

Cultural and Political Geographies of the AIDS Crisis in Ireland



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Contents

Abstract.....	2
Acknowledgements.....	3
List of Tables/Figures.....	5
1. Research Overview.....	6
1.1 Introduction.....	6
1.2 The Irish AIDS Crisis and Cultural Context.....	8
2. Conceptual Framework. Biopolitical Precarity and AIDS Governance.....	14
2.1 Biopolitics and The Government of Life.....	14
2.2 Precarity and Precarious Life.....	22
2.3 Precarity and Services/Organisation.....	29
3. Research Design.....	34
3.1 Methodology.....	34
3.2 Ethics.....	39
3.3 Participants.....	41
3.4 Methods.....	43
3.4.1 Ethnographic Observation.....	43
3.4.2 Interviews.....	46
3.4.3 Documentary Research.....	46
4. Performances of Precarity in Ireland’s AIDS Quilts.....	52
4.1 Background to the AIDS Quilt.....	52
4.2 Ireland’s Voluntary Sector Quilt Projects.....	55
4.3 Naming, Shaming and The State of Stigmatisation.....	59
4.4 Quilting and the Queer Diaspora.....	72
4.5 Pathworks of Precarity In-Place.....	80
5 Precarious Blood and the Legacy of Ireland’s AIDS Crisis.....	99
5.1 Space Blood and the Body.....	99
5.2 Donation Disease and Deferrals.....	103
5.3 Bad Blood and Political Geographies of Precarious Citizenship.....	109
5.3.1 The Irish Blood Transfusion Service: An Introduction.....	109
5.3.2 Regionalizing the Blood Donor Pool.....	113
5.3.3 The Space of Confession.....	119
5.3.4 Encountering Exclusionary Citizenship.....	124
6. Concluding Remarks.....	138
References.....	141
Appendices.....	165

ABSTRACT

This thesis is a geographical study of the cultural and political performances of AIDS in Ireland. It takes, in particular, an institutional/ organisational approach to focus on the practices of the state and non-state sector and their interaction with the 'AIDS' body through two embodied practices; AIDS Quilting and blood donation. Drawing on a Butlerian conceptualisation of precarity and precariousness, it configures a landscape of HIV/AIDS care provision that is implicated in the production of the precarious body and the precarity of the state. My study of Irish AIDS Quilts explores the practice of AIDS Quilting among voluntary HIV/AIDS organisations that have been operating within a context overshadowed by religious moralization, and shaped by an inequitable geographical distribution of disease. I begin by locating Ireland's AIDS Quilting projects within the context of Ireland's HIV voluntary organisations, I then take up three geographical expressions of precarity that we can see communicated in the Quilt; a stigmatising state, a queer diaspora and a precarity of-place. Through an institutional ethnography of interviews with Quilt producers, ethnographic observation of the quilts aesthetic properties, and documentary research, this example demonstrates that Ireland's attempts to memorialize marginalised collectives is at variance from other cultural contexts with a more visible and arguably more insurgent gay community, such as the United States. My second example focuses on the practice of blood donation in the aftermath of the AIDS crisis and examines how the cultural memory of AIDS continues to affect the institutionalised culture of the Irish Blood Transfusion Service, where tactics of governmentality are expressed and experienced spatially with a particular impact on the bodies of non-normative subjects. Overall, the thesis elucidates a complex relationship between the body, state service and voluntary organisation, determining in particular that the state sector above all, continues to be instrumental for inducing precarity on the bodies most affected by the AIDS crisis.

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List of Tables:

Table 1: Methods Used in Main HIV/AIDS Organisations Investigated. Produced by Researcher.

Table 2: Documentary Research Used in Research. Produced by Researcher.

Table 3: Ireland's AIDS Quilt Projects and Associated Voluntary Organisations. Produced by Researcher.

Table 4: Status of MSM Ban as of 2016 in Selected Countries. Produced by Researcher.

List of Figures:

Figure 1: Illustrations of Michel Foucault's Power- Knowledge Apparatus. Produced by Researcher.

Figure 2: A Selection of Irish NAMES Quilt Panels. Photo taken by Researcher

Figure 3: The Quilt of Hope (A)* completed by women of Open Heart House 2013. Photo by Researcher.

Figure 4: AIDS Quilt Panels of the Irish Diaspora taken from the digitized US NAMES Quilt Photo courtesy of the Names Project Foundation.

Figure 5: AIDS Quilt Panels of the Irish Diaspora taken from the digitized US NAMES Quilt. Photo courtesy of the NAMES Project Foundation.

Figure 6: 'Quilting in the Community' 1993- 2008 by Rialto Community Quilt Group. Photo courtesy of AIDS Care Education and Training.

Figure 7: Map of Rialto including prominent local services such as Rom Massey's Funeral Home, Rialto Taken from Google Maps.

Figure 8: Image of Rom Massey's Funeral Home, Rialto.

Figure 9: Rialto's Community Quilt. Courtesy of AIDS Care Education and Training.

Figure 10: The Rialto Community Christmas Tree. Courtesy of AIDS Care Education and Training

Figure 11: Sample Floor Plan of the Irish Blood Transfusion Service.

Figure 12: A Racially Homogenous Group of Irish citizens endorsing the Irish Blood Transfusion Service's 'It's in Your Blood Campaign.'

Figure 13 The Irish Blood Transfusion Service 'Health and Lifestyle' Questionnaire as of 2016. Provided with kind permission from the IBTS.

CHAPTER 1: RESEARCH OVERVIEW

1.1 INTRODUCTION

This thesis is a geographical study of the cultural and political performances of AIDS in Ireland. It takes, in particular, an institutional/ organisational approach to focus on the practices of the state and non-state sector and their interaction with the 'AIDS' body through various forms of management and/or care. My substantive chapters provide two separate examples of these embodied practices; one of which is focused on the performances of precarity in AIDS quilting projects run by Ireland's voluntary HIV/AIDS care organisations, and the other which explores the spatial surveillance and management practices of blood donation among the state funded Irish Blood Transfusion Service. My first substantive chapter begins by locating the Quilt project within the context of Ireland's HIV voluntary organisation service provision. I then take up three geographical expressions of AIDS and precarity that we can see communicated by the quilt; state, diaspora and place. Drawing upon an institutional ethnography consisting of mixed method archival research, testimonies of Quilt creators, and the aesthetic properties of the Quilt itself, I explore how the Irish AIDS Quilt essentially 'performs' the precarious geographical imaginaries of the crisis which differ from its cultural production in other locations, such as that of the United States.

In my next substantive chapter, my findings move chronologically into the contemporary forms of HIV/AIDS management with a particular focus on blood securitization during the HIV/AIDS crisis, and the legacy of institutionalised blood bans which have induced precarity on some of Ireland's most dedicated but marginalised blood donors. Findings from this study indicate there exists a cultural memory of HIV/AIDS in the state-funded Irish Blood Transfusion Service, something which I unearth through an illustration of the spatial tactics that it employs in the cultivation of its national blood donor pool as well as the exclusions it introduces for marginalised citizens who are continually viewed as the embodiment of disease. In this substantive chapter I draw primarily on ethnographic data taken from the Irish Blood Transfusion Service as well as documentary research and interviews with two individuals who have been directly affected by these policies as they account for their own experience.

The thesis makes a disciplinary contribution to the field of geography as it theoretically advances the geographical study of embodiment and state -induced vulnerability through the bodily interaction of subjects with the spaces of HIV/AIDS services and practices. Critical geographers, both in Ireland and internationally who often focus on HIV/AIDS, typically do so by approaching the topic as a security concern (See; Ingram 2012; Elb; 2005). While there is merit and indeed validity to this approach, such studies circumvent a focus on the body, as either conceptualised and/or responded to by the state and civil

society partners. As such, the subjectivities which are produced and solidified by and through material and effects of disease on the body as well responses from state service provision, are almost entirely absent from traditional 'geopolitical' scholarship. This research is underpinned by theories such as Butlerian precarity and Foucaultian biopolitics which re-centre analytic attention to the body, emphasising it as a fundamental geographical scale and site in itself, capable of shaping public space and reflecting the political conditions of its environment. Through ethnographic and embodied research with the practices of the HIV/AIDS based services and adopting these theoretical positions from the outset, this project aims to foreground the interplay between the AIDS body and the power relations of Irish society. With the exception of Brown (1991), critical geographers have often abstained from assessing civil society actors and focusing almost exclusively instead, on grassroots activism in the lifeworlds of subaltern populations. Yet to do so, is to neglect the reality that very often, subaltern populations find themselves requiring the engagement with non-governmental or faith-based organisations as the first ports-of-call in regimes characterised by uncertainty, instability and unpredictability. Voluntary organisations are an undeniable and inescapable feature of our humanitarian present and to avoid their inclusion in a study about HIV/AIDS in society would negate their influence with subject-citizens dependent on their services. This study therefore assumes that there is relevance and practical value in investigating power relations of state and civil society and by exploring their service delivery from within the material circumstances of subjects everyday activities.

But perhaps most significantly, this thesis makes a substantive contribution to the queer history of Ireland's LGBT community, and the wider field of sexual health and HIV/AIDS studies in Ireland. To the best of my knowledge, this thesis is the first empirical study to date on Ireland's AIDS Quilts and the MSM blood ban, thereby making the findings both unique and wholly relevant for better understanding an important, but nevertheless silenced period in Ireland's political-geographical history. Furthermore, current talks are underway with the co-ordinators and facilitators of the original Quilt projects in an effort to convene a series of meeting, ahead of World AIDS Day 1st December 2017, to investigate the possibility of digitising Ireland's AIDS Quilts, which would be the first attempt to officially preserve, and making readily available, the display of Ireland's Quilts, before eventually granting them with a more permanent home.

The thesis is structured as follows. Chapter 2 introduces theories of socio-spatial marginality and bodily vulnerability by drawing on the work of notable political philosophers; Michel Foucault and Judith Butler, in order to provide a theoretical understanding of the ways in which the body acts as a geographical site of power, and of vulnerability to power's effects. Fundamentally at stake here, is the contention that our susceptibility to HIV/AIDS, and vulnerability to its effects, is a profoundly political and spatially uneven phenomenon. I add to these theoretical contributions by questioning in what ways state- based HIV/AIDS services may either mitigate or respond to one's disproportionate exposure to state-induced vulnerability,

providing a foundation for what will be later explored more in-depth in the substantive chapters. Chapter 3 outlines my methodological approach of an institutional ethnography (IR) and its accompanying mixed methods approach including that of ethnographic observation, semi-structured in depth interviews and documentary research. IR research is relatively new to the discipline of geography, and in this chapter I suggest that we can better understand the practices and effects of domestic and local organisations when conceptualized in tandem with wider geographical formations such as scale, place and porosity with the state. In chapter 4 we are beginning to move into the body of the substantive findings where I grapple with the cultural legacy of the AIDS crisis as it is depicted through the voluntary organisations practice of AIDS Quilting. I consider how AIDS quilting ‘materializes’ in a country rife with Catholic social thought, as well as considering a place-based response to the AIDS crisis, as seen through the geographical formations mentioned above. Chapter 5 acts as a contrast to the findings of the earlier chapter, as it considers the practices of a state-based service and its involvement with AIDS management in the legacy of the AIDS crisis, focusing in particular on the Irish Blood Transfusion Service. Finally, the closing chapter provides some concluding remarks on the overall findings of the thesis as well as offering direction for future research having now opened up two new lines of inquiry, which have not yet been previously explored. I begin however, with an overview of the cultural and historical context of the AIDS crisis, within which this wider study takes place.

1.2 THE IRISH AIDS CRISIS AND CULTURAL CONTEXT

The emergence of AIDS in Ireland tended to initially reflect that of other Western countries such as the United States and England whereby the first official cases of AIDS were reported in 1982 among homosexual males who presented with the medical condition; Kaposi’s Sarcoma (Duffy, 1993). This was later followed by haemophiliacs, intravenous drug users and the heterosexual population (Seery, 1993). According to the first report by Ireland’s National AIDS Strategy Commission in (1992), there were 23 cases in the homosexual community as of 1991 and at the same time, the virus was growing among IV drug users which had reported only one case in 1985 and 31 by 1991. By 1991, there had been a total of 266 cases that met the US Centre for Disease Control (CDC) definition of AIDS, and of these, 103 had died (HPSC, 2016). There were 11 reported cases among the heterosexual population in 1991 and the first case of mother to child transmission also occurred in the same year. The scale of reported HIV cases was even greater with 619 cases among IV drug users, 188 among the gay community, and 129 in the heterosexual population (National AIDS Strategy Commission, 1992). But as a country that had been dominated by teachings of the Roman Catholic Church, Ireland was ill-prepared for the advent of a disease rife with moral signification.

The Catholic Church has been a mainstay of Irish life since being systematically enshrined in ‘Bunreacht na hEireann’ Ireland’s Constitution, since the foundation of the State in 1937. Article 44 for example, gives explicit recognition to “the special position of the Holy Catholic Apostolic and Roman Church as the guardian of the Faith professed by the great majority of the citizens.” Articles 40-45 are correspondingly suggestive of this Catholic social thought by “vindicat[ing] the life, person, good name, and property rights of every citizen” and, what was to become a particular point of contention: promising to uphold “the right to life of the unborn.” In a similar vein, the Constitution asserts that the family is a “moral institution” and a “natural primary and fundamental unit-group of society,” It therefore “guard[s] with special care the institution of marriage” which must be protected “as the basis of a social order.” Howes (2002 923) as cited in Redmond (2015:73) makes the assertion that in the post-independence era, the Irish state was principally concerned with “establishing and maintaining order” and sexuality merely constituted a “principle of chaos.” Sexual behaviour and its regulation became a national obsession in the post-independence era, in an effort to prove decency, respectability and capability in governing Ireland as an independent nation. Yet the government's efforts to regulate sexual citizenship did not go unsupported, as 89% of the population pledged allegiance to the Church’s teachings, making it the highest percentage of practicing Catholics in Europe (Cassidy and Devitt, 1999). This has been a direct causal factor in the lack of a social movement or political opposition to have challenged the legitimacy of the Church (Smyth 1998).

Given the Church’s overwhelming influence in the formation of the state, it is no surprise that subsequent legislation would be similarly reflective of its position on morality and social thought. Ireland’s largest and most historically prominent Political party: Fianna Fail upheld the Family Planning Acts of 1979 and 1985 which imposed a ban on the importation and sale of contraceptives. Homosexuality was criminalised, prisoners with communicable diseases were segregated and there was an entire absence of sexual and/or health education in schools (NASC, 1992; Quinlan, 1994; Seery, 1999). The Church was even found to have instructed politicians that “it was their duty to ensure that legislation should direct men and women to lead a moral life and that Catholic values should permeate society” (Smyth 1998; Cooney, 1986: 13). While 1988 saw the introduction of a pilot programme on sexual health and HIV in secondary schools, given that the majority of schools were under Catholic patronage and could choose to adopt the programme or not, unsurprisingly, the programmes failed to be subsequently adopted in many cases. Sexuality, for the Irish state, was what Jakobsen and Pellegrini (2003: 13) have referred to as, a subject so “morally fraught that it [always] require[d] a chaperone.” In other words, sex was the problem and Catholic social thought was deemed to be the only solution.

As a result of this inherent moralization that accompanied the disease in Ireland, society exhibited a profound lack of awareness as well as extreme stigmatisation of people living with the disease. This was captured in a survey of Irish general practitioners (GP’s) conducted by the Irish College of General

Practitioners in 1991 which showed that out of 400 respondents, almost 50% of GP's felt that they had not got did not have sufficient knowledge about on HIV, and this was particularly so for rural practitioners. A further 50% felt that their practices would suffer if other patients knew they tended to HIV patients in that surgery (Nation 1991 as cited in Duffy 1992: 31). Over one third of GP's felt that homosexual patients were 'hard to deal with' while nearly nine out of ten felt that intravenous drug users were even more difficult to manage (Nation, 1991 as cited in Duffy 1992: 31). The first national AIDS Awareness Survey which was launched in 1994 revealed that while 36% of participants understood HIV/AIDS to be a sexually transmitted infection, more than 50% were worried about sharing utensils and yet a startling 64% still felt that they "knew as much as they needed to know." (AIDS Awareness Survey, 1994 :9). The main educational source on the virus was Ireland's national broadcasting station 'Radio Teilifis Eireann' (RTE) which, as one of my interviewees recalled: "had Archbishop Diarmuid Martin going through CVs" at the time. The same AIDS Awareness survey showed that 69% of participants found RTE to be a 'very good' source of information, but while people were less likely to get their information from British media sources, interestingly, those who did, were more likely to rate that information as 'excellent' or 'very good' with 95% for the BBC and 84% for English newspapers respectively (AIDS Awareness Survey, 1994). Clearly there was an absence of coherent and accurate information regarding the disease and which was undoubtedly heavily impacted by the Catholic Church's teachings on abstaining oneself from all sexual relations outside marriage.

Medical and care services were also entirely ill-equipped to respond to the onset of the Irish AIDS crisis. As in Britain, the first major intervention campaign by the Irish government was in 1989 with the production of an educational leaflet entitled: 'AIDS- The Facts.' However, due to the extent of illegalities surrounding homosexuality, drug and condom use in Ireland at the time, the leaflet was unable to contain little more than basic information about "casual sex spread[ing] AIDS." (Seery (1999: 3). This education leaflet, was made available only within health centres and community pharmacy's instead of being sent to everyone's homes, as was the case in the UK, and therefore as Marcella (1993) has commented, it was entirely inaccessible to those who were unable to attend clinics. Reflecting on the available services for AIDS patients, Dr Derek Freedman of the Genito-Urinary Clinic in St James' Hospital comments that the facilities for the control of sexually transmitted diseases were "lamentable" in the 1970s and 1980s (Duffy, 1993: 17). By the early 1990's it was recognised that resources for AIDS care would have to be primarily channelled into palliative care, given that most diagnosis had been made in the mid to late 1980s and which had been expected to put increased pressure upon the acute hospital sector. Ireland did have one Genito-urinary consultant, along with one Centre for Haemophilia, but because they were both based in St James' Hospital, any person in the country diagnosed with AIDS would have to travel to Dublin (National AIDS Strategy Committee, 1992). The respite centre; Cherry Orchard was built to ease up the demands on hospital beds in 1991, but, with only 22 beds, it was also wholly inadequate given that 10 times that number were being diagnosed with AIDS (Duffy, 1993). Social workers were also made

available in St James' Hospital from 1995 in order to conduct pre and post test counselling to prevent known or at-risk individuals from becoming infected, while also attempting to prevent those living with the virus, from transmitting it to others (Quinlan, 1999). However many service users expressed frustration around non-HIV positive medical staff telling positive people how to cope with their illness; "nobody can sit there and tell you what it feels like having the virus. They read all about it, that's all it is. They don't know" (Combat Poverty Agency, 1999). When testing was introduced in 1985, it was decided not to make this a mandatory practice, except in certain circumstances. For example, anonymous unlinked antenatal screening for HIV was routinely introduced for pregnant women as of 1992 when it was found that the HIV positive rate per 100,000 births to HIV positive mothers was 22.9% (Quinlan, 1999). Mandatory HIV testing was also enforced in the Irish Blood Transfusion Service as of 1985 for all potential blood donors, a policy which I will return to and explore more in depth in my empirical chapter about the IBTS and the precarious blood ban in Ireland. People also feared getting tested for HIV or being provided with written confirmation by the national Virus Reference Laboratory as there were reports among gay men, that it prevented the likelihood of one getting life insurance or mortgage protection.

The problem with such services however, is that they have overwhelmingly focused on, and targeted specific collectives, by aiming to punish them and alter their behaviour, without accounting for wider environmental factors that shape the communities within which AIDS victims are embedded. As with many countries, HIV/AIDS in Ireland has been unevenly spatially distributed across the inner city communities with 42% of those who tested positive being IV drug users and those who are concentrated in areas where social networks and supports have been removed. From 1989 to the early 1990s, a study conducted by the national drug treatment centre on Jervis Street revealed that out of 398 drug users tested for HIV, 28% were HIV positive and were overwhelmingly clustered in the inner city of Dublin, an issue I will return to in chapter four (Dublin AIDS Alliance, 2012). An 'AIDS Resource Centre' was set up as a statutory organisation on Baggot Street Hospital in Dublin 1989 to respond to the extent of HIV cases among intravenous drug users. Having been described by Smyth (1999: 665) as the "most innovative statutory service in Ireland" the centre began by simply providing a needle exchange programme, but following harm reduction recommendations in the '1991 Government Strategy to Prevent Drug Misuse', the clinic began providing an oral methadone maintenance programme which allowed drug users to stabilise their addiction through an indefinite supply of a heroin substitute. Harm reduction is essentially a "humanistic approach" which identifies and counteracts mediating structures that have the potential to create adverse health effects among large groups of people, (Open Society Institute). The clinic was to later expand its operations to include a women's project for sex workers, and, following the decriminalisation of homosexual acts in 1993, it also developed a gay men's health service, (Quinlan 2004). During this period, a number of voluntary HIV and IV drug use related organisations were emerging also, but I will discuss these in more detail in chapter four in relation to the emergence of Quilt projects.

In 1992, Mary O'Rourke, then Minister for Health, established the National AIDS Strategy Commission; a body that was to have wide representation from both Irish statutory and voluntary sectors, on the premise that "co-ordination between both sectors will lead to more effective service delivery" (NASC, 1992: 64). Largely influenced by the multi-sectoral approaches of the EU and UN, this marked a profound change in how Ireland would respond to the management and care of venereal disease. The Commission is composed of three sub-committees; Surveillance, Care and Management and Education and Prevention, all of which are unable to implement policy, but are tasked with making recommendations for effective policy practice within their respective fields of expertise. In 1992, NASC's first report on AIDS was released, primarily dealing with the development of palliative care, given that many HIV/AIDS patients were terminally ill at the time of publication. The report appointed a national AIDS co-ordinator; Dr James Walsh, who was largely responsible for overseeing the direction of HIV policy and being notified of new HIV cases as they were returned by UCD's Virus Reference Laboratory. One of the core recommendations in its 1992 report was for the establishment of a second Genito-urinary consultant to be based on the south side of the city, a recommendation that, although was highly needed, was not to be subsequently taken up by the Fianna Fail government. Of the many far-reaching changes introduced in this report were the introduction of anonymous unlinked HIV screening for pregnant women, the decriminalisation of homosexuality, desegregation of prisoners with HIV and the availability of condoms in vending machines around the country. The Commission have released two official national publications to date, one in 1992 and another in 2002, whereby HIV was upgraded as a 'notifying disease' under recommendations of the health and surveillance committee. However, due to the opposition by the Education and Prevention Sub-Committee, the decision was taken not to introduce contact- tracing or partner notification. Instead, partner notification is only strongly advised during post- test counselling. The Commission continues to meet only when required, but it has not met regularly since 1995, given that the shift away from AIDS to a focus on sexuality has, in recent years, altered the committee's scope and remit, rendering its current status ambivalent.

In October 2015, then Minister for Health Leo Varadkar launched Ireland's very first national Sexual Health Strategy 2015-2020 in conjunction with the National AIDS Strategy Commission (NASC) in response to increasing upward HIV trends in the past decade, particularly among young MSM. According to Ireland's Health Protection Surveillance Centre, between 1995 and 2013 sexually transmitted illnesses increased in Ireland from 3,361 to 12,753, with the greatest burden being among Ireland's youth under the age of 25, and in particular, among men who have sex with men. Part of the strategy's recommendations was to allocate 150,000 euro for the immediate implementation of rapid HIV testing in pubs and nightclubs in the city of Dublin, as well as "ensuring that everyone in Ireland has access to high quality sexual health information, education and services." At the heart of this document was the realisation that

HIV/AIDS has not simply gone away or been eradicated in society, despite having become a more manageable condition through the state's provision of antiretroviral medication. An editorial in the Guardian by Boseley (2011) for example warned that of an ever-growing laxity among Western governments towards HIV/AIDS which has been "wholly inadequate" given the sharp increases in HIV that we have witnessed in the last decade. Since 2016 in Ireland there has been a 75% increase in the incidence of HIV with 128 new cases diagnosed within the first three months of 2016 (Cullen, 2016). It was within this context that I sought to engage with the HIV/AIDS services in Ireland and better understand how these services were responding to the lived condition of HIV/AIDS in Ireland. I turn now to my conceptual chapter which will demonstrate in more detail, the theoretical lens through which I will conduct this research.

CHAPTER 2: CONCEPTUAL FRAMEWORK BIOPOLITICAL PRECARITY & AIDS SERVICES

Undertaking this research moved me into places, and brought me into contact with an array of people affected by the legacy of AIDS in Ireland. I began this research with an interest in the political ways in which certain people are made more vulnerable to disease, and as such, was interested in extending this exploration to the interaction between bodies and state supported systems of AIDS management and care. As I researched newspaper articles on the Irish AIDS crisis, read about the work of state agencies and voluntary organisations, or spoke to activists about AIDS-related issues, I found not only diversity, but conflict in their competing perspectives (Brown 1997). After meeting with staff, and studying some of their work, it became clear that AIDS services sustained by volunteers had needed to move into urban areas affected by the crisis and respond with innovative creations in the absence of formal state protection. The legacy of this crisis is still felt today however; several activists I met with are still engaged in a battle with the state over what they see as continued stigmatizing and discriminatory practices as a result of the AIDS crisis. It was for this reason that my research organically emerged at the intersection of bodies, state-induced precarity, and organisational practice. In doing so, I examined the work of medical staff from state-based services, activists, volunteers with civil society organisations, and community groups, all of which intersect across a range of spaces and scales. These organisations and services are an undeniable and inescapable feature of our humanitarian present, and are therefore an important subject of study for critical geographers interested in politically -induced vulnerability and efforts to counter it. By positioning the service/organisation as an accessible nodal point between state and precarious body, my conceptual framework combines contemporary critical theories of vulnerable bodies with institution and organisation literature to explore how services such as those in my study, either exacerbate or mitigate precarity.

2.1. BIOPOLITICS AND THE GOVERNMENT OF LIFE

In order to better conceptualise the porosity between the citizen's body and the actions of the state, it is useful to first begin with a brief overview of some of Michel Foucault's (1926-1984) central concepts of biopower and biopolitics. His work is especially significant for researchers (such as myself) concerned with the role of medical humanities, for his theory intensified the study of the relationship between the practices of the body and the governing of the state (Mills, 2014). My own research has been particularly influenced by the published texts *History of Sexuality Volume 1, Discipline and Punish (1977 [1975])* (Foucault 1978 [1976]) and *Discipline and Punish (Foucault 1977 [1975])*, together with some of his Lectures at Collège de France, published from transcripts and notes since his death, *Society Must be*

Defended (Foucault 2003 [1997]) and *Security Population Territory* (Foucault 2007 [2004]).' 1987-89 which have been published from notes and transcripts since his death. Some commentators on Foucault's work believe that, in his later works, the notion of biopolitics was inconsistently applied, or even abandoned and supplanted instead with a consideration of security, liberalism and governmentality (Adorno; 2014; Schinkel, 2010; Elden, 2007a). Rather, I find Collier's (2009; 2007) 'topological' analysis more persuasive as he maintains that Foucault's central investigation of the power-knowledge apparatus was widely adopted to his different topics that he was serially concerned with across his career. These different nexuses of power are certainly inter-related and thus while the concepts of biopolitics and biopower were given different inflections in various works they retain a general coherence.

Foucault (1982: 777) presented a conceptualization of power that served as a radical departure from the unitary Leviathan state, which, up until this point, had served as the predominant (and highly masculinized) conceptualization of government. Power, in Foucault's formulation, was not merely juridical or oppressive, but was instead capillary and rhizomatic, flowing diagrammatically at every level of social and environmental relations (See Figure 1 below). By approaching the question of power in terms of how it is produced and how it functions in the everyday, Foucault showed that power simply cannot be understood as juridical laws or prohibitions, nor as something concentrated in the hands of hierarchical positions or fixed only within certain spaces and domains (Muble in Lumm and Vatter, 2014; Mills 2015; Erlenbusch, 2013). Power infuses everyday life and exists not so much as a possession, but as a series of techniques and practices that produce subjectivities of people residing within a polity (Foucault, 1977). For a power relation to begin, one need only have to act upon another. In this way, Foucault is curious about how the relations between people and how they are *changed* by virtue of them being in a power relation (Kristenson, 2013). Power, for Foucault, thus *produces* not only subjectivities but forms of knowledge and truth, that, contrary to much belief, were conceived by Foucault as neither good nor bad, and certainly not only repressive. Foucault did recognise, however, that under this schema of power, domination and unequal power-relations could exist in society, but he refrained from acknowledging total domination because, admittedly at the limit, there is always the possibility of that one may take their own life, as no one other person can die your death for you.

The sixteenth to eighteenth century (or the end of the Classical age, and the beginning of the modern period) was identified by Foucault as a break with previous configurations of sovereign power and monarchical regimes (Foucault 1971 [1966]). Foucault is ultimately concerned with the spatial change in the sovereign jurisdiction that was creating difficulties in the practices of governing and opening up possibilities for new procedures of power to adapt and preserve sovereign power under a new formulation. In particular, previously effective juridical laws that had established and maintained order for the sovereign, were now beginning to work "more on the side of the norm, knowledge; life [and] meaning" (Foucault, 1998: 148). In 'Society Must be Defended' Foucault states that: "far too many things were

escaping the old mechanism of the power of sovereignty both at the top and at the bottom, both at the level of detail and at the mass level” (Foucault 2003 [1997]: 124). The reconfiguration of sovereign power was however, also premised upon a reorganization of space. Commenting upon the shift in the political order In *History of Sexuality Volume III*, he wrote:

“Rather than imagining a reduction or cessation of political activities through the effects of a centralised imperialism, one should think in terms of the organization of a complex space. Much vaster, much more discontinuous much less closed than must have been the case for the small city-states, was also more flexible, more differentiated, less rigidly hierarchized than would be the authoritarian or bureaucratic Empire that people would attempt to organize after the great crisis of the 3rd Century...It was a space in which the centers of power were multiple, in which the activities, the tensions, the conflicts were numerous, in which they developed in several dimensions” (Foucault, 1986 [1984]: 82).

Philo (1992) argues that the ordering and patterning of space was a principal concern in Foucault’s “archaeological method” that attempted to recover aspects of the past without totalizing history or making claims to its continuity. Drawing on Foucault’s (1986 [1963]) readings of poet Raymond Roussel, Philo shows how Foucault’s troubling of the geographical positioning of ‘things’ and ‘objects’ in Roussel’s exotic poems and novels nurtured his own post-modern geography. Philo (1992: 150) sees this as emblematic of Foucault’s methods: “When Foucault gazes out on the social world of the past he sees... spaces of dispersion through which the things under study are scattered across a landscape and are related to one another simply through their geography.” Hence, for Philo, it was this positioning of things, their locations and distances through space and time that presented to Foucault, not so much a “chaos” of history, but a “connectedness of order” that was transient and which can be ‘archaeologically’ uncovered so as to determine the various rules and norms that governed them (Philo, 1992). This fundamental reorganization of space and power in the jurisdiction of the sovereign creates a dispersed set of power relations where new norms can be made, new subjectivities formed, and the contexts altered of vital decisions affecting human ways of living. But, crucially for Foucault, this de-centering of power and its normalization also came with the problem of ‘truth.’

Hitherto, the quest for truth had been the preserve of the King who spoke and acted on behalf of the God(s). Biopower asserted controls over human life that intruded on matters that formerly had been under religious sway. With the emergence of biopower, the sovereign was no longer sustained by religious fiat. Truth was produced and recoverable only through the acquisition of knowledge and governance required scientific legitimation. For Foucault, power simply could not be conceptualised without knowledge, for both were imbricated in one another in the formation of subjectivities and in the hierarchies that it manifested between them. In his text on ‘Subject and Power’ Foucault identified three modes of ‘subjectivation’; how an individual comes to be formed as a ‘subject’ of power: scientific objectifications (how human beings are objectified), dividing practices (how individuals become separated from others

both metaphorically through categories, and physically through spatial and material formations) and self-subjectivation (the ways in which people are incited to recognize their own moral obligations). These techniques and their accompanying bodily practices, were what ultimately constituted the ‘power-knowledge apparatus’ in society and included among it, governmental techniques such as inquiry, examination and confession; all of which were integral for acquiring truths about the subject and thereby legitimating biopolitical state techniques and scientific knowledge (Foucault, 1978). Acquiring knowledge on or about the population, then, was only reached when these techniques had acquired a certain level of acceptability (through repetition and so on) through time, and were continually legitimated through an accompanying set of normalizing practices. For Foucault (1977) people could only become the objects and subjects of institutional knowledges by submitting to their regular empirical measurements and normative standards of behaviour. It was this solidifying of knowledge through practices that led to the production of ‘truth’ as life itself began to enter a ‘reflexive prism’ of scientific investigation and political thought. Foucault’s reference to the ‘reflexive prism’ merely refers to the apparatus mechanism that combined both the constitution of the subject according to governmental techniques of power, with the formation of knowledge and truth that fed back into this formulation of power (See Figure 1 below). The prism, Foucault maintained, could be isolated and investigated for the purposes of ‘problematization’ or research (Guntar, 2014).

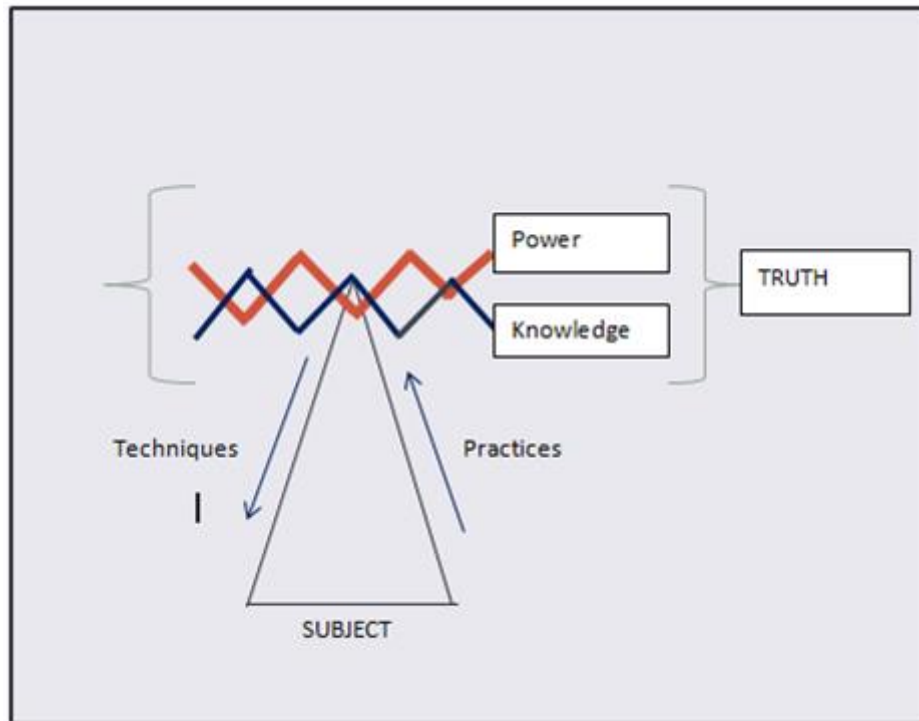


Figure 1. Illustration of Foucault’s Power- Knowledge Apparatus. Produced by Author.

Biopolitics, then, can be seen as an element of biopower where biological life begins to enter this field of political techniques that aim to regulate and produce life and subjectivities in accordance with a particular norm (Schinkel, 2010). ‘The threshold of modernity’ as Foucault discussed, rests where biological ‘species’ became the “object of [their] own political strategies.” (Foucault, 1978: 141). Biopolitics is what Foucault referred to as a ‘normalizing’ power that operates through forms of regulation in the form of statistics on birth and death rates, public health, urban environment and welfare/ security. At its core, biopolitics is concerned with two issues: (A) affirming health and removing disease from society in order to maximise utility of the population, which is interrelated with (B) excluding or even doing away with some life deemed unworthy to live so that certain privileged lives may flourish. Lemke (2011) argues that biopolitics is applied on three axes: reinforcing life, sexuality and race. At the level of the population, all of these axes intersect as part of governmental interventions for they are intertwined with some of the most significant biopolitical constants that affect the population, such as reproduction (the preservation of the state) and disease (an internal threat to the flourishing of the state). Because life was considered to be worth protecting and reinforcing, one was required to invest in ‘themselves’ and spend their “whole life, as Foucault argued, “learning how to live” (Foucault, 1986: 51). In *History of Sexuality* Volume 3, Foucault elaborates on one of the ways in which biopolitics works in the form of what he refers to as ‘techniques of the Self’ or ultimately how one transforms themselves into a subject of power by turning their entire biological existence into a permanent exercise. Importantly for Foucault (1986) care of the ‘Self’ had to be understood relationally, as caring for oneself was never something that could be fulfilled as a solitary practice; to better understand oneself, one had to compare oneself with others, and against a standardized norm; one had to confess their wrong-doings to another, and adopt health regimens that were applied at the level of the population. Sexuality was deemed to be another biopolitical axis of Foucault’s concern that reproduced certain ‘truths’ about the subject, and was what Repo (2011:84) has referred to as the “life function” of the state, rivalled only by the “death function” of eugenic racism. States not only target, but heavily invest in heterosexuality as the domain in which body and population meet. It is precisely because of its imbrication with social reproduction, that sexuality is what Collier (2007: 89) observes as “a matter for discipline but also for regulation” or in other words, the topological intersection of both disciplinary power applied to the scale of the body, and biopolitical regulation at the level of the population.

In Foucault’s formulation of power, any bodies that were identified as being ‘non-normative,’ non-conformist or indeed ‘abnormal’ became an object and ‘problem’ that necessitated wide-scale governmental intervention. As Stephen Legg (2005) has discussed for the case of India, it was the demographic explosion of the population at the turn of the century and its movement from country to town, that brought with it an array of problems that required systematically planned “remedial measures” centred on where to ‘place’ people who would be considered ‘abnormal’ according to normative Western scientific rationalisations and calculations. This is where we can see biopolitics overlap with the

'anatomy-politics' of disciplinary power as the body becomes a discursive and disciplined site intended to be reformed, optimised and maximised for the purposes of efficiency in a productive national workforce. Again, I borrow here from Collier's (2009) topological analysis which affirmed that biopower and disciplinary power were never intended by Foucault as antithetical, but rather, that, once elaborated, these forms of power worked together at various scales. Disciplinary institutions for example began to proliferate on the outskirts of urban areas to house and segregate certain groups of citizens for the safety or the so-called general population. These institutions included prisons, asylums and workhouses and all of which were premised upon their own unique set of techniques for managing subjects and altering human behaviour. In *Discipline and Punish*, Foucault ([1977] 1995) details the way in which the body's materiality and corporeality becomes a central site for the diagram of 'disciplinary power' that individualizes the body according to an arrange of tactics such as investigation, spatial segregation, and control over comportment and the insertion of the body into a set of daily rhythms (Foucault, [1977] 1995: 205). Disciplinary power was thus an individualizing power at the scale of the *body* but again, it had as its object the entire population in order to produce a more manageable and effective workforce that would be compliant with these same institutions that governed them according to different ends. Panopticism, as Foucault argued, was thus not merely a spatial apparatus applied to the body, but was a form of power that enabled the smooth and compliant functioning of an entire population;

“This is why discipline fixes; it arrests or regulates movements; it clears up confusion; it dissipates compact groupings of individuals wandering around the country in unpredictable ways; it establishes calculated distributions. It must also master all the forces that are formed from the very constitution of an organized multiplicity; it must neutralize the effects of counter-power that spring from them and which form a resistance to the power that wishes to dominate it...” (Foucault [1977] 1995: 219).

