF1 activism than I encountered the London-based neurofibromatosis charity, Nerve Tumours UK (NTUK).

Sven was my first point of contact with this charity. He is, at the time of writing, the Marketing and Operations Manager of NTUK. A friendly and soft-spoken charity worker originally from Germany, Sven has been pivotal to the workability of this project. Not only was he responsible for recommending my project to NTUK's Medical Advisory Board for approval, he also continuously connected me with his own contacts to expand my understanding of the NF1 community in the United Kingdom. Thanks to Sven' enthusiasm, as soon as my project received ethics approval from NTUK in September 2020, the charity immediately began circulating my calls for participants. This involved advertisements on their Twitter, Facebook, and Instagram pages, as well

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[5] During the Covid-19 pandemic, the British government ordered three comprehensive "lockdowns". During these periods, people were instructed to stay at home. The first lockdown occurred between March 2020 and the early summer of 2020. In September 2020, social gatherings of more than six people were banned, and a second formal lockdown began in November 2020, continuing for one month. In January 2021, England entered its third and longest lockdown, with legal limits on social contact lasting until the summer of 2021 (Institute for Government 2022).

as in their newsletters. I should stress that I was never formally employed or sponsored by NTUK. Their agreement to circulate my research came with no formal conditions. However, because of their assistance, I received immediate interest in my project. What began as an instant and overwhelming influx of interest from potential participants transformed into a steady flow of sign-ups throughout the autumn of 2020. In the end, (over a total period of 19 months of fieldwork between September 2020 and March 2022, and not including my participant observation,) I conducted 93 interviews with 56 participants—all of whom live in England and Wales, and all but one of whom was sourced through NTUK.[6]

Most of these interviews—in terms of the frequency of calls—occurred in the autumn of 2020 and early spring of 2021. Several participants mentioned they had free time to participate in research since they were furloughed or working from home during lockdown restrictions. Others stated that they were keen to participate to avoid loneliness—a motivation of which I was mindful when considering the ethics of my project. It was during this time that I first met Stewart, my key participant. On a late autumn morning in 2020, Stewart and I spoke for over an hour. Whenever I recall our first meeting, I remember how Stewart interrupted our discussion to answer his landline phone and chide a telemarketer. Suffice it to say that Stewart was not afraid to use colourful language. Although I do not deal with cold-callers in this way, I was nevertheless impressed by Stewart's lack of pretense: he did not hide his bluntness from me, not even at the very outset of our calls. It quickly became apparent that we would get along well. After quizzing me on my research interests and motivations, Stewart was happy to recount—in detail—his clinical and personal experiences of NF1. Stewart's confidence—in dictating how he would like to tell "his story", which is fully detailed at the conclusion of this introductory chapter—coupled with his curiosity, empathy, and humility, led me to rightfully suspect that he would be a central figure in my project.

Along with Stewart, there are six other "key participants" in this ethnographic project. These participants were selected based on their availability and willingness to interview regularly, and the rapport we built. There was no formal selection process. Rather, over the course of several months, key participants naturally emerged. As my fieldwork progressed into 2021, I invested more time into these participants. Of the 93 interviews I conducted, 53 were follow-up interviews. This meant 40 participants were interviewed once, nine participants were interviewed twice, and seven participants—my

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[6] I was put in touch with my first participant, Tara, by a family friend after I mentioned my research interest in neurofibromatosis. She is my only participant not sourced through NTUK or snowball sampling.

key participants—were interviewed on three or more occasions. The minimum number of meetings to warrant a participant being considered a key participant was three, but many key participants took part in five or more interviews.

To offer an index—which may become useful when reading the body of this thesis—my key participants were as follows:

Amy
a geneticist, in her 40s, lives in the north of England, recently diagnosed with NF1

Chris
worked in tourism, recently deceased, was in his early 30s, lived in London, had NF1

Jamie
works in media, in his 30s, lives in Wales, has NF1

Sven
a NTUK employee, in his 40s, lives in London, unaffected

Sharon
a retired nurse, in her 70s, lives in Essex, has NF1

Stewart
a retired nurse, in his 70s, lives in Bristol, has NF1

Tara
a teacher, in her 40s, lives in London, unaffected, daughter has NF1

In addition to these seven key participants, I also wish to call attention to two participants whom I mention repeatedly in this thesis, Seren and Zoe. Although these women were not recurring participants—they took part in one and two interviews respectively—our conversations were highly productive. Their candid reflections well-summarised crucial findings I observed in other interactions. I feel it thus pertinent to highlight their details:

Seren
a family doctor, in her 40s, lives in Wales, unaffected, daughter has NF1

Zoe
a small business owner/seamstress, in her 40s, lives on an island off the coast of England, unaffected, daughter has NF1

I had initially set out to only speak with people who had NF1 themselves. However, I found myself expanding my participation criteria. While any ethnographer inevitably speaks to people beyond their specified participants—in my case, this involved people at the NTUK office, as well as children and partners during online calls with participants—I decided to begin inviting people without NF1 as full participants themselves. I felt it was important to explore how NF1 was viewed by those whose children had a spontaneous mutation, as well as those with relevant professional experience. I moreover decided to include people with the much rarer condition, NF2-related schwannomatosis,[7] as a point of comparison to my interest in NF1. By the end of my fieldwork, my selection criteria for ethnographic interviews were as follows: participants should either have NF1 themselves, have an immediate family member with NF1, work for Nerve Tumours UK or a similar organisation, be a healthcare provider for patients with NF1, work in NF1 medical research, or have NF2. Of my 56 formal research participants, 35 participants had NF1, two participants had NF2, six participants were unaffected mothers of a child with NF1, and 13 participants were unaffected NTUK employees or NF1 researchers. To reiterate, of my seven key participants—that is, those whom I called regularly—five had NF1 themselves, one was an unaffected mother of a child with NF1, and one—Sven—worked for NTUK.

Towards the end of 2021, upon the relaxing of Covid-19 precautions, I was able to move my research into the physical field. This in-person fieldwork primarily involved conducting participant observation at NTUK events in London—including various marathons where runners were fundraising for the charity. Furthermore, where possible, I travelled to in-person interviews to meet established participants in their homes or local towns. In the autumn of 2021, I spent considerable time speaking with Stewart and Tara respectively. Stewart would send me extended passages of self-reflection over email, which we would then discuss for several hours at a time. Meanwhile Tara kept me up to date with her daughter's progress at school, and her own religious life. I had originally planned to complete my data collection at the end of 2021. However, I decided to extend my research ethics and insurance timeframe by a few months to interview a mother who had lost her daughter to complications associated with NF1 several years prior, and a leading expert in NF1 treatment. Sven felt it was important for me to speak with these two participants since they offered two unique perspectives. He also held, and I concurred, that it would be rude to turn keen participants away.

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[7] This genetic condition was, until recently, known as "NF2". To remain in keeping with the language used at the time of my data collection, I refer to NF2-related schwannomatosis as NF2 throughout this thesis. Despite the fact NF1 and NF2 can both be referred to as "neurofibromatosis", since they both cause nerve tumours, NF1 and NF2 are discrete conditions pertaining to genes on different chromosomes.

Thus, my fieldwork came to an end in the late spring of 2022. In summary, I would characterise my research as continued conversations with participants who were dispersed in terms of geography, but connected through a loose biosocial community, NTUK. Although this project is not primarily an ethnographic study of a charity—but rather an exploration of the lives and philosophies of people sourced through this charity—it is still important to stress the centrality of NTUK to the workability of this project. As such, I will now describe not only the logistics of life with NF1 in the United Kingdom, but also the structure of NTUK as an organisation.

Living with NF1 in the United Kingdom

At present, there is no ‘cure’ for NF1. Whilst the possibility of gene therapy is currently being explored (Cui et al. 2020), the standard practice for NF1 patients in the United Kingdom is symptom management. Through the National Health Service, (the NHS),[8] people with an NF1 diagnosis can access numerous healthcare provisions. These include regular scans to identify rapid tumour growth, speech and language therapy, operations to correct scoliosis and other bone abnormalities, and plastic surgery to remove functionality-impairing neurofibroma lumps. Preimplantation genetic diagnosis (PGD) has also recently been made available through the NHS so that parents may choose to ensure their child does not inherit their NF1 (NHS Commissioning Board 2013). These services—like all NHS services—are free. For most people in the United Kingdom, the NHS forms the foundation of their healthcare. 89% of the population does not have any form of private health insurance (the King’s Fund 2014: 3), and even those who seek private healthcare often do so in tandem with NHS services. As such, when discussing experiences of NF1 in the UK, it is important to understand the current state of the NHS.

It has become increasingly difficult for all people—those with NF1 and those without—to access adequate and timely healthcare on the NHS. Even before the Covid-19 pandemic added unprecedented pressure, budget cuts resulted in ever-increasing delays to routine, consultant-led, and emergency care. The following statistics are taken from the NHS in England[9] to illustrate the concerning situation. In the five years

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[8] In the words of historian Ellen Welch, “the NHS is the largest and oldest publicly funded healthcare system in the world and provides anyone registered with an NHS number with medical care, without a medical bill at the end of the consultation. It is funded chiefly from taxation and National Insurance contributions… Today, as we live longer, demand for services continues to grow, and the NHS budget gets stretched thinner and thinner... The slow privatisation of the NHS is moving away from the core values that it was founded upon.” (Welch 2018: 9)

[9] In the late 1990s, the NHS was decentralised. Each of the United Kingdom’s four countries—England, Northern Ireland, Scotland, and Wales—were given charge of their own healthcare system. There are now differences in implementation between each system. For example, the NHS in Scotland offers free

between 2014 and 2019, the number of people in England on waiting lists for consultant-led treatment rose by 44%. In 2019, nearly a quarter of patients waited longer than four hours to receive care at major accident and emergency departments (A&Es). What is more, although the NHS had historically met its target for cancer treatment waiting times, this standard was breached—for the first time, and in five out of twelve months—in 2019 (Baker 2020: 5). According to a paper published by the British Medical Journal, there are "fundamental problems within the NHS… that existed pre-pandemic" (Jefferies 2022).

During the Covid-19 pandemic, the NHS was pushed to—or perhaps beyond—its limit. To redirect resources for the care of people affected by Covid-19, and to maintain social distancing, between March and December 2020, there were 2.9 million (34.4%) fewer planned inpatient admissions than intended (Morris 2021). This created a dangerous backlog. By October 2021, when I was well into my fieldwork period, there were over six million people waiting for NHS planned hospital care (Morris 2021). My participants spoke of having to forgo physical palpations of their neurofibromas—to check for any concerning irregularities—as well as surgery delays and cancellations. In November 2021, 10,646 patients in need of urgent hospital admission waited more than 12 hours on a trolley. This was five times the level of November 2020—evidencing that the pandemic's effects were not isolated to 2020. Many judge that the NHS is now overwhelmed and in chronic crisis (Jefferies 2022).

Accessing care for neurofibromatosis type 1 in an overstretched and complexly organised healthcare system is especially difficult. The NHS is enormous. It employs roughly 1.5 million people and is separated into an ever-shifting matrix of sub-organisations (Welch 2018: 112). All patients find accessing appropriate care "confusing" (Welch 2018: 112), and even doctors struggle in this labyrinth of bureaucracy. People with NF1 face the added complication of having their symptoms sit awkwardly between different healthcare specialties. My participants spoke of being bounced between neurology, genetics, orthopaedics, and plastic surgery, before, if ever, encountering an NF1 specialist. Moreover, as for many services in the UK, there is a "postcode lottery". That is, patients living in some geographic areas have access to better services than others. Whereas people living near NF1 centres in London, Oxford, and Manchester may receive excellent care, those in more rural areas, such as the southwest of England, can struggle to access specialist doctors. For my participant,

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prescription drugs for the over-65s. This is not the case in the NHS in England, which has been judged as the most "market-oriented" system of the four countries (Welch 2018: 113).

Stewart, who lives in Bristol, it has taken a lifetime to find a doctor who understands—in his words—the "whole picture" of NF1.

In response to an overstretched NHS, non-profit organisations are increasingly filling the gaps in non-urgent care provision. The United Kingdom has a long history of negotiating private charity initiatives with nationalised paternalism (Evans 2019), yet unlike in the United States—where people turn to crowdfunding to cover their healthcare costs—people in Britain largely take pride in centralised healthcare.[10] Accordingly, many perceive the increasing scope of charities to be a failure. My participant Sven—himself a charity worker—concedes that in an ideal situation of adequate state provision, medically focused charities would be obsolete. To close this exposition on life with NF1 in the UK, I will now describe the structure and function of NTUK, the United Kingdom's largest NF1 charity, which was vital to the workability of my research project, and integral to the lives of my research participants.

Nerve Tumours UK (NTUK)

On their website, NTUK describes themselves as "*the* national charity providing support to people with conditions that cause nerve tumours, such as neurofibromatosis [emphasis my own]":

> Nerve Tumours UK provides support and information, as well as campaigns and raises awareness on behalf of over 26,500 people in the UK who have Neurofibromatosis (NF1 and NF2) and Schwannomatosis. We're here to improve lives for people with nerve tumours, by making sure those affected have access to the help they require. (Nerve Tumours UK 2021)

The charity was founded under the name LINK—*Let's Improve Neurofibromatosis Knowledge*—by two mothers in 1982. These women both had a child with NF1, and their goal was to find other families affected by the condition to establish a network of support. Over the years, the group increased in size and rebranded to the Neurofibromatosis Network. Several of my participants still refer to the charity as the NF Network or, as Stewart jokes, "whatever they're calling themselves nowadays." In 2018, the charity rebranded again to Nerve Tumours UK. Over the last several years, NTUK has expanded considerably under the leadership of Claire, the current charity director. An affable yet no-nonsense proud Northerner, Claire is the first director of the charity with a background in finance. She is certainly a force to be reckoned with. In my first interview with Claire, she explained that her aim has been to run the finances of the

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[10] To give but one example, we can look to the overwhelmingly positive reaction to the NHS tribute during the opening of the 2012 London Olympic Games. One could also trace this pride to historical sentiments, such as in the late 19th and early 20th century, when "justice not charity" was the slogan of the National League of the Blind of Great Britain and Ireland (Reiss 2015).

charity like a business. Over the past few years, she has set aside a portion of the charity's income to establish a "rainy day fund"—that is, an allocation of liquid assets to keep the charity afloat should there be a drop in fundraising revenue. Thanks to Claire's foresight, NTUK has been able to stay afloat despite the impact of the Covid-19 pandemic on fundraising efforts.

According to Claire, NTUK primarily acts as a "facilitator" for people with neurofibromatosis. NTUK puts individuals with NF in touch with appropriate medical specialists—an important feat given how difficult it can be for patients to obtain an appropriate referral for their NF symptoms. When needed, NTUK helps individuals with NF navigate the benefits system to ensure they gain access to the support and finances to which they are entitled. The charity also offers to educate schools and employers on how NF1 might impact their pupils and employees. In addition to this facilitator role, NTUK also offers emotional support for those with NF1. This is namely through the operation of its national phone helpline, as well as its moderation of a NF1 Facebook group—which offers a safe space for people to seek advice and solace from other online users.[11] Beyond helping individuals with NF1, NTUK also works to increase public awareness of neurofibromatosis—through advertisements and informative literature—as well as facilitating academic and biomedical research related to NF1. The charity evidently has manifold functions, and it is telling that even my few participants who have qualms with NTUK as an institution still respect the charity for its impressive output of information and support.

In terms of the charity's structure, NTUK is divided into an office team, a board of trustees, a medical advisory board, and a specialist NF Nurse team. The office team is comprised of seven members of staff, most of whom are part-time employees, and based in the charity's central office in Wimbledon, London. Each staff member has a specific job title—such as Digital Content Creator, or Head of Fundraising—but they all chip in to help with each other's work where necessary. Separate to the office, the specialist NF Nurses are seen as the backbone of the charity. The term "Nurse" is used to refer to these professionals, even though some are occupational therapists, not nurses, by training. Each of NTUK's Nurses covers a geographic region, such as Wales or the southwest of England. The demands and resources available in each region differ, and consequently each Nurse has a unique job. Examples of roles performed by NTUK Nurses include operating the NTUK helpline, presenting educational talks at schools, and running specialist clinics in NHS hospitals. These Nurses are often simultaneously

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[11] I was unable to access this Facebook group as it is a closed community exclusively for people with NF.

employed by the NHS and NTUK, with each organisation paying one half of their salary—illustrating again the embeddedness of the NHS in all aspects of healthcare in the United Kingdom.

While not all people with NF1 in the UK know of Nerve Tumours UK, it is fair to say that the charity has a sizeable impact. NTUK is one of only two NF1 charities recommended by the NHS on their webpages dedicated to neurofibromatosis, and it is worth noting the other charity, the British branch of The Childhood Tumour Trust, is limited in income and scope when compared to NTUK. According to the Charity Commission for England and Wales, NTUK has an income over five times that of CTT. Moreover, CTT only serves children with NF1 and their families, whereas NTUK serves all people affected by the condition. Furthermore, at this time of writing, when you enter "NF1 charity UK" into Google—NTUK is the first website suggested. As such, it is fair to say that if someone with NF1 in the United Kingdom wanted support from an NF1 charity—or if a researcher such as myself wanted to learn more about people's experiences with NF1 in the United Kingdom—it would not be long before they encountered Nerve Tumours UK.

Section 2: Contribution

Research Questions and Central Argument

At the outset of this research, I hypothesised that living with a known genetic condition might provoke introspection among my participants—such that they think about their genes more than an unaffected person. In the field, I was able to confirm this presumption and answer the following research questions, all of which concern the work of genetic knowledge[12] in the everyday lives of my participants:

- Where do genes fit into participant cosmologies? According to my participants, how do genes work and what do they work on?
- How does knowledge of the underlying genetic component of NF1 impact my participants' perception of the condition?
- Do my participants see their genetic difference as an inalienable part of their individual identity?
- To what extent do people with NF1 partake in biosocial communities *because* of a shared genetic identity (as opposed to shared logistical interests)?

Linking these more-specific research questions are two overarching lines of inquiry:

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[12] For a full explanation of my use of the term "genetic knowledge", please see page 29.

- When are genes seen to be significant?
- When and why do participants choose to avoid thinking about their genes?

Having pursued these questions in the field, I discovered a critical realisation—that genetic knowledge has the potential to be existentially unsettling. That is, when my participants think of themselves in genetic terms, they are pulled out of their usual flow of time and compelled to consider themselves and others as mere individuals within a larger species. Faced with this alienating perspective, my participants have realised their preference for mystery when considering their genetic origin and the future. I must clarify that this finding should not be taken as evidence that my participants did not wish to be informed patients. Far from it. The people I met were far from willfully naïve about the details of their condition. Rather, my participants cultivated wisdom by acknowledging and then eschewing viewing life in genetic, evolutionary terms. In short, by attending to the fallout of genetic introspection, my work ultimately explores my participants' ethical agency vis-à-vis their deliberation over what kinds of knowledge are relevant to their values and ways of seeing the world.

This thesis adds ethnographic detail to Nikolas Rose and Carlos Novas' (2000) discussion of the politics of life itself, namely their idea of a "new molecular optic" wherein people learn to see themselves in genetic terms (2000: 487). At the turn of the century, Novas and Rose argued that individuals have come to "think of themselves as molecular-genetic beings" and "develop[ed] a language to narrate and reflect upon their genetic identity" (Novas & Rose 2000: 487, 503). Rose later expanded on this proposition, reflecting that the "'philosophical status'—indeed the very ontology—of human beings is being reshaped", and as such people are rethinking "what kinds of creatures we are" (Rose 2001: 20). Rose identifies this new molecular optic as a "style of thought" (Rose 2001: 24), and, in an ensuing paper, asserts that in different styles of thought, "certain phenomena are accorded significance, certain things are designated as evidence… a style of thought also embodies a way of identifying difficulties, questioning arguments, identifying explanatory failures and trying to correct them" (Rose 2007: 12). To borrow Rose's terminology, my project explores how my participants negotiate different "styles of thought"—including a style of thought within which people see themselves in terms of their genetics, and another style of thought in which people exist beyond or before their genomes.

That being said, my purpose has not been solely to test Rose and Novas' theorisations against ethnographic evidence. The main purpose of this research is to make a theoretical contribution to the discipline of anthropology. I contend that my research findings are important because they provoke a productive discussion between discourses and subdisciplines in anthropology which are too often discrete. Although my fieldwork focus evidently pertains to the anthropology of medical genetics, I hold that in studying my participants' understandings of genes, I have also inevitably attended to their experiences of temporality—insofar as people anticipate the future and imagine themselves as future ancestors—as well as their ethical life. While threading the links between these two theoretical discourses, I argue that the anthropology of knowledge is an area of untapped potential. Although many academics have accounted for how knowledge is interpreted, translated, and communicated, I agree with the anthropologist Roy Dilley (2010) that few have attended to situations of cultivated ignorance. I contend that attention to knowledge-avoidance practices is of particular importance when discussing a substance as potentially disquieting as genes.

Thesis Outline

The chapters of this thesis are structured around topics—from reflections on cosmology to healthcare experiences—yet each contributes to my overall argument: that the fluctuating significance of genes can be explained by my participants' response to the existentially-upsetting nature of genetic knowledge. Chapter 1 introduces my participants' thoughts on the nature and significance of genes. In this chapter, I utilise reflections on identity formation to canvass the place of genes in my participants' cosmologies. I introduce my participant Zoe, along with her thoughts on the interrelationship between genes, NF1, and her individual identity. I compare her reflections with other participant's gene talk—finding both surprising overlap and interesting divergences. While much of this chapter is dedicated to exploring cases where participants ascribe great significance to genes, I also note situations where genes are eschewed as irrelevant. Most notably, I detail instances of participants abstracting themselves, and future people, from any specific genome. The purpose of this chapter is to highlight the inconsistent significance of genes—even and especially when this inconsistency exists within a single participant's narration.

The fluctuating significance of genes is further explored in Chapter 2, which analyses collective identity practices. I recount the evident desire among my participants to foster community with other individuals who have NF1. NTUK is discussed as an example of such an endeavour, alongside other smaller NF communities encountered by my participants. In this chapter, I go beyond passive commentary on the proliferation of biosocial communities in wake of the Human Genome Project, and instead probe the strength of the foundation of "imagined genetic communities"

(Simpson 2000). I utilise anthropological discussion of ethnicity to unpack how and why individuals might put stock in shared genetic traits. Ultimately, I find that my participants are often left dissatisfied with their NF1 community ventures: many concede that genes are an insufficient or else uncomfortable basis on which to structure a meaningful collective identity. Thus, as with Chapter 1, this chapter demonstrates the tension between lip service paid to the importance of genes, and the reality that genes cannot—or should not—hold that weight that is ascribed to them.

Chapter 3 discusses the false promise of genetic knowledge in clinical settings. I trace my participants' health seeking behaviours—from preparing for doctor's appointments, to conducting their own research online—before bearing witness to their disappointments in medical institutions which cannot provide NF1-symptom predictions or preventions. Rather than making the obvious argument that the NHS is under resourced, I turn my attention away from medical bureaucracy and towards the expectations placed on knowledge. I argue that it is the very promise of knowledge, not just the NHS, which has failed my participants. A considerable portion of this chapter is dedicated to noting the burden of knowledge on my participants, before discussing this finding in tandem to Roy Dilley's (2010) discussion of cultivated ignorance. At the end of this chapter, I posit that it is not just any knowledge which has caused my participants distress, but frustratingly partial *genetic* knowledge.

Whereas Chapters 1 and 2 trace the fluctuating relevance of genes to everyday life, and Chapter 3 discusses the limited utility of knowledge, Chapter 4 addresses my participants *response* to such knowledge. In this chapter, I argue that genetic knowledge is particularly promising and upsetting because it disrupts normal temporality and initiates existential introspection. I reflect on how partial genetic knowledge in the present tempts parents to focus on their young children as future ancestors. I contend that my participants' discipline—what I describe as their 'temporal discipline' in the face of the temptation to imagine the genetic future—demonstrates their agency in managing the impact of genetic knowledge on their daily lives. Thus, in response to my overarching research question, I find that genes fluctuate in relevance because (a) genetic knowledge is unsettling, and (b) my participants accordingly negotiate when, and when not, such knowledge is worth their time.

In addition to temporal discipline, my participants also negotiate the significance of genetic knowledge when considering different outlooks on life itself. This is the focus of Chapter 5. I detail my participants' various thought management practices—from dismissing thoughts with which they do not agree, to their ability to hold two "parallel truths" at once. I consider two potential explanations for this epistemological self-awareness and flexibility—including an explanation based on therapeutic motivations, and another on the role of etiquette and maintaining social norms—before presenting a more holistic account of my participants' decisions. I argue my participants' response to genetic knowledge should be analysed as ethical action. Specifically, I contend that in deliberating between different outlooks on life itself, my participants enact ethical work on their own thought practices, (rather than on their actions per se.) Within this unpacking, I draw on theorisation made by theorists in the anthropology of ethics, along with insights made by Anne Kerr and Sarah Franklin on genetic ambivalence (2006). Ultimately, in response to my overarching research question, I synthesise my findings as follows: that to explain the fluctuating relevance of genes in my participants' lives one must attend to people's decision to avoid a genetic optic. In my conclusion, I locate my findings—on my participants' conscious decision to refrain from ascribing significance to genes in certain contexts—within and beyond anthropology.

Literature Review

I have deferred my literature review until now for two reasons. First, I hold that only after detailing the aims of this project is it possible to precisely situate my work within existing literature. Secondly, I intend to use this contextualisation to further clarify the purpose and novelty of this project. To begin, I turn to not-so-distant history. Whilst this project principally stems from later anthropological work in "the long shadow of the Human Genome Project"[13] (Santos and Maio 2011: 32), it is relevant to note the "longstanding and continuing collaboration between the social scientists and specialists in genetic medicine" (Featherstone 2006: viii). Despite more recent commendable collaborations between genetics and anthropology,[14] physical anthropology has historically used genetics to underpin racial serology amongst other dangerous and flawed arguments (Marks 2012: S162). Authors such as Alison Bashford and Philippa Levine go so far as to posit that all early anthropology, including its predecessor ethnology, was inextricably linked to the intellectual environment that allowed for and encouraged the development of eugenics (Bashford & Levine 2010: 56). Whilst modern medical genetics has disassociated itself from "earlier twentieth-

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[13] The Human Genome Project was a collaborative international effort to determine the order of base pairings in the entire human genome. The project began in 1990 and declared a success in 2003, although it was not until 2022 that the first "truly complete" human genome was sequenced (NIH 2022).

[14] Many are keen to praise medical anthropology's use of both human and microbial DNA to predict health outcomes as early as the 1970s (Singer and Baer 2007: 19).

century eugenic projects" (Shaw 2018: 2), anthropology is—or ought to be, as posited by Marks (2012: 395)—engaged in continual acknowledgement and rectification of its history.

In addition to the ethical imperative to acknowledge this dark history, it is also of relevance to my project to be alert to these historic logics and their contemporary iterations. Bashford and Levine define eugenics as the desire to "affect reproductive practices" through the application of "theories of heredity" (Bashford & Levine 2010: 4). This can involve preventing life, bettering life, generating life, and ending life. According to Bashford and Levine, the core, flawed, evaluative logic of all eugenics movements is that "some human life [is] of more value—to the state, the nation, the race, future generations—than other human life" (2010: 4). While early eugenicists such as Galton were unaware of the complexities of molecular science, contemporary authors note that genetics is furnishing these old prejudices with a new language (Nelson 2018: 524; Roberts 2011: 57). It is thus important to be mindful that contemporary people living with known genetic differences may face the legacy of eugenics when they are called justify their existence and the existence of future people like themselves. This prejudice certainly continued to affect the lives of my participants, as will be discussed in the body of this thesis, especially as they introspected on their reproductive decision making with an autosomal dominant condition.

More recently, advances in technology and medicine—such as the availability of new reproductive technologies, and the popularity of genetic tests for personal use—have encouraged the study of genetics from a sociocultural perspective. In an account which traces "the crossroads of genetics and anthropology over the last century", Marks asserts that "the value of anthropology for contemporary genetics probably resides strongly in helping to explore the cultural assumptions that inhabit the production and interpretation of [genetic] data." (Marks 2012: 170) There is a wealth of such literature. A sizable body of research is dedicated to utilising technological advances to revisit and transform historic anthropological interest in kinship.[15] To consider just a few examples of such ethnographic research, there is Kaja Finker's (2002) work on how the tracking of genetic histories for medical purposes leads to the medicalization of kinship in the United States; Katie Featherstone's (2006) study of family responses to the revelation of genetic risk; Rayna Rapp's (1999) monograph on gender and prenatal testing; as well as Heath, Rapp, and Taussig's unpacking of how families with "genetically defined

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[15] Whereas some anthropologists claim there has existed an uninterrupted anthropological interest in kinship, others credit advances in science and technology as the source of revived interest in kinship (Clarke 2008: 153).

syndromes" rethink their genealogical relationships in light of new genetic information (Heath et al. 2001: 385). This list is by no means exhaustive. Rather, it serves to demonstrate the range of work that has been conducted into how the meaning of genes affects familial dynamics, decisions, and conceptions of relatedness.

Beyond studying genetic conditions vis-à-vis kinship discourse, other anthropologists have attended to experiences of genetic conditions among specific ethnic groups. To give a few examples, Alison Shaw (2009) explored how physicians and British Pakistani parents diverged in their understandings of genetic inheritance and risk; Santi Rozario (2013) and Sophie Gilliat-Ray (Rozario & Gilliat-Ray 2007) studied how British Bangladeshi families came to make decisions about genetic disorders in relation to their Muslim faith; and Karen-Sue Taussig (1997) investigated how an ethnic-religious sect of Christians in the Netherlands interpreted genetic conditions as the will of God. In these cases, each researcher studied a range of genetic conditions given the presence of multiple dominant and recessive conditions present in any given population.

The work my project most directly associates with does not focus on family or ethnic groups per se—although family dynamics and ethnic identity of course inform the experiences of my participants—but rather centres on a single health condition in an otherwise unrelated group of people. An example of such work includes Heath, Rapp, and Taussig's discussion of genetic citizenship in the context of dystrophic epidermolysis bullosa activism and the ensuing "kinship of affliction" (2001: 155). I should stress that my project is not the first anthropological work to focus exclusively on biosocial neurofibromatosis groups. Joan Ablon conducted extensive ethnographic research on people with NF1 in the United States in the 1990s. In her monograph, *Living with Genetic Disorder: The Impact of Neurofibromatosis Type 1* (1999), Ablon unpacks the impact of stigma—as theorised by Goffman (1963)—on the lives of the 54 adults she interviewed with NF1. Ablon breaks down her analysis into discrete chapters structured around topics in participants' lives, from school years to employment to marriage. She uses extended quotes from her subjects to give a detailed account of life with the condition, and asserts this ethnographic data underpins her previous argument (Ablon 2012: 674), that NF1 is upsetting because of anxiety over the possibility of disfigurement, an anxiety which is not helped by the misconception that NF1 was the affliction of the Elephant Man (Ablon 1995).

Ablon has received well-deserved praised. In a *Medical Anthropology Quarterly* edition dedicated to her life work, it was asserted that "she is one of the best examples of those anthropologists who focus on what U.S. society considers a single impairment disability, as opposed to a cross-impairment-disability perspective" (Shuttleworth and Kasnitz 2004: 143). What is more, Ablon has inspired future generations of anthropologists and sociologists to focus on NF1. Both Santi Rozario and Daniele Carrieri—whom I draw on in my discussion of NF1—make specific mention of Ablon as a crucial forerunner for their respective works (Rozario 2007: 552; Carrieri 2011: 9). Ablon's writing is evidently commendable—which should come as no surprise since her research stems from a rich history of anthropologists studying the impact of genetic conditions on family life, ethnic identity, and patient group formations.

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Given the extent of ethnographic research on genetic conditions, and the fact that NF1 has been previously studied by anthropologists, how then does this project make a new contribution? It is here pertinent to note some of the limitations of this previous research. Ablon's work, although praiseworthy, rarely engages with anthropological theory. She is happy to concede policymakers and clinicians, not academics, are the intended audience of her work. In the preface to her monograph, Ablon notes that "there is no book that health care or social service providers or affected persons and their families can read [to learn about NF1]", and that she intends for her work to remedy that shortcoming (Ablon 1999: ix). While anthropological works are certainly helpful for those outside of the discipline,[16] writing exclusively for non-academic audiences limits the researcher's ability to build theory, construe nuance, and attend to sociocultural specificity. Ablon has been criticized for "never conceptually link[ing] her informants' experiences of stigma with broad and diverse cultural contexts" (Shuttleworth and Kasnitz 2004: 153-154). Moreover, she does not attempt to unpack *why* stigma proliferates within a particular culture and matrix of values. Through her work, one cannot ascertain the meaning of genes to her participants. The only attention to genetics is how participants feel stigmatised by the symptoms of a condition which happens to be genetic in origin. Accordingly, Shuttleworth and Kasnitz call for the use of "new *theoretical* approaches to broaden the anthropological approach" to "impairment disabilities" such as NF1 ([emphasis my own] Shuttleworth and Kasnitz 2004: 153).

Aside from the limitations of Joan Ablon's work, I hold that other anthropologists have not yet exhausted the potential of attending to impairment disabilities with a known genetic basis. To reiterate, clinical decision-making and

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[16] For example, Rayna Rapp's work has been called "important reading for those working clinically or academically in any realm of reproductive health" (Fessler 2001).

experiences of health conditions have largely been studied by ethnographers in terms of the heuristic utility of such data to the researchers' primary interest in understanding family networks and clinical practices.[17] But apart from using genetic conditions as a tool to study different topics in anthropology, what might attention to the genetic dimension of such conditions reveal? In a comprehensive review of the anthropology of biomedicine, Lock and Nguyen (2018) write that although much literature has been dedicated to the "anticipated impact" of genetics on everyday life, work remains to be done:

> A great deal more research is needed before questions about the possibility of a radically transformed subjectivity as a result of knowledge about one's genotype can be answered. The findings to date… suggest that usually it is above all family dynamics and kin relations that influence the way people respond [to genetic screening and testing] … But it remains an open question as to whether information about one's genotype, whether positive or negative, profoundly alters the subjectivity of the majority who are tested, even though a degree of certainty about individual futures may result." (Lock & Nguyen 2018: 318)

This thesis thus responds not only to Rose and Novas' theorisations, but also to the anthropological question "of subjectivity and to what extent individuals may experience themselves as profoundly changed on the basis of knowledge about the genetic self." (Lock & Nguyen 2018: 304) I thus concur not only with Lock and Nguyen but also with Braff ([reviewing Pálsson (2007)] 2010: 277), that to correctly study the "implications of current-day genetics"—on " the cultural logics of genetic knowledge" and our understandings of "nature-culture, the body, kinship, biopolitics" and so forth—it is first necessary to understand the content of such knowledge.

What I am attempting is a contribution through specificity. I identify my work as a response to Katie Featherstone's call for the chronicling of local understandings of genes—what she has termed "ethno-genetic knowledges" (2006: ix). Over a decade ago, Featherstone noted that while "we insist that the cultural bases of ideas about inheritance, health and disease need empirical research across multiple sites and cultural milieu… there remains much work to be done to document the ethno-genetic knowledges of many populations around the world." (Featherstone 2006: ix) I thus identify my project—along with all responses to Featherstone's call—as part of a "set of sub-projects [which] concern themselves with people's views of *what is*." (Carrithers et al. 2010: 160).

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[17] Admittedly some authors in the anthropology of genetics – such as Peter Wade – explain that while they "focus primarily on kinship", such a focus is used as a means by which to access the "broader" significance of genes (Wade 2007: 1-2).

Throughout this thesis I utilise the phrase "genetic knowledge" to refer to knowledge produced – or influenced – by the science of genetics. This is a broad catchment—broader than Featherstone's usage of the term ethno-genetic knowledge—and requires further explanation. A distinction is often drawn between "lay" knowledge and "professional" knowledge of genetics. Lay knowledge, or "public" knowledge (Richards 1996: 249), could also be said to could encompass "folk" knowledge (Friedberg 1999: 2-3, 14-15; Edwards 2014: 57) and knowledge of "traditional" medicine (Shaw & Hurst 2008: 378), since lay knowledge is often defined against formal biomedical knowledge, rather than being an obvious category in its own right. By contrast, professional knowledge of genes—also referred to as "scientific" knowledge (Strathern 2005: 9), "formal" knowledge (Richards 1993: 573), or "biomedical" knowledge (Shaw & Raz 2015: 4)—is narrower in scope, addressing knowledge utilised in institutional education, practice, and outputs. While all these various terms for lay and professional knowledge each come with their own associations,[18] for the sake of focus, (and since the authors I engage with use certain terms interchangeably,[19]) I work with the assumption that the following terms—"lay" and "public" versus "scientific" and "professional"—refer to the same contrast: that is, the contrast between knowledge taught and utilised in western biomedicine, and the knowledge which concerns all people's reflections on inheritance, descent, kinship, and relatedness.

While there are certainly benefits to understanding how lay and professional forms of knowledge differ from each other,[20] I contend it is also important to note that both are influenced by cultural and personal contexts – with professional knowledge being no 'better' than its lay counterpart. To explain this stance, I first discuss how lay knowledge should be understood in its social context – such that its divergence from

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[18] While the terms folk knowledge and traditional knowledge are used in a nuanced manner by the authors referenced in this section, authors outside of the anthropology of genetics utilise such terminology in a markedly different manner – for instance, Atran looks at "folk biology" to explore "cognitive universals" (Atran 1998: 569), while Rozenblit and Keil dismiss "folk science" as "fragmentary and skeletal" when compared to biomedical explanations (Rozenblit & Keil 2002: 522).

[19] Martin Richards discusses both "the public's knowledge and beliefs about inheritance" (1996: 249) and "widely held lay beliefs about inheritance" (1993: 567) interchangeably.

[20] For instance, there is an array of insightful literature on professional versus lay knowledge transmission. For an ethnographic account of how expert knowledge is taught, see Shaw's (2003) work on how medical students learn to identify the facial dysmorphology of genetic conditions. Regarding lay knowledge of genes and beliefs about inheritance, authors such as Martin Richards note that these "are [largely] transmitted within families" (Richards 1993: 579), as will be discussed presently in my next paragraph.

professional knowledge is no longer always seen as a shortcoming. I then discuss the ways in which professional knowledge is also influenced by culture. Finally, I offer insight into why I have chosen to explore both professional and lay knowledge at once in my thesis – and accordingly use "genetic knowledge" as a catch-all term.

Martin Richards has provided detailed consideration on the creation, content, and social function of lay knowledge of genes, which he sees as always entangled with "lay beliefs about inheritance" (Richards 1993: 579). He criticises genetic counsellors who see their clients' "ideas about inheritance… as unscientific or irrational" (Richards 1993: 576). He instead cites previous research (Davison, Frankel & Smith 1989 in Richards 1993: 577-588) which demonstrates that lay accounts of inheritance often "owe little or nothing to any ideas from scientific genetics. Indeed, [such beliefs] probably serve quite different purposes in families: to 'place' individuals through their physical features and other characteristics within lines of descent and to build their identities as members of the kinship" (Richards 1993: 578).[21] Richards thus argues that lay people's knowledge should not be understood as ignorance to (or miscomprehension of) formal biomedical knowledge. In fact, he posits that when genetic counsellors fail to appreciate how "people may have pre-existing beliefs about inheritance"—and thus fail to understand the social function of knowledge (such as 'placing' a child)—these professionals remain ignorant of the social forces which "determine their [clients'] whole attitude to genetic services" (Richards 1993: 577).

On the nature of professional knowledge, Richards highlights how scientists also bring their own motivations and assumptions to the creation and transmission of knowledge. Richards outlines that from the perspective of a social scientist, "the concept of an exchange between a professional and a client in which the professional is simply a neutral provider of information is implausible" (1993: 581).[22] Richards holds—and I concur—that no knowledge is objective. All humans interpret and utilise

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[21] In a later publication, Richards (1996) revisits this argument, referencing both his professional and personal experiences. He writes that the way "family members greet a new baby demonstrates the important process of 'placing' the new baby in terms of characteristics shared with forebears… [In my own family,] I am said to get my nose from my mother's family but have a temperament more like some of my father's male relatives." (Richards 1996: 249)

[22] Richards later underpins this argument when reflecting on the following pattern: "[when] a disease is female and inherited, such as some cases of ovarian and breast cancer, the emphasis on female members of the kinship is such that both the professionals involved and lay family members may fail to consider kin members who might have inherited the gene mutation via a father" (Richards 1996: 261).

knowledge according to their cultural-cum-personal contexts. In the following excerpts, which Richards' directly references (Strathern 1992 in Richards 1996: 267), Marilyn Strathern describes how knowledge is interpreted according to cultural schemas and associations:

> Culture consists in established ways of bringing ideas from different domains together, [always with the potential for new combinations] …
>
> [In cultural life] the ideas that reproduce themselves in our communications never reproduce themselves exactly. They are always found in environments or contexts that have their own properties or characteristics… opportunity, class, gender, expertise and so forth [affect] how the world is perceived… Natural association means that ideas are always enunciated in an environment of other ideas, in contexts already occupied by other thoughts and images. Finding a place for new thoughts becomes an act of displacement. (Strathern 1992: 3, 6)

As a final observation on the cultural embeddedness of scientific knowledge, and to bolster my reliance on Richards, I draw on Friedberg's observation that "the divorce between folk and scientific knowledge appears most clearly" when we consider how "each person conceives his own insertion within the framework of the relations with his peers and with the world" (Friedberg 1999: 14-15). Her paper—on what anthropologists can teach other academics—argues that knowledge becomes lay or professional not because of its accuracy, but because of the kinds of knowledge certain people are expected to know to fulfil their personal and professional obligations. In review, in detailing both the social function of lay knowledge and the cultural embeddedness of scientific knowledge, my intent has been to demonstrate that the purpose of knowledge differs depending on its context – be it to obtain status in a professional field, to practice medicine, or to negotiate one's place (and the place of others) in a matrix of kin. Lay knowledge is not a poor interpretation of professional knowledge, but rather, each serves a specific purpose.

In my own research, I interviewed both professionals (including specialist doctors, general practitioners, physical therapists, nurses, and genetic researchers) as well as people outside of the medical field. However, the boundaries between these two categories were not always salient. Regarding my lay participants, they were often vivacious readers of medical journals – such that even though they were never formally employed or trained in biomedical institutions, they still had access to professional knowledge (please see page 100 on participants' collection of medical knowledge). By characterising my project as an investigation into all forms of knowledge about genes, I wish to acknowledge that both scientific and lay knowledge of genes is value laden and culturally embedded,[23] while also highlighting that the line between expert and lay is often blurred in the context of NF1 since patients are so often as informed as their own doctors. As a separate and final point, I should note that I am also interested in my participants' own reflections on the nature of knowledge. In this thesis, my participants and I both considered questions such as whether there is a limit to knowledge's utility, whether certain ways of describing genetic conditions are helpful, and whether having a personal health issue affects one's professional medical practice. Rather than prescriptively categorising my fieldwork data in terms of lay and expert knowledge, I find it more interesting to consider how new knowledge of medical genetics is always interpreted according to personal and cultural factors—such that the line between lay and professional becomes trivialised—while also prefacing my participants' thoughts on the nature of knowledge. I thus wish to close my explanation of my use of the term "genetic knowledge" with the following quotes:

> The public's knowledge and beliefs about inheritance have not arisen de novo with the coming of the new genetics, or even with Mendelian genetics at the turn of the century: they have long been part of family culture. (Richards 1996: 249)
>
> [The] more (Euro-)Americans learn about the biological facts of procreation, the more they feel informed about the facts of kinship… [this was] Schneider's 'key perception about the relation between scientific knowledge and kinship'. (Strathern 2005: 9)

Returning to the question of what my research adds to existing literature, I hold that my work is important not only because it pays attention to the content of genetic knowledge, but also because I heed the advice of experts to attend to the fluctuating significance of genes. According to Weiser, "whether geneticization has happened or not, people come to think about their life (and that of their children) in genetic terms only in very specific situations" (2017: 75). The anthropologist Gísli Pálsson pre-empted this observation, noting that "although the gene is a central element in both biological theory and public discourse", it appears to be a "boundary object" insofar as the meaning ascribed to genes seems "fuzzy", imprecise, and variable (2007: 212-213). My project responds to these recommendations by attending not only to the content of gene talk, but also to fluctuations in the significance of genes and genetic explanations.

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[23] I have established the cultural embeddedness of such knowledge in my previous paragraph but wish to add that I am also drawing on the example set by Santi Rozario. During her research into experiences of NF1 in the United Kingdom, Rozario noted that although "what is true of the United States is largely true of Britain as well", each participant has a different "moral imperative because of her culture" which colours their experience of NF1 (Rozario 2007: 553, 558).

To close this literature review, I wish to make a few remarks on my anthropological approach. Whereas academics have debated whether the new genetics has ushered in an era of genetic determinism,[24] genetic reductionism,[25] or gene fetishism, I am primarily interested in my *participants'* thoughts on the transformative power of genetic knowledge. I would thus characterise my anthropological approach as tantamount to Karen Blu's (1980) approach to ethnicity, in that we are both more interested in our participants' theorisations than in entering the field site with the intent of pushing any one theoretical perspective.[26] In her twentieth century research among the Lumbee Native Americans, Blu did not seek to use her fieldwork to bolster definitions of ethnicity from esteemed theorists such as Barth, but instead sought to understand her participants' own conceptualisations of ethnic identity. Marcus Banks (1996: 39) summarised Blu's position as such:

> She states that it is… self-perception that should concern the analyst (1980: 2, 228) … she is concerned with the sense in which [her participants] see their ethnic identities as being deep-rooted and linked to their sense of their own history and to folk conceptions of biology.

I aim to emulate Blu's approach by taking my participants' theorisations—on the nature of genes and their fluctuating relevance—seriously. As will imminently be detailed in my methodology section, I chose to focus on ethnographic interviews as a "means of getting at how respondents understand, interpret, and observe the social processes in which they are embedded. Those revealed observations (found in interviews) can be just as meaningful as the ethnographer's own" (Rinaldo & Guhin 2022: 53).[27] In review, I contend that my work offers a fresh perspective to an established anthropological interest in genetics because it attends not only to the fluctuating relevance of genes, but also to my participants-as-agents who negotiate and reflect on the significance of genes to their lives with genetic difference.

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[24] Genetic determinism, also known as biological determinism, is defined as "the idea that an individual's personality or behaviour is caused by their particular genetic endowment, rather than by social or cultural factors" (Chandler and Munday 2011).

[25] Genetic reductionism, judged by some as an equally "counterfactual" approach to human behaviour as genetic determinism, is defined as "the idea that an understanding of genetic influences is all that is needed to understand human behaviour" (Lerner 2015: 178, 180). In review, "[Genetic] determinism refers to causality—what has caused this to occur—while reductionism is concerned with what we need to study in order to understand something fully." (Hayes and Stratton 2018: 138)

[26] That is not to say that I am uninterested in anthropological theory. Far from it. I have only just detailed how I differentiate my work from Ablon's based on my interest in anthropological theory and discourse. Instead, I wish to emphasise that I entered the field without a theoretical agenda, and, only after having understood my participants, did I finalise which theoretical approaches to utilise and develop in my analysis.

[27] To reiterate, I do not see my participants as co-theorists. I do, however, see their perspective and reflexivity as the central interest of my project.

Section 3: Method

"Focused ethnographies", as defined by the sociologist Sarah Stahlke Wall (2015), involve entering the field with formally specified research questions. She distinguishes this method from the limits of traditional ethnography, where researchers tend "to begin the project with no prior conceptions of the field and letting the setting tell [them] what's going on" (2015: 14). Since people with NF1 are largely isolated from each other, and because this project has specific questions pertaining to the meaning of genes, this project draws on Stahlke Wall's recommendations of making adaptations to "traditional" ethnography to optimise the workability of research. This project also draws on Marcus' (1995) recommendation of using a "multi-sited" ethnography to circumvent the "traditional overreliance on a bounded, territorially based, and supposedly homogeneous entity—whether a culture or a society—as a field or even as a unit of analysis" (Marcus 1995 in Boccagni 2016: 4). Such an approach was moreover helpful during the Covid-19 pandemic when the feasibility of in-person research was ever uncertain. Given my deviations from more traditional ethnographic practice—deviations which will be canvassed in this section—it is fair to say that this project is somewhat unorthodox in its methodology.

To review, during the beginning of this project—when social distancing measures prevented in-person research—online ethnographic interviews were the primary means of data collection. The definition of an "ethnographic interview" is contested. I use the formulation offered by the sociologists Bauman and Adair, which is here summarised by Rinaldo and Guhin (2022: 48):

> Bauman and Adair (1992) propose that the ethnographic interview is defined… by particular characteristics, including being unstructured and open-ended, collecting descriptive data and focusing on everyday experience, aiming to understand the informants' experience from his or her point of view, and treating the informants' language as data.

In such interviews, participants can offer narratives—including life histories, narrations of events, illness narratives, and the performance of narrative reasoning (Mattingly 1998)—as well as opinions, hypotheses, and philosophies. In this way, interviews are apt at accessing what Rinaldo and Guhin (2022: 37) categorise as "declarative culture"—that is, what participants can articulate about themselves and their worlds. In addition, ethnographic interviews can access more subtle behaviour, such as "certain speech norms [as] habituated practices" (Rinaldo & Guhin 2022: 36, 56). It is this variety of available data which leads Wuthnow (2011) and Pugh (2013: 51) to conclude that ethnographic interviews should be understood as social encounters in and of themselves.

In addition to the content of ethnographic interviews, I also gathered contextualising information throughout my fieldwork. Geertz (2008) asserts that interviews only become anthropological[28] with sufficient "local knowledge". According to Rinaldo and Guhin's summary of Geertz' perspective, such contextualising knowledge can include, but is not limited to:

> Gossip from other informants, social media postings or interactions, texts produced by or that are related to the informant… knowledge of the cultural schemas or scripts used or referred to by the informant, and observations and more general knowledge about the immediate … organization, or spatial location. (Rinaldo & Guhin 2022: 47)

For this project, I was fortunate to have access to each facet of this contextualising information. In interviews, participants frequently referenced or described other participants in my research. In between meetings, I inspected a wealth of online data—and was impressed by the breadth of content available on NTUK's website. On their webpage, I accessed recorded lectures on NF1 given by medical professionals, long-running blogs by people with neurofibromatosis, testimonials on the impact of NTUK, and informational pamphlets targeted at every profession, age, and demographic. To compare the style and tone of NTUK's online presence with other similar platforms, I regularly visited *Inspire's Neurofibromatosis Network*, an open access online forum, the neurofibromatosis subreddit;[29] public Facebook pages for people with NF1 and their supporters; and the websites of similar organisations such as *The Children's Tumor Foundation* and *NF Midwest*.[30]

To further furnish my understanding of NTUK as an organisation, whenever possible, I remotely engaged in their day-to-day activities. This included helping the office team proofread features for their magazines, and tuning into awards ceremonies and lectures when NTUK was featured. In terms of gathering contextualising information on individuals who were not employed by NTUK, several participants invited me to connect on social media—including Instagram and Facebook. I read numerous books referenced by participants in our calls, including a published autobiography written by a participant with NF2. A few key participants even entrusted

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[28] While I draw on methodological recommendations made by sociologists, I attest that my project remains anthropological because of this contextualisation, and because of my contribution to anthropological theory within the "larger culture project" of the discipline (Carrithers et al. 2010; Ingold 2014).

[29] https://www.reddit.com/r/neurofibromatosis/

[30] https://www.ctf.org/; https://www.nfmidwest.org/

me with diary entries—allowing an intimate perspective into their everyday reflections. Finally, in terms of "knowledge of the cultural schemas", I did have a certain degree of "shared knowledge"—to use Rozario's (2007: 553) term—with my participants as an anthropologist conducting research 'at home' in the United Kingdom. In line with Eliasoph and Lichterman's assertion that talk is never "cheap" when it has a context (2003: 743), I hold that my interactions were deeply informative because they were thoroughly contextualised.

My initial reliance on interviews could be critiqued by pointing to inevitable divergences between speech and action, or by asserting that a culture cannot be accounted for by talking to discrete individuals. In response to these critiques, I wish to reiterate the aims of this project. I did not seek to detail a singular culture nor paint a uniformed picture of life with NF1 in the United Kingdom. I was moreover uninterested in criticising any inconsistencies in my participants' narrations. Instead, my very purpose was to attend to any irregularities in my participants opinions on the significance of genes. To demonstrate the candid and reflexive nature of my encounters, I can point to the fact that on multiple occasions, my participants wished to reflect with me on *why* their actions did not always match their opinions or values.[31] I do not believe my participants never lied or exaggerated. However, I concur with Pugh that any inconsistencies or limitations from ethnographic interviews are good insofar as they offer "intriguing paradoxes" for the anthropologist to explore (Pugh 2013; Rinaldo & Guhin 2022: 55). To quote once more from Rinaldo and Guhin (2022: 58), "the difference between attitudes and behaviour goes from being a problem to being data; in some contexts, it might even be the goal."

Interview Technique

The interviews I conducted were largely open-ended. Participants were free to discuss whatever came to mind, NF1-related or otherwise. For example, Stewart would keep me updated with the fortunes of various local bakeries as they navigated the pandemic-induced produce shortages.[32] Participants were also encouraged to raise points of discussion. One asked why I had yet to broach the subject of pain—an oversight of mine which I am glad she corrected. Others challenged me on why I was asking certain questions or would test and correct me on my knowledge of NF1. This

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[31] For example, several participants noted that although they dislike new technologies preventing the birth of people with NF1, they themselves opted to not have biological children because of the risk of the child inheriting NF1.

[32] Our "snack breaks"—where we would simultaneously enjoy tea and cake—were coincidentally often the most candid and informative moments of our meetings.

flexibility and the equal footing I had with my participants evidently went beyond what would be expected in a more clinically oriented study.

Be that as it may, I also went into each interview with a preplanned structure. These notes could be relied upon if a new participant was shy, or if an established participant had nothing pressing on their mind. With new recruits, after oral consent was obtained, interviews commenced with the following set of questions:

- Do you have any physical NF1 symptoms?
- When were you first diagnosed with NF1? Did the diagnosis come as a surprise to you/your parents?
- Can you tell me a little about yourself, such as your age, the region you grew up in, where you've lived, and what you do?
- How do you explain NF1 to friends and coworkers?
- Have you ever heard someone talking about NF1—or read online comments about NF1—which you thought were unhelpful or misleading?

These questions were designed to put participants at ease. I discovered at the beginning of my fieldwork that if I opened with more informal questions, such as, "tell me about yourself and your life", people were uncomfortable and not so forthcoming. I should note that not all participants were asked the same set of questions. Before each interview, I conducted preliminary research. Based on the participant's profession and according to the degree of their openly accessible online presence, I catered questions to their interests and expertise. This preparation was particularly important when conducting interviews with medical professionals such as nurses, doctors, and NF1 clinical researchers. Moreover, I would adapt questions according to the flow of discussion. I should also note that on multiple occasions, I returned to previous points of discussion or asked participants to elaborate when they were speaking directly to a research question.

During interviews, participants were also free to share non-verbal data. Oftentimes participants opened interviews by describing the scene behind them on their video. To give an example, my participant Zoe opened our first call by explaining the low-hanging wooden beams I could see behind her. She elaborated that the house—and attached farm—had been in her husband's family for generations. Despite the fact only audio recordings—not video recordings—were stored from interviews, having this glimpse into the physical surroundings of participants was enriching. Moreover, numerous participants held up objects—such as football jerseys, photographs, crafting projects, and books—to their computer camera to furnish their stories and descriptions. What came as a surprise was the frequency with which participants would show me their own body when asked to explain NF1 or their experience with the condition.

Participants were often quick to offer to send pictures of their neurofibromas, or a series of images to illustrate their recovery from a surgery or the progression over several decades of their physical symptoms. In addition to photographs and visual demonstrations, participants would frequently send scans of fundraising pamphlets or doctors' letters when they felt it was relevant.

Most interviews lasted between one and two hours. On occasion, calls were as short as 40 minutes or as long as four hours. Most calls were performed over the videoconferencing platform, Zoom. When the Wi-Fi connection was insufficient, or upon participant request, calls were conducted over mobile and landline phones. In terms of in-person interviews, one occurred in a participant's home in London, and one was conducted in a café in Leicester. These interviews occurred alongside participant observation at various fundraising and community events. In summation, on balance, I would characterise my style of interviewing as an admixture of open-ended discussion with pre-planned, focused questions. Although I did revisit topics of conversation which were of direct relevance to my research questions, for the most part, interviews were largely participant-led.

Data Analysis

Interviews were analysed as ethnographic encounters. I have not used scraping nor coding to analyse my data. Instead, I made physical notes during as well as after each interview. I wrote down the main points of discussion, and the tone of the interaction—such as whether the participant was nervous, when they were talkative, and how willing they were to steer the direction of conversation. If there was a particular line of dialogue which struck me as revealing or unexpected, I would go back to the audio recording and transcribe the dialogue verbatim. However, few interviews were transcribed in their entirety. Those that were transcribed, or partially transcribed, were chosen on the basis of speaking directly to research questions or were transcribed because they were conducted with key participants.

Separate to this thesis, I may perform basic data processing to identify patterns should NTUK be interested in such information. For example, I may look at the correlation between people being told they had NF1 at a young age—as opposed to finding out in early adulthood—and people being well-adjusted to the condition later in life. Ablon concluded her monograph on NF1 with a detailing of these of correlations (1999: 143-153). However, in this thesis, it is not in my interest to point to the causation of behaviour. To reiterate, I am interested in what my participants think. Moreover, I do not presume to know or make speculations on the psychological state of my participants according to biomedicine—as both Ablon (1999: 103) and Rozario (2007: 554) have done in their assertions on the internalization of stigma, and the causes of anxiety in people with NF1. I identify myself as a social anthropologist. I understand these interviews to be encounters*,* in which the participant and I explored their cosmological reflections, their imagination of community, and their ethical deliberation, among other themes. In short, I do not want this thesis to be understood as anything other than a study of a loosely defined biosocial community with the purpose of contributing to sociocultural anthropological knowledge. I accordingly do not include any quantitative analysis or causation speculations. Figures are only offered in the next section to illustrate the scope of my sample—they have not been calculated to serve arguments.

Demographics of the Sample

Despite having over 50 participants formally taking part in this research, it cannot be claimed that this sample is representative. All but one participant was sourced through NTUK, meaning that people uninvolved in NF1-communities are underrepresented. More women than men took part, with 38 and 18 participants respectively, despite the fact NF1 affects men and women in equal numbers (NORD 2023). Participants were overwhelmingly middle class. Based on occupation, parental occupation, and location—facts which were established over the course of the interview, rather than through a questionnaire—19 participants could be described as lower middle or working class, 30 could be described as middle class, and seven could be described as upper middle or upper class. Participants' ages ranged from 17 to 79 and skewed towards the younger age range. Participants in their 30s and 40s were overrepresented compared to other ages. The ethnicity of participants was as follows: two were South Asian, one was Black, and 53 were white—of which one was Jewish. Overall, 35 participants had NF1, two participants had NF2, six participants were unaffected mothers of a child with NF1, and 13 participants were unaffected NTUK employees or NF1 researchers—one of whom had a son with neurofibromatosis.

Data Management

In all remote-interview situations, audio recordings were made using Zoom and stored on an encrypted computer and hard drive. In this thesis, most participants have been given pseudonyms. In a limited number of cases, participants have requested further anonymity due to their employment. Moreover, several participants have asked that their real name be included in research outputs. When conducting interviews, physical notes were taken without any identifying information included in the notebook.

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To summarise my method, this project can be characterised as a long-term engagement with a biosocial NF1 community over a year and a half of fieldwork. I conducted numerous, lengthy online interviews with the individuals in my study which constituted direct participation even before I entered the physical field. In the latter half of my project, I was able to participate in various NTUK in-person fundraisers, as well as meeting with key participants in their homes and local surroundings. My methodological focus on interviews within a multi-sited ethnography is well-suited to my interest in the significance—or lack thereof—given to genes by my participants. As such, my methodology can be underpinned by the following logic:

> Young (2006) argues that because ethnographic interviewing is a method that attempts to discern what people know and think about themselves and their social worlds, it is particularly well suited for investigating "what people articulate as their own understanding of how social processes work and how they as individuals might negotiate the complex social terrain rather than simply looking at their actions." (Rinaldo & Guhin 2022: 49)

Introducing My Key Participant: Stewart

I have decided to close this chapter by introducing my key participant, Stewart. He was the participant I came to know best, and his reflections have helped form the backbone of this project. Moreover, my hope is that this brief ethnographic portrait can serve to evidence the nature and breadth of content covered during my regular calls with key participants, as well as the differing ways in which NF1 can present over the course of a lifetime. For Stewart, his symptoms of—and experiences with—NF1 have shifted over the decades. Stewart is in his early seventies. He is a retired nurse who lives in Bristol, a city in the southwest of England. His politics, language, and energy seem more in line with a young undergraduate student than with what some might expect from an upper-middle-class white man raised in the 1950s. Passionate about transgender rights, young adult literature, and the right-to-die movement, Stewart is kind, quick-witted, and—as I increasingly appreciated over the course of my research—exceptionally wise. Stewart's diagnosis of NF1 seems the least interesting facet of him, although it is perhaps the first thing you will notice upon meeting him.

Stewart has numerous benign neurofibroma tumours, including many on his face and neck. He is more than aware of stolen glances from strangers. He is far fonder of outright questions posed by young children who are open and—in his opinion—innocent in their curiosity about his visible difference. "Why do you have bumpy skin?" and "what do your lumps feel like?" are inquisitions frequently fielded by Stewart. In one of our earlier meetings, he joked to me, “how do you explain clinical genetics to a four-year-old?” It struck me that Stewart was, in fact, more than adept at explaining his neurofibromatosis to children and adults alike. “I was born different”, he explains to young children. To slightly older children, he might describe genetics by referencing eye colour: “we all have recipes that make us, *us*. Your recipe gives you green eyes, and my recipe gives me these spots on my skin. That’s why you can’t catch my lumps, they’re unique to me.” One could attribute Stewart’s communication skills to his decades as a paediatric nurse. A substantial portion of his job was explaining complex conditions to scared parents and—in his mind—too-often-belittled children. However, my inference is that it is not simply his career which enabled such clear explanations about his NF1. Stewart’s introspection, candour, and humour are all his own.

In my first interview with Stewart, he explained that he wanted to contextualise his current opinions and outlooks by first describing his history of NF1 symptoms. He began with his first memories. As a young child, Stewart underwent surgeries to improve the function of his leg—as his NF1 had caused a bone abnormality. Stewart told me most of his first memories involve staying in the local hospital, frightened, while recovering from operations. On the one hand, Stewart was grateful. He received a bone graft—a new technique which prevented the default protocol of leg amputation. He was moreover thankful for the nurses. He remembers their friendliness and their allowance of unusually generous visiting hours. Be that as it may, Stewart was still lonely. The hospital was 15 miles away from his house. While that distance may not seem dramatic by contemporary standards, Stewart explains that in rural Kent during the nineteen-fifties, that was, “a long way away”. His older sister, Linda, would visit him during his recovery—looking at him through a glass window, as per hospital policy. Linda later explained to Stewart that she wanted to look to be sure “that you were really still alive”. Even though doctors were able to improve the function of his leg, he still walked with a limp and could not fit into normal shoes—much to his dismay as a school child since he wore different shoes to his classmates.

In addition to this visibly apparent symptom of NF1, Stewart’s school years were further complicated by cognitive differences. Stewart has dyspraxia, which he locates as stemming from his neurofibromatosis. He explained to me that while he enjoys excellent hand-eye coordination, he has always struggled with fine motor control. Linda also had neurodivergences associated with NF1 which became apparent during her school years. Yet despite the fact these two siblings inherited the same NF1 difference, their cognitive complications were markedly different. In Stewart’s own words:

> Her handwriting was impeccably neat. But she couldn't catch a ball to save her life. And yet, when I used to play cricket with my friends out in front of the houses, I was the one who would stand very close to the batsman. I could catch a ball just like that! [Our NF1 affected us in very different ways.]

Stewart later elaborated:

> My handwriting was messy. It's better now, but it's still very effortful. I can't draw and I can't make tools work for me. What tends to happen is that people will say [about a certain DIY task,] "It's perfectly easy. All you need to do is this." And my reply is, "No. It might be very simple, but it's not easy." It's like, I know I have to put the screwdriver in the slot of the screw and turn it like that. Yes, that's *simple*, but it's not actually *easy*.

Over the years, Stewart has learned to make adjustments in order to play to his talents and work around his limitations. He has excelled in his demanding nursing career. He jokes that he is still learning to optimise his neurodivergence. For instance, following the rise of video-calling during the Covid-19 pandemic, Stewart moved and reorganised his desk to minimise distractions. My impression is that Stewart is confident in his intelligence and accordingly comfortable asking for any adjustments—such as requesting I repeat or clarify a question during our meetings.

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After explaining the limited use of his leg, his cognitive differences, the neurofibromas he has had removed, and his more recent digestive issues, Stewart was then keen to narrate the psychosocial impact his upbringing had and continues to have on his sense of self. Stewart claims that despite his struggle with various physical symptoms of NF1, what has been far harder to live with are the unkind attitudes of various people, including his mother. Stewart laments that he was the "wicked messenger" to her. Through Stewart's NF1 diagnosis, both his mother and older sister were identified as having the same genetic condition. Despite the fact genetic testing for NF1 was not available at the time, Stewart's physicians were confident he had the condition based on his physical presentation. The hospital staff told Stewart's mother that her son had von Recklinghausen's disease—the historic name of NF1. She was confused. She had never heard of this diagnosis. As the doctors explained the condition, they looked her up and down and—noticing the small, soft growths on her arms—added, "you have this disease too".

Stewart went on to explain—with much frankness, considering this was our first meeting—how this surprise diagnosis impacted his mother and her attitude towards him:

> When I was born with NF, and then my mum and my sister were diagnosed, it was a huge shock to her. Because she was the one with the NF, [the one I

> inherited it from.] And in some way, I think I was the wicked messenger that brought the bad news… In some way [she believed] it was my fault. I could never be perfect in her mind. That there was something unfortunate about me.

Stewart reflected that even during the periods of his youth when he was largely asymptomatic, having a known genetic difference was enough to disqualify him from being "perfect" in her eyes.[33] During many of our later calls, Stewart would continually say he was made to feel "in-valid"—a term he deliberately reappropriates from the outdated term "invalid".[34] Above all else, Stewart was particularly hurt by his mother's insistence that he must never have biological children:

> She was always telling me: "You must never have children". Because I think I learned quite early that this was genetic... And I can remember on at least one or two occasions her telling me, "If I had known that I had had NF, I would never have had children" … Which is tantamount to telling me, "You shouldn't be alive".
>
> I think I internalized it on a level. [Through] my rational, moral understanding, [I knew she was saying] utter bullshit—and you know I *am* going to use words like that—[But] somehow, on some level that I can't access, I think I still believe [what she said]. Yeah. [That] it would be morally wrong for me to have had [children]. So, I haven't had children.
>
> I think my mother felt that she was protecting me from future hurt, by telling me all this shit, when actually she was doing the opposite. And I think one of the things I feel so strongly now is that … any child who is ill, particularly who has something inherited… needs to hear from their parent, "well, actually, from my point of view, you're perfect." [Parents should say,] "You don't need to be any different for me to fully accept you." And I think what went on for me was that I was never fully accepted as I was with my NF. That's had lifelong, *lifelong* effects. And I think it took me a long, long time to work my way through that. And to come to some sort of acceptance in myself that I have NF.

Given Stewart's articulation of his mother's shortcomings, I was surprised when, in later interviews, he expressed sympathy towards her situation. He conceded the nineteen-fifties were a different time. He reflected that she had no support and was coming to terms with her own diagnosis. In one of our later meeting, Stewart elaborated on his relationship with his mother:

> My mother would have wished [I did not have NF1], which is understandable, and even more understandable, I think, in the context of the 1950s—how disability and things like that, things like having conditions like NF1, was seen then. I think the way she viewed me has to be viewed within the context of

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[33] Stewart's reflections are here underpinned by Joan Ablon's observations. She noted that even before symptoms arise, "Persons with NF1 and other genetic disorders often find that they are stigmatized by the very fact they are carrying a condition that is imprinted in their intrinsic genetic makeup" (Ablon 1999: 12).

[34] Stewart argues that "the problem" is with society, *not* with people with NF1. He elaborates that his experiences of exclusion should not be attributed to *his* difference, but *society's* inability to accommodate such differences. He is therefore not someone who is invalid, but someone who has been made to feel less-than-valid by others.

> societal attitudes of the time. Nevertheless, it still affected me profoundly.
>
> The other phrase I come up with is this: I think I was ‘damaged goods’ [to my mum]. I was damaged goods in her mind because she herself was damaged goods [because she also had NF1]. I think if she could have put me in a parcel, sent me back to Amazon, and ask to be replaced with a better child [she would]! I laugh but it's something that's stuck with me. [There was] something in her attitude. I can understand her feelings, but I find it difficult to reconcile her actions, her repeatedly telling me throughout my childhood and adolescence that “you must never have children”, because I internalised that. I think the internalisation comes from an actual belief that, ‘she's right, that I must never have children.’
>
> It wasn't until I was an adult that I questioned [the idea that I should not have children], but by that point it was already internalised. Like I said, I could rationalise my way out of it, but there was still that inner feeling somewhere. Mum said, ‘if I had known I had NF, I would have never had children myself’, which is tantamount to saying, ‘you shouldn't exist’. I felt there was a lack of acceptance of me as I was.

Stewart and I spent considerable time in our meetings discussing parenting styles, parental responsibility, reproductive decision making, natalism, and antinatalism. Although Stewart has no living immediate family members, it is my impression that he has cared for, and continues to care for, many friends who have become a found family. He maintains a quasi-father role to a young woman named June—who turns to him for support during mental health crises. However, despite his rich social life and busy retirement—including a leadership role in a not-for-profit assisted dying advocacy group—Stewart still maintains that he laments not being able to enjoy a romantic partner. In his opinion, during the nineteen sixties and seventies, if an individual was unable or unwilling to have children, this disqualified them from being seen as a viable romantic partner. Although decades have passed since that time, Stewart claims the invalidation he experienced as a young person continues to haunt his self-esteem in that regard.

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When not discussing reproductive politics and choices, Stewart and I broached subjects as far ranging as gender identity, local politics, neighbourhood dynamics, atheism, humanism, theology, and literature. We both approached our calls with a relaxed seriousness. Stewart would often send me written thoughts ahead of our meetings to give us food for thought and discussion. Whenever I would thank Stewart for his candour, or thorough thoughts on a niche matter, he would insist that he very much enjoyed and looked forward to our meetings. “I got the impression you were interested in hearing people’s stories,” he stated—referring to my call for participants research poster, “and from our talks I see that that’s true.” He felt it was important for people to share their stories in a frank manner, that is, to not be overly optimistic or overly fatalistic about living with a genetic condition. In the body of this thesis, I hope to do him justice.

Chapter 1: Gene Talk

> NF1 is a whole person condition, a whole person divergence. That makes it different from heart failure or kidney disease. Kidney disease might affect a whole life, but it arises from kidney problems. Whereas because NF is genetic, it is a whole person thing.
>
> - Stewart [taken from an interview]

> NF1 is not something I "have". It is part of who I am. It's not all of who I am but it's an intrinsic part of me and I would not be the "me" that I am without the NF1.
>
> - Stewart [taken from an email exchange]

To begin investigating the fluctuating relevance of genetic knowledge, it is first pertinent to explore the following questions: what do my participants understand genes to be? How are genes seen to act? And when are genes accorded explanatory power? While reviewing my data and considering how best to present my research findings on this matter, I realised there was an organic avenue with which to begin: my participants seldom reflected on genes without simultaneously commenting on how these units of DNA contributed to their sense of identity as individuals. Whether discussing their health condition or their lineage, the association between genes and identity held strong. Considering this association, I feel it is not only appropriate but also necessary to explore my participants' thoughts on genes in tandem with their reflections on their individuality. This intersection—that is, "the idea that essential truths about identity inhere in sequences of DNA" (Tallbear 2013: 4; Fox Keller 2000; Imhoff & Kaell 2017)—is referred to as "gene talk".

To attend to my participants' participation in gene talk, in this chapter, I first turn to two fruitful conversations I had with Zoe, an outspoken mother of a young daughter with NF1. I describe and analyse her detailed reflections on the nature, workings, and significance of genes. During this dissection of "Zoe's theories", I argue that genes—as opposed to any other substance of biological relatedness—are integral to her understandings of inheritance and identity. In doing so, I highlight Zoe's interest in ruminating on the tension between an individual's agency and the determining power of their genome. In the second section of this chapter, I contrast Zoe's gene talk with the more subtle reflections of my other participants. Included within this section is attention to my interview question, "do you think you would be the same person if you did not have NF1?" I note that on multiple occasions, my participants abstracted themselves and others from any single genome. In the third and final section of this chapter, I detail instances where participants were reluctant to take part in gene talk altogether. Ultimately, the purpose of this chapter is to demonstrate the complex and often contradictory ways in which genes are understood and ascribed significance by my participants. Although gene talk was prevalent in my fieldwork, participants' prima facie support for the explanatory power of genetics did not always align with their later, more-balanced reflections on other determinants and aspects of identity. To many of my participants, genes are both cosmologically seminal and yet nominal to everyday life.

Before I begin, I should preface that I am aware of the complexities inherent in working with the concepts of "identity" and "cosmology". On the term identity, Appell-Warren notes that the term is often conflated with "personhood" and ideas of "the self" in anthropological discourse (2007: 2, 94). She asserts that by attempting to define these "key analytical tools", we enter larger "overarching" debates about the subject of anthropological enquiry (Appell-Warren 2007: 88, 94). I do not attempt to offer resolution on this matter in one chapter. Neither do I necessarily champion the analytic utility of any one definition of identity over another. Instead, I work with a variety of conceptualisations depending on each participants' preference and circumstance. For instance, in congruence with Caughey's writings on "personal identity" (1980: 174-175), at points in this chapter I address the character, values, and life story of an individual. In other instances, I discuss gender identity and sexuality as an integral component of an individual's sense of self. In Chapter 2, I will work with yet further analytic approaches to identity—including analytics from both Erikson (1994) and Eriksen (2001)—to explore the synthesis of personal, collective, and social identities. For now, in this chapter's exploration of gene talk, I take seriously any and all of my participants' reflections on what makes them who they are as individuals.[35]

When introducing my research project, (on page 6 of this thesis), I stated that I was interested in mapping British cosmologies. It is now timely to define and justify this terminology as I begin discussing my participants' thoughts on genes as substance. I use the term "cosmology" because I am interested both in what my participants believe genes to be—that is, their ontological nature—and in how these understandings interact with my participants' broader philosophical reflections and speculations. To demonstrate why I believe cosmology is the term by which I can best characterise this dual focus, I first trace the changing usage of the term in anthropological discourse,

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[35] I am aware of Bird-David's caution that there "clearly lurks a 'methodological individualism' of sorts… in that the bounded individual is still the unit of observation and analysis" (Pálsson 2007: 211). However, I hold that where my participants see themselves as individuals, it is appropriate to work with this assumption—at least during this chapter.

before explaining why my conversations with participants ought to be understood as cosmological reflection.

The term cosmology comes with intellectual baggage. Once employed to address indigenous belief systems, Holbraad and Abramson (2014) characterise the three facets of cosmology's historic usage as follows. First, cosmology was seen as a discourse about the total order of society. Where "societies were imagined as pre-structured wholes, cosmology was given the role of reflecting upon the nature of this totality" (Holbraad & Abramson 2014: 5). Next, cosmology was thought of as but one piece of the "jigsaw puzzle" for the anthropologist (2014: 6). That is, cosmology was deemed discrete from other pieces, such as kinship or economics, which required their own attention and analysis. Thirdly, Holbraad and Abramson argue this historic interest in cosmology worked to uphold the "hierarchy of 'modern us' over 'primitive them'" (Holbraad & Abramson 2014: 9). In short, indigenous cosmologies were seen as "largely powerless [albeit useful] fictional representations" (Holbraad & Abramson 2014: 15). Yet despite the term's association with outdated anthropological practice, Holbraad and Abramson believe—and I concur—that interest in cosmology still holds utility. In their edited volume *Framing Cosmologies* (2014), Holbraad and Abramson continue that "cosmology is no longer assumed to connote a dedicated cultural domain reserved for naturally total, totalising and always exotic discourses about the world" (2014: 15). In fact, the authors go so far as to claim "a concern with cosmology is now more apposite to the contemporary world than it ever was to putatively 'primitive' ones." (Holbraad & Abramson 2014: 10). They assert that people's speculations regarding their place in the cosmos—that is, their cosmology—is often "a defining feature of the 'late' and 'liquid' modernity of neo-liberalism" (Holbraad & Abramson 2014: 10), citing Humphrey's chapter in their volume (Holbraad & Abramson 2014: 22; Humphrey 2014: 223) as an apt example of why cosmology has not outlived its usefulness.[36] For Holbraad and Abramson (2014: 7), collapsing "the contrast between indigenous cosmology (as something others have), and science… as 'our' ultimately *truer* equivalent" is both important and possible through continued anthropological attention toward cosmological forces in all relevant contexts.

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[36] Humphrey writes, "cosmology in contemporary Russia cannot be tidied away into a capsule called something like "religion" and separated from practical [often political] consequences… [Russians engage with] cosmologies in which "gods" coexist with planets, electrons, black holes and mysterious, invisible cosmic forces" (2014: 223-223).

Having detailed this renewed interest in cosmology, it is pertinent to unpack why this term best describes certain features of my ethnographic data and analysis, before outlining exactly how I utilise this term in my thesis. In part, my reasoning for using cosmology is simple. From an exhausted mother projecting positive thoughts to the clouds (page 147 of this thesis); to a devout Christian contemplating her God's purpose in disease (see footnote 58); to an atheist entertaining the idea of his soul (page 147), my participants were evidently interested in considering cosmological forces[37]. Even when *not* reflecting on gods and souls, my participants treated genes as cosmological entities. To unpack what I mean by this claim, consider the following observations made by Sahra Gibbon—an anthropologist whose work I draw on regularly in thesis—along with Kilshaw and Sleeboom-Faulkner (2018). They note that "in various contexts, genetic disorders are attributed to forces beyond human understanding, such as fate, destiny and gods, as if in a kind of biological predestination" (Gibbon, Kilshaw & Sleeboom-Faulkner 2018: 3). Gibbon, Kilshaw and Sleeboom-Faulkner thus coin the term "genetic cosmologies" (2018: 3) to denote the way genes are brought into reflections on humanity's place in the cosmos. In a separate paper, (in the same journal volume as Gibbon, Kilshaw and Sleeboom-Faulkner's paper,) Parkhurst, points to how "the link between genes and gods can be…. a rather rapid one", and accordingly claims discussions of "genetic determinism" inevitably relate to "cosmology" (Parkhurst 2018: 77).[38]

On my own use of the word cosmology, I have two final points to make. First, I speak of British cosmologies in the plural since I have multiple participants each with their own cosmological reflections. I remain cognizant of how each participant draws from their own specific cultural background—that is, their intersectional experience—when making these personal reflections. Second, I wish to note that while this first chapter may appear primarily interested in addressing my participants' ontological

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[37] In his discussion of Bedouin cosmological understandings of genes, Parkhurst discusses situations among his participants where "the connection is not made with 'Gods', but it is still made with religious cosmological entities" (Parkhurst 2018: 77). I accordingly characterise my atheist participant's reflection on the soul as cosmological, even if it is not necessarily part of any formalised religious adherence.

[38] I was struck by Parkhurst's writing on the human body as "populated by cosmological agents that can affect one's life and well-being" when discussing the cosmologies engaged by his participants in the Southeastern Arabian Peninsula (Parkhurst 2018: 74). I find it interesting that he identifies cosmologies at different scales – arguing that just because genes are small, that does not mean they do not concern cosmological questions regarding humanity's place in the universe.

reflections[39]—insofar as it charts different participants' thoughts on what genes are and how genes act— my participants were not lecturing me on the content of their worlds. Rather, in our discussions, my participants were *working through* their own understandings of what is means to be a part of the cosmos – with all its known forces, presently unknown forces, and "forces beyond human understanding" (Gibbon, Kilshaw & Sleeboom-Faulkner 2018: 3). I thus utilise the term cosmology to acknowledge this ontological humility and plasticity – which draws concurrently on scientific facts and spiritual possibilities. As per Holbraad and Abramson's recommendation, my hope is that this terminology highlights how 'modern' participants are by no means "a-cosmological" in their reflections on the substances present—and forces at play—in their lives (Holbraad & Abramson 2014: 13).

Part 1: Zoe's Gene Talk

Zoe lives on an island off the coast of England. Originally from the mainland, she moved offshore years ago so she and her husband, Joel, could settle near his family. Zoe enjoys the slower pace of life on the island. She and a friend run an upholstery business—revamping and repairing furniture—but business is never bustling. Instead, Zoe spends most of her time looking after her five young children. Her family enjoys a large farmhouse built by Joel's family generations ago. During our Zoom calls, the exposed wooden beams of the structure were visible over her shoulder—along with flashes of various children and household pets running by. Zoe thinks this island life suits her family well. She can dedicate time to her hobbies and friends in the small but robust community, while Joel can happily spend his working days in his own company on the farm. Although Zoe concedes missing her siblings and the bustle of the mainland, in our meetings she was nevertheless eager to stress how contented she was. Her family of seven can live comfortably on Joel's single income, the public services on the island

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[39] Another reason why I have chosen to utilise the term cosmology is to differentiate my analysis from the important yet disparate debates in the recent ontological turn. Heywood summarises the ontological turn as a rejection of the following supposition: that nature is singular, whereas cultures provide multiple readings of this objective reality (2017: 1). Although my work clearly benefits from analytic clarity brought on by the famous ontological debate at the University of Manchester in 2008 (Carrithers, Candea, Sykes, Holbraad & Venkatesan 2010)—namely Venkatesan's point that "by focusing purely on… the ontological realm" we "render invisible the translation and mediation that are crucial to acting in the world" (Venkatesan 2010: 154)—I am not looking to comment on whether there are singular or multiple 'natures', or any other "metaphysical" discussion (Heywood 2017: 1). I believe certain ethnographic material – such as de Castro's discussion of Amerindian perspectivism and cosmological deixis (1998) – is better placed than my own to engage with such questions.

are outstanding, and her home is full of life. Zoe is quick to count herself lucky, and I could understand why.

However, life has not always been so easy for Zoe, especially when the health of her youngest daughter came into question several years ago. Zoe and Joel's five children include two sets of non-identical twins. When the youngest twins were infants, Zoe enjoyed playfully pointing out differences between the two girls. Whereas Darcey was outgoing and energetic, Poppy was fussy and sleepy. Poppy was also noticeably smaller than her twin sister. Zoe thought nothing of this contrast. Her three eldest children were all quite different from each other. Why should this be any cause for concern? Yet when a family friend pointed out that there was "something not quite right" with Poppy, Zoe took this comment seriously. After all, Zoe reasoned, this friend knew a thing or two about medicine after her own son was born with a cleft palate. Together, the two women watched as Poppy struggled to sit up and support her own weight. Seeing this, and considering that Darcey was already crawling, Zoe decided to follow her friend's advice and get Poppy "properly checked out".

To begin with, Zoe suspected Poppy had Marfan's syndrome. Zoe had "done some Googling" and thought this condition might explain why her daughter was so "floppy". Zoe became confident that her family history of "really, really tall men" was further evidence for this diagnosis. Their general practitioner (GP) agreed to refer Poppy to a geneticist on the mainland to "have her checked over and see what's what." Following a quick physical examination at the larger genetics' clinic, the specialist told Zoe that she did not suspect Marfan's but instead thought Poppy "might have something called neurofibromatosis". The doctor pointed out the numerous café-au-lait marks on Poppy's torso. Zoe, surprised that Marfan's syndrome was not the answer, rebutted that she herself had numerous freckles. How could simple discolouration explain developmental delays? The geneticist took time to explain the variety and variability of NF1 symptoms. Ultimately, she decided to run a genetic test both for 18-month-old Poppy as well as for Zoe and Joel. When the diagnosis itself came—that Poppy had a spontaneous case of NF1—Zoe, in her own words, "spiralled":

> When the geneticists phoned me and said Poppy has neurofibromatosis, I instantly went online, and I found out information. It was like, "holy fuck", you know. I really felt like—and you can retract the swear word [if you want]—but I really felt like, "oh my God, my baby's gonna die. She's gonna get brain tumours." And it was that bombardment of information, and [it's] taken me years and time to understand that, actually, Poppy's okay.

In the seven years since her diagnosis, Poppy has developed a myriad of symptoms. Following a bout of severe headaches, she underwent numerous scans.

These revealed that Poppy has an optic pathway glioma—a potentially serious tumour associated with NF1, but which has not yet affected her sight. On occasion, Poppy uses a wheelchair to give her loose ligaments a rest, and Zoe has noticed a small number of neurofibromas developing on her trunk. Yet none of these symptoms have prohibited Poppy from enjoying life as a happy and engaged child. Zoe admitted to me that Poppy quite enjoys the regular visits to their local paediatrician. “She’s one of five kids,” Zoe laughs, so naturally she enjoys her “special time with mum.” What is more, Zoe notes that Poppy loves watching the doctors. Poppy is fascinated when medical staff draw her blood or enter notes into the computer. “She’s a bright girl”, Zoe boasts, “she wants to be a vet, or something in the medical field.”

In many regards, Zoe and Poppy’s mother-daughter relationship was not unlike others I encountered during my fieldwork. In due course, I will discuss Seren and Bethan, as well as Tara and Tatleen—two other unaffected mothers raising daughters with spontaneous cases of NF1. However, my discussions with Zoe were unique in that she was keen to discuss her ideas on how genes work. She playfully referred to these ideas in the third person as “Zoe’s theories”. At the outset of our first meeting, Zoe qualified that these theories are “not necessarily fact”, but rather the way she “likes” to think about her family’s situation. I have decided to detail her wide-ranging thoughts on genes to demonstrate a situation wherein a participant had forthright opinions on the nature and significance of genes, before I later address situations wherein “gene talk” was not always so explicit as Zoe’s theorisation.

Zoe’s Theories

In her gene talk, Zoe makes various interrelated points of analysis. For the sake of clarity, I have grouped these thoughts into three categories. The first category pertains to Zoe’s thoughts on the complex workings of genetics in the general population. Consider the following extract from Zoe, taken from the beginning of our first conversation:

> I've got a real rudimentary understanding of genetics and biology and everything else. And obviously, you know, we're made up of our X and Y chromosomes … and I think everything is on a spectrum, and when it comes to genetics, everyone’s DNA and their makeup is on a complete spectrum… You've got blue eyes, my husband's got blue eyes, but your eyes and my husband's eyes are going to be a million miles apart, but they're both blue… And I think people are starting to understand and realise that actually everything has some kind of [genetic] connection.

In hindsight, I find it interesting that Zoe opened her gene talk with a caution. In this extract, Zoe notes the complexities of gene interactions. She also considers the variety of genotypes that can lead to similar phenotypes. Whereas later in our discussion she offered more confident assertions on the power of genes in determining various characteristics, to begin, she articulates that it is oftentimes difficult to interpret and evaluate the work of genetics. I find her initial hesitancy telling. Zoe was careful not to appear over eager to claim authority in understanding the work of genetics.

After this preface, Zoe went on to detail her beliefs on the causes of her daughter's NF1. I identify these thoughts—on her family as a genetic case study—as the second category of Zoe's gene talk. Zoe locates Poppy's NF1 as stemming from the same genetic quirk which caused her son to have a structural hand abnormality and her daughter to be transgender (MtF):

> I think genetically Joel [Zoe's husband] and I are very well matched. We make babies very easily… There is no foundation to this, and this is just Zoe's theory, but I do think, you know, when people struggle to get pregnant—and like I said, this is my theory, there's no foundation on this—I think sometimes genetically they're not compatible. That potentially the egg and sperm isn't genetically compatible... I think Joel and I are really genetically compatible, but there's a little bit of something in there that makes a little hiccup along the way. Something [in the way] our chromosomes come together, [we] make human beings [with] those little hiccups… So, Poppy has a mutated gene. If I had NF, then that would [be inherited from me,] but hers is a mutated gene. [My trans daughter] is genetically male, but her brain is a female. I think that's a mutated gene, you know. And [then] the little finger - you know, [my son's] thumbs? That's a little mutation there as well. So, I think all of those things are connected genetically. That's when my brain stops working at that point.

Later, Zoe added:

> [My son] has fused thumbs, so his thumbs don't bend at that knuckle. They don't bend, and that's genetics. They've all got a little tweak of imperfections and they're perfectly imperfect. But I do think that is, you know, something where Joel and I our match isn't quite perfect when it comes to making children.[40]

I remember being intrigued by Zoe's analysis. I had never before heard someone speculate on the causes of infertility in terms of the genetic compatibility of gametes. I also did not prompt Zoe to discuss this matter—I simply asked whether she thought much about the genetic component of NF1, and she offered these evidently pre-thought-out ruminations.

The third category of 'Zoe's theories' pertains to her belief that genetics "is a massive part" of what makes each person who they are. I would characterise this final category as her reflections on the relevance of genes to the formation of individual identity. From our first meeting, Zoe was interested in discussing her interpersonal relationships and hypothesising why certain family members had developed into the

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[40] Zoe later amended this comment by stating that she does not see her daughter as imperfect because she is transgender.

adults they are today. She recounted, with a certain degree of nonchalance, “so, just a very brief summary of my history. I had parents that were drug takers. My dad was very abusive, he left home when I was seven. Mum is lovely, but she struggled.” In our second meeting, Zoe expanded on her life story, and interspersed within this longer narration was consideration on the extent to which genetic inheritance “determined”—in her words—who her family members were “at our core”. In the excerpt below, Zoe attributes significance to genes in some instances, while in others dismisses their power or relevance:

> My sister, Susannah, her partner of three years has never yet met the ‘real Susannah’. The Susannah that gets stressed and swears and argues and things like that. That's how Susannah was in her environment when she was younger. She learned to deal with things that were going on [in our childhood home] by putting up this front and this wall and that [wall has] stayed there forever. And then you've got my other sister, Harri, and her childhood [was so different] it could be that she was brought up by a completely different family [because of the age gap between my sisters]. So, Harri sees her childhood completely differently to how [me and Susannah] do [although we all experienced trauma.] … So, Susannah has a brick wall and doesn't let anything in, where Harri doesn't have a wall. But Harri has fibromyalgia, which I think is a psychosomatic condition. My sister is in pain. She has real chronic pain… it is a psychosomatic condition through the trauma that she suffered when she was younger.
>
> But that isn't genetics, that's environment, so Susannah being the way she is now isn't anything to do with genetics. I think that's completely environment. And then you've got me, who's perfect! [Zoe laughs.] Not really. Obviously, I have a balance of [features.] I have my “Mrs. Bouquet” wall,[41] and then I have no wall. So, I'll tell [a person] my life story one day. The next day, I won't want to share anything. I think that is very much environment, but genetic-wise we all have our dad’s explosive temper. We can shout really easy. We're all quite fiery. And our emotional side of our mum as well. And I think genetics does play a big part…
>
> Another thing that's really interesting, which I think is definitely genetic, [is how my brother is different to the rest of us.] So, like I mentioned, my brother, he's [over a decade younger] and he has a different dad [from me and my sisters]. [His dad] and my mum split when my brother [was a baby]. So, my brother never had a father. He very sporadically saw his dad. Maybe once every two years. Or you know, very, very sporadic. However, his [dad’s] genetics I think are within my brother entirely, because his mannerisms and his body language. When my brother played on his computer [as a] kid, he would stick his tongue out and he'd pull a face and it's the same face his dad pulled. And when he wanted to play fight with you, his body language was just the same as his dad. But my brother hasn't *learned* that from his dad 'cause he had never been with his dad. So that was genetics and that was his dad. It's his DNA within him coming out, so you know, I don’t know [how to make sense of it].