In other words, the objective of disciplinary power was the internalization of certain ways of being that accrued with particular norms and rules applied at the level of the population. One arena in which we can see this intersection of bio and disciplinary power is in the state's explicit control over sexuality education in schools. Globally, Sexuality education remains entirely premised upon the assumptions of conventional gender norms with the intent of creating “acceptable sexual citizens” within a monogamous, marital framework (Elia and Eliason, 2010:31). According to this framework, only heterosexuals are capable of 'love' while “marriage” between a man and a woman - with the intent of reproduction - is the ideal (Elia and Eliason, 2010:30). Any citizen that identifies as non-heterosexual has their health needs and sexual desire, almost entirely ignored by state-based sexuality curricula (Francis and DePalma 2014; Francis and Msibi 2011; Butler et al (2003:17). Ansell (2009) has also argued that in an environmental context of epidemics that are sexually transmitted, such as HIV/AIDS, sexuality education which remains crucial for the state's vitality, can be causing more harm than good, when applying what is assumed to be gendered and age-appropriate norms for it assumes that some members of the population have not been exposed to

the ills of an environments in which they are already embedded (Patton 1996).

Biopolitics, as a new economy of power served the mechanized and routinized production of industrial capitalism, and thus the study of biopower requires understanding its mutual relations with political economy. Having explicated biopower in his lectures of 1974-5, "*Society Must Be Defended*," Foucault's took up questions of security, governmentality and liberalism in his lectures of 1977-9, now published as *Security, Territory, Population*, and *The Birth of Biopolitics*. Governmentality was essentially an 'art' of government that directed human life in a certain form and according to various ends - such as wealth, prosperity and personal security. Governmentality worked in conjunction with biopolitics as a way in which to secure the health of the population and the 'vitality' of the state. While Foucault recognised that governmentality included both government of the Self and of the polity, his primary concerns in his Lectures are those of the latter as opposed to those that are taken up in his earlier works on 'History of Sexuality.' Here I concur with the observations made by both Legg (2005) and Collier (2009) who recognise that it was biopolitical developments first and foremost such as calculative mechanisms acquired on or about the population, and the controlled insertion of these bodies into disciplinary institutions or mechanisms, that advanced the development of Capitalistic production.

Both Lemke (2005) and Collier (2009) share the conviction that govern-mentality is essentially a 'problem-space' or, an intellectual rationality upon a reality that shapes the conditions of possibility for governmental technologies to intervene. In Elden's (2007b) analysis of Foucault's Lectures, he identifies three apparatuses of security: town planning, vaccinations, and food shortage. Elden (2007b) argues that all three demonstrate similar preoccupations with the space of security, the emergence of an 'event' (that is, how to manage unpredictable and contingent risks in society), and the normalization of the apparatus of security in everyday life. He discusses how security was premised upon geographical conditions such as circulation and movement, which emerged as preventative measures against uncertainty. The crisis of grain shortage for eighteenth century mercantilists for example, was believed to be the result of over-regulation and lack of exchange enforced upon 'natural' processes, and could only be improved through the deregulation of grain (Kearns 2014). Rationality and reason were given as legitimate reasons to leave the grain open to the 'truth' of the market which it was hoped would establish an equilibrium of its own, through self-regulation (Foucault, 1978; Lemke, 2014). While discipline may have regulated through enclosed and bounded spaces, security was thus premised upon transgressions of spatial enclosures and the emerging task of government was to facilitate the unhinged freedom of movement and circulation of people and goods by controlling people, without it necessarily appearing as though they were 'disciplining' them (Lemke, 2014).

Biomedical technologies that are “oriented towards the goal of bodily optimization” is one such governmental strategy that has received sustained attention among medical humanities researchers, for it is where we can see biopower and governmentalities intersect (Kearns and Reid-Henry 2009). Because capital requires an adequate workforce, “management of the economy” then becomes predicated upon “the organization of therapeutic citizenship” (Kearns 2014:773). Therapeutic citizenship, coined by Nguyen (2012) emerged as the hallmark of a “politics of life itself” during the global AIDS crisis whereby activism oriented around access to AIDS biomedicine was defined as a struggle to survive purely in biopolitical terms. Global pharmaceutical industries and Western states have typically controlled the monopolization of biomedical ARV production and distribution, and are thus able to manipulate the productive capacity of certain states by assisting them with the vitalization of their workforce. In essence “life and economy” become caught in distinct geopolitical power-plays, as some states effectively “rent” their workforce from a combination of global pharmaceutical industries and Western-based aid (Kearns, (2014:774). Yet, at the level of the body, ensuring a successful rollout of ARV provision by the state also requires a form of self-subjection, that instils individual habits and attitudes towards medicine, one’s body, and ideas of ‘risk’ (Prince, 2012). Subjects are expected to practice techniques of ‘positive living’ and ‘self-care’ which require adherence not only to medication, but to strict food regimes, minimal alcohol use and changes in their sexual behaviour. In this way, as Biehl (2007: 103) has discussed, HIV/AIDS medication has become a “ boundary and institution-making technolog[y]” for making certain hidden or marginalised populations more visible and hence ‘treatable’ by the state. Adherence to medication thus produces a subjectivity of its own that crystallises embodied inequalities; those who ‘perform’ good behaviours expected of them by the state, are permitted access to new and improved biomedical technologies, while those who fail to comply for a variety of reasons often beyond their control, are left abandonment by health systems, and in many cases, are simply left to perish. In one of my substantive chapters to follow, I consider in more detail the political geographies of blood donation, and how on an international scale, there is a geopolitics mobilized around the life-saving therapeutics of blood transfusion, but which is also premised upon the smaller-scale practices and performances of a secularised biopolitical regime of ‘confession’ which not only elicits certain truths about the subject, but which is also premised on this disciplinary technique of absence or presence of reward. I will now turn to consider the concept of precarity which advances further, the inequitable allocation of life and death in biopolitical life.

2.2 PRECARIETY AND PRECARIOUS LIFE

In contrast the geopolitical context of the elaboration of the concept by Judith Butler, within Human Geography, precarity has been taken mainly to refer to difficult lives of poor people, particularly vulnerable migrants. While undertaking this thesis, I had the fortunate opportunity to present part of my research at a ‘Precarious Geographies’ conference in Royal Holloway, University of London, February 2015. And after what I found to be a really enjoyable experience getting to learn from other young geographers researching this area, I still could not help but wonder why precarity seemed to have only a narrow empirical application in the field of labour or migration studies - a realisation which was not least evinced by the keynote speakers Louise Waite and Hannah Lewis on their ESRC- funded project, the ‘hyper-precarius’ lives of migrant labourers in London. Apart from a few studies that took flight in considering precarious housing along the US rust belt (again, a kind of market condition) or the lived conditions of artists in Balfron Tower, there nevertheless appeared to be a general ‘theme’ emerging from within the disciplinary research of the day, and one which I did not see my own research on the political-geographies of disease sitting so readily or comfortably within. Precarity has undoubtedly become shorthand for market unpredictability and instability in our contemporary present. Prior to entering the English parlance, as geographer Waite (2009) writes, the term featured prominently in Europe for characterizing labour-market conditions and the so-called ‘precariat’ or working-class poor. Waite (2009) recalls how precariat was a term designated by French Sociologist Pierre Bourdieu (1963: 361) to denote the economic welfare state of the post-Fordist economy and which was intended to connect the European experience of being in employment but still experiencing poverty and job-insecurity. Since then, the concept has been largely appropriated by radical left-wing social movements as a way in which to characterize, and mobilize against, short-term labour contracts, migrant-labour, and other forms of economic instability that derive from the labour market (see Lee and Koffman, 2012). Though Waite (2009) acknowledges in her ‘critical geography of precarity’ that it can be understood as a broader form of societal malaise, she enthusiastically endorses this perspective and argues that it is only abstracted labour conditions which truly usher in the kind of instability and unpredictability that characterizes the lives of migrant labourers. I recognise that neoliberalism, flexible labour and migration are undoubtedly all parts of the ways in which we precarity may materialize, but the problem with this analyses is that it runs the risk of transforming ‘precariety’ and its potentiality into nothing more than a market-based category, or even worse, an identity mapped to certain bodies.

Perhaps closer to my own perspective, but still diverging in some ways, is Geographer Nancy Ettlinger’s (2007) analysis who understands precarity to be an “unbounded” condition of uncertainty, expansive in application and not easily mapped as a consequence of particular time-bound events. She writes that

precarity is a condition “grounded in the everyday” and whether through oppressive street surveillance, labour insecurity, or violence in the home, “precarity spares no one, haunting even privileged people, who, like everyone else, cannot escape the terror of disease...” (Ettlinger 2007: 322). There are a number of problems with this perspective. First of all, it diminishes the political urgency and expediency of a lived condition that is unequally distributed and felt. And secondly, it individualizes precarity as a sort of psychological experience that can “haunt” anyone, without accounting for the structural conditions that produce or differentially allocate it. Precarity is not a generalised state of anxiety. Neither can it be reducible to existential conditions alone. In making these claims, it is not my intention to endorse a unitary concept of precarity that risks becoming normative, but rather, it is to stress that some readings of precarity eclipse the more politically urgent, affective and psychic dynamics that can inhere in its nuances. In contexts where certain lives are disavowed more than others, there are certain groups of people that are, as a result, systematically exposed to more urgent and violent forms of regulation, foreclosure, exclusion and control. So if precarity is not an economic nor an existential identity, then what is it exactly?

My understanding of precarity is closely aligned with the ethics of political philosopher Judith Butler who develops a thoughtful analysis of the conditions under which structural marginality, bodily exposure, and political potentiality are induced. As Watson (2012: unpaginated) has eloquently put it: “she defines precarity ... in terms of life and death, mentioning economics and labour only insofar as these are necessary to sustain a life.” Because I apply this biopolitical conceptualisation of precarity throughout my research, I have aimed to provide a more detailed reading of it here, and in doing so, I touch upon some similarities and differences between Foucault and Butler as I explicate my own use of the term.

Judith Butler offers a sustained and thoughtful analysis of political marginality that critiques the philosophical study of ontology in itself for it refocuses our analytic attention away from ‘being’ in the world, and instead towards our politico-ethical relation with another. She begins her analysis by drawing a careful distinction between two principal concepts of precariousness – corporeal death, and precarity – a *political* and *eventual* corporeal death, (Watson, 2012). According to Butler (2004), all subjects are predisposed to ‘precariousness’; a universal, intrinsic and undeniable form of corporeal vulnerability, or in short, our own material finitude. Because life and death are shared conditions of existence, and because bodies – right from conception – depend on one another in order to exist and to thrive, it is this very precariousness that unites us all in the form of an ethical relationality, or mutual bodily dependence on another. Butler’s (2004) philosophical position on relationality proceeds from Jewish philosopher Emmanuel Levinas’ who claimed that there exists “a foreignness to ourselves - we may not know it, but it constitutes the ‘I’”...[and as such] Butler argues that “we are from the start and by virtue of being a bodily being, already given over, beyond ourselves, implicated in lives that are not our own.”(Butler, 2004: 26). While she recognises that ‘bodies’ (and which she often uses interchangeably with the word ‘life’) are bounded and bordered beings with their own capacity for judgement and reflection, she still maintains that

the shadow of the other always “lives on the fibre of the boundary that contains [us]” (Butler, 2004:27).

Here, Butler’s (2004) ontological position is closer to Jacques Derrida (2000) rather than Levinas, who argues that we can never make a claim to wholeness or ‘ipseity,’ in terms of our (self) identity, which in reality is only ever formulated in dialectical relation with another. I am only *me* because I am not *you*, and hence, these two bodies must arise together simultaneously and without hierarchical arrangement. Butler (2004) finds a similar example through the ‘deconstruction’ of desire. I cannot claim desire to be ‘mine’ for it is always already constituted *for* another, (according to normative conditions which exceed me) and which must be given over to that other in order for life to endure; “what I want is only produced in relation to what is wanted of me” (Butler, 2009: unpaginated). Like Derrida however, Butler (2009) believed that avowing our relationality is in some ways an ethical aporia for these mutual ties that bind us do not always presuppose a comfortable and mutual reinforcing existence.

Because bodies are never fully private, nor even our own, this makes them a profoundly *political* phenomenon cast over into the public sphere where “regimes of discourse and power [come to be] inscribed” (Butler, 1990: 602). We can never separate out the materiality of our ‘body’ from discursive regimes that come to constitute and regulate it. For Butler (2004), the subject is reflexive; it has the capacity for agency, but can never separate itself out from the “passionate attachment” it holds to discursive norms that bind us (Butler, 2002 as cited in McIvor, 2012: 416). One is only constituted as a legible and recognizable subject if they comply with these “vectors of power and history” that govern our conditions of recognizability. Norms act upon us productively to constitute us as subjects but they are in turn stylistically ‘performed’ and solidified by subjects through a series of bodily iterations. She writes: “indeed, there is no reproduction of the social world that is not at the same time a reproduction of those norms that govern the intelligibility of the body in space and time.” (Butler, 2009: xii). To put it a different way: performativity is ultimately what creates the conditions that norms name. As can be seen, both Foucault and Butler reject any *a priori* theory of subjectivation in this sense (such as they exist in existentialism or phenomenology), by arguing instead that the subject only comes to be constituted as such, through techniques of government and performative iterations that ensure its bodily submission. As Dow Magnus (2006) highlights, “subordination is a necessary prerequisite in becoming a subject and a central element of our everyday embodied realities.” We can see on a greater scale, that for both Foucault and Butler, the normalizing society works to transform collectives into manageable and self-governable ‘populations’ that can be systematically surveyed and spatialized according to various normative criteria. By their very design then, norms can be limiting, moralizing and exclusionary, and as such, subjectivities in the normalizing society often entail forms of exclusion, docility, and even bodily harm.

These societal norms which work upon many scales, find a resonance with the psychic foreclosure of her earlier writings on gender, sex and melancholia as the state comes to determine what kinds of (sexual) relationships are permissible and what kind of same-sex desire gets disavowed. This is one place where we see Butler and Foucault part ways. For Butler, same-sex desire is produced from common processes of psychoanalytic development which then get repressed by social/judicial power and laws. On the other hand, for Foucault, desire cannot be said to be pre-linguistic, instead it is itself produced, proliferated and regulated through discursive *techniques* and practices (such as confession) which occur within the power-knowledge-apparatus. Butler (1990) is critical of this mechanistic schema of power and does not see the production of biopower as having taken place through some historical shift away from sovereignty, but rather that the force of sovereign power has simply been changed or concealed from the start.

The state of the body and the body of the state are thus intimately interlinked in this way, and one's vulnerability can either be minimized or maximized by the various (in)actions of government (Mills, 2015). 'Precarity,' then, is the exploitation of our social ties and which is produced, realized and actualized through the inequitable distribution and differential allocation of precariousness (vulnerability) by uneven geopolitical arrangements. Precarity designates; "the politically induced condition in which certain populations...become differentially exposed to injury, violence and death." She adds that it is a condition of "maximised vulnerability and exposure of populations to arbitrary state violence; enacted by states [but also] against which states do not offer adequate protection" (Butler, 2009:2). The violence of precarity is effectuated when the subject (and which can also take the form of a national collective subject) "(auto)-immunizes" itself against the thought of its own precariousness. The immunity principle is important here, for it is suggestive of the Foucaultian biopolitical paradigm that describes how certain populations who seek survival, continuity and vitality, require the death of anyone perceived as a threat. It should be stated however, that the category of 'life' for Butler is by no means an anthropocentric account of human life that mirrors that which is arguably employed by Foucault. Recall that 'life' for Foucault, was one that was fixed within the domain of the biological sciences as flesh became the object of scientific observation and knowledge. 'Life,' for Butler, is more expansive, relational and indeed *political* and thus cannot be so readily demarcated without accounting for the material and environmental infrastructures which support it; "we can neither lodge the human in the Self, nor ground the Self in the human." (Butler, 2009b).

Since precarity is produced by juridico-political arrangements, Butler (2009) is resolute that precarity is not the result of a Foucaultian 'discourse' on dehumanization. Conversely, precarity arises at the limits of discursive life, or, essentially, at the utmost periphery of our intelligibility, which is structured according to prevailing norms in any given historical period and which precede and exceed us at all times. Instead of adopting a (neo)liberal lexicon of empowerment or resilience as a way for subjects with a 'false consciousness' to escape their precarious conditions, Butler (2004) incites us instead to move toward an

ethical horizon of avowing the (disembodied) face of the Other; something which she argues is made possible only through the political potentiality of 'grief.' These (chronologically and ontologically) inter-related concepts of precarity and precariousness are echoed in the double valence of 'dispossession'; a relational concept which on the one hand implies forcible theft and/or deprivation of the subject and on the other hand signifies our relational bonds, which are undone through the loss of that part of ourselves which is composed of by the 'you.' In the latter sense, we speak of being 'bereaved' or 'bereft' ; a disorientation caused by having lost that part of ourselves that was composed of by another. Butler states: "we can only be dispossessed because we are already dispossessed" (Butler and Athanasiou, 2013: 28). Because precariousness and precarity are interlinked in this way, the subject's corporeal failure must be understood as the product of our collective societal failure that results not only in the loss of human 'bodies' but also in the wider destruction of environmental webs of sustenance (such as the bios) that sustain us: "no one person will experience the dangers of disease, lack of shelter or food and so on, without a societal failure to organize for these necessities." (Butler cited in Puar 2011: 164). Here again, Butler deliberately employs the 'plurality' of bodies acting as a collective (as opposed to community) to illustrate her defiant opposition to the (neo)liberal, individualizing rhetoric, which, she adds, " is an accomplishment [in society but] not a presupposition and certainly not a guarantee" (Butler, 2004:26). Consequently, the spatially organized networks within which we are embedded, either sustain us all, or fail to do so.

The immunity principle of the modern biopolitical paradigm has meant that under conditions of precarity certain non-normative and minority subjects are not afforded the status 'human,' ,and as such, their lives are not only rendered disposable; but their deaths ungrievable (as in Agamben's *homo sacer*) (Watson, 2011). There are two interesting spatial arguments in relation to this account of ungrievable life. First, she advances a geopolitical argument around biopolitical life by examining conditions of non-normative bodies and their relations to the state, law and the media across multiple states and between populations. And secondly, she claims that the potentiality for avowing life is premised on occupying and transgressing public space where bodies can assemble as a political collective. Butler (2004) draws upon the US-led War on Terror in Iraq and the actions of the Israeli state to critique Foucault's shift from juridical to productive power (i.e. sovereignty to governmentality) and grapple instead with the way in which governmentality re-animates a "spectral sovereignty" to liberal powers. I believe we can trace this shift in Butler's thinking from her earlier work in 'Antigone's Claim' to her more recent work in 'Frames of War.' Butler's (2000) earlier work in 'Antigone's Claim' exemplifies the formation of a (gendered) subject who defies the sovereign power of the state. In the opening of her lectures, Butler asks: "What happened to those feminist efforts to confront and defy the state?" and here she is seeking to work through the ways in which bodies might oppose political violence and demand recognition in ways that exceed prevailing norms but which would not demand retribution. In the Greek play, Antigone's brother, who she

is in a near incestual relationship with, is killed for defying her uncle, Creon the King, and because of this, is later sentenced to death without proper burial. In defiance, Antigone buries her brother and later refuses to deny it, thereby resulting in her exile and loss of citizenship. In doing so, she experiences a kind of political death having been forcibly removed from the sphere of visibility and political inclusion, and which eventually leads to her own corporeal death by her taking her own life.

Antigone represents for Butler, a subject whose performative speech-act reveals the contingency of sovereign law; a law which is unable to contain the boundaries of normative behaviour that Antigone exceeds. Hence, in some ways, Antigone has become the figure of bare life who has in fact resisted state power. Butler (2000) allegorizes this figure by comparing her to other contemporary abject populations who confront the state and who are transformed into modern-day war critics opposing an arbitrary and violent sovereignty. But her argument is nevertheless premised on a singular subject's abjection and resistance to state sovereign power *vis-à-vis* the Greek polis. Political geographer Elden (2005) has, however, effectively developed a geographical critique around this context, by arguing that her analysis failed to attend to the true spatial formation of the polis under ancient Greek civilization and which he argues took the form of a more heterogenous bounded political community rather than a sovereign state, and as a result, Butler's (2000) reading does "violence" to the original premise of the text (Elden, 2005: unpaginated). In terms of the central concerns of my dissertation, the Antigone tale and Butler's reflections upon it, are suggestive because the confused impurity of social relations (the source of Antigone's incest, the source of King Creon's authority since it derives from fratricide) sets a limit to the normalising ambition of the state and creates impossible subject positions that are lived as intolerable (Antigone cannot be true to herself while denying her obligations to her brother/lover, whereas King Creon cannot retain authority unless he exercises it in absolute terms leaving him no opportunity to accommodate Antigone's distinctive needs). Norms are erected upon acts of exclusion that haunt and disqualify the very norms themselves. Even the act of mourning can assert a more radical and inclusive community. The AIDS pandemic has given many examples of mourning as a radical act of social inclusion. I will discuss below one such case in my account of the Irish AIDS quilts.

In *Frames of War* and *Precarious Life* however, we see the problem of ungrivable life becoming more of a geopolitical concern that now implicates an array of global actors and states. Butler recognises that while a sovereign decision is taken when war is declared, other techniques of governmentality are required to sustain and amplify war. Building on the work of Foucault, Butler (2004; 2009b) argues that the sovereign state is vitalized through forms of governmentality or else risks falling into decline. Governmentality, she argues can be broadly understood as "a mode of power concerned with the maintenance and control of bodies and persons, the production and regulation of persons and populations, and the circulation of goods insofar as they maintain and restrict the life of the population" (Butler, 2004: 52). This form of power, she argues, operates diffusely within and through government departments,

institutions, non-governmental organisations and legal mechanisms, alongside sovereign powers.

Butler's ontology of bodies also connects these international geopolitical formations of governmentality, with smaller spatial scales at play when bodies transgress street spaces. For Butler (2013: 193) space is not a fixed 'site' but rather a "performative plane" where ungrievable lives can collectively mobilize and resist their unliveability. It must be stressed, however, that, although Butler conceived of non-normative 'planes' being occupied for the purposes of protest (as opposed to normative political/ parliamentary channels), Butler did not conceive that subjects could be 'liberated' from power, as many on the radical Left believe, but neither did she believe that we are somehow trapped by it in a psychoanalytic or Foucaultian sense. She draws heavily from the Arendtian "space of appearance" or "vita activa" which has, at its root, the claim that a politically qualified existence is only one that can occupy and transgress public space for the purpose of demanding "the right to have rights." Butler too, argues that "when people amass on the street ... they are [saying that they are] still here; they persist; they assemble and so manifest an understanding that their situation is shared and even when they are not speaking or do not give a set of demands, the call for justice is being enacted." (Butler and Athanasiou, 2013: 193). Butler, like Arendt, implies that the enactment of rights cannot be exercised by only one person alone, but that it ought to be a collective enterprise, realizable only through their visibility in public space.

This is perhaps one of the central differences between Butler and Foucault, as the arena of public space for Foucault, was totalized by a panoptic gaze infused with normalization. And this in itself invites another important spatial question as to where and how we position subjects relative to discourse. For Foucault, there was no outside to discourse - instead abnormal bodies were the central focus of scientific analysis and investigation and they themselves structured the prevailing norm, whereas for Butler, certain bodies are placed on the constitutive outside of discursive power as a result of their exclusions and foreclosures which structure what can be seen, and it is within this space of abjection that manifests political potentiality. For Butler, public space is demonstrative of the place of protest and resistance; where our relationality is avowed; where rights are performatively enacted, and where a silenced collective can begin to insist upon their visibility. She argues that those who protest express that: "we have not stepped quietly into the shadows of public life." One of the examples Butler (2009) gives, among many, are the Mexican immigrants in Los Angeles who stage a performative act of resistance to their illegality, by collectively marching and singing the US national anthem in both Spanish and English on the streets of Los Angeles. Firstly, collectively bringing our bodies together in an effort to protest exemplifies for Butler (2009) the relational, social and environmental bonds that sustains us; the very bonds that have been disavowed through precarity, bordering, securitization and normalization. But Butler (2009a) also maintains that this galvanization of bodies is significant for performatively enacting a right of assembly under conditions where it has been explicitly denied. This raises an interesting question however, on whether the performative articulation of a 'right' can evoke that very same right as we would

understand it normatively. If we agree that it does, then undoubtedly this act momentarily reveals the contingency and fragility of these societal and legal norms while also creating the potentiality for new norms to emerge. The assertion of our political demands that must be ‘voiced’ in the public arena, and which can additionally provide an opportunity for one to spatially ‘encounter’ the other in a performative display of grief and mourning, is a theme that I take up and consider in more detail in the substantive chapter on the erasure of public names from Irish AIDS Quilts. Because it has not been a matter of political urgency for Butler to date, the ontological question of space and urban architecture in the formation of a political praxis, still remains largely undetermined in her analysis. At times she slips, somewhat unconvincingly, between reifying an epistemological conflation of appearance, with the assertion of political demands. I hesitate against making these claims in my substantive chapter on blood donation which raises the possibility of enacting rights claims in a hidden and geographically dispersed nature.

2.3 PRECARIETY AND SERVICES/ ORGANISATIONS

This leaves us, then, with the question of how non-governmental organisations and services are implicated in the production of biopolitical precarity. Initially as I was going into the research field of the HIV/AIDS sector I was unsure of what types of organisations I would find or how they were responding to vulnerable bodies. Literature on the geographies of institutions, including the legacy of asylum spaces is vast (c.f. Philo, 1997; Philo and Parr 2000; Philo, 2000; Barker et al, 2010; Davies; 2000; Del Casino Jr, 2000; Took, 2000). There has also been a sustained interest among economic and political geographers in the role of non-governmental organisations and the spread of neoliberalism particularly in the global South (Hughes, 2007; Goodwin, 2005; Amin 2001). This brief review can do no more than suggest how precarity and the governance of organisations intersect but will elucidate some of these themes further in the substantive chapters.

The theoretical approaches mentioned previously, tend to indicate that the state may have once stood as a unitary Leviathan, but it now makes sense to describe our contemporary world as polycentric, with multiple agencies sharing power and governance through a range of spaces and scales (Burrin et al, 2008). While it is undisputed that organisations assume a particular agency in civil society, their role and contribution to the field of geopolitics is a complex and undetermined one. Kearns (2009: 270) has argued that it is precisely because “non-state actors have complex relations with states...[that] any theory of geopolitics must account for their role in the creation and maintenance of global social relations.” Hiemstra (2012) has demonstrated the slipperiness between the concepts of ‘governance’ and ‘governmentality’: while governance has traditionally focused on state-centred ways in which populations are controlled, governmentality focuses on techniques of governing, including a range of regulations,

knowledges and representations that control populations through a range of state and non-state institutions (Butler, 2004; Sparke 2006; Hiemstra, 2012).

Governance, then, when conceptualised as governmentality, accentuates this scattered and indirect impact of the state through various other assemblages, nodes, and networks. Given that governmentality has been infused through forms of non-governmental power, non-state organisations have often been critiqued by scholars for extending a neoliberal regime and accentuating the precarization of marginalised subjects. Athanasiou (2005: 45) notes that they are fast becoming a realm where “philanthropy and militarism cross[es] paths to shore up moralistic rhetoric and a spectacle of pain and mitigation rather than a political discourse of justice.” In an interview with Judith Butler (2009b) she takes up the question of ‘responsibility’ and asks whether anyone can be said to have the right to be ‘responsible’ for another (Antonello and Farneti, 2009: unpaginated). Butler conceives of the NGO as a “subject of responsibility” given that they conceive it as their duty to ‘intervene on behalf of’ another often more marginalised sector of the population. Drawing on the Derridean claim of ‘response-ability’ she argues in short, that responsibility must first be premised on *recognizability*, but many Western based organisations, particularly those driven by (neo)liberal or philanthropic humanitarianism, are simply unable to *recognize* and therefore respond to life whose cultural or linguistic background do not “transparently conform to [the] prevalent images of our own.”(Butler, 2009c: unpaginated). Nally and Taylor (2015) have examined this process through their geographical history of the US Rockefeller’s global ‘green’ agricultural revolution programmes, noting that its motivations for assisting the poor were driven out of Western security, fears of population growth, and insurgency during the period of Communism.

Duffield (2007) also claims that services which focus on ‘human development’ do so as a result of the ‘liberal problematic of security’ by defusing the threat posed by the movements of the ‘surplus population’. An ‘empowerment’ discourse which is emulated by many voluntary organisations, according to Duffield (2007), constructs self-interested, self-governing, and disciplined individuals, or ‘homines oeconomici’ that can be utilised in the smooth functioning of a market economy (Duffield 2007). As a result, ‘uninsured’ life is reduced to nothing more than ‘human debris’ or ‘bare life’ given that their skills, status, and arguably, their very existence, “[are] in excess of prevailing market conditions and requirements” (Arendt [1950] (1998); Duffield 2007:23). Finn and Sarangi (2008) link the ascendancy of (global) non-state actors in India, to the consolidation of a neoliberal health regime, which, as they observe, have resulted in distinct changes in the form of health policy, and most notably the introduction of forced sterilization which acts as a biopolitical counter to the perceived crisis of ‘over-population’ (Finn and Sarangi, 2008). Through ethnographic interviews with representatives from the non-state sector across India, they find that a ‘quality of life’ empowerment discourse seeks a neoliberal and autonomous agent capable of minimising their own forms of bodily ‘risk’ and making the right choices in the name of their ‘health’. As a universalised, ahistorical and apolitical discourse, ‘empowerment’ can contribute to

the precaritization of people, compelling them, in true Foucaultian fashion, to become entrepreneurial agents capable of acting upon themselves for the sake of 'quality' of life. Biradavolu et al (2009) makes the important point however, that not all subaltern populations are dupes of biopolitical liberal organisations. Instead, they claim that NGO's and community based organisations (CBO's) can act as an effective platform for subalterns to mobilize and resist. Critiques of the non-state sector thus comprise only one part of a much greater reality that we face in our humanitarian present.

Non-state organisations are also finding themselves responding to, or mitigating conditions of precarity. The power voluntary organisations possess relative to the state undoubtedly can serve as a medium to counterbalance the violent force of the state, by delivering much needed services and resources to those who need it most. While the nation-state typically wields military and economic power, another "attractive power" exists in cultures, values, and society which can influence governmental or human behaviour towards more positive and health sustaining ends (Nye, 2004:7). Fowler (1991: 56), for example, is adamant that the overarching goal of the NGO is to help revision the world as an ever-growing web of "non-exploitative relationships" Kearns (2009: 270) too has noted that while non-state actors may have "no coercive powers [of their own]," they do in fact "enable the soft power of networks to collect information, formulate campaigns and lobby" on behalf of people most affected by socio-spatial marginality. Hague (2004) for example, has shown that NGO 'soft-power' is prevalent in the Bangladeshi state, and in some instances has even eclipsed formal governmental authority. Because more than 54% of local government representatives are members of non-governmental or community based organisations (CBOs), its members are viewed by the state as legitimate and collaborative partners with government and their input is respected in the development of official state policy (Hague, 2004). Biradavolu et al (2009) in their study on the activities of a HIV prevention programme in a feminist NGO in India is also a good example of how organisations might positively respond to the production of state violence. From their study, they are able to show that women's CBO's, when linked up with and resourced by a larger (unnamed) transnational NGO were able to successfully confront and reform arbitrary police violence associated with sex work. Local organisation representatives and affected sex workers were provided with a safe space to meet and talk, were taught educational skills, and provided with an effective channel to participate in India's governing structures. Most significantly, Indian police were pressurized to participate in 'sensitization' training which urged them to consider the larger public health concerns that were at stake through their unnecessary police violence (Biradavolu et al, 2009). Due to the collective efforts of the NGO and CBO's, sex-workers at risk of HIV, who had previously been afraid to carry condoms, reported feeling much more confident and safe in their local area given the noticeable improvement in police behaviour (Biradavolu et al, 2009).

This reconfiguration between voluntary groups and the state can also be found in the entire history of HIV/AIDS activism that surrounded access to medical treatment. Biomedical treatment or 'therapeutic

citizenship' discussed by Ngyuen (2012) and Biehl (2014) no doubt constitutes a fundamental biopolitical contract between citizens and the state, but is also predicated on a series of interactions with state agencies and non-state actors who have rendered treatment a *social*, as well as a biological process (Paparini and Rhodes 2016). Perhaps one of the most successful expressions of this kind, was by the Treatment Action Campaign (TAC) which rallied around the provision of AIDS treatment for marginalized citizens in South Africa. Within the US-based ACTUP activism, a distinct strand developed around access to medicines and from 1994 this organised itself as the Treatment Activist Group (TAG). TAG was both an inspiration for and an active supporter of TAC South Africa. Heywood (2008) has documented how the TAC has been involved in many progressive practices, not least the "treatment literacy" of marginalised communities affected by AIDS and their right to access health care. Founded in 1998 when global pharmaceutical companies were profiting from HIV/AIDS medication, the TAC was able to successfully compel the South African state to legislate for the provision of affordable HIV medication at a time when first-line treatment was costing in the region of 4500 dollars a month (Heywood, 2008). And not only were the TAC involved in "litigation, lobbying [and] advocacy" as many (traditional) non-governmental organisations do but their activists also exhibited a radical edge, by acquiring t-shirts that stated unashamedly that: 'I am HIV positive' thereby ensuring visibility to this highly stigmatised condition (Treatment Action Campaign, 2016). It is for these kinds of reasons, that, as Kearns (2009) has argued, the non-state sector can, and often does, forge an alternative progressive geopolitics among state powers, that displaces the role of state forces and (re)defines existing geopolitical imaginaries.

When we speak of 'precarity' we may also be inclined to consider how 'vulnerability' on a more local or intimate scale, might be 'cared' for by the state or non-state sector. There has been a sustained interest among geographers in the role of medical care, particularly that which takes place in geographical settings such as the home, institutions, carceral spaces, hospitals, hospices, or informal day-care centres, (Milligan; 2000; Conradson, 2010; 2003; Parr, 2003; M.P Brown 2003). Care has been defined by Conradson (2003:508) as "the proactive interest of one person in the well-being of another" and the many practices that it involves, such as listening, feeding and administering medication is often disproportionately undertaken by women (Conradson, 2010). His study of care provided by a voluntary drop-in centre in the UK is insightful for demonstrating not so much how, in Foucaultian fashion subjectivities come to be *produced*, but how the everyday running of organisations can contribute to the relational experience of *those* subjectivities. He argues that organisation spaces typically approached from a Foucaultian perspective are often too narrowly focused on the hierarchical and oppressive forms of power that structure them, without accounting for the health sustaining psycho-social dynamics that are evoked through interaction with their caregivers (Conradson 2003). Some welfare service organisations, he argues, provide communities with a place to talk, or somewhere to go and 'just be' with no sense of external demands or pressure. He argues convincingly that "in a neoliberal polity where welfare transactions are increasingly instrumental and output focused, the significance of such places [drop-in-centres] for marginalised citizens should not be underestimated" (Conradson 2003: 519).

Such care based organisations can contribute to the normalization of precarity however, by failing to engage in more radical acts of subversion. Evans (2011) and Waters (1992) are suspicious of the “compassionate response” of the homeless shelter assemblage whose routine acts of care they argue contribute to the unending cycle of destitution of homeless people and provide little more than “tea and sympathy.” Lancione (2014) has also shown from her study of Italian Catholic soup kitchens that marginalised people have become symbolically representative of Christ himself and thus conditional charity care merely engenders compliance, obedience and the production of ever-more docile subjects. Sociologist Jensen’s (2014) research regarding the role of welfare services and care provision resembles that of a Butlerian perspective for she claims that organisation narratives, policies and practices form a fundamental part of our “citizenship regime” and are responsible for continually defining the boundaries of inclusion and exclusion regarding who, and at what times, certain normative subjects are entitled to access state service provision. The influence of the Catholic Church in the Irish state, means that these concerns about the projection of faith-based ideologies onto recipients of care is particular acute within many of the Church-run social services, reconciling (or failing to reconcile) religious imperatives with the rights and needs of the people they claim to serve. In the Irish experience of HIV and AIDS, the influence of the Church over sex education in schools and in society more generally, has curtailed the subversive practices of voluntary HIV/AIDS agencies. By denying the existence of homosexuality in Irish society, as I will come to discuss in chapter four, religiously influenced medical care has exacerbated the vulnerability of people at risk of contracting HIV.

To conclude, this conceptual chapter has discussed the role of biopolitics and precarity, key terms that are taken up in this thesis and later explored through substantive chapters that investigate how Ireland’s HIV/AIDS services has been managing and responding to state-induced precarity in the form of an AIDS crisis and its legacy. Foucault and Butler share important theoretical insights and in this way, make for a complementary approach to a post-modern study of biopolitical geographies. In the following chapters, I investigate their usefulness when applied to service provision in the Irish HIV/AIDS context but first this thesis will turn to consider my methodological approach and study design.

CHAPTER 3: RESEARCH DESIGN

Thus far, the thesis has outlined my research rationale and purpose, while my conceptual chapter has addressed the ways in which the citizen-subject, as an agent of power, produces practices that in turn impact upon the subjects themselves. This thesis claims that our understanding of precarity is limited when we seek to isolate the body as the only site or scale of experiences of ill-health alone. Instead, as O'Neill (2012) and Carson et al (2008) have argued, the body must be considered in tandem with the formal and informal domains where state policies get enacted, produced, and which are networked into processes located beyond the locus of the state. An 'Institutional Ethnography' was thus chosen as the most suitable methodological approach for this thesis; one that would consider the porous interface between body and organisation practice as well as its connections with multi-scalar forms of power. The chapter will proceed descriptively, by first outlining what distinguishes institutional ethnography from conventional ethnography, followed by an elaboration of the ways in which it has been used in HIV/AIDS research as well as in geographical scholarship. Then, I will detail more specifically how methods in IE research (observations, interviews and documents) were used in this study, as well as giving due consideration to their various limitations.

3.1 METHODOLOGY: INSTITUTIONAL ETHNOGRAPHY

Institutional Ethnography (IE) is understood as a mode of inquiry aimed at "understanding the everyday world through ruling relations: the various processes of administration and governance that shape people's activities in that world" (Smith, 1987: 152). In very general terms, IE begins by examining taken-for-granted scenes of everyday life that have been constructed or shaped by policies and procedures of larger social organisations. Winkelman and Halifax (2007) distinguish between institutional ethnography and conventional ethnography by suggesting that IE takes both a subjective *and* an objective view of organisation processes, whereas conventional ethnography focuses singularly on participant views. In terms of methods, IE is similar to other forms of ethnography in that it relies on interviews, participant observation and text-based analysis for the production of data. But for DeVault and McCoy (2005) it is primarily the investigative approach of "textually mediated [forms of] social organisation" that distinguish it from other conventional forms of ethnography. Their reference to 'text' here is important for it refers not only to documents, but encompasses "language codes" and other forms of material culture (DeVault

and McCoy 2005). Language, and the way it is understood, used, and developed within certain contexts, is an important element of institutional ethnography for it enables the researcher to connect everyday practices with discursive systems, (Smith, 1987). In order to build an institutional ethnography, one typically begins with the examination of organization practices, followed by an analysis of how the subject is coordinated through these practices and forms of text. Typically, IE begins with an acknowledgement of one's subject positionality or commitment to a particular group's standpoint and which is then followed by detailing the kind of organisation practices that produce that experience. Unlike conventional IE's, I argue that our understanding of the power of text is limited unless we are attentive to the multi-scalar processes that are coordinated and managed extra-locally. The benefit of an institutional ethnography, is its ability to bring to the fore problems in this system and offer suggestions for social change, (DeVault, 2002; Walby, 2006; Billo, 2014). Institutional Ethnography has been influenced by a range of theoretical positions including Marxism, Feminism, Phenomenology and Ethnomethodology yet it is most typically associated with the Sociological perspective of Dorothy. E. Smith.