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[41] Zoe is here referencing the fictional character, Mrs. Hyacinth Bucket, from the British television show, *Keeping Up Appearances*. The character is known for pretending to be upper-class. Under this pretence, she pronounces her surname as “bouquet”. Zoe is making a parallel between her own trauma response—of putting up a “wall” and thus hiding her true, authentic her—and this character’s deliberate act of hiding her class background.

Whereas Zoe identifies certain traits as genetic—such as her brother's mannerisms—she attributes other features—such as putting up a defensive "wall"—to upbringing.

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One might be tempted to say that the proliferation of gene talk is simply a rehashing of the much-pondered nature versus nurture debate with a new vocabulary. However, I contend that my participant is being highly specific in her rumination on the influence of genes as a unique substance. To bolster this claim, I have four analytic observations. My first two points are inferred from my data with a degree of speculation. I thus invite criticism and doubt on my interpretation. By contrast, my latter two are firmly grounded in Zoe's own words, and as such, form the basis of my argument that Zoe sees genes—not the influence of nature in an abstract sense—as integral to the construction of individual persons. My first observation pertains to the possibility that Zoe identifies certain features as more genetic than others. We can see this most obviously suggested in her repeated mention of eye colour. At the outset of Zoe's gene talk (please revisit page 57), she uses the assertion—that eye colour is a direct result of gene expression—as a presumption upon which to build the rest of her argument. Later in our discussion, she again mentioned pigmentation—this time hair as well as iris pigmentation—as an obvious example of the work of genetics. She remarked: "I do believe your hair colour is genetic. My hair colour was always going to be ginger. And that's my genetics. My eyes are hazel, and that's genetics… from the moment my mom and dad, the egg and sperm came together, I was always going to be ginger." I find Zoe's repeated referencing of eye colour to be curious. There are other physical features—such as ear shape or hair texture—which are equally set at conception. Why then did Zoe repeatedly choose pigmentation before any other example? This could just be happenstance. It could also be explained by historic associations between complexion, ethnicity, and inheritance—as will be discussed in the next chapter. But could there be an additional explanation?

Zoe was not alone in her repeated invocation of eye colour as an example of the work of genes. Five other participants referred to iris pigmentation when asked about their thoughts on genetics.[42] Of these five, two recalled their general secondary education in England and Wales, where pupils are taught about recessive and dominant inheritance patterns vis-à-vis the inheritance of brown and blue eyes. Regardless of how eye colour is studied by professional geneticists, to these participants, eye colour was

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[42] Including Stewart, who—when accounting for how he explains his genetic children to children—stated: "we all have recipes that make us, us. Your recipe gives you green eyes, and my recipe gives me these spots on my skin. That's why you can't catch my lumps, they're unique to me."

understood as the product of just one section of DNA with two alleles, (albeit with a variety of different alleles capable of producing the same colour iris—as mentioned by Zoe at the beginning of her gene talk.) I find it interesting to consider that perhaps this repeated mention of eye colour evidences a broader association. Could there be an inverse correlation between the number of genes involved in a phenotypic feature and the degree to which that phenotypic feature is viewed as genetic by my participants? That is, if a feature is understood to be the product of one gene, (as opposed to multiple genetic interactions,) does that feature appear more *obviously* genetic?

If this association could be demonstrated,[43] I could argue that single gene conditions, such as NF1, are perceived in profoundly different ways to complex, "multifactorial" genetic syndromes.[44] Furthermore, I could build my argument—that "genetic" thought is more specific than ascribing explanatory power to nature in the abstract—by demonstrating that many people in the United Kingdom are interested in tracing genotype to phenotype, even if this specific technical terminology is not used. If I extrapolate even further, I hypothesise that in certain cosmologies, a feature is understood as "genetic" not according to its immutability, but through simplicity. In other words, a feature is seen to be most genetic when the line between genotype and phenotype is perceived to be most direct. I do not have sufficient data to support this speculation at present. I certainly do not want to put words in Zoe's mouth. However, I do wish to consider that Zoe's repeated mention of eye colour suggests her belief that genes are linked with specific, observable characteristics. Zoe was considering the extent to which certain traits could be considered genetic with select examples, and as such, I do not believe we should eschew her reflections as an abstract musing on the impact of nature in general.

My second observation concerns the extent to which Zoe's theories align with the binary pattern of Mendelian inheritance. In opposition to other cosmological understandings of inheritance—such as cosmologies wherein children are understood to

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[43] As I say, I am currently speculating based on the logic of Zoe's gene talk, along with a handful of participants mentioning eye colour.

[44] I would recommend further ethnographic investigation into whether certain genetic conditions are perceived by the general public to be "more genetic" than others. If this were true, it would challenge academic predictions that health conditions will becomes less linked to underlying genetic code. In 2006, Hacking predicted that in the future, "genetic markers will not be causes but risk factors" (2006: 89), and while this dissociation may be true for geneticists, it is worth investigating why this might not be the case in local ethnogenetic knowledges.

inherit substance in gendered[45] or uneven[46] patterns—in biomedical understandings stemming from Mendel's research, a child is understood to inherit fifty percent of their genetic substance from each parent. Moreover, the contribution of each genetic parent is understood to be scrambled during the process of meiosis. As such, it is impossible to isolate one parent's contribution to a single substance—such as blood—since every cell in the body is seen to contain DNA inherited from both parents. Zoe did not mention Mendel or peas or alleles. She did, however, acknowledge NF1 as an autosomal dominant condition. Zoe explained to me that Poppy's potential future children either will *or* will not inherit her NF1. There will be a 50:50 chance for each child, and if a child does *not* have NF1, they and their descendants will be entirely spared. Zoe's explanation that there is no such thing as a carrier of NF1 demonstrates a Mendelian understanding of NF1's inheritance pattern. Be that as it may, at points, there was ambiguity over whether Zoe's understandings of genetics always perfectly mapped on to Mendelian genetics. In the excerpt concerning her adult siblings, Zoe speaks of her brother's father's genetics as being "entirely" within her brother. I could argue she is considering the degree to which her brother's father's DNA is expressed at the expense of their mother's genetic contribution. However, I could equally argue that she believes her brother inherited *more* DNA from his father than his mother, which would not be consistent with a Mendelian framework.[47] The ambiguity of Zoe's wording reduces my analysis to speculation. However, I do believe it is fair to say that, in Zoe's understanding, genetic features—such as NF1—are inherited in binary Mendelian patters. In short, Zoe theories clearly draw from—although do not exactly match—Mendelian models of inheritance.

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[45] An example of such a cosmology can be seen in the Dravidian kinship system of the Mukkuvar community in Kerela in the 1990s. Cecilia Busby's participants believed there were "male and female ways of being related" (1997: 262). While each child was understood to receive biological material from both parents, specific substances were believed to be inherited in highly gendered ways. For example, children were seen to inherit blood only from their fathers (Busby 1997: 263)—a specification with profound implications for Mukkuvar kinships structures and incest taboos.

[46] According to historic ethnographic accounts by Malinowski (1927) and Austen (1934), certain Trobrianders did not acknowledge the fertilizing power of semen in producing a child.

I reference these works with a caution. Monica Konrad (2005) has rebuked Austen's analysis. Specifically, she is troubled by Austen's suggestion that Trobriander cosmology resulted from ignorance to 'rationality'. Konrad notes, and I concur, that people can simultaneously understand Western biomedical accounts, while still championing "diverse practices of coming into being" wherein one dismisses the medicalization of fertilization, gestation, and kinship (Konrad 2005: 52).

[47] I should add that when lay people deviate from Mendelian genetics, this does not necessarily imply a complete refusal of the model. As posited by Lock and Nguyen (2018: 313), "lay understandings of heredity [may] conflict with Mendelian genetics, because the scientific account does not assuage the feelings of families dealing with the lived experience of genetic risk", and because when, "genetic information is incorporated into accounts about illness causation, such knowledge supplements rather than replaces previously held notions about kinship, heredity and health."

Thus far in my analysis of 'Zoe's theories', I have noted her repeated invocation of iris pigmentation as an example of gene expression, and her fluctuating congruence with Mendelian understandings of inheritance. I have suggested that these observations imply her interest in genes—as opposed to any other substance of nature—given her consideration over which features of a person should be seen as *most* genetic, and her reflection on how genes are inherited and expressed in each generation. While I find it interesting to contemplate these findings, I must exercise a degree of caution. I concede that in my reflections on Zoe's thoughts on pigmentation and inheritance patterns, I have worked with Zoe's ambiguous wording, or extended her logic with a degree of inference. I thus cannot rely on my analysis of this data to make claims about the place of genes in Zoe's cosmological understandings. What I am left with is the not-too-dismal option of working with instances where Zoe was unambiguous in her reflections. To begin, and to start my third point of analysis, I turn to Zoe's thoughts on genetic determinism.

Unprovoked in our first interview, Zoe attested that "who we are… it's within us already, so my eggs will predetermine my children". The general idea—that we are born with substance which determines who we are—is neither culturally specific nor unique to genetic discourse. However, Zoe's practice of deliberating over agency by evaluating the immutability of each genetic trait is, I argue, yet further indicative of her interest in genes as a locus of individual identity. Zoe gives two examples of traits which, in her mind, only ever "come down to our genetics". She details, "[my daughter] is trans and that isn't a choice. It's genetically within her, you know, her brain and her body doesn't match. So, I do think that trans is a genetic thing… Just like your sexuality. You are genetically in-built [with your preference]." In Zoe's view, both gender identity and sexuality are non-negotiable expressions of genetics. In contrast, Zoe offers thoughts on genetic predispositions which *can* be resisted. While discussing the "fiery" temper of her family members, Zoe pondered, "I suppose some parts of it will be your genetics. So, depending on your strength as a person, you may or may not be able to resist [your genetic inheritance.]"

Admittedly, Zoe's reflection—on sexuality and gender identity as fixed facets of a person—may well be best explained by her sociopolitical affiliations. She considers herself a progressive person and thus an advocate for transgender rights. Nevertheless, I hold that Zoe's deliberation over the immutability of various genetic traits—from temper to mannerisms—engages with a culturally specific obsession with agency which is firmly couched in what has been called the "language of genetics" (Novas & Rose 2000: 502). Consider the following quotes—taken from Nikolas Rose' discussion of genetic determinism—and their relevance to Zoe's reflections. I can confidently say that Zoe ascribes "a deep ontological reality" to genes when she contemplates "them as the hidden truths that produce and determine a realm of observable effects." (Rose 2007: 130) I am not claiming that Zoe has been directly influenced by this academic debate. Neither am I necessarily interested in evaluating Rose's thoughts on ontology.[48] I *am* arguing, however, that Zoe's gene talk exists within a cultural schema—the same schema inhabited by Rose—wherein the question of agency is naturally associated with genes.[49] Put another way, it would be impossible to debate genetic determinism without some preconceived understanding that genes might determine certain features. So, while Rose and Zoe disagree on the explanatory power of genetics, they both engage with a broader cultural anxiety over "relatedness and identity[being] frequently reduced to genetic connections" (Wald 1992: 704). Zoe is not merely offering musings on the inheritance of substance: she is discussing genes in tandem with the question of agency *because* genes—not blood, not intelligence—are at the heart of discourse around determinism within this specific cultural conversation.

My final argument—on why I hold that Zoe is speaking to the influence of genes specifically, rather than the work of nature in the abstract—is predicated on the fact Zoe stated clearly that she believes Poppy would be a different person if she did not have NF1. I enjoyed listening to Zoe recall a humorous incident. A few years back, her mother—Poppy's grandmother—phoned Zoe to incorrectly announce that scientists had found a cure for NF1:

> My mum - when they started talking about the CRISPR thing - she was like, "you gotta read this! They can take all of Poppy's DNA out of her and give her new stuff and [her NF1] will be gone!" [To which I thought] "Fantastic! [Sarcastically] Give us the phone number then, lol."

After recalling this anecdote light-heartedly, Zoe began a more serious reflection on the extent to which Poppy's genetic difference defines who Poppy is as a person. Specifically, Zoe contemplated the hypothetical situation of someone someday removing Poppy's NF1 from her. Zoe posited:

> I think it's like a double-edged sword, in that if someone came tomorrow and said, "we can take this NF away", let's say with the guarantee that everything is gonna be fine, then yes, I probably would. But [what these scientists are talking

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[48] Although I will say that I find his writing on the matter to be unclear. Moreover, I disagree with his assertion that "the genetic code is no longer thought of as a deep structure that causes or determines" (Deleuze 1988 in Rose 2009: 130). Zoe evidently thinks of the genetic code as a deep structure. What separates my approach (as an anthropologist) from Rose's sociological perspective is that rather than dismissing my participants' thoughts as "popular and pseudophilosophical accounts" (Rose 2009: 130), I have instead made them the focus of my project.

[49] Marilyn Strathern reflected that "you can tell a culture by what it can and cannot bring together". For example, commerce and kin "naturally" go together in some cultures but not in others (1992: 6).

> about] is with an embryo. I have Poppy now, this nine-year-old child who has her personality, and I know who she is… Taking out and altering and changing that [NF1 gene], I don't know if I could do that.

Zoe believes that Poppy's NF1—even though it is a single gene condition—is significant enough that if they were to remove the NF1, they would inevitably change what makes Poppy who she is today. Such is the extent to which Zoe puts purchase in the influence of genes as units of identity, she would consider declining hypothetical treatment for her daughter since, in her eyes, this would change Poppy as a person. Considering this conviction, it is fair to say Zoe sees genes as potent, potentially critical, determinants of identity.

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In this first section, I have detailed Zoe's thoughts on the characteristics and effects of genes—both for humans in general and in her family specifically—to demonstrate that genes are significant to this participant, and to tease out the nuances, specificities, and difficulties of thinking in genetic terms. Zoe faces many contradictions in her musings. To reiterate, she believes genes are immutable when it comes to encoding sexual preference, but resistible when they determine temperament. Moreover, she is the first to admit that hers is not the most consistent of cosmologies. I have noted that at times her gene talk aligns with Mendelian ideas of inheritance, and at times is more ambiguous or specific to her. On balance, one can see Zoe's theories as both a case study of a genetic diagnosis prompting detailed thoughts on the significance of genes, and as a demonstration on the creative and inconsistent logics that can simultaneously exist within an individual's cosmology. Zoe is but one example of many people I spoke with, and I can say she was unusual in both the content of our gene talk and her willingness to discuss such musings unprompted. This will not be the last we hear of Zoe, but for now, I return us to the mainland to explore whether my other participants concurred with Zoe's claim—that if you were to remove an individual's NF1, that you would change an intrinsic part of their identity.

Part 2: Indirect Gene Talk

Although none of my participants—save Zoe—offered extensive commentary on genes unprompted, many still provided indirect insight into the significance of genes. This second section attends to these alternate avenues through which to access participants' gene talk. I found that where NF1 is understood to be a genetic condition, participant reflections on their neurofibromatosis allowed insight into the place of genes in their cosmologies. Specifically, I increasingly appreciated that it was productive to attend to participant convictions on genetic trait selection technologies, and to the hypothetical scenario of having been born without NF1. The purpose of this section is not to map a singular, neat, coherent cosmology. Rather, the aim is to demonstrate that my participants held complex, idiosyncratic, and often contradictory thoughts on the nature and significance of genes. Only after this complex picture is painted, will it be appropriate, in later chapters, to propose explanations on why such varied and dynamic views of genes can flourish.

My participants offered varied responses to my interview question, "do you think you would be the same person if you did not have NF?" Some interviewees were surprised by this question and asked for time to consider. Others appeared keen to share pre-thought-out ideas. One of my key participants, Chris, quickly replied, "yes, I would still be me, because I would still have had the same family." Chris saw his upbringing as essential to his identity in that it instilled him with the values by which he defined himself. Such values included but were not limited to the importance of hard work, and not letting obstacles become—in his own words— "excuses".[50] Chris was not the only participant who referenced his experiences as a determinant of his singular individuality. Another key participant, Tara, when reflecting on her daughter's NF1, determined that her daughter would be the same person without NF1 because she would still have the same family and religion. Tara later added the caveat that perhaps her daughter, Tatleen, would be a "little different" since she would not have undergone the "trauma" of invasive NF symptom checks.[51] One could summarise both Tara and Chris's perspectives as a belief that their individuality is a sum of their life experiences—with some, but not all, of these experiences being influenced by their NF1 diagnosis. That is, if you were to take away Chris and Tatleen's NF, all you would take away from them would be their respective experiences of medicine and stigma which have influenced but not defined them as people.

This perspective was not matched by other participants. It was not even always matched by Tara, who later reflected that she believes NF affects Tatleen's "personality", "because she was born with it". When I met with one of my youngest participants, an 18-year-old who I will call Noa, I was struck by her insistence that she would be an entirely different person if not for her NF1. Her reasoning was that her NF1

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[50] I had the pleasure of meeting Chris's sister in a separate interview as a research participant herself. I believe neither sibling was aware of the other's participation. Chris's sister was full of praise for her brother. She considered his resilience and determination in the face of adversities to be an "inspiration" for other people with NF. In turn, Chris was full of praise for his family.

[51] Tara believes this adverse clinical experience is the source of Tatleen's anxiety. She lamented: "Tatleen is so worried about needles; she won't eat or sleep for days [leading up to her doctor's appointment.]"

"causes" her autism. Without this neurodivergence, Noa held that she would not be herself. Noa demonstrates the belief that possessing a different brain is synonymous with being a different person. Where people understand NF1 to affect the brain—either through an associated neurodivergence, or through something less medicalized[52]—people with Noa's conviction cannot imagine that they would be the same person if they did not have NF1. Because of this viewpoint, several of my participants—including Noa and Stewart—do not narrate NF1 as something that 'happens' to them. A happening implies a time before their condition manifested. In their minds, there was no 'Stewart' or 'Noa' before their genetic code was set. Whereas people with other sudden onset, fatal genetic conditions—such as Li-Fraumeni syndrome and Huntington's disease—can imagine themselves without their condition, the congenital cognitive presentation and gradual progression of NF1 leads participants such as Noa and Stewart to see their genetic difference as an inseparable part of their identity. Such participants thus live their everyday lives in the "temporal paradox" (Konrad 2005: 75) of a liminal prognosis that problematises how they define themselves and the degree of their 'illness'. Furthermore, and more saliently, this perspective problematises the idea of the 'self' beyond the genome.

One could point out—using my own argument (from page 58) against me—that Noa appears to speak with the "language of cognition", rather than with the "language of genetics". To this point, I wish to further reflect on the perceived distinction between things that *happen*—such as experiences, upbringing, and chance—and things that *are*. While the brain *could* be said to sit between the two categories—since people can learn new skills and knowledge and can also lose cognitive function through age and accident—I hold that Noa's reflection on her brain are couched firmly in the latter, along with genetics. She is speaking of an inevitable cognitive presentation which is a product of her genetic difference. To clarify and unpack this analytic distinction, I draw on reflections made by the American environmentalist, Bill McKibben (2003) on "designer genes". While McKibben's article may appear at first glance to pertain to a disparate conversation on the ethics of designer babies, I find his reflection on the nature of genes to be helpful in elucidating exactly why some participants hold their NF1 is an inalienable, intrinsic part of their individuality. The essence of McKibben's argument is that it is wrong for parents to choose their offspring's genome because in doing so they are not simply determining what can *happen* in their children's lives, they are limiting the very essence of what these children can be. He writes:

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[52] My participant Stewart does not have a diagnosis of a neurodivergence, but he does still locate his inability to concentrate when multiple conversations are occurring around him as a result of his NF1.

> You cannot rebel against the production of that protein [which has been genetically engineered.] Perhaps you can still do everything in your power to defeat the wishes of your parents, but that protein will nonetheless be pumped out relentlessly into your system, defining who you are. You won't grow feathers,[53] no matter how much you want them. And maybe they can engineer your mood enough that your lack of plumage won't even cross your mind. (McKibben 2003)

McKibben's overall stance—regarding genes and identity—is that while people are not readouts of our genes, genes nevertheless give us the possibility within which we can act. Using his binary—between the essence of who we are and the things that happen to or from us—one can see that Noa is addressing the former while discussing her brain. Moreover, while my participants speak to both these aspects of a person, it is nevertheless important to be mindful of the distinction when attending to gene talk.

Consider the following. One of my key participants, Jamie, reflected that he is glad his mother did not place him in special education because of his NF1. He believes that if she had done so, he would be a different person today. He states: "there have been too many restrictions [put on me because of my NF1.] I'm thankful [my mum] didn't go down that road [of putting on more], of registering me as disabled and putting me in a special school, 'cause I think I'd have been a different person [now]." If we return to Tara, we can see a similar retrospective evaluation of the impact of an NF1 diagnosis on an individual's life course. Tara wishes Tatleen did not have NF1 check-ups since she holds this medical experience has given her daughter pronounced anxiety which has changed—or one could say moulded—her as a person. In both these instances, Tara and Jamie are speaking to the consequences of having NF1—be it its impact on educational aptitudes and resulting school choices, or the necessity for checkups. In *other* conversations—with Jamie and Tara and with other participants—interviewees spoke to the discrete point of how NF1 affects the *baseline* potential of each person. For example, Zoe, when reflecting on Poppy's NF1, asserted that you cannot part from someone what will always be a part of them. In Zoe's words, Poppy's NF1 is "knitted in" to her. So, while Tara and Chris may speak to the importance of experiences and family context in determining who a person is, this does not negate the salience of separate observations on how genes prescribe the *options* of who you can be.

None of my participants saw their genome as a sufficient explanation for who they are now, but several—including Zoe, Stewart, and to a lesser extent, Tara—concur with McKibben that your genes set the goalposts within which your individuality develops. I wish to give these goalposts the moniker of "genetic potential". So, while I cannot say with certainty exactly how genes act on brains within these cosmologies—

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[53] McKibben is here referencing his earlier observations on the possibility of genetically engineering farmed chickens so that they do not have feathers which would need to be plucked.

since my participants themselves are not sure—I can argue with confidence that genes are seen to determine some abstract facets of brain functioning. To evidence this claim further, I turn to a young participant in London, whom I call Hannah, who told me: “I wouldn’t be much different without NF1, but maybe a little. It’s hard to know. What factors of my personality are from NF1.” I hold that Hannah’s agnosticism speaks volumes. Although she is unsure exactly what parts of her brain are determined by her genes—she speculates rather than asserts that genetics might have determined her personality—she hold that her genetics determines something in her brain. In Hannah’s measured consideration, we can see how the language of the brain and the language of genetics *both* exist in—and perhaps are collapsed within—McKibben’s category of ‘what is and will always be’.

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Whereas I provoked my participants to abstract themselves from their genome through my research question, “do you think you would be the same person without NF1”, I was surprised to find that numerous participants engaged unprompted in abstracting other people from their genomes. For instance, one of the neurofibromatosis specialists I spoke with commented about a gifted patient of hers: “imagine how even more brilliant he would have been if he hadn’t had NF1!” In this remark, she is separating this patient’s true self, his raw potential, from the limiting factor of his genome. Separately, there were instances where I encountered participants abstracting *future* people from any specific genome. A woman in her thirties, whom I will call Imogen, confided to me, “I don’t want my child to have NF1, so [in the future] I will choose an embryo without NF1”.[54] Her future offspring is accordingly anticipated in a way that is divorced from any specific genome. I am not the first scholar to be intrigued by the practice of bringing the future into the present by imagining future kin. To give one example, Marilyn Strathern was interested in gamete cells insofar as “a link with the future” could be “anticipated” through these cells (1997: 174-175).[55] I am, however, novel in attending to the contradiction inherent in *my participants’* participation in such practices. How can Imogen both define herself by her genetic condition—which she did earlier in our conversation—and simultaneously abstract her future kin from any

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[54] I find Imogen’s comment is here reminiscent of Ablon’s participant, who reflected, “I don’t think I want to have blood children because I know what I could do to my children.” (Ablon 1999: 37) I hold it is interesting how this participant sees NF1 as something you do *to* a child, rather than an intrinsic part of a child.

[55] On a broader level, Novas and Rose note that people “plan their present in the light of their beliefs about the future that their genetic endowment might hold” (2000: 489). In Chapter 4 of this thesis, I discuss how a genetic diagnosis can affect the anticipation of future kin, among other temporal consequences of genetic knowledge.

genome? While one could point to “the questionable difference between potential as opposed to actual identity” (Strathern 1992: 175) or dismiss genes as “slippery” objects of inquiry (Pálsson 2007), I instead wish to double down on my interest in the place of genes in my participants’ cosmologies. To do so, I return to Stewart. In our conversations, he demonstrated many of the logics and tensions I have noted thus far—including the practice of abstracting individuals from their genome—and as such is a useful case study with which to map how one person can hold disparate views on the relevance of genes.

Stewart chose not to have children. In part, he explains this as an unavoidable outcome of the fact he never found a life partner. He believes the reason he was unsuccessful in dating was because of internalised stigma, lamenting that because he could not see himself as a viable romantic partner, he could not project the confidence needed to successfully date women. Separate to this, Stewart holds that even if he did find the right person, he still would not have fathered biological children. He was quick to qualify that this was not because he thinks there is anything “wrong” with creating a person with NF1, but because he believes he would not have been capable of parenting such a child because of his own internalised stigma. He also attests that he might have found it hard to watch a child suffer through the same physical symptoms he has struggled with. I here identify Stewart’s reproductive reasoning as pertaining to the *consequences* of NF1. Much as Jamie and Tara spoke to their difficult experiences of limited educational and medical systems, Stewart is speaking to the difficulties of living in a society which is unwelcoming to people with genetic difference. In an analytic sense, Stewart is discussing his inability to acquire full personhood in a natalist society which prizes parenthood, rather than discussing the influence of genes on his individuality. Nevertheless, the fact that Stewart discusses these consequences of NF1 does not negate the fact that elsewhere he *did* directly speak to ‘genetic potential’. For instance, Stewart addresses the idea that genes can affect a person through essence, rather than experience, when discussing the ethics of genetic trait selection methods.

If we revisit Stewart’s recollection of his mother, we can see that Stewart finds fault with her advice on genetic trait selection techniques, in part, because he identifies NF1 as an intrinsic part of his individual identity:

> [My mother] was always telling me: “You must never have children”. Because I think I learned quite early that this was genetic... And I can remember on at least one or two occasions her telling me, “If I had known that I had had NF, I would

> never have had children." Which is tantamount to saying, "you should never have been born".[56]

Stewart did not take his mother's comments to mean, 'I wish, you, Stewart had been born without NF1'. Instead, he understood her as saying, 'I wish you, Stewart, had not been born because you are a person with NF1.' Much as disability rights activists attest, "I would rather be me than unborn" (Hacking 2006: 89), Stewart is here identifying his NF1 as an inalienable part of himself. NF1 is such an intrinsic part of Stewart's identity—or at the very least, this was his mother's opinion, which he then internalised—that he believes without this genetic difference, himself, and future people like him, would and never will exist.

Thus far, I have detailed how Stewart sees NF1 as defining himself through experience—that is, the consequences of genetic stigma on his reproductive choices—as well as through his genetic potential. These two influences on his identity are discrete—one concerns the consequences of living with NF1, while the other concerns how NF1 is intertwined into a person's essence—yet both influences speak to how Stewart defines himself as a product of his neurofibromatosis. In contrast, in other parts of our discussion, Stewart detaches himself from his NF1 entirely. In our later conversations, Stewart entertained the idea that there is an essence to himself, a "soul", which existed before he was conceived. Although he is an atheist, he explained that he finds it helpful to entertain the thought of people choosing their lives before birth. In particular, he likes to think that he chose this life to learn important lessons missed in past lives. Although Stewart treated this abstraction of persons as more of a thought-exercise than a truth, (a distinction I will unpack in Chapter 5,) I hold this abstraction is nevertheless telling. I find it helpful here to reverse Strathern's theory of association. Whereas she writes that what can be brought together in specific cultural contexts is telling (1992: 6), I hold that what can be separated in specific cultural contexts is equally intriguing. The fact that Stewart can imagine his true self as separate to his genome speaks to the plasticity of his cosmology. So, while Stewart attests that if a child had been born to his mother without NF1, then that child could not have been him, at the same time, he can imagine himself separate to the genome he now inhabits.

In review, given the content of other participants' gene talk, it is unsurprising that for Stewart too, the significance of genes fluctuates. On the one hand, Stewart thinks with genes in a variety of circumstances. He does so when considering the lives and identities of future people; he defines himself in the present in reference to his

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[56] Even though new genetic selection *technologies* were not available in the 1950s, we can still identify the decision—to not have children in light of a known genetic condition—as an example of a genetic selection *technique*.

genetic condition, which has endowed him with a unique body, skill set, and brain; and he considers the impact of genetic stigma vis-à-vis how living with a genetic difference in an unforgiving society has led him to become a kinder and more empathetic person. And yet, on the other hand, Stewart states that while NF1 "is part of who I am, [it's] not all of who I am". He can imagine himself beyond his genome within thought exercises. The way genes permeate Stewart's life and philosophy is complicated and inconsistent, but I do not believe it is incoherent. By exploring the more subtle gene talk of my participants—including Stewart, but also Tara, Jamie, Imogen, Noa, Hannah, and of course, Zoe—we can see that there is a great deal of flexibility to the place and significance of genes in their cosmological understandings. Genes can be understood to affect the very goalposts of genetic potential, and yet the exactitudes of their influence—such as on the brain—remain characteristically imprecise. In summary, given the presence of genetic explanations in participant cosmologies, I believe it is fair to say that genes are salient to the ontological and epistemological thinking of these participants, however, I cannot overstate the elusiveness of genes and genetic explanations.

Part 3: Missing Gene Talk

Whereas genes are at the forefront of Stewart's mind, for other participants these units of heredity are avoided or else eschewed altogether. This chapter's third and final section addresses this reality. To begin, I return to my participant in southwest London, Tara, and her daughter with NF1, Tatleen. Tara was eager to tell me how her religious belief affected her experience of having a daughter with NF1. She saw her faith as essential to every aspect of her life, and especially crucial in giving her the strength to navigate family life with NF1. In contrast, when I asked how her religious belief affected her *perspective* on genetic difference, Tara was at a loss for words. I was surprised by this contrast. Throughout most of our discussion, Tara was quick to bring the conversation back to God. She spoke of Christian apologetics, "Christian family values", Christian perspectives on death, Christian attitudes to work and money, and the importance of a Biblical education. She even asked if I was a "Christian anthropologist"—a question aimed at ascertaining whether the underlying purpose of my research was to promote "the glory of God" and to spread the Christian message.[57] I was expecting, perhaps hoping, that Tara would mimic the supposedly widespread

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[57] To reiterate, Tara was my only participant not recruited through NTUK. I was introduced to her through a family connection. My late grandfather, who was a church minister in Hertfordshire, had worked with her husband, who headed up their small church in London.

American belief, that “genes have soul-like, mystical properties... [That DNA is seen as] immortal… sacred… and even at times divine itself.” (Nelkin and Lindee 1995: xix) Thus I was taken by surprise when Tara did not defer to a predefined “Christian” perspective on genes and on the ethics of genetics as a science.

Of course, Tara held opinions on new reproductive technologies which were informed by her faith. In her own words, scientists should not be “messing around” with reproduction. But aside from this Christian natural law stance, Tara did not eagerly offer specific views around genetic trait selection technologies. When I pushed her on this—which I admit was perhaps not best practice—she simply stated that one would be “going against God” if you tried to intervene in reproduction. Tara did later add some further reflections on the matter. On one occasion, she brought the conversation back to NRTs and mused on Tatleen’s reproductive future: “[I would] only be okay [with NRTs intervention] if Tatleen could have whoever the child was, NF or not.” As I consider this off-handed comment now in hindsight, I am struck by how Tara succinctly summarises the tensions I have discussed in this chapter. To rephrase Tara’s comment, she remarked that *if* scientists could hypothetically remove NF1 from a person without changing who that person was or could be, only *then* would it be okay to treat NF1 in the germline DNA. If this treatment-without-identity-change cannot be guaranteed—either through technological or philosophical limitations—then Tara would not feel comfortable with such an intervention. Yet aside from this brief, profound comment, Tara would not engage further in reflections on the nature and significance of genes. When I asked—and again, in hindsight, it was perhaps ill-advised for me to pose such directed hypothetical questions—whether Tatleen would have NF1 in heaven,[58] Tara considered the question, but ultimately deflected, saying, “I would have to ask my husband. I don’t know what to think about that.”

Tara never did get back to me on what she or her husband thought about NF1 and heaven. We spoke several times after,[59] but she never revisited her gene talk. I could dismiss her lack of commentary on the significance of genes as a symptom of the fact

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[58] I asked this question in part to try to access her gene talk, but also to revisit a comment she had made previously. Earlier in our meeting, Tara had explained that Tatleen’s classmates would sometime ask her about her café-au-lait marks. Tara taught her daughter to respond that they were “God spots”, or “special spots which God has given me”. If God gave Tatleen these marks—which are part of the diagnostic criteria for NF1—then will these marks exist on Tatleen’s body in the afterlife? Within Tara’s evangelical Christian understanding, Christians will be given new, perfect bodies after the rapture. My question of whether Tatleen will have NF1 in heaven was designed to ascertain whether NF1 is a part of who Tatleen is at her core—and accordingly who she will be in heaven—or a disease that will be erased when “heaven and earth [pass] away” (NIV: Matthew 24 verse 35).

[59] Which I note in part to reassure my reader that I had not upset Tara with my questions, merely confused her.

she was a busy mother with little time to introspect, but this would be disingenuous. Tara gave much thought to our discussion and various facets of her life. In fact, we both commiserated over self-identifying as “over-thinkers”. Instead, I hold that her lack of apparent gene talk speaks to a general pattern I observed among most of my research participants: genes were accorded significance whilst simultaneously not given much thought. Tara was not alone among my interviewees in eschewing thoughts on genes. She evidenced that she was not unique even in her church. Tara recalled to me a humorous exchange when Tatleen was a sick newborn. A group of ladies had taken it upon themselves to pray for Tara and her baby, and informed Tara with enthusiasm, “we have prayed that God will remove the NF1 from her [Tatleen]!” Tara rolled her eyes when recalling this interaction, and elaborated, “of course, I didn’t correct her. She didn’t know NF1 isn’t like other diseases. But I did think to myself how silly it was that she was praying for that [since it is something that does not exist as a possibility].” After narrating this incident in good spirits, Tara became more serious. Recalling the church’s misunderstanding of the nature of NF1 reminded her of how lonely and isolated she had felt in those early years of Tatleen’s life. Her “church family” was always there for her, and more importantly in her mind, God was always there for her. Yet the people in her life could not understand how she felt.

I believe that Tara’s isolation problem was not simply a result of the fact that NF1 is a complex and largely unknown health condition. I hold that the congregation’s ignorance to the peculiarities of NF1 evidenced a distinctive attitude—an attitude wherein genes are simultaneously accorded significance and ignored. To evidence the workings of this dynamic, consider the following contrast. Whereas some communities believe genes do *not* affect biological life all the time—such as Shaw’s participant who dismissed “‘genetics’ as ‘what happens when you marry cousins’” (Shaw 2009: 248)—for Tara’s congregation, genes *did* matter all the time. However, that does not mean genes were always thought about. In fact, in Tara’s church, there appeared something of a preference for people not to think about genes too much. If we return to Tara’s difficult experience during Tatleen’s infancy, we can see that Tara was not only faced with her daughter’s difficult physical symptoms, but she was also dealing with the isolation of being compelled to think about her daughter in genetic terms—an introspection she found isolating in that there were no others she could turn to who also thought about the influence of genes. I wish to conclude this section by noting other instances where it was obvious that genetic introspection was an uneasy practice.

Hannah, whom I have quoted earlier in this chapter, was uncomfortable revealing too much about her thoughts on genes. Hannah is in her early twenties. Much of our conversation concerned her media and communications undergraduate degree, which she completed recently, and during which she interviewed the actor Adam Pearson for a documentary filmmaking assignment. As we discussed her years at university, Hannah recalled an unpleasant incident in which a close friend made casual and hurtful comments regarding genetic health and ethnicity:

> A second-year friend at uni [who was a medical student] asked if I was Ashkenazi. She then said there was a connection between that and [my] NF1. I don't think that's true. But I know Ashkenazi people are more susceptible to certain conditions because of a smaller gene pool. I'm not sure of the words. Jews are more common to get things because we don't tend to marry out. There are so many words I don't want to use because it's difficult… I stopped using the word "disease"—implies you can catch it or that there's something majorly wrong with me… There are so many words I don't want to use because it's difficult… I don't know the [right] words… I don't think I've experienced antisemitism connected to my NF as far as I'm aware, but yeh, [I was uncomfortable with her association between NF1 and Ashkenazim].

In this passage we can see Hannah's discomfort at the association between genetic risk and her ethnicity, as well as her own hesitancy to comment further on the genetic dimension of her condition. Of course, part of Hannah's hesitancy can be explained as fear of technical inaccuracy. She would certainly not be alone in this. One of my key participants, Amy, was so worried about saying something inaccurate that she requested the right to proof every quote I used. Yet where Amy is a professional geneticist with colleagues' opinions to worry about, the source of Hannah's reserve appears obviously disparate, or at the very least more complicated.

Hannah, like Zoe in the preface to her gene talk (please revisit page 52), was wary of appearing too keen to talk about genes. While I can only presume Zoe's awareness of historic associations, Hannah made it clear that she feels the specter of twentieth century eugenics haunts modern discussion of genetic selection techniques. In Hannah's words, one, "has to be careful how you approach genetic screening. You don't want to say, 'those that do have [NF1] don't have the right to exist or are not as human as us.' If [you reason for genetic selection techniques] that way, then that's offensive. Where's the line? You're going into what the Nazis did with their 'better' human ideas. You have to be careful how you approach it." To a certain degree, I am disappointed that Hannah did not wish to comment further on this association. I was intrigued to hear her thoughts on the motivations which spur people to use new reproductive technologies. Be that as it may, I had to respect her tacit discomfort, and, in the end, understand that her unwillingness to comment further on the matter was data in and of itself. Where participants did not want to partake in gene talk became just as telling as the content of any gene talk—and neither approach negated the importance of genes in participant cosmologies.

Conclusion

To conclude this chapter, I wish to reiterate that the difficulties I faced in accessing participants' gene talk went from being a stumbling block to an opportunity. Genes were evidently seminal to my participants' understandings of the organic world. From potential, to personality, to fertility, this chapter has demonstrated how my participants apply genes to a vast variety of phenomena. However, the relevance of genes and genetic explanations to everyday life evidently fluctuated. Rather than becoming disheartened or dismissing genes as “slippery” objects in an ill-defined cosmology, I have instead paid *increasing* attention to these fluctuations. To reinvoke a quotation used in my introductory chapter, “contradictions and paradoxes are powerful tools” in ethnography, often becoming “the point of the work” themselves (Pugh 2013: 48). So, while my participants' gene talk might at points appear contradictory, sparse, or even hesitant, I hold it is all the more important to ask why.

In responding to the scarcity of gene talk by paying increasing attention to genes and their relevance, I invoke the logic of previous anthropological works which have accessed core issues of cultural difference by attending to phenomenon which at first appeared confusing or disappointing. One such example is the early work of my undergraduate dissertation supervisor, Paloma Gay y Blasco (1999). Gay y Blasco entered her field site excited to speak to her informants about their history, only to find that such talk was taboo. Rather than relocating her PhD project, she persisted, and came to learn that this taboo evidenced a specific practice of cultural transmission.[60] In the same vein, having completed my fieldwork, I have found that fluctuations in the significance of genes, and unease around gene talk, are in fact signposts to a culturally specific practice of knowledge management. Yet before I can fully detail my argument vis-à-vis my participants' management of genetic knowledge, I must continue to lay contextualising groundwork by detailing the place of genes in my participants' cosmologies. Such has been the purpose of this chapter, and such is the purpose of my following one. As such, I wish to close by summarising and reviewing the various ethnogenetic knowledges which I have thus far canvassed.

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[60] Rather than passing down heirlooms which invoked all too painful memories of passed loved ones, the Gitanos community with whom she worked passed on their culture through instruction of sexual morality (Gay y Blasco 1999).

During my fieldwork, I came to appreciate that Zoe was unusual in her enthusiastic participation in gene talk, but not exceptional in her belief that genes specifically—as opposed to nature in the abstract, or any other substance—are the locus with which to think about individual identity and agency. Zoe, along with numerous other participants, struggled to imagine a person without their NF1. In Zoe's words, when a genetic difference is "knitted in" to who someone is, it is impossible to take it away without changing the very essence of who they are and can be. At the same time, other participants enjoyed abstracting themselves and others from any specific genome. The disparity of these two perspectives were oftentimes collapsed in the gene talk of a single participant. For example, Stewart identifies himself so much with his genome that he laments genetic trait selections methods which would ensure people like himself were never born. And yet at the same time, Stewart entertains the idea that he existed apart from and before his genetic lot in life. There was evidently an ontological fluidity to genes, which resulted in highly idiosyncratic and dynamic ethnogenetic knowledges. While Zoe was interested in reflecting on how genes determine a person's sexuality and gender identity, Noa preferred considering how NF1 can lead to neurodivergences, all the while Hannah remained unsure as to the extent to which NF1 affected her personality. In terms of the exact working of genes, it seems that for my participants, it is to each their own.

Despite these idiosyncrasies, or perhaps because of them, my participants can all be said to align with the following perspectives on the role of genes in identity formation. Within certain cultures, such as the ones I observed, a genome is not synonymous with identity. Identical twins are two different persons despite identical DNA (Green 2001: 31) because they each call themselves a discrete "self" (Appell-Warren 2007: 109). That being said, a genome is still more than a marker or a precursor of personhood. Where genes are understood to affect cognition as a part of the goalposts of genetic potential, they are seen to be critical to individual identity formation (Kass 2003: 16; Nelkin and Lindee 1995: 9). In short, genes sit somewhere between a determinant and a full explanation of individual identity. Within this framework, the exact workings of genes are left to the individual to decipher or ignore. To a certain extent, it is surprising that within a culture so enthralled by genes there remains so much freedom for this substance to be interpreted. Yet it is this very freedom which continues to fascinate myself as a researcher and my participants as negotiators of the significance of such knowledge.

Chapter 2 Prelude: The Day of the London Marathon

On an exceptionally windy day in October 2021, I conducted my first in-person fieldwork with NTUK. When I arrived in London from my home in Cambridge, I was excited to meet Sven for the first time. Admittedly, I already knew Sven well by this point. To review, he is the Marketing and Operations Manager of NTUK and oversees much for the day-to-day running of the charity. It was Sven who replied to my first email to NTUK back in the August of 2020, Sven who advocated to NTUK that they should assist in advertising my research, and Sven who advised me on whom I should contact and whom I should interview to gain a better understanding of NTUK. Owing to the scope of his assistance, we had been in regular contact by both video and email for 12 months. However, despite this familiarity, and despite his own participation in one of my interviews, I was nervous to meet him and other members of the office team in-person. (I anticipate I was not alone in feeling socially rusty after the isolation of the pandemic.) I had been instructed to wait outside an Italian restaurant near the finish line of the London marathon at 1PM. I could tell I was headed in the right direction as I approached Trafalgar Square. Busier even than usual, the crowds were sprinkled with victorious runners wrapped in foil blankets and adorned with medals. The end of the race had already begun. I remember quickening my pace to the restaurant, nervous that I was late when in fact I was comically early. (Only later was I to appreciate that runners would still be completing the race late into the afternoon and evening.) I arrived five minutes before Sven, who was also exceptionally early.

Sven is hardworking, to say the least. Just a few weeks before my day at the Marathon, I interviewed a member of the office team who was keen to sing Sven' praises. She reminisced about a day at the London Marathon several years prior. A NTUK runner was not feeling well after completing the race, and Sven stayed on until late into the evening to check they were okay. Another employee told me of how Sven monitors his phone out of hours, often replying to emails in the pub after work. (Sven explained to me that he checks his emails out of office hours in case someone has contacted NTUK in distress. He does not want to sit with the idea that a person with NF1 is waiting for a reply, feeling worried and alone.) Suffice to say, Sven is industrious. He is also relatively well known. Sven is so involved in NF1 outreach—and so distinctive given his German accent and unusual way of speaking—most of my participants knew, or knew of, Sven.

Once Sven arrived and we had exchanged pleasantries, we got to work setting up NTUK-branded balloons. I am terrible at blowing up balloons. What is more, as soon as our balloons were inflated, the wind snatched them away from our outdoor table. We began tying the balloons down to the restaurant chairs and weighing down NTUK posters and leaflets with our bags. We needed some way for the NTUK runners—that is, runners who had booked their place at the marathon through NTUK and were fundraising for NTUK—to recognise us. After about an hour, the NTUK runners started to trickle in and continued to do so throughout the afternoon. Sven and I greeted the runners along with their families who had come to support them and handed them NTUK goody bags. We also took photographs of these families for the NTUK website. The runners were mostly men unaffected by NF1 who had children with NF1, although there were several runners who themselves had NF1. Claire, the charity director, arrived about an hour into this ad-hoc meet and greet. I watched her interact with the families and was surprised by how many of them she knew by name. I was also surprised by how candid she was with me, explaining—in the down time between the group visits—which of the families were big donors, how many years each of the runners had been competing, and so on.

After a few hours, I joined another office team employee of NTUK in the marathon stands on the Pall Mall. Our mission was to support and photograph the NTUK runners still racing. It was difficult to identity the NTUK branded jerseys among a sea of runners. Even with an app that allowed us to track the progress and location of our runners, and even though our jerseys were bright orange, we struggled to find our people. I noted to myself how many runners were fundraising for medical causes. I remember shirts for various kinds of cancers, mental health conditions, dementia-causing-conditions, and so on. The marathon commentators over the loudspeakers made note of “the important causes we’re running for.” Amusingly, there were two runners in extravagant papier-mâché rhinoceros costumes who were fundraising for animal conservation efforts. My NTUK-companion pointed them out with a tone implying she thought their cause was not serious enough to warrant a place at the marathon. After I had been in the stands for two hours taking photographs, I returned to the restaurant to find Sven and help take down decorations. Sven was grateful for the few pictures I managed to capture of the runners, and immediately went to work inserting them into a press release for the website. I imagined other charity workers were doing the same that evening. Each jersey I saw, each biomedical charity, was most likely backed by an office team with their own hardworking-Sven eager to share the day with their respective biosocial community.