Writing in the 1980's, Dorothy Smith (1987) began her institutional ethnography with the standpoint of women and their everyday lives. She stated from the outset that she intended to create a "sociology for women" that explored how they were organized and determined by social processes that extend beyond one's immediate everyday environment (Smith, 1987: 152). The "standpoint" of women who she worked with, were, in her opinion, the most politically urgent element of the research, and as such, she sought to produce a knowledge for them that neither erased their voice, nor objectified them in her analysis. Smith's methodological approach is most heavily influenced by Garfinkel's (1967) framework of ethnomethodology who argued that the invisible workings of social life must be explored. Yet Merleau-Ponty's phenomenology can also be seen as an influencing factor in her work given her commitment to individual women's voices and their subjective meanings of social existence (Smith, 1987). Her study began by observing how single -mother families are constructed within dominant narratives of schooling where she observed a clear incongruence between her participants' standpoints, and the institutional discourses that characterized them. These discourses, she believed, were discoverable both in the ethnographic observation of institutions, their mediating texts, and in the lives of those interacting with the space (Smith, 1988: 214 in Satka and Skehill, 2011: 194). Her argument was that discourse (by way of 'language codes' and organisation practices) objectifies individuals and creates locations between them, and most of all, displaces their alternative forms of knowledge; most notably knowledge from experience (Satka et al, 2011). Smith (1987) thus concluded the "standpoint" of mothers disappeared in texts, leaving the work of mothers and teachers to become co-ordinated through a socially- regressive discourse about the "normal" Western family.

Importantly for Smith (1987), her findings were not simply an affirmation that the treatment of single

mothers is a matter of prejudice, but that the prejudice experienced by women was produced through the unequal spaces of organisation practice.

Subsequent institutional ethnographies have sought to follow Smith's (1987) framework, but they diverge somewhat from her orthodox approach. An important study in HIV/AIDS research nature is G. Smith et al's (1995), who, working under the instruction of Dorothy Smith, conducted an institutional ethnography of how HIV/AIDS was organized in Ontario, Canada, during the 1980's AIDS crisis. G. Smith et al's (1995) analysis in D. Smith (2006), begins with a commitment to the "standpoint" of Ontario AIDS activists who pressed for state provision of experiential AIDS treatments made available only for people living in the US at the time, but unavailable for those living in Canada. His IR research sought to uncover why this was the case, and to explore whether it had any connection to the homophobia exhibited by state bureaucracies. Through conversations with government officials and health workers, he found that there had been no treatment available for people living with HIV/AIDS, as the state simply did not have the infrastructure to support them. Instead, as he argued, the government financed palliative care, and therefore (mis)allocated much of the limited resources that exacerbating existing precarious conditions.

The subjugated 'standpoint' of AIDS activists was that their condition would not have been fatal if it were not for the greater state- investment in experiential AIDS treatments that could preserve their vitality; a view that was, as G. Smith et al (1995) shows, both silenced and erased from institutional text. G. Smith et al's (1995) research asks the same types of questions initially posed by D. Smith (1987; 2006), around the hegemony of knowledge and whose ultimately counts. McCoy's (2003) institutional ethnography of the doctor-patient relationship in Southern Ontario Canada is a more micro-scale intervention focusing on subaltern perspectives of people living with HIV/AIDS and engaging with healthcare professionals. The discursively constructed doctor-patient "medical encounter," she discusses, has implications for people's "lived experiences of patienthood" (McCoy, 2005: 795). Though McCoy (2005) uses focus groups as her preferred method for explicating participants subjective meanings, her research is still undoubtedly situated at the interface of bodily experience and organisational practice. The rationale behind McCoy's (2005) ethnography was to avoid reducing the experience of people living with HIV to objectified terms like "care-seekers" which reflect the knowledges of professionalised health discourse. Instead, she sought participants' own understandings of their body, so that these "modes of knowing" ...[would become] "the objects of critical study." (McCoy 2005: 804). Similar to G. Smith (1995), her ethnography is able to elicit the hidden voices of participants in an effort to confront the prevailing norms in medical care, governing authorities and organisational practice.

These studies show us that there is no one specific way in which to conduct an institutional ethnography, as all will depend on divergent field sites, participants, and researcher goals. But what these approaches do share, is a commitment to participants, who are followed through a series of investigations, observations, conversations and interviews, and all are united in their nuanced and contextualised understanding of subaltern subjectivities vis-a-vis practices of oppression. These IE's prove insightful, but they are nevertheless problematic for accentuating what geographer Agnew (1987) identifies as a "cult of the state," or essentially, privileging the state as the locus and scale of political power without accounting for the multifarious ways in which they are connected with other multi-scalar forms of power that have implications well beyond their domestic reach, (Gregory, 2011; Bhungalia, 2014). Embodied precarity can be reconfigured, and perhaps more disconcertingly, through extra-local modes of governing that we would otherwise consider to be humanitarian or benign, (Bhungalia, 2014; Weizman, 2011). Such practices remain a significant force in the making and unmaking of the domestic HIV/AIDS subject, and as such, they too, should become part of our intellectual reflection. This chapter will now turn to consider how institutional ethnography has been adopted to date in the geographical scholarship.

Institutional ethnography has been widely adopted in interdisciplinary scholarship ranging from sociology to public health, but its application is relatively new to the discipline of geography. Billo and Mountz's (2015: 3) remark plainly that literature on institutional ethnography remains "under-engaged and under-cited"; something rather surprising when we consider how there has been a sustained interest among geographers in the study of institutions; (Anderson 1991; Herbert, 2004; Philo and Parr, 2000; Hyndman 2000; Mountz 2010). Mountz and Billo (2015: 3) make the case for its greater embrace, given that it can be a "valuable, useful and productive" approach for uncovering uneven institutional terrains and their accompanying socio-spatial relations. Institutional ethnographies on the practices or interventions of transnational NGO's in the global South, have been an area of interest to geographers. King (2009: 415) has attempted to "get at" the internal workings of an environmental conservation group in Mpumalanga South Africa and expose how its modern discourse of 'conservation' impacted on the management of rural space by local farmers. He is committed to the standpoint of rural farmers by acknowledging that their voices have been erased through texts of transnational environment NGOs. While he remains attentive to the multi-scalar networks that affect conservation governance, he provides a historically-specific examination of the Mpumalanga Park Board (MPB) and its relative place in postcolonial spatial politics. Of interest is his collection of archival data from the African Eye News Service which he used to historicize the roots of the MPB and its institutional restructuring, as well as telling us how and *why* certain policies came to be adopted over time. Bebbington et al's (2004) study of policy debates at the World Bank headquarters resembles that of King's (2009) for its concern with the production of organisation discourse and its translation into material practice. But just as D. Smith's (1987) original IE focused on women's marginalised voices, Bebbington et al's (2004) understands language exchange to be

more central in producing the kinds of knowledges that have profoundly material effects. Through detailed ethnographic observation at World Bank meetings, and interviews with World Bank actors, they conclude that discursive shifts in global development policy emerged from a decade of shifting verbal debates that hinged on concepts of poverty, sustainability and participation. Perreault (2003) alternatively presses geographers to “scale-up” their IE analysis in his examination of Ecuadorian indigenous community-led movements and transnational networks. Like D. Smith, (1987), he too, is interested in networks and practices of oppression, by showing how marginal indigenous groups are engaged in “relationship -building” with powerful transnational organisations so as to enable them to overcome “scalar constraints to [their] agency.”

Geographers have also conducted IE “on the outside” of the organisation across a geographically expansive and uneven topography, in order to study how these non-state actors contribute to the “everywhere war” of our “colonial present” (Gregory, 2004). Hiemstra’s (2011) institutional ethnography of extra-border deportation geographies in Ecuador, is perhaps the first IE to interrogate organisation processes on either side of a state border. She interrogates the “master narratives” of USA’s homeland security and maintains that the “chaotic geographies” of the organisation which it produces. What I found interesting from Hiemstra (2012) and Mountz’s (2012) analysis was their use of “embodiment” as a conceptual tool when studying spaces marked by profound precarity. Embodiment, they argue, focuses on “people, their performances and responses to the ways in which they experience and interact with state policies” (Hiemstra, 2012: 172). It shifts the scale of analysis to the body in order to reveal processes, relationships and experiences that are otherwise obstructed when we focus singularly on the state. They observe the kind of bodily acts and performances that reveal (2012) emotional responses to the incomprehensibility of a US homeland deportation system and the distress exhibited by those who struggle to enact discriminatory policies (Hiemstra and Mountz, 2012).

Yet institutional ethnography is not without its limitations. Critiques of institutional ethnography are beginning to increase and would therefore tend to suggest, that as a research method, it is growing in application. Kevin Walby (2007) has questioned for example, whether it can be said that any subaltern voice exists as 'pre-textual'. In this sense, he is wary that we may never fully de-objectify a subaltern standpoint simply because their voices materialize in language and forms of text. He not only argues that some level of objectivity is always present, but goes further to suggest that objectification is in fact a precondition of any intelligible scholarly practice. We can only strive instead, he claims, to “reconfigure the relation of research towards a lesser degree of objectification” (Walby, 2007: 105). In order to do this, Walby (2007) proposes that the researcher must subject their own text to a practice of on-going scrutinisation. The point Walby (2007) makes is both an important and a valuable one. Undoubtedly

researchers must be continually reflexive about their work but this arguably constitutes a difficult task for those of us who remain steeped in a discourse of their own academic discipline. Nevertheless, the challenge of reflexivity for those working within a set of “ruling relations” did not escape D. Smith (1987), and we, as geographers, should be equally attentive to the ways in which academic prejudice can infuse elements of our research, leading or indeed producing, researcher bias. Another criticism levelled not so much at institutional ethnography itself, but at those who conduct it, is that it should only ever be carried out from a position of personal experience (Dyck, 1998; Hyndman 2000). In responding to this critique, I would only argue that in researching HIV/AIDS vulnerability as an outsider in Ireland, we know that there are inequitable state forces that have rendered certain bodies more vulnerable to disease, and we are aware of the structuring silence of these individuals’ lack of inclusion and standpoint both in organisation policies and indeed, among AIDS research. This dissonance, thus situates me as a researcher, on the other side of what is known, and brings with it, a certain responsibility to give voice to subaltern epistemologies, languages and representations in policy and practice, and to do so, will inform and guide the process of much of this research.

3.2 ETHICS

Ethical approval was secured for this project from the Maynooth University Social Scientific Research Committee (SRESC), (see appendix 1). In addition to following the guidelines stipulated in the formal ethical process (ie. consent for interviews and photographs, maintaining confidentiality, and providing the option for anonymity), my research was additionally foregrounded by a sense of shared humility and openness between myself and my research participants. At all times, I strove to meet participants on their own terms and in a place where they felt best suited their own needs and requirements. In nearly all cases, this entailed meeting in the place of their work (and which also provided opportunities for ethnographic observation) or alternatively in local cafes and restaurants. At one point, the research took me to an elderly woman’s home in North Dublin which she had proposed as her preferred place of interview. Lou and Pike (2010: 62) have stated that “the professional relationship is also a social relationship” and as a result, the researcher has an obligation to redress, or at least minimize, conditional inequalities that exist between researcher and participant. Sharing time together at this woman’s home and eating croissants as she showed me family photos, was, I felt, the right decision for trying to build more lasting and meaningful relationships with individuals involved in this study.

While the majority of my participants were already involved in the line of HIV/AIDS care or management either as an activist or as an (ex)service employee and hence were not especially ‘vulnerable’

by the terms set out in the SRESC guidelines, the sensitive nature of the subject could nevertheless elicit strong emotions, particularly as some had directly cared for families and friends lost to HIV/AIDS, or had been disproportionately affected by discriminatory HIV/AIDS policies. As such, provisions were put in place to stop the interview at any time deemed necessary, as well as providing an information sheet with a more detailed list of Irish support agencies along with their contact details. Generally, participants did not seem to exhibit any sense of distress during the data collection process, and even in some instances expressed gratitude for helping to co-create a collective space where they could impart their knowledge, in a safe and respected manner. I recognised from the outset that my research was never going to make any profound changes to the provision of HIV/AIDS care in Ireland, but I still strove, with the input of participants, to address some of these past injustices and give voice to the participants own creations or alternatives within the parameters determined by limited research resources.

Throughout the study, I continually re-engaged with participants by checking in with them via phone or email, speaking with them regularly online, and generally supporting them in any other way that I could. Participants were also remunerated in small ways throughout this process and in most cases this took the form of a small monetary allowance enclosed within thank you cards, but other times it covered the person's travel, lunch and the provision of small gifts of thanks. From an ethical point of view, participants were only informed about remuneration or received small tokens *after* having agreed to participate in the project, and therefore remuneration could not have served as a motivating factor for their participation. Furthermore, I strove to ensure that the write-up phase of my project represented the voice or "standpoint" of participants accurately, critically, and with the kind of reflexivity that Walby (2005) called for, though admittedly I would add that this may not have always been possible.

Despite entering the field with previously held conceptions of what I would be doing, who I would be meeting with, and what I would be asking people, the research took many an unexpected turn and often led me to other activities and interests of my participants that became alternative research leads within a totality of Ireland's HIV/AIDS care and management. Nevertheless, the methods I used, and which are detailed below, emerged at the interface of these relationships and the organisation practices which I followed. In sum, like conventional methods in IE, the project adopted ethnographic observation, interviews and documentary sources as well as many more informal conversations about the topics under study. Here, I have also attempted to outline some of the issues that emerged, particularly those regarding participant access, and the politics of positionality. All these difficulties proved to be very fruitful personal and professional learning experiences, and they demanded of me as a researcher, more methodological improvisation and flexibility when compared with many 'textbook' ethnographic approaches. I begin firstly by providing an overview of my research participants.

3.3 PARTICIPANTS

Participants in this study were adult activists or professionals who were either working in, or who had previously engaged with, voluntary and statutory organisations involved with HIV/AIDS management or surveillance in Ireland. Participants were identified beforehand and contacted on the basis of their insider perspective and in-depth knowledge. All were of mixed backgrounds and identities and the majority of which had high levels of educational attainment. A list of Dublin-based organisations had been drafted from the outset and it was found that many of these organisations sat on the relevant sub-committee's of the National AIDS Strategy Commission and which included (but were not limited to) HIV Ireland, ACET (AIDS Care Education and Training), the Health Protection Surveillance Centre, The Guide Clinic from St James' Hospital and the Irish Blood Transfusion Service (IBTS). As the research became more focused, I studied more closely the activities of two voluntary organisations: ACET Ireland and HIV Ireland for the purpose of learning about Ireland's AIDS Quilts. After repeated contact with these organisations, I was also fortunately introduced to many more individuals and community based organisations that were working within specific niche areas of the organisation, including the production of AIDS Quilts.

After an interview had taken place, participants were likely to suggest other people who they knew in this line of work, organically generating a 'snowball' sampling method, which typically begins with a small number of respondents and policy-makers and gradually grows in size, as one is introduced to other people working in the same field of work, (Schutt, 2005). Again, because research meetings and conversations occurred over a period of sixteen months, and were often held in the organisation space, each visit provided further opportunity for ethnographic observation and reflection, only some of which are incorporated into the ethnographic chapters to come. For my second study on blood donation, I followed closely the organisation processes and activities of the Irish Blood Transfusion Service (IBTS) and made contact with participants directly affected by their policies, but who had nevertheless chosen to be public in their views and activism, both in national newspapers, and on public social media platforms. Social media such as Twitter and Facebook proved to be an unexpected, but valuable source in which to reach participants. Many had taken to it as an outlet to express their disappointment or disgust with the lack of official engagement with HIV/AIDS or LGBTI issues, and based on these public statements of disapproval, I was able to establish contact with them through private messages. Another participant learned of my study on AIDS Quilts through one of my postings about a conference, and reached out to me on this basis, so as to add their own experience and input into the project.

Gaining access to participants was not, however, without its difficulties. Throughout, I was prompted to reflect upon my own positionality as an outsider; both geographically, temporally, and in terms of my own personal identity. As a HIV- negative, heterosexual twenty-something -year -old female living outside of Dublin, nor affiliated with any LGBTI group, nor even alive during the onset of the AIDS crisis, I knew from the outset that being aware of the individuals knowledgeable for this project, and further, gaining access to them, was going to be a challenging task. As an unknown quantity, and possibly even a little naive in the field, my experience tended to reflect that of Nast (1998) as cited in Parr (2001) who detailed empirically how her own embodied presence felt 'out-of-place' while conducting research in Kano Palace, Nigeria. Though I was conducting fieldwork in a local and relatively ethnically homogenous space, in some ways too, I experienced my own body as "culturally different" from the field site in which I was engaged (Nast as cited in Parr, 2001: 159). I found myself having to rely to some degree on 'gatekeepers' working within main organisations to provide details of known individuals in the HIV/AIDS service or activist arena and who could be reached directly by phone.

Because some of these organisations acted as intermediaries on my behalf, the known individuals suggested to me were often more than willing to participate in the study. Other participants were identified and contacted by phone, and in some cases I was directed to put my queries in an email but many again unfortunately went unanswered. Follow up contact was made in all cases. In the end, a total of eight interviews were recorded and while the non-response was admittedly high, it compares not unfavourably with similar studies conducted in other geographical locations (see for example; Coffey, 2012; Yancey et al, 2006). As Corcoran (2004) has discussed, it is likely of course that the time-space compressions of the 'digital age' which sociologist Giddens (2001) spoke of, have resulted in many of these services feeling increasingly pressurized with unsolicited requests through a variety of mediums. And it must be acknowledged that for many further still, the nature of my particular research request involving ethnographic interaction and in-depth interviews could be cumbersome for those where time acts as a major deterrent (Corcoran, 2004)

3.4 METHODS

3.4.1 Ethnographic Observation

Direct observation may well be one of the oldest and most reliable sources of acquiring data, and though it is assumed to be a casual process, with the correct documentation and analytical methods, it can be a useful systematic tool in IE research (Ulin et al, 2016). Indeed it is near impossible to imagine a scenario of data collection that simply begins and ends with interviews without accounting for the running of an organisation, or how a particular phenomenon might occur within and through an organisation space. Ethnographic observation is generally understood as a qualitative method in which “natural social processes are studied as they happen” and which aim to capture the field site in the same way that participants themselves see it (Schutt, 2012: 287). Recall in Dorothy Smith’s study, it was her observation of schooling that proved integral for problematizing the ways in which single mothers were understood and conceived. One had to study these “objective” processes in order to juxtapose them with lived experiences of motherhood. As can be seen from table 1 below, I distinguish between two different types of ethnographic observation; detailed descriptive and reflexive accounts of the organisation space taken as an overt researcher, and secondly, the role of covert ‘embodiment’ which observed how people’s bodies (as well as reflecting upon my own) moved through organisation space (Parr, 2001; Hiemestra, 2012). It should be stated however, that in completing this project, ethnographic observation did not assume a primary position in the data collection as the opportunities for such were both irregular and infrequent. Descriptive and reflexive notes were only taken at field site visits with organisations such as HIV Ireland, ACET, Cairde, AkiDwA, Men’s Sexual, the Health Protection Surveillance Centre (HPSC) and the Irish Blood Transfusion Service (IBTS).

In many cases, writing ethnographic notes blurred with many other forms of data collection. For example, when conducting weekly archival research in ‘HIV Ireland’ though my purpose was to source documents on or about HIV, I realised that this was also an opportunity to take detailed descriptive accounts of what I sensed around me, and which also happened to include the display of Ireland’s ‘Quilt of Hope.’ Upon further exploration into this topic, other AIDS Quilts were sourced and brought into the organisation for me to physically encounter, and in this instance, the Quilts prompted a more autoethnographic and reflexive account of my emotional responses to the ways in which these memorialized lives were retold. Later this involved me travelling out to meet participants in some of places disproportionately affected by the AIDS crisis and which were likewise responding through the creation of their own place-based community Quilts. Undoubtedly being located within the organisation space, and engaging with its

people, surroundings and display, facilitated the kinds of conversations, memories and recollections necessary to build a more comprehensive understanding and appreciation for the field site and research topic.

For my second study on the role of the Irish Blood Transfusion Service and its production of marginal citizenship in the aftermath of the AIDS crisis, I found myself having to meet with affected participants *outside* of the organisation space so that participants could talk more freely and safely away from the material site that had caused them a stigmatizing encounter. To triangulate this data, I used Parr (2001) and Himestra's (2012) covert 'embodiment' as a research tool at two of Dublin's blood donation clinics; the IBTS headquarters and apheresis clinic at St James' street, as well as the main public donation clinic on D'Olier Street. The role of corporeal embodiment has been a largely overlooked component in IE research, despite the body being a central site for assessing messy geographies of organisation space. Here I draw upon geographer Parr's (2001) embodied mental health research in Nottingham England which emphasises how (covert) bodily observation can contribute to our re-imagining of the corporeal, with respect to public space. Whereas Parr (2001) identified her participants through covert observations of bodily (ab)normality in public parks (and which, as she notes, raised some important ethical questions) I strove to observe only how organisations produced, and responded to bodily normativity within space, and how potential blood donors were recruited through an assessment of much the same criteria. Furthermore, Parr (2001) focuses primarily on the performance of mental ill- health within and through social space, but I build on these assumptions by demonstrating through observation, text, and interviews, how the bodies of potential blood donors are assessed heteronormatively by a biomedical gaze that has profound implications for those with dissident sexualities.

METHOD	HIV Ireland	ACET	IBTS	HPSC
Archival/ Text Based Research	X	X	X	X
Embodiment	X	X	X	
Descriptive Notes	X	X	X	
Reflexive Notes	X	X	X	
Recorded Interviews	X	X		
Conversations/ Research Meetings	X	X	X	X

Table 1: Methods Used in Main HIV/AIDS Organisations Investigated. Produced by Researcher.

Literature on ethnographic observation often makes a distinction between unobtrusive direct observation whereby the researcher exists merely as an ‘outsider’ in conventional terms, and participant observation, whereby the individual is more involved in the lives of their participants. The split typically implies a hierarchical division that privileges participant observation for its more dedicated commitment to relationship- building and for its ability to acquire richer data by virtue of one’s personal involvement in the field. But if the true purpose of participant observation is to get “close to people and make them feel comfortable” to such an extent that it may be possible to record aspects of their lives, then this project would tend to support the claim that this may well be possible to achieve with less familiarity and within relatively shorter periods of time (Loue and Pike, 2010: 68). Not once, but several times during my research I was taken aback by the openness, reciprocity and generosity of spirit demonstrated by a small cohort of participants who welcomed me into all aspects of their lives and described activities in which they were engaged, which went well beyond the confines of the organisation-based practice. These same individuals endeavoured to make their organisation activities and processes transparent for the purposes of my ethnographic observation and transcription. This was the difference, perhaps, between the voluntary service sector (and community groups) with whom I was engaged, and the formal state-based institutions such as the IBTS which were predicated on a very different value system, entirely different histories, and which had much less of a sustained presence in the lives of the communities who they intended to serve

3.4.2 Interviews

Because my research was seeking to gain subjective, as well objective experiences of organisation processes, I knew that interviews would also be necessary with those who had either worked in, or had been affected by, the organisations with whom I was generally engaged. Interviewing has been more broadly described as a qualitative social -science research method that allows researchers to engage more attentively, and arguably appreciate more fully, “people’s experiences, thoughts and feelings,” (Wolcott, 1995: 102). Dorothy Smith (1987) observed that people alone were not the ‘objects’ of an institutional ethnography but that interviewing served as a sufficient “entry point” into studying and understanding the interface of organisational practice and affected subaltern populations. D. Smith’s (1987) study of women would have been arguably insufficient had she not spoken to single mothers in an effort to understand how they themselves felt and responded to the ways in which they were perceived by the school institution. Like other forms of qualitative method, interviews share a commitment to learning about people and their work, in depth, on their own terms, and often within the environment of their own living situation (Ulin et al, 2005). They range in technique from structured and standardised question scripts, to loosely unstructured, open-ended interviews; the specific type being determined by the nature of the research and the level of responsivity in participants (Reinharz 1992; O’Reilly, 2010). For this study, semi-structured interview questions with pre-determined themes of interest were identified ahead of meeting participants (for a more detailed list see appendix 4). In addition to coming away with intended data, the looser structure had the added advantage of exploring other interesting tangents or unexpected outcomes that arise within and through conversation and thus allow for methodological agility and the adaptation of pre-existing themes (Mason 2002; Schutt, 2012). Interviews were conducted with members of voluntary service organisations who had completed AIDS quilt panels, in an attempt to better understand the process, the emotions and the conceptual work that goes into their creation as well as more broadly accounting for how these organisations attempted to care for, and memorialize people within the panels. Other interviews were conducted with people directly affected by IBTS blood donor regulations in the aftermath of the AIDS crisis to understand the ways that AIDS management continues to contribute to stigmatization of certain groups even into the present day.

In addition to formal interviews, I had many more informal conversations (and which were often subtly guided by my research interests) with employees from other organisations involved in the management and regulation of HIV/AIDS in Ireland. For example, some members of state organisations such as the

IBTS, tended to meet with me on a more informal or off- the- record basis. But this also occurred at various other biomedical and public health events, such as the Princeton University Fung Forum on ‘Modern Plagues’ where, at this two day symposium in University College Dublin, I met with clinical specialist doctors from the Guide Clinic at St James Hospital, as well as representatives from Ireland’s Health Protection Surveillance Centre, and I met and spoke with other scientists and epidemiologists from the United Kingdom Wellcome Trust, the United States Centre for Disease Control (CDC), and national and international HIV/AIDS care workers. Other similar events which enabled me to participate in, engage with, and learn from experts in the field were the Outburst Queer Arts Festival in Belfast with a conference on AIDS Memory and Performance, as well as conferences such as the ‘AIDS: Global and Local Perspectives’ held in Maynooth University ‘AIDS and the Irish Media,’ to mark World AIDS Day, and another symposium on the Policing and Regulation of Sex work in Ireland, held in Belfast, all of which I was fortunate enough to meet with, and learn from members from ACT UP Dublin, Mr Andrew Tucker from Anova Health, South Africa and Mr Tonie Walsh of the Irish Queer Archive, as well as activists and members from LGBTI groups and Sex Worker groups in Ireland.

3.4.3 Documentary Research

I use the term ‘documentary’ here as a deliberate alternative to ‘archival’ research in an effort to distinguish the wide array of text, film and secondary based sources that were interrogated for the purposes of this research. Documentary research is one of the most unobtrusive ways in which to contextualise and historicise social phenomena (Ulin et al, 2005) and for a seismic event that wreaked such personal devastation, documentary research may well be one of the safest and most ethical way of understanding the AIDS crisis in Ireland (Ulin et al, 2005). Furthermore, because methods of surveillance and control are increasingly and pervasively textual and discursive, documents are fundamental artefacts for researchers conducting an IE and seeking to study how the body is totalized by various forms of text. Medical charts, blood donor questionnaires, member reports, and any other strategic organisational literature are all worthy of explication for their implicit “language codes” may reveal how experiential knowledges can be lost through organisation processes (DeVault and McCoy, 2005). Documentary research undoubtedly formed the greatest and most extensive part of the data collection process, and Table 2 identifies a total of thirteen different types of documentary source that were utilised throughout. Scott (1991) has helpfully categorized these according to ‘public’ ‘personal’ and ‘private and I have attempted to distinguish the sources according to these classifications. Public documents are any that have been acquired from national archives or government records; personal can include biographies, photographs and other personal mementos, while private literature is often reserved only for certain use, or is held specifically within organisations, made available under Freedom of Information legislation.

In the first instance, a vast array of public documents were utilised in the preliminary data collection phase in order to contextualise and historicize Ireland’s HIV/AIDS service provision and to account for its changes under different governmental regimes. Documents ranged in focus but were generally either produced on or about the AIDS crisis, some involved secondary studies, old organisation pamphlets, AIDS awareness surveys dating from this period, and many department or health reports from the sub-committees of the National AIDS Strategy Commission. All such sources were made publicly available via: ‘Lenus’ Ireland’s digitised national public health repository. Other public documents regarding the AIDS crisis including blood transfusion and haemophiliacs, were collected from the Irish Queer Archive, the National Library of Ireland or the National Archives of Ireland.

DOCUMENTARY SOURCES	
Census/OSI Maps	Public
Dail Proceedings	Public
Irish Queer Archive	Public
Lenus Health Repository	Public
National Archives	Public
Oral History Projects	Public
Organization Literature	Private
Newspaper Databases	Private
‘HIV Ireland’ internal Archive	Private
IBTS documentation by FOI	Private
AIDS Biographies	Personal
Rialto Community Quilt DVD	Personal
AIDS Quilts (Varied)	Personal

Table 2: Documentary Research Used in Thesis.

The study would have been incomplete however, if it were not for the ‘personal’ documentary sources such as AIDS Quilts, biographies (admittedly few and far between given the illegality of homosexuality during most of this period and the ongoing stigmatization of AIDS in Ireland) and a documentary film

about the making of Rialto's community Quilts edited by the Rialto Community Drugs Team in 1996. Though AIDS Quilts 'travel' and are publicly showcased, I refer to them here as personal artifacts for their intimate and biographical nature. Archivists and cultural geographers Foley and Murphy (2005: unpaginated) have argued that documentary sources (particularly those in the digital humanities) can too often present us with 'siloed' information that spatially and conceptually flattens "wider political, social and economic contexts." For this study, personal documentary sources such as quilting has therefore been understood and approached relationally as a process of rhetorical significance that exceeds the realm of the personal itself. As a form of 'discursive communication' its language (or its absence) was deemed to reveal much about the ways bodies are cared for (across scales) and connected to wider state-induced systems of oppression.

The recently digitised NAMES Project Foundation Quilt (the original AIDS Quilt) acted as another "digital form of spatial information" bearing 60,000 panels that were used to search for Irish names or display locations (a more detailed description is provided in substantive chapter four) (Foley and Murphy, 2015: unpaginated). This aimed to capture observable cultural, historical and geographical trends that structured the lives of gay men during the AIDS crisis (Balsamo, 2012). But while the NAMES Quilt proved to be a valuable archival source, it was perhaps no substitute for encountering the materiality of Ireland's own AIDS quilts. It was intriguing to learn that in the Irish context, none of these items had been officially archived, and many were left in the care of voluntary HIV/AIDS organisations or their workers homes with no suitable 'place' for their display. By refusing classification according to legible archival categories, these items evoke the kinds of questions asked by historical geographer DeSilvey (2007: 879): "What are we to do with the things that don't appear to belong in the archive or the collection?" Uncatalogued and ephemeral items such as these, still constitute important elements of our material culture and indeed our history, and therefore I would argue that they are worthy of explication in IE research. As people come to produce, embody and encounter them, they work to deconstruct imaginary binaries between material bodies and immaterial organisation space (Woodward, 2013).

Private historical newspaper databases such as the Irish Times, the Irish Historical Newspaper Archive, Outmost Gay Community News and the Irish Medical Times were also systematically searched within for any HIV/AIDS organisation names or for stories on the production or display of AIDS Quilts. Private literature was also collected from within every organisation I had listed in Dublin and this was used primarily to gain a more thorough understanding of the organisation history, purpose, values, mission, as well as accounting for its client base and public interaction. HIV Ireland' happened to possess its own private archive which I was auspiciously granted permission to access, and it was here I conducted research for up to three days a week for roughly two months prior to Christmas 2015. Though not all the findings were later incorporated into the final chapters, all the documentary sources were coded systematically according to reoccurring themes such as AIDS and stigmatization, AIDS and the diaspora

and so on. Like traditional forms of IE research, these documents were supported by other secondary sources such as journal articles from other contexts and across scales, and then compared with the narratives of participants.

The difficulty with private archives, as Mogalakive (2009) attests, is that many can be kept concealed or made impenetrable to the public. This proved to be the case as I attempted to access documentation on or about blood donation in Ireland (see appendix 3). While there was some available literature from the National Archives of Ireland or the National Library of Ireland on the founding of Ireland's blood transfusion service, no amount of Freedom of Information (FOI) requests put into the IBTS was to unearth documentation commensurate with their claims to hosting a very detailed private archive, (see appendix 4). There was virtually no documentation detailing the implementation of a blood ban, nor board minutes from meetings from the early 1990's, nor any pamphlets or guides detailing the procedures and selection criteria of blood donors. On an off-the-record basis, I was informed that during the Lindsay Tribunal of Inquiry (on the infection of haemophiliacs with HIV/AIDS), the majority of historical documents were handed over to Solicitors and/or "lost" outside of the organisation.

Due to the very helpful and persistent efforts of the Freedom of Information Officer and then Medical Director however, I was fortunately provided with sample blood donor questionnaires as recent as 1995, a report that had been written by the Medical Director as well as powerpoint presentations from what was dubbed the 'Consensus Conference' held in April 2016 in regards to relaxing the Irish MSM blood donor ban. Like Bennett (2009) researching the blood ban in the US, I too experienced the lack of historical documentation to be a frustrating challenge to the completion of this research. Mr Tonie Walsh of Ireland's Queer Archive has gone to significant lengths to gather an archive of the important moments in our queer history including the AIDS crisis, but there remains many oblique and unknown elements that structure this period, including the AIDS Quilts and implementation of a blood ban. If power can be said to produce history, then this discovery proves insightful for geographers for it reveals how the AIDS crisis, as with any form of public memory, is delimited by spatial absence. Geographer Kenneth E. Foote (1990: 82) in commenting on the role of the archive and collective memory, claims that the ability or effort of an institution to preserve a representation of the past is always specific to its institutional mandate and therefore the attempts to conceal or reveal aspects of our history, are often complicit with violent institutional agendas.

By way of conclusion, this chapter has detailed the research design that guided much of this research and has included among it, a reflection both of institutional ethnography, as well as its accompanying

methods; observation, interviews, and documentary sources. In particular, I suggested that conventional IE research needs to be expanded through a geographical imaginary of scale, power, embodiment and porosity. I also reflected on my own researcher positionality and the unexpected difficulties that can arise when acquiring participants. Though my research took many an unexpected turn, the subsequent chapters still demonstrate that my IE research was organically guided by following organisations involved in HIV/AIDS management in Ireland and it attempted to uncover how these organisations were either inducing or responded to, embodied precarity. The following chapters will now turn to consider how some of these various practices were brought into effect, both in the production of AIDS Quilts, as well the IBTS' control over blood donor services.

CHAPTER 4: PERFORMANCES OF PRECARITY IN IRELAND'S AIDS QUILTS

My engagements with Ireland's HIV/AIDS voluntary care organisations brought me to the margins of society where the emphasis was put on care, healing and creative innovations to educate the public about the crisis. The practice of AIDS quilting continually re-emerged as one of these important practices of memorializing the lives to the AIDS, and helping families deal with their grief. In the organisation; 'HIV Ireland' where I began conducting my archival fieldwork, one of Ireland's completed AIDS Quilts; the 'Quilt of Hope' completed as recent as 2013, was proudly and visibly hanging on display. The display consists of twenty- five brightly coloured hand-sewn panels that form a wall-mounted canvas of the lives and stories of people affected by HIV. ' On one of the afternoons that I visited, the Director of the Organisation encouraged me to interact and feel the Quilt, and as I stroked its felt panels, the organisation space suddenly seemed more than it initially appeared. Interacting with the panels was an intimate, if not invasive experience, as I fondled personal memorabilia and textual fragments of people I never knew, and indeed, would never know. While its bold but feminine shades allured me, resounding political statements towering above my head also addressed me. What had initially appeared as a soft, delicate and inviting piece of cloth, was now a device that was strong and self-assured in its political expression. Through interacting with the Quilts fibres, one is befallen with an invitation to participate in the spaces and places of those who were not only memorialized, but implicated in the process of its creation. It was through this experience of "personally seeing and touching th[e] panels", that the Quilt acquired new meaning, impacting the viewer's sensibilities on everything from "pedagogy", "politics" and "scholarship" (Morris, 2011: 299). Just as Morris would have expected, encountering an AIDS Quilt for the first time, rendered me deeply affected by its politicized aesthetics. It was only within and through such situated praxis that I could truly appreciate how its mnemonic properties performed a contextually specific experience of Ireland's AIDS crisis. In this chapter I reflect on the nature of these AIDS Quilts which were an important practice conducted by Ireland's HIV voluntary sector for memorializing lives lost to AIDS, and I consider some of the geographical tensions between scale, place and state that are performed by the Quilt.

4.1 BACKGROUND TO THE AIDS QUILT

The first AIDS Quilt, or what was to later become the NAMES Project, emerged at a crucial point of visibility during the US AIDS epidemic. At the height of the 1980s Reagan administration, AIDS had already begun to reach global epidemic proportions, yet its pattern of devastation was primarily visited upon gay men alone. From the onset of the epidemic, the gay community was shrouded in pervasive fear, stigmatization and shame. As prominent cultural critics Sturken (1997) and Hawkins (2002) have pointed out, early victims of AIDS deaths were not identified in obituaries, while gay friends and lovers were often excluded from participating in the funerals of the deceased. Forced to face the rapid erasure of their community alone, it became increasingly apparent that their capacity to grieve could no longer withstand the scale and extent of the epidemic. This was eloquently captured by AIDS Quilt activist Gini Spiersch who affirmed: “in your lifetime, you think you will have to bury a relative...or maybe there will be a freak accident. Who the hell would think you’d go to 15 funerals in 19 months?” (Ruskin, 1988: 11). Yet widespread homophobic discrimination was one of the many callous attitudes which characterised the domestic response to AIDS (Rand, 2007). It wasn't until May 31, 1987 that President Ronald Reagan, at the Third International Conference on AIDS, publicly muttered the word ‘AIDS’ for the first time, at which point over 21,000 lives had already been lost; a disproportionate number of whom were gay men, (Hawkins, 2002). And, if only to add insult to injury, his remarks that AIDS was America’s “public enemy number one” were voiced only in order to advocate regressive and discriminatory testing procedures (Rand, 2007: 659). As the ‘San Francisco AIDS Foundation’ have chronicled, the insouciant and neglectful response by authorities was undoubtedly exacerbated by a Federal Government who had in fact proposed an 11 per cent reduction in federal AIDS spending in the same period: from 95 million in 1985 to 85.5 million in 1986. Similarly, an inattention afforded to AIDS by American drug companies and medical institutions has, by now, been well documented (Patton; 1990; Hallet; 1997; Rand, 2007). It is unsurprising then, that early AIDS activism would conceive of providing a dignified public memorial for gay men, who, because of their sexuality, had been widely “viewed with revulsion and hatred” (Rand, 2007: 659).

It was during a protest against this revulsion, silence and inaction, that San Francisco’s gay community, led by activist Cleve Jones, conceived the idea of an AIDS Quilt (Sturken, 1997). Jones had asked participants at a demonstration to carry placards bearing the names of people who they knew had died of AIDS. When the names were posted on the wall of the San Francisco Federal building, the patch-work image resembled that of a quilt, (Sturken, 1997). While the first panel was completed by Cleve Jones in memory of his friend Harvey Milk, it was to subsequently catch on both regionally and internationally until being defined as a “national effort to create a hand sewn tribute to tens of thousands

of American's stricken down by AIDS", (Brown 1997; Ruskin,1988:7). Anyone can make a panel for someone who they knew has died of an AIDS related illness. One can even make a panel for an entire stranger who has died from AIDS (Brown, 1997). There are also no limits to the number of panels which can be completed for an individual. Once a panel has been completed, it is sent to a local chapter of the NAMES Project, who attach it to other 12 by 12 foot panels to form a Quilt for public display. Unlike a traditional head stone or a grave plot, panels come together to form a mobile memorial that is crafted through a collective practice, and in its completeness, it communicates a relationality made possible through the interaction of multiple bodies across space and scales. The Quilt made extensive use of what its founders called "traditional American symbolism" in an effort to "reach out to mainstream American hearts and pocketbooks", (Capozzola, 2002: 92). Jones himself recalled that there was a need to communicate to the public that AIDS was in fact; "a very American epidemic" and to do so through the medium of a quilt would be most effective given that "every family has a quilt." (Sturken (1997:191). Jones later added that because there was "nothing beautiful about AIDS...It does hideous things to people's bodies and minds", but the beauty, softness and vibrancy of a Quilt could begin to "touch people in a new and open way" (Ruskin, 1988: 18). Stories in the NAMES Quilt no longer become "stories of illness" in this sense, but instead become stories of "courage, fear, anger...and love" (Ruskin, 1988: 18). And perhaps the sentiment of the Quilt project is most eloquently captured by Cindy Ruskin's (1988: 3) in her foreword to the volume of Stories from the NAMES Project where she states: "the Quilt gives us our most direct feelings back, our feeling of belonging, our sense of the precariousness of life...it is a rare and intense experience of what it means to be human."