Chapter 2: Genetic Community

> Critics [tend] to suggest that the new medical genetics leads to a focus upon the individual as an isolate. We disagree. Within such practices, individuals are subjectified through their location in a matrix of networks.
>
> - Novas and Rose (2000: 490)

> I get this all the time, "can I meet someone else with it?" And the first answer is actually everybody's different. Just because they've got [an NF1] diagnosis, doesn't mean they're gonna be the same as you. And I think that's really important [to stress], 'cos if you want to set up a self-help group for NF, everybody that goes to that group is gonna be different and have different needs because it is such a variable condition.
>
> - Bea, NTUK Specialist Nurse for the Southwest of England

These two excerpts illustrate a tension I observed during the course of my fieldwork: namely, that the collectivising potential of genetic knowledge appears incongruous with the idiosyncrasy of NF1 experiences. Bea, a participant in my research, did not want to introduce her NF1 patients to each other. She felt that a mutual diagnosis of neurofibromatosis was, on its own, not enough to warrant a meaningful connection among otherwise geographically dispersed individuals. In the end, it was a shortfall in funding, rather than Bea's conviction, which prevented the establishment of an NF1 patient group in the southwest of England. Nevertheless, I found her caution to be productive in that it challenged me, and by extension her patients, to consider why someone with NF1 would want to meet another person with NF1 even when there was a near guarantee they would not share a symptomology.

In this chapter, I explore this tension between the evident desire for community among my participants, and the reality that genetic similarity—based on the mutual presence of a biomedical condition, rather than shared ancestry—does not generate an obvious or easy kind of collectivity. The purpose of focusing on such genetic collective identities is threefold. First, it is helpful to lay the terrain of my fieldwork. Interactions between various NF1 groups and individuals coloured the experiences of my participants. It is necessary then to contextualise my participants' thoughts, actions, and stories within a broader "matrix of networks"—to borrow Novas and Rose's turn of phrase. Second, this is an opportunity to question the received wisdom that NF1 groups are a straightforward example of biosociality. By developing the analytic work of Ablon (1999) and Carrieri (2011; 2016), I unpack why Rabinow's concept of biosociality—along with later iterations of this theory—cannot sufficiently account for the motivations, behaviour, and understandings of my participants who are deeply engaged in NF1 communities.

Thirdly, and ultimately, my intent is to investigate the shifting significance of genetic knowledge in the context of collective identity initiatives. To what extent is there (or to what extent can we speak of) an 'NF community' that is based on participants' understandings of genetic affinity? At the outset of my research, my presumption was that people with NF1 are drawn to each other, at least in part, because of a mutual identity rather than simply shared experiences, symptomatology, and an interest in healthcare advocacy—important as these might be. In my research, I found that while my participants were certainly interested in speculating on a shared genetic identity, I was not able fully to confirm this hypothesis. The NF1 communities I encountered appeared more successful in furthering mutual interests than in generating a shared identity. That being said, the *desire* for shared genetic substance to be a sufficient basis for community was nevertheless palpable among my participants. As such, with this chapter I further my exploration of cosmology not with an analysis of what people have said about genes, but with an analysis of how participants' behaviour towards others with NF1 speaks to their understanding of the significance, however small, of sharing genetic material.

The structure of this chapter is as follows. First, I describe the NF communities encountered during my fieldwork. A brief working definition of community will be offered, but for the most part this subsection will remain descriptive rather than analytic. In the next section, I consider the shortcomings of existing theorisation on NF1 collectivity. Rabinow's writings on biosociality—along with subsequent developments of this concept—will be evaluated, before I unpack how we can better understand the connection between genetic knowledge and my participants' identity formations. The final subsection will address the "imagined genetic community" (Simpson 2000) I observed in the field with references to anthropological literature on genetics and ethnicity. Throughout this chapter I continually draw on the experiences and wisdom of three key participants with NF1—Sharon, a retired nurse in Essex; Jamie, a young professional in Wales; and Chris, who lived in London—along with insights made by a select few others, to illustrate the broader patterns I observed during my fieldwork.

Definition of terminology

My use of the word "community" is qualified. Whilst the term is commonly employed both within and beyond academia, its definition is contested. Anthropologists and sociologists, such as Novas and Rose (2000: 490), make the explicit point of referring to patient groups—composed of individuals with a shared "genetic risk"—as a form of community. They argue that in the context of the new genetics, people "are brought into relation with novel networks of interaction—those not of 'society', but of 'community'—groups, associations, communities of those similarly at risk; groups of patients at particular hospitals or clinics; participants in trials of new therapies" (2000: 490). In contrast, my participant Bea—quoted in the opening of this chapter—believes sharing a genetic diagnosis is insufficient grounds for community. In response to my question of whether she thought, "it was hard for people to foster a sense of community given the fact NF1 is such a variable condition?" Bea challenged:

> I don't know what 'NF community' is. I'm not really sure what that is. I think, from a medic point of view, there's a bunch of doctors and nurses who have been in the field quite a long time, and I suppose that's a medical community in that we all share and use the same skills and knowledge, we all share the aim of wanting to help patients. Does that extend to patients? I don't know. There are so many patients with NF1. With NF2, it's slightly different because there's a smaller patient group, but again, my [NF2] patients wouldn't think of themselves as a community.

Moreover, while Bea champions physical interaction as the defining feature of a community,[61] Anderson (1983) posits that *not* meeting other community members can be a key feature of an imagined community. For the sake of clarity, here in this descriptive exposition I use the following working definition: NF communities can be defined as people with NF1 either becoming aware of, or actively engaging with, others with NF1.

Part 1: Description

Mapping NF1 Communities

While the primary purpose of this chapter is to test the significance of genes in the context of collective identity formations, it is first necessary to lay contextualising groundwork. To do so, in this section, I chart who knew whom among my participants, and describe the various offline and online communities I encountered during my fieldwork. In the introduction to this thesis, I have already covered the structure and practice of Nerve Tumours UK. I wish to add only a few comments on how this charity facilitates community among people with NF1. First, through their social media channels and physical quarterly magazine distribution, NTUK creates common points of reference for my participants. Five participants mentioned regularly reading blogs circulated by NTUK—including an almost bi-weekly blog by a teenage girl with NF1,

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[61] When discussing the lack of transport infrastructure in her area, she lamented that, "it can take hours for the bus to come if it comes at all. How are [people with NF1] supposed to be a community if they can't even meet?"

which was particularly popular. Even if my participants did not know her name—referring to her simply as "that girl in the blogs"—they would still regularly check the NTUK website and social media channels to keep up to date with her progress at secondary school. In addition to these para-social relationships, NTUK also hosted the occasional large in-person event where people with NF1 could meet in a setting sponsored by NTUK.

While NTUK was central to the workability of my project, several of my participants felt their most tangible connection to others with NF1 was *not* through this charity. Five of my participants discussed at length their regular involvement in offline NF1 groups independent of NTUK. Throughout this chapter, I refer to these groups as alternative NF1 communities.[62] To illustrate how these autonomous groups can differ in scale and style, I draw on two participants—Sharon and Jamie—and their respective experiences of non-NTUK NF communities.

Sharon's Local Essex Meetup

Sharon is a retired nurse who lives in Essex and enjoys gardening and playing with her niece's children. During her nursing training, decades ago, she was diagnosed with NF1 after a biopsy revealed a worrisome lump to be a benign neurofibroma. Sharon insists she feels "very lucky" with her NF1. In our meetings, she referenced several friends "[who] have got lots of NF problems", including curvature of the spine and bowing legs. Her "mild" NF, as she sees it, is nothing in comparison. Sharon met her "lumpy friends" through a local NF support group two decades ago. Inspired by her already established love of volunteering and charitable work, Sharon decided to take a turn running this group. Sharon boasts that each meetup would attract about twenty attendees. Most of these regulars were unaffected parents, with affected children,[63] who travelled no more than ten minutes by car to the church where the meetups were hosted. Over our various calls during the autumn lockdown of 2020, Sharon was keen to reminisce about the eclectic mix of activities she coordinated for the group. During her recollections, she stressed how she endeavored to make the group a social club, and not

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[62] When I refer to "NF1 communities in the UK" in this chapter, I am addressing both larger structured organisations such as NTUK, along with smaller, grass-roots level collectives.

The term "NF1 community" is used as a good-faith placeholder: while this chapter debates and sometimes refutes the coherence of any NF1 community in the UK, I believe it would be cumbersome and disparaging to speak of "attempted NF1 communities".

[63] Sharon does not have children but enjoys volunteering with young people and getting involved in the lives of her friends' children. During our calls, she explained that she decided not to have "her own" after receiving her NF1 diagnosis. However, later in our conversations, Sharon reflected that "if she had her time again", she would not let NF1 prevent her from pursuing dreams of having her own family.

just a support group. She wanted to balance fun and reflection. In our second meeting, Sharon accounted for the formation and life of the group:

> The Essex group started off being run by a lady called Gilly. She had got a young son with it… she did it for quite a few years. Then somebody else took over from her because she wanted to spend more time with her son, 'cos he was quite disabled at the time. He had NF1 quite badly. Jim did it for quite a few years, and then [Sara and I] thought 'perhaps it's nice if there's a change of people doing it.' So, myself and Sara took over running it. Penny wouldn't come to the meetings, but Carol used to come…
>
> We all ran the group differently. I didn't want us to come and sit in a semi-circle in the church hall, with biscuits and cakes, just talking about our lumps. I wanted us to be doing some fun things as well. So, what I tried to do was try to always have one fun thing [to look forward to]. I think we met every couple of months…
>
> I did a Ploughman's lunch,[64] and then one Easter we did an Easter egg hunt… me and Carol made bunny ears to put on the kids… I got somebody from the Red Cross to come to show us how to camouflage your lumps… Sara, she did a sponsored swim. I managed to take the children to the panto,[65] and we took them to Southend-on-Sea for the day: the local firemen had already raised the money and they wanted a charity to give the money to, so they gave it to us [and we took them to the beach.] We also gave some of the [firemen's] money to Carol so she could decorate the children's bedrooms, 'cos they were quite young at that time… What else did we do… We went to the park; we did all sorts of things.
>
> I tried to make them fun things if you know what I mean, rather than just always talking about "what was wrong with us". But we tried to alternate it, so we did have time, if people *did* want to talk about their lumps. But as the children grew up, the parents didn't have a need for the group, so it just dispersed really, [about twenty years ago].

Sharon explained that she harbors no sadness over the group's disbanding. She acknowledged, "people just move on, not in a bad way", and reassured me—since I must have looked concerned over Zoom—that she still has a robust social life in her retirement. Along with volunteering at a local school, Sharon now regularly engages with the "NF association group"—by which she means NTUK—which is where she learnt of my research. I asked if she was still involved in the local church where the NF1 meetings took place, to which she explained that the location was never really a religious priority for her.[66] In fact, Sharon and I spent considerable time in our later meetings discussing the duality of her Christian identity with her distant Jewish roots. During the course of our calls, we sadly also had occasion to discuss the loss of her friend Carol's son, who died young of complications associated with NF. Sharon told me, "Since I've spoken to you, very sadly, Carol's son has passed away with NF1. He

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[64] A Ploughman's lunch is a meal consisting of bread, pickles, and cheese.

[65] A pantomime, here abbreviated to "panto", is an interactive play which is popular in the UK, especially around Christmas.

[66] Although she identifies as a Christian, Sharon is quick to note that no one in the group was trying to "plug God." The church was no more than a convenient meeting place.

had an NF tumour that ruptured apparently, which I've never heard of before, so sadly he passed away. [It's a] tough time [for Carol] 'cos he was her carer."

Sharon is now offering care to Carol, to help fill the void left by her late son. Although time has moved on from the days of the Essex NF1 meetup, it is evident that Sharon has continued to develop the friendships forged during that period. While of course this young man's death brings to the fore the realities of NF1 complications, over the years, the role of NF1 in bringing these friends together seems less and less relevant. Sharon spoke to me of her "lumpy friends" in much the same way she discussed her nearby relatives. I would contend that her friends— "lumpy" or otherwise —have become part of her local environment (Ingold 1995: 57): that is, they are people she knows on adjacent streets and in neighboring villages, people whose houses she walked by during the long days of Covid-19 lockdowns, and people whom she can rely on. What began as an NF1 patient group, with NF1 as its unifying factor, has developed into friendships beyond the unifying diagnosis.

Jamie and "Midsummer Madness"

In contrast to the local focus of Sharon's Essex group, another one of my key participants, Jamie, is involved in a much larger independent NF event. Jamie is originally from Cornwall. This picturesque county, located at the very south-westerly tip of England, is where Jamie's mother organises an annual NF meetup called "Midsummer Madness". Anyone with NF, or a family member with NF, is welcome to attend. The aim is to offer a fun opportunity for people with NF1 to meet others with the condition. Jamie describes the event as, "not a weekend of woes and concerns [but] friends and family sharing life experiences." He notes with humour that the gathering is, "nothing fancy, it's just in caravans, [it's] bring your own car and tent". There are always outings to the beach involved, come rain or shine, and the central event of the weekend is a barbeque.

Jamie observed that Midsummer Madness has changed very little over the years, although perhaps it is now a little "more relaxed" and less structured than it was during Jamie's childhood. Jamie claims that through his annual attendance of Midsummer Madness, he has "met most of the people in the southwest with NF1." Moreover, Jamie beams, "people come from all over UK, even Blackburn, all the way to Cornwall for it". Although Jamie's mum has been involved in "the NF Association"—that is, NTUK—since Jamie was first diagnosed as a young child, Jamie is quick to emphasize that the summer meet-up was "never run as a part" of NTUK: it has always been "more of a mum-alone thing".

Jamie was diagnosed with a spontaneous mutation of NF1 when he was just four years old after developing facial asymmetry. In addition to having what he calls the "tell-tale signs" of NF1—including multiple café-au-lait marks—Jamie also has an eye which, in his words, "grew weird… like the Hunchback of Notre Dame".[67] In our second meeting, unprompted, Jamie rummaged through his living room to find a picture of himself from around the time of his diagnosis. In the photograph, a young Jamie—small, blond, and smiling with a slight squint—is sitting merrily on a sandy beach. Jamie explained that he wanted to evidence how different he looks now, with his thick, dark hair—which he attributes to his "Cornish blood"—and his now more pronounced visible difference.[68] Throughout his life, Jamie has undergone numerous tumour-debulking surgeries. Yet despite time lost to hospital procedures—both on his face and in his hand—Jamie has made impressive advances in his career. Now in his late thirties, he holds a managerial position at a large media company in Wales and is one of the most affable people you will ever have the fortune to meet.

Even with his busy professional life, Jamie makes time for Cornwall. He regularly stays in touch with his childhood friends and is happy to answer any questions their young children might have about his facial difference or the "bumps" on his neck. What is more, between our calls, Jamie often made the long journey between Wales and Cornwall to keep his mother company, help her with heavy work around the house, and to assist in preparations for Midsummer Madness. Jamie's mother needs his help. Several years ago, there was a freak accident: a shop sign fell onto both Jamie and his mother. Although Jamie bounced back quickly, it has taken his mother years to recover, and she still has pain associated with the blow. Yet despite her physical difficulties—compounded by interpersonal struggles, including a divorce from Jamie's father, and attending to the needs of her other son, Jamie's estranged brother— every year, for the past 26 years, Jamie's mum has run Midsummer Madness. What she and her ex-husband started in response to their young son's NF1 diagnosis, she now continues to run for other affected children and their families across the UK.

I imagine the respective communities (of Midsummer Madness and the Essex meetup) deeply appreciated the organisers' dedication in keeping these events running for so long. Several of my participants—including a young woman in Yorkshire and a

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[67] I was surprised to hear Jamie make this comparison. To reiterate, Joan Ablon (1995) argued that people with NF1 in the United States are "haunted" by NF1's mis association with other conditions and differences.

[68] The UK charity, Changing Faces, prefers the term "visible difference" to "disfigurement" when describing "a scar, mark or condition on your face or body that makes you look different" (Changing Faces 2023).

middle-aged mother in west London—wished meetups like Midsummer Madness were run in their area. While NTUK does offer a variety of events, these functions are seldom as local in focus as Sharon's meetup, nor are they as open ended in structure as Midsummer Madness. As noted earlier in this chapter, NTUK Specialist Nurse Bea remarked that patients often express a desire to meet others affected by NF1. However, unless local clinics offer local contacts and contact details, people with NF1 are isolated from each other. Their options are to travel to larger cities to attend NTUK events, or to rely on online support networks. One participant spoke of her frustration over the scale of NF1 events run by NTUK. She never knew if she would meet the same person twice, and as such it was hard to foster friendships.

Online Communities and Shared Knowledge

It is difficult to offer an exhaustive list of online NF1 communities engaged by my participants due to the sheer number of available websites. There are forum options—such as *Inspire*'s Neurofibromatosis Network—which provide spaces for discussion and from which my participants sought information upon an NF diagnosis. Facebook groups were popular, especially with my middle aged and older participants. NTUK's private group was the most frequently cited example, but smaller, more niche groups—including one exclusively for distance-runners with NF1—were also repeatedly mentioned. It is fair to say that most of my participants—a skewed sample, since all but two were recruited online—regularly engaged with numerous online NF communities.

Separate to—although likely fueled by—the proliferation of online communities, many of my participants shared in the knowledge of various "NF celebrities". By NF celebrities, I refer to figures who are often known to people with NF in the UK, but who are not famous among the general public. The most frequently cited NF celebrity by my participants was the actor and advocate Adam Pearson. During his career working in media, my participant Jamie has enjoyed several chance encounters with Adam. Another one of my participants, Hannah, managed to secure an interview with Adam as a part of her undergraduate media degree. She was delighted to recount how helpful and approachable he was, despite his relative fame and success. An additional example of a well-known person with NF1 is a young Instagram influencer whom I'll call Aisha. Three younger participants mentioned her fashion page. Aisha showcases her interest in long-sleeved fashion, which covers neurofibromas on her arms and legs, and uses the platform to "raise awareness" of NF1. In addition to media personalities and social media influencers, several medical professionals were repeatedly referenced in interviews. An NF1 researcher and healthcare provider—whom I'll call Barbara—was named, unprompted, by five of my participants. In my own interview with Barbara, she recounted how, after her retirement a few years ago, people in online NF1 chatrooms began speculating whether she had died. She found this both amusing and telling. Barbara articulated, and I agree, that the panicked response of the online networks illustrates the fact that NF1 specialists are known to, and deeply valued by, people with NF1 in the UK. These NF celebrities—medical and otherwise—illustrate the extent to which people with NF1 in the UK have common points of reference.

Finally, I should note that several of my participants knew one another. Sometimes this mutual awareness came as a surprise. After several respective interviews with two discrete participants, I realised I was talking to a brother and sister—neither of whom was aware the other was also partaking in my research. Other times, the connection was more apparent. To give one example, consider the following thread between four geographically dispersed participants. Amy enjoys running and is based in the northeast of England. Sven, my main point of contact at the NTUK office in London, mentioned Amy's running achievements on several occasions. Sven was, in turn, frequently referenced by my participant Emily. She and Sven are good friends. Emily has published about her experience with NF2, which resulted in her losing her hearing as a young adult. Susannah, a younger participant of mine, cited Emily as a source of inspiration. Susannah knows Emily not only through her publications but also through their attendance of the same evangelical church in the south of England. By tracing this thread of connections—from Amy to Susannah—I am not claiming there is a coherent and singular community of people with NF1 in the UK. Rather, I am noting that geographical distance did not always hinder community formation among my participants.

Part 2: Analysis

Reviewing the concept of biosociality is an obvious starting point to this analysis, in part, because Paul Rabinow referenced neurofibromatosis groups when defining his new term in what is perhaps the first mention of NF1 by a prominent social scientist. Of greater importance, however, is the concept's relevance to discourse on identity formation with regard to genetic knowledge. Dimond et al. (2015: 1) attest that biosociality "recognises the central role of biomedical knowledge in constructing genetic identities and producing and reproducing social relationships". By deconstructing the concept of biosociality, I explore "the implications of genetic knowledge for how individuals understand themselves [and] relate to others" (Gibbon & Novas 2008: 2). In this way, I enrich and extend my focus in Chapter 1 on 'gene talk' by addressing the collective as well as individual bases of social identity (Atkinson, Glasner & Greenslade 2007: i). I should mention that in this section, I am not commending biosociality as an analytic tool. In fact, much of my analysis concentrates on highlighting Rabinow's disappointing shortcoming in eluding to, but not fully defining, "genetic identity".

In *Essays on the Anthropology of Reason* (1996), where Rabinow first introduced the idea of biosociality, he sought to compound the nature-culture divide by attending to groups which are at once biological and social. Whereas Hacking posits that an obvious example of a biosocial group is a family or extended kin structure (2006: 81), Rabinow elected to focus on groups formed around knowledge of highly specific genetic variations. Rabinow accordingly referenced neurofibromatosis (1996: 102):

> There already are, for example, neurofibromatosis groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment and so on. That is what I mean by biosociality. I am not discussing some hypothetical gene for aggression or altruism. Rather, it is not hard to imagine groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and "understand" their fate.

Whilst Rabinow's highlighting of neurofibromatosis groups is commendable—given that NF1 is often overlooked despite its relative frequency in the general population—it is, regrettably, insufficiently developed as an example. The main objective of his chapter was to discuss how nature has become a "locus of artificiality" (Gibbon and Novas 2008: 4), and NF groups were invoked merely as an illustration. Rabinow does not specify which neurofibromatosis groups he is addressing, nor does he unpack why he chose NF as an example. My first point of analysis is to argue that NF1 communities are a difficult instance of biosociality, not least because the condition is idiosyncratic to every individual. To allow me to evidence why I hold that biosociality is insufficient in the context of NF groups, I return to my ethnographic observations.

Chris' Story

Chris was an incredible person. He took part in my research between October 2020 and July 2021. During the course of our calls, he was diagnosed with cancer for the third time. Chris died in March 2022. He is survived by his wife, parents, and sister—all of whom he loved fiercely.

> *Having recently discovered his obituary online, I feel grief. Chris was my age. He was generous, wise, and deeply empathetic. He is someone I will always look up to.*

Chris was thirty years old when he first took part in my research. He worked in the tourism and heritage sector in London and had time on his hands after being furloughed during the Covid-19 pandemic. Chris had previously taken part in other NF1 research projects and awareness campaigns. He wanted to increase knowledge of NF1 in part because he had previously encountered difficult employers who did not appreciate that the reason he walked with a limp was the same reason he struggled to write shift schedules. NF1 is multifaceted, and Chris sought to use his public speaking skills to encourage workplaces to be more understanding of complex differences. Although Chris was proud of his employment and advocacy—and even prouder of his wife's impressive career in finance—he felt his employment was only a small part of his life. Moreover, rather than being remembered as a person with NF1, Chris told me he would like to be understood as a book lover, diarist, and writer. It was his love of words, not his condition, which defined him.

Having been diagnosed with NF1 as an infant, Chris was—in his view—relatively unaffected by the condition until he was diagnosed with cancer twice in his early twenties. With intense treatment, he was able to enter remission on both occasions. Whilst undergoing treatment for the first of these cancers—a Malignant Peripheral Nerve Sheath Tumour (MPNST)[69]—a cancer charity called the Teenage Cancer Trust put Chris in touch with another young man his age who was also undergoing treatment for a MPNST. The hope was that these two men could support and understand each other since they both had NF1 and an NF1-associated malignancy. While Chris recovered from that cancer, the other man died. Chris felt survivor's guilt, along with a slight frustration that the two had been connected in the first place. Despite sharing an NF1 and cancer diagnosis, they had very different clinical cases:

> His was bad, mine wasn't. He passed, and that was difficult for me. It was my first encounter [with someone with NF1 outside of my family]. It's a difficult example because that isn't what NF is about. But it goes to show - they took two people with the same sort of cancer, [they thought] "let's put them together", and it didn't really work. It was a sad experience. I didn't know him too long. but [I guess it was] an interesting experience too.

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[69] MPNSTs are rare in the general public, but it is estimated that around 10% of people with NF1 will develop a MPNST in their lifetime (Reynolds 2021). Malignancies such as nerve sheath tumours contribute to the shortened expected lifespan of people with NF1. According to the American Medical Association, "patients with NF1 [have] a life expectancy 10 to 15 years shorter than the general population." (Alcindor 2021)

In a later meeting, Chris elaborated that even if—hypothetically—their prognoses had been the same, that still would not necessitate a productive interaction. According to Chris, sharing symptoms does not automatically generate a friendship:

> I'm not particularly scarred by the [Teenage Cancer Trust] experience, but it had a sad ending. If friendships are gonna happen, they're gonna happen. But it's not the most natural way [for friendships to develop]. If that kid had survived, we probably wouldn't be talking now.

After this difficult introduction, Chris became more reserved when a stranger with an NF diagnosis asked to meet him. Chris explained to me that he would go into such interactions with his "work front" on. That is, he would not be as open and vulnerable as he would otherwise be in his personal life. Chris maintained this protective distance online as well as in person. On various NF forums, Chris befriended and then distanced himself from several young men who felt their NF1 prevented them from developing romantic relationships. Chris could not relate to their experiences: he was confident in his appearance and adored his wife. While these young men shared Chris' NF1 diagnosis—and whilst they may well have shared his symptomology more so than his MPSNT contact—they did not share his attitude or outlook on life. Chris was all too aware that NF1 did not automatically generate a meaningful connection and accordingly entered all such encounters with hesitation.

Chris often found that trivial, non-biosocial allegiances could be more useful in igniting a friendship than a shared diagnosis. He recalled with humour an instance at an NF support group in London when he was excited to see another attendee wearing a Leeds United football shirt. Their mutual support of a sports team was more interesting to Chris than their mutual diagnosis. Even though Chris continued his involvement in various forms of NF community, he became increasingly pessimistic that NF1 would be central to his social life. He succinctly summarised and analysed his experiences with NF1 communities as follows:

> I think it's almost impossible to have a really tightknit [NF] community. We can support one another, but nobody really has a shared experience. The only shared thing would be [the mutual experience of going for frequent] scans… It's difficult because we're all affected differently, so we can't unite to say, "this is what I did [which helped me,] you try," and that's the most important part because you *want* to help... but I've never met anyone who's had a similar experience to me.

I would describe Chris' complicated interactions with others with NF1 as instances of uneasy biosociality. The people Chris encountered shared his genetic diagnosis, but not his specific symptomology or prognosis: moreover, while some might share his experiences of stigma, they did not share his outlook on life. As such, Chris shared neither biological nor social similarity with others in his supposedly biosocial network.

While NTUK and other NF communities I observed in the field can be described as biosocial groups, this description is limited in its capacity to account for the nuanced and difficult experiences of my participants.

Uneasy biosociality can be located not only in awkward interpersonal interactions, as experienced by Chris, but also in the dilemma of representation. NTUK and other collectives struggled to put forward a "poster child"—a term used by several of my participants to describe people with NF1 who are championed by NF communities as advocates and spokespersons. Often, being a poster child involved being featured prominently on NF websites. Even though NTUK has a variety of different "NF stories" highlighted on their webpage, several of my participants still felt this collection was not sufficiently representative of the whole community. Some took issue with the overrepresentation of able-bodied people with NF1 on the NTUK outlets[70], whereas others felt the charity should better highlight the fact NF1 is not always disabling or disfiguring. At first, Chris wanted to put himself forward as a "poster boy", since he was comfortable speaking about his NF. That was, after all, part of the reason why he took part in my research. But after his cancer returned, he changed his mind:

> [My cancer] no longer feels like NF… A year ago, I would've happily been a poster boy for NF1, I would speak about it, that's why I signed up to your thing straight away. I would have been pleased to be on the front of a magazine or whatever. But now... I would be hesitant because I don't want people to think, 'oh my god [this is NF1.]' If someone's considering having a child, I don't want them to look at me and think [this is what NF is], because this is quite a rare story now.

While Chris' experience was indeed a "rare story" within my sample—of my 56 participants, he was one of only two going through cancer treatment, and the only person facing terminal cancer—his perception of his experience was in fact not unusual. More than half of my participants identified as *not* having a "textbook" case of NF1. Participants gave various explanations for their asserted uniqueness. To offer just two examples, Jamie attested that he had a more pronounced facial difference than most people with the condition, and Amy claimed that it was unusual for her to be missing three whole exons from her NF gene. Suffice to say, there is no standard NF patient. This idiosyncrasy results both in a struggle to choose representatives for NF communities, and in tenuous connections within NF communities altogether.

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[70] One such example is my key participant, Stewart. He criticized the fact so many people featured on the NTUK website were extraordinary physical achievers. Stewart once retorted to me, "you don't have to climb Everest to be a good person with NF1!"

To return to my analysis of Rabinow's concept, I would go so far as to suggest that NF1 is perhaps one of the most difficult conditions Rabinow could have selected to illustrate biosociality. I am not alone in this conviction. Joan Ablon observed that the "diversity of NF1" makes building a sense of "we-ness" unusually difficult (1996: 128). Underpinning the observations of my participant Chris, Ablon noted that the "attitudes" of NF support group members "varied as widely as their symptoms and other characteristics" (1999: 126) and that severity of symptoms did not correlate with outlook on the condition. Ablon contrasts NF1 to other genetic conditions which, she feels, are more conducive to group alignment:

> Most genetic disorders exhibit a similarity of symptoms among individuals in the same family, if not with all others with the condition. However, the diversity of symptoms of NF1, even within members of the same family, may serve to make each feel his or her condition is uniquely bad… The distinctiveness of each case, [that is,] the lack of common expectations discourages not only family communication but may preclude the benefits of social support from NF support groups or other sources (Ablon 1999: 155).

The sociologist Carrieri picked up the mantle left by Ablon by making the explicit analytic link between the idiosyncrasy of NF1 and its limitations as an example of biosociality. In his doctoral thesis, Carrieri set out to "empirically investigate whether there is 'biosociality' for NF1, and—if so—how it is structured" (Carrieri 2011: 64). Carrieri attests that he observed several "crucial hindrance[s] to a NF1-biosociality" (2011: 260), including the variability of NF1, such that, "a unified symptomatic identity for such a variable and unpredictable condition like NF1 is less [than] likely to emerge" (2011: 261). In addition to "confirming" observations made by Ablon on NF support groups (Carrieri 2011: 260), Carrieri also cites a group of genetic counsellors who conducted a study on LINK—that is, the earlier iteration of NTUK.[71] Carrieri insists the observations made during this research—that people with NF1 join LINK "more to get information about the condition rather than to use it as a social networking service"—evidences the "serious challenges to the actual and potential existence of a biosociality or biocitizenship for NF1" (Carrieri 2011: 236, 260; Benjamin et al. 1993: 572).

In review, my observations—on Chris' difficult biosocial endeavours, and on the hurdles involved in NF1 representation—confirm existing observations made on the limited workability of NF1 as an example of biosociality, and the limited utility of

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[71] I have not previously quoted Benjamin et al.'s study as a deliberate choice. My approach differed significantly from this group's investigation into the psychosocial impacts of NF1. I am not interested, as Benjamin et al. were, in assessing people's "competence" in medical genetics. I feel this approach works at cross purposes to my anthropological interest which aligns more closely with Simpson, who writes that he is "not policing whether they are understanding genetics "correctly": I am not examining scientific facts so much as the cultural work of metaphor and analogy" (Simpson 2000: 4).

biosociality to explaining the experiences of people with NF1. This shortcoming is not a surprise considering criticisms of biosociality separate to discussions of NF1. Various authors have noted that Rabinow's influence can partly be explained by his timeliness,[72] and that the utility of biosociality lies more with its later utilisations than with his 1999 publication alone. In their investigation into the work done by biosociality, Gibbon and Novas (2008) imply that the theoretical and empirical value of biosociality does not lie solely in Rabinow's 1996 publication per se, but rather with how his work has been utilised by later authors. To see how biosociality has been productively developed, one need only look at the concepts of biocitizenship and genetic citizenship (Petryna 2002).[73] To focus my analysis, I wish to consider a specific discussion on genetics and identity, rather than investigate power and subjugation—as has already been attended to by Petryna among others. What remains to be specified is how to understand people with NF1's interest in building community despite a lack of symptomology or common interest stemming from shared symptomology.

Beyond Biosociality

In the introduction to his thesis, Carrieri observes that, "theoretical constructs like genetic responsibility, biocitizenship, biosociality, [and] medicalization of the family—whilst acknowledging the complexity of genetic information—rest nonetheless on the assumption of a link between genetic information and a sense of certainty and identity." (Carrieri 2011: 12) Carrieri attends to this assumption by exploring this link in the context of neurofibromatosis. He writes:

> The identities of [my participants] with NF1 were fragmented around specific symptoms. Mildly affected individuals often did not want to identify themselves (or be identified) with the more seriously affected, and vice versa. These findings have important implications for the discussion on the notion of genetic subjecthood, responsibility and citizenship. At first glance… NF1 and its genetic nature could actually be relevant for the patients and families interviewed. However, *the salience of genetic information was not a stable, life-long phenomenon*, but tended to vary within and between individuals and to surface at certain critical junctures in the life courses of the participants, who, otherwise,

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[72] According to Pálsson (2007: 212), Rabinow "invented [biosociality] partly as a joke, to challenge the biological determinism of the "sociobiology" fashionable at the time", but with the new genetics, a strong interest in Rabinow's concept emerged. Pálsson thus concurs with Hacking, who claimed that "the [increasing] genetic imperative"—that is, the drive to find genetic underpinnings for all things human, "in sickness or in health, in success of in strife"—fuelled unprecedented "fascination" with the concept of biosociality (Hacking 2006: 81).

[73] According to Mulligan, in "the earliest ethnographic monograph that employs the term biological citizenship", Petryna (2002) analysed how people affected by the Chernobyl nuclear disaster "made demands on the Ukrainian state for access to medical care and social welfare" (Mulligan 2017). In leveraging their "biological injury" to gain access to state-controlled resources, Petryna's subjects are enacting biosociality through what Petryna calls "biocitizenship" (Mulligan 2017).

> deployed downplaying and minimising [genetic] discourses towards their disorders [emphasis my own] (Carrieri 2011: 253).

Whilst Carrieri's attention to this link—between genetic information and identity—is commendable, it is short lived. The focus of his thesis is on uncertainty at the expense of attention to identity. That is, he focused much of his analysis on the consequences of the uncertain correlation between genotype and phenotype in the context of neurofibromatosis. Carrieri claims that because doctors cannot predict if and when NF1 symptoms might arise based on the specific spelling mistake on the NF gene, "the authority and salience of genetic information" is undermined (2011: 118). He thus abandons any further investigation into the link between genetic information and identity formation and returns to this discussion only fleetingly in his conclusion, where he repeats that "the salience of the genetic aspect of [NF1] was not a stable phenomenon in individuals' lives" (2011: 332).

I contest that Carrieri's discontinuation of his investigation into the link between genetic knowledge and identity is a shame. In contrast to his opinion that instability is an analytic stumbling block, I attest that any inconsistency in the application of genetic knowledge to my participants' lives is of the utmost interest. In fact, this inconsistency is part of the main point I wish to make in this thesis—that to my participants, genes are at once significant and insignificant. Accordingly, in the remainder of this subsection, I argue that NF community formations are difficult because there is an evident desire for community—in part because people identify with others with whom they share a genetic similarity—but that this genetic identification is not always constant or satisfying. To begin my analysis of the evidently unstable link between genetic information and identity, I turn to insights made by Rapp, Heath and Taussig ten years before Carrieri wrote his thesis.

Rapp, Heath, and Taussig were interested in investigating "what makes a relative" during the advent of the new genetics (2001). In doing so, they considered a fundamental anthropological query in a new context. The authors refined their research question as follows: "those who ''share a gene'' (or chromosome) for a disorder are felt to be related. But on what is their ''diffuse solidarity'' based?" (Rapp, Heath, & Taussig 2001: 393). This, to me, is the crux of the issue which I have been trying to access. As such, when I encountered this paper, I was eager to hear their thoughts, in order to unpack my own participants' community building endeavours. Rapp, Heath, and Taussig's response is twofold. First, the authors draw on previous ethnographic work conducted by Heath (1997) on Marfan's syndrome. At a conference in the United States, the husband of one of her participants "looked around the dining hall with affection and bemusement, declaring, I used to think those deep-set eyes belonged just to Mary, but now I see them everywhere. It's like a family reunion" (Heath 1997 in Rapp, Heath, & Taussig 2001: 394). The authors claim that this "diffuse solidarity" is based on a popular "reading of the body", with importance placed on "looking alike". Such was the weight given to physical resemblance, that Rapp, Heath and Taussig claim that, through an increasing mobilization of "identity anchored in a genetically marked category", individuals come to identify *more* with other affected individuals than with their own genetically related kin.[74]

In these observations, I find an uncanny similarity with comments made by my participant Jamie. He noted that people with NF1 share physical features which are not otherwise described as "symptoms":

> I've noticed quite a few people [at Midsummer Madness] who had that kind of misshape in the skull, here, like a dip in my skull." [Gestures towards his temples.] "it's just one of these things, and I only noticed it after a few years. But yeah, small things like that. You just you pick up different characteristics. It's the way people speak. It's the way they act. And it's sometimes even in their eyes - it's the shadows [around the eyes.] We all look different, but then I'm guessing we have a lot of similarities.[75]

Jamie here posits, although not in so many words, that one small genetic change can lead to a significant effect on appearance and behaviour. In his view, the impact of this specific gene is vast and visible. Whereas "the reclassification of a disease as being genetic in origin poses some profound questions in terms of how individuals identify themselves in relation to an illness and how they relate to similarly affected others" (Gibbons & Novas 2008: 2), Jamie is making even more radical claims of genetic affinity based *not* on a shared illness but on a shared genetic make-up. Jamie attests that the mutation in his NF1 gene does not just lead to NF1 the genetic condition, but also to NF1-features in his appearance which are separate from his facial tumours.

The second component—of Rapp, Heath and Taussig's argument on how solidarity can be built between those who "share a gene" (2001: 393)—concerns the power of an "imagined community" when tied to "deeply historical ethnic-racial

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[74] Rapp, Heath, and Taussig claim that this extra-familial identification also occurs in other genetic conditions. They write that "those with Down's syndrome [are seen to] have "more in common" with one another than they do with members of their family of origin." (Rapp, Heath, & Taussig 2001: 393).

[75] I must admit I was initially skeptical about Jamie's comments. Surely, he could not recognize others with NF1 based on skull shape? However, later in my fieldwork I encountered literature describing NF1's effect on facial morphology, including the growth of the sphenoid wing (Lampe, Seymour, Thompson et al. 2002), lending 'legitimacy' to Jamie's claim. (I am nevertheless disappointed in myself for not taking his comment seriously prior). One could describe Jamie's identification of others with NF1 as an intuitive diagnosis based on facial morphology, not dissimilar to the practice of Shaw's physician participants (Shaw 2003).

referents" (2001: 394). The authors discuss how the prevalence of genetic diseases within certain populations can reify ethnic identities:

> Where autosomal recessive conditions run at relatively elevated risks among ethnically defined populations, group identity is multistranded. For example, a mother whose child had recently died of Familial Dysautonomia—as mentioned earlier, an Ashkenazi recessive disorder—[wrote] "I'm still a proud carrier of that stubborn gene… I'll continue to say "we" … After all, we will always share that common ancestor way back when in some shtetl" (2001: 394).

Whereas Rapp, Heath and Taussig's first point of analysis—on the "reading of the body"—relates directly to comments made by my participant Jamie, this second point of analysis is trickier. My ethnographic data do not obviously pertain to literature discussing the prevalence of genetic conditions within specified populations. First, unlike conditions such as Familial Dysautonomia, NF1 is no more prevalent in any one ethnic group. According to the Neurofibromatosis Clinics Association, "NF is worldwide in distribution, affects both sexes equally and has no particular racial, geographic or ethnic distribution" (NFCA 2023). Moreover, and of equal importance, my participants do not *perceive* an association between NF1 and any specific ethnic heritage. (While Hannah detailed a friend's association between NF1 and Ashkenazim, she mentioned the association only to condemn it.) Furthermore, discussion about the "frequency of risk" is irrelevant to my sample because my participants—apart from NTUK employees and healthcare professionals—either had NF1 or had a family member with NF1—and as such, any risk had already manifested.

These obstacles beg the question of whether I can garner anything from Rapp, Health and Taussig's second reflection on how people with a shared gene build an identity. I contend that it is this very divergence which helps advance my insight. Rapp, Heath and Taussig's discussion, along with other literature addressing the intersection between genes and ethnic identities, helps my analysis insofar as it illustrates the weakness of genetic identity without mutual ancestry. Consider the following literature addressing people's eagerness to use genetic explanations to fuel existing categorisations. Roberts (2011) observes that researchers in the United States routinely force genetic samples into pre-existing racial categories (2011: 73).[76] Similarly, Sans notes that in Uruguay, genetic research has been interpreted to support the "perceived

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[76] Roberts argues that the spectre of racial science continues to fuel Euro-American fascination with genetics. She attests that the Euro-American association between ethnicity and genetics is "repackage[ing] race as a genetic category rather than replac[ing] it" (Roberts 2011: 57). She continues that any such association is an expression of "a false belief that biological races really do exist" (Roberts 2011: 77; Kelsey in Roberts 2011: 77). Roberts posits that "ancestry is a far more accurate tool than race for describing human genotypes" (2011: 63), yet even so, putting stock in geographic ancestry "does not solve the problem of race (Roberts 2011: 64, 74).

national identity" regardless of what the supposedly "objective" science demonstrates (Sans 2011: 205). Genes can evidently matter when they are utilised to support existing structures and hierarches. But what about my participants? Their struggles to form a coherent cohesive community—and struggle they did—evidences the reality that there is little power in genetic unity without pre-existing motivations such as nationalism or ethnicity claims.

To reiterate and summarise their struggles, I return to Jamie. While people with NF1 may indeed share certain physical characteristics, Jamie himself conceded an NF1 diagnosis does not generate a salient social bond. Jamie, like Chris, ultimately concluded that a mutual NF1 diagnosis does not generate a friendship, let alone affinity based on shared substance. While Jamie was keen to make friends with people on Midsummer Madness, he was in fact far more excited to encounter people with Cornish ancestry in Wales. He felt a deep affinity with people from Cornwall based on a sense of ethnic similarity. Whereas people with NF1 might have faced the same life experiences as Jamie—such as disfigurement or operations—he identified himself more with others who shared, in his words, "Cornish blood", regardless of whether these individuals had led a similar life to himself. So, while Jamie noted physical similarities between people with NF1, he found it difficult to ascribe meaning to these resemblances. Jamie's experience evidences the reality that knowledge of shared genes—without mutual interest or pre-existing identity categorisation—does not hold as much influence as some of my participants had expected. Genes can be seen to be important if they support a historic identity claim, but in the case of NF1, appear insufficient to generate their own, new collective identity.

To close this section, I turn to the idea of "imagined genetic communities". This term, coined by the anthropologist Bob Simpson (2000), draws from Anderson's (1983) notion of an imagined community. Simpson does not offer a direct definition of an imagined genetic community, but rather notes that what he takes from Anderson's concept is the idea of a community "made up of people whom one could assume were 'just like us'" (Simpson 2000: 3), before offering an example of British people fearing the influence of donated Danish sperm which might spoil the "imagined genetic community" of White Britishness (2000: 4). Nevertheless, I find the concept, along with the conclusion of his article, of interest to my work. At the closing of his paper, Simpson writes that "the possibility of reworking ethnic identities as imagined genetic communities" is troubling and to be avoided, lest hard eugenics continue into the 21st century" (Simpson 2000: 6).[77] What I wish to add to this important warning is the observation that while genetic knowledge may charge ethnic identities with dangerous rigour, genetic identities themselves without shared ancestry are—at present, and in the context of my participants—meagre. Whereas other authors have utilised Simpson's idea of an "imagined genetic community" to discuss genetic images which work to serve political purposes (Kent et al. 2014: 738), I cannot claim that I witnessed a particularly effective imagined genetic community in my research. While NTUK does conduct important work, and while smaller NF1 communities are deeply valued, these groups operate more out of mutual interest than as a manifestation of coherent identity. Perhaps NF1 is simply too idiosyncratic. Or perhaps genetic affinity, independent of other forms of identity, is less seminal than one might imagine.

Conclusion

In this chapter, I have sought to clarify where my participants acted out of a desire for collaboration—that is, to further their own healthcare interests—and where they express an identity based on their shared genetic difference. What I have found is the presence of an imagined genetic identity, albeit a fragile and confused one. I wish to conclude this chapter with the observation that several of my participants elected to avoid further involvement in NF communities—or to not get involved in the first place, in the case of Tara—precisely because they did not *want* NF1 to be a part of their identity. Tara explained that she deliberately avoided NF1 support groups and NF1 speech and language therapy for her daughter because she did not want Tatleen to feel the label of "NF1" applied to her. Tara explained: "I'm just trying to support her as best I can with this, with the things she's going through with speech and language, so with *local* things, I'm not really going to NF1 websites, I'm just going to normal speech and language stammer therapy… [If I went to NF1 specific support] I would be making it more of a big deal. And because she has anxiety anyway, she's very anxious and very sensitive, so I think if I did kind of go into [NF support then it would be] labelling." Stewart mimicked this sentiment, stating, "I am not a neurofibromatobe [sic]. I am a person who happens to have NF1." Although Stewart, and to a lesser extent Tara,

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[77] This is reminiscent of Hacking's (2006: 88) warning: "If the genome begins to override culture, then all citizens must rise up and insist that social bonds are what make us people. But we must also understand that knowledge of genetic 'identities' will forge social ones, creating new communities of shared recognition based on partial science. That is not intrinsically bad, but it is still a phenomenon that can be grossly abused."

identified NF1 as an integral component of an individual's identity, they did not want to be people labelled[78] by the condition.

Ian Hacking wrote that there is a "certain ambivalence, or ambiguity" towards "the genetic imperative" to explain human individuality in terms of genes. While people want to put stock in genes—Hacking discusses the search for the "gay gene", and the "alcoholism gene"—the way in which genes are allocated significance is inconsistent:

> Those who hope for an alcoholism gene believe that the discovery will prove beyond all doubt that alcoholism is a disease or, at any rate, an innate disability. Those who hope for a gay gene believe that such a discovery will prove beyond all doubt that homosexuality is not a disease or disability. Such contradictory pairings remind us that we are still in the adolescent phase of thinking about biosociality (Hacking 2006: 90).

In my own research, I have certainly observed contradictory attitudes to the establishment of an NF identity. What is more, I enjoy this passage from Hacking insofar as it highlights the agency of people in determining the significance of the genetic basis of certain biosocial communities. My supposition is that there is potential for the genetic affinity between my participants with NF1 to increase in salience. Perhaps in a decade or so, or in the context of other medical conditions, Rabinow's prediction will come to fruition:

> Rabinow was right to foresee, fifteen years ago, the increasing role of genetics in life and self-conceptions… he was not primarily interested in the use of genetics for racial identification… No, he was looking further into the future when, for example, risk markers for disease and causes of death might prompt people to identify themselves as that sort (Hacking 2006: 83).

Yet despite this possibility, I can also hypothesise that in the future, people with NF1 and other single-gene conditions may not wish for more coherent biosocial NF communities. The absence of such communities may indicate that mutual interests—such as better care, and research for better treatments—were completed. Moreover, and of greater relevance to my interests, people with NF1 and tantamount single-gene conditions may not want such communities simply because they do not *like* the idea that they would be defined by their genome.

Relating these findings back to my overall research questions, it appears that in the context of NF1 community initiatives, genes do not matter as much as I had expected. There is evidently a drive for people with NF1 to foster "community." To

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[78] Hacking's paper *Making Up People* (1986) is of relevance here. He explains "labelling theory", wherein certain academics hold that "social reality is conditioned, stabilized, or even created by the labels we apply to people, actions, and communities", before recommending Foucault's thoughts on the "constitution of subjects" as a more nuanced approach. The latter addresses how people are "gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, materials, desires, [and] thoughts" (Hacking 1986: 163-164).

quote from my NTUK-employed participant, Bea, she lamented that, “it can take hours for the bus to come if it comes at all. How are [people with NF1] *supposed* to be a community if they can’t even meet?” Yet despite my participants’ interest in meeting others with NF1, and despite the need for such communities to further NF1 interest, my research has demonstrated that NF1 community is difficult to generate and maintain. Although NF1 may affect physical features even beyond symptoms, these features—and the genes which supposedly underlie them—were not accorded the significance one would see in discussions of ethnic identity. For better or worse, in the context of my participants, genes only matter to collective identity formation when reinforcing more salient pre-existing categorisations. Taking the findings of this chapter alongside those from Chapter 1, it is fair to say that while one gene is enough to contribute to individual identity—it is insufficient, in the context of NF1 at least, to establish a collective identity. The conclusion of these first two chapters, put simply, is thus as follows. Genes are salient to identity, but only to an extent, and often only to the extent with which a participant is motivated for them to matter. Fluctuations in the relevance of genes can thus, at least in part, be explained by participant motivation.

Chapter 3: On Knowledge

Seren's family live in a beautiful, recently renovated home in one of the poorest parts of rural Wales. "Our area has some of the worst metrics for preventable disease in all of Europe," Seren explains, "apparently eighty percent of what doctors see could be prevented through lifestyle changes." Seren is a general practitioner—that is, a family doctor, known in the UK as a GP, working in a local health centre. Her young daughter, Bethan, has NF1. Bethan was diagnosed as an infant, in part due to her mother's coincidental prior knowledge of NF1 from medical school. It was Seren who insisted to doctors that Bethan should be genetically tested based on her symptomology. Yet despite Seren's suspicions, the diagnosis came as a shock to Seren and her husband. Neither of them has any family history of neurofibromatosis. In the six years that have passed since the diagnosis, Seren asserts that she has completely changed her attitude as a mother and as a doctor. Whereas before the birth of her daughter she claims she was on track to be "a highly strung mum", now, Seren prides herself on her ability to be present with her two children and personal with her patients.

Seren and I chatted on a balmy April evening in 2021. The birdsong outside her window and the minimalist home décor of her generous attic room were nearly distracting in their pleasantness. I say "chatting" because Seren was so at ease, even when discussing deeply personal issues. As I learnt over the course of our call, Seren is no stranger to talking to strangers about her family life. During the past few years, she has become increasingly interested in meditating, lowering stress, and other facets of what is known as "lifestyle medicine"—which she blogs about in tandem to blogging about her experience of having a child with NF1. When I asked Seren if her patients were receptive to her medical advice—including advice which stems from lifestyle medicine's focus on the prevention of illness through behavioural adjustments—she explained that they trusted her "because of Bethan": "they know about her, and so they know that I'm on the other side of it too. I'm not just a doctor."

Most of my participants are "on the other side of it", as Seren puts it. That is, they are patients or parents of patients visiting doctors and other medical professionals with uncommon regularity. One participant with NF1 joked to me that people with NF1 become "professional patients", since they are continually bounced between medical specialists and must advocate for their own interests to doctors who often know little about NF1. This chapter is, in part, about these power relationships between doctors, nurses, and people with NF1. It is also about medical surveillance beyond the clinic. Yet the linking theme of this chapter is not institutional hierarchies, symptom management, nor even biopower. Instead, the analytic focus of this chapter concerns my participants' highly ambivalent relationship with knowledge, particularly as it relates to knowledge about their body and genome in the context of medicine.

In Chapters 1 and 2, I have discussed how my participants utilise genetic knowledge to their advantage. I might even go so far as to say my interviewees *enjoyed* using knowledge about their genome when contemplating their identity and haphazardly building community. But what about a situation where genetic knowledge is anxiety-inducing? How does occupying the role of 'genetic patient' influence my participants' thoughts on the relevance of genes and genetic explanations? Although an NF1 diagnosis is beneficial insofar as it allows earlier and more regular preventative scans through the NHS, (such as for breast cancer,) during my fieldwork, I came to realise NF1 genotypes are seldom used in patient care or symptom management. While most people are now diagnosed with NF1 using a genetic test, (rather than based purely on their symptoms,) the sequencing of the genome seldom leads to personalized medical care. A patient's sequence of base pairings may be "on file", but this information is only used in new reproductive technologies—not in every day medical care, nor even in NF specialist care. How then do my participants relate to medical knowledge when it is of such little direct applicability to their medical care? In this chapter, I address these questions while introducing theory from the 'anthropology of cultivated ignorance' (Dilley 2010) to analyse my participants' self-reflections on the benefits and limitations of knowing for knowledge's sake. Those I interviewed all held a deep respect for biomedicine: however, in their experiences of living with NF1, my participants have discovered there are limits to the utility, comfort, and relevance of certain forms of knowledge.

The structure of chapter is as follows. First, I analyse a pattern I observed during my research wherein my participants—particularly the mothers of affected participants—collected and later disregarded medical literature. I discuss the extent to which this dynamic can be accounted for by Gay Becker and Sharon Kaufman's (1995) theorisation on the limited utility of medical knowledge in situations of uncertain chronic illness. I then address the strange phenomenon wherein several of my participants kept up to date with medical information, despite its limited utility to them as patients, in order to inform their own doctors. I describe four frustrations associated with this upturned hierarchy, including difficulty accessing specialist care; difficulty accessing convincing emotional support; fatigue over explaining NF1; and heightened awareness of NF1. I proceed by unpacking the burden of medical knowledge on my patients. I consider that their hardships might stem not only from a dysfunctional NHS, but also from the obligation to know about the details of their genetic condition. Later in this chapter, I examine why—in a cultural context where knowledge is supposedly valued, and informed patients are the ideal—my participants might prefer to practice ignorance. I thus follow Roy Dilley's advice—to diverge from anthropology's "current trend" of focusing on "knowledge transfer"—and instead ask why my participants might cultivate ignorance "as a willed and intentional stance towards the world" (Dilley 2010: 189, 177). At the end of this chapter, I begin to consider whether knowledge about genes is different in kind to other forms of knowledge, and whether this difference offers insights into the role of genetic knowledge in the everyday lives of my participants. In short, this chapter attends ethnographically to knowledge management in the context of medicine but is theoretically interested in exploring the limits of the appeal of knowledge.

Informed Patients: Collecting then Disregarding Medical Literature

A distinct pattern I observed across numerous interviews with mothers was their seeking out of medical literature upon their child's NF diagnosis, only to later discard the information when they realised it offered no predications or preventative techniques. When I asked Seren if she did any further research into NF1 after her daughter's diagnosis, she immediately replied:

> *Oh yes!* I went really in depth; it was driving me crazy. I was on PubMed, [I was on] all the journals. I was reading everything, which actually didn't help. She was a tiny baby at the time, and I was up all night trying to boost her weight because she was so small even at full term. I was breast feeding her. She took 40 minutes to feed every two hours. I was getting no sleep, and I was reading [NF medical literature] in between the feeds.
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> I've probably read everything with "NF" in it, including latest developments—which wasn't relevant. It's not like I was actively seeking a new treatment, I was just curious how far off we were from an absolute cure for NF. I just looked up everything, everything to do with prognosis: what's the rarest things, what's the scariest things. And it didn't help, it made me way more anxious.

Seren added later in the interview that she also "made the mistake" of going on NF forums to learn of possible complications from NF1. In hindsight, she does not blame herself. "I had to know all of that. I had to read it all", she explained. But now, she reflects that the research did not and could not help her "as a mum" because Bethan's case, like all NF cases, is entirely unique. The knowledge Seren once desperately sought—garnered through medical literature and forums—was only informing Seren of problems her daughter may well never develop.

Seren's actions—of collecting and then later dismissing NF medical literature—were echoed by numerous other participants, including Tara, Zoe, and Amy. Unlike Seren, Tara has no medical training. Tara once worked in business management but is now a part-time teaching assistant in London, a career change she made to spend more time with her two children. When her daughter, Tatleen, was diagnosed with NF1 as an infant nine years ago, it was a difficult time for Tara and her husband. Baby Tatleen was having trouble with allergies, and Tara was still appeasing her Sikh-Punjabi family over her conversion to Christianity and marriage to a Pakistani Christian. The diagnosis compounded an already stressful situation, and Tara developed physiological problems in response to the stress. In our third meeting, Tara reflected that, "It's amazing how the body does respond to stress like that … you can have [stomach] ulcers from worrying… It was so bad, the first year of Tatleen's life. I had so much pain here, in my stomach." During this time of hardship, Tara turned to medical literature to seek "control"—as she puts it. Tara still has the NF1 textbooks she purchased during those first year of Tatleen's life. When I asked her what the titles of these books were, she searched in her living room for them—a search which was necessary since she had not referred to them in years. Tara reflects with hindsight:

> I think [in] those early days I just did too much Googling on the Internet and it was too much information. And because this condition is so varied from person to person, there's no one thing that I can say, "oh this is definitely gonna happen".

In one of our later meetings, Tara elaborated:

> When Tatleen was first diagnosed, I was on Google. A lot of the [web]sites took me to American sites. [You get] better informed through them… After a while I stopped looking because you could see the worst of it. I think once I had the initial research, I understood what it was, how NF1 was different to NF2, [then that was enough].

Whilst Tara conceded that she would still be interested in percentages—of how many children with NF go on to develop each of the possible symptoms—she does not have the time at present to seek out this medical information on NF1. When I asked if she would consider looking up more recent research, she replied, "if there was something we could do now to help the progression be less, then of course I would want to know. But we have no control and no idea of what will happen, so no, I don't [want to know any more]."

Tara was my first participant. When other mothers, including Seren, began independently telling me of their collection and later disregard of medical literature, I paid increasing attention to participants' desire to know about—or decision not to know about—the biomedical details of NF1. To give another example, I can point to Zoe, whom I introduced in Chapter 1, who recounted:

> So, when the geneticist phoned me and said Poppy has neurofibromatosis… instantly I went online and I found out the information and it was like "holy shit", you know, I really felt like… "oh my God, my baby's gonna die. She's gonna get brain tumors." [In] the beginning I got information wherever I could, so I literally typed in 'NF1', 'NF2' [into every search engine.] And it was that bombardment of information, and [it's] taken me years and time to understand that, actually, Poppy's okay.

I noticed that it was not only mothers who dismissed the utility of personally knowing the medical details of NF1. People with the condition themselves felt knowing more about their NF1 was not always wise—although I should preface that all my participants wanted further biomedical research to be conducted by medical professionals. This preference, to not conduct personal research, certainly was the preference of Amy, one of the last participants to join my research. Amy is a geneticist who herself has NF1. Yet despite her field of research, Amy has never felt compelled to study NF1. In fact, she advises her students *not* to study conditions which affect them or their families lest they feel exceptional pressure to obtain certain results. Amy also insisted that her interest in genetics at a young age had nothing to do with her mother and brother having a diagnosis of neurofibromatosis—it was simply that genetics was an exciting, emerging field at the time for her to explore as a young scientist.

Amy's stance—of not studying NF1—did not change even when her own NF1 diagnosis came as a surprise later in life. Amy was only diagnosed with NF1 a few years ago. As a child, Amy appeared too unaffected to be genetically tested for an NF1 mutation based on symptomology, even though she had immediate family members with the condition. She recalls:

> I was thought to be unaffected. Back in the day, a molecular biology lab would take a month or more to sequence [the NF1 gene, and so mine was never tested.] When I was 18, I was turned over [to a neurologist and] he looked for Lisch nodules on me and couldn't see any at the time. So, I was in the grey zone for the symptoms. And so, it was thought I didn't have it because I didn't have too many symptoms. This was when, you know, we were still learning about the penetrance of mutations and so forth.

It was Amy's partner who recommended she get tested. Amy's mother had died of breast cancer in her forties—a cancer which Amy associates with NF1, insofar as "women with NF1 have a higher propensity for breast cancer"—and so, as Amy entered her forties, they thought it wise for her to be tested for NF1, just in case. Amy narrates lightheartedly, "I thought 'well, you know, pretty sure I don't have it,' but [my partner], she has a good point… the [breast cancer] screening would be a good idea. So, I got [the genetic test], and surprisingly I had the same three exons missing from my NF1 gene, [just like my brother and mother.]"

Amy's NF1 diagnosis allowed her to take part in regular breast cancer screenings. Sadly, these screenings turned out to be crucial. Over the course of my fieldwork, Amy was diagnosed with breast cancer. Amy was keen to call regularly to "document" her experience because she believed—and I concur—that it would be helpful for me as a researcher to witness one of the more extreme consequences of NF1. Yet even with these two diagnoses—of NF1, and then of an NF1-associated cancer—Amy insisted that her new interest in reading medical literature stemmed purely from her curiosity as a scientist, not because she thought it would be helpful for her to know as an NF1 patient. For instance, Amy was interested in knowing the exact mechanism of the chemotherapy drug she was being administered. She explained that her training as a geneticist involved a background in chemistry, and she was fascinated to understand how the chemotherapy operated at a chemical level. What was interesting to me was that Amy almost sheepishly admitted looking up a few "cohort studies" on breast cancer survival in NF1 patients, only to later dismiss these studies and cease looking for similar research. She explained that NF1 cohort studies cannot tell her anything about her individual situation, and that it would be more beneficial for her to know about her individual tumour biology than patterns of cancer survival among NF1 patients. Amy's reading habits thus kept with the general pattern I observed of participants acquiring and later discarding NF1-related medical literature.

Existing Literature on Uncertainty

My data support the following observations made by Gay Becker and Sharon Kaufman on the limits of the utility of medical knowledge in situations of "chronic illness" (Becker & Kaufman 1995). In a summary of their and others' research (Heurtin-Rob & Becker 1993; Becker et al. 1993), Becker and Kaufman attest, "if medicine's ability to *mediate uncertainty* appears to wane or its ability to *control* illness symptoms decreases, medical views may become less relevant to individuals' attempts to manage their illness trajectories" (Becker & Kaufman 1995: 167 [emphasis my own]). This insight succinctly articulates why my participants find NF1 medical literature disappointing. In terms of "mediating uncertainty", the correlation between genotype and phenotype in NF1 is presently poorly understood. While there are some known correlations between certain NF1 genotypes and more dramatic presentations,[79] these

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[79] Seren was keen to inform me of how a famous NF1 specialist, whom she met at a medical conference, assured her that Bethan's NF1 genotype was not one of the known "very bad ones".

associations are not guaranteed. As such, uncertainty proliferates. Amy, for instance, has "a whole three exons missing from her NF1 gene", and yet is markedly less affected by NF1 than her brother. As Lock and Nguyen observe (2018: 303), "many uncertainties remain even after the presence of a specific genetic mutation is known". Accordingly, it is fair to judge that medicine cannot "mediate uncertainty" (Becker & Kaufman 1995: 167) in the context of NF1 since it cannot inform patients as to the likelihood of their NF1 severity.

In terms of "control[ling] illness" (Becker & Kaufman 1995: 167), there are no means with which to prevent NF1 symptoms from developing. For example, although it is known that pregnancy and other periods of hormonal disruption—such as puberty—can accelerate the progression of neurofibroma growth, this knowledge does not allow for an intervention to prevent symptoms. Puberty—and to a lesser extent pregnancy—were largely seen by my participants as milestones they would not forfeit to manage their symptoms. (And again, there is no guarantee that puberty or pregnancy *will* cause symptom development, it is only an associated risk.) Moreover, while people with NF1 can attend regular screenings to identify the development of symptoms, such as NF1-associated cancers, I would argue that this screening is better described as 'monitoring health', rather than 'preventing' symptoms arising in the first place. In short, the medical literature on NF1 offers no avenues for symptom prevention.

I commend Becker and Kaufman's insight that "medicine by itself [appears] impotent" when its information "does not translate to neatly bounded, predictable interventions" (Becker & Kaufman 1995: 168). Given the idiosyncrasy and unpredictability of NF1, medical knowledge indeed fails to offer "comfort" (1995: 167) to my participants. However, despite these insights, Becker and Kaufman's writing cannot explain other nuances I observed during my fieldwork: namely my participants' continual engagement with medicine despite its limited utility—as I discuss in greater detail below, (from page 105). So, while my participants' initial acquisition of medical knowledge can be described as an attempt to mediate uncertainty, their keeping informed is not congruent with Becker and Kaufman's theorisation that medicine is decreasingly "relevant [to] their illness trajectories" when medical information is no longer useful (1995: 168). I attest that limitations in Becker and Kaufman's applicability to my data can be explained, in part, by the differing 'forms of uncertainty' experienced by our respective participants.

Becker and Kaufman (1995: 170) claim that "stroke lends itself to an exploration of how individuals and their physicians manage an uncertain trajectory because the prognosis is so uncertain." Yet whereas stroke patients look ahead to either recovery or decline, my participants anticipate a long list of potential symptoms over the course of a lifetime. In other words, my participants face the constant possibility of morbidity, whereas Becker and Kaufman's patients—along with the subjects of other literature on medical uncertainty[80]—grapple with the aftermath of illness' sudden arrival and the possibility of mortality. To illustrate the consequences of this divergence, I return to Seren. We had been chatting for about an hour when she made a comment which succinctly encapsulated much of what I had been observing in my research over the six months prior. This comment was that there were "certain uncertainties" with NF1. Seren explained that NF specialists cannot predict what will happen to her daughter, but they know what might.

For instance, Seren knew there was a chance Bethan's existing optic pathway tumour could grow and threaten her sight, but this was not certain. Seren also knew Bethan might develop neurofibromas on her face and over her body, but there was also the distinct possibility that Bethan would reach old age without any visible difference. The list of possible NF1 symptoms and complications goes on, and Seren is fully aware of this list. While Seren conceded that most parents worry about the health of their children, she pointed out that these parents are spared from worrying about specific maladies. By contrast, Seren is aware of exactly what could happen to her daughter and is left with the predicament of whether to prepare for these certain uncertainties. Should Seren still encourage her daughter to pursue activities which require depth perception? Should Seren adjust Bethan's aspirations based on *possible* future NF1 symptoms? Seren attested this "certain uncertainty" was absolutely the "hardest part" of Bethan's NF for her as a mother, and her sentiments were echoed by other participants. Tara posited that with other conditions, "you know this will come, then this will come, then that will come. But with this NF1 it seems like it could be something small or it could be something big and you just don't know." While most diagnoses do indeed generate a certain degree of uncertainty, I believe it is fair to say people with NF1 face a specific and *radical* uncertainty.

To supplement Becker and Kaufman's analysis of uncertainty in chronic illness, I here turn to Calkins' (2016) theorisation on how "uncertainty is processed and managed" in contextually specific ways (2016: 6). Calkins discusses various "subtypes

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[80] Consider Stavrianakis' (2020) ethnographic study of the uncertainty experienced by Alzheimer's patients as they face their mortality. Whilst he makes important insights on the nuances of 'haltung', or 'attitude-stance'—which will be discussed in Chapter 5—he addresses a specific situation of uncertainty. His patients have moved from health into terminal illness. My participants had no such life change. Moreover, the uncertainty NF1 patients face is not always over death. As such, Stavrianakis' writings on uncertainty—much like Becker and Kaufman's—cannot explain my participants' experiences due to diverging forms of uncertainty.

of uncertainty" (2016: 5). She writes, "we can hardly claim that the uncertainties experienced daily by [my participant] Rashaida in north-eastern Sudan are the same uncertainties that people experience elsewhere when engaging in highly risky activities, for instance, at the London Stock Exchange" (Calkins 2016: 12). While Calkins acknowledges that there is uncertainty in all action—since outcomes are always unknown—she stresses that uncertainty is not a *uniform* property of all action insofar as it is perceived and experienced differently depending on context (Calkins 2016: 2). Thus, while my participants are in a markedly different situation to Calkins'—whereas my key participant Sharon struggles with overindulging in food, Calkins' participants live in a "situation of scarcity" (2016: 6)—I nevertheless find her writing helpful in that it highlights the importance of attending to the idiosyncratic specificities of NF1's uncertainty.

Taking heed of Calkin's advice to pay attention to the specific, I should note another crucial divergence between my participants and Becker and Kaufman's subjects. I believe Becker and Kaufman's theorisation is insufficient since they address a situation wherein the acquisition of knowledge was only ever painted as a virtue. Their stroke patients never knew more about their biomedical situation than their attending neurologists,[81] and so never tested the limits of how informed a patient could or should be. In contrast, my patients—with their lay expertise of NF1—create an uneasy situation in which knowledgeable lay people must dance around physician egos to access adequate healthcare. This dynamic understandably causes various frustrations for my participants. The remainder of this section canvasses these grievances to bear witness to my participants' hardships, but also to explore that which could not be explored in Becker and Kaufman's data—that is, the burden of knowledge.

Between Uninformed Doctors and NF1 Patients

Whereas I have hitherto discussed my participants' gathering and disregarding of medical literature, it is now timely to add ethnographic detail to my participants' surprising practice of using this very medical knowledge to inform their doctors. To do so, I first return to Stewart. He offers just one example, among many I observed over the course of my fieldwork, of a participant utilising medical knowledge to advocate for their own care to doctors who are largely unaware but whose authority must be

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[81] While Becker and Kaufman do note patients were "motivated" to be informed and active in their own recovery (1995, 168), this patient-knowledge was supplemental to doctor expertise. Moreover, Becker and Kaufman never theoretically develop these passing observations: the authors never question why value is placed on patients acquiring medical knowledge in the first place.

respected.[82] Stewart spoke with me about the various GPs he has seen over the course of his life. In our second meeting, Stewart recalled with fondness the GP whom he trusted the most. Stewart explained that his trust in this doctor stemmed from the doctor's honesty over not knowing much about NF1. This segment of our conversation went as follows:

> Stewart: I believe [NF1] is the commonest dominant genetic condition, and yet even within medical training it's barely mentioned, certainly never mentioned during my nurse training unless I mentioned it.
>
> Me: Have you ever had to explain NF1 to a GP?
>
> Stewart: Yes! And in fact, the GP who I was most impressed by was a South Asian doctor who I registered with when I was in my early twenties, and in the first consultation I had with him, the just-getting-to-know-you one, I mentioned it and he said, "I've heard of neurofibromatosis, but you're the first patient I've ever come across who has it. I don't know much about it. Do you mind if I just get a book down?" And actually, right there and then, he actually got a book off his shelf! And actually that gave me tremendous trust in him. He was prepared to say, ["I don't know".] He didn't sit and read it there and then, but he said, "I'll read it before I next see you." That gave me a lot of trust in him.
>
> But no, on the whole—and I have heard this said in events that I've attended run by the NF Association[83]—the general experience is that you see a plastic surgeon who's a very good plastic surgeon, and you see an orthopaedic surgeon who's a very good orthopaedic surgeon, and you see this doctor, and you see that doctor, and they're all very good at what they do, but they know bugger all about NF [Stewart laughs].
>
> I have actually seen a few people during my life who are NF specialists, including the now-retired lead specialist[84] on it who I saw about 20 years ago. I saw her a couple of times… and talking to her was [like] "Aha! [Finally] somebody who understands the global picture!" … At Guy's, I've finally found [a specialist team] who holds me, who will understand the global picture of NF1.

Stewart lamented that while he was impressed with this GP back in the 1970s, and although he was relieved to have seen a specialist in the early noughties, he is annoyed that it has taken until the twenty-twenties to regularly access NF1-aware doctors at Guy's Hospital in London. If he had known about the expertise at Guy's earlier in his life, he could have avoided—in his own words—being "bounced between" different specialties at various hospitals.

Participants other than Stewart also saw knowledge as a critical tool by which to access appropriate medical care. Such knowledge included both knowledge of symptoms and knowing where to go for help. On the former,

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[82] For further reading on medical hierarchies within hospitals in the United Kingdom, I recommend Rapport's (2008) ethnographic work among hospital porters.

[83] The NF Association, and LINK, are old names for Nerve Tumours UK (NTUK).

[84] Stewart is here referring to my participant whom I discussed in Chapter 1 vis-à-vis her abstracting of a patient's raw potential from the limiting factor of their genome.

several participants insisted it was lifesaving to be aware of which NF1 symptoms require urgent investigation—such as a debilitating headache and changes in vision. In terms of knowing where to go, several NTUK employees—including Claire—told me that perhaps the most important function of the charity is to inform people where to get support for their idiosyncratic needs. Such knowledge not only streamlines access to care—such as knowing that plastic surgery is often better than neurology at dealing with nerve tumour removal—it can also ensure people receive the government benefits to which they are entitled. Returning to Stewart, he acknowledged that he recommends people to NTUK *because* he believed the charity was helpful in directing patients to the medical departments they needed. Stewart is not always the biggest fan of NTUK. In fact, he has written complaint letters to them because he thinks the charity portrays people with NF1 as "unfortunate" to generate pity and thus motivate fundraising. Nevertheless, Stewart concedes that the literature NTUK offers—to educate those with NF1 on NF1—has always been of the utmost quality. Thus, despite his reservations, Stewart insisted that he always recommend NTUK, including his own patients back when he was a nurse,[85] such was the perceived importance of such knowledge.

In addition to knowing where to go for healthcare, my participants also held that it was important to know how to behave once in the correct setting. Numerous participants made careful preparations before appointments with both general practitioners and specialists. Some mentioned rehearsing the appointment in their heads, while others spoke of writing down discussion points on a piece of paper. One of my participants, whom I'll call Flo, felt considerable anxiety over going to her GP. Flo is particularly shy and has notable learning difficulties. She accordingly often brings her mother with her to appointments. As her mother later

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[85] Stewart remembers one boy on his ward who was diagnosed with NF1 after doctors discovered that his brain tumour was a benign neurofibroma. Stewart recalls explaining the NF1 diagnosis to the boy's father. As Stewart explained that the boy did not have cancer, but rather a genetic condition that might cause more benign tumours to grow in the boy's body and on the boy's skin, the dad looked at the pea-sized growths on Stewart's face and asked, "is that what you have?" Stewart was able to answer, "yes." Stewart thought it was beneficial for the family to know he had NF1 so they could see that the condition does not necessarily prevent you from holding down a job, even a job as demanding as being a paediatric nurse.

However, in most other NF-related situations at Stewart's work, no one asked Stewart about his NF1. It was only this one father who made the connection between the description of the condition and the nurse describing the condition. Seeing as Stewart was a nurse, and thus at that time not in a position of sufficient authority to volunteer his medical knowledge unprovoked, Stewart's expertise remained untapped in this domain. So, whilst Stewart knew more about NF1 than most of the doctors he encountered in his care, and more even than most of the doctors he worked with, he had to abide within the existing hierarchy and underplay his expertise or else use it in a delicate way so as not to insult the doctors.

explained to me, Flo was more likely to secure the referrals she needed if her mother came with her. Flo and her mother's collaborative efforts testify to the reality that patients must know *what* to ask for and *how* to ask for it. If they misjudged their tone to a doctor, if they forgot to mention a symptom in a consultation, or if they were not insistent enough to obtain a referral, then they were afraid they would receive inadequate healthcare from the National Health Service. My participants did not have the authority of a doctor, however, they felt *as* responsible as a doctor for their own health,[86] and accordingly used knowledge—of information and behaviour—to obtain care. To reiterate, this knowledge was not maintained because it brought comfort or utility to my participants. Instead, it was utilised as a tool to access symptom management in an upturned hierarchy.

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This dynamic, between informed patients and uninformed doctors, was understandably deeply frustrating for my participants. It is my opinion that there were four discrete dimensions to this frustration. Some of these frustrations stem from dissatisfaction with the current state of the NHS, but others—if one attends closely—pertain more to the burden of knowledge in and of itself, and as such are of central relevance to this chapter's focus on my participants' ambivalent relationship with knowledge. The first and most obvious frustration experienced by my participants concerns the difficulty of receiving adequate care. Many of my participants asserted that it was not until they were referred to specialist centres—such as ones in Manchester and London—that they felt their clinical needs were met. If doctors were better informed, their journey from diagnosis to registration with specialist centres would be streamlined.

A second frustration experienced by my participants was feeling alone without someone to talk to who knew about NF1. What my participants sought was emotional support and camaraderie. My participants turned to doctors only to become quickly discouraged when they judged these physicians to be too ill-informed to understand their specific anxieties over NF1. Seren explained that she

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[86] I find that my fieldwork here relates to Rose's (2001) observations on how individual citizens are encouraged to become "an active partner in the drive for health, accepting their responsibility for securing their own well-being" (Rose 2001: 6). For my participants, it was certainly a 'begrudging acceptance' of healthcare responsibility. I could argue that my participants went further than being an "active patient and ally of the doctor" (Rose 2007: 110), since they in fact assumed the position of doctor in all but authority. For further reading on situations wherein "the patient is an ally to the doctor, a proto-professional, responsible in part for making themselves better" (Novas & Rose 2000: 490), see studies by Rabinow (2002).

desperately wanted to be able to turn to her daughter's GP for compassion and reassurance. However, she knew the GP would not have knowingly seen many people with NF1, and so Seren doubted how reassured she would feel by this person. Seren explained that she found help in the NTUK specialist nurses *because* she knew they had spoken to many NF1-parents before:

> What's Bethan's GP going to say? I'm the one that has read everything. The GP will say, "everything is going to be fine", which is what I wanted to hear, but it's not something I could believe from her. Bethan's pediatrician didn't help either.
>
> The NTUK website helped me more than anything. Best thing I ever did was ring the [NTUK] helpline. Now I donate to it every month. The helpline operator got me to pull myself together. [She said,] "You are totally normal to be this stressed and obsessed." I just cried down the phone and said how afraid I was. She reassured me most people are absolutely fine with this condition, that I had gone to extremes, catastrophizing. I had to get back to everything actually being fine right now. That was what I needed to hear. She was so calm and knowledgeable—I thought, 'she must have spoken to tons of people about this.'

Even if the helpline operator did not offer Seren any prescriptions or specific predications, Seren felt comforted knowing she was speaking with someone who had seen NF1 many times before. Seren did not have to explain NF1. She did not have to justify her worries. The NTUK employee already knew the context and knew "just what to say", according to Seren. This camaraderie was sadly refreshing in an otherwise isolating situation. Seren, along with other participants, were frustrated when doctors did not know about NF1 because it meant they could not speak "to someone who gets it", as Seren put it.

Related to the frustration of feeling isolated, my participants were also fatigued over having to explain NF1. Whilst some of my participants may enjoy explaining NF1, especially to children who expressed genuine curiosity, others resented needing to deliberate continually over how best to communicate the details of NF1 in various contexts. Hope, a lively and talented middle-aged mum of two, told me of how "disclosing" her NF1 to people in the workplace caused her anxiety. Every time she was promoted or moved office teams, Hope said, she carefully considered the wording of her NF1 explanation. If she painted NF1 as something too serious, she worried that her new managers would doubt her ability to work. If she failed to communicate the extent to which NF1 affected her life—including her dyslexia which she associates with NF1—she worried she would not receive the appropriate accommodations to perform to the best of her abilities.

In addition to the initial explanation, Hope felt she must also anticipate what colleagues might do *after* her disclosure—namely, she worries that they will "Google it." Hope, along with numerous other participants, fear photographs on Google Images will "scare" people into pity. While Hope finds this burden of description an anxiety-inducing addition to her already busy workload, other participants find it overwhelming.[87] It is not only in work, but in dating life, family life, academic pursuits, leisure activities, medical settings, and even in casual conversation, that people must account for their condition.[88] Such was the extent of this frustration that, when I asked my participants to explain NF1 to me at the outset of my interviews, several participants—particularly those above the age of sixty—retorted, "Well why don't you explain to me what you know about NF1 first." I came to understand that this was not intended as a rebuke, nor was it always a means to quiz me, it was instead the result of my participants' fatigue. They were tired of acquiring and then disseminating their knowledge of NF1 to a persistently uninformed public and health service.

The fourth and final frustration felt by my informed participants concerns how medical knowledge management took up their time, and thus their attention. Most of my participants conducted near-daily medical monitoring. They checked for new neurofibromas appearing, existing neurofibromas growing, along with potentially more serious symptoms such as changes in vision and personality. This imposition of the clinic into the home required diligent care—a time drain to say this least. More pressingly, however, was that this monitoring meant my participants struggled to "forget about" their NF1. Both Seren and Zoe respectively told me of how, when they bathe their daughters, they cannot help but check their child's skin for new neurofibromas. This habit annoys them both. They lament how this monitoring continually reminds them of their child's diagnosis, and by doing so prevents them from, in Zoe's words, "getting on with normal life".

In review, my participants have been frustrated over the time it takes to access specialist care, the need to seek comfort from NTUK employees rather than doctors, the effort that goes into explaining NF1 in various contexts, and the time and attention dedicated to monitoring symptoms which continuously calls attention to NF1. While needing to know about NF1 may be a feature of each of these frustrations—such as needing to know which symptoms to look out for to successfully monitor your child's health—and while the burden of knowledge is

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[87] One participant in his late thirties spent our interview detailing his dating experiences. He was equal parts delighted and relieved when on his first date with his current fiancée she disclosed that she herself had a disparate genetic condition. This made him feel less alone whilst also allowing for a natural opportunity for him to disclose his NF1.

[88] Ablon also discusses the dilemma of disclosing NF1 in the workplace (1999: 58) and romantic contexts (1999: 69).

hinted at—in the fourth frustration of participants' disliking being reminded of an NF1 diagnosis—this knowledge of NF1 has not yet been discussed as the primary source of frustration. To progress my analysis of my participants' relationship with genetic knowledge, I hold it is time to put knowledge to the test. If knowledge itself is a problem, this could explain why my participants' find their healthcare advocacy so difficult since they are not only required to know certain information, but they are also compelled to keep it at the forefront of their minds.

To unpack what I mean by the burden of knowledge, I want to discuss a participant who was something of an outlier in my research insofar as his preference—to not know *any* of the medical details of his NF1—was an extreme example of what other participants felt to a lesser degree. Dave is a man in his thirties with NF1. He identifies himself as an "Essex boy" and was living and working in Essex when he took part in my research during the autumn of 2021. After the arrival of the Covid-19 pandemic in the United Kingdom in early 2020, Dave was encouraged to work from home. He was delighted by this change in pace. No longer needing to commute into London meant Dave had more time to play football with his friends. When he started playing football in the 2020 autumn Covid lockdown, Dave noticed his football skills were worse than he had expected. He recounted to me, with good humour, "it wasn't like I was gonna be professional or anything, but I was able to hold my own [and it was a shock to realise I couldn't anymore.]" After initially chalking up his poor coordination to being out of practice, he eventually mentioned his difficulties to his doctor.

Dave's specialist explained to him how his NF1 was causing delays in messages from his brain reaching his feet. Dave's overriding memory of this doctor's appointment is one of shock. He explained to me he never thought NF1 would affect his spine. He always presumed it would just be "lumps and bumps" in his limbs, which he was fine with. He was now left with the fear of ending up in a wheelchair. Dave insisted he would have rather the doctor had kept this information from him:

> I'd rather not know, If I'm honest. I honestly sat there and said to him, "shall I just go down knacker's yard[89] then?" I honestly felt like I was gonna walk out of there with so many things wrong. He was like, "you're more at risk of getting cancer, you're this, you're that, you've got this, you've got that", I was like, "Jesus Christ, mate! Like?!"
>
> I suppose they got to tell you. They got a duty to tell you. They can't not say anything. I say I'd rather not know. If they could do something to prevent it getting worse, then I'd want to know in that sense. Unless it's gonna kill me, I don't care. Unless you say you need an operation... I'd rather not know unless it's

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[89] A knacker's yard is where injured or no-longer-useful animals are killed.

> serious and they need to do something. And they always speaking doctor jargon as well, don't they? I don't like that.

Dave was unusual among my participants in saying he would not want to know any of the details of his NF1 unless he needed an immediate operation or there was an imminent threat. In contrast, most of my other participants, as mentioned above, at least initially wanted to know about NF1 out of curiosity or to seek reassurance after their diagnosis. However, what became apparent was that Dave was not unusual in his preference, but simply unusual in voicing this preference so bluntly and to such an extreme degree.

To evidence less-extreme versions of Dave's preference for "not knowing", consider the following examples from my key participants. Chris thought "regular" people with NF1 should not undergo fully body scans, "because you'll just find abnormalities you didn't need to know or worry about." While Chris clarified that he "of course" thinks people with cancer and other NF1-complications—that is, people with 'irregular' (i.e., complex) cases of NF1—should go for scans, he insisted that knowing is not always good if there is nothing to be done with that knowledge. Jamie shed further light on the burden of knowledge by recounting an interesting dilemma he faced. A few years ago, Jamie noticed large café-au-lait marks on his neighbour's daughter's back while she was sunbathing and was not sure if he should mention it to her mother. Multiple large café-au-lait marks are indicative of neurofibromatosis, and if there are more than six marks, it is highly probable that person has NF1. Jamie worried, "what happens if the family doesn't know? There's nothing to be done to cure NF1, so maybe it's better that I let them be."[90] In this instance, Jamie found himself in the position of a healthcare worker insofar as he knew about another person's NF1 symptoms when they themselves did not. However, unlike a health professional, Jamie possessed the freedom to judge whether it was right to tell the affected person.

I hold it is revealing that Jamie ultimately decided to not bring the matter up with his neighbour. In doing so, he acted against what is expected and respected within healthcare settings, but he was nevertheless convinced he had made a kind choice. He wished to spare his neighbours of the burden of knowledge. In doing so, he concurs not only with Dave, but also with Zoe, who expressed a slight envy towards those who live unknowingly with NF1:

> I think not knowing is sometimes a little bit easier… I've read things [about] people [having] had NF all their life … and it's not until there is something

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[90] A similar ethical dilemma is discussed by Shaw and Hurst in a paper entitled "I don't see any point in telling them" (Shaw & Hurst 2009). The authors discuss how in Pakistani families they studied; individuals debated informing consanguineous kin about recessive gene risk.

> clinically wrong [with] one of their children that they then discover they've got NF1 themselves… [These parents with NF1] have gone their whole life without even knowing or worrying about [NF1], and then they have the information [about their NF1 diagnosis] and it's a double-edged sword really, isn't it, at the end of the day, 'cause you need to be informed to be able to act on something if it happens, but then you're informed and you have all this information but nothing might ever happen.

Thus far in this chapter, I have introduced an unusual behaviour among my participants of collecting, ignoring, and then utilising medical knowledge to seek care. This awkward position tests the social hierarchy of medicine, yet of greater relevance to my research interests—in participants' relationship to genes—is how knowledge itself is put on trial in this context. To account for my participants' relationship with genetic knowledge, I have found it necessary to attend not only to my participants' management of uncertainty, but also to their reflexive thoughts on knowledge. Further, to account for such reflexivity, I have sought to develop an appropriate theoretical vocabulary and it is to this I turn in the next section.

The Anthropology of Ignorance

For all that is written about the anthropology of knowledge, I am surprised to find relatively little on the anthropology of cultivated ignorance – that is, choosing not to know or think about something, as opposed to simply not knowing. As has been established in this thesis' introductory chapter, considerable literature has addressed the acquisition, interpretation, communication, utilisation, and weaponisation of genetic knowledge. I am not denying the wealth of literature addressing those who choose *not* to be tested for a genetic condition, and those who choose not to inform their kin of a potential risk.[91] Nor am I unaware of discourse concerning the negative societal consequences of widespread genetic susceptibility knowledge[92] along with the importance of the bioethical question of informed consent (as will be discussed on page 117). I am instead interested in the learning from the limited yet fruitful literature on the anthropology of ignorance. Using this literature, I wish to better understand how my participants relate to genetic knowledge which they already know, a knowledge which affords community, meaning, identity but also anxiety, disease, and stigma

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[91] To give just one example, I commend Monica Konrad's (2005: 87) ethnographic focus on families with Huntington's Disease disclosing their diagnosis to kin.

[92] Lock and Nguyen summaries and discuss literature concerning "the anticipated impact on everyday life of the dissemination of knowledge concerning embodied genetic risk." (2018: 304) They note, "It seems that a good proportion of the public are not as enamored with the idea that we will soon be able to solve the ills of the world on the basis of accumulating knowledge about genes as a few outspoken biologists would have us believe." (Lock & Nguyen 2018: 306).

Over a decade ago, in a paper addressing the “rarely considered” question of ignorance, Dilley attested, “knowledge and ignorance are mutually constituting. [They are] not just a negation of the other, but a dialectic” (Dilley 2010: 176-7). Dilley revisits the philosopher James Frederick Ferrier, who coined the very term ‘epistemology’ to denote the science of knowing and what is known. Dilley highlights how Ferrier was equally interested in the science of not knowing—that is, 'agnoiology'—however, this second field regrettably “never gained traction” (2010: 177). Using his own fieldwork in Senegal to offer ethnographic examples on agnoiological practices, Dilley describes how ignorance can refer both to the absence of knowledge and to “a willed and intentional stance” (Dilley 2010: 177). He details three terms (with their linguistic roots in Pulaar) which refer to different kinds of ignorance. The first, *hump* or *kumpy*, denotes a lack of information about a person, subject or event. *Kumpta*, the second term, refers to mystery, that is, to things which remain unknown. The final term, *humam binne*, is a pejorative term for an ignorant person (Dilley 2010: 180). While these terms and their usage are specific to Dilley’s fieldwork, the reference to ignorance as mystery (in the second term) is also an analytic concept which can—and has—been used outside of Dilley’s specific fieldwork context, as I will now detail with reference to respective analysis made by Frederick Barth, Nigel Rapport, and Marilyn Strathern.

In 2002, Barth reflected, ““mystery” is a philosophically rather sophisticated construction that entails not absence of knowledge but an experience of awe before phenomena and questions for which one believes there can [or should] be no comprehensible final answers.” (Barth 2002: 4 [addition my own]). I have added my own text to his reflection because I believe there is a distinction to be made between what is inevitably a mystery and what one would like to keep as a mystery. On the former category, that which will always be mysterious, Nigel Rapport offers the two following examples: the question of what happens after death,[93] and the true embodied experience of another person.[94] On the matter of that which people would like to *keep* mysterious, I have two examples. The first comes from a paper I have already referenced earlier in this thesis – McKibben’s (2003) discussion of designer babies. In

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[93] Rapport observes that “there is a “not-knowing” that is essential, fundamental. Archetypically, this appears to us in death… It is absolutely other and with an otherness that we can never transcend: death remains unknowable… death’s hold over our existence is mysterious.” (Rapport 2015: 259)

[94] Rapport argues that anthropologists much appreciate the inevitable, continual mystery of others: “Ignorance, one might say, is an existential and moral imperative: “It is my duty to recognize my ignorance of the other”; “It is my duty to recognize the other’s ignorance of myself.”” (Rapport 2015: 262)

invoking this example, I attest that there is a link between not wanting to act on genes, (thus McKibben's hesitancy over genetic engineering,) and not wanting to know about genes, (thus keeping some aspect of the human condition mysterious). McKibben draws on rabbi Jonathan Sacks' suggestion that "there is a mystery at the heart of human condition" (Sacks in McKibben 2003). Although mystery may be antithetical to many endeavours—McKibben concedes with a degree of amusement that engineers should not, and do not, "like" mystery—in the context of the human, McKibben attests that there is knowledge (specifically genetic knowledge) which should be left unknown and untouched (McKibben 2003).

My second example, on the impetus to deliberately keep certain phenomenon mysterious, comes from Marilyn Strathern. In another work I have hitherto utilised—Strathern's *Reproducing the Future* (1992)—she reflects that one's date of death[95] is an example of the kind of knowledge people prefer to not know: "One does not want to know how death will come; to anticipate would threaten the hope that is contained within the chanciness of when it will happen" (Strathern 1992: 176). Strathern offers this example in tandem with her reflections on one's genetic origin, noting that one does not want to know or anticipate the future of one's offspring through knowledge (or control over) that their genetic origin (Strathern 1992: 171). Her theorisation thus concurs with McKibben's observation that there is a drive to keep one's genetic origins mysterious.[96]

To close my reflection—on the relevance of the analytic concept of mystery to my participants' situation of genetic knowledge—I wish to suggest that there is a surprising cultural preference for mystery. I use the term culture in a deliberately broad sense. I do not wish to suggest my participants all come from the same sociocultural background. Rather, I am interested in how they all can be said to exist in a "Euro-American" context—to borrow Strathern's terminology (1992: 171, 173)—wherein knowledge acquisition is a central tenet of modernism. On this matter, David

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[95] One's date of death is a different to the question of what happens after death itself – the latter of which I have categorised as knowledge which will—according to some—always be mysterious.