In 1987, the Quilt was publicly unveiled on the Capitol Lawn, Washington DC; the symbolic heart of America's national government. Consisting then of 1920 panels, a space larger than a football field, it commemorated over 16,488 lives lost to AIDS that same year (De Luca et al, 2007). Hawkins, (1993: 760) commenting on these six -by- three foot panels argues that when stitched into "measurements of a standard grave plot", the Quilt transformed the national mall into a national cemetery, bringing with it a transformation of private grief, into public loss. As Sturken (2007: 186) imagined; it is this very tension between "the Quilt as a massive project, versus the quilt as a product of intimate local communities" which forms a major part of its complex effect. Situated only moments from the White House, the Quilt occasioned a symbolic display of the lives disavowed by the Reagan administration and in so doing, addressed the need for an incorporation of these people with AIDS not simply into a public memorial, but into the very political structures to which they had been systematically removed. Today, as DeLuca et al (2007:630) have reviewed, the Quilt bears the names of roughly 83, 440 people and when laid out in its entirety, "weighs 54 tons" and "forms a 52.25 mile trail of fabric." It is for that reason that the NAMES Foundation (2016) have referred to it as the "largest piece of folk-art ever created." And according to Brouwer's (2007: 705), one of its immutable characteristics is its "promiscuous mobility" given that it circulates vigorously and endlessly across the globe; "always [being] on the road." By the late 1990s, in

addition to its traditional local site displays in America, the NAMES Quilt now has 40 international affiliate chapters from Japan to Uganda, Romania, to Ireland.

4.2 IRELAND'S VOLUNTARY SECTOR QUILT PROJECTS

The growth of Ireland's voluntary service provision, and the emergence of a fragmented system of Quilt projects, tended to reflect and follow the spatial distribution of the clinical manifestation of AIDS. Gay Health Action (GHA) was the first voluntary organisation to be established in Dublin 1985 as a direct response to the crisis. Staffed almost entirely by angered volunteers, its remit from the outset was to assist a national gay client base in counteracting prevailing misinformation about HIV/AIDS along with challenging the government's incoherent and ineffective response. With help from the 'Terrence Higgins Trust' in the UK, this group produced Ireland's first leaflet on AIDS which contained accurate information already made available in many countries such as the United States. Gay clubs and bars such as Bartley Dunnes and the Hirschfield Centre in Dublin were used as the spaces in which to operate and disseminate much of this material. According to Duffy (1993), in 1989 the results of a survey commissioned by the group to gauge its success proved that many of its client base were adapting their behaviour to safer forms of sex. The organisation were almost entirely reliant on donations however, some of which were secured from international bodies, and others from the general public. Nowlan (1986), in documenting the group's emergence in the Irish Times, shows that while the Health Education Bureau provided £800 towards the provision of the group's first leaflet, no direct grant had been provided by either the Department of Health or the Health Boards [later replaced by the national Health Service Executive] because of the criminalization of homosexuality. This was despite the fact that the organisation was the only one in the country to have made preventative education materials available. The GHA soon found itself having to respond to the needs of both haemophiliacs and drug users who were also badly affected by the epidemic, and as a result, its off-shoot organisation; 'Cairde' (meaning: friendship), was established in October 1985 as a befriending or 'buddy' programme to provide practical help and emotional support to all families and people who were seropositive. Cairde took its inspiration from the volunteers of the San Francisco 'Shanty Project' whose relational approach to care was premised on mentorship, home help, and practical support. Although Cairde was to subsequently change its focus to migrant health needs in 2003, some individuals who had trained with them during the crisis, later formed ACET – AIDS Care Education and Training, which, as a multi-denominational faith-based organisation, continues to provide practical care and support for all people living with HIV.

Another umbrella coalition of HIV/AIDS organisations which emerged in 1987 was the AIDS Action Alliance. This Alliance comprised of many activists who had pioneered Gay Health Action but additionally included affiliates such as the anonymous ‘AIDS Helpline’ and ‘Women and AIDS.’ It provided a range of services from counselling, testing, family support and advocacy. In 1988 the different groups were brought together as part of a national effort on information dissemination and by sharing a building and general facilities, the Alliance of HIV organisations were able to pool resources in an effort to provide a unified response to client needs (Smyth, 1999). In 1989 the Alliance secured 450,000 pounds as part of the national lottery scheme on the provision that their initiatives would take “a street approach...by outreach workers to educate them [at risk groups] about AIDS and encourage them to come for treatment.” (O’Loughlin, 1992: 1). It was in 1991 after the death of a Dublin gay man, that the first Irish NAMES Quilt was formed in conjunction with activists of Dublin AIDS Alliance. The Irish NAMES Quilt later became an official international chapter of the NAMES Project and subsequently toured Ireland and America with the Quilts. The Project shared the Dublin Alliance’s office space on O’Connell Street, while many of its volunteers likewise took part in workshops being organised and provided by both groups. The Quilt group were also able to use their fundraising connections with the organisation to advertise and promote themselves within local newspapers. What had initially started off as a small group of friends, family and volunteers, became a much larger national effort with the help of the Alliance, as more families became both affected by the crisis and aware of the project. Divergent interests, movement of employees, and the emergence of new AIDS cases in other parts of the country, led to the regionalisation of both the Alliance, and the Quilt projects in the late 1990s– hence the division of the Alliance into Dublin AIDS Alliance, Cork AIDS Alliance, AIDSWEST and so on. Cork AIDS Alliance [now Cork Sexual Health] have as part of their regional HIV prevention efforts, included a ‘Quilt of Hope’ (B) to enable young people from the city of Cork to creatively respond to the global issue of AIDS. Panels are smaller and contain any visual representations of the global AIDS epidemic which are believed to draw attention to the issue. While all constituent groups including the NAMES Quilt have maintained contact, these organisations now largely function as autonomous bodies and have all since been renamed or disbanded.

Voluntary organisations also developed during the 1990’s in response to intravenous drug use and HIV, such as Merchants Quay and the Anna Liffey Project, both of which privileged a harm reduction strategy that made available syringe-exchange and methadone maintenance programmes. In particular, the Rialto Community Drugs Team was established in 1992 in partnership with the Eastern Health Board and the Rialto Youth Project as part of a national ideological shift towards ‘outreach’ among local communities and which would later combine some operations with the national Aids Care Education and Training (ACET), to form the Rialto Community AIDS Quilt Project in 1993. Given the extent of AIDS deaths associated with IDU among particular communities such as Rialto, a quilt project was conceived which

would respond to the specificities of their own neighbourhood. Although the community of Rialto were aware of an Irish NAMES project, which, by this time, had been well established, they still sought to respond to the crisis through the creation of their own quilt; “I said [to them] there’s a national NAMES project quilt – and we’d been down to see it - and he said – we know that but the people wanted to start their first community quilt so that it wouldn’t go out of the area.” (interview with ‘Tina’ March 2016.) The NAMES Quilt often prides itself as one of the greatest international efforts in response to the AIDS crisis. It’s very success has been built on the premise of just that; taking AIDS beyond its immediate area to be showcased (inter)nationally in order to command political attention to the issue. Given its wide- – scale applicability, the NAMES Project also has, to a certain degree, claimed legitimacy as the appropriate and conventional way to memorialize lives lost to AIDS. We should therefore read the NAMES Project as the ‘spatial’ response to a spatialized epidemic, emulated through its appropriation of national spaces such as the Washington DC Mall and further circulated on an international scale. Yet what if this in itself was problematic? It’s antithesis, of course, is the community Quilt established in places such as Rialto which have consciously chosen to disregard with its scalar politics. For the community of Rialto, the transnational and even national circulation of panels was deemed to erode its political efficacy. This set of place-based Quilt projects will be discussed in more detail later in this chapter.

As mentioned previously in relation to Ireland’s National AIDS Strategy Commission, the voluntary sector and its members have been overwhelmingly represented in the Education and Prevention sub-committee that, to date, has typically received the least policy implementations or government funding. Being co-opted onto such structures often involves a Faustian Pact for many; to become officially represented and receive governmental funding, often means having to stay silent on matters of interest and having to largely accept the normative approach promulgated by governing authorities. Of the main quilting groups that I met with, only one was to have an affiliate organisation represented on the Education and Prevention sub-committee – that being, the Irish NAMES Quilt with the Dublin AIDS Alliance [now HIV Ireland]. See Table 3 below for more details. Other quilting groups and their associated organisations have no representation on the Commission, which is indicative, at least in policy terms, that the community and therapeutic work of quilting groups is deemed to be of less critical value and insight in the prevention against disease.

Open Heart House was another HIV/AIDS voluntary organisation that had been established in the late 1990s, as a support group for people living with HIV. As part of their programmes, the organisation provided 17,000 meals a day, provided education resources and a place where HIV positive people could go and discuss confidentially issues affecting them. Between 2012 and 2013 the organisation ran a Quilt project specifically for women living with HIV in Ireland in order to highlight and overcome issues

specifically affecting women living with the virus. Inspired by the NAMES memorial quilt of 1987, but attempting to move away from a focus on loss and grief, the purpose of the ‘Quilt of Hope’ (A)* was to inspire the women’s aspirations and dreams (Gilmore, 2013). Taking the decision to close it’s doors in 2014 came as a shock to many, who had sought it out as a place of refuge to simply “gather, meet and chat.” (Open Heart House Press Release, 2013). Yet it was noted in a statement by the Board of Directors that there was a significant drop in the number of people availing of the services not least because of the advances in ARV medical care, but also due to the harsh economic climate and lack of (financial) support from the State sector. Since its closure, HIV Ireland have acted as stewards of the Quilt of Hope (A). At present, the Rialto Community Quilt Group along with Cork’s Quilt of Hope B* continue to function for their intended purpose, while all other projects have either ceased or have significantly changed since the AIDS crisis.

Quilt Project	Associated Organisation	Main Client Group	Location	Dates of Operation
Irish NAMES Memorial Quilt	AIDS Alliance with NAMES Project Foundation	Mixed – but predominantly gay men	Nationwide	1991 – No longer in Operation
Rialto Community AIDS Quilt	Rialto Community Drugs Team with AIDS Care Education and Training (ACET)	Mixed - but predominantly Intravenous Drug Users	Rialto and Dolphins Barn Dublin 8 and Dublin 9	1993 – Present Still in Operation.
Quilt of Hope (A)*	Open Heart House	HIV Positive Women	Dublin 1	2012- 2013 - No Longer in Operation
Quilt of Hope (B)*	Alliance Sexual Health Centre Cork	HIV Positive and HIV Negative Youth (18-25) from Cork City	Cork	1998 – Present Still in Operation

Table 3. Ireland’s AIDS Quilt Projects and Associated Voluntary Organisations. Produced by Author.

4.3 NAMING SHAMING AND THE ‘STATE’ OF STIGMATISATION

I begin my discussion where the practice of Ireland’s AIDS Quilting all began; with Joe Carthy and the Irish NAMES Project. I question here, what the practice of AIDS quilting has looked like in a country predominated with teachings of the Catholic Church and marred with an environment of stigma. The ‘NAMES QUILT’ was pioneered by volunteers from the Dublin AIDS Alliance (now HIV Ireland) in 1991, and, in comparison to its production in North America, this Quilt embodies and reflects the scale of Ireland’s homosexual repudiation, and AIDS-related stigmatisation that characterised Ireland’s response to the crisis. Reflecting on the Irish NAMES Projects’ humble beginnings, Founder Mary Shannon recalls:

“We had a family friend - ‘Joe Carthy’ who was a gay chap that used to babysit for us when the kids were only babies. Oh he was brilliant! He was always spending time in our house with the kids. He was like my right-hand man! But then when he tested positive, he was straight off to England... He came back a little while later when he got really sick you see, and he had this friend who had gone to San Francisco a few years earlier, who came back home to see him. And it was him who brought [with him] this book about the American NAMES Project. And I just thought: what a brilliant way to remember someone... I didn’t want Joe to be forgotten...so a few of us got together with the support of Dublin AIDS Alliance and that’s how it all began.” (Shannon Interview March 2016)

Settling into our interview about the Irish NAMES Project, its significance as an opportunity to recount the lives and stories of gay men who had died of AIDS, became abundantly clear. Indeed, at nearly every point in our interview, questions about the history and specificity of the Project, reverted back to the lives that the Quilt had memorialized. Having brought one of the original Quilts with her, and proudly unfurling it on the floor before us, Mary confessed: “As soon as I get going on the Quilt there’s no stopping me – you see people say to me, sure you’re well used to taking it out by now. But every time I take it out, it brings back so many memories.” Despite me naively expecting this emphasis to be a distraction from information I ‘really needed’, it became increasingly apparent that sharing the Quilt panels with me, and recounting the lives and stories of those memorialized, was of utmost importance to Mary for narrating the projects history. Mary had helped to make many of the panels herself, and where she hadn’t, she was still aware of nearly all the panel stories. In this way, her own time and emotional energy was invested not only into the artwork, but into the very lives that the quilt had memorialized. During the time that Mary got involved, as she recalled, there was “nothing you could do about it – there were none of these triple therapies”, as she reminded me. Facilitating with a family’s grief through the crafting of a quilt panel was one of the ways in which Mary intended to keep herself active as a voluntary care worker with this important issue.

So we walked around the Quilt. And together, we stopped to momentarily reflect on several panels which had particular salience for her memories of the project. “This is Joe” Mary announced, as she brought me closer to the friend and babysitter that had inspired it all. The *Irish Press* (1990:22) affirmed that at the “fragile age of only 29” Joe Carthy, a gay man from inner city Dublin was “the first name to receive dedication of an Irish Quilt.” Holmquist (1990: 3) writing in the *Irish Times* about Joe’s “brave and painful battle with AIDS” claims that Joe had decided to “quit life” after his three year battle with the disease. He was apparently “fed up with medical intervention needed every time he got an opportunistic infection” and “AZT [had] only caused him painful side effects.” Kneeling down to get a better view of the panel, one is immediately struck by the name ‘JOE CARTHY’ spelled out in large colourful lettering, against a pastel pink background. The message is simple, but nevertheless refuses to be timid. In its bold clarity, it leaves no mistaking for the viewer that his most personal feature - his name – be proudly positioned as the centrepiece of his display. All the letters are appliqued with different materials, and objects, but the letter ‘J’ is perhaps the most intriguing and visually stimulating of all. It is embellished not only with an array of false eyelashes, but with a diamante earring which he wore, “just to annoy people”, according to his friend Ann Marie Jones, in the *Irish Times*, (Holmquist, 1990: 13).

Eager to provide me with more context for its flashy lettering, Mary explained that the different letters were handed out to friends whose names began with those same letters, with the idea that “all of them would be brought back in different ways.” Letters in his name thus became conduits for illustrating a life as his friends would have remembered him. In this way, their individual input was brought together to form a fitting tribute for a life that was, as Mary recalls, truly composed of, and enriched by, his friends. One could even go so far as to suggest that this practice was an effort to emulate the dispersed nature of his friendship network itself. Joe had “loads of friends – some here [in Dublin], but he knew chaps in England and America” Mary recalls. In this spirit, the love and care that was shown by the transnational gay community to which he was a part, is poured into the material fragments of his remains. And while Joe’s panel remains spatially fixed within the city of Dublin - the place of his hometown – it has nonetheless been composed by and through a geographically expansive activity of scattered craftsmanship. In this sense, Joe is thus made symbolically ‘complete’ by his scattered loved ones.

Elsewhere within the frame of Joe’s panel is a three-dimensional stitched saucer, a children’s book to reflect his time spent babysitting, and an embossed handwritten note composed by a friend. The personal note reveals some reflections about the panel itself: “It is wonderful. I know you would love it. All

feathers and sequins, bright colours...in my opinion, [it] reminds me of you.” (Holmquist, 1990). Letters and personal notes are an interesting addition to the panels as they enable a temporary dismantling of spatio-temporal boundaries, so that the dead “may be continually addressed by the living” (Junge, 1999: 196). Gauging my reaction as I sat and read the note, Mary reminisced that Joe “loved to dress up.” He was “always putting on those girly tutus and dancing all over the house.” We are thus given the impression from Mary’s narrative, along with subtle hints provided in the note, that Joe had a personality that was indeed camp, colourful and fun. As Hawkins (1993: 764) writes, despite the enormous grief that attends a Quilt panel, tackiness and camp can still play an “irrepressible role” by enabling the “carnival [to] interrupt the wake.”

But apart from his name and the limited items mentioned above, Joe’s panel is noticeably bare. This suggests that while undoubtedly there is a story about Joe to be told, perhaps its simplistic elegance is an attempt to in fact conceal more than what would have been initially desirable to display. Concealment is made all the more evident in Holmquist’s (1990:13) *Irish Times* report on the Quilt, where she finds that “Joe knew he had AIDS for about two years before he told his parents in October 1989.” The report adds that: “mother and son never talked about how Joe actually became infected with HIV and did not feel it was necessary.” Perhaps more strikingly, there is nothing within Joe’s panel that is suggestive of a direct contribution by Joe’s parents, apart from signatures of Gay Byrne and Sean Kelly - references to a television appearance made by Joe’s parents on RTE’s ‘The Late Late Show’ in 1990. But, Mary is eager to remind us of another side to this ambiguous relationship to grief: “They adored him,” she stressed: “It was really difficult for them when – it happened.... But they were very brave and they did make an effort to speak openly about him.” An *Irish Times* interview with Joe’s father; Arthur Carthy, was to suitably capture this strained “effort to speak”, as he states clearly: “if we [as his parents are to] run away and hide, we force other people to do the same thing.” (Browne 1991: 3). The tenuous sense of grief and shame which surrounded Joe Carthy’s death renders his panel all the more politically salient in the context of Ireland’s AIDS crisis. And while his panel remains an indisputably significant artefact for his immediate family and friends, it also reveals important insights into the generality of homosexual repudiation and AIDS stigmatisation during the crisis.



Figure 2: Irish NAMES Quilt Panels: A second quilt panel completed for Joe Carthy by Mary Shannon's children, seen here alongside Philip, Brian, Grace and Limerick City's panels. Photo taken by Researcher.

Names are typically included on an AIDS Quilt, and for good reason. A name is a boundary-making technology. Because it individualizes, it enables us to set people apart in an effort to remember them (Junge, 1999). A quick scan of the American digitised NAMES Quilt shows that the name always remains a constant, but apart from this, there are no rules governing a panels' creation and no criteria as to the various assortments and arrangements of personal items which can be used (Browne, 1997). It is through the name first and foremost, that the panel is truly able to "bear witness to the details of a life" (Junge, 1999: 196). Hawkins (1993: 752) has even claimed that naming assumes a central role in the act of memory. It is in the aftermath of personal loss, he argues, that a common component of the grieving process is the "reiteration of a name" in an effort to almost "summon a person back." To prevent that 'summoning' voice from ceasing, names are written down (Hawkins, 1993). Embossing a panel with a name and personal items thus preserves their presence in a way, by enabling them to 'live on' and have the 'final word' in the face of death (Hawkins, 1993). Names are also capable of narrating what Junge (1999: 198) has referred to as a "history that has been taboo." As something which is often expressly verbalised during sexual acts, one can assume that in an environment marked by homosexual non-disclosure, 'releasing' a name, and stating it clearly on an AIDS Quilt, may induce a cathartic effect for the Quilter, becoming both an embodied act of sexual liberation and political defiance.

But naming not only bears a personal significance for families and lovers in this way. Scholars have additionally noted that once a name is stated and written down, “private grief is transformed into public loss”,(Hawkins, 1993: 765). Cleve Jones stipulated that his own motivation for the quilt was to produce public evidence of a “collective body count” in the face of a “lost generation” (Hawkins, 1993). It occurred to Jones that if the first 1000 corpses of the San Francisco AIDS crisis had been collectively laid out in a field, people would have noticed the extent of this loss, and responded accordingly. But with “death hidden behind closed doors” he felt that “we could all die without really knowing.” (Cleve Jones interview with Frontline, 2006). Both Sturken (1997: 159) and Ruskin (1988: 78) are adamant that being part of a collective of individuals enabled quilters to effectively ‘write against’ the secrecy and shame which they experienced. These spatio-political tensions in the Quilt are also evident in Ireland; a report from the *Irish Examiner* (1994: 3) found that “the quilt acts as a reminder of the individuality of the people who are affected by the virus,.” while the City Tribune (1994: 39) alternatively proposed that: “much more than statistics ever could, the Quilt reminds us of the enormity of the epidemic.” The Quilt also performs “a roll call of the dead” that has a similar rhetorical function to the Vietnam memorial wall of names which functions as a form of public ‘testimony’ that this person was in fact ‘here.’(Hawkins, 1993; Junge, 1999; Blair and Michel 2007). The name is therefore indispensable for engendering a recognition of, and national remembrance *for* the deceased.

Despite this however, some scholars have debated the ways in which the act of mourning depoliticizes the AIDS quilt. Famous LGBT rights activist and cultural critic, Larry Kramer, has for example, suggested that mourning merely entraps subjects into selfish and unproductive channels redirecting attention away from more urgent forms of AIDS activism (Brown, 1997). I argue however from a distinctly Butlerian reading of the Quilt, that mourning may not be at odds with activism. In fact, there is something both political, worthwhile and indeed ethically *necessary* in the act of mourning. Judith Butler (2014) questions what, politically, can be made of grief, or essentially, how can we stay with grief to harness productive, as opposed to injurious behaviour on the other. McIvor (2012) explicates Butler’s approach to mourning and grief by proposing that her concept of mourning has a split orientation. McIvor (2012) argues that mourning, for Butler, operates as both an effective means of mobilizing rage against existing discursive powers while simultaneously involving an ethical responsiveness to the other and avowing precarious life. This ethico-political dualism inherent in the performative act of mourning is what makes it so powerful in reconstituting our realities and shifting the discursive norms that constitute us. Grief then, becomes the ultimate political act, as opposed to a private solitary emotion. Returning to Antigone to illustrate the important dualistic power of mourning; this figure demonstrates how acknowledging and grieving ‘bare life’ enables us to shift discursive and violent norms which constitute us and define what it is to be human. Ostensibly then, for Butler (2000:58), Antigone is exemplary for in making “the unspeakable heard

through borrowing and exploiting the very terms that are meant to enforce its silence.” But McIvor (2012) maintains that mourning also has significant ethical as well as political potential. Mourning is not simply about registering the loss of another, but, more importantly, it is about yielding to the unwanted transformation of the ‘self’ where neither “the full shape nor the full import of that transformation can be known in advance” (Butler, 2014: unpaginated). In loss, or essentially, in the dispossession of another or of a place, we become aware that we have lost that part of ourselves which was composed of by the ‘you’ and this uncertainty, the element of ourselves which we do not fully know, precisely reflects the anonymous foreignness of the other which comprises the self. For Butler (2003), this precious decentering and disorientation of the self during grief brings with it an ethical responsibility and an opportunity for political justice. Prominent cultural critic Douglas Crimp (1989) argues in ‘Mourning and Militancy’ that the violence that ‘is’ the AIDS crisis, is found not only in state murder, but in the systematic prevention of proper mourning and remembrance. Mourning, he describes, has been met with suspicion among members of the gay community, but having been swiftly replaced with militant action, has become merely melancholic and harmful towards gay men for signalling a denial of reality and loss of community. He calls for an activism which incorporates both mourning and militancy, which, I would additionally argue, extends to the role of AIDS artwork itself. In the online ‘Visual Aids’ database, (2017) Crimp (1989) is cited as tasking artists to champion an aesthetical “call to arms” which, through their visual representations of the crisis, can draw attention to the state’s violent homophobia. Explicit messages and depictions such as the double entendre of “bring my fucking friends back” serve as provocative pieces which, in his words, not only “transgress the epidemic” but incite the state to put a rapid end to it. Names, faces and political messages function as the paradigmatic ‘call to peace’ of the AIDS crisis, and in this way, their inclusion on the quilt is essential in order for lives to be avowed and for the transformative potential of mourning to begin (Visual AIDS 2016).

Naming an Irish AIDS Quilt, however, would appear as anything but a straightforward matter. Joe Carthy was the first gay man in Ireland, and indeed one of only two people on the island of Ireland, to use a full name on the Quilt, (Power, 1991). Writing on the emergence of the Irish NAMES Project in 1991, Power (1991: 7) recalls that a total of only “14 panels have been completed in Ireland but only two bear both the Christian and surnames of the AIDS victims.” It was not uncommon at the height of the AIDS crisis for battles to ensue between families and lovers over the refusal to accept their loved one’s lifestyle, or fear that they would acquire homosexual shame by association, (Sturken, 1993). Out of the many panels produced in Ireland, Joe Carthy’s is thus an exception to the rule: it was one of “rare acknowledgement” of the reality of AIDS and homosexuality (Browne, 1991: 3). This “special form of coming out,” characteristic of Joe’s panel, is emblematic of a ‘risk aesthetics’ whereby acknowledging oneself as having the disease, meant having to risk “griev[ing] alone, worrying about the loss of a job, insurance or personal relationships” (Ruskin, 1988:). A press release by Gay Health Action dating from 24th February

1986, voices these fears that without any “anti-discrimination law” in Ireland, confidentiality and anonymity of HIV testing cannot be safeguarded and hence “people who are antibody positive, [would] be discriminated against in housing, employment, health, life assurance and social contacts.” It is no wonder that Browne (1991:3), documenting the Irish AIDS Quilt in the *Irish Times* has remarked that for any AIDS Quilt to begin, “you need to have very brave people to stand up and say that their loved ones died of AIDS, and it’s very difficult to be the first one.” Joe’s panel is indeed a panel of firsts. Not only was it the first of a series of panels to be made for AIDS victims in Ireland, but was undeniably the first to demonstrate openness about a non-normative lifestyle in an environment characterised by its illegality and repudiation.

Given the extent of the moralization and religious influence of the country, many members from Ireland’s HIV/AIDS organisations spoke of Ireland’s stigmatisation being of a much greater scale and extent than could be experienced in the US. This was illustrated best from when the NAMES Quilt was taken beyond Ireland’s borders and was showcased among those from other locations in the traditional display in Washington DC 1996:

*“People in America couldn’t believe that we had AIDS in Ireland. It was like – What?! Holy Catholic Ireland has AIDS?! People just couldn’t believe it. I tell you we were like film-stars, we were never interviewed here [in Ireland] – no one was bothered - but when we took the Quilt to America, we were interviewed left, right and centre. We had every camera, every television station on us. And we would wear our t-shirts with the map of Ireland, and our badge with the Irish NAMES Quilt. I remember one reporter came up to me and said: “But you’re wearing your cross? [*pointing to the Crucifix]* – it was just this really old cross and chain my husband had bought for me long and ever ago- And I said, So? - What difference should that make? What I’m doing here should have nothing to do with my Church...”*

Given the pervasive influence of the Catholic Church, US AIDS activists believed that being homosexual or acquiring AIDS in Ireland ran not only contrary to Catholicism, but contrary to the very ‘essence’ of Irishness itself. Such comments would support the claim that the existence of AIDS in Ireland was not only morally reprehensible, but in fact not ‘Irish’ at all. The erasure, silence and denial of the crisis in Ireland has produced non-normative Irish figures to appear in discord with their own homeland. This sentiment is affirmed in Conrad’s (2001) ‘Queer Treasons’ where she argues that homosexuality is produced as the sexual and cultural limits of ‘Irishness.’ She isolates two pivotal events; namely Roger Casement (Irish Republican icon) and the seizure of his ‘Black Diaries’ which detailed his homosexual activity, and the exclusion of the Irish Lesbian Gay Organization New York, from the New York City St Patrick’s Day parade, as examples which have rendered homosexuality (and arguably AIDS) as a ‘foreign’ discourse, that is simply incompatible with a geographically emplaced Irish nationalism.

The impact which this would have upon the Quilt Group was by no means insignificant. Frank Mills, Chairperson of the Irish Quilt Tour, reflecting on the Project's attempts to gain official sponsorship and funding, confirmed to the Irish Press in 1991 that Irish companies refused to sponsor the Quilt or any other major AIDS awareness event because they were "unwilling to associate their names with the deadly disease" (Buckley, 1991: 17). While the Quilt group did successfully conduct a six-city tour of Ireland between January and February 1991, raising 20,000 pounds for AIDS awareness projects, the majority of company donations were made on "conditions of anonymity" (Buckley, 1991:17). My interviews with Irish AIDS Quilters supported this claim, that the greatest "regret" they faced throughout the Project, was the lack of national funding and support by the national government:

"I laughed once because they sent us a cheque of 10,000 pounds – not for the Quilt Group but for the organisation - and I just thought – yeah – that has to be for 1000 pounds. And I was very honest! I rang them up – and the guy on the other said – wohhhhh – someone put in an extra digit! – we're only giving you 1000 they said."(Interviewee1B March 2016)

"Well homosexuality was illegal at the time, so the government was often reluctant to be seen supporting anything that promoted it...."(Interviewee1C May 2016).

When we started out with the Alliance, they didn't want to know. We had to practically beg for money. They knew everything. We knew nothing. There was once we had to actually close up – now it was only for a few days and we reopened again - but we had to actually close because they wouldn't give us anything.

So yeah- the government didn't want to know anything about it, the health services didn't want to know anything about it. There was some collaboration there between the authorities and the alliance – but with us? – No. Unless there was something big on, like the Mansion House opening where they would be seen. Because AIDS was something that did attract the press at that time you know, so they would be at those things, but generally, they didn't want to know. Like I remember we had a photo call in the Parliament buildings when we were getting ready to set off for America to display the Quilts – and the government were very happy to wave us off, but they didn't give us any money for it. We had to do it all on our own bat. (Mary Shannon - Interviewee1A March 2016)

The belief was therefore that AIDS should only be treated only by medical establishments, with voluntary organisations and their AIDS quilting being a marginalised form of care provision. Documentary footage produced by and for the Rialto Community AIDS Quilting group illustrates a similar stigmatizing response which the Quilt elicited from the general public in greater Dublin. Standing outside Crumlin Shopping Centre after a day of fundraising, the group deliberate on the pervasive stigma which they have just experienced: "the minute we arrived in the shopping centre we felt under pressure." "The manager didn't want to know. He wouldn't let us film. He wouldn't let us hang the Quilt. ...I think it's the nature of the collections and what we're collecting for" one of the volunteers interjects. "I felt a real stigma this morning. It was even a bit worse than last year. Last year we could say it was Irish AIDS Day, but we just couldn't even say anything today." (Rialto Community Quilt Group DVD, 1993) The feelings of shame

associated with their efforts would appear to stand in marked contrast to the generosity that was bestowed on the American NAMES Quilt when it first established roots in San Francisco: “There is no other neighbourhood that has been so generous – local merchants paid \$2000 for the Projects’ first month rent. The storefronts previous tenants provided track lighting. Someone else left a gift of 500 dollars in the donation box.” (Ruskin, 1988:132) Additionally, Brown’s (1997) analysis of the NAMES Quilt’s fundraising activities in Vancouver Canada, suggests that there were little difficulties encountered by the Tour group as they successfully raised over 40,000 Canadian dollars for national AIDS efforts.

This wide-scale homosexual occlusion and denial which resulted in extensive discrimination, has also been materially embodied, and embedded, within smaller scale frames of the Quilt panels themselves. To illustrate this point, Mary contrasted Joe’s panel to that of a man named ‘Philip’ - an “Irish celebrity” whose family made plain to the Irish NAMES Quilt that his panel was to remain “totally anonymous.” While ‘Philip’ can be seen in black lettering running diagonally across a colourful striped background, revealingly, his panel bears no personal fragments or memorabilia which could later connect him back to the Quilt. We do not know how Philip acquired AIDS because, as Mary attests; “if they didn’t tell us, we didn’t ask”, but the “double-life” of Ireland’s hidden homosexuality, is unambiguous in a separate anonymous panel completed by a local woman known only as: “Anne,” for her husband lost to AIDS. Known as a “pillar of the [local] community,” Anne reports in the *Irish Times* that her husband was a “gay man who continuously refused to agree to a separation” and given his closeted sexuality, Anne’s desire was to craft a panel that would keep his profile anonymous, while creating “two faces on it” (Browne, 1991: 3).

Anonymity and the nature of closeted Irish gay life was a matter continually contested in the formation and display of AIDS quilts, enabling the nation to effectively mourn the loss of these men. Ger Philpott, notable Irish film and TV producer; whose own panel for former lover and four year partner ‘Paul’ – the very first man to die of AIDS in Ireland in 1983, found itself in the grip of disputes over anonymity. Writing about his turbulent relationship with Paul in his personal memoir, *Deep End,* Philpott expostulates over the desire of gay men to stay closeted: “they spend a lifetime denying their sexuality. To cover up for the double lives they lead. I can understand why; given the society we live in. [But] it’s insulting to people who are out.” (Philpott, 1995: 101). Nearly a decade after his demise, Philpott became aware of, and involved with the NAMES Quilt project in the Dublin AIDS Alliance, and sought to make a panel in Paul’s honour that would be open and proud of his sexuality. As the NAMES Project team prepared for its first All-Ireland NAMES Quilt Tour in 1991 which at that time consisted of fourteen panels, Philpott settled on a panel with a simplistic but elegant style that included Paul’s name, date of death and a pertinent political message previously stated by Paul himself: “change a little and a lot can

happen.” Philpott (1995: 86). While undoubtedly this statement had its own personal story for Paul, Again, in contrast to Joe Carthy’s panel, Paul’s is emblematic of what can happen in Irish society when a politically charged panel is caught between a lover’s need to grieve, and the sense of societal shame: “His family objected to the panel and wanted it removed” he writes (Philpott, 1995: 159). In order to prevent the panel from being publicly displayed as part of Ireland’s Quilt Tour, Paul’s elder brother [Denny] telephoned Ger Philpott to caution him that “mother is very unhappy about the panel.” And, at one point, the breakdown in relations had escalated to a point where Philpott (20151995: 158) adds, that “Paul’s elder brother had even threatened to take me to court.” Evidence suggests that because of the visibility that was being brought to this collective through the Quilt tour, members of the Project committee were encouraging Quilters where possible, to include family names and for this reason, Philpott decided not to have the panel or its full name removed from the tour, on the premise that it “would have [only] generated the wrong type of publicity for the family.” Over my dead body! He proudly proclaims. “They can’t rob me of this expression of my grief” (Philpott, 1995: 159). Yet at times however, the decision to occlude a name and conceal one’s identity, rather surprisingly came from the voluntary HIV/AIDS workers themselves. As ‘Tina’ one of the volunteers working with the ACET Organisation’s quilting practice recalls:

*Because I’m the coordinator, I have to make sure people don’t tell their personal stories. I was offered big pay by the media –but you have to hold people back from this – they think everyone wants to hear this stuff and I’m saying ‘hold on now – they can hear part of the story but not the full story.’ You have to think of future generations. People don’t want to see Granny’s AIDS panel in the local newspaper....
(Interviewee1C, March 2016).*

An ‘understanding’ was often required to be reached with the families in exchange for participating in the Quilt project, something which was also reiterated in conversation with Dublin AIDS Alliance activist and Quilt founded; Mary Shannon:

“We always got family permission to use the name....but we did have a lot of panels without names or panels to remember several anonymous lives...We’d just have to say- that was fine. – They didn’t have to use a name. We would always do the panel whatever way the families wanted.” (Shannon interview March 2016)

Despite the evident tensions, it would appear that the heteronormative familial kinship bonds of traditional Irish life, were privileged first and foremost in the practice of memorializing men lost to AIDS. Given that the majority of Ireland’s quilt panels were produced by families as opposed to lovers, it was the families who were deemed to be the guardians over the panels and what was appropriate first and foremost. Hence heteronormative values were often privileged over the kinship communities created and sustained by queer men. Taking the decision to withhold a name was also often done in order to protect members of the heteronormative *families*, rather than attending to the grief of gay lovers.

The same can be said for Ireland's most recently completed HIV/AIDS Quilt Project -the 'Quilt of Hope' (B) that was carried out by the voluntary organisation 'Open Heart House' in Dublin, 2013 for women living with HIV, as can be seen from Figure 2 below. Though I was unable to meet with any of the Quilt creators, we can see in brief from the panels themselves that among many other factors, they are explicitly political which is evident in their relationality; "AIDS is not an illness" as one reads, and which is joined by another panel underneath stating; "But a stimulant of Life." Where bodies feel unable to meet and speak, the potentialities of the artwork perform and fulfil much of this function instead. Their assertive political demands directly call our attention to the widespread stigma which these bodies have acutely felt; "there is more to me than HIV" as one of the panels reads. Quilters desire to make visible their experiences of stigma and voice this as one of their main political concerns, but we can only discern that their way of comfortably expressing this, is to be metaphorically 'hidden' behind its cloth. In this way, while the artwork is an extension of the Self, the women continue to collectively speak from a vantage point of safety. Without the 'risk aesthetics' and political urgency that is associated with their exposure, their venture is unlikely however, to directly challenge or change the status quo. In the only newspaper article to have covered the Quilt of Hope, one of the quilters in interview with Cashion (2013) comments upon her regret in withholding her name: "I would love to be able to give you a photograph of myself and say: This is Sandra and she has HIV, but I'm still hiding behind this wall of shame and guilt that doesn't belong to me." "I can't come forward because society will not accept me. Society will punish me for doing that and my family will get the backlash." Of course, we cannot simply blame Quilters when it is "society [who] makes outcasts of people suffering with aids" (Ruskin, 1988: 101). But as Brown (1997) reminds us, the Quilt project simply cannot succeed as a space to work through grief and mourning, when marred by an environment of stigma.



Figure 3: Quilt of Hope (A) – completed by women in ‘Open Heart House’, now stored in the basement of ‘HIV Ireland’. Photo taken by Researcher.

Revealingly, only a handful of anonymous panels have appeared as an anomaly to the original US NAMES Project, so much so that they are often afforded with an analysis in their own right. In Ireland however, maintaining anonymity was so commonplace, that it merely became a normative and standardised feature of the Quilt. To be part of an AIDS memorial in Ireland, was to become nothing more than a nebulous abstraction concealed in the very fibres of the Quilt itself. Browne (1991:3) has indicated that while “American quilt panels testify to an empowered gay community which has “come out,” the anonymity of most Irish panels may reflect hidden, double lives– the shame of homosexuality, of drug use and of AIDS.” And as Irish AIDS activist Jeanette Kojijane has asserted; “a project like the Quilt,

complete with names is more feasible in America. In large [American] gay communities, many people had made a break from their families and that break, and that strength, gave the friends and lovers the moral authority to invite families in to help with quilt making.” (Browne, 1991:3). That necessary space in Ireland to cultivate a break from the close-knit familial community life, particularly one that was controlled by, and infused with Catholicism, proved to be entirely absent.

For Erin Rand, (2007), the legacy of the American AIDS Quilt, is that of a “mourned subject position.” This is a useful term, and while it is not my intention to dispute it, merely I wish to qualify it within the context of Ireland. Rand (2007) suggests that the United States’ ambivalent reaction to gay men in the late 1980s together with the State’s repeated commemoration of the NAMES Project, has produced a specific subject- positioning of gay men vis-à-vis the nation. This ‘mourned subject position’ which she has termed, is importantly, “not self-fashioned by those who occupy it” but only “becomes intelligible through a national discourse about AIDS and homosexuality” (Rand, 2007: 656). In other words, gay men only become politically recognizable subjects through the nation’s ritualized act of mourning. Drawing on Butler’s theories of subjectivation, she claims that gay men have become the cathexed object of the nation, and are therefore unable to simply refuse or deny this position, as to do so, would be to deny their very existence. While Rand (2007) argues that this subject positioning disarticulates a more liberatory potential achieved only through militant activism, she still acknowledges that being constituted as a mourned subject has in fact had some “enabling” qualities insofar as it grants “visibility, identification and recognition” of the subject, (Rand, 2007: 665).