[96] While admittedly Strathern utilises the word "chance" rather than "mystery" (1992: 171-172) in her reflections, I believe she is still referring to mystery insofar as leaving one's genetic origin to chance is a technique by which mystery is maintained. Moreover, in a separate section of her 1992 book, she engages with Hapgood's discussion—on the "secret" and "mystery" of human gestation—to consider the "interpretative impasse[s]" of humans trying to understand their own origins (Hapgood in Strathern 1992: 139; Strathern 2011: 250) – demonstrating her engagement with the concept of mystery, even if her use of the term itself is sparce.

Seidenberg considers that while mystery might at first appear antithetical to modernity, intentional mystery is nevertheless embraced in many different 'modern' contexts:

> The question of mystery in modernity also presents a unique hurdle, because modernism in an ideological sense is the rejection of mystery, both as an ontological category and as a feeling. An "Age of Enlightenment" perspective would see anything mysterious as that which is insufficiently known and explained.
>
> At the same time, many trends and schools of thought that question aspects of modernity embrace the value or truth of mystery and unknowability, even though they are thoroughly embedded in the cultural context of modernity. These include transcendentalism, existentialism, and holistic or integral thinking. (Seidenberg 2022: 371)

Ignorance as Blessing: Sparing Future Kin from the Responsibility of Informed Consent

These theoretical considerations—on the prevalence and importance of mystery as an analytic concept—are relevant to my fieldwork context wherein the virtue of knowledge is continually touted and yet oftentimes eschewed. I have hitherto discussed Jamie's decision not to inform his neighbour of her daughter's NF1. I wish to add another ethnographic example, this time on the matter of reproductive decision making.[97] During my fieldwork, my participants often discussed preimplantation genetic diagnosis (PGD). I was surprised, however, by one participant's justification for opting to utilise this technology. This woman with NF1, whom I will call Stephanie, explained she would use PGD to prevent the birth of a child with NF1 *not* because she did not want a child with NF1, but because she wanted to save her future child from having to make the "tricky" decision of whether to use PGD themselves. In other words, Stephanie was saving her future kin from having to make a hard choice. I hold that she was not only taking away a potentially guilt-inducing decision, but she was also taking away the burden of engaging with knowledge. I anticipate she will tell her future offspring about her diagnosis and choice to use PGD. This is not a discussion of nondisclosure. Instead, she is sparing her child, and perhaps herself, from the continual relevance of the genetic details of her NF1. Stephanie was not troubled by NF1, but the responsibility of continually managing knowledge about NF1.

Stephanie's choice to forbid NF1-knowledge's relevance is reminiscent of Porz and Widdershoven's (2011) participant, Daria. In their discussion of the existential dimensions of genetic knowledge—which I will address more fully in due course—they introduce Daria, along with her mother who suffered from Huntington's disease. In response to the possibility that she too may succumb to the disease, Dalia cultivated a

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[97] Knowledge and choice are interrelated. Novas and Rose reflect, "Once choice is seen as paramount, knowledge is required to make informed decisions" (2000: 505).

"specific kind of consciousness" (Porz & Widdershoven 2011: 348). Dalia's life is inevitably "coloured by the disease", but by refusing to work with genetic knowledge and technology, Dalia refuses to give Huntington's any more presence. Throughout their discussion, Porz and Widdershoven compare Daria's situation to Camus' (1942) retelling of the myth of Sisyphus. Porz and Widdershoven posit that a myth or narrative is only "tragic" insofar as the hero is "conscious" of the tragedy (2011: 348). If Daria—and by extension my participant, Stephanie—choose to forgo continually thinking about genetic knowledge, they negate the negative impact of this knowledge on their lives.

In bioethical discourse, knowledge and choice are esteemed. The pillar of informed consent depends on agency and information management (Beauchamp & Childress 2013: 122). However, Jamie and Stephanie's respective ethical decision making demonstrates the virtue of cultivating ignorance. Their actions do not speak to the consequence of knowledge vis-à-vis outsiders' opinions,[98] but rather the wisdom and kindness involved in sparing oneself and others from the personal burden of living with (and holding to attention) such knowledge. Appreciating the virtue of ignorance in this context (that is, ignorance as a verb, to *ignore*, rather than as a state of being uninformed) might further explain my participants' experiences as patients. With an upturned patient-doctor hierarchy, my patients are compelled to work with information which ought to be the remit and responsibility of doctors. One could thus say the utility of doctors is not simply their expertise, but their 'holding' of such knowledge. Stewart earlier asserted the doctors at Guy's Hospital are brilliant because they "hold him". I remember being struck at the time by his use of such nurturing language. I wish to borrow this language by suggesting part of what Stewart and other participants value is someone else 'holding' the medical details of their NF1. If doctors are the ones who think about the details of NF1, then the patients can ignore such knowledge in their everyday lives. Much as Tara's textbook on NF1 sits at the recesses of her bookshelf, such knowledge preferably sits at the back of my participants' minds. Linking these insights back to my overall research questions, I can begin to appreciate that genes fluctuate in relevance because genetic knowledge is invoked only when it needs to be.

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[98] The consequences of genetic knowledge—such as stigma or being denied health insurance—are of course important. However, as aforementioned in my introductory chapter, they are secondary to my interest in how genetic information affects people's self-reflections. I thus find the following quote helpful in articulating relevant bioethical concerns, but it ultimately digresses from my research interests:

> The right to know comes into tension with another right, the right not to know, the right not to be known, the fear of the consequences that that knowledge may bring for one's conduct of one's own life and for one's treatment by others—friends, employers, teachers or insurers (Novas & Rose 2000: 505).

That Which Should Remain Unknown: Genetic Knowledge as Taboo

A question I have yet to explore fully is why knowledge of NF1 might be unappealing to my participants. Many medical diagnoses and revelations of risk have the potential to be anxiety inducing, but can I be more specific? Can I use this situation of cultivated ignorance to explore whether genetic knowledge—as opposed to other forms of knowledge—might be particularly burdensome. In this section, I offer two potential explanations for why my participants choose in many contexts to ignore genetic knowledge of NFI, before refuting these explanations in favour of a more comprehensive theorisation on the taboo nature of genetic knowledge.

There are various literatures which discuss genes as sites of harm. In Gibbon's (2003) research at two cancer genetic clinics in the UK, one could say certain genes were seen by her participants as merely the site of the mutation clinically identified as causing their condition. Gibbon noted that "genes were often discussed in terms of the presence or absence of a 'bad' gene. The latter was often imbued with cancer causing potential and hence seen almost as a 'quasi pathogen' (Yoxen l982)" (Gibbon 2003: 55). If this perspective were echoed by my participants, it might explain repulsion towards certain genes and any ensuing genetic knowledge. However, this was evidently not the case among my interviewees. Not only did my participants never articulate such thoughts, but I also hypothesise it would be difficult for them to maintain such a single-minded perspective on genes given the enmeshment of genetic material with their identity—as has been established in Chapter 1. If it is not the existence of 'gene as pathogen', why else might knowledge of a genetic condition be so particularly burdensome?

A second explanation might be found in the partial nature of NF1 genetic knowledge. NF1 is not a predisposition, but it does give an incomplete picture of what the future holds—what Seren termed the "certain uncertainties" of NF1. In opposition to what is usually expected of knowledge, with *more* knowledge of NF1 comes *less* certainty about the future. As Zoe explained to me:

> I just think the worst thing with the NF is not knowing. I think that has always been the hardest thing. And not being able to have answers [for Poppy] as well. It's the unknown destiny and an unknown future. I think that's always been the hardest part of it... And you know, you can spend all that time worrying and then nothing actually bloody happens [in terms of NF1 symptoms developing further]. The worst part of my journey has been not being able to know what's gonna happen. I think that's probably me being a bit of a control freak. But I suppose we all want to know what's going to happen.

Perhaps, as suggested by Zoe's reflections, the root of many of my participants' anxieties is knowing too much and too little simultaneously. I discuss the consequence of this uncertain previewing of the future further in Chapter 4, but for now, I wish to probe further this facet of NF1 genetic knowledge by considering a hypothetical. Even if such knowledge were not partial— if an NF1 genetic diagnosis *could* tell you exactly about your future—would my participants necessarily want to know? I hypothesise they would not.

A pertinent question to ask here is whether the genetic component of such knowledge cause particular unease? I argue genetic knowledge qualifies as taboo knowledge because it is excessively existential. I am not so much interested in genetic disease as an existential threat vis-à-vis a threat to life, but rather in how genetic knowledge causes existential introspection. Returning to Porz and Widdershoven's (2011) paper on the "existential absurdity" provoked by predictive testing in the context of Huntington's disease, I commend their observation that the availability of genetic testing may "play the role of a catalyst in the affected person's search for meaning" (2011: 342). Specifically, they consider how existential crises are provoked in their subjects when a genetic diagnosis upends their expectations of life (2011: 345), pulls them out of the normal flow of daily living (2011: 346), and—to my mind, most interestingly—defamiliarizes the foundations of the world (2011: 345). I find Porz and Widdershoven writings are here reminiscent of Rose and Novas' theorisation of a molecular optic (2000: 487). The former write, "A world that can be explained… is a familiar world. But, on the other hand, in a universe suddenly divested of illusions and lights, man feels an alien, a stranger" (2011: 345). Although Porz and Widdershoven never explicitly use the term "genetic optic", I find their observation—that genetic diagnoses can provoke an "odd state of soul" (2011: 347)—to echo the sentiment that genetic knowledge causes existential introspection.

I am wary of peddling a functionalist explanation—i.e., that the function of keeping genetic knowledge taboo is to prevent members of a society becoming "alienated" (Porz & Widdershoven 2011: 345) and thus depressed—nevertheless, I am still interested in further unpacking why genetic knowledge is so unsettling. As already established, it is not simply genetic knowledge's potential to offer too much insight into the future—although this prospect is of course disquieting. Rather, what is unique to genetic knowledge is the suggestion that the future is already inscribed in your molecular essence. I and others argue this knowledge sits uncomfortably in a cultural context where the future of each person is seen—or, rather, is preferably seen—as unknown and open to intervention. Decades before I conducted my fieldwork, the seminal anthropologist Marilyn Strathern made the following observation:

> One does not always want one's origins predetermined… where the presumption is in favour of variability and keeping a range of possibilities open, anticipation could be disabling… [In the American context,] one baby should not be exactly like another. The child's guarantee of individuality lies in genetic origin: its characteristics are the outcome of a chance combination from a range of possibilities… [Genetic potential] maintains an array of possible characteristics from which an entity might emerge; the future is known instead by its unpredictability, and one would not necessarily wish to anticipate it (Strathern 1992: 171-172).

I find her articulations—on a culturally specific conception of the future—to be helpful to my investigation. Strathern posits that in Euro-American contexts, genes are perceived simultaneously as the *determinants* of individuality and also the basis of an as-yet open and preferably unknowable future. Where "destiny"[99] is perceived to be affected by a genetic condition, the comfort of an unknown yet promising future is denied to individuals.

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To recap and synthesise my findings, I return to Zoe. On page 118, I detailed Zoe's lamentation that "it's the unknown destiny and an unknown future [for Poppy]" which causes anxiety. Considering her other four children also have unknown destinies and unknown futures, why then is the unknowability of Poppy's future so troubling? In Strathern's words, it is the *anticipation* which is disabling. If we take Zoe's remarks in context, and in the light of my findings in this chapter, we can appreciate it is not that Zoe necessarily *wants* to know Poppy's future. Instead, in her attempts to decipher her daughter's future based on partial genetic information in the present, Zoe is confronted with her daughter's genetic destiny. Genetic knowledge of NF1 is awkward for Zoe to handle because it troubles the comfort of one's future being unknown and promising. Revisiting Calkins' reflections on uncertainty, I commend her differentiation of situations "based upon the degree of reflexivity with which the knowledge [itself] is questioned" (Calkins 2016: 7). Reflexivity, according to Calkins, refers to critical probing about premises and grounds of interpretations and actions (2016: 3). Call it reflexivity (Calkins 2016) or call it an "odd state of soul" (Porz and Widdershoven 2011), Zoe is forced to consider her daughter's destiny as limited by her genome—and this contradicts the idea of an unknown future.

For all the discussion of minimising uncertainty and calculating risk in healthcare, it is difficult to acknowledge a cultural preference for mystery. If we focus

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[99] Novas and Rose posit that "as a result of these new [genetic] knowledges, individuals may be specifically identified… as if their nature and destiny was indelibly 'marked' by this genetic flaw" (2000: 505).

too much on the healthcare logistics, we cannot see the wood for the trees: that a drive to know more genetic knowledge might conflict with the simultaneous desire to remain ignorant. To close, I wish to furnish my insights with a more sophisticated vocabulary. Rather than stating my participants have an 'uneasy' relationship with genetic knowledge in the context of medicine, I wish to draw on work of sociologists Anne Kerr and Sarah Franklin (2006) by attesting my participants have an "ambivalent" relationship with such knowledge. They write, "'Ambivalence' is traditionally defined as conflicting or opposing impulses that are simultaneously present… [However, in our view,] ambivalence conveys the sense not only of mixed emotions, but of opposite and coincident views or feelings" (Kerr & Franklin 2006: 41). My participants can both respect the value of knowledge acquisition whilst simultaneously preferring to avoid the burden of such knowledge. Genetic knowledge is a burden because in the context of my participants, the future—and the future's residence in the present via DNA—ought to remain unknown. As is so often the case in anthropological projects, it is appreciating the cultural specificity which makes all the difference. In my participants' cultural frameworks, the concept of genetic destiny is something of an oxymoron. I thus wish to close with the following quote from Kerr and Franklin:

> Social actors' constructions of, and responses to, genetic information involve the sophisticated expression and management of ambivalence according to the complex relationships and contexts in which they are located." (2006: 53)

Conclusion

In this chapter, I have discussed how medical knowledge is impotent to prevent or predict NF1 symptoms. As posited by Solhdju and Rivières, when there is a diagnosis with no corresponding treatment, medicine is forced to "reckon with its own limitations" and the diagnosed person is left in "profound disarray" (2021: 48). Such knowledge is nevertheless utilised by NF1 patients to negotiate medical attention from doctors. This upturned hierarchy has evidently caused anguish for my participants. It is immediately apparent that my interviewees desired and deserved better care. But aside from evidencing the want for a better funded NHS, my participants' frustrations—at being their own healthcare advocator—have enabled far subtler insights into the virtues of knowledge and ignorance. My participants and I have discovered one of the benefits of being a patient is forfeiting the burden of 'holding' one's personal medical knowledge. By admitting the appeal of ignorance, my participants are not downplaying the authority or relevance of medical establishments but are instead questioning the relevance of medical knowledge to their everyday life. The second finding of this chapter concerns the specificity of genetic knowledge. Heeding Calkins' advice of attending to contextual specificity, I have demonstrated that my participants possess an underlying and unrealised preference for indeterminacy. This cultural preference—to ontologically separate destiny from genetics—explains why my participants face existential unrest following their and their children's NF1 diagnoses.

Now that I have established why genetic knowledge is so troublesome to my participants—that is, its existentially disquieting potential—it is now possible to analyse my participants' management of this knowledge. The following chapters explore my participants' discipline when (a) remaining grounded in the present (Chapter 4), and (b), eschewing unkind molecular optics (Chapter 5). In these two culminating chapters of my thesis, I hope my reader remains mindful of why my participants possess an ambivalent relationship with genetic knowledge. As has been demonstrated thus far in this thesis, such knowledge has the potential to allow introspection on identity and build community, whilst also holding the potential to alienate, radicalise, and reduce individuals. For my participants, it is a difficult form of knowledge with which to engage.

Chapter 4: Temporal Discipline

> I worried about Bethan's future. When she was diagnosed with NF1, I worried about whether she would have kids. But then I think, 'what about my [unaffected] son?' He could have fertility problems in the future. His future partner might have infertility problems. He could be gay, and they could have hurdles if they wanted to have children. And I don't think about that with him. So why was I thinking about this with Bethan? This one-year-old child, why was I thinking about her children?
>
> \- Seren

> Knowledge about genes can initiate or else inhibit action and increase or reduce anxiety. Inevitably the future is brought into the present.
>
> \- Lock & Nguyen (2018: 315)

The remaining chapters of this thesis address how my participants respond to the implications of genetic knowledge. In this chapter, I detail how my participants are pulled out of the normal flow of time by genetic knowledge, and how they reintegrate themselves into the everyday. The purpose of this focus is two-fold. First, it allows an opportunity to further unpack what an existential crisis entails in my participants' experiences. By attending to temporal disruption, I can detail how introspection is provoked through the anticipation of future kin. The second reason for focusing on my participants' temporal engagement is to demonstrate their agency. I highlight that my participants make wise decisions when refusing to allow reproductive futures to define themselves in the present, and I argue it is this conscious deliberation which contributes to the fluctuating relevance of genes and genetic knowledge to my participants' lives.

By "temporality", I refer to how people experience and think about time. In recent literature, temporality has been defined as one's own "conception of time"—with various "notions of time" existing within and between cultures (Iparraguirre 2016: 2). Academics are cautious "not to reduce the phenomenon (time) to only one interpretation (temporality)" (Iparraguirre 2016: 5):[100] although linear temporality is arguably hegemonic, it is by no means a universal experience (Iparraguirre 2016: 4-6). Throughout this chapter, I discuss and analyse my participants' comparatively unusual temporal experiences. In my reflections, I draw on Grøn and Mattingly's (2018: 310) examination of "complex temporalities".[101] I contend both my participants and Grøn's experience a kind of "time consciousness" (2018: 311), which works to differentiate

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[100] I should note that while Iparraguirre understands time as an observable phenomenon, other academics, such as Earle and Letherby, speak of time not as a fact but as an ideal (Earle & Letherby 2007: 236).

[101] In this paper, Grøn and Mattingly discuss the intricacies of temporal idiosyncrasy based on the experiences of two people from Grøns' research in a Danish dementia ward.

their experiences from those of their peers. Concerning one participant, Thea, Grøn and Mattingly reflect:

> [Thea's] ability to explicitly attend to this level of time-consciousness… is not available to our ordinary practical stance, a stance akin to what Bourdieu refers to as our "habitus," Geertz describes as "common sense" and Husserl terms our "natural attitude." [Understanding her experience] depends upon exercising a "phenomenological epoché" in which we consciously suspend this natural stance in favor of a more reflective investigation of the basic structures of experience, which are normally hidden as a part of our taken-for-granted lifeworld. (Grøn & Mattingly 2018: 311)

My participants differed from Thea in many respects. Indeed, Grøn's other participant, Vagn, was in a markedly different situation to Thea's—despite the fact they both lived at the same Danish dementia ward. Nevertheless, I find Grøn and Mattingly's approach—of focusing on time-consciousness—to be of great relevance to my research since both their participants and mine exist outside of a normal habitus.

Owing to my research interests, I diverge from Grøn and Mattingly by focusing on how genetic self-knowledge provokes unique temporal experiences. The central questions of this chapter are thus as follows: what are the temporal consequences of genetic knowledge in the context of NF1, and how do my participants respond to these consequences? Specifically, I ask how my participants live every day when their genetic diagnosis prevents the anticipation of expected biological life events. In doing so, I draw on Earle and Letherby's (2007) approach in their study of the interrelationship between temporality and fertility. Earle and Letherby observed that their participants' "expectations" of biomedical events—such as becoming parents or grandparents—led to disappointment and introspection when a participant's sense "of control over reproductive time and the body" was revealed to be an "illusion" (2007: 236, 246).[102] Throughout my analysis in this chapter, I furnish an argument I have been working towards in my previous chapter—that although participants state they wish to know more about their future NF1 symptoms, they remain largely unaware of their simultaneous desire for the future to remain unknown and separate from the present.

To open this chapter, I turn to Kiera—a woman in her twenties living in the northeast of England. Kiera was diagnosed with NF1 as a young child after her father's diagnosis. Although I spoke with Kiera only once, she offered an array of nuanced insights into her experiences of gender, natalist expectations, and the limitations of the NF communities in her region of England. Throughout our discussion, she also crucially

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[102] Earle and Letherby assert that "although the notion of a lifecycle is regarded as a generally outmoded concept, it is still useful [to be mindful of]" since this temporal orientation inevitably informs participants' perspectives (2007: 237).

elucidated on how knowledge of her NF1 has continually disrupted her life through the exceptional intrusion of the future into her every day.

Kiera and Her Ever-Present, Non-Existent Children

Kiera does not want children. She has never wanted children. She resents the repeated question at her annual NF1 check-ups, "are you pregnant?" She scoffs when friends suggest her dog is simply a warm-up for human offspring. Yet despite Kiera's child-free attitude, she cannot stop thinking about her reproductive potential and future. Unlike her non-NF1-affected peers, who prepare for having a baby by saving up money or finding a suitable partner, Kiera instead finds herself preparing for the possibility that she might one day change her mind. If she did one day decide to have a child, it would not be simple. Kiera insists she would only ever have a biological child if she used preimplantation genetic diagnosis (PGD) to prevent the gestation of a foetus with NF1. In ten years, when she will be in her late thirties, will PGD still be available to her on the NHS? Will her future partner think differently of her if conception does not happen at home but in a hospital? These questions continually bounce around her mind, despite her staunch child-free stance.

It is both mine and Kiera's opinion that her experience is not simply that of normal societal pressure. While Kiera believes—and is keen to discuss[103]—how women in Britain are trained for motherhood, she asserts that her reproductive options are continually brought to the forefront of her mind *because,* at a very young age, she was informed of PGD as an important possibility for her:

> I think from my perspective it's questions that have suddenly been put in your head which wouldn't have been normally… and even as a child, and I hadn't even started puberty yet, it's "should I be thinking about this [PGD]?" And even now, and I don't want children, I do think, "but what about a day when I do? Is this something I'm going to have to ring the specialist about?" And it's a bit of paranoia, like, if a doctor sees [my reproductive future] like this, then what's a future partner going to see it as? Are they gonna be like, "oh I don't want your damaged children"? And then are we going to have to get an egg donor, or a surrogate, and how much does this cost? And it suddenly becomes this terrifying speal of questions you're asking yourself. Because of one element [NF1] and of one question you've been asked [the question of have you considered PGD]. And you suddenly feel this extra responsibility to procreate, and to procreate correctly.

The idea of "damaged children" and the compulsion to "procreate correctly" will be discussed in Chapter 5, when I address my participants' deliberation over whether to

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[103] Kiera asserted that women's magazines and media often show motherhood as an inevitable part of a woman's life, and something which should be prepared for. I found it interesting how Kiera lamented that "women in my generation [born in the 1990s] are having 'em young again… All the girls I went to school with have kids, whereas my mum waited till she was in her thirties, she had a life first."

indulge a genetic optic. For now, I wish to focus on time. How might genetic knowledge—specifically, genetic knowledge about a heritable condition—cause exceptional temporal experiences? Does the intrusion of reproductive decision-making too early into Kiera's life speak to a broader pattern of anomalous temporal experiences among my participants?

The Manifold Temporal Effects of NF1

To begin this chapter, it is pertinent to canvass the various ways in which experiences of time can be affected by knowledge of NF1. Only after this canvassing can I justify my focus upon the temporal consequence which I find to be most relevant to my central argument—that is, the anticipation of future kin. First, the anticipation of future symptoms can create an anxious present. This temporal consequence of genetic knowledge has already been alluded to in Chapter 3, when I discussed the certain uncertainties which accompany an NF1 diagnosis. To reiterate, people are told of a long list of possible NF1 symptoms, but do not know if or when any symptom will develop. I have already detailed the anxiety this partial knowledge generates among my participants. However, I have not yet analysed this anxiety as a temporal phenomenon. I thus open this canvassing by considering the mechanisms of an anxious present—namely, the unwelcome intrusion of the future into the present. Consider the following.

Schmidt Nielsen and Stage (2023: 140) make the obvious but important point that "the desire for knowing and controlling the future" is what fuels interest in medical testing. They echo previous authors, such as Lock and Nguyen,[104] who in turn draw on Evans Pritchard's work to compare the motivations for genetic testing with the motivations for consulting an oracle. Lock and Nguyen observe, "A man's future health and happiness depend on conditions that are already in existence and can be exposed by the oracles and altered" (Evans Pritchard in Lock & Nguyen 2018: 303, 349; see also Lock 2005: 47). From Evans Pritchard, to Lock and Nguyen, to Schmidt Nielsen and Stage (amongst other authors), numerous academics have noted that knowledge of the future is deliberately brought into the present by people who wish to control what is yet to come. As established in Chapter 3 of this thesis, with NF1, there is no hope of such control. Thus, rather than the present imposing itself on the future as intended, the

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[104] I was surprised Schmidt Nielsen and Stage did not reference Margaret Lock's work, despite their near identical research interests. I should also note there are some misdated references in Schmidt Nielsen and Stage's 2023 paper. I have chosen to nevertheless quote their article given their commendable discussion of the politics and logic of anticipation.

future instead “haunts”[105] the present—a backfiring consequence of oracle seeking behaviour.

To demonstrate the workings of this haunting, I can point to Kiera’s awareness of possible NF1 symptoms and her shortened life expectancy. One of the motivations for her participation in my research was to recount her late father’s story. He had NF1 and recently passed due to heart complications. Although Kiera was unsure whether NF1 was the underlying cause of her father’s death, she testified that his premature passing had initiated introspection on her own mortality and lifespan. Through her father’s NF1, (both the memories of his passing and the NF1 gene she inherited), along with her potential future NF1 complications, Schmidt Nielsen and Stage might describe Kiera’s present life as being haunted by the spectre of past and future. I wish to add the suggestion that Kiera’s existential reflections on her own mortality may have inadvertently become entwined with the subject of NF1. Her situation is not merely anxiety over what is to come, but rather a profoundly altered way of seeing one’s life and one’s situation. Put simply, thinking of NF1 makes her think of the brevity of life. I here find the following reflection by medical anthropologist Vincanne Adams and colleagues helpful insofar as they highlight the profound consequences of living with altered temporality: “As an affective state, anticipation is not just a reaction, but a way of actively orienting oneself temporally. Anticipation is a regime of being in time, in which one inhabits time out of place as the future” (Adams et al. 2009: 247).

Separate to anticipation of future symptoms, the following ways in which NF1 might affect temporality were not discussed with Kiera. However, since they were mentioned by other participants of mine—as well as by participants in Joan Ablon’s (1999) earlier research—I wish to make note of them for contextualisation. The first is that NF1 affects aspiration. Where participants perceive NF1 to affect their present and future capabilities, people with NF1 might alter their career goals and life plans. Ablon reported that of her 54 research participants, 26 “reported that their NF1 condition had intruded significantly upon their aspirations” (Ablon 1999: 55). For many of my participants, their aspirations were deflated by the others’ diminished expectations. In an article written for the NTUK in-print magazine, one of my participants with NF2 reflected, “I realise having a complex genetic condition means you have likely had to

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[105] Schmidt Nielsen and Stage draw on Derrida’s concept of “hauntology” to discuss “pre-patienthood”—a condition generated by the “prognostic abilities of gene testing technologies” (2023: 143). Schmidt Nielsen and Stage write that the present is haunted by both the past and an “insecure” future (2023: 143). Thus, genetic testing seems to create a hauntological situation in which future illnesses become present (Schmidt Nielsen & Stage 2023: 141).

endure a lifetime of people often telling you what you can't do, setting your expectations and trying to tell you what you can achieve."

More often, for my participants with NF1, I noticed it was a self-motivated adjustment of expectations. My participant Hope noted that she had previously been "unambitious", since she believed her learning differences would prohibit her professional success—although this changed when a new manager encouraged her to reach her full potential. The logic behind these self-imposed limitations in aspiration were as follows. Since one's abilities are (supposedly) less, one's lifespan is shorter, and the duration of time with one's current ability is highly speculative[106]—one should be less ambitious than one might have been otherwise. When there is an abrupt realisation of the extent of NF1's possible impact, this may cause distress. To quote again from Porz and Widdershoven, they observe when there is "a strong discrepancy between [one's] own life expectations and the actual situation he is experiencing… it rather shakes one's sense of reality" (Porz & Widdershoven 2011: 345).

The final point I wish to note for context—regarding NF1's broader impact on temporality—concerns speed. Learning differences associated with NF1—such as dyslexia—often entail slower reading speeds and auditory processing in affected individuals. When people with NF1, such as Hope, become conscious of their relatively slower work pace, this generates an increased awareness of the societal preference for efficiency. I do not have the time to comment on the compulsion for optimisation in neoliberal work environments. However, I do hold it is important to consider that being "slower" because of NF1 is yet another temporal divergence caused by some people's experiences of NF1.

Reproductive Temporality

In the remainder of this section of my chapter, I contend that the most significant yet least theoretically addressed temporal consequence of life with a genetic condition is an increased awareness of reproductive temporality. By reproductive temporality, I refer to the anticipation not of symptoms, but of kin. I hold the continual imposition of the question of procreation reminds my participants of two interrelated realities. First, their

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[106] One could say people with NF1 are "risky" employees. Novas and Rose (among numerous other academics) discuss how one can become "genetically at risk" through genetic knowledge (2000: 486), while Ablon notes that people with NF1 are disqualified from joining the US Army due to the risk that their health could deteriorate during deployment. I anticipate even non-military employers discriminate against candidates with genetic conditions due to the risk of future symptoms developing, and accordingly, people with NF1 do not put themselves forward for certain jobs for fear of this discrimination.

position within their kinship structure; and second of how they are valued because of their potential to make more kin. These two reminders cast doubt on the significance of the individual—particularly when this individual is discouraged from reproducing. It compels participants to introspect on what is valued within their sociocultural sphere, taking them out of their habitus, and thus creates the potential for an existential crisis. This section of this chapter will now detail this argument.

Admittedly, most people ponder their position among their kin. What is more, this conscious location is often temporally inflected. Marilyn Strathern—who frequently makes observations on lay Euro-Americans' ideas of kinship—claims that incorporated into all such introspections are "certain ideas about the passage of time, relations between generations and, above all, about the future" (Strathern 1992: 5). What I intend to demonstrate is that for people with NF1, this temporal awareness is exceptional. In Seren's reflection—which I quote at the opening of this chapter—she remarks that it is unusual for a mother to worry about the reproductive future of her one-year-old:

> What about my [unaffected] son? He could have fertility problems in the future. His future partner might have infertility problems. He could be gay, and they could have hurdles if they wanted to have children. And I don't think about that with him. So why was I thinking about this with Bethan?

I find Seren's self-questioning to be telling. While Seren (elsewhere in our interview) conceded that many NRTs are no longer alien concepts to the public, she insisted it was unusual for her as a new parent to worry about their availability for her children while her children were themselves so young. She claimed it is her daughter's NF1 which has accelerated these concerns. I find Seren's thoughts to be reminiscent of introspection made by one of Kathy Weston's queer informants, who stated, "I think we think more" [than heterosexual people about reproduction]. [Queer people] think about how they want to raise that child… They don't just go out [and do it]" (Weston 1997: 190-191). Although Seren makes explicit reference[107] to her awareness that queer people might "think more" about reproduction than their heterosexual peers, she still claims she and her husband are thinking *even further and earlier* about reproductive time than LGBTQ+ individuals—and that this intrusion is all because of Bethan's NF1.

It is important here to consider why a genetic condition might provoke a different kind of reproductive anxiety than that experienced by queer people, (not least because queerness is not a health condition). One could argue that an NF1 diagnosis comes early in life—often children are diagnosed as infants based on physiological

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[107] That is, she mentions the possibility that her son might be queer and speculates that he therefore might face heightened reproductive deliberation.

anomalies present at birth—and it is this timing which explains exceptional anxiety. However, there are parents who claim they were aware of their child's queerness from a young age. Moreover, I do not believe it is so simple. I contend—as I have previously in this thesis—that it is the genetic nature of this knowledge which makes the difference. Through a genetic diagnosis, Seren has been made aware of a potentially limiting condition located within her child's very genome. I here wish to introduce my argument that knowledge of a child's NF1 is particularly upsetting because of how children are viewed: in Britain, as in many other locations, children are cherished precisely because they inhabit a stage of life where one has undifferentiated potential. Returning to Marilyn Strathern's writing on kinship in the wake of new medical technologies, I find her reflections on anticipation to be of great relevance:

> The child's guarantee of individuality lies in genetic origin: its characteristics are the outcome of a chance combination from a range of possibilities... Genetic potential… maintains an array of possible characteristics from which an entity might emerge; the future is known instead by its unpredictability, and *one would not necessarily wish to anticipate it.* (Strathern 1992: 172, emphasis my own.)

Rather than perceiving Bethan as one would perceive any other child—that is, as an expression of an unknown future, as a being with undifferentiated potential—Seren is instead left to reckon with known genetic limitations on the possibilities of who Bethan can become. As discussed in Chapter 1, one could say the goalposts of Bethan's potential are made known through her genetic diagnosis. The future is intruding into the present where there is, in fact, an underappreciated cultural preference for mystery in childhood.

This underappreciation will be discussed further in the next subsection of this chapter, but first, I wish to make one final observation on the pervasiveness of reproductive temporality. I found it telling that my participants often used future children as a locus with which to articulate anxieties over the future. Both Kiera and Stewart expressed concern over a future in which NF1 was selected against, and they discussed these concerns with reference to abstract future children—that is, children who do not yet exist and who were not their own descendants. Kiera worried that if families with NF1 chose not to have children with NF1, then children born with spontaneous mutations would face an increasingly hostile and lonely world. Meanwhile Stewart admitted he did not like the idea of a future in which no children with NF1 were born. In my participants' lives and logics, children—especially future children—were both highly valued and conceptually useful for imagining an optimistic future.

Good Futures Are Mysterious Futures

It is now timely to focus on the underappreciated cultural preference for mystery which I observed during my fieldwork. I say "underappreciated" since my participants repeatedly expressed the belief that their distress was caused by insufficient knowledge of the future. They wanted to know more about the future, whereas I hold that it is knowledge of the future which causes distress. Consider the following extract from Zoe, which counters my argument that people prefer their children's future to remain unknown:

> I couldn't see [my trans daughter's] future as I didn't know what which way her future was going. And it was the same with Poppy's future. I couldn't see it [after the NF1 diagnosis]. That was the thing that upset me and distressed me the most. I just think the worst thing with the NF is just not knowing. I think that has always been the hardest thing—just not knowing and not being able to have answers as well, you know. It's the unknown destiny and an unknown future. I think that's always been the hardest part of it…
>
> The worst part of my journey has been not being able to know what's gonna happen. I think I'm probably being a bit of a control freak, [but] I suppose we all want to know what's going to happen.

To Zoe's reflections on the distress caused by not-knowing, I have four responses. My first two responses follow her logic—that NF1 is distressing because of what is unknown—while my latter two reflections disagree with her presumption. I ultimately argue that, rather than ignorance, it is in fact unwanted knowledge of the future which generates a difficult present.

I first wish to comment on the partial nature of the knowledge in Zoe's possession. Indeed, there is merit to the argument that it is an incomplete picture of the future—painted by Poppy's genetic information—which causes Zoe distress in the present. Zoe knows something about her daughter's future, but not enough to allow for preparation or action. Again, this is a dynamic which I have covered in Chapter 3 of this thesis. Zoe is faced with a frustratingly partial glimpse into what is yet to come. If genetic knowledge of NF1 was complete rather than partial—such that, say, there was a better understanding of how genotype correlates with phenotype—then Zoe might be spared the worst of her anxiety, (although certainly this knowledge may cause its own distress. On this point, consider my participant Emily's reflections on her inevitable NF2 symptoms[108]). In short, if more knowledge was available, Zoe would be able at least to prepare for guaranteed future symptoms.

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[108] To emphasise the extent to which my participants are left in a state of uncertainty, I can contrast the experiences of my participants with NF1 to my participants with NF2. Emily, a member of the NTUK Board of Trustees, has NF2. When Emily was diagnosed with NF2 as an older teen, she knew there was a near guarantee that she would lose her hearing in the next few years. In preparation, she was able to adjust her educational plans and begin learning sign language whilst still in possession of her hearing. In

My second point of reflection concerns intention. To a certain extent, Zoe encountered genetic knowledge by accident. When Zoe and Poppy travelled to the mainland genetics clinic, Zoe was looking for an answer to Poppy's developmental delays. In other words, she was hoping for a diagnosis which would allow treatment for her daughter in the present, rather than necessarily seeking information about Poppy's future. It is possible that Zoe did not anticipate the oracle-like nature of the genetic test performed on Poppy. Suddenly, information was available to Zoe regarding what was uncertain or risky about her daughter's future. Whereas previously all was unknown about Poppy's future—according to her undifferentiated potential as a child—Zoe was abruptly made aware of her own ignorance regarding genetic knowledge. Zoe was faced with the realisation that every child's future is, debatably, circumscribed by their genome, but that this information is for the most part unknown since most parents do not think to test their child's genome. Through genetic testing, Zoe is made aware of her ignorance regarding what *can* be known about a child's future from genomic science, and this realisation of ignorance scares her. Through the science of genetics, the future becomes scary—full of risk—rather than promising. As Zoe articulate, "It's the unknown destiny and an unknown future" which causes distress, whereas previously—I believe—this unknown future was exciting.

In my third point of reflection, I disagree with Zoe. This is not to say I think Zoe was lying or shortsighted, but rather that she was unaware of her preference for mystery. I hold that in Zoe's situation—of anticipating Poppy's future symptoms—it is not ignorance but knowledge which causes distress. If Zoe was ignorant of all the possible NF1 complications Poppy could face—that is, if doctors did not share the full details and consequences of an NF1 diagnosis, and if this information was not available online to the public—then Zoe would instead manage each NF1 symptom if and when it arrived. I am not advocating for this paternalistic style of medical practice. Indeed, it is my opinion that withholding such information would be unethical. Rather, I am detailing this problematic medical practice as a heuristic hypothetical to demonstrate that it is knowledge, not ignorance, which causes some distress. I hold that it is both academically and therapeutically important to appreciate how the future is cherished

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a poignant excerpt from her autobiography, she recounts preparing to lose her hearing by selecting the last song she would ever listen to the night before an operation to remove a tumour near her ear:

> I knew that sleeping through my last night of hearing would be a complete waste… I wanted to fill those last twelve hours with music. Creating memories for silent tomorrows. So I had been trying to decide what the last music I'd ever hear would be. In the end, after much thought and consideration, I chose something that was not only beautiful music but also full of meaning for me… Handel's *Messiah*. (Owen 2016: 105)

precisely because of its unknowability. If we ignore the benefit of ignorance, we remain unaware of the nuances of Euro-American temporalities. To invoke a final quote from Strathern, "where the presumption is in favour of variability and keeping a range of possibilities open, anticipation could be disabling... One does not want to know how death will come; to anticipate would threaten the hope that is contained within the chanciness of when it will happen" (Strathern 1992: 171, 176).

My fourth, final, and perhaps most consequential point on this matter—that is, on the underappreciated preference for mystery—concerns alienation. Life with an unknown future is a temporality which (a) reduces anxiety, but also (b) maintains normality. I hold it is important to realise how my participants' knowledge of the certain uncertainties associated with NF1 separates them from their peers. While most of Zoe and Seren's respective friends and family orient themselves against an open future—inhabited only by anticipated biological milestones, such as the birth of children and grandchildren—my participants are left alone with a drastically altered temporal orientation. I hold there are three dimensions to this alienation. The first, is that heightened anxiety over NF1's specific array of symptoms is unusual. As discussed in Chapter 3, Seren felt lonely in her concerns about Bethan. Second, it is unusual within a natalist society to not anticipate kin. Although many of my participants had children, many did not and did not plan to. Moreover, even those with children worried about their children's children—as established by Seren. The third dimension of my participants' alienation from their peers was their regular existential thinking. This includes reflections on the length of one's lifetime, as evidenced in my discussion of Kiera's diminished life expectancy in this chapter. I also observed that among my participants, there was increased awareness of oneself as a finite individual within a larger chain of descent or kin group. It was not that my participants were preoccupied with their death, but they appeared more aware of their mortality, and more aware that a long life is not guaranteed to any of us. On this point, I turn again to Grøn and Mattingly's articulations. They note that Grøn's participants live with a different "kind of temporality" when "the possible futures they speak of are in fact so uncertain, so indeterminate, so ever receding that they resemble the open-ended horizon of death" (Grøn & Mattingly 2018: 312). I believe it is fair to say that any experience is necessarily difficult when it is unusual within a sociocultural group. Loneliness can be lethal.

Community and communal experiences offer both a balm to existential concerns along with a daily life wherein such concerns seldom arise. Relatedly, it is important to appreciate the balm of familiarly. As posited by the philosopher Camus, quoted in Porz and Widdershoven (2011: 345), “a familiar world can be explained, but man can suddenly feel an alien when lights and illusions of universe divest.” I am not suggesting that philosophical reflection—existential or otherwise—is bad; far from it, I am indebted to my participants’ introspection and wisdom. Rather, I wish to insist on the importance of appreciating the difficulty of alienation. A divergent temporality should be appreciated both as the consequence of genetic knowledge acquisition, and as the mechanism of my participants’ alienation.

To synthesise my observations on my participants’ temporal experiences, and on the underappreciated preference for an unknown but promising future, I draw on Daniel Knight’s work on temporal vertigo:

> When all that was ever known faces eradication, unfamiliarity breeds temporal disorientation where timelines are shattered, inverted or bear little resemblance to previous conceptions of linear trajectory. Simply, commonly held notions of life in ‘progress’ ‘toward’ a foreseeable or tangible future—the actualisation of everyday orientations such as speculations, aspirations, hopes—are held in hiatus, raising existential questions of self-identification, personal becoming and societal directionality (Knight 2022: 38).

Although Knight’s research addresses economic uncertainty in Greece, whereas mine concerns the hauntological situation generated by genetic knowledge, I find his reflections to be applicable to my work since both our participants are displaced from a ‘normal’ orientation towards the future. During my research, I have found that my participants diverge from their peers since they possess knowledge of possible symptoms; they experience the constant intrusion of the question of reproduction; and they are reminded that they themselves—like all people—will not live forever. It is not necessarily that my participants expect bad things from the future. Rather, my participants’ entire temporalities have been upended by existential reflections following genetic knowledge.

Temporal Discipline

As a response to disrupted and divergent temporalities, my participants have developed techniques to reintegrate themselves into their everyday lives. I call the practice of these techniques “temporal discipline”. In many instances, temporal discipline involves a simple response to a complex problem. Regarding the anticipation of children’s symptoms, Seren and Zoe spoke of the importance of remaining grounded in the present. Seren reflected:

> There could be a million scenarios. But you need to deal with the here and now… It’s a natural way of dealing with that uncertainty, trying to pull as much certainty as you can together through [hypothetical] solutions, so you feel like you’ve got less uncertainty, but it doesn’t really help… The reality is [with NF] that most

> people are fine. And if something changes, that becomes your new normal. If Bethan develops any NF problems, you'll just move your normal expectations. It's limitless [the possibilities] and you can't spiral out of fear. You have to be anchored to the present.

Zoe echoed her sentiment:

> My husband always said, "You know if Poppy has a brain tumour, we'll deal with it. If we get there, then we'll deal with it. But for now, I'm not gonna sit worried that she might get a brain tumour. I don't want to miss out on a child that is absolutely fine." He will actually say this. [And I agree with him, because] you can have all that time worrying, and nothing actually bloody happens.

I hold that the mechanisms involved in this 'living in the present' are not as simple as they may appear. Ignoring the future is easier said than done. Where my participants have been taken out of their habitus—in a process which Porz and Widdershoven describe as the breaking of the "chain of daily gestures"[109]—it is difficult if not impossible to fully reintegrate themselves. They cannot forget the genetic knowledge they know. What they can do, however, is deliberately change their temporal orientation (yet again), and by doing so, ignore the significance of this knowledge. To detail my participants' reorientation, I draw a comparison with the temporal innovation of Grøn's participants', Vagn and Thea.

Both my participants and Grøn's learnt to practice a form of hope which does not rely on the promise of a boundless future. Grøn and Mattingly term this phenomenon "responsive hope" (2018: 306, 310). Mattingly and Grøn discuss how Thea and Vagn's family members hoped that Thea and Vagn would live well in their last days. Grøn and Mattingly claim that by working backwards from an imminent and inevitable death, Thea and Vagn's family experienced a "complex temporality" involving "a backward orientation" (2018: 310). To further furnish their theorisation of responsive hope, Grøn and Mattingly reference Mattingly's (2010; 2014a) earlier fieldwork. They reflect:

> [What Grøn observed at the dementia clinic in Denmark] resonates in an interesting way with what Mattingly found in her research [among] African

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[109] Porz & Widdershoven (2011) discuss the importance of a "chain of daily gestures" in upholding a habitus. They write that a genetically diagnosed individual "is dispossessed not only of a situated present, but also of a comprehensible relationship to past and future, alienated from every possible mode of existence… The chain of daily gestures is broken" (Porz & Widdershoven 2011: 345). By "chain of daily gestures", Porz and Widdershoven refer to an individual's ability to live life without concern for what is to come. They detail how their participant, Daria, was removed from this chain of daily gestures when her mother first struggled to walk at a shoe store. While Daria already knew of her mother's Huntington's diagnosis, (and thus her own possible diagnosis,) it was this shoe shop incident which suddenly and permanently ensured Daria was aware of the "existential absurdity" of her own situation (Porz & Widdershoven 2011: 347). "Daria gained a specific kind of consciousness of her situation as inevitably being coloured by the disease", and thus could not reestablish the broken chain of daily gestures (Porz & Widdershoven 2011: 348).

> American families caring for children with severe chronic diseases: the way that hope shifted over time.
>
> Mattingly's key interlocutors, the parents of these children, were not necessarily giving up an earlier hope (e.g., the miracle of a cure) but, paradoxically, their day-to-day practices indicated the simultaneous formation of a different—one might even say a contradictory—vision of hope that could include death itself. Parents enacted a shifting hope by repositioning themselves temporally, expressing hope for a death that would only come after a life well lived, even if that life lasted just a few short years.

I hold that my participants practiced a similar form of responsive hope. They learnt to no longer view children as beacons of the future, but instead appreciated the lives of their children in the present. Despite (or perhaps because of) knowledge of possible symptoms and a shortened life expectancy, my participants Seren and Zoe were able to remain in the present. What is more, this practice of temporal reorientation works as a response not only to the anticipation of symptoms, but also an existential perspective to one's whole life. In this way, temporal reorientation can combat both anxiety and existential crises.

Regarding the constant imposition of reproductive temporality, my participants practiced temporal discipline by learning to refute reproductive futurism. As Lee Edelman, the theorist who developed the idea and critique of reproductive futurism, recommends, "within this fatal embrace of a futurism so blindly committed to the figure of the Child… [society justifies] refusing health care benefits to the adults that some children become… [We must therefore say,] Fuck the social order and the Child in whose name we're collectively terrorized" (Edelman 2004: 29). In short, my participants refused to value themselves only as future ancestors. Again, this technique is not easy. Arguably Britain is still a natalist society. Accepting oneself as potentially non-reproductive is as radical as it is difficult. Nevertheless, I saw my participant, Kiera, beginning to master this technique.

When Kiera seeks treatment and support for her NF1, she says she feels second to mothers seeking care for their children. She expressed this as, "it's more polite to worry about kids than yourself." Regardless, she continues to push for the medical care to which she is entitled. One could thus see Kiera as a moral pioneer. She is setting an example by articulating her own health concerns without hiding behind the pretence that she is doing so for a child or for children to come. Allowing oneself to matter in the now, not as a potential parent or forerunner of the future, is, I contest, an effective form of temporal discipline.

Significance to My Overall Thesis Argument

Temporal discipline evidences my participants' agency. After being ruptured from their accustomed temporal experiences through knowledge of NF1, my participants choose to—or are perhaps compelled to—reintegrate themselves into their lives. In this chapter, I have detailed how Seren, Kiera, and Zoe create a liveable present by denying the relevance of a partially known future. Insofar as genetic knowledge intrinsically concerns the future, (as well as the past,) this temporal orientation can and should be understood as a refutation of the significance of genes.

As evidenced in chapters 1 and 2 of this thesis, my participants certainly do still speak about genes. Zoe is quick to reference genes when discussing her eye colour and disposition, while other participants alluded to the genetic dimension of their ethnic heritage, or else the genetic similarities between themselves and others with NF1. Be that as it may, this chapter has demonstrated that participants might also choose to downplay the significance of genes—and the genetic dimension of NF1—in certain situations. My participants—including Kiera, Seren, and Zoe—choose not to think about NF1 as something that could haunt their children's future and the lives of hypothetical descendants, and instead remain anchored in the present. Indeed, although I do not have sufficient data at present to confirm this suspicion, I would hypothesise that people might benefit from conceptualising neurofibromatosis as a cosmetic or neurological anomaly, rather than defining it as a genetic and thus heritable condition. While genes might be fruitful to think with in certain contexts, such as individual or collective identity formations, that does not negate the difficulty of living with certain aspects and consequences of genetic knowledge.

Genetic knowledge—like any knowledge—is certainly unappealing when it predicts negative outcomes. I imagine people new to any oracular practices are less inclined to accord them significance when they receive an unfavourable reading. Accordingly, and understandably, my participants adjust the power they accord to genes. As I have argued in this chapter, my participants do so by negating the temporal consequences of genetic knowledge, whilst simultaneously choosing not to see oneself as merely a genetic-ancestor-to-be. As will be detailed shortly in Chapter 5, my participants also deny the relevance of genes and the power of genetic explanations when they refuse to abide by a genetic optic on life itself. My central point here is this: when genetic knowledge brings harm, such as via existential unease and temporal disruption, and my participants accordingly choose to eschew the relevance of such knowledge, this action contributes to fluctuations in the relevance of genes. In the introductory chapter of this thesis, I noted that some anthropologists claim genes will always remain "fuzzy", "boundary objects", whose wavering significance to various publics will never be explained (Pálsson 2007: 212-213). I disagree. This chapter has demonstrated how individuals proactively effect these fluctuations in the significance of genes. My participants choose to downplay the significance of genes and the consequences of genetic knowledge in certain situations. While temporal discipline and other expressions of agency might be unable to explain *all* such fluctuations, it is shortsighted to miss the impact of the judgements and actions of my participants.

Conclusion

Novas and Rose argue that "[r]e-cataloguing illness and pathologies along a genetic axis does not generate fatalism. On the contrary, it creates an obligation to act in the present in relation to the potential futures that now come into view…. individuals seek to plan their present in the light of their beliefs about the future that their genetic endowment might hold" (2000: 488). In this chapter, I have demonstrated a situation in which the opposite occurs. Rather than planning or bracing for a "potential future" which has come into view, my participants have rather made the decision to ignore such a future. The temporal discipline of my participants is a practice of non-anticipatory action. When faced with the constant intrusion of reproductive temporality, the sudden creation of risk in their employment ventures, and an existential perspective, Seren, Kiera, Zoe have worked to reorient their temporality into something they can live with. It is not that they have fully returned to their previous lives. Genetic knowledge once known can never be unknown. Rather, they have learnt to ignore such knowledge, and in doing so, have negated the relevance of such knowledge.

To close this chapter, I wish to add some closing thoughts on temporality and NF1. In the body of this chapter, I have focused on participants' responses to the future at the expense of considering the role of the past. Solhdju and Rivières observed in their discussion of predictive and presymptomatic tests that risks become "a sentence or, to be precise, a curse that overpowers not only a person's present and future but also, assuredly and retroactively, her past" (Solhdju & Rivières 2021: 48). In future research, I would be interested in exploring how people's knowledge of NF1 colours their relationship to those who come before them.

One of my participants, a young man with NF1, explained to me that he wished to have children because he "owed" it to his family. He saw having children as an expression of love for his father and grandmother—it was a means of continuing the family. Moreover, I would be interested in exploring whether people felt the future was resident in the present (but also the past) explicitly in the form of genes. Evans Pritchard made the following observation separate to any consideration of genes, but I would be interested in unpacking whether genes as substance are the locus with which people think about the future and past inhabiting the present:

> The future depends on the disposition of mystical forces that can be tackled here and now. … when the oracles announce that a man will fall sick … his 'condition' is therefore already bad, his future is already part of him. (Evans Pritchard in Lock & Nguyen 2018: 349)

Chapter 5: Refusing a Genetic Optic

> Philosophy used to approach knowledge in an epistemological way. It was interested in the preconditions for acquiring true knowledge. However, in the philosophical mode I engage in… knowledge is not understood as a matter of reference, but as one of manipulation. The driving question no longer is "how to find the truth?" but "how are objects handled in practice?"
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> \- Mol (2002: 5)

Thus far in this thesis, I have explored how genetic knowledge—often brought to the fore by an NF1 diagnosis—affects my participants' everyday lives and introspections. In my chapter 1, I have covered what my participants believe genes to be, and considered how these units of heredity affect my participants' sense of themselves as individuals. In chapter 2, I have then analysed the role of genetic knowledge in forming genetic communities and shown that while a desire for community exits among my participants, genetic identity is insufficient and sometimes in tension with this desire. My first two chapters have thus shown that in some situations my participants' genetic identity matters, while in others it does not. I continued by exploring the limits of genetic knowledge's appeal both within and beyond medical care. I charted how my participants have come to know knowledge as a burden. I then reflected on the academic importance of attending to ignorance as well as to knowledge. Finally, I have detailed how sometimes, in certain contexts, my participants ignore genetic knowledge and its implications in a process that I have termed temporal discipline. Yet while I have traced the relevance and irrelevance of genetic knowledge to my participants' everyday lives, I have not fully examined how my participants evaluate such knowledge. In this final chapter, I therefore move away from asking when genetic knowledge is relevant, to investigating why my participants might emphasise or eschew its relevance.

The primary focus of this chapter is how my participants negotiate different outlooks on life itself. By "outlook", I refer to an individual's conscious cultivation of values. A synonym for outlook could be 'world view', or 'ethos', since I am interested in how my participants' choose to think about the universe and their place within it. Whereas in chapter 1, I discussed my participants' *reflections* on the forces at work in the world and in themselves, (that is, their cosmology,) in this chapter, I address my participants' *evaluation* of different values and ways of seeing the world. In this chapter, I introduce various outlooks on life itself. One outlook—which I call a 'genetic optic'—prioritises utilitarian considerations. Within this outlook, genetically different individuals are valued because of their contribution to population diversity. Other outlooks, by contrast, refute the imperative to evaluate human life based on its usefulness. Indeed, many of participants' idiosyncratic outlooks on life itself involve championing kindness over hard logic, (as will be discussed on page 153).

In this chapter, I argue that my participants' cultivation of their outlook on life itself (a) must be understood as ethical action, and (b) explains why genes and genetic explanations appear to fluctuate in significance within the lives of my participants. To begin building this argument, at the start of this chapter, I offer ethnographic description of my key participants' epistemological introspection. I discuss how Stewart, Chris, and Zoe respectively manage their thoughts; acknowledge their feelings; and entertain contradictory truths. In the following section, I consider two analytics by which this ethnographic data can be analysed, one focusing on therapeutic motivations, the other on etiquette, before arguing that a third explanation—centring on outlook deliberation—is necessary. In this alternative analysis, I introduce a participant whom I have not yet mentioned, Wendy, along with her experience of a friend voicing an uncomfortable truth about Wendy's daughter, Sophie-Ann. I use this as an opportunity to consider kindness as a distinctively British imperative. In this chapter's final section, I then tie in my analysis—on outlook deliberation—with existing literature by drawing on the anthropology of ethics. I argue that this body of literature is crucial to understanding my participants' deliberation between—and building of their own—outlooks on life itself.

The purpose of this chapter is threefold. First, I highlight why outlook cultivation should be understood as ethical action in order to encourage further collaboration between the anthropology of ethics and the anthropology of genetics. Second, I add detail on my participants' knowledge management practices to address what has been previously overlooked in chapters 1 through 4. (Whereas in chapter 4, I address how my participants learn to *ignore* knowledge to enact temporal discipline, in this chapter, I account for my participants' *dismissal* of certain truths. I specify that my participants do not disagree with truths, but rather eschew their relevance with considerable deliberation and occasional contradiction. In this chapter, I thus address a discrete technique by which my participants respond to genetic knowledge.) Thirdly, and ultimately, the purpose of this chapter is to answer my research question, on why genes and genetic knowledge appear to fluctuate in relevance to my participants. In this chapter—along with my previous chapters—I demonstrate that genes are not "fuzzy" boundary objects (Pálsson 2007: 212), nor are they merely a new vocabulary through which the public engages nature-culture debates. Rather, genetic knowledge—and the truths derived from such knowledge—are consciously and carefully managed by my participants so that they can cultivate an appealing outlook on life itself.

A Note on Terminology

Within this chapter, I use certain terminology in highly specific ways, and as such, it is pertinent to offer a comprehensive definition of terms. First, let me unpack my use of the term “truth”. In my ethnographic description, I will make observations such as “my participants refute the relevance of certain truths”. In doing so, I am not suggesting that my participants doubt the existence of objective truth, nor am I claiming they necessarily disagree with the truth being presented. Rather, when I speak of my participants “refuting truths”, I refer to how they deny the relevance of constructed truths. Crucial to this refutation is my participants’ awareness of how so-called truths are (a) based on human interpretation of scientific facts—including genetic knowledge, and (b) often used to further specific agendas. Examples of such truths could be as follows: the probability that genes play a significant role in delineating the confines within which a person develops, and the idea that each human is but one individual in a species which—like all species—is in the throes of evolution. Thus, when I say truth, I am addressing any claim or observation locating its authority in scientific rationality.

One might ask why I do not use the term “knowledge” or “idea” in lieu of the term truth. My reasoning is that I wish to remain in keeping with my participants’ language use (see Stewart’s reflections on page 147), as well as the terminology used by relevant authors such as Anne Kerr. In a review of Kaja Finkler’s publication on the new genetics, Kerr criticises the assertion, “that DNA gives us truth because it is inherently impersonal” (Kerr 2001: 416). Kerr and I concur that there is no such thing as impersonal knowledge. In a later publication, Kerr—along with Franklin—argues that “authoritative knowledge, judgement, and above all truth are often thought of as singular, particularly when scientific ‘facts’ are concerned”: however, “doubt and ambivalence” are apt responses when one becomes aware of the construction of scientific knowledge (Kerr & Franklin 2006: 47). I thus use the term truth as a nod to this seminal literature on the constructed nature of scientific facts—honouring Kerr and Franklin, along with Richards (1993; 1996), Latour (1993) and the philosopher Anne Marie Mol, the last of whom I have quoted to open this chapter.

To add some insight to my use of the term “outlook”, which I have introduced briefly on page 140, I offer the following contextualisation. In my use of the term outlook, I draw on Rose’s conception of a “style of thought”, albeit with a few adjustments. As previously described in my introductory chapter, Nikolas Rose defines a “style of thought” as a “viewpoint in which certain phenomena are accorded significance… a style of thought also embodies a way of identifying difficulties, questioning arguments, identifying explanatory failures and trying to correct them" (Rose 2007: 12). In short, for Rose,[110] a style of thought concerns looking at one's world and deciding what needs to be explained within it.[111] When I speak of an "outlook" on life itself, I am—like Rose—also addressing how people view and evaluate life itself. However, unlike Rose, I am explicitly addressing my participants' *conscious* cultivation of their outlook via the synthesis of choice truths and values into a world view. Whereas Rose speaks of how new values emerge subtly—"values about who we are, what we must do, and what we can hope for" (Novas & Rose 2000: 488)—I claim that my participants deliberately decide on these values. I thus often speak of "outlook deliberation" to acknowledge this deliberate approach.

A 'genetic optic'—my own terminology—is one possible outlook on life itself. It is an outlook which evaluates the value of an individual's life based on their utility to humanity as a whole. This outlook is something of a heuristic strawman for my participants and for my thesis. I did not encounter anyone who championed a genetic optic as their preferred outlook during my fieldwork. I did, however, observe my participants reacting against such rhetoric. Consider the following quote from the popular novel, *The Fault in Our Stars*, which was mentioned by several of my participants. A character snaps at a young cancer patient: "You are a side effect… of an evolutionary process that cares little for individual lives. You are a failed experiment in mutation" (Green 2014). I find it telling that this quip struck a chord with several of my interviewees who mentioned either this novel or its film adaptation. Unlike other authors, such as Lippman (1991), who try to establish whether geneticization has happened or not, I am interested instead in what my participants feel they are acting against. I have thus offered detail on a genetic optic as a hypothetical outlook against which my participants develop their own outlooks. Put another way, regardless of whether this genetic optic does in fact exist or not, in the minds of those my participants encounter, a genetic optic is *felt* to exist—and as such, this optic informs the outlook-cultivation practices of my participants.

As a final contextualising note, I wish to acknowledge that I coined the term genetic optic from Carlos Novas and Nikolas Rose's term, "a molecular optic" (2000: 487). As a reminder, for Novas and Rose, a molecular optic refers to an ontological shift

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[110] Rose himself borrows the term "style of thought" from Ludwig Fleck (1979 in Rose 2007: 5).

[111] Rose offers the example of a "molecular" style of thought, wherein heredity is conceptualised as an ancestor passing on a set of base pairings, and personality is explained by protein synthesis. He posits, when "the body becomes the subject of a molecular gaze, life is recast as a series of processes that can be accounted for and potentially re-engineered at the molecular level" (Rose 2001: 487).

wherein “the body becomes the subject of a molecular gaze, life is recast as a series of processes that can be accounted for and potentially re-engineered at the molecular level” (2000: 487). In Rose and Novas’ writings, they allude to (but do not explicitly discuss) an outlook on life inspired both by this molecular gaze and by a eugenic logic. Consider the following quotes. Rose notes that in a new molecular optic, “we have become the kinds of people who think of our present and our future in terms of the quality of our individual biological lives and those with whom we identify” (Rose 2001: 22). Although Rose is here speaking of one’s quality-of-life, rather than necessarily evaluating which lives are of quality, I find this quote telling insofar as it demonstrates an interest (or anxiety) in what we leave our descendants. Consider this extract in tandem with two other quotes from Rose. With Novas, Rose claims people are increasingly obligated “to calculate choices” vis-à-vis their own interests, “but also in terms of their relations to others, including… actual and potential kin, past and present” (2000: 488).

Although making decisions based on the collective good is not inherently eugenic, visualising heredity “as inheriting a sequence of bases from an ancestor” (Novas & Rose 2000: 487) whilst considering oneself as a genetic ancestor with obligations to future kin, leads to an uncomfortable outlook—which I term a genetic optic. I believe this genetic optic is felt particularly acutely when my participants are discouraged from reproducing people like themselves—lest they pass on the supposed molecular burden of their genes. Now that I have defined my use of the terms “truth” and “outlook” (along with “genetic optic” as one possible example of an outlook), it is possible to begin my analysis of my participants’ approach to their own thoughts – and the outlook such thoughts contribute towards.

Participant Reflections

My participants had manifold thoughts on their thoughts. For clarity, I have divided these thoughts into the following three groupings: thought management, the acknowledgement of emotions, and the acceptance of contradictions. Beginning with my first category—instances where my participants explicitly discussed their thought management practices—I turn to a video published on NTUK’s website. In this video, a man reflected on how he turns to NTUK when he is “thinking thoughts I don’t want to think” in order to find those who can encourage him to change his perspective. Although this man himself was not one of my participants, I find his assertion useful. He well-summarises a sentiment which was echoed by nearly all my participants—that one can separate oneself from one’s thoughts, and that one can acknowledge a thought without letting such thoughts define you. In short, most of my participants held that one is—or ought to be—conscious of one's thinking.

Oftentimes, my participants delighted in their successful control of their thoughts. For instance, Zoe confided in me that because she "doesn't want to think" about Poppy's NF1 as a limitation, she simply chooses not to think that way. While this thought—which could be described as an expression of genetic essentialism—may well cross Zoe's mind on a regular basis, she has learnt to dismiss it. She thus celebrates her agency in preventing this thought from becoming a belief. Along with celebrating the successful dismissal of unappealing thoughts, participants also spoke of effectively instilling beneficial thoughts and perspectives. In my discussions with Chris, he hypothesised that people with NF1 train themselves to conceptualise NF1 as a unifying diagnosis. Although Chris himself abstains from this attempt at comradery—reflecting, "I've never *tried* to think about NF as the something that ties me to other people [emphasis my own]"—I find his observation, on the popularity of this thought-cultivation, to be interesting.

Other times, my participants discussed their failed attempts at modifying their thoughts. Stewart acknowledges that, much to his own frustration, he has internalised his mother's attitude towards him. As previously discussed in my introductory chapter, Stewart's mother told him—when he was just a young child himself—"you must never have children." Stewart knows this is not true. He asserts that he is entirely "valid" as a person, and that he would have been perfectly justified in having a biological child. However, he laments that he could never bring himself to act on this conviction. He reflects that despite his best efforts to convince himself otherwise, "a part of me still believes what she said was true, [that it would be wrong for me to have children.]" Stewart, along with other participants, thus conceded that certain thought patterns were beyond their control. All in all, whether discussing their successes or failures in cultivating thoughts, my participants demonstrated a conviction that thoughts are passing, and that attitudes are—to a certain extent—pliable.

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My second grouping—of participants' thoughts about their thoughts—concerns emotion. Several of my key participants explained that they acknowledged their feelings, regardless of whether they saw such feelings as rational. For instance, my late participant Chris discussed his guilt over the thought of leaving his partner behind after his impending death, even though this was obviously not his fault. He reflected, "I feel bad for what I've put her through. It wasn't deliberate, but it's a natural feeling."

To give a second example of how my participants approached their emotions, I turn to Zoe. In our discussions, Zoe often deferred to gendered explanations. She believes that, on the whole, women deal with stronger emotional responses than men. To evidence this claim, Zoe would continually contrast herself with her husband—whom she believes is more level-headed. Consider the following extract, where Zoe reflects on how she was prone to catastrophise following Poppy's NF1 diagnosis:

> My husband would say she's fine. But, you know, it was really difficult. I can look back on that and I can quite happily say that I was irrational and stuff. But when you're in that moment and it is your baby, it's really hard to bring yourself out of it …I think it's something that women do. We have that as an in-built thing. Catastrophisation, or whatever it's called.

Later in our conversation, Zoe reiterated her thoughts on gender while considering her experiences of intrusive thoughts:[112]

> I think as a woman you kind of catastrophize things. I definitely put myself in that category. I think at that time [of Poppy's diagnosis] I did [catastrophise often]. Not so much now though… I can't help it; I think it's something that women do... I remember when the children were little and we were driving along, I suddenly thought, 'what if I hit that curb and the car flips over and we go into the field, and I am unconscious.' … You know it's completely ridiculous, but your brain does silly things, doesn't it?

As I observed with Chris, Zoe acknowledged this undesired experience before moving on. Neither Chris nor Zoe berated themselves for being illogical. Yet equally, neither Chris nor Zoe was interested in giving credence to their unwanted feelings.

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My final grouping—of participant reflections—concerns contradictions. I am interested in situations where my interlocutors reflected on inconsistencies within their own reasoning and values.[113] While describing his religious beliefs—or lack thereof—

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[112] While intrusive thoughts are not necessarily emotions, I group them here with unwanted emotional responses since both can be deemed experiences beyond an individual's control. Moreover, I consider an intrusive thought to be different to a passing thought (which I have discussed in my previous category) since intrusive thoughts are seldom entertained with seriousness.

[113] I here follow the advice of Anne Kerr. I have found Kerr's work highly useful to this my final chapter, especially where she criticises other academics in the anthropology of genetics for overlooking "some of the loose threads—the doubts and uncertainties, the inconsistencies and contradictions, expressed [in] interviews" (Kerr 2001: 416). Together with Sarah Franklin, Kerr argues anthropologists must attend to why people oftentimes possess "opposite and coincident views or feelings" when faced with genetic knowledge (Kerr & Franklin 2006: 41):

> In contrast to the view that the 'best' and 'most correct' relationship to genetic information is simply one of clarity, accurate understanding, and rational decision making, ambivalence is in some situations a desired goal of communicative outcomes concerning genetic information… [When] ambivalent responses are seen less in terms of being inadequate, immature, and irrational and more in terms of being wise, inclusive, and

Stewart once told me, “I am able to hold two parallel truths at once”. He was here referring to how he balances his agnostic atheism[114] with his interest in Buddhism. On numerous occasions, Stewart explained that he finds great comfort in the idea of reincarnation, even if he does not necessarily believe it to be true:

> I don't actually believe in it, but I found I could make use of it. So [I was] introduced to the idea of reincarnation. [Specifically], that between incarnations, the soul—or whatever you want to call it—makes a wise choice about its next incarnation. So, what if I chose this? What if I chose to have NF? What if I chose to have a mother who couldn't accept that I had NF?
>
> And I thought, well, actually, the experiences I have had as a child—of being in hospital and of being temporarily disabled—have given me not only a knowledge but also a wisdom that I bring to my nursing… I have also learned that it is possible to live on one's own. Maybe it's not ideal, but there are actually benefits to [being single.] …
>
> And, actually, I don't believe in reincarnation really. But I felt I can use that perception [that I chose this life] to give me a different take on my NF.

I find it interesting that Stewart here demonstrates epistemic self-awareness. He acknowledges that he can find comfort in—and accord power to—an idea he does not necessarily believe to be true.

To an extent, I believe Stewart was able to practice his “parallel perspective” approach due to his agnostic atheism. He was humble in the face of what he did not know and thus hesitant to make assured convictions. He reflected to me:

> I have some sense of there being something that is outside the purely rational human. But I don't really know what that is. I certainly don't believe in any sort of a god or any sort of a directive, creative being. But maybe there is something that is not purely rational that is going on. Which isn't to deny the rational. It's only to say that there might possibly be something that I can lay alongside the rational that the rational can't comprehend. But I don't know. I think I welcome uncertainty.

Where Stewart entertained the *possibility* of supernatural, Zoe was more eager to try and identify various currently-unknown phenomena working in the natural world—and I believe this openness coloured how she lived with her own contradictions. Consider Zoe’s reflections on how she coped with her daughter’s broken bone years ago:

> empathetic—[then this will] raise many questions that will be the subject of future studies. (Kerr & Franklin 2006: 42)

My ethnographic attention here is thus a response to Kerr and Franklin’s recommendation.

[114] Stewart explained to me: “I use the word ‘atheist’ because it's just the easiest single word that people understand to convey what I mean. I don't actually think of myself as an atheist because, first of all, I don't think of myself as any sort of “-ist”. That puts me in a box. Secondly, if I did put myself in a box, I wouldn't want that box to be defined by a negative. I don’t want to be defined by what I don’t believe. I want to be defined by what I do believe.”

> When Darcey [Poppy's twin sister] fell asleep [after hours of treatment at the hospital], I went outside and I talked—not to god, 'cause I didn't really think that there was one. I still don't.[115] But I just talked to the clouds and whoever. And I just put out there that she's gonna heal really quickly. I said, 'She's doing so well. She's going to be okay.'
>
> And Darcey should have been in traction for six weeks, but her leg healed in three. And you know, I'm not saying because I spoke to the cloud, her leg healed. But I do massively believe in that positivity. [On the one hand,] I think she just healed really quickly 'cause she was a 3-year-old, and I don't think I made her leg better with respect to the clouds. But [on the other hand] I think about that positive projection. I really do think [it did something].

Although Zoe's partial—or perhaps potential—belief in the power of manifestation contrasts Stewart's more cautious musings, I find it interesting that both acknowledged the appeal of ideas which contradict their more general beliefs about the observable world. I do not believe my participants were merely entertaining divergent thought practices as metaphors with which to articulate their experiences; nor do I necessarily believe they were fully convinced by the supernatural. Rather, I contest that Zoe and Stewart—along with other participants—exhibited a humility in the face of the unknown. They also—crucially—evidenced a respect for ideas which they deemed untrue, but with which they would nevertheless *like* to agree. In review, in their thoughts about thoughts, my participants respected the appeal of ideas which run contrary to their established beliefs (or lack thereof.)

Possible Explanations for Participant Thought Management Practices

In light of these ethnographic observations, it is pertinent to ask *why* my participants might entertain that which is not obviously true. In this section, I entertain two possible explanations, before introducing a third, more subtle, more theoretically interesting understanding of my participants' thought practices. The first possible explanation concerns the therapeutic potential of certain thought reorientations. When I consider this explanation, I am reminded of my participant, Emily. In a video posted on the NTUK, she discusses the surgeries she underwent to manage her NF2. With moving and saddening honesty, Emily reflected, "I had to accept my new body [a body that was partially paralysed and deaf], otherwise I couldn't have carried on living." She continues:

> In the end, I did realise I had a choice. Either I move on, or I don't. So either I just stay wallowing in this life—I'll be honest, I didn't want this life. But I could either live it or I couldn't. So, I chose to carry on. Getting through the next five

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[115] Zoe quipped to me elsewhere in our discussions, "I don't believe in him, but thank god Poppy doesn't have NF2."

> minutes, days, weeks… I realised that actually this life I didn't want is okay. And actually, I almost do want it, because it's fine.

Emily's need to reorient her perspective is palpable.[116] I would not be surprised if a psychologist explained Emily's thought cultivation as an effective therapeutic technique by which she has reached acceptance. That is, by telling herself she was going to be okay, she learnt to be okay.

If I were to apply this therapeutic explanation to the actions of my other participants, one might see Chris' journal writing—in which he entertained various thoughts and superstitions—as a means by which he learnt to accept and work through his terminal cancer diagnosis. Ever since he was a child, Chris made regular journal entries. Consider the following extract from my interview with Chris where he discusses his writing practices:

> I have a theatre stub from last March [pasted into my journal], which was my last normal day [before the terminal cancer diagnosis]. As a journal should be, mine's self-indulgent. It's intriguing to look back. I have a documentation of this growing thing [the tumour]. Sometimes it's interesting to look back and see what you find to write about. I'm not so much interested in what I was doing, but what I was thinking… I include how I feel—[such as] annoyance at NF, because I can't do certain things. I'm on page 213 now [of my current journal,] which I started on January 11th. I've got journals from age 11, including 9/11, my first girlfriend, going to uni. It's not something I was told to do to help me on my medical journey, I was just encouraged as a child. It's a bit cringe sometimes, but I would never burn a teenage journal like people do. There are moments of elation and despair. I can look back on my first date with [my partner] and see this is exactly how I felt.

Chris entertained the idea that he could pinpoint in his diary entries the exact date when his cancer reappeared, (even if he was unaware at the time that his malignant peripheral nerve sheath tumour had returned). He reflected, "I get why people wouldn't correlate [a shift in tone in the diary with a return of the cancer]. It's logical for them to doubt that. But I'm still interested in it, so for me, it's an important thing to do." In a separate interview with Chris, he explicitly discussed with me his entertainment of illogical thoughts as a technique through which he can process the absurdity of his situation. Reflecting on a coincidence—that at the time of his diagnosis, he had recently decided to be more vocal about his NF1 in the workplace—Chris commented:

> Now that I'm talking about NF more than ever, and then something happened again [the cancer returned], I almost felt like I planted it. [I know that's not true,

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[116] I am here reminded of a quote from Porz and Widdershoven's paper, (which I utilise frequently in chapters 3 and 4 of this thesis): in a comparison between their research participant and the myth of Sisyphus—a comparison drawn since both characters must acknowledge the hopelessness of their situation and find new meaning—the authors reflect, "One *must* imagine Sisyphus happy" (Porz & Widdershoven 2011: 349).

> but] it's hard to process the things that have happened in the past three years. You have to go with it, [to accept the cancer diagnosis] and take it all on board well.

It is easy to see how an academic or physician could effectively argue that by acknowledging his irrational thoughts (regarding the timing of his cancer's return), Chris was helping himself process his situation.

In addition to this therapeutic explanation of my participants' thought management practices, there is also the possibility that etiquette explained much of what I observed. During my fieldwork. I was struck by the frequency with which participants would say, "I'm lucky I don't have it worse," or "I must remember how lucky I am." I do not believe my participants believed in luck per se. Rather, they were practicing a culturally specific etiquette wherein one must not appear too unhappy with their lot in life lest they appear ungrateful. In other words, my participants would articulate convictions on luck – which they did not believe to be true – to appear polite. This explanation would account for several details in my discussions with Chris. For instance, in our first meeting, when I said I was sorry to hear he had cancer as a young man, he batted away my sympathy, saying, "oh, it was nothing that matters now," and, "don't be sorry—it's not your fault!" I was surprised then, when I mentioned my own father's cancer diagnosis, how quick Chris was to say "I'm so sorry to hear that"—invoking the very phrase he had brushed off. I hold Chris' inconsistency evidenced courteousness.

There are evidently benefits to remaining mindful of the prevalence of etiquette practices among my participants. From pleasantries expressed in interviews, to my participants' anxiety over being judged for criticising respected figures, (such as parents or institutions such as the NHS,) it is clear etiquette dictated much of what was said in my ethnographic encounters. However, I do not believe subconscious etiquette practices can explain all my participants' hesitations, convictions, and conscious contradictions. When discussing their opinions on sensitive matters or narrating significant life events, my participants' thought management practices were clearly affected by something more than rules of etiquette and therapeutic initiatives. In the remainder of this chapter, I argue that at various instances in my participants' lives, different truths were evaluated and eschewed as a part of a conscious deliberation over different outlooks on life itself. To illustrate what this deliberation can look like—and to underscore the importance of attending to this deliberation within my analysis—I introduce one final participant, Wendy.

An Alternative Analytic: The Imperative to Develop a Better Outlook

Wendy herself is unaffected by neurofibromatosis, but her daughter, Sophie-Ann, was born prematurely with NF1 thirty years ago. Sophie-Ann is now a medical professional herself. Although NF1-associated epilepsy impacts her life—including some of the physical demands of her nursing career—Sophie-Ann loves her work. However, despite a happy present, Wendy is haunted by a comment made to her when Sophie-Ann was a sick infant.

> When Sophie-Ann was born, the doctors weren't sure if she was going to make it. She was so frail, she had so many complications… I was talking to [a family friend] about it, and she said "well, if Sophie-Ann doesn't make it, then she won't have to live suffering with disability". And I was just [shocked]. Of course, what [the friend] was saying was honest. But still, what an evil thing to say.

Like Wendy, I was struck by this comment. My first reaction was that such a remark was untactful. Perhaps the friend was not necessarily judged for thinking this thought, but for sharing it. I am here reminded of Roy Dilley's article—on knowledge and ignorance practices—where he discusses the social function of knowledge denial. Whereas Dilley's participants understood that a "knowledge of [witchcraft] should not be publicly acknowledged by individuals" (202: 184), Wendy's friend failed to appreciate that some thoughts—while truthful—should not be articulated. However, to account for why Wendy is still troubled by this comment, it is not enough to say that Wendy's friend failed in her etiquette practice. After all, the comment was intended to soothe Wendy, (although it did not have the intended effect.) A complete account of the situation requires an explanation of why the sentiment was deemed undesirable in the first place.

I believe a full explanation of the situation requires an appreciation of how this friend's articulation was interpreted by Wendy as incongruent with her outlook on life itself. Although I do not think this friend had intended to suggest disabled lives are less valuable than non-disabled ones, this was perhaps what Wendy—in a state of stress—might have taken away from the interaction. This begs the question of why Wendy was so quick to have made this leap. To this, I posit that Wendy's defensiveness demonstrates a distinctive approach to a "good enough life".[117] Whereas some might seek an outstanding—or at the very least pain-free—life for their children, Wendy was content with her daughter having a less-than-perfect, ordinary, or even sub-par life. The fact that Sophie-Ann has grown up into a happy, highly skilled, largely pain-free nurse

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[117] I am here drawing on Daniel Miller's (2024) reflections on what most ordinary people achieve and the respect this ordinariness deserves.

is irrelevant to Wendy's outlook on life itself. For Wendy, these facets of Sophie-Ann's life were never a requirement for her existence.

I wish to hypothesise that Wendy's acceptance—of a good enough life for her daughter—evidences a particularly British approach to cultivating one's outlook on life itself. Since outlooks are built through the prioritisation of certain values over others (as discussed on page 140), cultural differences over values become increasingly salient. In my early online ethnography, I certainly noticed that Brits and Americans often differed in their prioritization. For example, I kept up to date with a blog in which a young American woman with NF1 spoke of wanting to become a nurse to "give back" for all the medical attention she received as a child. Her sentiment reminded me of a separate article—highlighted by a US neurofibromatosis charity—wherein two unaffected brothers praised their sister for her involvement with the U.S. armed forces. These brothers were proud that their sister had distinguished herself despite her physical limitations with neurofibromatosis. Moreover, elsewhere on forums, I saw how upset users were to learn that people with NF1 were disqualified from actively serving in the U.S. military – since neurofibromatosis is deemed a high-risk pre-existing condition. My impression was that this disqualification robbed them of the opportunity to become exemplary American citizens. All this to say, there appeared an apparent desire for people with NF1 in the United States to be useful, if not exceptional.

While NTUK does adopt some of this American sentiment on its website—for instance, it echoes the American Children's Tumor Foundation's use of the term, NF "heroes"—it is notable that several of my participants disliked this impetus to prove oneself as useful or even competent. Many echoed Stewart's sentiment, "you don't have to climb Everest to be a good person with NF1". For example, Chris reflected that his cancer had not robbed him of a successful life, but a happy one. I remember him laughing, "[my partner], she's the successful one! I don't need to be a go-getter like her." There was not only a dismissal of the impetus to be ambitious, sometimes there was even outright hostility towards success. Jamie admitted that he worried over his family in Cornwall seeing him as too career driven. He was anxious that they-thought-he-thought he was too good for them.[118] I believe it is useful to consider that while

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[118] As a more personal note, I recently learnt of the term "tall poppy syndrome" from a Scottish friend, (who insisted the sentiment originated in the UK before becoming better known as an Antipodean phenomenon.) In Australian English, "tall poppies are usually individuals who, [having] amassed fortune or fame, have become targets for criticism… They become the victims of a widespread tendency, known as the tall poppy syndrome, to scrutinize high achievers and cut [them] down" (Peeters 2004: 1). Such a distaste for aspiration appears in stark contrast to the American celebration of striving which I witnessed on various NF forums. I find this contrast surprising considering how Australia, England, Scotland, and the United States are often collapsed into the cultural catchment of Euro-America (for instance, by Marilyn Strathern (1992: 171)).

Americans (on the whole) seek success, independence, and exceptionality, people in Britain are quicker to prioritise kindness insofar as they respect their fellow man regardless of that individual's success, talent, or utility.

My use of the word "kindness" here is highly specific. In this thesis, I utilise the term kindness as a rebuttal of any eugenic reasoning wherein some people are seen as more valuable than others based on their utility. Thus, by "kindness", I mean the antithesis to utility. My distinction—between kindness and utility—draws on the long-established division between virtue ethics and utilitarianism. In Beauchamp and Childress' overview of biomedical ethics, they list kindness as one example of a "moral virtue" (Beauchamp & Childress 2013: 381): that is, kindness is an ideal of action which a virtuous moral agent might pursue. By contrast, "utilitarianism accepts one, and only one, basic principle of ethics: the principle of utility… often formulated as a requirement to do the greatest good for the greatest number" (Beauchamp & Childress 2013: 354-355). An anecdote which has helped my think through the distinction—between kindness and utility—is as follows. One of my ethics professors made the offhand remark that older parenthood should be encouraged. He explained that the older people are when they reproduce, the more likely they are to produce offspring with genetic mutations. The point, he spelled out merrily, was that genetic difference was valuable since it generated greater variation in the gene pool. With greater variation, the human species is better equipped to evolve with various demands from the environment.[119] While this professor's explanation is a creative and interesting defence of genetically different individuals, it did not sit right with me. With hindsight, I can see that his argument still appeals to the utility of human life, albeit by highlighting the benefit of species diversity to the overall population, rather than a benefit for one line of lineage. A non-utilitarian (dare I say more British) outlook on genetic difference, by contrast, would refuse to compete in a game which required humans-with-genetic-difference to be useful in order to be valued.

I hope this anecdote has helped demonstrate that I do not intend to use the term "kindness" merely as a verb, (that is, to show kindness, or to care for someone).[120]

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[119] The professor was here following the logic of Fisher's fundamental theorem of natural selection, although he did not make reference to it.

[120] While showing kindness and care may be an *outcome* of an outlook, I am less interested in my participants' reflections on the (often gendered) burden of care, and more interested in their existential reflections on life itself. So, while care for the disabled might be a manifestation of a kindness-driven outlook, it is not necessarily the analytic core of this outlook. To further clarify my reasoning, and to contextualise my analysis, consider the following distinction made by Arthur Kleinman between "caregiving" as an action and "care" as an analytic concept. While reviewing his ethnographical attention

Rather I am discussing kindness as recognition of inherent human dignity, a rebuttal of evaluating human life based on its utility. To properly combat a genetic optic—which is what I believe Wendy and other participants were interested in doing—one must treat people well regardless of what they can do for you or for society as a whole. An outlook valuing kindness would thus not be antithetical to a genetic optic because of its disinterest in genes, rather, a kindness-focused outlook on life itself would diverge from a genetic optic in its refusal to evaluate people based on their utility.[121] I cannot say that all British people value kindness before all other virtues and truths when constructing their outlook on life itself. But I do wish to suggest Wendy's anti-utility stance evidences a cultural phenomenon. I speculate that the American desire to be brilliant is in some way related to the impetus to assure people of their usefulness. By contrast, in the United Kingdom, (while this impetus surely exists too,) my participants demonstrated a resistance to this drive – such that people did not feel the need to be special. They were allowed to simply be.

I wish to close this point of analysis by reiterating my awareness that Wendy's friend was not intending to be eugenic in her comment. This friend was talking about the avoidance of pain rather than the need for utility. However, Wendy's sensitivity to this comment has compelled me to consider two insights. First, that there are cultural differences regarding what people expect for their children – either a magnificent life, or a good enough life. And second, that Wendy's dislike of her friend's comment is a part of her outlook deliberation. I am reminded of Beauchamp and Childress' reflection that "in irresolvable and tragic dilemmas [such as Wendy's situation of having a sick infant], the virtues [including kindness] help direct agents to appropriate responses, including appropriate attitudes and emotions such as moral distress" (Beauchamp & Childress 2013: 380). I thus understand Wendy's response to her friend's comment as "moral distress", since she feels—rightly or wrongly—that her daughter's existence was being evaluated. While we can see the friend's comment as *being* kind (in her attempt to offer

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to caregiving throughout his career, Kleinman reflects: "I have had an extensive and many-sided involvement with this subject, being a long-term observer, caregiver, and recipient of care. No; it is more than this: for me care is irrecusable as the core structure of my life and, I believe, life itself" (Kleinman 2023: 305). Kleinman then references his relatively recent publication, *The Soul of Care* (Kleinman 2020). Within this earlier publication, he reflects, "care is not just a tool for getting through life by helping one another. It is also a necessary condition for living a life of passion and purpose" (Kleinman 2020: 245). Kleinman, like myself, thus differentiates between care (or kindness) as a one-off action and care (or kindness) as a value around which one structures their life's meaning.

[121] As a reminder, within a genetic optic, one is encouraged to consider the genetic endowment of the next generation. Put another way, one is encouraged to put their best genes forward. Please revisit page 143 for a full definition.

reassurance), Wendy's rebuttal can be understood as upholding kindness as a critical component of an anti-utilitarian outlook on life itself.

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My final reflection—on this exchange between Wendy and her friend—is that Wendy's response exemplifies a distinctive technique by which my participants managed knowledge. In chapter 4 of this thesis, I demonstrated how my participants *ignore* unwanted knowledge of the future. It is now timely to attend to how my participants can *eschew* certain truths as an alternative technique. I believe it is highly probable that Wendy in fact agreed with her friend's conviction that with death comes peace, along with the relevance of a quality-of-life metrics to medical decision making. Nevertheless, Wendy eschews these truths for the more relevant, parallel truth that disabled lives are of value. Wendy is not *denying* the rationality of her friend's comment, but rather, she is favouring a competing truth – that one should not evaluate the worth of a human life based on such metrics. I call this thought management mechanism a "practice of emphasis". I have seen such a practice of emphasis in literature as well as during my fieldwork. For example, in the following quote, what Franzen calls "a blind spot", I see as successful eschewing of an unappealing truth:

> Where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self.[122]

In the first ethnographic section of this chapter, I detailed my participants' dismissal of thoughts to which they would rather not give credence—regardless of whether such thoughts were deemed to be logical. I also included my participants' ability to acknowledge the appeal of a thought or belief without thinking it necessarily true. Consider now that my participants might extrapolate this approach—from evaluating certain truths to evaluating entire outlooks on life itself. If a comment is seen to be irrelevant to an outlook—in that, say, it is associated with a utility rather than kindness—both the thought and the outlook it contributes towards are managed through the same mechanism of dismissal: that is, rather than denying the logic, my participants instead preferred alternative truths and outlooks.

Outlook Deliberation as an Ethical Imperative

I contend that my participants' thought management practices—namely, their deliberation over (and protection of) their outlook on life itself—must be analysed as

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[122] This reflection was made by Jonathan Franzen (2001) concerning his father's illness and quoted by Lock in her discussion of people's refusal of "genetically informed identities" (Lock 2008: 56, 72).

ethical action. By drawing on insights from the anthropology of ethics, I can better articulate my research findings regarding outlook deliberation, while also considering how my participants' ethical ingenuity echoes that of other scholars' participants. This subsection of my chapter has four parts. First, I detail the importance of possessing the freedom to choose between (and build one's own) outlook. Second, I concede that while outlook deliberation is a creative individual endeavour, each participant is nevertheless still a produce of their environment. Next, I clarify that my participants are working on their thoughts, not their actions. And finally, I explain why attendance to my participants' agency avoids the trope of the suffering subject. Before I begin, I must first briefly describe the ethical turn within the discipline of anthropology, and explain why my participants' deliberation qualifies as ethical action.

The anthropology of ethics has been attributed to a "fruitful engagement" between anthropology and moral theology (McKearney 2019: 221), which led to a number of key anthropological publications from the year 2000 onwards.[123] While some reflect that anthropologists have always been interested in ethics insofar as ethical life has always "pervaded" social life (Laidlaw 2014: 2), it was not until relatively recently that anthropologists started "studying explicitly the ethical lives of their informants" (McKearney 2019: 221). James Laidlaw—one of the scholars whose work is noted by McKearney as part of the ethical turn[124]—claims people are ethical where "they have the capacity to reflect, to stand back from their own conduct and constitute it as an object of knowledge, and to act so as to change themselves; and this reflective freedom is the basis of ethics" (Laidlaw 2017). I see my participants' thought management practices as ethical practice insofar as their outlook deliberation is evaluative. In their questioning, of which values to prioritise over others, my participants are establishing their moral priorities.[125]

What is crucial—both for my analysis, and for the very possibility of this evaluative practice—is that my participants enjoy the freedom to choose between different outlooks on life itself. For Laidlaw, freedom is the central concept through

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[123] On "the emergence of the anthropology of ethics", McKearney (2019: 221-22) lists 11 key publications ranging chronologically from Mahmood's (2004) book *Politics of Piety* to Lambek's (2015) work *The Ethical Condition*.

[124] It is relevant to note that Laidlaw identifies the anthropology of ethics as not so much a new sub focus in the discipline, but rather a radical transformation of social theory. In the same way feminist anthropologists sought to revolutionise the discipline in the 1980s, Laidlaw asserts his ambition was to rethink social theory to "address directly the ethical dimension of social life" (Laidlaw 2014: 1).