The AIDS Quilt should thus be read as the material trace of this subject positioning and through its repeated commemoration, the ‘mourned subject’ is resurrected and sustained. Importantly for Rand (2007), recognition and visibility copper -fastened by the Quilt’s rhetorical qualities, would not have been made possible without the adoption of panel names. She states clearly that: “if those included in the Quilt have already been named and remembered, what incites us now to name and remember the means of their memorial? It is precisely the state’s impulse for a “repeated remembrance” of the ‘names’ within the NAMES project, that, she argues, has solidified a responsive, (albeit conservative), mourned subject position. Crucially, Rand’s argument rests on a presupposition that gay men who have come to acquire and occupy a ‘mourned subject position’ have in fact had their names incorporated into the quilt. But, as Sturken (1997: 189) has correctly pointed out, while America may have had little difficulty naming the deceased, given that only “10% of names were fully or partially withheld from quilts in the 1980s” (continuing to an even smaller number in the 1990s), in Ireland we know that that figure in fact stands somewhat closer to 80% (Power, 1991). If each panel functions as a graphic biography of sorts, then one

can reasonably assume that anonymity occludes an individual's life from being fully remembered. And, if we are to accept Rand's word at face value, the Irish NAMES Quilt fails in its ability to produce a mourned subject as it denies the face behind the disease and presents no discernible memorabilia for us to connect with or relate to. As such, Ireland's AIDS Projects are unable to truly solidify and collectivize loss experienced by the nation, which is needed for the transformative potentialities of grief to be realized. Refusal to name is likewise refusal to give testimony to a life. But one could go further still; by withholding a name and identity, the Irish NAMES project becomes an unwitting participant in a cultural performance of homosexual melancholia and shame.

4.4 QUILTING AND THE QUEER DIASPORA

Ireland's melancholic response to homosexuality, and the Queer diaspora which it produced, is also depicted in the geographical formations of the NAMES Quilt. Recall that Mary's earlier references were to a Quilt project that had been largely conceived within and through Joe Carthy's queer diasporic kinship. 'HIV Ireland' revealed that many of its efforts at addressing the AIDS crisis had been inadvertently hampered by the extent of gay male volunteers or activists that were emigrating during the AIDS crisis. Mary drew my attention next to another panel placed directly under that of Joe's, this time for a man named 'Brian' from Cork, who died of AIDS in England. Unlike many of the family's panels mentioned above, it was Brian's partner, also from England who completed his memorial panel:

*"Brian and his partner were living in England you see – they had jobs with Aer Lingus– they were trolley-dollies the two of them – See the planes here? [*Indicating towards the Panel] - these were just some of the ways his partner wanted him to be remembered." (Interviewee1A- Mary Shannon).*

As the national air- carrier founded by the Government in 1936 to provide air services between Ireland and the UK, Aer Lingus and its shamrocks have become iconic symbols of 'Irishness' around the globe. In Brian's panel, these planes are depicted as neither taking off from, nor indeed approaching, any particular country. Instead, they are airborne, and flying gracefully side by side against a plain white backdrop. One could interpret this as Brian and his lover's' relationship having reached 'new heights' while suspended outside or beyond the borders of Ireland. And indeed it is not simply the Aer Lingus planes which depict these themes of journeying, love and power, but another automobile which catches the viewer's eye; that of a great black steam train. In the right hand corner of Brian's panel (seen in Figure 1) the front and side of a large steam train can be seen nearing the viewers' gaze. The train is in motion, and appears as if almost ready to run right off the panel. According to Mary, it depicts Brian's domestic travels from Dublin to Cork. Having been born and raised in rural Ireland, Brian would ride the train after his stint in England, where he would retreat to his aunt's house for her infamous toasted cheese sandwiches. Travelling back home in this way after several months working abroad, became a way of life

for the 10 million other men and women who emigrated from Ireland since the 1980s out of economic necessity (Glynn et al, 2013). Throughout this period, England remained the destiny of choice for over 80% of emigrants (Barrett, 1999). A report entitled: 'Poverty Lesbians and Gay Men' commissioned by the Irish Combat Poverty Agency (1995: 12) demonstrates how emigration was widely used as a "strategy to avoid, cope with and resist discrimination" by over 60% of Irish gay men and women. For those who could afford it, emigration became a necessary sexual health strategy to overcome scalar religious constraints to their agency. It is thus conceivable that the train in Brian's panel may not only represent one's *literal* travels, but also a symbolic inward journey of having to 'move' to find one's true self.

AIDS has been an under-researched catalyst in Ireland's queer diaspora. Undoubtedly, emigration for Ireland's LGBT community was exacerbated in a period marked by illegalities surrounding homosexuality and AIDS; forcing gay men, in particular, to live a life in exile. Irish Census Bureau statistics clearly indicate that the 1980s and early 90s; the period of Ireland's AIDS crisis, were among the highest years of emigration on record, with 56,300 people emigrating in 1990 alone. The hidden nature of Ireland's LGBT youth was compounded by living in rural areas where LGBT youth felt unable to be themselves in certain places steeped in Catholic social thought. This was captured in an oral history project by an Irish emigrant working in the voluntary HIV/AIDS sector in London; "I guess I was always gay but growing up as I did in County Clare, the word gay didn't exist, and if it did, it was Irish eyes are smiling, all the word is bright and gay...I had tried so hard not to be gay. I would buy some *Playboys* with naked women to, you know, see if I could turn myself on in that way but it was all self-deluding. When I became aware of it, I was very afraid of it. I immediately gravitated towards a Catholic support group" (Door to Door.org, 2016).

"There was always a history of gay men going right back to the 70s. For those who lived in Dublin there was access to bars like Bartley Dunnes and the Hirshfield Center- but if you were even from a town like Drogheda...you had to maintain like, a secretive double life."(Interviewee1C- Brendan Fa y, March 2016).

Multiple scholars have pointed to the spatialities of queer citizenship by noting in particular, the global appeal of metropolitan centres and their associations with sexual tolerance (Weston, 1995; Houlbrook, 2006; Ryan-Flood, 2009). Weston (1995) speaks to the search among LGBT youth for anonymity in urban cities while Houlbrook (2006) identifies London as a particularly attractive city for lesbian and gay lifestyles given its gay-friendly commercial district of Soho. Ryan-Flood (2009) has additionally noted how the Castro District, where the Quilt project first emerged, attracted many queer migrants from all over the United States given its liberal laws on homosexuality.

From Ryan-Flood's (2009) study of LGBT migrant experiences in London, we can only ascertain that the arrangement of LBGT emigration suited many customary rural Irish families given that the "suitable

compromise” of emigration still enabled queer youth to enjoy the “freedom to live a gay life” in the cities, while still retaining a “sense of secrecy within the [local Irish] community.” Fortier (2003: 119) in her essay ‘Making Home’ argues that the figurative ‘coming out’ experience for gay men is often equated with the literal ‘moving out’ of the domestic space, as bodies must ‘migrate’ instead towards what they experience to be their “true homosexual selves.” Given that the ‘homeland’ is typically conceived as a function and effect of heterosexuality, queers’ entitlement to home is often questioned; they are cast as “foreigners within the[ir own] nation” and are hence forced to leave because of the “incommensurability of being queer.” (Eng, 2010: 28). For Judith Butler, diaspora functions as the melancholic response to cultural exclusion. The societal scale heteronormative matrix, as she argues, is born out of repressed same-sex desire during subject formation. A moral directive becomes internalized in the child, forcing him or her to give up his/her oedipal attachment to the same-sex object (McIvor, 2008). When disavowal of the homosexual attachment is adopted by the wider regulatory authority, what ensues is a “culture of gender melancholy” which installs heterosexuality as a “consecrated” norm, strengthened only through the very repudiations which it performs, (Butler, 2005: 140). Importantly, this is accompanied by an inability to grieve on the national scale and can be overcome only through the public act of mourning (McIvor, 2008). Worse still, homosexual desire is produced as a site of guilt in this pathologizing matrix, as anger towards the homosexual disavowal is directed inward towards the Self. “Impoverishment of the ego” which ultimately results, is marked by self-displacement, depression, or in this case, exile from the homeland (Butler, 2005:141).

Returning to Brian’s Quilt panel then, one can see that while the destination of the train is unclear, moving to Britain would be indicative of his personal desire to move to a more open and potentially subversive lifestyle. Trains not only depict ‘journeying’ but they are in fact a powerful engine that is controlled by someone or ‘something’ other than itself. Thus it could be said to depict a sexual energy that has assumed a life of its own; one that while approaching its desired object, quite literally moves ‘full -steam ahead.’ But perhaps most significantly, Brian’s panel shows us that in order for these sexual acts to take place, and for cultural acceptance of a subversive lifestyle to materialize, the queer subject – again depicted by the planes - must be placed outside or beyond the borders of Ireland. Brian’s panel therefore displays not only the travels of an Irish emigrant, but in fact performs the precarious conditions of a cultural rejection of the Irish LGBT community during the 1980s. Brian’s panel communicates a queerness which is fast-paced, potentially dangerous, and in constant motion. In this way, queerness and mobility become collapsible, projected here upon the same life and story; or theoretical twins that as Wesling (2008) argues, transgresses and disrupts “static categories of being.” (Wesling, 2008).

Limerick's voluntary HIV/AIDS organisation, 'The Red Ribbon Project' reflects a similar theme of scattered mobilities through an anonymous group panel dedicated to the lives lost to AIDS within the city. Placed in the centre of a yellow and blue panel is a globe with red wool threads which burst beyond Limerick's walls and transgress the borders of not only Ireland, but the entire globe. And when I questioned Mary about the nature of this panel and what it conveyed, she claimed it was the idea that: "AIDS connects Ireland to the rest of the world." "We want to show people that AIDS has no borders and boundaries." "It affects everyone and that's what we need to educate people on." she added. Hence, implicit in this representation is that AIDS has come from somewhere else beyond Ireland and continues to circulate as a result of clandestine mobilities.

Mobility during the Irish AIDS crisis was associated with looser morals and sexual depravity. A country that has, by virtue of its physical geography, been an insulated island economy located on the periphery of Europe, multiple mobilities from within and beyond the borders, have always been perceived as posing a national risk. Historian Jennifer Redmond's (2015) study of young female Irish emigrants in early 20th Century Ireland is particularly instructive in this regard as it testifies to the way in which the Catholic Church's preoccupation with policing mobile bodies, did not necessarily stop at the country's borders. Emigrants, she argues, were targeted for being "no longer under the watchful eye of family and community" and for being potentially "at risk of sexual transgression" once the bonds of "propriety exercised so strongly on them at home were gone" (Redmond, 2015: 80). Because many emigrants at this time were under the age of twenty-five, unmarried, and undoubtedly some of which were gay men, there was a very real fear among the Catholic Clergy that these bodies would become "reckless through life in English cities" (Redmond, 2015:78). This was a sentiment later reiterated by Ireland's voluntary 'AIDS and Mobility Network' which was established as a reactionary measure to European Union enlargement and the unprecedented movement of people and disease: "The risk of STD's and HIV infection is greater for travellers* [understood here simply as people who travel*] and migrants, as away from home, different sexual mores or rules seem to apply."

The queer subject was marked as a particularly mobile subject at the height of the crisis, compelling the state to implement an AIDS policy which particularly linked the mobile with the queer and diseased. Smyth's (1998) study of HIV in Ireland picks up on these themes of "insularity versus external threat" as she notes from her interviews with departmental officials, that the perception of AIDS in Ireland was that it was only "a disease of American homosexuals" while there "was[n't] much homosexuality [going on] in this country." Ireland's 'National AIDS Strategy Committee' (1992: 65) embodies these anxieties towards mobile bodies as it attempts to grapple with the "high proportion of gay men and young emigrants" involved in "at-risk behaviour." The Committee report recommended that the most effective

means of reaching this group is through the production of an “information leaflet” which would be made available at “travel agents... information offices as well as at all points of exit from the country.” (NASC; 1992:65). Smyth (1998: 669) has additionally identified that Ireland’s large black “forbidding” poster, stating “not to send AIDS home” was deliberately situated in the country’s ferry ports and airports in order to target those traversing the state’s borders. The National AIDS Strategy Committee in partnership with the voluntary organisations running the AIDS care projects (as well as the Quilt projects) went on to advocate for on-going links with emigrant groups abroad particularly among Catholic Groups in London and New York, in order to continually “monitor and evaluate the situation.” a report by O’Hanlon (1998a) in the *Irish Echo* (a newspaper of the Irish-American diaspora established in 1928), showed that while a dozen Irish immigrant organisations across seven US cities were to receive \$253,000 dollars between them in 1998, New York’s ‘Irish AIDS Outreach’ was entirely side-lined. Organisations which were providing fundamental direct care and support for AIDS patient were seen as subservient to the charitable partners of the Church, whose funds could be redirected to adapt and uphold certain forms of ‘moral behaviour’ among Irish expats. \$59,000 dollars was given by the Department of Foreign Affairs to ‘Project Irish Outreach’, a division of the Catholic Charities, while according to O’Hanlon (1998), Irish AIDS Outreach, an arguably much more urgent organisation, was, in shocking disparity, to receive only \$1200. My interview with Brendan Fay of the ‘Lavender and Green Alliance’ an organisation which works directly with the LGBT and AIDS community in New York, revealed that even in America, “Catholic priests and nuns managed the service provider centres.” The *Irish Echo* affirms that it was Cardinal John O’Connor, Archbishop of New York who was involved in the opening and running of ‘St Clare’s Hospital to AIDS patients’, suggesting that even spaces which provided AIDS care for the Irish diaspora, were overwhelmingly Catholic and uninviting for gay men and women who were not part of the missionaries (Keaney and O’Hanlon, 1999).

Despite this, Irish gay men, including those with a concealed HIV status, were still opting to leave not only given the perception of fairer testing services abroad, but due to an inability to either mourn, or be mourned on Irish soil. Reporting on services available to AIDS patients in the US during the crisis, my interview with Brendan Fay of the ‘Lavender and Green Alliance’ – an Irish emigrant LGBT organisation, was to reveal that:

“In Ireland, there wasn’t enough information and Irish health care lagged behind on new HIV meds....But here in the US, for Irish immigrants who were HIV positive, you could access the AIDS Drug Assistance Program (ADAP) which provides free medications for the treatment of opportunistic infections... (Interviewee1C May 2016)

At the height of the crisis, it was voluntary organisations who were calling on the Irish government to address its haphazard and regressive approach to the crisis, which they argued merely “accentuate[d] a

slow and painful death” and “add[ed] to a climate of fear and isolation.” In 1990, during Ireland’s first Dail Eireann debate on AIDS in 1990, Labour Party TD, Deputy O’Howlin’ summed up the situation bluntly:

“Life in this country for an AIDS patient can be particularly grim. It is common for patients who have been diagnosed as HIV positive to lose their jobs, to lose their accommodation and to experience a lack of access to some of the health and medical services. These factors have influenced many to either suppress the problem of AIDS under the surface of public awareness or simply to emigrate to London.”

Siobhain O’Dowd from the Cork AIDS Alliance writing in the [Cork’s] *City Tribune* (1994:39) was also to similarly claim from her activist experience that:

“Sixty –nine people have died already in Ireland but those are just the figures we know about. Many infected people have moved to London where there is a stronger concentration of services and a bigger HIV community. In most cases for the gay men, it’s emigration for sexual rather than economic reasons. Many of them would not have told that they were gay and many die without even being able to be open and make their farewells. We can be sure that many of the people who have died from AIDS in England or the United States are Irish, so the total number must be far greater than the published figures”

Mairead Lyons of Limerick’s Red Ribbon Project later interviewed by Tony Purcell in the *Irish Examiner* (1996: 26) similarly commented that:

“Provincial Ireland continues to struggle against prejudice and discrimination. Many funerals are quiet, discreet affairs. There is no mention of AIDS. This is in contrast to the elaborate funerals of people who die from a socially acceptable disease. Our greatest tragedy is in excluding Irish people living with AIDS overseas from the pleasure and dignity of dying at home, surrounded by loved one’s, family ,friends and neighbours they grew up with”

And this was echoed again by one of Ireland’s first AIDS- expats who revealed to the press; “I couldn’t tell my family. I went to London to try and remain anonymous. I felt it was easier to die than to live with AIDS in Ireland.” (Siggins, 1989: 3). And as Purcell (1996:26) writing in the *Irish Times* adds: “Some Irish people feel compelled to remain abroad because of the stigma attached to the illness. Other families, accepting the loss of a loved one, still feel that they cannot discuss and share their grief with the community.”

Perhaps then, the only visible expression of a nation’s ability to grieve for these exiled and mobile subjects, can be found within the diaspora panels of the NAMES Quilt. The American and United Kingdom NAMES Quilt panels provide us with part of the picture of our Irish AIDS diaspora. Searching for the panels was undertaken by putting combinations of over 20 common Irish family names (eg. Byrne, Dunne, Fitzpatrick, Gallagher, Kavanagh, O’Neill, O’Shea and so on) along with common male Irish

and/or biblical names (Michael, Paul, John, Kevin, Joe) into the digitised NAMES Quilt. Other entries included Irish county and province names, along with any other references to Irish life during the 1980s and 1990s, for example ‘Father’, denoting someone in the Priesthood. The results brought up a small, but nevertheless visible collective of panels crafted with many cultural references to Ireland such as shamrocks, Celtic crosses and the colours of the Irish flag – green, white and gold. Beginning with the US NAMES Quilt, Block No. 00995 contains the phrase: “In memory of my Irish Brothers. *Le Grá* (With love) while in Block No. 03312, we can see a thatched cottage in the countryside against a rolling green hill backdrop in Billy O’Connell’s panel. Entanglements of place and belonging are made manifest through the geographical origin of Ireland that is reimagined here as a queer space of belonging; a yearning which, may have been especially heightened in the experience of death overseas. Though the panel paints a rather serene and romanticised image of quiet country Irish life, its depiction may perform other geographical imaginaries reserved for a non-heterosexual gaze. ‘Cottaging’ may signify the well-known leisure activity of anonymous sex between homosexual men. In skilful fashion, homosexual acts become written into the very landscape of Ireland itself, and by withholding its explicit inscription, the panel captures a precarity of Irish society which cannot simply be reducible to prescriptive or formulaic text.



Figures 4 and 5: AIDS Panels of the Irish Diaspora, taken from the Digitised NAMES Quilt. Seen here are Billy O’Connell’s panel on the left and Patrick Coughlin’s panel on the right. Photo’s courtesy of the NAMES Project Foundation.

For others, emigration is explicitly sewn into the very fibres of the panels themselves. In Michael J O’Connor’s panel, both aeroplanes and boats can be seen moving across a wide sky and ocean, (Block No. 00627). Robert D. Murphy’s panel, who we learn lived from 1960 to 1987, contains the statement: “on my own....for now.” (Block No. 00671). And again Patrick Coughlin’s panel from Block No. 02047

seen in figure 5 above, poignantly reads: “he just changed addresses.” Collectively, these panels may illuminate a sense of cognitive dissonance experienced by men whose religion formed a fundamental part of who they were, yet may have also become a site of contention or guilt while sexually experimenting while overseas. The sense of guilt or shame is rendered all the more tangible in a panel completed for an Irishman who ostensibly felt unable to live a life as himself: ‘Born Robert S. Doyle 1945 and died Patrick. A. Doyle 1989.’ (Block No. 01264).

Quilt panels produced by and for the Irish diaspora tended to show that despite being an openly or closeted gay man, there remained a desire for their Irish Catholic roots to be a large part of how they wished to be remembered, even while dying of an AIDS- related illness. Kenny O’Brien’s panel expresses the infamous Catholic phrase: ‘Blessed Be’, while in Block No. 04391 a green panel for Brian Stephen Gallagher 1949- 1994 displays a quote enveloped by a large holy cross: “The Lord is my Light and Salvation.” Two green and white panels have been completed for ‘Father Jim Moran’ and are peppered with correspondingly coloured miniature shamrocks. His green liturgical garments are arranged in an ‘M’ shape while a white faceless figure dressed in Catholic vestments preaches from the centre of the panel. Religion also features prominently in the UK Names Quilt. Though there are only a total of 48 panels currently publicised from the UK Quilt through the UK AIDS Memorial Conservation Partnership, Irish Quilts depict a Holy cross and bible for ‘Patrick’ or ‘Packy’ as it reads 1958 to 1992 and in a cream panel for “Irish John.” Ireland’s diasporic panels could therefore be said to mediate a tenuous relationship between the AIDS body and the Catholic body. Read together, these panels deviate from the typical Names Quilt references with their politically overt, secular references to American pop culture, a gay subculture, personal hobbies and the Arts. Instead it would appear that the search for political insurgency is largely replaced with that of religious clemency.

But even accounting for their individual nuances, what additionally gives many of these panels a sense of commonality, is their use of full names. While gay men may have felt compelled to emigrate, and indeed many of them continued to be targeted as vectors of disease either by the Church or by the state, working with voluntary Quilting projects overseas with a more proud and open international gay community may have opened a creative space of possibility to be mourned and remembered by the nation. Article 2 of our Irish Constitution makes a firm commitment to “cherish its special affinity with people of Irish ancestry living abroad who share its cultural identity and heritage.” In some ways then, the practice of quilting by voluntary organisations whether it be Terrence Higgins Trust in the UK or the US NAMES Quilt is inadvertently using and affirming its legislative appeal in order to hold the Irish government to account – not only in terms of the precarious conditions it has induced upon the LGBT diaspora, but indeed to defend the rights of expats to enjoy both a dignified life and death overseas.

4.5 PATCHWORKS OF PRECARIY IN-PLACE

“Memorial quilts are depressing!” I was told one afternoon whilst having a phone conversation with the founder of Rialto’s AIDS Quilt. She seemed bewildered as to what had me so interested in such a bleak subject. Granted, my limited knowledge of the NAMES Quilt and lack of personal involvement would have surely aroused suspicions. But by this stage into my research, my curiosity had been peaked nonetheless. “I’m just really fascinated by the whole thing!” I replied. “I’d really love to get to find out more if you had some time!” Her tone soon changed and she eventually conceded, though not without uncertainty; “Well, the rest of the group will be anonymous, but if you come out to Rialto, I’ll show you the Quilt and be happy to talk to you.” This was a unique opportunity – it was the first I was to learn about an AIDS memorial Quilt that had been made not specifically for a set of bodies, but instead, made directly by and for a ‘place.’ A place otherwise known as Rialto and Dolphins Barn, home to the regenerated Fatima Mansions tower block, that as it would transpire, had been marked by its very own form of spatial disadvantage during the AIDS crisis. Asking of me to travel out to this particular place was hardly coincidental. I wondered whether perhaps it was test of my commitment to the origin and inspiration of the Quilt itself. After all, how could one begin to learn about the lives, without learning about the place? It was clear from our phone-call that in Terrie’s mind, memorializing lives lost to AIDS, was synonymous with memorializing place itself. One could not be understood without the other.

At first, I was apprehensive. Given what can only be described as my middle class comforts, it wasn’t a place I was used to travelling to, after all. Nor had I any reason to; I didn’t know a single resident and my only prior knowledge of the place was stretched at an opaque appreciation of the areas’ social disadvantage. The Quilters’ suspicions about me were probably justified. Despite this, I was certainly willing to learn, and so I eagerly capitalized on Tina’s extended invitation. Upon my arrival to Rialto and Fatima Mansions what I was to find however, was “neither mansions nor gardens and...[and] no ecstatic visions.” (O’Toole 1996:14) Some remaining tower blocks of social and corporation housing can be seen lining the horizon. The blocks are tall; there are perhaps fifteen red brick four- storey blocks in rows with 27 units included per block. They are arranged in a linear fashion and are enjoined linked by narrow communal balconies and stairwells with no electric gates or lifts characteristic of modern day apartments. Each flat has its own coloured door and window with most windows bare or dressed only with white net curtains. While none of the blocks are painted, many of them have been tagged with graffiti and their desolation and poverty speaks a truth which rings loudly over and above the absence of any sound. Aphonic bodies inhabiting the space spill out over balconies and look down upon intruders with quizzical

brows. Outside of the flats are concrete pavements where cars are parked but no children can be seen at play. While there are few trees and green embankments, it is anything but an open and porous space. Flats are largely ‘hemmed in’ by their green iron fencing, and apart from the Luas line, there is only one main road connecting residents in and out of the area. Walking across the embankment, I became very aware of my own body within the space, particularly as I knew eyes were fixed upon me. As I skipped down urine-drenched steps, I expressed mild amusement at the sensation of being both connected with place, while feeling an intense sense of distance with it at the same time. What I was unaware of however, was that this sentiment was about to inform the entire conversation that awaited me.

Rialto is a residential area in South-West inner city Dublin, bound by the River Liffey to the North, Kilmainham to the East, and wider ‘Crumlin’ to the South. Lining the horizon are the remains of social-authority flats that were built as part of post-war “slum clearance” and while pioneering for their vintage, were subsequently acknowledged as urban planning failures and forced into a phase of demolition and regeneration (Grehan, 2010; Harbinson, 2016). Cycles of economic disinvestment and reinvestment in the city (see; Punch, 2001) coupled with the state’s urban abandonment (see; Benson, 2008; Corcoran, 2002), rendered this neighbourhood a spatially cut-off enclave bereft of vital services and supports. The closure of the Jameson distillery and other industries which were once large employers in the local area, had a profound impact upon the local experiences of poverty. My conversations with ‘Tina’ revealed that especially during the 1970s, there was; “no food - no fuel - no nothing. One of the clients was dying – and had been brought downstairs on a mattress and the family were burning shoes to keep him warm... We are talking serious poverty.” Clearly, we can see that while although as O’Toole (1996) reports, 750 million was invested in Dublin’s inner city over the past ten years, “none of it [has] touched the flats and estates where long term unemployed [i]s concentrated.” Resultantly, the area is “bereft of community facilities” with nowhere for children to go “but the street corner” (O’ Hara, 1995: 3). Marcuse’s (2002) “partitioned city” is exemplified in the ‘Pobal HP deprivation indices’ which numerically express the deprivation and despair of poor educational attainment, high unemployment, lone-parenting and health problems; all of which stand in marked contrast to areas from the wider city hinterland. Taken together, it has been described as “probably the most disadvantaged place in the state.” (Irish Times, 1995). But pumping its most extreme form of despair into the heart of this community was the 1970’s heroin epidemic, where so-called “shooting galleries” became spaces of self-medicated escape to assuage the ennui of its vulnerable men, (Butler 2001; O’Gorman, 1998). Exposure to HIV/AIDS was a matter simply of probability and time. Unlike England or North America, Ireland’s pattern of HIV distribution more closely resembles that of Spain where injection drug use is deemed to be the “highest risk behaviour in terms of HIV transmission.” (McKeown, 1999; Butler, 1991). Annual statistics from Ireland’s Health Protection Surveillance Centre (HPSC) show that intravenous drug use continues to account for approximately 51%

of total HIV/AIDS cases per year and perhaps more worryingly, this cohort are more likely to develop an AIDS-related *death* over and above any other social group diagnosed with HIV (McKeown :1999; Dorman 2011). A study conducted in 1984 to ascertain opiate use in south west inner city Dublin, found that within that electoral ward alone, all of the survey's 83 respondents were heroin users while 57% has been using drugs under the age of 25. The general sentiment among the government and established health community was that there was little interest in assisting the needs of people addicted to drugs. A medical study conducted by Stevenson and Carney (1971: 375) in the *Irish Journal of Medical Science* concluded that those involved in drug abuse are "often very deviant" and even have a "psychological disorder." Furthermore, a punitive and internationally inspired 'Misuse of Drugs Act' 1977 (later revised in 1984) was premised upon the regressive model of reducing supply and demand of drugs on the street, with little established in the way of harm reduction. As my interview with 'Tina' revealed;

"people who made policy decisions never looked at the real issues... the whole thing of drug addiction was linked to mental health. That was the thought around it. Rehab wasn't even around back then. You went from being 'mental' to being a criminal and agencies would just boot them out" [Interviewee1B March 2016].

Intravenous drug users at risk of HIV infection in Ireland were at worst criminalised and demonised while at best they were cast as a liability in need of 'sympathy' and support. When HIV testing was made available in 1987, 121 new cases of HIV were diagnosed among IDU, an overwhelming number of whom were young unemployed men with low educational attainment. Small area data on AIDS cases are unavailable in Ireland for reasons of anonymity, but as one of the Rialto Quilters who I spoke with recalled: "when we began in 1993, residents threw out at least 70 names of people who died of AIDS in that one area." Given what can only be described as the inadequate available literature on risks of HIV transmission, coupled with lower rates of educational attainment among the community, it is perhaps no surprise that residents found themselves at disproportionate risk of HIV transmission. As Tina recalled from her experience "living through it all in the 1970's - people didn't know that they couldn't share needles - hadn't a clue - hadn't even heard of aids - whole families died." Again this was reiterated by Tony McCarthaigh of the Rialto Community Drugs Team who expressed in the Aids Care Education and Training organisations' documentary footage that "a large number of this community died at a "tender age" with "3 or 4 [even dying] from the same families...[voluntary organisations] knew [they] had to do something to address this structural imbalance." (ACET Documentary DVD, 1993).

Judith Butler (2009) is resolute in suggesting that the inequitable distribution and differential allocation of vulnerability may be produced, realized and actualized through uneven spatial arrangements. This idea that a structural imbalance of disease distribution is mediated geographically by socio-spatial abandonment is, of course, not a new one. Anthropologist Didier Fassin (2007) researching AIDS in

South Africa, shows how the spatial inequities of this postcolonial disease overwhelmingly corresponded to the colour-line. Writing at the height of the epidemic in North America, Wallace's (1988) seminal study on 'planned shrinkage' of the NYC South Bronx similarly found that systematic 'redlining' of minority neighbourhoods altered the geographies of the AIDS epidemic. Removal of municipal fire services cultivated 'spatial foci' of urban decay, unsafe sexual behaviour and needle-sharing practices. This, he argues, was responsible for expanding the geography of drug use from a spatially clustered outbreak in South-Central Bronx, to a bifurcated pattern connecting this quarantined zone to a much larger area of the city. Corcoran's (1998) study on 'Fatima Mansions' would appear to demonstrate that Rialto residents too, recognised that their own urban environment had been politically produced as disproportionately vulnerable. 'Doing time in Fatima' and "going back to the barracks" were spatial concepts devised and cited by Rialto residents to express their sense of alienation and entrapment within their own neighbourhood.

My fieldwork was to reveal however, that Rialto was nevertheless experienced by residents as both a space *and* a place, a realization which, in self-professed ambiguity, resists being neatly captured by false dichotomies perpetuated by political-geographical distinctions. Residents in Fatima's Mansion's 'Dream Dare Do' manual regularly referred to their unique sense of community 'spirit' and connection while at the same time, heroin-related malignancies were often derided through humorous speech-acts; "it's Crazy Prices out there!" (*Irish Times*, 1998; Dorman 1998). These findings complicate and question our limits of the spatial, by providing insightful reflections as to the possibility of place-attachment and affiliation even within and despite its pathologies. Importantly, Butler (2004) claimed that precarity works in two principal ways: not only as a condition of existence, but as potentiality for change, (Waite, 2009). Crucially, it could be argued that the radical undoing and becoming of the Self that is necessary for political transformation, is both rooted in, and arises from, disaffection with place. An issue raised, though not yet resolved by Gregson and Rose (2000) is how the performative turn in geography, might begin to account for the spatial as opposed to the body, as an alternative articulation of performative power. They argue that because discursive citational practices require slippage between the body and space, spaces simply cannot pre-exist performance, but instead, they arise together as space is brought into being through the body. The body, as a subject of power thus not only 'takes place' through localized citational practices but further, our political mobilization and forms of site-specific interventions that are often directed at the state, occur more frequently (and, arguably just as forcefully) on local scales of participatory citizenship; places that both have meaning to, and are accessible for, its central protagonists (Desforges and Woods, 2005).

Despite this, place, as an antithesis of space, is typically conceived as a comforting abstraction, problematically devoid of either power or pathos. Prominent Geographer Yi Fu Tuan (1971: 151) in his seminal study on place-attachment or 'topophilia' conceives of place in analogous terms of 'meaning-

making' experientially encountered through sensorial perception with its many-faceted comforting artefacts. Special "bonds" we form with place are cultivated through "olfactory and tactile experience"; the genesis of place in this sense being the genesis of knowledge gained about it. But such a phenomenological approach is premised upon an assumption that place is first made, felt and experienced through a geographical distance from its objects – indeed objects in this way merely become the subjects of one's own sensory imagination and thought. Read from this perspective, the smallest geographical scale from which we can venture forth is the "home." Prominent philosopher of place; Edward Casey, (2001a) is perhaps more insightful in this regard, as he premises the body, and indeed its fleshy transgressions, as the medium of place. Rather than epistemologically deducing place from spatial formations of time, distance and power, Casey (1997:18) conceives place as an 'immediate' *a priori* form, without which, space itself could never be 'reached.' More than Tuan's (1975) "centre of meaning", place thus becomes a powerful site of *exchange* between materialities. Borrowing from Butler's bodily ontology then, we might argue that it is within and among precarious conditions that the need for bodies to *become* 'place' is in fact accentuated; finding oneself displaced or dispossessed of 'shelter' for example, need not necessarily mean that one needn't find 'home' in other beings- other *bodies*.

If place is altered by what Casey (2001a) refers to as the "active," then the 'place' of the body simply cannot be separated from lived conditions of precarity, or indeed its site-specificities of scripted momentary rupture. Hence, bodies are what we might refer to as a 'place of necessity'; more than pre-discursive, or at best neutral 'sites' where power regimes come to be inscribed, bodies are an indispensable element for how a vitality of place and its meanings and identities come to be formed. In this context, I view the production of an AIDS community quilt as an exemplary 'place-based practice' where conceptions of belonging, identity and place are reworked (Till, 2008). While the original NAMES Quilt has gained notoriety in terms of geographic expanse and politicized performance and has therefore claimed legitimacy as to the appropriate and conventional way to memorialize lives lost to AIDS, what remains under-researched is the role of 'place' in the lives of its creators, for ensuring longevity of Quilt panel displays. Here I argue that a 'place-specific' response to the AIDS crisis can be of comparable effectiveness for attending to community loss, and for healing more broadly what I refer to as a 'precarity-of -place.'

Conceiving the idea to hand-sew a quilt by and for the Rialto community arose from discussions about the emotional burden of memorial quilts. "AIDS memorials are hard" I was told in an interview conversation with 'Tina'. "You see, there's really a lot of grief involved." What motivated Tina and the wider quilting group, was the need to transgress spaces associated with bereavement, and begin using the Quilt "to look at other issues affecting the community." Musing on the decision to move out of memorial quilts 'Tina; states; "We've been a few years doing these ones [indicating towards memorial quilts] and it's always been about people who have died. There's always sadness around it. And we're actually having great fun

doing this.” What the community began to seek instead was a space in which to recount their stories and memories of home; not one’s simply marred by grief, but one’s which celebrated ‘place’ from the perspectives of residents themselves. It was, as Tina has described in elegantly understated style; a “different kind of message.” Recall that while any person may be able to craft an AIDS memorial panel for someone who they know to have died of AIDS, only those from within the community of Rialto were invited to partake in the making of this project. Yet apart from being a secluded affair, the project was intended to be an open and extensive piece of artwork from the beginning and not one merely (de)limited by individualized patchworks. The format which was agreed upon was that each quilt was to be placed on plain material to begin with, and aspects of the community would be shown; “the whole place would be done on material- shops, buses, people – you name it, it’s on it!” (Rialto Community Quilt documentary DVD 1993).

Two quilts were created as part of this same project, one of which was roughly seven foot long and depicts changes in the community from 1993 to 2008 while a smaller quilt was completed in the late 1990s as a more immediate reflection on the status of their neighbourhood. St Andrews’ Community Centre, a refurbished Church on South Circular Road, was chosen as the site in which to begin making this piece of art-work; a local site which not only had meaning for the Quilters, but which was ideally situated and accessible by foot from the centre of town. The group tasked with overseeing the project consisted of a core five quilters, of which other members, often kids, would come and go. Having children participate from the neighbourhood was important in the cultivation of place-making as children were deemed to be the future embodiment of the community itself; “I remember the kids used to come in and have fights with the teabags while we were quilting– they grew up in the group” as one of the quilters anonymously recalled (ACET - Drinking from the Same Cup, 2012: Unpaginated). Meeting fortnightly to plan and implement the project became a routine practice among the residents, so much so that Terrie would even later describe it as “a ritual” among the group. As one of the quilters recalled herself; “we met every Wednesday and there were loads of people coming – there was a great crowd in it!” (ACET – Drinking from the Same Cup, 2012: Unpaginated). Individual talents were also adopted by the group in the interest of the wider collective; “Myself and ‘Rose’ are the machinists and Tina does all the fiddley bits with it but I get to sew the bigger pieces” one of the volunteers expressed in documentary footage. “We had another woman who always did the painting” Tina added in interview. The collective responsibility of Quilting required the input of an array of bodies who were expected to share proximity and forms of bodily exchange within and across space. Describing a typical morning of quilting, Tina insisted on the importance of intimate informalities; “We meet at 10 until half 12 – I always bring cake, we all hug and thing –and then we catch up and we decide, what we’re all going to do for the day.” Again this was reiterated by quilters who felt that the safe space created by and through their friendship, facilitated with the production of their artwork; “*I really enjoyed the work and it was somewhere I could*

go and speak. Everything was confidential. I felt safe within the group.” - [Rita in documentary footage]

“In 1997 I was asked would I like to take part in the group. I enjoyed the sewing and I enjoyed the company...very much. It was very uplifting for me at a time when I needed uplifting.” - [‘Hazel’ in ACET documentary DVD 1999]

“I tell ye – it’s very relaxing having an owl yap while you’re doing it- and we have a lot of laughs too about whose doing what.” – [Tina in ACET documentary DVD 1999]

As can be seen, the same sentiments were shared equally among all the Quilters; having a laugh and being themselves was a fundamental way in which sense of place was generated. Quilting was a social occasion which demonstrated the powerful potentialities of a community coming to work together. Conversation was described as ‘uplifting’, even inspiring and became the soul of activity, instilling hope among the Quilters. Yet while conversation had its benefits, undoubtedly it also bore a certain level of risk. Being open about the personal ills and traumas encountered by families within the neighbourhood was premised on a certain form of mutual vulnerabilities;

“I could laugh. And I could cry. Because we had all been through and seen similar things.” – [Rita in documentary footage]

“I met people like myself who were in the same boat as me so we could have a conversation, And it seemed like we knew each other a lifetime.” – [Ann in documentary footage]

Memories of harm and trauma had the fortuitous effect of bringing bodies together in unison, and it was this proximity and porosity of bodies, that, as Gregson and Rose (2000) have outlined, constitutes an act of healing even greater than what was said. Narrating stories of the crisis that had divided this community, and being able to share these inter-subjective memories, created an openness and porosity between bodies that traversed a divide between Self and Other. As Judith Butler (2014) claimed, the ability of the ‘Other’ to address itself to the ‘you’ is a fundamental requirement in the linguistic condition of our very ‘survivability.’ Derrida (2000) further argues that through language, we communicate a statement that always means something ‘other’ than what it means in any particular context and therefore each statement is already indebted to the Other in order for it to even have a meaning. Sharing language by the quilters in this way involved a give and take that was tasked with bridging a divide between bodies. As such, language enabled bodies to become hospitable, crossing a threshold of the unknown, as distinctions between Self and Other were overcome. Part of the promise of artistic practice is, of course, that it is much more than a mere alignment between language and space. As we know, all that is visible, is not always expressible.

Indeed these ineffable qualities of place produced by a harmonisation of bodies culminated in Tina’s description of completing the quilts, where, “like traditional American quilts, all [the women] sit in a circle and add definition to the quilt by hand-sewing it - and we all do it together – it’s symbolic.” For

Tina, the indispensable ‘symbolism’ of this act was the proximity and porosity of bodies in space. This enabled the finished Quilt product to express the type of place that was both desired and fostered through its own creation; one which was not only responsible, but indeed *responsive* to all parties within the group. In the making of the Rialto AIDS Quilt, it was through the communicability of language, both spoken and unspoken, that bodies became open, relational and indeed ‘impinged’ upon one another in space, transforming it from a neutral zone, into an ethical and self-sustaining form of place.

Of course this is not to neglect the special role which the physicalities of place hold in our geographical imaginaries; connections with place and quilters’ knowledge of it, were often negotiated through intimate and tactile engagements with its materialities. For example, quilters collectively chose aspects of the quilt such as its fabrics, colours and mementos which they believed would ‘reflect’ their own neighbourhood. Of importance in this context was the legacy of the Dublin textile industry which stretched outward from inner city spaces, extending all the way to the Coombe Hospital. According to the ‘Dublin City Industrial Heritage Record’ (2011: 14) throughout the eighteenth and early nineteenth century, the ‘Liberties’ was merely a byword for the textile industry which took place there. Thomas Elliot & Sons, for example, was one of the remaining last specialised silk and poplin production plants which had featured prominently as a main source of employment from 1872, and only went into terminal decline from the late 1970’s. Sourcing textiles and sewing machines from residents who had worked in the local textile factories and shops that were now in decline was seen as a way in which to bring “authenticity” to the quilt while bringing quilters on vicarious journeys through their tangible connectedness to place;

“We used to go to different factories and get the leftover waste for our materials. One man was very generous and kept giving us bags of beautiful fabric as a donation, which meant a lot. At one stage we couldn’t use Terrie’s machine because she had run out of bobbins, so my husband robbed a few in the local supermarket so we could keep working!” – [Anonymous Quilter -ACET – Drinking from the Same Cup, (2012: Unpaginated)]

Just as Tuan (1979) would have imagined, the experience of Rialto as a place, grew imperceptibly with the subconscious imprint of touch, smell and sound. In this way, parts of place, and indeed the knowledge of a place in flux (decline of textile trades and their replacement with spaces of consumption for example) became embodied within the artwork itself. The quilt existed as an effective platform to articulate these stories that engaged sensory and emotional connections and changes of place, which could have only been intuited prior to its creation. But nevertheless, my crucial point here is that it was the *bodies* of place that was co-determinant in its production. This was evident in the lack of leisurely time that was set aside by the group outside or beyond the quilting spaces created by and for them; “it’s the only time we all get together and the only space we get to share things.” I was told. Hence the quilt group provided something of what Kearns (2006) has referred to as a “social shell” – indeed a ‘vital’ expression of solidarity in place which engendered a sense of social stability and security among residents. The “personal

interdependencies” of the shell, and their connections with inorganic, material entities, were also of central importance in the cultivation of social memory.



Figure 6. Rialto’s Community AIDS Quilt 1993-2008.
Photo with kind permission of AIDS Care Education and Training.

Being situated within that specific locale, and sharing space between bodies, enabled the appropriate memories to be drawn out in what Casey (2004:32) has referred to as an “active inducement of place.” As Casey (2004) reminds us, memories not only derive from place, but they are where memories are enacted. It was through involvement in a common project and the activation of what Till (2008) has referred to as activist “memory-work”, that place could be both fabricated in an artistic sense and in terms of its surrounding materialities . Yet while positive memories and engagements with place had the effect of forging subjectivities and a sense of healing, the need to ‘forget’ aspects of place was also apparent. Tina informed me about what was colloquially known as ‘suicide block’ and the sombre reflections which it evoked among members of the community: “You’d open the door and there would be someone hanging there— I know one of one of the families that happened to” I was warned. The quilting group had chosen “not to speak about it” and while although it had been an important factor in the making and shaping of their community, it was deliberately not given any reference in the quilts. Scholars such as Edward Said (2000) and Alderman (2006) have commented upon the exploitation of selective memory by political establishments. Collectivization and mobilization of memories by political regimes, they argue, forge

political allegiances and assist in the cultivation of a national citizenry, but undoubtedly often entail a negation of the indigenous and/or private memories of marginalised communities. Yet perhaps in some ways, this does not account for the more complex means in which memories can be selectively forgotten or subverted by marginal communities themselves as a form of resistance to re-orient their bodies, and give them the strength to endure among precarious conditions in the present.

Re-imagining place through the use of their bodies in this way also had the effect of strengthening intergenerational bonds that were necessary to support and protect children from an emergent drug economy and culture. Creatively recalling memories and stories of place enabled bodies to become porous further still, as these inter-subjective traces of the Self were shared within and across bodies in space. And in this way, participating in the place-based practice memorializing practice with family members (both young and old) as well as sharing memories with neighbours and friends, acted as a bulwark against the isolation and stigma of the AIDS crisis that can arguably be engendered through the individualistic production of the NAMES Quilt. Tina added from our conversation that unlike the national NAMES project, the art-work in these community Quilts had in fact enriched the lives of those who had participated in its making; “every person has done a lot of things on themselves – in a lot of different areas – because they live and work in very difficult circumstances.” For some, it had been a space in which to develop new forms of life- skills; “we taught one of the girls how to use the machines.” Thus the project induced what Till (2012: 7) has referred to as a form of “social capital” among participants as it gave them back a sense of personal fulfilment from their creations while continuing to memorialize their collective place at the same time. As Tina commented;

“The finished product was so incredible and they never thought they would be able to produce something that could be displayed. They had something someone else could come along and admire – that they had produced – that was so significant for them – they had the lowest self-esteem. (Interviewee2c ‘Tina’ March 2016).

The transformative power of personal attainment and pride in the AIDS Quilt had emerged first and foremost from pride in Rialto as a place itself, even within and despite its overwhelming sense of loss (a realization which, can, no doubt work in reverse). Journeying through place, was, as Casey (2001) would have imagined, also a way in which to journey through and with the Self, as both must be seen as co-constitutive. In this way, place came to be both practiced and remembered in dialectical movement between recollection and recreation.

The community AIDS Quilt can also be interrogated as a medium in which the precarity of AIDS memory, and indeed its subversion, gets performed. The Quilt uses synecdoche and metonymy to

showcase how place, as opposed to bodies alone, may be produced and shaped as a deviation from the norm. As can be seen from the community Quilt in Figure 5, the river Liffey acts as a predominant geographical marker to demarcate Rialto from its surrounding sense of place. Removed from the frame is any reference to greater Dublin area beyond that of Rialto and Dolphins Barn. Hence, we can see that their place emerged as a horizon of thought. It was place itself which bound and sustained their memories and experience of the crisis, while giving it its artistic shape, form and content. Within this frame a precarity of ‘place-memory’ bears witness to the sense of loss that was experienced by the changing role of place through the heroin epidemic and AIDS crisis (Casey, 2001). Written into the Quilt are caricatured references to Rialto’s “70” “ungrievable lives” whose deaths were not afforded with national recognition. Indexing AIDS deaths in such fashion was an attempt to showcase the sense of community loss that remains starkly absent from Ireland’s homogenized HIV/AIDS statistics. Rather than attending to certain populations or (trans)national social groups that may be more vulnerable to the effects of HIV/AIDS, this community opted to preserve and address place-based loss by stitching and hence preserving an exceptionally disadvantaged group of individuals within the very ‘place’ in which they ‘mattered’ most. As Casey (1997) reminds us, places are more than mere situatedness or locality, but arise through the process of a living ‘event’ – in this case, the lived experience of death and loss itself. Miniature facsimiles of previously completed panels are given new iterations alongside mottled red ribbons and phrases that include: ‘Rest In Peace’, ‘hope’, ‘love’ and ‘never forget’, all dedicated to those who had gone before. Despite the ostensible desire to move beyond memorials, visual explications of AIDS *con brio* are suggestive of its continued legacy within and through the landscape and life-worlds of the Quilters.

Hidden among the array of community buildings is perhaps the most forceful expression of AIDS-based precarity visited upon this community; a patchwork of Rom Massey’s funeral home with smoke billowing from its incineration of decaying bodies. The depiction of a funeral home moves our consideration of precarity and AIDS as something not only memorialized and embodied within quilts, but written into the very materialities of the urban landscape itself. ‘Roy’ of the Rialto Community Drugs team speaking in interview about the AIDS Quilt in documentary footage pointed out that,;

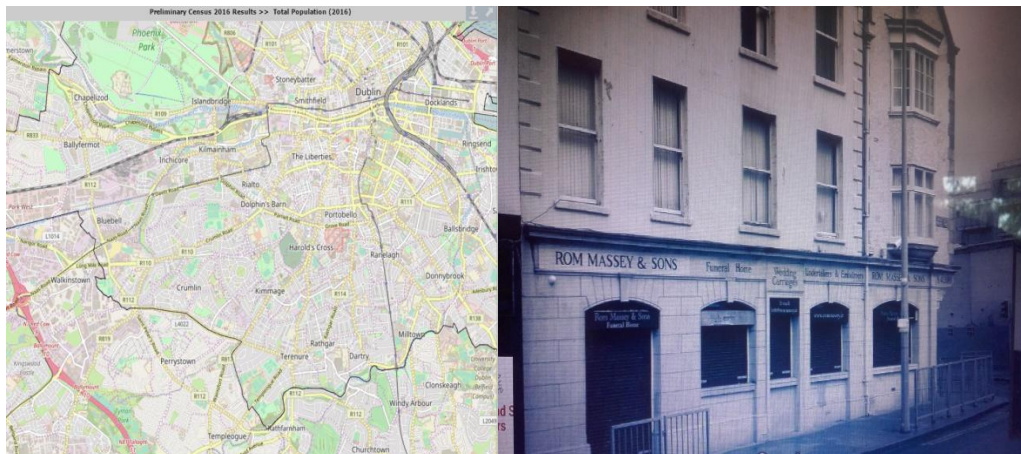
“A bit up the road from us [in Dolphin], about 5 or 6 years ago, there was a bank . Unfortunately that bank closed, and what is in it’s place? A funeral undertaker. And in that undertaker, are the many young people in the community who died of HIV-related illness. Many of them I know personally...I sat around their beds as they were dying, they were laid out in that funeral hall.”

From the Ordnance Survey Maps, one can clearly locate this funeral home on the corner of South Circular Road, along with its spin-off industry; O’Neill’s memorial headstones Ltd on Herberton Road, Crumlin. Since its establishment in the early 1990s, ‘Rom Massey & Son’s’ has become an iconic symbol of the AIDS crisis for the community, and continues to remain in operation today. Its mere presence points’ to the effect which AIDS had in altering the use of urban space and introducing micro-economies of power

which, although needed within the community, in some ways financially capitalised on local experiences of grief. This was highlighted by Tina in her AIDS activist work which brought her into a mediation role between families and the undertaker business:

“we had this family who could only afford a paupers funeral – so if you can’t afford the 11 o’clock mass — you do the earlier one – and we said no – he’s being buried at 11 and that’s it....we negotiated the pay. Because they couldn’t afford it. They wanted a proper funeral for their loved one’s like any of us do. But they wouldn’t go in and ask –so we went in and asked.”

Banks must be seen as powerful symbols of not only prosperity and wealth, but forms of exchange between local economies and their externalities. When situated in spaces that are economically thriving, banks represent transnational flows and connections within and between spaces. Its replacement with an undertaker however, suggest that new economies were required to adapt to an emerging sense of place that was both figured and focused inwardly towards its own forms of devastation.



Figure’s 7 and 8: Boundaries of Rialto on Census Map;
Prominent community service: Rom Massey’s Funeral Home.

Wallace (1988) was among the first to write that AIDS can (and would) have a “destabilizing” effect on communities and of the urban environment. With the presence of AIDS in a community he writes, landlords may be unwilling to maintain services out of fear of contagion, while homeowners may be prompted to seek home elsewhere, (Wallace, 1988). Several decades later, we can again see how the malaise of urban restructuring not only shaped AIDS, but how AIDS in turn shapes the making of place. For many in Rialto still, Rom Massey’s continues to function as a poignant and visible reminder of the systemic violence visited upon the neighbourhood. As my interview with Tina was to point out;

if you cross the Barn – you’ll see Massey’s funeral home. What does that say for a dying

community. That is a dying community. [Emphasis in original].*

For Tina, death had become an everyday feature of the living landscape. The community, in her opinion, were in the active process of ‘becoming’ dead, or, better yet, living through death. Something which was often conceived as a seemingly spatially and temporally distant ‘event’ for many, was now brought physically closer to their bodies within place. And thus, memories evoked through encounters with the spaces of Rialto’s streets, solidified the place as one of oppression. Death not only bound the lives of residents in this way, but in fact delimited their entire sense of place. Massey’s funeral home was to become such an important symbol for this community that it would be later depicted in both community AIDS quilts. Encounters with places such as Rom Massey’s funeral home, then, began to both materially render and reflect residents’ own finitude. A finitude that, as Butler (2008) would argue, is ultimately disavowed on the national scale from the very beginning. In this way, architectural structures began to symptomatically embody the lived experiences of being made abject while simultaneously fixing and holding these existential positions within place. Recognition was afforded to this in the ‘Fatima Groups United’ ‘Great Expectations’ document which assented further to the “burden of oppression” which became a lived reality for many and only served to “undermine the[ir] motivation for [community] change” (Whyte, 2005: 13). What this ultimately amounts to for Rialto, is what we might term a ‘precarity-of-place’ whereby not only bodies, but place itself, begins to embody and perform the precarious conditions inscribed upon it. If bodies are largely a product of inequitable environments, then one can reasonably assert that place itself can begin to bear the marks characteristic of bodies which it sustains, rendering precarity much more than an abstracted political force, but a contextually specific malaise.

But as Butler and Athanasiou (2013) imagined, precarity not only aims to capture the societal malaise of a place produced as- abject, but is in fact a central motif for the formation of radical consciousness. Having been conjured through “twin burdens of drugs and demonization” Rialto- as- place continues to struggle against an overwhelmingly negative media portrayal. Conway et al (2001) found from their media analysis of Fatima Mansions over the decade 1990 - 2010, that the majority of 104 newspaper articles showed Fatima Mansions through negative and sensationalist terms, focusing almost entirely on its difficulties with drugs and crime. In other words, these negative elements came to define place and negated all the other movements, stories and memories that created a depth of place within time. Of interest in this context is the media’s fixation upon Fatima’s urban design which is deemed to have been a direct causal factor in the development of the place’s drug culture. A caption from an *Irish Times* article (1998: 10) read that “planners could not have designed a better layout for drug dealing, with its ...hundreds of stairwells and balconies” while other articles unabashedly referred to the estate as “blight on the landscape.” (Conway et al, 2012: 562). But such a Cartesian reading of space was premised on the circumspection and suspicion about unruly bodily movement which never engaged the lived voices of people from their own neighbourhood. Tina, one of the voluntary workers with ACET expressed a

wariness of its negative portrayals too, and was eager to counter this through her own discursive manoeuvring;

“I go into the one bedroom flat and here was about five men standing around. All aged between 18 and 50. He [the client] is in the bed, right. And he was sick. He has a machete beside the bed. So I’m there – how’s it going? – fight breaks out. About what? Whose making me the tea! So THAT was the biggest issue. Was I under threat? Not for a second.” [emphasis in original]. – Tina in Interview.

As one report in the *Irish Times* (1998: unpaginated) reluctantly acknowledged: “every screaming headline describing the flats as a hell-hole is a blow to the people who run the football club, swimming classes, quilting groups and after-school clubs that glue the community together.” There was therefore a desire among Quilters to illustrate their own narratives of place through embedded practice and local expertise in order to counter this reading of their neighbourhood. Multiple pathways and movements have been imagined by the quilters to de-emphasize the dimensions of the tower blocks relative to their actual space. Rialto thus appears as a more porous, open and hospitable place which once again mirrors the effects of the quilts own creation. Of interest in this context are the vibrant colours and mnemonic properties of the Quilt which act as a praxiographic affront to the monotonous harsh grey concrete landscape that snakes among streets with brown-red tower blocks. The community is also busy at work and play with children in school uniforms laughing and holding hands outside of a school. Media perceptions of cultural and behavioural homogeneity are also countered through the representation of the first black woman within the neighbourhood, seen in figure 6 holding hands with, and working alongside her neighbours. These kinetic bodies have all been placed *outside*; thus suggesting that residents refused to be cooped up inside unhealthy and confining tower blocks, but instead have insisted upon their visibility, and can be seen actively occupying and even transgressing the political spaces of their own neighbourhood. Net curtains (again sourced directly from within the place itself) function as the exemplary leitmotif in the construction of class and communities;

*“*Seen indicating towards cut up net curtains in the quilt* you’d know the difference between Fatima and Dolphin anyway – they always washed their [net] curtains and Dolphin don’t wash their curtains – lazy shower over there!....Ah that’s only a bit of fun!!”- [‘Rose’ in ACET documentary DVD footage 1999]*

While net curtains police the hierarchies between neighbourhoods, they additionally enable the community to speak from a vantage- point of local expertise, using humour to disarm perceptions of pre-existing local rivalries. As Corcoran (2000) has discussed, internal divisions between estates often exist in places where overall quality of life is lowest. 70% of her tenant interviews with residents of Fatima Mansions did not feel part of the adjacent Rialto and Dolphins Barn and these divisions were most evident in everyday community activities from attending Church to participating in voluntary groups. Yet the visual portrayal of such a rich interactional space between communities, which has been quilted from an oppositional stance, is akin to the geographical practice of ‘counter-mapping’ which uses art to write

against its negative spatial constructions, and insists instead, upon an alternative geographical epistemology (Harris and Hazen 2006; Taylor and Hall; 2013).

The AIDS Quilt also enabled residents to revisit how they understood their place as having become susceptible to the AIDS crisis. In the left hand corner of the larger white community quilt (seen from Figure 6) exists a barely legible quote from the famous Irish ballad by Pete St John: ‘Dublin in the Rare Owl Times.’ While by all means no musical expert; one could only note in passing that this line has been part of a conscious cultural strategy to evoke a national nostalgia for a place that once was more health sustaining, but which has now been lost. Multiple references are given within this historic ballad to the changing geographies and forms of the city. A man named Sean Dempsey “as Dublin as could be” laments the expanse of his neighbourhood as “grey unyielding concrete make a city of [his] town.” The song is one of loss; not simply to a place, but to its beauty, evoked through the metaphor of a woman; “Fare thee well sweet Anna Liffey, I can no longer stay and watch the new glass cages that spring up along the quay.” The melody is set in four-four time signature, allowing for a slow and rhythmic progression which captures the wearisome body-memory of an elderly man, who, as “light declines” on his city, metaphoric darkness begins to cloud his own eyes. The song ends with an acceptance that change is inevitable; “I’m part of what was Dublin in the rare owl times.” By situating himself within his own past, the main protagonist assists in the cultivation and creation of place-meaning and brings the changing geographies and temporalities of the city into sharp relief.

Choice of music is often created through, and continues to reflect our existential positions at any given time, by creating a space to extend inner thoughts outward until it is united with our environments, almost as if occurring along a continuum. Use of a musical lyric such as this would thus tend to suggest that residents appear in discord with their own sense of place, particularly for those who find solace instead in the use of illicit substances; “the gargle dims me brain” as another line in the song reads. Further still, horses felling in the field are likewise anything but insignificant creatures that have been summoned back to ‘dwell’ among the life-worlds of the quilters. The horses act as proxies for the erasure of the commons. As Kearns (2015:) has argued, the erosion of Communitarian life became a geopolitical concern for Irish identity, having been largely “elbowed aside” to make way for colonial capitalism. Hence, Rialto’s exposure to the AIDS crisis was viewed as a multi-scalar phenomenon caught in complex entanglements with wider economic and political processes that can affect community ties and its

Set against the backdrop of a gentrified city along with nascent regeneration plans for Rialto, these multi-scalar references acquire a new resonance for a community that was stripped of their embedded knowledges and input regarding future plans for their community. In 1986, in the midst of an AIDS crisis

spiralling out of control, Dublin City Council undertook a modest attempt at regeneration of Fatima Mansions which was home to not one, but several members of the Rialto Community Quilting group. The refurbishment which cost 6.2 million pounds, focused entirely on a cosmetic enhancement of buildings and failed to open a dialogue with residents about the wider environmental and health needs that are required to sustain a community. As the heroin epidemic worsened, and Fatima Mansions became officially marked as a “no-go zone,” ‘Fatima Groups United’ began to argue that without a suitable social, environmental or health programme, “bricks and mortar” could sustain little in the way of community progress alone (O’Donohue et al, 2006). Written into a revised community strategy since 2001 however, which has since been implemented, is an acknowledgement of the arts in the production of healthy place; “involvement of artists in the regeneration process can bring imagination, skill and inventiveness to very practical and everyday objects.” (Regeneration Next Generation, 2001: 23). Using the quilt as a conduit to mourn this changing role of place, was important for the women as it enabled the “difficult role of memory- work” to begin, (Till 2008: 106). Quilters had in some ways to ‘let go’ of their memories of place prior to the AIDS crisis, so that healthier possibilities of place could be re-imagined in the present. Once quilters recognised place as an extension of their own bodily emotions, and indeed, their bodily labour, the community were able to assert their right to place, and creatively question for who, and to what end, economic progress ultimately served. By playing with iconography, narrative and aesthetics, residents were therefore able to use the place-based AIDS Quilt as a capacious medium of political expression for creatively “propelling the precarious into the realm of the political” (Butler and Athanasiou, 2013:101).



Figure 9: ‘Quilting in the Community’ by Rialto Community Quilt Group. Photo with kind permission from AIDS Care Education and Training.

Now, even several years after completing the Quilts, ‘place’ continues to be perceived, conceived and lived by residents as an integral factor for exercising what Butler (2004) refers to as a “right to grieve” for these AIDS deaths under “conditions where it has been [persistently] denied to them”. Etched into the community Quilt (of figure 1) is the figure of a plain green pine tree with the words; “what a disappointment” scrawled diagonally over and underneath. At first glance this meant very little to me, as one had to be *part* of the place in order to render it an intelligible reference. What ACET worker ‘Leanne’ referred to as the colloquially known: ‘Tree of Hope,’ had a legacy that ran deep with this community’s need for remembrance. First conceived in 1996 and bearing 69 stars and red ribbons for those who died of an AIDS or heroin- related illness, the community–led initiative commemorated the forgotten subjects with HIV/AIDS from the inner city (O’Doherty; O’Toole; 2001). Erecting a Christmas tree- themed memorial was thus significant for two primary reasons; firstly it was perhaps the first public acknowledgement that addiction was a collective issue, and thus warranted a collective response, and secondly, within the period of advent, the notion that a Christmas tree holds redemptive promise, is made all the more present.



Figure 10. The Community Christmas Tree.
Photo courtesy of AIDS Care Education and Training.

But the tree was not a celebration of lives as much a sobering reflection on the destructive potential of AIDS and heroin; “this tree and the ceremony lets the young kids see the devastation that drugs causes.” (O’Doherty,2001). Not before long, the Christmas tree became a beacon where drug users could not only meet informally to grieve, but could also engage in a negotiation of informal economies. It thus very

quickly earned a reputation as a place where “junkies [would] wait for their dealers.” (O’Toole, 1996:5). In an Irish Times interview with O’Toole (1996) an anonymous local woman informs him that she used to “polish the brasses of her front door at half past six in the morning so that she wouldn’t have to see the junkies queuing for a fix.” Because of this, the ‘tree of Hope’ was not renewed by Dublin City Council for the following year - not only because of the stigma associated with AIDS, but because disorderly and unruly bodies had been undesirably congregating upon or near local business premises. When I asked Lynn why the tree had been removed, her response was that; “well I suppose it was all the drugs and what not – the businesses felt mithered – they didn’t want it on their doorstep”. The tree was not to elicit the kind of dignified response from the general public that one would have initially hoped. Instead, it was manned by a local vigilante anti-drug coalition for 24 hours of the day as a way in which to police the bodies that encountered or circled the tree, (Anderson as cited in Citizens Free Press, 2006). Importantly, this transformed a much -needed ‘place’ of grief, into a regulated and uninviting environment. Removing the tree from inner city space only served to further marginalise this group both metaphorically and spatially as it pushed an already under-privileged population further from the site of public view. As Geographer Creswell (1996) eloquently quips, “public space is not always meant for the public” because so-called ‘undesirables’ including drug users, homeless people, migrants, and even women, can find themselves discursively excluded, or even physically removed from the inner city space. Clearing these unwanted and disorderly subjects from a prominent site of visibility was a way in which Ireland’s modernizing and neoliberal city could uphold a sanitized and specific spatial order. “Isolation and emptiness” were the resultant feelings among those who had sought it out as an effective space to grieve for loved ones (Anderson as cited in Citizens Free Press, 2006). Anderson (2006) writes that their fears were “needless” for “people took to the tree for what it was meant to be – a gift to brighten the dark days of winter.”

In some ways, then, the ‘place’ of a community AIDS Quilt, fulfils what the tree failed to realize. Scholars of the NAMES Project have emphasized how the AIDS Quilt, as a health intervention, fosters healing by “heighten[ing] awareness and inspiring action in the age of AIDS” (Knaus et al, 2000). However, the success of the Quilt relies in equal measure on a successful negotiation between the ‘space’ and ‘place’ of its display (Cant and Morris, 2006; Burke 2007). Circulating the quilt in and among Rialto may appear as though it were a relatively ‘safe’ and ‘appropriate’ option, but it was by no means conservative, as it highlighted the devastation of drugs and AIDS within and among a place in which it was needed the most. Despite the Tree’s precarious occlusion from inner city space, residents of Rialto were able to effectively ‘reclaim’ their own neighbourhood as a secure and confidential place in which to mourn the names and faces of their friends and families. ‘Friends Remembering Friends’ is a special memorial service dedicated only to people from within that neighbourhood and assumes a more salient role in the formation of place-

making when we consider how a generality of AIDS Quilts are now entering a broader crisis of visibility. This Rialto-based initiative, which began in the late 1990's, runs every November on Sean McDermott Street as a place in which new and old work produced by the community Quilt group is showcased, as well as constituting an unwavering reminder to local families that their loved ones are "remembered on that day" which, as Tina recalls, "means so much to them." Triangulating an AIDS Quilt with a place-based ceremony materializes 'place' as much more than a conceptually flat geographical notion which exists as 'is,' but instead which works *as* methodology for situated praxis. Functioning as a kind of *modus vivendi*, the AIDS Quilt, together with a place-specific ceremony, bears witness to the particularities of a precarious 'place' that too often gets written out of the expansive grieving space of the NAMES Quilt. In doing so, it prevents the homogenization of this marginalised place from being perceived as voiceless and invisible, while enabling its residents to educate future generations as to the dangers of its precarious past.

In sum, quilting has been, and remains an important practice among Ireland's HIV/AIDS voluntary organisations and one that has provided families with care, while also acting as a more radical act of political subversion. The material and embodied qualities of Ireland's AIDS Quilts have been interrogated through my engagements with the organisations as a medium through which the AIDS crisis, and its service based response is refracted. While precarity has become somewhat of a catch-all neologism, this chapter foregrounds analytic attention to geographical tensions between scale, diaspora and place as alternative articulation of performative power. In doing so, this chapter has questioned what the practice of AIDS quilting has looked like among voluntary organisations in a country predominated with teachings of the Roman Catholic Church. It has also explored an inner city's community organisations' place-specific response to the AIDS crisis, which has been particularly attentive to the inequitable spatial effects of the crisis. The unorthodox process of memorialization, and care that was exhibited by an integrated community in the making of a place-based AIDS quilt raises intriguing geographical questions as to the limitations of the scalar extent and geographical expanse of the NAMES Quilt. Despite variations in its form and content, such unorthodox versions of the AIDS quilt remain an inventive way in which bodies and collectives attempt to mark the anniversary of friends lost to AIDS. I turn now to consider other geographical formations of power in the state's service response to the AIDS crisis, this time in the form of blood donation and its ban on non-normative subjects.

CHAPTER 5: PRECARIOUS BLOOD AND THE LEGACY OF IRELAND'S AIDS CRISIS

Some policies from within the state service sector continued to harm the very groups that experienced marginalisation at the onset the HIV-AIDS epidemic. One example is Ireland's so-called 'blood ban', which, since the early years of the epidemic, has prevented gay men from donating blood since the AIDS crisis. It is now in the process of being lifted, thereby bringing Ireland into line with the majority of Western countries (Heneghan, 2015). This chapter examines the spatial practices and procedures of the Irish Blood Transfusion Service in the aftermath of the AIDS crisis, and how their practices and policies have induced precarity upon the bodies of non-normative subjects by continuing to blame them for the spread of disease. I begin with an overview of how the culturally significant spatial fluid of blood moves between the body and the body-politic and I then explore the types of exclusions introduced into blood donor services internationally. Finally, I provide an ethnographic reading of the spatial tactics that have stigmatized the non-normative donor population in Ireland, drawing in particular on two case study experiences.

5.1 SPACE, BLOOD AND THE BODY

Produced in the bone marrow, composed of red and white cells, and never varying in temperature between five or six degrees Celsius, blood serves as the ultimate vital force that enables bodies to both function and flourish. As a fluid, blood spans the entire scale of the body, occupying many locations and enacting multiple mobilities as it circulates within its enclosed, bounded space. A simple cut to the finger allows blood to cross a porous boundary between inside and outside, visible and invisible, momentarily disrupting contingent notions of stability and fixity in bodily form. From time immemorial, blood has punctuated the most prominent moments in the evolution of human life: sex, child-birth, marriage, and death (Titmuss 1971). Indeed, blood is an intimate substance: the 'bond' it generates between bodies renders it a vital space of exchange; something which others not only need, but which is everybody's right to give away. And although we are often unable to see it, blood still determines how we see others. As Nelkin (1999) and Schwarz (2009) have discussed, blood is a highly symbolic fluid, as national, religious, racial, gender and sexualised logics all determine where and when blood can acquire and occupy a position that is either in, or out- of -place. The awe and deference shown to this most prized and precious bodily fluid is palpable still among blood 'rituals' which feature prominently in Catholic countries such as Ireland, where the bread and wine of the Eucharist is substantiated as the body and blood of Christ (Starr, 1999; Nelkin 1999). But blood can also inspire alarm and repulsion, given that it is ordinarily censored in Western media, or when it is shown, is often part of a deliberate attempt to evoke emotional appeals of

urgency and exceptionalism. Perceptions of ‘danger’ associated with blood have also been largely responsible for reproducing historic gender binaries between male and female, as menstruation comes to symbolize defilement, dirt and disorder, while bodily fluids such as semen are rarely treated with the same contempt (Mumtaz, 1999). Crucially, blood is capable of what we might refer to as ‘up-scaling’ the saving of life, as advances in biomedical knowledge and medical transfusion therapies have enabled it to become a transferable tissue prolonging life on an exponential scale (Feldman and Bayer; 1999; Starr 1999; Waldby, 2002). When whole blood is extracted for transfusion, it is rarely transfused into another in the same way in which it was removed. First, it is screened and broken down into its constituent parts: red cells, white cells, platelets and plasma. In this way, the fragments which compose blood are afforded with an agency of their own as they move across geographically expansive pathways; its capabilities always becoming more than the sum of its individual parts.

When blood moves out of the body, it shapes public space, changing form, and developing new relations between bodies, places and technologies (Waldby and Mitchell, 2006). This erratic, but nevertheless purposeful and predictable movement along vast networks of people and technologies imitates the ebb and flow of a workforce that circulates among the state, conceptually tying the blood of the body, to the spaces of a metaphoric body-politic. Blood has always been territorial; it brings national space into effect not only by legally legitimating a citizenry through the policy of ‘*Jus Sanguinis*’ (‘right of blood’), but also functions as an integral expression of solidarity and community by enabling states to bind members of a collective polity. Some of the most seminal geopolitical moments of our time, such as World War II or the attack on the Twin Towers on September 11th 2001 (hereafter, ‘9/11’) exemplify the way in which donors can be cultivated and mobilized at unprecedented scale by evoking a symbolics of sacrifice, nation and brotherhood (Simpson 2009; Bennett, 2008). During the course of my fieldwork, blood donation also re-emerged as a matter of comparable significance following the mass homicide of gay men in the ‘Pulse Nightclub’ in Orlando, Florida. An exponential rate of donations had been mobilized in response to this incident, as Florida’s regional blood bank reportedly received 28,000 units of blood in one week alone, far exceeding its average of 18,000 units (Hudak, 2016; Brinkmann 2016).

For a catastrophe of this scale, there is no telling just how many units of blood are required, but according to Irish Health (2001), just one car accident can require up to 30, while a bleeding ulcer can require between 3 and 30. Neither medical advances in transfusion technologies nor attempts to adopt pig and/or synthetic blood have yielded success when compared to whole human blood and as a result, national citizens aged between 18 and 65 (up to 70 in some countries with GP approval) are regularly incited by the state to donate a ‘unit’ or ‘pint’ of blood every three to four months (Titmuss 1971; Reubi, 2010). Many states will still experience shortfalls in their national blood collection however, as narrow age, weight, medical, travel and sexuality restrictions render over half the population ineligible and, as such,

'clinically-dependent' on others leaving a mere 1% of citizens responsible for meeting the state's blood requirements (Busby et al 2016; Titmuss, 1971). Though blood transfusion is centrally managed by national services, blood drives occur more often on local scales of participatory citizenship (such as schools, hospitals, churches, town halls, clubs) where donors are perceived to be spatially 'closer' to the communities in receipt of their 'gift.' As geographers are all too aware, governance is always projected through space (Rasmussen and Brown 2005). It is this territorial mentality of the state which means that in practice, local communities often become the preferred locations for such performances of citizenship. Even the micro-scale space of blood donation is itself typically infused with disciplinary power, such that its material surroundings appear more inviting and comfortable, evoking what Reubi (2011) has referred to as a "cozy experience." Mimetically then, blood donation acts a site of convergence both for performance and governance that is enacted by bodies and states upon multiple scales, and in doing so, brings the borders and boundaries of citizens and non-citizens into full effect.

In many countries, blood donation relies on a voluntaristic or 'altruistic' form of civic engagement. The seemingly innocuous concept of 'altruism' has its roots in the writings of Richard Titmuss (1971) in his seminal publication: 'The Gift Relationship.' Writing at the height of a 1970's blood-product boom and its accompanying hepatitis transfusion-transmission scare, Titmuss argued that people who conceived blood as a 'gift' (evoking the classical anthropological notion of social contract as exemplified in the work of Marcel Mauss) and not a commodity, would be less likely to infect the blood supply as they would be giving altruistically, and not because they wanted money for drugs, alcohol or other morally deviant behaviours. He argued "the fact that... [the] program [which] operate[s] commercially of paid donors relies to a substantial extent on supplies of blood from Negroes suggests that the risks of transmitted disease may be increased" (Titmuss, 1971: 67). Thus, in the absence of hepatitis blood screening methods, Titmuss called for a *pre-emptive* blood strategy, one that would locate the risks to the blood supply not so much within the blood itself, but within donors, all of whom are assumed guilty until proven innocent. Or, as Glied (2010: 327) has put it: better quality donors, yield better quality blood.

Though it is the case that correlations do often exist between lower socioeconomic status and higher rates of morbidity, the danger of applying such a logic to donation is that it not only fails to attend to social disadvantage, but further punishes certain groups by symbolically stripping them of their ability to express this important practice of citizenship. Related to this, was Titmuss (1971: 126) argument that commercial blood provision would create an economic "crowding- out effect" that would lead to supply shortfalls and hence drive up the price of blood. Amid blood shortages and uncertainty, states would be forced to import from a potentially dangerous supply of international blood products. He, therefore, concluded that the 'silent killer' of hepatitis had been exported worldwide and was responsible for the disproportionately high rates of hepatitis-related deaths among developed nations, such as Japan where 98% of all blood products were bought and sold (Titmuss, 1971).

It is important to note that Titmuss' project has been criticised for its unreliable data (see Frow 1997) and particularly so in relation to the motives of so-called 'voluntary' donors (see Poel et al 2002: 285; Erwin et al 2009; Glied 1999). Yet his dubious assertion that marginalised and non-normative 'Others' deceive the national blood supply when given the opportunity, has become an irrefutable fact, not least by health organisations, but also in the generality of medical and scientific literature. Brooks (2004 :282), for example, has stated that, "when a significant incentive is offered [for blood donation], the likelihood of a donor being untruthful increases." "Giving a gift that has been misrepresented for the purpose of making the giver feel better about himself [sic] is immoral and selfish" (Brooks, 2004). I argue here, however, that rather than take these claims as self-evident, we can see instead that Titmuss' policy of self-sufficient non-remunerated blood donation was ultimately about securitizing blood and redrawing the boundaries of citizenship in an effort to establish blood as a substance that no longer could be universally donatable.

Blood, then, has become central to a widening repertoire of life-enhancing therapies that are subject to pre-emptive securitization and the legitimation of what some scholars have referred to as "medicalised Warfare" (Elb, 2010). In effect, this means that blood has been transformed from a prized and celebrated cultural substance into a site of regulation, securitization and management with profound implications for marginal citizens. In his lectures 'Sécurité, territoire, population and Naissance de la biopolitique,' Foucault (1977) found concrete reference points for his neologism 'governmentality' (or, essentially the preoccupation of postmodern states with altering and directing human behaviour) in the discursive management and containment of disease. Unlike the biblical-scale social exclusion of people with leprosy, modern states could more easily manage disease outbreaks with mass vaccination and national health campaigns targeted at the population but which, crucially, were also preventative in their logic, so as to securitize against *impending* disease threats. Blood represents one of the greatest biopolitical anathemas of modern medicine: not only is it a scarce raw material that emanates from life and thereby affirms life through use in transfusion therapies, but along with sex it has become symptomatic of the perils of disease, danger and death. As Strong (2010) has argued, both blood and sex are indexes of modern power. Blood is central to the symbolic *and* somatic reproduction of the state. As we have seen, governmentality worked in tandem with biopolitics and in doing so utilised as its coercive dispositif a range of rational calculations and circulations. Modern security, as Foucault argued, was ultimately concerned with the circulation of objects by 'eliminating dangerous elements, making a division between good and bad, and maximizing the good circulation by diminishing the bad' (Foucault [1977] 2007: 18; Ingram 2010;2011; Walters, 2012). It is in these dividing practices, or maximizations of power, where we might witness the logic and language of a Titmussian 'gift economy' (Simpson, 2009).

Securitization of blood began in 1975 when the World Health Assembly (WHA), undoubtedly influenced by Richard Titmuss (1971), ratified Resolution WHA 28.72 after expressing anxieties regarding the geographic expansion of blood and blood-based products during the international hepatitis crisis. Several decades later, HIV/AIDS became another critical moment rendering this ‘haemato-global assemblage’ the target of a securitizing logic (Roberts, 2010). The form that this securitization took was twofold: international, in the form of a booming ‘blood-economy’ and global HIV securitization; and subsequently domestic in the form of exclusion guidelines (see; Starr 1999; Connell 2017). According to the CDC, for example, since 2004 PEPFAR has provided approximately \$437 million in bilateral aid to strengthen Blood Transfusion Services in fourteen countries with high HIV rates. Because blood donation can function in an outreach capacity through targeted education campaigns and mobile HIV testing units, the Health Minister of one of these recipient countries, Uganda, maintains that blood donation has been one of the major instruments of AIDS control, rivalling if not exceeding other publicised AIDS prevention strategies (Makubmi, 1995). However, the WHO together with the World Health Assembly have also overseen 36 World Health Resolutions since the emergence of HIV/AIDS and hepatitis, all of which attribute blood safety and quality to standards in *domestic* regulation and screening. The predominant European Union Directive stresses that “blood supply for transfusion is very safe as the risks from blood-borne pathogens including HIV are minimal *because of exclusion guidelines* and extensive blood testing” (Directive 2002/98/EC) [my emphasis]. Hence, many people who are eligible to donate blood are therefore politically (as opposed to clinically) unable given the extent of blood donation ‘deferrals’ which are legitimated domestically by European exclusion guidelines. Because donors couch their willingness and desire to donate in terms of community and solidarity, deferral from this practice often engenders a sense of alienation from the wider polity (Polonsky et al, 2012).