[125] On the overlap and distinctions between "morality" and ethics", see Mattingly and Throop's (2018: 479-480) discussion of these "terminological difficulties".

which anthropologists should come to understand the ethical life of their informants. He argues,

> The notion of freedom is central… [Foucault] speaks not of achieving but of exercising freedom, and does so to refer to the extent to which and the ways in which people can exercise choice or are subject to coercion. One can have more or less freedom, and it takes difference forms, in different historical situations (Laidlaw 2002: 323).[126]

On the concept of freedom, Webb Keane introduced the idea of "ethical affordances" (Keane 2015: 27-28): that is, depending on the particularities of each situation, a person may have more or less freedom to exercise their ethical autonomy.[127]

I imagine my reader might anticipate that I will here claim my participants are in a position of heightened affordance for ethical action. (After all, to justify my project at the outset of my research, I claimed my participants had exceptional cause to think about their genetic difference.) However, I am eager to demonstrate that this is not necessarily why I have chosen to draw on the anthropology of ethics. While some academics have certainly argued that advances in science and technology give rise to new and heightened ethical dilemmas—including the obligations which arise from new forms of identity, such as being "genetically at risk" (Novas & Rose 2000: 487); or the more straight forward point that new technologies require evaluation from patients and bioethicists alike (Kerr & Cunningham-Burley 2000: 283)—I must stress how academics in the ethical turn have effectively demonstrated that smaller questions are just as much a part of the ethical field as bigger moments.[128] Thus, in my own research, I can appreciate that my participants' outlook deliberations are just as much a part of their ethical life as more obviously bioethical decisions—such as whether to use PGD. What is more, even everyday dilemmas – such as how often to visit one's parents –

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[126] The word freedom might be used elsewhere in discussions of genetics, such as in the debates regarding genetic determinism. For example, in a UNESCO statement in 2003, it was asserted that "a person's identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom." (Penchaszadeh 2011: 238) However, Laidlaw's concept is highly specific, and thus diverges or else adds precision to wider conversations about agency and determinism vis-à-vis genetics.

[127] Keane explains ethical affordances with the helpful analogy of a chair. One can do many things with a chair—one may sit, one may throw it, one may stand on it, and so forth. All these different options constitute the *affordances* of the chair. One is not compelled to do any of these actions with the chair—much as one is not compelled to make any ethical decision in any given situation—but one's options are circumscribed by the nature of the chair (or ethical situation).

[128] For instance, Cheryl Mattingly discusses her participant Tanya's ethically fraught decision of whether to let her son play soccer (Mattingly 2014b: 481).

should be considered a part of my participants' ethical life. The key feature is that my participants have a choice in these matters.

Yet just as the anthropology of ethics helps highlight the scope of freedom my participants enjoy in outlook deliberation, (and other more mundane parts of their ethical life,) this ethical turn also encourages analytic attention to the various contextual factors which influence this deliberation. In a joint chapter, Mattingly and McKearney consider how the enactment of moral autonomy always relies upon "relationships of dependence" (Mattingly & McKearney 2013: 561). Moreover, in earlier article, Mattingly posits of her participant: "The virtues that Tanya is called upon to cultivate are also, as Laidlaw and others suggest, a pedagogical project in the sense that her moral efforts are at least partly informed by preestablished norms and values she has inherited from the communities in which she has grown up." (Mattingly 2014b: 481) If I consider this insight – on interdependence and context – vis-à-vis my own research, I am reminded of how Stewart was introduced to disability studies literature by fellow online forum members, along with friends from the not-for-profit he is involved with. I can also consider that another key participant, Sharon, explained how her view of NF1 was ever informed by the experiences and wisdom of her "lumpy friends". My participants do not exist in a vacuum. So, while I can appreciate the idiosyncrasy of each participant's outlook on life itself, (since their outlook is an incredibly personal decision), I remain mindful over how outlook deliberation is informed by the environment in which each participant lives. I accordingly find the following reflection—on Foucault, who is frequently drawn on by theorists in the anthropology of ethics—of great help:

> For Foucault the process of subjectivisation was not just a manifestation of individual introspection… The question of self and identity is not just a question of a human individual's attempt to discover who one is, but of external forces which make the self and are folded in the becoming of a human being. These external forces are integrated to build a self. (Venkatesan 2007: 177-178 in Atkinson and Glasner 2007)[129]

Another reflection I would like to make in tandem with literature from the anthropology of ethics concerns the locus of my participants' ethical work. I wish to clarify that in my participants' deliberation between outlooks, they are not so much

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[129] One could say it is not only my participants' outlook deliberation which is influenced by their context, but even their very sense of self. Faubion argues that one cannot know and work on oneself without becoming vulnerable to alteration in the process. He posits, "the ethical field is thus a field of the self at risk" (Faubion 2001: 100).

interested in improving their actions as they are in reorienting their perspectives. Thus, their ethical work on the self is concerned more with “their own thoughts” than “their own conduct” (Foucault [1997] in Laidlaw 2014: 101; Mattingly 2014b: 477)[130] I here draw again on Mattingly’s ethnographic work with African American families, since Mattingly is—like myself—interested in how her participants “find themselves propelled in a quest to imagine a new sort of life for themselves” (Mattingly 2014b: 481). Mattingly’s participant Tanya was not so much interested in making drastic changes to her family’s life—such as seeking out a new career for herself to fund further healthcare—rather, she made “a transformative effort to reimagine not only what will happen, but also what ought to happen, or how one ought to respond not only to difficulties and suffering but also to unexpected possibilities” (Mattingly 2014b: 481). Likewise, my participants’ outlook deliberations do not necessarily entail suddenly dedicating one’s life to disability rights activism. As already covered, my participants do not feel the impetus to prove themselves or to give back to their society. Rather, my participants have chosen to change how they “imagine”—to borrow Mattingly’s (2014b: 481) term—life itself.

To further evidence this claim—that participants are left wanting for a world with better values, rather than a better version of themselves—consider the following extract written by Stewart, (which he emailed to me ahead of our discussion in March 2022):

> It is not me that creates a problem. It's a culture that looks at me and finds something lacking or something unacceptable. A culture that imposes on me the perception that I would be a better, a more whole, person, if [NF1] was not part of my make up. A culture that tells me I can never be good enough… I was told that, no matter how good a person I might be or become, no matter how good a partner I might have made in terms of human relationship, my "NF-ness" made me unworthy.

While Stewart is involved in various activism efforts—namely assisted dying advocacy—I would characterise his outlook deliberation as ethical work on his thoughts rather than work on his actions. In our conversations, Stewart was looking to reorient his outlook on life itself such that he could see his existence in a favourable light, and thus enjoy it. Stewart, like my other key participants, deliberates over which values he

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[130] Foucault characterises the techniques of self-formation as follows: “to effect, by their own means, a certain number of operations on – their own bodies, their own souls, their own thoughts, their own conduct – and this in a manner so as to – transform themselves, modify themselves, and to a certain state – of perfection, happiness, purity, supernatural power.” (Foucault 1997: 177, 255)

wants to see championed in an ideal outlook. Whether or not he himself exemplifies these values as a good person is an entirely different question.

The final and perhaps most important insight I can take from the anthropology of ethics as follows: that by highlighting my participants' agency, I avoid painting them merely as suffering subjects.[131] Without an appreciation of my participants' freedom to choose between outlooks, lazy characterisations of people with NF1 may proliferate. Consider how Messner and Neff Smith note that "practitioners throughout the literature consistently describe NF patients as generally being "creative, sensitive, unusually kind individuals, not embittered by their condition"." (Messner & Neff Smith 1986: 462 in Ablon 1999: 19). Without appreciating how people "are evaluative" (Laidlaw 2014: 3), the lack-of-bitterness expressed by people with NF1 may be read as mere optimism or sweetness. (As such, they could be read as the noble suffering subject.) In reality, people with NF1 are no more or less likely to be intrinsically good-natured than their peers. Virtue is not a medical consequence of their condition, nor is it necessarily a consequence of their experiences of stigma. Rather, my participants have *chosen* to cultivate kindness as a key facet of their outlook on life itself. Again, this is not that they themselves attempt to be kinder as individuals, but that they choose to reject any evaluation of human utility as a relevant metric to treating someone with human decency. If this highlighting of ethical deliberation enables a more holistic description of what might otherwise be a deceptively rosy picture, then the anthropology of ethics surely has more to offer to the anthropology of genetics.[132]

I wish to close this section by emphasising that I do not believe my participants' cultivation of a different outlook to be insincere. Choosing to see the world in a different way is not a light-hearted fantasy. To admit the human construction of logic and various truths was difficult for certain participants, (including Stewart, who might otherwise base much of his identity on being logical.) Since my participants treat the evaluation and construction of outlooks on life itself with earnest sincerity, I owe it to them to take it seriously too. I thus find the following quote of great relevance:

> We need to be attentive to the way people orientate to and act in a world that outstrips the one most concretely present to them, and to avoid dismissing their

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[131] On the trope of the suffering subject, Joel Robbins notes that "over the last twenty years or so… it has often been the suffering subject who has replaced the savage one as a privileged object of our attention. (Robbins 2013: 450). He continues, "in the 1990s, 'the human being suffering from trauma ... became the very embodiment of our common humanity'… it is the very commonness of trauma, its universal quality, that has made it so prominent as a lens through which to view the world" (Robbins 2013: 453).

[132] I must caveat that I am aware of how I have only scratched the surface of insights made in the anthropology of ethics. Nevertheless, I hold it is important to *begin* bringing this area of theory to bear on the anthropological study of those who live with genetic difference.

> ideals as unimportant or, worse, as bad-faith alibis for the worlds they actually create. (Grøn & Mattingly 2018: 312)

Conclusion

In Chapter 4, I detailed how my participants responded to the temporal fallout of genetic knowledge. I argued my participants' temporal discipline evidenced a negotiation of the relevance of such knowledge to their lives. I moreover contested this proactive negation is an answer to my research question of why genes appear to fluctuate in relevance to my participants. I have now ended this thesis by attending to the cultivation of outlooks on life itself, which I hold is a parallel and perhaps more profound negotiation. I have demonstrated that rather than ignoring truths, (as is the technique used in temporal discipline), my participants instead dismiss the relevance of certain truths. Through a practice of emphasis, participants such as Stewart demonstrate how one can successfully eschew truths, along with the outlooks on life itself to which these truths contribute. It is not that my participants deny the logic of a genetic optic. Rather they make a conscious decision to dismiss its relevance in favour of a kinder outlook on life itself—that is, one which does not appeal to the utility of certain genes and individuals.

While I am not saying that my participants harboured no interest in bettering themselves, I believe it would be misleading to calim performing virtuous deeds was their primary interest, or their most interesting ethical action. My key participants demonstrated a dissatisfaction not with themselves but with various outlooks on life itself, and so cultivated a better outlook—which I contend is their most marked ethical ingenuity. This is the culmination of my thesis argument: that my participants respond to genetic knowledge in specific ways—the most revealing of which being their disinterest in esteeming truths which counter a kind outlook on life. This disinterest contributes greatly to the apparent fluctuation in the relevance of genes in my participants' lives.

To close this chapter, I wish to make a few notes on what I hope my reader takes away from this chapter. The question of kindness (or compassion) versus utility-based logic is complex. Ethicists have often considered this tension, and by highlighting my participants' approach to this conundrum, I am not advocating for one approach over another. This is not my prerogative as an anthropologist. Furthermore, I anticipate a reader might skim the themes I address in this chapter and surmise I am advocating for—or at the very least highlighting—a criticism of science and medicine. This is not the case. My participants were not anti-vaxxers, Covid-deniers, or others of that ilk.

(Although if they were, this would certainly not disqualify them as participants. I hold it is possible to explain-whilst-not-excusing certain viewpoints.) Rather, during my research, I found it interesting to observe how a deep respect and reverence for medicine and science can coexist with a refusal for certain optics (supposedly inspired by such practices) to define my participants' outlook on life. To mirror the quote from Mol at the beginning of this chapter, I wish to close this chapter with two excerpts—one from Katrin Solhdju and Alice Rivières, and the other from Sarah Franklin and Ann Kerr. My purpose in doing so is to reiterate that I am less interested in evaluating my participants' rationality, and more intrigued by their pursuit of a good life—which, I believe, necessarily involves negating the salience of truths which support a genetic optic.

> One of the conundrums of modern medicine is the way in which an entanglement of epistemological, ethical, moral, and legal features consistently separates facts, deemed scientifically objective, from values, deemed subjective and unmoored from these same facts. (Solhdju & Rivières 2021: 49)

> Genetic knowledge must always be acknowledged to have multiple meanings, which are equally and simultaneously true, and may well point in divergent directions. (Kerr & Franklin 2006: 49)

Conclusion

This thesis has addressed the work of genetic knowledge in the lives of my participants and called attention to their responses to such knowledge. I have detailed my interlocutors' gene talk—namely their appeal to genetic explanations when reflecting on their individual and collective identities—along with the shadow side of genetic knowledge, including its limited therapeutic utility and existentially unsettling potential. I have observed that when my participants contemplate what is known about their genome, they are pulled out of their usual flow of time. What is more, when confronted with a genetic optic, my key participants find themselves reflecting on their lives and the lives of others as mere individuals within a larger species. Faced with this alienating perspective, my participants have realised two things. The first is a preference of mystery with regard to the future. The second is that they have come to appreciate the importance of kindness as an outlook on life itself. In response to these realisations, my participants have employed various tactics to manage the impact of genetic knowledge. One such tactic involves cultivating ignorance towards partial knowledge of the future, a practice which I have termed temporal discipline. Participants also eschew certain truths and outlooks, considering them irrelevant to their daily lives, a tactic that I have called a practice of emphasis. Thus, in response to my research questions on the role of genes in the daily lives of my participants, I have found that the relevance of genes oscillates, and argued that it is my participants' agency which shapes these oscillations. Rather than applying the label of inconsistency, I have argued we should instead appreciate these fluctuations as the outcome of wisdom. Consequently, I contend that my participants' practices of interpreting and managing genetic knowledge should be analysed as ethical action. Thus, in conclusion, while I cannot evaluate whether geneticization has happened or not among the general public, I can confidently assert that for my participants—certainly for my seven key participants—genes are only as relevant as desired.

In this conclusion, my objective is three-fold. First, I reiterate how each of my chapters has contributed towards my overall argument on participants' negotiation of the (in)significance of genes. I then offer some comments based on the outcomes of my project. Second, I discuss the impact of my findings both within and beyond the discipline of anthropology. Finally, I offer one last portion of ethnographic description to illustrate the breadth of data gathered from my participants, but which does not formally pertain to the work of genetic knowledge. While NF1 may colour my participants' everyday experiences, at least to the extent that the condition is seen as an inalienable part of who they are, NF1 is not always at the forefront of their minds.

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Before I recap the content of my chapters—along with reiterating how each builds my argument—I first wish to offer a brief reminder of the ethnographic details of this project, along with the contributions of my key participants. In the late summer of 2020, I began advertising my call for participants with the London based neurofibromatosis charity, NTUK. Although I do not see my research as an ethnographic investigation within this charity, I can appreciate that it was through their support that I was able to garner my 56 research participants. I interviewed a variety of people affected by neurofibromatosis—including those with NF1, a few with NF2, parents of children with NF1, and people whose works focuses on NF. Concerning my in-person fieldwork, participant observation and a few face-to-face interviews were conducted to supplement the in-depth conversations I had with established participants. From the later summer of 2021, I attended several fundraising and publicity events run by NTUK and ran a few ethnographic interviews in London and Leicester. My fieldwork concluded in March 2022. Yet despite the formal end to my data collection period, I remain in contact with several participants.

Even among my seven key participants, I consider Stewart my main interlocutor. As a retired nurse, he had ample free time for discussion. We covered topics as far ranging as his right-to-die advocacy, his enjoyment of young adult literature, his physical symptoms of NF1, people's response to his many visible facial tumours, his relationship with his late sister and various friends, along with his childhood in Kent. I felt Stewart displayed great wisdom when he reflected that could understand his mother's feeling—that it would have been easier to not have had genetically different children in the 1950s—but that he resented her articulations. Namely, he believes she was wrong to tell him, "You must never have children." Concerning my participants who did have children, Tara was the only one of my key participants with a child—although Seren and Zoe—who were not key participants but whose views I draw on regularly in this thesis—also each had a daughter with NF1. Tara also was my only participant *not* recruited through NTUK. She was far more involved with her church than with any biosocial group. By contrast, my participant Jamie is continually involved in his mother's running of Midsummer Madness—a weekend away for families affected by NF1. Jamie's reflections on how he believes NF1 affects appearance greatly helped me consider the basis of imagined genetic community. Of course, Jamie was not as involved in biosocial endeavours as Sven. While Jamie works in media, Sven is employed by NTUK—and offered many insights into their work, along with the struggles the charity faces in providing support and comfort.

Another key participant whose work addresses NF is Amy. She is a scientist, rather than an employee of the third sector. I found it highly interesting to speak with a geneticist who herself has NF1, and who was diagnosed during the course of my research with an NF1-associated cancer. While Amy is on the road to recovery, my participant Chris sadly passed away from an NF1-associated cancer, a malignant peripheral nerve sheath tumour. I enjoyed many a discussion with Chris about his efforts to increase NF1-awareness, his love of writing and reading, and his relationship with his partner and family. The last of my key participants, Sharon, was as much a joy to speak with as all of my other interviewees. Like Stewart, she is a retired nurse. She was able to recall in great detail her grassroots NF1-community ventures, along with how NF1 impacted her career and dating life. If my reader would like a further reminder of the details of these my seven key participants, please revisit page 14.

Chapter S*ynopses*

A highly simplified overview of the structure of this thesis is as follows. My first two chapters detail the significance accorded to genes by my participants, while the last two chapters attend to my participants' diminishment of the relevance of genetic knowledge. As a means of transition, my middle chapter notes the limitations of genetic knowledge's utility to NF1 treatment, and thus opens a reflection on the burden of knowledge more generally. Of course, this overview misses many important nuances. I will therefore now offer a more detailed synopsis of each chapter of my thesis. In my Introduction, I argued that people with NF1 have exceptional cause to think about the influence of genes—particularly the impact of just one gene as a singular unit of heredity. Accordingly, conducting in-depth ethnographic interviews within an NF1 biosocial group (however loosely this may be defined) offers an opportunity to answer the following research questions. First, when are genes seen to be significant? And second, when and why might individuals choose to avoid thinking about their genes? I explained that in attending to these questions, I aimed to respond to an overlooked research problem on the fluctuating relevance of genes. At the outset of this introductory chapter, I moreover explained that while I cannot say my participants are co-theorists—since I am the one deciding the analytic direction of this write-up by focusing on the existential introspection provoked by genetic knowledge—their thoughts and theorisations are nevertheless the crux of this thesis.

Further into my Introduction, I accounted for how I would draw on and synthesise a broad range of relevant anthropological theorisation. This assemblage included literature on biosocial community constructions; discussions of ethnic identity vis-à-vis genetics; the anthropology of ignorance as well as the anthropology of knowledge; temporality and anticipation; the anthropology of ethics, as a means to attend to participants deliberations between different outlooks on life itself and finally, as well as obviously, insights from the anthropology of medical genetics—including existing arguments on the proliferation of genetic ambivalence. I furthermore noted that I would be adding ethnographic detail to Novas and Rose's (2000) writings on a new molecular optic, and Rose's (2001; 2007) interest in styles of thought. However, my primary interest would be in contributing towards—as well as encouraging greater collaborations between—various foci within anthropology.

My introductory chapter also included a literature review, which I summarise briefly here. I argued that, unlike academics such as Joan Ablon who attend to genetic difference as a means to explore stigma, or as an avenue via which to revisit kinship, I felt it was important to start with the content of my participants' gene talk. I took inspiration from the following conviction: that before we can establish whether geneticization has happened or not, before we can speak of the impact of new genetic knowledge on "nature-culture [debates], the body, kinship, biopolitics [and so forth]", it is first necessary to understand the content of such knowledge (Braff 2010: 277). Finally, in my introductory chapter, I detailed my fieldwork logistics whilst also commenting on how my methodological choices complemented my anthropological interests and ethos. I explained that I was hesitant to enter the field with the intent of furthering any one theoretical perspective: instead, I sought to understand what my participants thought. Then and only then did I feel it was appropriate to make a final decision on which theoretical literature to use in order to analyse my participants' thoughts. I moreover chose to conduct ethnographic interviews—although it would be more accurate to say I was happy to rely on online interviewing given Covid-19 social distancing restrictions—since interviews are an apt means by which to access each participant's own thoughts and theorisations.

In Chapter 1, I detailed the content of my participants' gene talk. In doing so, I sought to introduce what my participants understood genes to be, whilst beginning to trace when genes are seen to be most relevant. Since my participants often spoke of genes when discussing their identity—in particular, on how NF1 is intertwined with their sense of self—I decided to structure the first two chapters of my thesis around personal and collective identity practices respectively. To begin Chapter 1, I introduced my participant, Zoe. I noted that she has evidently spent considerable time reflecting on the genetic component of her daughter's NF1 diagnosis. I canvassed how she playfully discusses her thoughts on the work of genes in the general population, as well as in her family as a unique case study. I argued that Zoe's gene talk should *not* be understood as a mere shorthand for the work of nature, as opposed to nurture. Rather, her reflections on Poppy's identity, and the identity of her other family members, are firmly couched in the unique language of genetics.

In the second half of Chapter 1, I compared Zoe's theories to my other participants' less direct insights into the work of genes. I detailed the responses to my interview question, "do you think you would have been the same person if you had been born without NF1?" I also addressed several scenarios in which participants abstracted people—present and future—from any specific genome. In doing so, I began to note inconsistencies within participant's cosmological reflections. For instance, in one interview, my participant Tara claimed her daughter would have been the same person without NF1 because of her religious upbringing, but in a later discussion, Tara claimed NF1 determines her daughter's personality. Instead of dismissing my participants' reflections as inconsistent, I instead noted the plasticity and creativity with which my participants could think with genes. I ended Chapter 1 with a discussion of missing gene talk. I detailed instances where participants deliberately avoided talking about genes, or else simply had little interest in bringing genetic explanations to bear on certain aspects of their life. I argued that any reluctance to reflect on the relevance of genes did not negate the importance of genes in their cosmology. Instead, in this chapter's conclusion, I argued the following. That genes are omnipresent in my participants' understanding of organic life; that they are a substance with which individuals had remarkable freedom for interpretation; and that genetics is not always—nor even frequently—addressed in everyday parlance.

In Chapter 2, I evaluated my participants' endeavors to generate and maintain imagined communities based on knowledge of shared genetic substance. In doing so, I contextualised my participants' engagements with various NF communities and continued my exploration into the place of genes within participants' cosmologies. The central theme of this chapter was the tension between the evident desire for community among my participants, and the reality that genetic similarity—based on the mutual presence of a biomedical condition, rather than shared ancestry—does not generate an obvious or easy kind of collectively. Whereas Chapter 1 was dedicated to ethnographic description alongside my own analysis—with appeals to other authors for support[133]—Chapter 2 engaged more directly with existing theory and literature. I critiqued Rabinow for his lack of interest in testing the strength of connections based on shared biological characteristics. I suggested NF1 communities are in fact a difficult example of biosociality since the condition is so characteristically idiosyncratic. I commended Carrieri for noting the *assumption* of a link between genetic information and identity. However, in contrast to Carrieri's opinion—that because the salience of genetic information is unstable, it is difficult to investigate—I attested that it is important to probe specifically why genes fluctuate in relevance. To take up Carrieri's mantle, I drew on earlier theorisations made by Rapp, Heath and Taussig. I considered how both my own and Heath's respective participants built solidary and identity by appealing to physical resemblances. I then analysed the strength, or lack thereof, of imagined genetic community *without* shared ancestry. Ultimately, I found that my participants were often disappointed with their NF1 community ventures. Many came to realise, as I did, that genes are an insufficient or else an uncomfortable basis on which to structure a meaningful collective identity. Thus, as with Chapter 1, Chapter 2 demonstrates that despite the cosmological importance of genes, the reality is that genes are not as easy to think with as my participants might hope or anticipate—especially when it comes to their collective identity cultivations.

Chapter 3 moved my argument further by testing whether knowledge is always deemed virtuous by my participants. While much of the ethnographic details of this chapter touched on medical bureaucracy and institutional hierarchies, my analytic focus was not on healthcare provision nor even biopower. Instead, I used my participants' experiences—of gathering and using medical knowledge for their own care—as an opportunity to explore the limits of knowledge's appeal. While I commended Becker and Kaufman's theorisation on the matter, I lamented that their work could not account for my participants' *continual* engagement with medical information. I argued that Becker and Kaufman's writings were insufficient, since they addressed a situation wherein the acquisition of knowledge was only ever painted as a virtue. By contrast, my participants learnt to appreciate the appeal of cultivated ignorance.

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[133] Which is not to say I did not engage literature and theory at all. In Chapter 1, I drew on McKibben's (2003) formulation—of the distinction between what *happens to* a person, and what *is* at the core of who a person can be—to clarify my participants' discussion of their acquisition of personhood versus the essence of their self. I also found it helpful to note Strathern's cautions on, "the questionable difference between potential as opposed to actual identity" (Strathern 1992: 175). Furthermore, by structuring this chapter around "gene talk", I was inevitably benefiting from past theorisation addressing, "the idea that essential truths about identity inhere in sequences of DNA" (Tallbear 2013).

I emphasised that it was not that my participants wished to be uninformed about their NF1, although this *was* in fact the preference of my participant, Dave, who was something of an outlier. It was also certainly not that my participants had a preference for the return of a paternalistic style of medicine. Rather, my participants learnt the appeal of cultivating ignorance. I here drew on Dilley's attention to mystery as a virtue, and on his appeal for academic attention to agnoiology, the science of not knowing. When my interlocutors were compelled to keep up to date with medical information to inform their own doctors, it was not this upturned hierarchy which caused the greatest grief—although this inversion was certainly uncomfortable. Instead, it was the burden of knowledge itself which caused my participants the deepest frustration. In keeping up to date with medical information, my participants ever held knowledge of their genome at the fore of their minds. To close this third chapter, I considered whether it was the partial nature of this knowledge which caused difficulty, before emphasizing the importance of appreciating the appeal of mystery. Thus, to understand my participants' relationship to the more difficult aspects of genetic knowledge, I underlined how genetic knowledge threatens mystery—and thus accounted for why my participants might wish to reduce the impact of such knowledge on their lives.

Chapter 4 addressed how my participants are pulled out of the normal flow of time by genetic knowledge, and how they reintegrate themselves into the everyday. I began by introducing my participant, Kiera. Despite the fact she does not want children, Kiera could not stop thinking about a potential future in which she might change her mind. She and I both attributed this thought-imposition to natalist pressure on women, but also to the inadvertent genetic counselling Kiera received as a young child. I thus noted how knowledge of NF1 profoundly affects experiences of time via the exceptional anticipation of future kin. While the middle of this chapter covered other ways in which NF1 might cause temporal divergences—such as future symptoms haunting the present, differing productivity speeds, and adjusted career aspirations—I argued it was reproductive temporality which caused the greatest difficulty for my participants.

I analysed this shift in temporality vis-à-vis the unusual introspection it caused. I discussed how my participants became increasingly aware of their position within their kinship structure. Moreover, I noted that my interlocutors grew frustrated at the value placed on making future kin—often at the expense of being cherished as individuals in and of themselves. I argued it was not simply natalist imperatives which troubled my interviewees, but this natalist imperative *coupled with* a divergence from normal habitus. The later purpose of this fourth chapter was then to highlight the effective ways in which my participants minimised the relevance of genes when reintegrating themselves into the everyday. I also addressed how Seren, along with other mothers whom I spoke with, were left to reckon with known genetic limitations on the possibilities of who their children could become. Rather than finding ways to make the future optimistic again, my participants learnt—just as Mattingly's participants did—to hope for a life well lived. In doing so, they rejected seeing their children as beacons of the future, or else as mere future ancestors.

Chapter 4's focus on the deliberate rebuttal of reproductive temporality mirrors my fifth chapter, on my participants' refusal of a genetic optic. Both of my final chapters centred on how my participants negotiated the relevance of genetic knowledge. Specifically, they detailed how the relevance of genetic knowledge is diminished. In Chapter 5, I addressed how my participants eschewed an unkind outlook on life itself—which I term a genetic optic. I defined a genetic optic as the perception that humans are merely vessels for forwarding genes. Within such an optic, one evaluates individuals vis-à-vis their utility to the successful evolution of the human species. One would moreover see oneself as a future ancestor before all else, with an obligation to pass on good genes to future kin. In the introduction of Chapter 5, I explained that I did not encounter any participant with this outlook. However, my participants *felt* they were working against such an optic, and as such, much of their epistemic introspection focused on refuting the eugenic logic underpinning this view. To open the chapter, I canvassed my participants thoughts on their thoughts. I discussed how Stewart, Chris, and Zoe each respectively managed their thoughts; acknowledged their feelings; and entertained contradictory truths. From Chris processing his feelings, to Stewart entertaining the idea of reincarnations, to Zoe's ability to let irrational thoughts and feelings pass her by—I noted that my participants demonstrated a conviction that thoughts are passing, and that attitudes are—to a certain extent—pliable.

I considered two analytics by which to understand this ethnographic data—one focusing on therapeutic motivations, and another on etiquette. While the former was mostly self-explanatory, I offered new ethnographic detail to unpack how etiquette might explain my participants' inconsistencies and epistemic convictions. I introduced my participant, Wendy, along with her friend's voicing an uncomfortable truth about Wendy's daughter. Ultimately, I decided neither therapeutic explanations nor accounts of social etiquette could sufficiently explain Wendy's unease towards her friend's attempt at comfort. It is not enough to say that Wendy's friend failed in her etiquette practice: a more complete account of the situation requires an explanation on why the truth this friend articulated was deemed undesirable in the first place. It is for this reason that I accounted for why certain truths—and the outlooks they contribute towards—are deemed unfavourable. I explained that Wendy was not *denying* the rationality of certain truths, but rather, in her dissatisfaction with her friend's comment, she favoured a competing truth—that one should not evaluate the worth of a human life based on metrics such as quality of life. I termed this thought management mechanism a "practice of emphasis".

I then offered a third, alternative analytic on my participant's thought management practices. It was here that I turned to the anthropology of ethics. I argued that what is crucial—both for academic understanding, and for the very workability of this choice between outlooks—is that my participants enjoy the freedom to evaluate and choose. I then offered my own thoughts on how my participants acted more on their outlook than on their actions. To close the body of this chapter, I reflected that people with NF1 are no more or less likely to be intrinsically kind than their peers. Kindness is not a medical consequence of their condition, nor is it necessarily a consequence of their experiences of stigma. Rather, my participants have chosen to cultivate kindness as a central tenet of life itself.

To conclude my final chapter, I reiterated the following: that in the context of evaluating outlooks on life itself, rather than ignoring truths—as is the technique used in temporal discipline—my participants instead dismissed the relevance of certain truths. It is not that my participants deny the logic of a genetic optic. Rather they make a conscious decision to dismiss its relevance in favour of a kinder outlook on life itself—that is, one which does not appeal to the utility of certain genes and individuals. The end and crux of my thesis was thus this: that my participants respond to genetic knowledge in specific ways—the most revealing of which being their disinterest in esteeming truths which counter a kind outlook on life. This disinterest contributes greatly to the supposedly confusing fluctuation in the relevance of genes.

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Based on these research findings, there are several comments I wish to make. I have implied—but not explicitly addressed—that the fluctuating significance of genes is as much a consequence of ethical deliberation as it is of incongruences with formal biomedical knowledge. Having focused on the former, I would now like to add some detail on the latter. Most of my participants' genetic knowledge was never completely aligned with formal biomedical convictions—perhaps with the exception of Amy, who was herself a geneticist. At the outset of my research, I expected that my participants would comment on the fact there is no uniform NF1 gene. Although all people with NF1 have an abnormality somewhere along their NF1 gene—which affects the production of neurofibromin—one person's NF1 difference will likely be disparate to another unrelated person's NF1 difference. Put simply, there is no combination of As, Gc, Cs, and Ts common to all people with NF1. The fact my participants did not comment on this detail, and that it did not affect their NF1 community-building ventures, does not diminish my overall argument. It also does not necessarily evidence my participants' ignorance towards this detail. Still, I feel I must caveat that my participants' ethical agency is but one of several contributing factors to the fluctuating relevance of genes. Another factor was most probably that my participants' views frequently diverged from biomedical convictions concerning the scope and relevance of genetic explanations. Much as Zoe's theories sometimes concurred with Mendelian ideas of inheritance, while at other times were incongruent, I suggest that my participants were free to detach themselves from formal biomedical understandings—leading to fluctuations and idiosyncrasies in the significance ascribed to genes and genetic explanations.

My other comments concern the place of the individual within broader cultural schemas. It is pertinent to ask whether my findings can be generalised to the British public. Relatedly, it is also sensible to ponder the extent to which my participants' gene talk was the result of individual preference as opposed to cultural influences. On the question of generalisability, I wish to suggest that the value placed on kindness and mystery is most probably also the case for other people living in the UK.[134] While only a segment of the overall population is compelled to reflect on genetic difference daily, the values of kindness and mystery no doubt colour the everyday lives of many people. To the question of how to distinguish individual agency from cultural influence, I have no simple answer. Much like Stewart, I am unsure how to disentangle personal creativity from cultural association. Stewart put it best when he said to me, "I suspect that maybe I am unique [in my thoughts about NF], but I doubt it." I will, however, say this on the matter. I find the following two arguments—highlighted by Lock and Nguyen—to be helpful in that I believe they can both be equally valid. On the impact of cultural factors, Lock and Nguyen highlight the following stance:

> Several researchers, including Rapp and Browner, have shown that when genetic information is incorporated into accounts about illness causation, such knowledge

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[134] It is perhaps easier to argue the popularity of certain values than to claim a whole social group interprets genetic knowledge in the same way. On this matter, I find the following caution to be helpful:

> "It is clear that we must avoid the temptation on the part of social scientists and other to create sweeping generalizations about profound changes in identity in connection with genetic testing. People interpret what fate has dealt them in the form of genes in numerous ways that are unpredictable and not wholly consistent… even to themselves." (Lock & Nguyen 2010: 319)

> supplements rather than replaces previously held notions about kinship, heredity and health. (Lock & Nguyen 2018: 313)

Regarding the idiosyncrasy of each individual, they highlight:

> Ann Kerr and colleagues commented some years ago that, in effect, individuals act as their own authority in the interpretation of genetic information (Lock & Nguyen 2018: 355)

In agreeing with both of these convictions, I am not diminishing the ethical agency experienced by my participants. I am claiming, however, that specific sociocultural contexts will influence people's interpretation and management of genetic data.

Significance for Anthropology

This project has demonstrated that when studying the consequences of new knowledges, it is critical to attend to people's agency in negotiating the impact of such knowledge. My hope is that with a greater appreciation of agency, we may progress a variety of discourses within the discipline. Take anthropological interest in kinship, for example. Academics have long debated, "whether the new genetics has heightened the salience of biological relatedness" (Featherstone 2006: vii). I would like to see more research address how people *choose* whether to accord significance to biological relatedness through a practice of emphasis. Moreover, I hold an appreciation of participants' agency will be critical in allowing for a greater collaboration between the anthropology of ethics and the anthropology of genetics. If we see genetic knowledge as something imposed rather than something that is evaluated, we miss both participants' wisdom and the opportunity to apply a wealth of insights from anthropologists interested in conscious ethical deliberation. Again, I am less interested in using the anthropology of ethics to comment on clinical decision making, although I do offer thoughts on bioethical issues on page 175. Rather, it is in life beyond the clinic that I believe the most interesting ethical action occurs.

I hold that the anthropology of ethics can benefit from—as well as contribute to—anthropological interest in cosmology. One cannot gain a full picture of ethical life whilst overlooking cosmological detail. I hold that people's belief—regarding the makeup of the world, and on what is to come—inevitably impacts ethical practice. To evidence my point, I turn not only to my own findings but also to ethnographic observations made by Joel Robbins (2004). During his research among the Urapmin of Papua New Guinea, Robbins observed a collective perception of moral crisis. He noted, "with the future so uncertain, no one knew how to operate in the present" (Robbins 2004: xxv). Similarly with my participants, I saw that the certain uncertainties of NF1 paralysed their everyday life. One might ask what makes this paralysis ethical. To this point, I offer a simple response. One's expectation of the future always determines one's action in the present—and ethical action is no exception. Consider that if one believes they will die tomorrow, they will most probably adjust their outlooks and priorities—and they will certainly operate with different assumptions than if they anticipate a long life followed by a guaranteed afterlife.

In addition to the role of expectation, I hold that attention to changes in cosmology—spurred on by religious conversion, new genetic knowledge, or an entirely different catalyst—can help both the theorist and the subject understand new ethical imperatives. Through attention to cosmological detail (and thick description) Robbins was able to highlight how the Urapmin considered their ethical action in light of their Christian conversion.[135] He was moreover able to decide which theory was best suited to evaluating their ethical practice.[136] Finally, I wish to highlight how the question of responsibility is always linked to convictions on what substance determines action. Where genes are seen to contribute to temperament, one's ethical responsibility comes under question. In summation, while my project has mapped my participants' cosmologies, with the intention of investigating the place of genes within them, and thus contributing to the anthropology of genetics, I believe I have also made a small contribution to the anthropology of ethics insofar as I have highlighted the importance of attending to substance (along with other cosmological details) in building a complete picture of ethical life.

To close my suggestions on how my project has contributed to the discipline I have three final, miscellaneous, and slightly more speculatory points to make. At the outset of my project, I sought to add to the chronicling of local genetic knowledges. Yet despite this local—even individualised—focus, I suspect my findings can add to the anthropological study of Britain more broadly. I doubt one can effectively analyse much of life in the UK without an understanding of why people would eschew the rational and ambitious in favour of the kind. My second point concerns kinship studies. Having seen how some of my participants avoid reproducing, I am left wondering how anthropologists might attend to kinship without the promise or anticipation of future generations. And finally, my third point concerns the anthropology of ethnicity. In my project, I have attended to a situation of spontaneous genetic similarity—as opposed to

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[135] Robbins noted that to his Urapmin participants, commendable behaviour was seen to be the result of the holy spirit working through the individual, rather than the individual's will (2004: 225).

[136] Robbins draws on Foucault at several points in his book, but ultimately does not favour a Foucauldian analytic. He explains that Foucault's telos does not always align with the Urapmin's Christian motivations. On this matter, he notes that his Urapmin participants were not trying to be good people for the sake of it, but because salvation "promises more than the sum of the outcomes of the individual moral acts" (Robbins 2004: 218-219).

inherited genetic similarity. I suspect spontaneous similarity may challenge ideas that ethnic identity is based on shared ancestry rather than shared substance. As I say, these final points are more comments than analyses. I trust and hope my project's main contribution has been on my participants' freedom to negotiate the (in)significance of genes.

Significance Beyond the Discipline

In Chapter 5, I highlighted how my participants' practice of emphasis challenges the imperative to justify the existence of people with genetic difference. It is now timely to clarify the significance of this finding for disability studies. There is a wealth of theorisation and activism which frames disability—including disability stemming from genetic difference—as a mere difference, and, moreover, a natural part of human diversity. In a paper that criticizes this view DeVidi and Klausen note, "The mere-difference view is nicely summarized by Elizabeth Barnes as holding that "disability is … a natural part of human diversity—something that should be celebrated, rather than pitied and ultimately 'cured.'"" (DeVidi & Klausen 2017: 259). An author regularly featured in this mere-difference discourse—and repeatedly mentioned by my participant Stewart—is Rosemarie Garland-Thompson.[137] Stewart was eager to recall a podcast featuring Garland-Thompson. He recounted to me her reflections on how a wheelchair-user will notice the beauty of the ground on a hike, whereas an able-bodied hiker may well miss this texture. Stewart and Garland-Thompson's appeal to the utility of this disability—in its ability to increase human appreciation of the natural world—is moving. However, I find this logic to be problematic insofar as it appeals to the utility of difference. Much as the professor I encountered (see page 153) reframed genetic difference as a useful enrichment to human diversity, I find any such attempts to celebrate difference uncomfortable insofar as difference must be justified—and not simply allowed to be.

A second set of remarks—on how my research findings relate to and hopefully contribute towards discourse beyond anthropology—concerns bioethical discourse. First and most obviously, my Chapter 3 pertains to debate over informed consent. I have demonstrated, as Margaret Lock and many other before me have done, that there is a weight to partial foreknowledge—especially when this knowledge is genetic in nature. Lock reflects on this dilemma:

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[137] DeVidi and Klausen reference Garland-Thompson's conception of mere-difference (2017: 358) as a nuanced argument more convincing than the paper they criticise.

> Should such genetic testing be limited to the world of research, in which case individuals would not be made aware of their genotype until such time as they actually became sick, when, possibly, such knowledge might be of relevance for their care? Or should patients routinely be tested and receive information about susceptibility genes as part of basic medical care prior to the onset of sickness, in the same way as we are already informed about cholesterol levels, blood pressure, and the results of prostate-specific-antigens (PSA) tests? Even though information about susceptibility genes is inevitably subject to misunderstanding (some would insist that this is "disinformation"), it is often argued that people have a "right to know" about their genomes." (Lock 2005: 48)

To reiterate, I am not interested in a return of paternalistic medicine in which the patient is never informed or consulted. But equally, I am wary of knowing being deemed beneficial in all situations. In concurrence with Lock and other anthropologists who have studied the fallout of genetic knowledge before me, I commend the current pattern wherein informed consent has "given way" to a broader participatory approach (Pálsson 2007: 217).

The second way in which my research might contribute to bioethical research concerns debate over genetic engineering. In my master's thesis (Marshall 2018), I argued that before we can evaluate whether it is ethical to alter embryonic germline genomes, it is first pertinent to know what genes are. Or, more specifically, it is important to know what genes are understood to be within different socio-cultural contexts. For the participants in my doctoral research, as I have demonstrated, while a genome is not synonymous with identity, it is still more than a marker or precursor of personhood. Genes are seen to set the goalposts of genetic potential, and thus are critical to individual identity formation, (for more detail, please visit the conclusion of my first chapter). By chronicling the nature of genes in my participants' cosmologies, I have added data which I would have benefited from in my earlier analysis of genetic trait selection technologies.

Thirdly and finally, in my attention to NF1—and, to a lesser extent, NF2—I have contributed towards (however meagrely) increasing awareness of these respective conditions. This raises an interesting dilemma. While my participants obviously desire better awareness of NF—such that more funding might be given to NF research—I hypothesise that there is some benefit to limited public awareness. Whereas the general public might bring certain prejudices to a person with Trisomy 21, many people with NF live with only a semi-readable condition. By this, I mean the public is unaware of the details of NF1, and so people with the condition are free to explain their neurofibromatosis however they might like. Of course, the need for such explanations is a burden, (see page 109). Moreover, detailed ethnographic accounts of NF1 will inevitably combat inaccurate, misleading, or meagre[138] portrayals of NF1 and NF2. Still, I remain aware of my responsibility—as an academic focusing on neurofibromatosis—to highlight without hyperbole.

Life Beyond NF1

In this thesis, I have chosen to include examples—among hundreds offered by my participants—based on whether they addressed my research interests in the significance given to genes, existential anxiety, and the burden of knowledge. Consequently, there is much data which I have been compelled to omit in the body of this thesis. For example, I never mentioned that my key participant Amy is a keen runner. Nor have I covered Jamie's interest in landscape gardening. I thus cannot claim to have offered a complete ethnographic portrait of all my participants, or even of some of my key participants,[139] since I have been obliged to miss these details in the interests of time and the overall flow of my argument. I now wish to end my thesis by introducing a small fraction of this ethnographic data which I have missed. My aim is to illustrate, again, the breadth of topics covered in my ethnographic interviews, and—perhaps more importantly—to demonstrate that NF1 is not always the most salient facet of my participants' lives.

The participant I wish to close with is Tara, who also happened to be my first participant. In my very first interview with her, Tara explained that the most painful moment of her life had nothing to do with Tatleen's NF1. Instead, it concerned the distance between herself and her family based on religious divergences. Whereas Tara and her husband are both devout converts to evangelical Christianity, her wider family remain Sikh. Whilst in recent years, Tara has been on better terms with her parents, she repeatedly told me that tensions have ever run high:

> You know, when my eldest brother got married, my parents wanted me to go into the temple for a ceremony. And I remember I was with Tatleen and I said, "I'm not gonna go in." 'Cause when you go in, you kind of have to bow down. So, I said I'm not going to go in.
>
> But my parents said, "oh never mind, just go in and sit at the back." But you know, I felt the Lord used that to kind of test me. I know it's not for everybody, but for me, I really felt that I'm not supposed to go in, because I'm not worshipping that god.

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[138] As a coincidence, I recently finished reading Verghese's novel, The Covenant of Water (2023). While I found the book to be deeply moving, I felt a little uneasy about the final reveal—that several main characters were affected by NF2. I was especially uncertain of one character's conviction (admittedly not the author's conviction) that NF2 entailed "tumours of the personality." I am still uncertain as to whether I feel this a helpful representation of NF2-related schwannomatosis.

[139] Perhaps I have only offered a complete ethnographic portrait of Stewart.

> So, all of my relatives made a line. They passed me, one by one, going up [to the temple], my grandmother, my aunties. I cannot tell you, Naomi, it was the worst experience in my life, because I'm such a people pleaser, it just killed me.

Although Tara did go on to relate this experience back to her daughter's NF, this connection was a secondary concern to her. Tara's more pressing objective was communicating to me the nature of her "spiritual battle" and Christian journey:

> I think from that time on, [after remaining outside the temple at my brother's wedding,] you know, it's been a lot easier to follow Christ. After that day, I really felt like something was released—like there was that bondage that was released, that was broken. I've been able to grow and develop, and that's what's helping me with my children.
>
> And with my, you know, the situation with Tatleen with NF1—what else can we do? We pray that she doesn't develop more symptoms, or we pray that she won't get severe tumors, or [we pray] that they won't affect her eyes or her organs. But, you know, ultimately whatever God does, he's so wise that there [will be] some good and it will be for his glory.

NF1 is a large part of Tara's life, but it is not her whole life. Likewise, while genetic knowledge may press on the minds of my participants, it would be disingenuous to suggest explaining their experiences of—and thoughts on—their genetic difference offers a complete account of their lives. I thus wish to conclude this thesis with the following quote and my adjustment to it. Bernhard Wieser, a professor of Science and Technology Studies, once wrote, "People come to think about their life (and that of their children) in genetic terms only in very specific situations" (Wieser 2017: 75). Based on my research, I have found that people *choose* to think about their life in genetic terms only in very specific situations.

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