5.2 DONATION DISEASE AND DEFERRALS

Going by Titmuss's assertions in the 'Gift Relationship', we might argue, then, that blood is a relational fluid that unites us all, and which is everyone's right to give away. This is why Pinker's (2006) point is more pertinent here, as he claims that altruism is not only made possible when the needs of a society are met through collectivist values that prevail socially, but that the actual type of altruism that prevails in society is a *conditional* one. The anonymity principle between donor and recipient he argues, prevents the “unfettered altruism” of every able-bodied person willing (or wishing) to donate. Valentine (2005: 120) similarly supports these claims by arguing that when “the condition of gift-giving is truth-telling,” and when donors are asked not merely to give but to give *correctly*, marginalized groups are, in his words, “devalued twice”: “in their ineligibility to assume the identity of blood donor, and in their imagined willingness to distort dishonesty.” Lengthy donor questionnaires forensically examine the donor's place of birth, travel history, recent sexual activity and a litany of other intimate practices. Blood Services, on the

other hand, typically paint a monochromatic picture of power by claiming that their selection criteria are standardized, fair, and in the interests of “safeguarding” a national blood supply. Indeed, the blood they claim to be interested in is secular, clinical and devoid of cultural context (Simpson, 2009). The outcome can be excessive and discriminatory donor exclusion policies centred primarily around controversial and intimate aspects about one’s race and sexual orientation, both of which I will now briefly discuss.

‘Foreign Blood’ has always been viewed as suspect. Racial exclusions in blood donation often masquerade as geographical or travel-based restrictions when bodies from particular locations are spatially located closer to the epicentre of infection. But as Foucault has argued, governmentality exists, such that finding oneself living in an area more badly affected by disease can act as a form of naturalistic ‘proof’ that one has failed to conduct oneself as a moral or rational agent (Biggs, 2005). Evidently, despite their ostensibly neutral appearance, we know that the legacy of race relations has historically been responsible for shaping the cultivation of a national donor pool, even long before the emergence of an HIV threat. This was evinced in the US, where black citizens were unable to donate blood until the 1960s (and 1970s in some Southern states) over perceived dangers of interracial blood mixing (Starr, 1999; Love 2001). Apartheid South Africa also historically relied on blood donors from white communities from as early as 1977 and this policy was only later re-examined having impinged on the long-term sustainability of their national blood supply (Bekker and Wood, 2006). Even after the foundation of its ‘Rainbow Republic’ in 1994, racial profiling of blood donations continued and reached a politically tangible point when President Mbeki’s blood was discarded under the existing policy (Bekker and Wood, 2006).

Haitians (regardless of their US citizenship) also found they were the target of a national blood ban on US soil at the height of the AIDS crisis, which Haitian-American scholar Fouron (2013) describes in detail. Drawing from US media reports that had systematically depicted Haitians as lazy, decrepit “boat people,” Fouron (2013: 341) shows how securitization of national blood was merely another trope in America’s anti-Haitian polemics. Fouron’s (2013) explication of his own discriminatory experience remains a critical intervention for revealing how the US state’s true intentions were not that of ‘blood security’ for driving a chasm between groups of citizens and creating a naturalised association between race, blood, and security. It is perhaps no surprise, then, that Charbonneau and Y-Lang Tran’s (2015) have documented in their paper on Haitian donors in Quebec Canada that, although this community are generally motivated and positively inclined towards donation, most understandably refuse to do so out of distrust and disillusionment of medical establishments.

In the early 1990’s, the Israeli state had been routinely collecting voluntary donations from Ethiopians while secretly discarding it under a ban unpublicised until late 1996 (O’Neill. 2003; Nelkin 1999; Farmer; 2006; Fouron, 2011). An article in ‘The Lancet’ covering the issue in (1998: 1127) documented the ways in which Ethiopians were already subject to systematic testing for HIV at border entries and thus

any supposed 'risk' which they posed to the Israeli population through blood donation was "vastly overestimated" at the time. It provoked international outcry among this community who took to the streets in protest, bearing placards that insisted upon the material realities of blood's universality and relationality: "Our blood is just as red as yours." (O'Neill, 2003). Polonsky et al (2011: 339) similarly explores the motivations of African immigrant blood donors in Australia only to find that for many, their belief was that: "white people can't accept the blood from Africans." Again, these testimonies speak to Strong's (2009) principal argument that the national blood supply developed as an index or metaphor of national security, which legitimises exclusions as an accepted or inevitable part of the blood donation practice.

Sexual orientation has also featured predominantly in blood donor securitization having placed gay men in particular at the centre of its exclusionary logic. The dispute over the prohibitions on blood donation from the so-called 'behavioural' collective, 'men who have sex with men' (MSM), refers to any sexual activity between men without confining this to sexual orientation (Bennett 2008). Restrictions on the ability of MSM to donate can take the form of both temporary and indefinite deferrals, depending on the geographical location (see Table 1). The ban came into effect in the US and Canada in the late 1970s and early 1980s during the emerging AIDS crisis, when little medical or scientific knowledge was known about HIV/AIDS and sexually active gay men, in particular, became the national focus of fears surrounding the disease. Self-exclusion during this period was achieved primarily through the provision of information leaflets about the virus, and did not include any targeting or stigmatizing donor questionnaires for people deemed to be of greater risk of acquiring infection (Feldman and Bayer 1999; Gilmore and Somerville, 1999). There is even evidence to suggest that the more informal and relaxed nature of self-exclusion criteria implemented during the crisis was unproblematically complied with as a preventative measure and never challenged among the gay community, as it had been among Haitian immigrants (Murphy, 2015).

But as Martucci (2010) has argued, when the FDA decided to relax its donor deferrals for Haitian immigrants, it simultaneously strengthened an association between HIV/AIDS and sexuality that would later become the source of significant international reverberation. It was in 1992 that the FDA officially upheld this ban and the policy became quickly normalized and embodied in the donor questionnaires of over twenty countries including Ireland, the United Kingdom, Canada, New Zealand, Australia, France and Germany (see Table 1). According to the previous Medical Director of the Irish Blood Transfusion Service, Dr William Murphy, Ireland primarily "look[ed] to the US and Germany as the most scientific and sophisticated states in managing blood transfusion... [and therefore] when the US instituted this policy, we felt that it was a reasonable position that was defensible" (Murphy 'Research meeting' Sept 2016).

The ban remained in place, however, without scientific evidence to support it but rather mounting international evidence to suggest its indefensibility. The most recent developments by the FDA in NAT-nucleic acid testing since 2014 show that it is now possible to detect HIV within blood by identifying viral DNA, as opposed to waiting for antibody detection in previous Western ‘blot’ tests (Stramer et al 2004; Pilcher et al 2010). As with most Western countries, it is now standard practice to test each and every donation for HIV, hepatitis B and C, as well as syphilis, even if the individual has already had a lengthy donation history with the service (Give Blood.ie). In Ireland, if a blood sample tests positive for any one of the above infections, the Irish Blood Transfusion Service is legally obliged to notify donors about their results, as well as passing this information onto the national Health Service Executive (Blood Donor Guide, 2013). The testing methods have been responsible for significantly reducing what those in the medical profession refer to as the ‘window period’ which refers to the short time gap between initial exposure and detectable infection, which for HIV, currently stands at a period of less than nine days, but could be as “low as a few hours” according to Dr Murphy (Murphy et al 2015: 12).

Blood screening has proven so successful in recent years that the so-called ‘residual risk’ of HIV transfusion transmitted infection is now (conservatively) estimated to be 1 in every 4 million (UK SABTO report, 2011). Because of this, international LGBTI groups claim that the policy (whether temporary or indefinite) constitutes nothing more than institutionalised discrimination on the grounds of sexual orientation. For gay men, part of what has made this policy inherently divisive has been what Garlandeau (2003) has referred to as the “inequitable risk tolerance” exhibited by transfusion services between sexually active heterosexuals and gay men. In the majority of countries that have upheld the ban (such as the US, Canada, the UK and Ireland), claims about discrimination have been accentuated by the lack of similar deferrals for heterosexual men who have had multiple sexual partners, have had sex with a sex worker, or females who have had sex with MSM, the latter of which has been typically been deferred for a period of six months only. Public health literature from the US statistically plotted the implications of a relaxed deferral for gay men versus women who have sex with MSM, relative to the size of the overall blood donor pool:

“If all women who had sex with MSM were excluded, only 1 infected donation every 980 years would be saved versus 758 donations lost. A lifetime deferral policy for MSM achieves a risk reduction that is 5 times higher compared to the reduction that would result from a lifetime deferral of FMSM.” (Germain et al, 2003: 428)

“Relaxing this criterion [of a permanent MSM ban] to a 12 month de-selection or to no de-selection, is expected to increase the risk of HIV transmission by approximately 60% to 500%...This would be the cost of an increase in donor numbers of less than 2%” (Soldman and Sinka, 2003: 273)

Though the figures are dated, the premise has remained the same that this marginalised minority have been told that their perceived danger as a vector of disease outweighs any beneficial numerical gain that would result from their inclusion in the donor pool. Instead, this group are given a curtailed politics of location, relative to that of blood recipients: “blood services exist solely to meet the needs of patients in terms of safety and supply. Donors are [merely] a means to an end” (Franklin, 2007: 127). The prevailing rhetoric is one that therefore insists that gay men are being more helpful to the body-politic when they quietly acquiesce to their exclusion and refrain from enacting their citizenship, while the heterosexual majority on the other hand, are given dangerously false assurances as to their own susceptibility to infection (Garlaneau 2010).

The primary difficulty in challenging the ban has been that European laws and regulations governing transfusions have facilitated a national territorial system that, by its very design, in fact *encourages* disparate international decisions to be taken on the ban. Franklin (2007) has discussed how legal rulings such as those taken by the Human Rights Commission in Quebec Canada, have insisted that blood donation does not constitute a human ‘right’; a decision which has precluded an agenda of justice and equality being sought on this basis. Franklin (2007) acknowledges, however, that blood donation has been a slippery legal landscape to navigate given Article 14 on the Convention of Human Rights, which prevents discrimination in the provision of services and the European Union CPA which requires that humans be protected from harmful ‘products’ (Franklin, 2007). As a result of the CPA, European Law has ruled that some form of an MSM ban is ‘discriminatory’ but one that nevertheless remains defensible in certain jurisdictions if ‘evidence’ can be deemed to support its ‘proportionality’ to the risks of HIV posed by this minority collective (Chrisafis 2015). This has been the case since the 2003 European ‘Treaty of Amsterdam’ and its accompanying European Commission Directive 2004/33/EC on the provision of the European Parliament to legislate on the quality and safety of blood products. There are no provisions within this Directive for a temporary or permanent deferral on MSM blood donation, but the Directive does stipulate that individual European states *can* make provisions to ban certain groups of people who, in domestic terms, are “disproportionately high-risk” of acquiring infection. Annex III of this European Commission Directive 2004/33/EC is suggestively vague in its assessment of what constitutes relative ‘risk’ and makes no clear distinction between someone who is ‘at-risk’ or who is ‘*high-risk*’ (or indeed for what specific infection one may be presupposed to).

National epidemiological statistics are regularly cited by the state to justify MSM exclusions. Previous national court rulings taken in the Netherlands and Finland on the basis of MSM discrimination were upheld for treating this group differentially, although this decision was overturned in 2013 (Murphy, 2015; Franklin 2007). The most recent litigation case taken by a French citizen in the European Court of Justice (ECJ) on April 2015 ruled a more progressive, but nevertheless similarly conservative outcome

that, where possible, countries should seek a “less onerous” means to protect the blood supply that fails to target people on grounds of sexual orientation (Chrisafis, 2015). By definition, then, European legislation surrounding blood donation is peculiar, for it establishes a territorial or federal-like system that restores power to jurisdictions which can endorse their own national prejudice, and renders the ban more difficult to *challenge* on the basis of geographically based knowledge or ‘evidence’ that would otherwise be held within the hands of only a small medical and scientific community.

Selected Countries	Current MSM Deferral Status as of 2017	Year of Change (If Any)
Ireland	One Year Temporary	2016/17
The United Kingdom (Scotland, England, Wales and Northern Ireland)*	One year Temporary (with intent to change to four months)	2011 for England Scotland and Wales. 2015 for Northern Ireland*
United States	One Year Temporary	2015/16
Canada	Five Years Temporary (with intent to change to one year in 17/18)	2013
Australia	One Year Temporary	2013
France	One Year Temporary	2016/17
Germany	One Year Temporary	2016/17
Spain	No Deferral	2005
Italy	No Deferral	2005
Belgium	Indefinite	No Change

Table 2: Status of MSM Donor Deferrals in Selected Countries as of Jan 2017.

Several countries have already begun to demonstrate leadership in this area by reducing or removing the indefinite MSM deferral due to pressures from an active LGBTI lobby, and not least from the emerging blood donor (heterosexual) youth many of whom have acted in solidarity refraining from donating blood

until provisions have been met for its removal (Healy 2016). Italy and Spain were among the first European countries since 2005 to entirely do away with a targeted ban and replace it instead with a general physician interview/ medical assessment for all at the point of donation. While this policy has been hailed among LGBTI activists for having eliminated discrimination, it was criticised by Ireland's Blood Transfusion Service in their review of the policy for contributing to a three-fold increase in the risk of HIV "window infections" in the blood supply.

The most common change, therefore, is the reduction from an indefinite to a temporary MSM deferral. Within the EU, the United Kingdom, as well as Germany and France have taken this approach, while outside of the EU, Australia, New Zealand and the United States have since followed with this initiative since 2015 (see Table 1). Canada instituted an incremental five year deferral in 2013, which is now likely to be further reduced to a one year deferral on the basis of a further positive review. As cases of litigation have generally been unsuccessful, the reasoning that is often been cited for the change indicate that a one year deferral would adequately lower the risk of window infections while putting the policy in line with that of females who have sex with MSM, and heterosexual men who have sex with female sex workers. During the course of my fieldwork, Ireland's MSM ban was still being upheld, but like many countries internationally it was in the process of being subsequently lifted as of January 2017. The current policy implemented in Ireland is now a 12 month deferral for gay men since the period of last sexual encounter (Give Blood.ie 2017). In the next section, therefore, I provide a closer analysis of the political geographies of Ireland's blood donor system in the IBTS and how its exclusionary policies have been expressed spatially, drawing in particular upon the personal accounts of two named individuals who encountered this exclusion.

5.3 BAD BLOOD AND THE POLITICAL GEOGRAPHIES OF PRECARIOUS CITIZENSHIP IN IRELAND

5.3.1 The Irish Blood Transfusion Service: An Introduction

Since 2002, the statutory 'Irish Blood Transfusion Service' (hereafter 'IBTS') has been charged with providing and overseeing a national blood transfusion service in Ireland which includes making available a regular and safe supply of blood and blood products, as well as organising and administering a service for assessing the more unexpected and undesirable effects of blood transfusion (Give blood.ie). This work is overseen by a national Chairperson, a Medical Director, and a team of hierarchically organised medical

and administrative staff that include consultant haematologists, nurses, general practitioners, laboratory scientists, and clinical directors. The IBTS Headquarters is located on the grounds of St James' Hospital, one of the largest hospitals within the city of Dublin. The IBTS has been designed as an administrative out-house of the main hospital with several floors of glass offices. Among the clinical white halls and floors is a room with a reception desk and a large black book placed on top to immediately indicate that one is required to 'sign in' and thereby make one's presence and purpose known to authorities of the Centre.

The architectural design of the space is such that it forces one into a state of introspection from the moment they walk in; it is possible to see your face in nearly every surface you look upon, from the sheen of the floors, to the clear glass office doors and for the face of the non-donor such as myself, the face looking back at one can be rather disconcerting. Unlike the main hospital, however, no ambulance sirens can be heard inside, no wards are lined with hospital beds, and there is no sense of impending urgency or chaos. The awkward silence is only occasionally punctured by the clatter of high-heels on tiled marble floors; otherwise the space is characterised by a notable absence of any sound. In general, a lack of chit-chat was exhibited by all members of staff upon my visits, most of whom kept their heads down and hurried between office rooms and floors. During my visit, as I stood in the main lobby and tried to make sense of the unease that engulfed me, I experienced my body as physically larger, almost as if I were awkwardly occupying and transgressing more of the space. Unlike the 'cosy' experience that Reubi (2011) describes in characterising the blood donor clinic in Singapore, this space was very much the administrative heart of blood donation and transfusion in Ireland; a space layered with history and controversy and one where my own presence as a research student was not going to be so readily entertained.

Over the last two decades, the political context within which the Irish Blood Transfusion Service has been working has substantially changed. The Service has struggled to rebuild a public image of itself that was damaged by the weight of public scandals that revealed its egregious mismanagement of haemophiliacs during the AIDS crisis. The publication of the findings of the 'Lindsay Tribunal' in 2002 found that under the remit of the previous 'Blood Transfusion Service Board' (BTSB) a total of four hundred haemophiliacs had been exposed to, and infected with either HIV/AIDS or hepatitis C between the years of 1970 and 1990 from blood products that were manufactured, sold or distributed under the BTSB's control. The controversy first emerged following growing international awareness among the medical community of the possibility of emergent non-A-non-B (NANB) hepatitis as well as HIV/AIDS in commercial concentrates Factor VIII and Factor IX; two indispensable blood clotting agents which provide the most effective line of treatments for haemophiliacs, despite not being the safest. Both the Lindsay Tribunal (2002) in Ireland and the Archer Inquiry (2009) in the United Kingdom make reference to alternative therapies that were available for haemophiliacs during this period, such as cryoprecipitate

(liquid frozen plasma that is self-administered through injection); a policy option pursued by Finland, for example. Ireland and England, however, remained wedded to the provision of commercial concentrates due to the freedoms that it had been providing haemophiliacs, and the belief among many in the BTSB that in the unlikely event of haemophiliac exposure to hepatitis C, it would be nothing more than a chronic but “manageable” condition (*Lindsay Tribunal* 2002). HIV/AIDS emerged as a matter of comparable concern from 1983, after two AIDS diagnoses were made among Irish haemophiliacs, one of which proved to be fatal (*Lindsay Tribunal*, 2002).

By this stage, the UK had already witnessed 33 haemophiliac-related AIDS deaths, and there had been 1600 in the US, which prompted the international medical community to implement blood donor leaflets self-excluding at-risk groups such as gay men and haemophiliacs but which also failed to directly specify AIDS related symptoms (Feldman and Bayer 1999). As Taylor and Power (2011) write, “by 1983, the incidence of AIDS among haemophiliacs had increased from 3 to 7 but many haemophiliacs thought that their immuno-suppression was the result of their treatment with concentrates.” The Lindsay Tribunal (2002) speaks to the lethargic response to the emerging AIDS crisis in Ireland, not least because the BTSB delayed heat treatment of commercial concentrates until after 1985, against medical advice (Farrell 2011; Taylor and Power 2011). Witness testimonies also expressed their sense of fear, loneliness, and dissatisfaction with the way in which the IBTS had treated them, a sentiment that was best summed up in the concluding remarks of the Lindsay Tribunal Part II (2002: 33) : “the tribunal was left with the impression of a group of people who had suffered and endured very significant degrees of grief, pain and hardship with considerable fortitude but with an abiding sense of hurt, anger and resentment as a result of their experience.” Haemophiliacs in general have often been regarded as the “greatest victims” of the crisis (Nesbitt, 1987: 11). A lexicon of morality governed the distribution of AIDS deaths rendering the experience of haemophiliacs as incompatible with gay men; differential categorisations that produced a massive silencing- effect, further marginalising and pathologizing the experiences of gay men. As Ireland’s only public service and corporate body that has been historically responsible for overseeing blood transfusion and which retains sole expertise in the provision of blood products and the safety in which they are distributed and supplied, the findings of the Lindsay Tribunal pointed to an “iatrogenic disaster” in Ireland’s medical history. It left an indelible mark on the manner in which the IBTS organises its services and responds to certain collectives today. It was within this broader context and against the backdrop of Ireland’s AIDS crisis, that I attempted to engage with the service and better determine how blood donation was being managed.

On the days in which I visited the centre, I took ethnographic notes on the intersections of blood donation and management. Typically, blood donors would start filing into the space from around 10am or shortly thereafter, and this would continue up until around 8pm at night. In the mornings, like clockwork, the nurses (demarcated in rank by their yellow and blue coloured uniforms) would appear busier, moving

hurriedly in and out of the offices carrying clipboards and paper files in preparation for the visitors. The donors would present themselves to the reception desk and smile collegially to staff members on duty before being escorted into an anteroom lined with refreshments and a flat screen television. People waiting to donate would regularly smile at one another and make occasional small talk as they took to their seats, but avoided getting into the personal histories that had brought them to the Centre that day. Posters on the wall would solicit the donor through eyes of a young girl addressing the donor in a fictitious voice: "Thank you for saving my life." It was perhaps no surprise that the interior mirrored this theme of a children's crèche as large blood-type letters A, B, and O decorated the walls and hung down from the ceiling in the form of balloons. The anteroom was lined with a comfortable couch and offered an array of refreshments including pastries, muffins and ice-cold drinks, while the television gave the space a comfortable feel.

Adjacent to the anteroom is the main hall with a check-in desk and a booth fit for no more than one nurse and a potential donor (a practice which I will return to). Behind is the aphaeresis room, partially concealed by glazed glass panels, where the procedure of blood donation takes place. In the aphaeresis room there are a number of leather chairs lined up with various medical instruments, and to their right is a table of free trinkets that include coffee mugs, stress balls, and T-shirts placed nearby as a way to offer rewards and thank donors once the process is complete (see Figure 1 for floor plan). The majority of people who presented to donate were middle-aged or older individuals, the majority of whom were men, but some of whom had come with their wives and were presenting as a couple, and thereby turning their donation experience into a kind of bonding or kinship-related exercise. Here in the inner Dublin Headquarters, one could presume that the donor catchment was local, but one that was decidedly not from the predominantly marginalised areas that surrounded the clinic. Instead, the men wore expensive brand label clothing, appearing to be primarily wealthy and/or college educated. Unbeknownst to me at the time, these men lay at the heart of the Services targeted and discriminatory donor selection practices.



Figure 11. Sample Floor Plan of Irish Blood Transfusion Service Donor Clinic. Right to Left: Apheresis Room; Questioning Booth; Anteroom with refreshments. Style after Parr 2000 and Conradson 2011.

5.3.2 Regionalizing The Blood Donor Pool

Donor selection is an elaborate process that involves much more than the scientific testing of blood. Rather, it begins when the potential donor walks through the door of the blood donation Centre. My encounter in the clinic was supported by claims of participants who argued that there appeared to be a relatively stable ‘type’ of Irish blood donor that one could witness attending centres and clinics dotted around the country : “oh well you know, it’s mainly the older married couple - kind of thing” [Interviewee 2B]. According to a report by the Medical Director of the IBTS, there are a total of 2,000,000 people in Ireland who could come to donate, and of these, only 100,000 come in any given year, but over 80% ‘pass’ donor selection procedures. So-called ‘at-risk’ groups are assumed to be self-excluding, leaving the composition of the donor pool to be an ethnically and homogenous group of heterosexual males, the majority of whom are college educated and with only one (female) sexual partner (McCullough 2011: 31). As noted in the IBTS report: “blood donors [in Ireland] may not be the same in several relevant ways as the non-donating healthy population, especially in relation to infectious disease incidence or prevalence - they have lower levels of risk of lifestyle acquired infections than the overall population, from a combination of passive and active excluding factors” (Murphy, 2015: 6). I argue that these differences are not merely coincidental, and cannot be sufficiently explained by shifting demographics or altruism alone (Murphy et al 2015; O’Reilly 2004). Instead, we should partly attribute

the cultivation of a national donor pool to the systematic political tactics that are employed by blood transfusion services and which have material effects when expressed spatially.

The kind of universal voluntary blood donation service that Richard Titmuss (1971) imagined, has created an administrative problem for the state, as it demands a particular set of strategies and tactics to be implemented in order to attract certain ‘voluntary’ donors while excluding others. Ireland’s ‘Give Blood’ website, for example, cites ‘donor testimonies’ that seem to attract or appeal to this relatively stable and ideal type of family-oriented donor, that has both good ‘Christian’ community values and only one sexual partner. Take ‘Roy and Susan’s’ story for example:

“My wife collapsed and lost almost two litres of blood within 90 seconds. There was panic and a team of 15 people around her working so fast. They got her back, but later that day she collapsed in the toilet. The same team of 15 rushed in and it all happened all over again. She then received 2 units of blood and was monitored around the clock. Three days later we got home with baby Eve. The crazy thing was that the day before, Wed the 30th, I had just given a pint of blood in Carrickmacross. I queued for over an hour because the Phoenix Centre was packed, but am so glad I waited... –Roy and Susan- (GiveBlood.ie, 2016).

For ‘Roy’ and his wife ‘Susan’, the nature of this event was surely traumatic. As a blood donor study, it both moves and affects, thereby succeeding in its desired aim. The reader counts themselves fortunate to be in receipt of their full faculties while being brushed with a sense of privilege that comes from helping another in need. But herein lies the admission of Ireland’s idealized blood donor traits. This married couple represents the paradigmatic trope of traditional Irish familial life. Susan, positioned here as both wife and mother, is constructed through seraphic imagery that depicts her as not only ‘giving life’ but being ‘brought back’ from another transcendental realm. Susan is giving birth but the episode is retold with excessive discretion, as the corporeal body-part(s) from which she loses blood is not mentioned. But perhaps most significantly, Susan is exemplary for affirming a normative ‘Self’: a middle aged family woman, she is someone who the heterosexual majority readership can not only readily identify with, but whose passive feminine qualities make her a desirable damsel for any man to ultimately ‘save.’

Her husband, on the other hand, is constructed as both victim and hero. Though he nearly loses his wife, it is implied that it may have been *his* act of donating blood only one day prior, that ultimately brought good ‘faith’ to the family by virtue of his wife’s survival. These testimonies are premised on a particular type of corporeally-abstract blood *recipient* whose vulnerability works to elevate the masculine donor to the position of heroic saviour. One can see from the majority of these online donor stories that the patriarchal family is asserted through use of what Kitzinger (2005: 479) refers to as “person-references” – in other words, linguistic codes that emanate from the social construct of the family. The state deploys these

“person-references” as the predominant and recognizable cultural frame of our existence, contrary to a multiplicity of other descriptors that could be utilised in designating one as either patient or blood user.

The connection between heteronormativity and patriarchy in familial arrangements, is of course, not a new one, and has been widely asserted among feminist scholars (Kim 2010; Butler 2005; Ferguson 2005). As with all patriarchal arrangements, the woman is expected to be above her children, but nevertheless beneath her husband who speaks about her, and on his family’s behalf. Susan’s passivity here is not unlike the majority of Ireland’s blood transfusion recipients, whose voice, whether adult or child, is rarely heard among blood donor testimonies. Given that there is strength in speech, preserving their voicelessness is paramount to the discursive construction of their helplessness and dependency upon a service that exists *for* them, rather than simply *involving* them. Busby’s (2010: 374) narrative account of blood banking in England buttresses this perspective by showing how communal responsibility required for blood donation is first engendered through an awareness that one’s own immediate family member might require a blood transfusion; thus, blood donation is (re)imagined as a space to “help someone like my mum.” Because Ireland happens to be “one of the least materially rewarding countries in the developed world in which to donate blood,” and donation is assumed to be principally driven out of voluntarism as opposed to material gain, familial motivation continues to constitute a “major pillar of safety” (Murphy, 2015). The intergenerational and kinship component of blood donation proved to be a decidedly common motivating factor among all my participants:

“I’ll tell you why I started donating blood. My granddad used to donate blood his whole life. And when he died, - you see now I feel like I’m giving blood in his place.” [Interviewee 2C]

“When I was really young, I used to go to the blood donor clinic with my mother at the time. She did go a fair bit...I remember being constantly around that and blood donation in general. Our dad didn’t actually donate blood because he had a fear of needles or donating or blood flow or something. Then after my sister turned eighteen and did it, I decided to do it too after all that build up it just seemed like the obvious thing to do.” [Interviewee 2A]

“Well my father was a regular donor in Ardee and I suppose it was his influence...it was something that was just done in our family and I suppose I would have saw it from a young age. [Interviewee 2B]

This speaks to McCullough’s (2012) argument that blood donation is first cultivated not only within the family, but within certain *types* of family that take on a blood donor ‘role’ that is strengthened through inter-generational commitment to the practice, as well as the formation of peer networks that similarly hinge on its regular adherence. By pedalling this association between a ritual space of citizenship, and traditional familial values of heteronormativity, the IBTS works to effectively keep the practice of blood

donation 'along blood lines' and thereby securitize it from non-normative subjects who are placed outside or beyond the traditional nuclear family. The heteronormative matrix, as Butler (2005) tells us, is more than a mere ideology, prejudice or phobia, but is produced in almost every aspect of our social relations, so much so that it becomes difficult for us to even recognize or delineate. Regimes of heteronormativity are constituted by the unproblematic assumption that there are only two sexes attracted to one another while institutions such as marriage exist merely for the purposes of procreation and to socially sort society along these lines of opposite sex-pairing (Rondahl, 2012: 21; Brown, 2010). As Kitzinger (2005) has argued, the 'family' is never an "objectively meaningful" construct, but requires consistent attention and (re)construction thereby rendering it an on-going and spatially mediated practice (Hubbard 2008; Kitzinger; 2005). Geographers have made critical interventions into the study of heteronormativity as a particularly violent and exclusionary regulatory context, noting in particular, how sexed and gendered expectations are themselves inscribed in space, and how these in turn come to relationally produce one's experience as abject in space (Hubbard, 2008). Knopp and Brown (2009), for example, have mapped the emergence of gay venues where it is culturally permissible to express one's gay identity, yet they acknowledge that while these spaces are openly celebrated among the LGBT community, they are nevertheless often 'othered' and spatially located 'away' from the morally superior domain of the family within areas of the city. Crucially, for scholars such as Brown (2011), Nast (2002) and others, there is an unspoken assumption that heterosexuality remains the 'default' or 'normal' perception of one's socio-spatial experience, while gay leisure, homophobia and/or stigmatisation are produced as a mere *effect* of this spatial encounter. Heteronormativity does not merely occur in a spatial vacuum, but is itself organized and expressed profusely by the national blood donor service on a national scale particularly to attract certain types of family donor that are deemed to be spatially located (both geographically and socially) away from epidemiological variations in disease.

Until the mid 1950s, the epicentre of Ireland's blood donation activity was focused entirely within the city of Dublin. The earliest blood donation centre was established at 115 Grafton Street, city centre Dublin 1945 by then Minister for Defence Oscar Traynor who coordinated blood transfusion for the purposes of military use and who appeared to have had little desire to (re)allocate it elsewhere. In a statement from 1945 he said: "Over a period of six weeks, posters advertising the work of the NBDC were displayed in all buses and trams operating in Dublin... one Dublin commercial firm has donated space in the Dublin Press to advertise the Centre. An advertising campaign is being inaugurated in the Dublin Press. In addition, Lantern slides have been shown in a Dublin cinema" (Robert Briscoe Papers, 1791- 1981). In July 1945, by means of a written question to the Minister, Mr Robert Briscoe T.D asked: "whether consideration has been given to the operating of a mobile unit so that Centres, close to Dublin, could be visited for accepting donors of blood." ('Robert Briscoe Papers 1971-1981'). The response was put plainly: "...in view of the amount and expensive nature of equipment required and the disproportionate overhead charges likely to be incurred, it is considered that such a scheme would not be practicable."

(Robert Briscoe Papers 1791-1981).

At this time, the state's central blood donor bank appeared to be frequented predominantly by wealthy and/or educated Christians who conceived blood donation as a moral as well as a societal good, and as a performance of citizenship that could enable them to effectively draw boundaries between them and their morally inferior 'Others.' A circular in the Protestant newsletter, the 'Church of Ireland Gazette' written by Mr Vivian Mercier in 1946 alluded to such Christian values inherent in blood donation, and its association with a predominantly Protestant upper class;

"there is surprising ignorance as well as superstition. An educated woman, that we know, who should have known better, thought that a pint of blood once lost, could never be made up again...we feel it is the duty of educated people to give a lead in doing a service against which there is still much ignorant or superstitious prejudice. Gazette readers as a class are educated people, and we would urge them to set the necessary example. The principle which underlies blood donation, is, after all, an eminently Christian one." (Blood Bank Social Aspects in Ireland, Vivian Mercier 1919- 1989)

However, growing urban poverty, a perceived decline in moral standards in the city, and increasing fears of a spatial clustering of disease all gave rise to very new spatial configuration of blood donation in Ireland. Within less than a decade, the National blood transfusion board was subsumed under the remit of a new 'Department of Local Government and Public Health; as a result of the 1961 Blood Transfusion Service Board (Corporate Bodies) Act, which gave Ireland three regional blood donation hubs in Dublin, Cork and Limerick all of which could additionally spread their territorial reach into rural areas by acquiring 'mobile' clinics in over 260 different venues across the country.

Ireland has historically had a disproportionate share of its disease burden concentrated within the city of Dublin, even when compared with other cities in Ireland. The 'Finlay Tribunal' (1997), for example published findings on the cause of hepatitis infection in women from the 1970's and had expressed concern over the spatial clustering of an initial pool of five women found to have donated plasma infected with hepatitis C from a localized zone on the northside of Dublin City. More recent epidemiological data gathered since the emergence of the AIDS crisis overwhelming indicates a vast spatial inequity in Ireland's disease burden, with 182 out of the 273 new cases of HIV located within the Eastern Health Service Executive Area, a region which extends from North county Dublin to South Wicklow. These trends have remained remarkably consistent over time.

Against this backdrop, the national blood transfusion service has recently partnered with the Gaelic Athletic Association (hereafter 'GAA') for an "It's in Your Blood" (2014) campaign that adopts a moralizing rhetoric to similarly emphasise this link between blood donation and traditional values of the

rural 'GAA community':

“With similar attributes like community spirit, pro-social commitment and volunteerism, we believe that the GAA community is key in helping us in our continued mission of maintaining a safe and sustainable blood supply, whilst building a community spirit around blood donation.” (Blood Donor Guide, 2014).

The GAA is undoubtedly the largest and most significant cultural sporting body in Ireland that asserts a particular relation between the individual (masculine) body and the body-politic (Mandel 1987; Cronin 1998). The historic British Army attack on civilians that attended a Croke Park GAA match in November 1921, otherwise known as 'Bloody Sunday' especially enabled the GAA to position itself at the heart of an anti-colonial mission, so much so that, as Cronin (1998: 93) argues, the 'turf' of its current headquarters at Cork Park, remains “drenched in patriot blood.” Its discourses of “muscular Catholicism,” as McDevitt (1997: 2) writes, can be seen not least in the 'christening' of club names, nearly all of which are named after heroic male national figures. National goals, as he claims, could now be sought “not in parliament or on the battlefield but on the playing field.” (McDevitt 1997:2).

Although the GAA is headquartered in Dublin, the sport has been historically prominent in rural counties such as Kilkenny and Kerry; counties which are inclined to be more racially homogeneous than the cosmopolitan centre of Dublin. Partnering with the GAA, then, enabled the IBTS to extend its power within and through space by giving it “access to services and clubs” while “educating club members on the importance of blood donation” (Blood Donor Guide 2013). This strategic decision has undoubtedly facilitated the targeting of physically fit, young Irish heterosexual males who reside in an imaginary sanitized and morally superior part of the country that can act as a bulwark against the risk of infection. Blood collection activities are thus determined by heteronormative values that are expressed spatially by the variations in epidemiological disease markers in an effort to avoid its concentration within large metropolitan areas. The 'rural,' as Kearns (2011: unpaginated) discusses, is an imagined space and an object of government looked to as the repository of traditional civility, while the city is “feared for its degrees of instability and innovation.” Indeed this 'rural body' is often portrayed as the desirable cultural safeguard against modernity; a space to uphold and reproduce traditional heteronormative assumptions regarding masculinity and femininity (Hubbard, 2008). Crucially, this heteronormative arrangement manifests in profound implications for members of Ireland's non-normative collectives who find themselves either stigmatized or entirely excluded from the *internal* space of the blood transfusion Service, as I will now show.

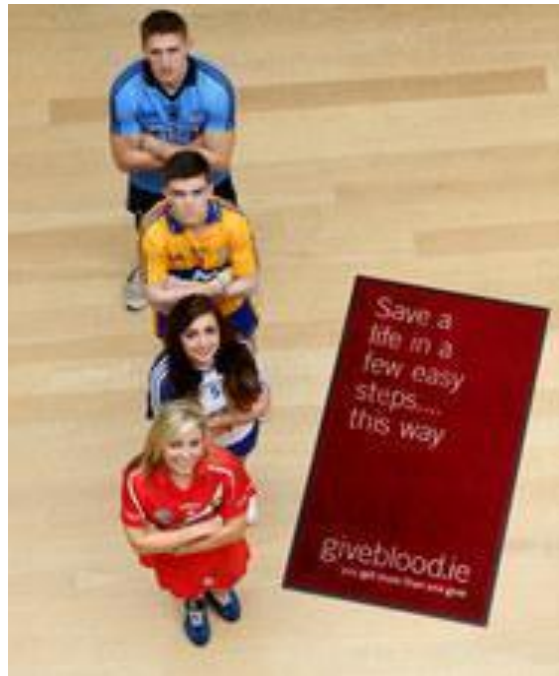


Figure 12. A racially homogeneous group of Irish citizens endorsing the IBTS 'It's in Your Blood' Campaign

5.3.3 The Space of Confession

The embodied encounter of the blood donor interview has become a necessary spatial tactic employed by the Irish blood transfusion service to securitize the national blood supply. The process begins when the potential donor enters the Centre and is directed to a reception desk where all one's personal details are taken, and which are then checked against an active blood donation registry. New and unknown donors are escorted by a nurse to a questioning booth for an interview that intends to unearth all aspects of one's medical history, as participants submit to an entire visual examination of their appearance and behaviour. This reconfiguration of the classic doctor-patient relationship is characteristic of what Foucault referred to as the "secularised regime of confession" which establishes certain 'truths' about the subject and solidifies medical knowledge: "our society has become obsessed with the infinite task of extracting from the depths of oneself, in between the words, a truth which the very form of the confession holds out like a shimmering mirage" (Foucault, 1978: 59). Confession is ultimately the practice whereby one verbalises aspects of oneself and one's sins to a higher Master who can offer them remission for their admission. The act of verbalising one's behaviour thus makes confession a *public* as well as a private act that brings one's private details into the public arena as a way to understand one's relation not only with the Self, but between the Self and others. Confession is now so profuse throughout society (in medicine, psychiatry, the Catholic Church, policing etc.) that one rarely conceives of it as a constraining effect of power (Feges

2013). For Foucault, confession was in fact a *productive* form of power that not only produced knowledge and discourse, but offered confirmation of who the subject ultimately was. Foucault acknowledged, however, that because confession could be an arduous task given the subject's own resistance or disinclination to verbalise aspects of their behaviour, confession works best, as Crampton and Elden (2012: 14) have argued, within a particular *spatial* configuration of power: "in order for the confession to be heard effectively."

By making reference to the way in which the donor clinic is arranged, I will elaborate briefly on how the space and procedure of blood donation works discursively on the subject in order to effect certain exclusions and foreclosures upon non-normative subjects. In the donor interview, it is generally assumed that the potential donor will conceal aspects of their ill-health. The entire blood donor interview is staged according to struggles between the visible and invisible, what is sanctioned and what gets punished. In the questioning booth the potential donor is typically handed a 'health and lifestyle' questionnaire which consists of thirty-six questions routinely provided every time one presents to donate, in case the donor's conditions have changed (Give Blood.ie). The purpose here is to construct a medical-geographical-history of the body to capture bodily practices that cannot be visually assessed on the day itself, and which reveal the 'truths' of disease that are no longer simply spatial but temporal (Foucault, 1973). The questioning, it is hoped, will encourage the donor to self-identify as being part of the 'high risk' group and voluntarily opt out of the procedure on this basis. Crucially, for Foucault, (2003: 163) the 'sinner' never preceded the act of confession, but was instead constituted through it according to values which the Master has itself ascribed. The esoteric questioning, and its spatial ordering on the paper, is deliberately designed to unsettle and confuse. For example, "do you weigh under 7st 12lb's?" could imply that a person must be *below* this weight in order to be eligible for donation as there is no follow up question about an upper weight limit. Implicit in this form of questioning is that the size, and hence the *appearance* of the body are immediately assumed to be an indicator of one's general health, productivity, and therefore safety. A range of bodily particularities are universalized in the name of security; medical conditions from cold and flu to serious illnesses such as cancer result in the same form of deferrals, despite there being no scientific evidence to suggest that either can be transmitted through blood (McCullough, 2011). Further still, questions are marked with heteronormative phrases based on scientific perceptions of bodily 'parts' ie; "if you are a woman" or "if you are a man," questions which, Ms Aoife Martin one of my participants and a trans woman argued, had found particularly offensive and exclusionary given that she did not feel that either of these binary categories adequately captured her own identity. "Why is there no box for 'Other'?" she exclaimed. "I felt as though there was no place for someone like me." (Aoife Martin interview 2nd December 2016). Though the IBTS declined to comment as to why it did not enforce non-binary donation questions, Canada's Red Cross Blood donation service made the discrimination quite plain when they commented that gender-neutral questions "would be too broad" and may therefore result in more deferrals

than would be necessary for the *heterosexual* population. Once again, this violent negation and oppression of non-normative identities is permitted in an effort to protect and promote the interests of the gender normative majority. The porosity of bodies and their environments is captured in the fears of acupuncture, tattoos and body-piercings, all of which result in deferrals ranging from two weeks and up to six months, depending upon the act itself. Moral deterioration is also conflated with corporeal proximity with bodies that are deemed to be less healthy, and therefore more morally suspect:

“In the past four months have you been in close contact with anyone with hepatitis?” Q 5.Donor Q.

“I remember I got a question about being in ‘close contact’ with a haemophiliac. Sure what does ‘close contact’ mean? I had to tell them that I had a good friend who had haemophilia at the time - God was that a mistake - I shouldn’t have said anything as it was more trouble than it was worth..Two nurses spent a good fifteen minutes asking me the same sets of questions trying to catch me out....I think they were trying to find out whether this person was a sexual partner or something, but sure he was only a friend!” [Interviewee2B]

One is therefore continually confronted with new and imagined aspects of the ‘Self’ as the IBTS seeks to determine whether deferrals and exclusions should be applied to the body. As Foucault imagined, even prior to its secularisation, the Catholic Confessional was designed to *modify* the person in question, thereby functioning not simply as a way to constitute the sinner, but to prevent one from acting inappropriately in the future.

Within this spatial configuration of power, the subject’s body is also positioned in such a way as to minimize the potential of the confessional being heard publicly while maximizing the body’s visibility for the purposes of medical scrutiny. The wall of the questioning booth is laid entirely bare and the space is empty apart from two white plastic chairs that face one another and are separated only by a small table placed in-between. According to the Give Blood (2016) website, the service stipulates that it does its best to undertake this performative ritual in “an area that provides as much privacy as the setting allows.” Segregation thus implies protection *for*, rather than from, the general public. Within this spatial configuration, distractions are minimized so that there is nothing separating the nurse’s gaze from the materiality of the donor’s body. As such, the corporeality of the flesh is deemed to ‘reveal’ a truth about the subject which cannot be so readily uttered by the speaking subject. Drawing upon Foucault’s writings on the ‘anatomo-clinical gaze,’ philosopher Edward Casey (1987: 352) makes the claim that, although the ‘speaking subject’ is often assumed to be constitutive of the post-modern power arrangements, it was in fact the *visibility of the body* as a geographical site and origin of sin in itself, that was “even more primordial” a concern for the practitioners of biomedicine. It is this corporeality of one’s bodily flesh that remains an indispensable visual modality by which all aspects of one’s normative behaviour can be assessed and surveyed: arms are scanned by nurses for signs of intravenous track marks, while one’s bodily movements are read so as to determine whether one is under the influence at the time of donation.

As Parr (2001) has discussed from her ethnographic observations of mental ill-health in Nottingham, body-talk is always expressed spatially according to normative power regulations that have been inscribed over movements and within particular locations. Drunk bodies, as she discusses, are assessed normatively by visual swaying, blurred speech, and relaxed facial muscles, while over-dilated pupils and 'erratic' arm gestures may indicate other forms of illicit drug use or states of 'madness' (Parr, 2001).

My participants were very much aware of these cultural expectations that surrounded and structured the confessional space of blood donation. Ms Aoife Martin, blood donor, activist and transgender woman for example, felt unable to walk in unannounced into her local donation clinic wearing female clothes on her normatively perceived 'male body,' as she believed that "being in their domain" not only "put her at a disadvantage" but would have automatically 'outed' her trans identity. As a result, Aoife would only converse with the blood donor clinic over a spatially distant phone-call. During the period when Ireland's MSM ban was still being implemented, other forms of sexually dissident citizens such as gay men feared that if they continued to donate, they might be 'spotted' or 'found out' and would therefore have to work harder at suppressing or regulating their own bodily movements in space: "it's uncomfortable...they keep you there and ask lots of questions but all that's going through your mind is getting in and out of there as soon as possible" (Interviewee 2B). When blood drives were held in workplaces and universities, many gay men had to navigate the Service's spatial foreclosures in the midst of public social interaction, compelling many to donate blood so their ineligibility would not have been inadvertently 'outed' in front of unwitting family members and work colleagues (Rainbow Project Northern Ireland, 2013). One of my participants recalls being informed about blood donation in school at the age of sixteen, when a classmate turned to him and informed him: "you won't be able to do that....because you're...you know" and, as he recalls, "[he] wasn't even out at the time."

The experience of the blood donor encounter has thus been experienced profoundly differently for non-normative subjects. Drawing on Butler's concept of performativity, Seidman (2001) has claimed that non-normative minorities can never be "entirely eliminated" from society, only the spaces in which they move can become the targets of regulation and control. He provides the example of LBGTI parades and cultural venues where it may be permissible to openly celebrate non-normativity; but within spaces that are afforded with biomedical knowledge and authority, gay men find themselves either repeatedly shut out and excluded, or having to downplay their bodily comportment and acquiesce to heterosexual normativity (Johnson, 2002). The confessional space therefore operates according to a territorial logic that acts as an injunction on who can enter or fully participate, manifesting in either tangible material exclusions, or internalized foreclosures. This boundary making process becomes another form of repressive everyday violence that is perpetuated by the state against non-normatives in an effort to protect the 'purity' of the heterosexual. Unlike Foucault who claimed that all public space is infused with panoptic regulation and normalization however, here I draw upon Butler's (2009) concept of performativity to demonstrate that

even within this highly regulated confessional space, the donor body can still be formulated as a site of resistance. Bodily tactics such as silence and ‘dishonesty’ can be appropriated by the subject in order to resist and trouble the anatomo-clinical gaze that is fixed upon them, while still enabling them to continue pursuing their goals:

“sure if I’ve queued for two hours I’m hardly going to tell them I don’t feel well now” [Interviewee 2B]

“I know a fair few who will conceal....it’s not that they do it maliciously. They actually go and get tested beforehand...it was suggested that that’s what they do - not by the Service - but by people and friends - just as long as you know that you’re fine then it’s okay” [Interviewee 1A]

Butler (2009) has claimed that for a ‘right’ to be exercised, it must be ‘performed’ by a collective who are asserting their bodies visibly and relationally through the public space of the street. We can see here however that this collective of non-normative donors have at times acted in a form of ‘silent solidarity’ with one another, across time and space, but are still very much visible, *by virtue* of their invisibility. ‘Non-compliance’, the medical term applied to those who fail to adhere to the blood ban, is profuse in the medical literature and has become especially troubling for countries such as Ireland expecting to relax its blood donor deferrals, given that the rates of non-compliance can never be adequately statistically plotted (Murphy, 2015). Hence, by acting collectively in a hidden and disjointed manner, non-compliant blood donors have radically disrupted and troubled the IBTS selection regulations, as well demonstrating their ineffectiveness as a protection method from the outset. As was admitted by the Director of the IBTS Dr William Murphy and medical colleagues (2015: 12) in a report to Ireland’s Department of Health: “the donor interview process may be ineffective as a barrier to prevent at risk donors from donating. While it may prevent some infected donors getting through to donate, there are no data to give any meaningful estimate of the proportion that is excluded at this point.” Hence, the marginal subject may be ‘punished’ by a Panoptical spectre, and stigmatized through this encounter; but there are moments that nevertheless reveal its normative fragility and instability forcing transfusion services to have to modify their tactics in response to the subjects body. I turn now to explore in more detail, two personal examples of the nature of this discriminatory experience.

Please read carefully and complete before donating by placing a tick ✓ in the appropriate box. If you are uncertain of any answer, leave the box blank and speak in confidence with a health care professional

Your COMPLETE HONESTY in answering all questions is essential for your safety and the safety of patients who receive your blood.

ALL INFORMATION YOU PROVIDE IS CONFIDENTIAL

NEVER GIVE BLOOD TO GET A TEST FOR HIV OR HEPATITIS IF YOU DO YOU RISK INFECTING OTHER PEOPLE

Are you: Yes No

1. Well and healthy at present?

2. Involved in a hazardous occupation or hobby?

In the past 48 hours have you: Yes No

3. Taken an anti-inflammatory?

In the past 5 days have you: Yes No

4. Taken aspirin or any tablet with aspirin in it?

In the past 4 weeks have you: Yes No

5. Been in contact with anyone with an infectious disease?

6. Taken any tablets or medicines other than the pill or HRT for the menopause?

7. Had treatment with Proscar, Propecia, Roaccutane, Isotrex, Retin-A or Zorac?

8. Had treatment from a dentist?

In the past 8 weeks have you: Yes No

9. Had a vaccination?

In the past 3 months have you: Yes No

10. Had any illness or received any treatment from a doctor, nurse or other health care professional?

In the past 4 months have you: Yes No

11. Had acupuncture?

12. Had ear, face or body piercing?

13. Had a tattoo or cosmetic treatment that involved piercing the skin?

14. Suffered a needlestick-injury, human bite or a blood splash into your eyes, nose or mouth or onto broken skin?

15. Had an endoscopy (scope)?

16. Been in close contact with a person with hepatitis?

Have you EVER: Yes No

17. Had a blood transfusion - red cells, platelets or plasma?

18. Had or been treated for syphilis or gonorrhoea?

Since 01 January 1980 have you: Yes No

19. Had any operation, eye surgery, laser eye treatment or root canal treatment in the UK?

UK includes Northern Ireland, England, Scotland, Wales, the Channel Islands and the Isle of Man.

Since your last donation have you: Yes No

20. Had any serious illness or medical condition?

21. Been treated by a Dermatologist or skin specialist?

22. Had an operation or any surgery?

23. Had jaundice or hepatitis?

24. Had a sexually transmitted infection?

25. Been told that any of your relatives had Creutzfeldt-Jakob Disease (CJD)?

26. Taken care of or handled monkeys or their body fluids?

After your last donation did you: Yes No

27. Faint or have any problems?

Travel: Yes No

28. In the last 12 months OR since your last donation (if less than 12 months ago) have you been outside Ireland or the UK for any reason e.g. business or holidays?

29. Have you EVER had malaria or an unexplained fever or an illness which you could have picked up while travelling?

30. Have you EVER lived in a malarial area for 6 months or more?

31. Have you EVER lived in or visited Mexico, Central or South America for 4 weeks or more?

If you are female: Yes No

32. Have you EVER been pregnant or are you pregnant at present?

33. Have you received a donated egg or embryo since 01 January 1980?

34. For all donors: Yes No

• Are you donating **JUST** to be tested for HIV or hepatitis?

• Do you or your partner have HIV?

• Do you or your partner or close household contacts have hepatitis B or hepatitis C?

• Have you **EVER** injected or have you been injected with non prescribed drugs - **EVEN ONCE OR A LONG TIME AGO**. This includes body building drugs.

• Have you **EVER** been given money or drugs for sex?

• **IF YOU ARE MALE**, have you **EVER** had oral or anal sex with another male - with or without a condom or other form of protection?

35. In the past 12 months, have you had: Yes No

• Sex with anyone who has HIV or hepatitis?

• Sex with anyone who has **EVER** been given money or drugs for sex?

• Sex with anyone who may **EVER** have had sex in parts of the world where HIV is very common? This includes Africa and South East Asia.

• Sex with anyone who has **EVER** injected or who has been injected with non-prescribed drugs, **EVEN ONCE OR A LONG TIME AGO**. This includes body building drugs.

• Sex with anyone with Haemophilia or other blood clotting disorder who has **EVER** been treated with Clotting Factor Concentrates?

• **IF YOU ARE FEMALE**: Sex with a male who has **EVER** had oral or anal sex with another male, with or without a condom or other form of protection?

All of the above apply even if a condom or other form of protection was used.

36. In the past 12 months: Yes No

• Have you been imprisoned?

• Have you snorted Cocaine or any other drug?

BT400A-Ver 3 May 16

Figure 13. The Irish Blood Transfusion Service ‘Health and Lifestyle’ Questionnaire as of 2016. Provided with kind permission from the IBTS. See also attached as appendices.

5.3.4 Encountering Exclusionary Citizenship

TOMAS

From the beginning of the AIDS crisis in 1983, right up until January 16th 2017, any sexually active gay man who presented to donate blood in Ireland was met with Question 35 of the donor questionnaire [see figure 2]; “for men; have you *EVER* had oral or anal sex with another man, *EVEN ONCE*, with or without a condom or any other form of protection?” [emphasis in original]. This was ultimately where the panoptical spectre of the international AIDS crisis, and the legacy of Ireland’s haemophilic scandal, cast its gaze back over the bodies of Irish gay males in the contemporary political climate, in an effort to legitimate their exclusion from the space of blood donation. Three days before Ireland went to cast its vote

on the ‘Marriage Equality’ Referendum, 22nd May 2015, journalism student Mr Tomas Heneghan was informed by medical staff at the IBTS in Dublin that, because he was now a sexually active gay man, he would no longer be able to donate blood in Ireland. Little was known about Ireland’s ‘gay blood ban’ during this time, apart from those within the medical professions, or men who had found themselves directly affected. Despite the issue having featured in the Irish media (The Journal, 2016; 2015; Heneghan 2016; Carolan 2016; 2015) and blog postings (Healy, 2016) there has been no comprehensive study about the Irish blood ban, its effects or challenges to date. Even among Ireland’s LGBT organisations, the predominant focus of equality issues had been the Marriage Equality Referendum which was passed to allow marriage between two persons in Ireland irrespective of their sex. Growing on the back of this highly politicised and successful movement was a small but powerful voice from Ireland’s students who were becoming increasingly aware of the discrimination that the ban perpetuated. What began as a Student Union petition to the IBTS in 2003, signed by over 3000 students to “reverse [the] ban on blood donations from homosexual men,” marked the beginning of a slow but sustained interest surrounding this matter (Irish Examiner, 2003: 3). The issue received further media attention following the UK’s decision to ease its ban in 2011, forcing representatives of the IBTS to make a statement on the matter to which they concluded: “evidence [in Ireland] was not yet available” for a change, resulting in further anger and disappointment among Ireland’s gay community. In 2016 the matter reached climactic proportions when the IBTS prompted Heneghan to begin a year-long legal challenge against the state. As Tomas informed me in an interview (16th November 2016), “I always felt that change was coming... I just didn’t realise that I would be the one to bring it about.” (Heneghan Interview November 16th 2016).

Although the official change came into effect on January 16th 2017, for the majority of this research project Ireland’s MSM blood ban had still been in place, and I therefore refer to Tomas’ story to elucidate his experience donating blood and encountering this ban as a gay man in Ireland, as opposed to unearthing the legal intricacies surrounding the court case. Tomas was one of Ireland’s few but desperately-needed donors, who constitute a mere 1% of Ireland’s blood donor population. He describes the practice of donating blood as not merely something that he used to “stick to” but something that he took the time to “follow around.” He claimed that because it was every four months, “if there wasn’t a clinic being held in my local area, I would get someone to drive me to this random place in County Galway over half an hour from my house by car so I could donate in a hotel from there.” By the age of twenty, blood donation had become a routine and normalized practice for Tomas, but one that was nevertheless significant for enabling him to become a “good citizen,” capable of ‘giving something back’ to those less fortunate: “you feel like you have done something really good with your time. In my head, there just doesn’t seem to be much reason why someone should not do it once you have done it and everything has gone fine.”

When Tomas got his first serious boyfriend at the age of nineteen, he felt compelled to discuss early on with him that blood donation was a big “part of [his] life [that he simply] wasn’t ready to give up... So [he

and his partner] withheld certain [sexual] acts that would have prevented [him] from donating blood.” For Tomas, this was a particularly precarious balancing act, which required him to repress or negate his true identity in exchange for being part of an important space of citizenship. Tomas acknowledged that within his circle of gay male peers, it was perhaps more commonplace for some to simply go ahead and “tick that questionnaire box that said ‘no’.” But Tomas was fervently opposed to doing something he felt uncomfortable with, and chose instead “to be honest” with the Service, given that he had, by now, become wedded to its normative principles; “the Service relies primarily on a donor being completely honest because not all tests are 100% so they need you to be 100% truthful....But it’s a good system to have the two [barriers] to stop any diseases or infections coming through.” As one of the Service’s ‘good gay’s’ who had not yet been sexually active, Tomas could donate honestly and with ease without the perceived ‘danger’ of his acts weighing in on his conscious. It was only some time later, when he and his boyfriend agreed to take their relationship further, that Tomas came to the realisation that he should not have to hide who he truly was, just so that he could be considered as a full member of this rather exclusionary space of citizenship. He noted: “It was kind of the idea that – there was nothing to be ashamed of in the behaviour that they banned. I didn’t want to hide what I had done, just to be able to donate.” Hence, the blood ban was constitutive of a particular *moral* boundary for Tomas, for it had established a distinction between the safe/sanitary citizen that had previously defined him, and the indulgent queer who was merely a bodily vector of the AIDS crisis. By engaging in a sexual act with his boyfriend, Tomas thus feared that he would be morally transgressing this previously held identity that had championed normative principles of blood donation, and that he would now be marked instead with a blemished character. As it transpired, Tomas and his boyfriend decided to end their relationship shortly thereafter, without him having engaged further in any sexual relations.

Ireland is unique in that it facilitates a system whereby the general public can call or write into the IBTS (anonymously if they so wish) in order to inform the Service about the behaviour of any one of their donors who they believe will infect the national blood supply. According to the ‘Give Blood’ website, all such information is followed up with in a very serious manner in the form of a confidential donor interview, while the details of the informant, on the other hand, are never released (GiveBlood.ie). It was this “anonymous tip off” that in fact sparked the initial controversy between Tomas and the IBTS. The Headquarters, as Tomas recalls, received “an email from someone saying this guy has been engaging in homosexual activity and is still donating blood.” The tip-off immediately placed Tomas on a national deferral list without even his awareness or consultation (Interviewee2A). Such an accusatory system is problematic for two primary reasons. Firstly, it conflates the interests and safety of those who do the informing with a heterosexual majority that are endangered by the many forms of MSM desire. As we have already seen, the ‘public’ or national blood donor system in Ireland is constructed heteronormatively according to “good” moral Catholic Christian values that are deemed to be the antithesis of homosexual acts. Despite Ireland’s LGBT legal advancements in the form of the Marriage Equality Referendum, the

blood supply has been continually viewed as a culturally (and religiously) symbolic fluid that exerts a greater moral imperative for protection from MSM “erotic territories” (Painter, 2005). We are unaware of who informed the blood service about Tomas in this case, (and cannot make speculations) but there is no reason to believe that any number of individuals (from the MSM collective or otherwise) could have made a claim that was a fabrication of reality in a deliberate attempt to hurt or punish someone. The practice, which is still endorsed in Ireland, is therefore arbitrary and flawed, for it is based entirely on anecdotal evidence that assumes the ‘truth’ of a heterosexual majority who act as guardians of ‘their’ national blood supply over and against non-normatives, who simply cannot be trusted.

Secondly, the flippant reference which had been made to Tomas’ ‘homosexual activity’ blurred an already ambiguous context for it could have encompassed any range of non-high-risk sexual activity, including anything from kissing to oral sex. Tomas informed me that he and his boyfriend had engaged in an act of oral sex that had occurred during a period when Tomas had not even been donating blood. He recalls clearly:

“There was no reason to put me on a deferral. The [sexual] act was described on a men’s sexual health service by the HSE - as carr[ying] no risk of sexual infection, whereas the Blood Service argued that it carried a high risk. So we [Tomas’ legal team] thought, either the HSE’s right or you’re right. And considering you’re both arms of the Department of Health, one of you has to be wrong here.... So we were arguing that the IBTS was in the wrong rather than the men’s sexual health service - so that was a big part of the problem, was that that particular sexual activity didn’t carry the risk that they were claiming it did.”

Tomas was justifiably confused as to why a donation service so saturated with fears of sex, ironically failed to take the necessary care to define, or indeed make explicit, the full range of MSM sexual activity. The IBTS questionnaire made it explicit that both penetrative and oral sex is forbidden in terms of MSM blood donation even if a condom has been used. But as Tomas discussed, these are two entirely different sex acts with very different medically and scientifically proven outcomes in terms of susceptibility to infection. Ireland’s HSE ‘Man2Man’ information and awareness website clearly acknowledges that: “The risk [of HIV] for oral sex is not as high as the risk for unprotected anal sex,” while the American Centre for Disease Control (2016) [which Ireland claims to be the definitive voice on STI surveillance] also states that “there is little to no risk of getting or transmitting HIV from oral sex.” And though both information sites acknowledge the possibility of other infections being transmitted through oral sex, these risk factors hinge on everyone’s susceptibility to infection: lack of awareness of one’s STI status or inadequate use of protection methods. The suspicions that surrounded Tomas’ body therefore led him to conclude to the Irish media that: “I realised a man didn’t have to have sex with a man to face problems donating blood. All a man had to do was openly identify as gay, and he would automatically be viewed as a problem” (Carolan 2015).

Moran (1996: 206) writing about homosexuality and the law, has shown that this prevailing perception of the gay male body within an institutionalised framework would not, however, be a deviation from the norm. The typical discursive construction of the male body through law and policy has been what she describes as “buggery” “sodomy” and indecency...with “considerable significance in jurisdictions such as Scotland, Ireland, Canada, the USA, New Zealand, and Australia.” Since the legacy of the AIDS crisis however, these representations have taken upon themselves, a new “chain of associations” with the manifestation of death, disease and decay. Representations of the AIDS body marked with Kaposi Sarcoma lesions or wasting due to fat and muscle loss, constituted what Douglas Crimp (2002; 85) has referred to as “portraits of abjection and Otherness” that have been a significant part of the cultural memory of AIDS, not only for giving AIDS a ‘face,’ but for decontextualising the body and reproducing phobic responses to the men they illustrated. AIDS activists from ‘Act Up’ have also been historically critical of these images for serving to construct disease as an individualized problem, rather than a social responsibility (Watney 1990: 190 in Campbell 2000). Varas-Diaz and Toro-Alfonso (2003) present a more insightful analysis of these images however, by claiming that the diseased body is symbolic of the material destruction of the wider body-politic. Such representations have not been erased from our cultural memory and have arguably become an institutionalised feature of the contemporary blood donation practice. In his deliberations with the Department of Health on the proposals of the Irish state to relax the MSM ban, Medical Director of the IBTS, Dr William Murphy et al (2015: 10) made a striking admission:

“What therefore is the deferral based on, if not HIV, and if it is not grounded in a consistent approach to microbiological threats? It appears to be, at its simplest, a fear that what happened in the late 1970s and 1980s could happen again and we had better remove the measure that helped reduce the spread of infection then. This is not an irrational fear - it would be naive to think that a new infection or mutant HIV strain could not arise in the same way...sexually transmitted infection spreads much faster in the MSM community.”

Such a startling and prejudiced remark is in fact an honest reflection of the ways in which the gay male body is deemed to be not only untrustworthy, but continuously mapped as a space to project future fears of a diseased, decaying and death-ridden polity (Bennet 2015). A review of policy documents in the IBTS ‘Consensus Conference’ held in April 2016 on the future of the MSM blood ban in Ireland showed that the agenda on whether to take a progressive decision regarding the ban was largely overshadowed by fears of so-called ‘emerging infections.’ Ireland, for example, lamented that the “greatest devastation from blood transfusions” had arisen when “a new infectious agent arises in the blood donor population and spreads to recipients before the disease is recognised.” (Murphy, 2016). Given that the HIV virus was a new blood-borne infection in the 1970s and had a major impact upon blood transfusion, Services

internationally have been understandably concerned about the possibility that this may be repeated in the future. As O’Leary (2014) comments that the spread of STI’s among gay men has been labelled a “syndemic” and that even prior to HIV/AIDS, STI’s were frequently associated with the ‘gay lifestyle’ with multiple partners, and the emergence of “chem-sex.” Randy Shilts, writing on the emergence of the HIV/AIDS epidemic has also been responsible for promulgating this discourse of a dangerous gay lifestyle riddled with repeated infections such as “gay bowl syndrome” which had become the norm among gay men during this period. However, the Centre for Disease Control (CDC) Transfusion Transmission Diseases Committee has since reviewed “69 agents” of transfusion risk including vCJD (mad cow disease), Middle East Respiratory Syndrome (MERS), Zika Virus and Chikungunya all of which are transmitted through food, insect bites, and geographical travel; infection routes which cannot simply be attributable to so-called non-normative behaviours associated with anal sex or illicit drug use (Bennett, 2010; O’Neill; CDC 2016). Bennett’s (2015) exceptional analysis in his text ‘Banning Queer Blood’ provides an unparalleled and distinguished analysis of the blood ban in the US told through the role of gay men’s acts of ‘passing and protest.’ Commenting on the role of emerging infection, Bennet (2012) too, is adamant that the imaginaries surrounding the gay body as a harbourer of the unknown, and therefore threatening, reveals that the untenable assumptions which are made by blood donor services about its objective and value-free reality are in large part determined by conjecture, chance, and what Healy (2016: unpaginated) refers to as: “phobia in the truest sense of the word.”

Tomas was thus forced to ‘confess’ that he had engaged in this low-risk sexual encounter following a written summons to attend the IBTS headquarters for a highly invasive and publicly humiliating litany of questions. He describes this stigmatizing encounter;

“The way they handled it was really inappropriate...It was half an hour of really weird questions. We had agreed to discuss my previous donations in the email... Right, no problem there.... But instead what they kept asking me was about everything - my entire sex life right up until that day. And I just thought, my past six months was none of their business?! I hadn’t been donating blood at that time anyway... But they insisted that I answer all the questions - which I did. But I was uncomfortable, and felt tricked almost. And at the end of the whole interview I was told; “I hope this doesn’t put you off donating and I just thought: “Really...?!” I didn’t go back...it was such a bad experience.” [Interviewee2A]

This highly embarrassing encounter ultimately transformed Tomas into nothing more than an object of medical scrutiny and discussion, as all remnants of his past sexual ‘behaviours’ were now exposed to members of a higher authority in the interest of ‘public safety.’ As Bennett (2015) has discussed, when non-normative subjects become an object of public surveillance in this fashion, they may experience their

citizenship as being both geographically in, but nevertheless ‘outside’ of the nation. Ervin Goffman (1963) recognized that it was the body, that acted as a particular delimiter of stigma, or what he referred to as a “spoiled identity” that is produced within and through intimate social interaction. But undoubtedly the type of stigma that Tomas endured was greater in both scale and effect than a mere “blemish of character” and was more broadly symptomatic of what Herele and Glunt (1988: 868 in Varas Diaz and Toro Alfonso, 2003) have referred to as “AIDS related stigma” – or the kind of stigma mentioned in my previous chapter which is “directed at persons perceived to be infected with HIV regardless of whether they are actually infected or are manifesting AIDS-related symptoms.” Making public the personal and intimate AIDS-related stigma, meant that the issue of MSM blood donation was no longer Tomas’ alone. Instead, Tomas came to symbolically stand for all gay men living in Ireland whose private sexual acts were a matter of national security concern: “all that that interview told me, was that this process for this particular sexual act [oral sex] was actually very common, and would continue to happen. And I thought – really?! You can’t keep doing this to people. It’s shameful.” Hence, it was the *national-scale* discriminatory perception of the gay male body as a plague (or plague in waiting) on the body-politic, irrespective of whether the sexual acts posed a real or imagined risk of HIV, that ignited within Tomas an even greater desire for change.

Following six month of failed attempts at political lobbying, Tomas felt that it would be better to challenge the ban directly through the rhetoric of medical access, rather than through the formation of a political movement. Drawing on the political history of medical litigation in the country, Tomas was adamant that the only way in which political change could come about in Ireland for marginal citizens was through the normative domain of the law. He explains:

“I spoke to a few people who [have] told that me they were in the same position but wouldn’t have thought of a legal challenge. But I guess for me, my background – like my undergraduate was in criminal justice and psychology, so I had knowledge of the power of a legal case to affect change - obviously it wasn’t something I was going to run to - but when it was the only option left, it seemed like that was what was going to happen next”

Queer theory is often critical of LGBT activism for ascribing to normativity through the violent and arbitrary spheres of the law. In particular, proponents of queer theory maintain that gay identities can only receive recognition as such, when they aspire to conform to a normativity that does not threaten heterosexual values (Seidman, 2001). Undoubtedly, Tomas opted to pursue a conventional and normalized legal avenue for gay men in order to achieve recognition as a blood donor, but in doing so he was also very much *aware* of this normative sphere, and rather than seeking to blindly conform to it, he was attempting to study it strategically, and wield it to his advantage. The legal case against the IBTS was granted judicial review (legal permission to proceed) from Ireland’s High Court on July 2015 on the basis

that Ireland's blood ban contravened the European principle of proportionality (as I outlined above). This is why, as he argues, the Minister for Health and the IBTS "kept seeking an adjournment" on the case rather than letting it unfold as a public Court battle: "They wouldn't challenge it", he recalls, because "they [simply] didn't have anything to challenge it with."

Having spoken with members of the IBTS as part of my institutional ethnography, however, I was informed that during the period of court adjournments which spanned nearly one year, the IBTS had been gathering international scientific evidence on the efficacy of the MSM blood ban, presented at the 'Consensus Conference' held in the Royal College of Surgeons Ireland (RCSI) April 2016. The Conference heard from representatives of blood transfusion services internationally which either had, or were in the process of easing their MSM blood ban, such as Canada, the UK, Australia, New Zealand, Spain, Italy, France and Germany. Significantly, it found that there was no longer scientific evidence to support a lifetime deferral of MSM donors, even on the basis of emerging infections. Canada's incremental five year policy for example had witnessed an overall increase in so-called 'compliance' rates since MSM were more likely to now view the ban as a reasonable and defensible policy to adhere to, while the United Kingdom had even reported a *decrease* in their rates of HIV in the national blood supply since implementing a one year deferral. This could be because, as Garlaneu (2013) has argued, MSM blood donors are more inclined to get tested for STI's beforehand and therefore removing the ban is in fact a more sensible public health decision as it in fact *encourages* more positive and progressive health-seeking behaviours. On the basis of this Conference, and the medical information supplied to then Health Minister Leo Varadkar by the IBTS, a decision was taken to implement a one-year deferral in Ireland that would bring the country into line with these shifting international norms, while continuing to provide adequate protection from the 'window period' of undetectable infections as well as supporting other "compelling" reasons to implement a change (Murphy, 2016: 13).

Were it not for Tomas' legal case, as he argues, "change may not have come for another five to ten years." The legal pressure that had been imposed on the national blood service, to which there had been no legitimate scientific evidence to refute, resulted in the state being compelled to provide a normative and "tokenistic" gesture to the MSM collective that acted in Seidman's (2001:324) words as a "a fine balancing act between the pathologies of the homosexual, and the liberal fear of pathologising homophobia." For Tomas, however, the reduction to a 12-month deferral is not enough, for like many normative tokenistic gestures it continues to perpetuate exclusions against gay men, in this case with gay men in monogamous relationships who are still sexually active. His ultimate concern moving forward is to continue lobbying for a further relaxing of the ban to a period of four months, which, he argues would be a further "stepping stone" to removing it completely.

AOIFE

Ireland is a country that is becoming increasingly more accepting of trans identities. The implementation of the ‘Gender Recognition Act’ in July 2015 is the first piece of Irish legislation to officially enable trans people over the age of 18 to self-declare their gender, achieve full legal recognition, and allow acquisition of a new birth certificate to reflect that change (TENI, 2016). Despite this, however, the landscape of policy in Ireland continues to exhibit confusion around this non-normative collective, who, as Taylor (2007) has argued, are often confused with the gay community but have different policy needs and requirements. According to the international LGBTQ organisation ‘GLAAD’ (2017) transgender does not incorporate any one category of individuals, but rather incorporates many people whose assigned sex does not equate with their preferred gender, and which can include transexuals, transqueers, non-binary’s and cross-dressers. At present, it is not known how many self-identified transgender people live in Ireland, particularly given the widespread stigmatisation and public outlawing of cross-dressing (Hines, 2009; Taylor 2007). While the gay community are generally estimated to be somewhere between 1% and 10% of the population, transgender people can incorporate anything from 1 in 10,000 or 1 in 40,000 for males, and 1 in 30,000 and 1 in 100,000 for women (TENI, 2016). Though the non-profit organisation TENI has raised the visibility of this marginalised collective, particularly in relation to their health, blood donation did not arise as a matter of health and citizenship until Ms Aoife Martin was directly impacted by the IBTS policies.

Aoife grew up in County Louth. She now lives works in Dundalk, co-parenting two children with an ex-partner. She was proceeding through a male to female transition. Aoife recalls that she had begun expressing her identity as a cross-dresser earlier in life, but as she “grew more comfortable in [her] own skin” came to the realisation that this was her true identity that she wished to express, indefinitely. She had chosen to make her transition a relatively public phenomenon through postings on a social media website which she had established so that one could learn more about her emotional journey. When I met Aoife in September 2016, she expressed her trans identity through women’s makeup, clothing, a wig, and a padded bra, but was not intending to get surgical sex reassignment procedures undertaken, and was neither taking hormone replacement therapy. For many transgender people, such cosmetic procedures, hormone therapy, surgeries, and transition counselling can all be an additional expense that is neither recognised nor covered by private health insurance (Taylor, 2007). During this time, Aoife had just come out about her new identity to her family and though she worked primarily from home for a web-based company, she was also in the process of informing central management and “a few close colleagues” about her transition. She expressed feeling “very lucky” with how her transition had been received, both by the widespread public support and encouragement on social media, and in her workplace where management had presented her with a card and bouquet of flowers stating “acceptance matters to us”

(Murphy 2017: unpaginated). Aoife recognised, however, that this experience was not like all young trans people growing up in Ireland, many of whom are still considered to be among the most vulnerable and marginalised members of society and who can still regularly experience forms of discrimination, harassment and suicidality. According to the international watchdog, TransAdvocate, 41% of trans or non-binary people have attempted suicide, a rate which vastly exceeds the 4.6 % national rate in the US, for example. Yet it was this fortunate experience of ‘coming out’ that gave her the motivation and strength to be open about her identity to as many people as possible, including wider public services with which she was engaged.

Under her previous identity as a heterosexual male, Aoife had been a regular blood donor, having donated, as she estimates, close to thirty times in her adult life, with very little difficulty (Irish Times, 2016). Like Tomas, Aoife viewed it as a form of public engagement: “donating blood for me has always been a form of civic duty, I suppose... it’s just a positive thing to do, and when I leave, I always feel like I have done something nice - like a humane thing to do for someone else.” But in addition, it also constituted something that gave her a sense of pride and fulfilment: “I got my silver pin there a while ago and - I don’t know - I guess it makes you feel like you have achieved something.” And while these acted as some of the more personal motivating factors, Aoife was also aware of the wider economies of scale that can affect the management of a blood donor service: “We have to buy in blood products in this country, and surely if more of us did it, then it would be less expensive for us in the long-run.” Though Aoife had been presenting to the service as a heterosexual male for the majority of her adult life, and had therefore experienced few difficulties, she nevertheless recalled finding some of the IBTS questions on the blood donor questionnaire rather intrusive:

“sometimes you think - that’s a bit of a bloody personal question...you wonder why they’re asking those types of things? There’s a few on there about body-building drugs and things that, you just think - it’s hard enough for them to get people so why would they be asking things like that? To me it just seems real picky - weeding out all the people who actually want to donate - ”

Because there had never been a blood donor questionnaire explicitly addressing the nature of trans identities in Ireland, Aoife believed there would be no difficulty informing the IBTS to update her donor registry details so that she could now present as a woman:

“A few months back, I phoned the IBTS to tell them that I wanted to present as a female, and so I wanted to change my name on the system going through this transition and all, I just didn’t want to be called up in front of others [in the blood bank] using the name I used to go by....

They didn’t go into much detail, they just told me to come down [from Dundalk to Dublin] to the Centre to

...speak with them...They were very matter of fact. - But no - I'm not going, I said - Why should I?... I tried to explain to them that I wasn't even taking hormones or getting surgery. It was just my name so I was a bit surprised -"

Having donated all her adult life with very little difficulty and having had her blood routinely tested for HIV and other blood borne infections, she could not fathom what had warranted this sudden interrogation and ineligibility, particularly given that, as she noted, her “sexuality hadn’t changed” only the “clothes on [her] back.” Aoife had been justifiably asserting her body as a healthy space that could contribute positively to the health and well-being of the body-politic, but was responded to instead as a “panic figure” to be feared and excluded (Hubbard, 2008: 645). Her decision to refuse attending this interview was the result of having to travel from Dundalk to Dublin but also because she had nothing to hide from the service. As she recalled: “I told them what they needed to know - I wasn’t taking hormones - I was quite explicit about that.” By now however, the discriminatory treatment that Tomas had received from the Service was also public knowledge and it was likely that Aoife may have also anticipated that some form of ‘punishment’ would accompany her visit and may have resulted in unwarranted feelings of shame and guilt, despite the innocence of her confession. Following this brief but stigmatizing phone-call, Aoife was sent a letter from the Service addressed to her formal male identity making explicit that for the moment, she would be denied service and was advised not to donate until ‘clarity’ had been sought in the form of a donor interview. Aoife recalls that the letter was brief, matter of-fact and cited ‘evidence’ of her phone-call confession but gave “no [further] reason nor justification” for her exclusion. This letter was an especially violent form of spatial regulatory device as it worked discursively on Aoife’s body by exercising authority and control over her whereabouts and the spaces within which her new identity could materialize and gain recognition.

As a boundary-making technology, this letter not only prevented Aoife from entering the space of blood donation, but in fact foreclosed any possibility of her participation in the public space of citizenship, thereby relegating her new identity to what can be perceived in society as a culturally insignificant space of the home. Addressing this letter to her former male identity was particularly injurious and exemplifies the way in which the male body is viewed as an authentic and unchanging space, while her new female identity was rendered a fictitious aberration of this former Self. As she noted: “I just found it hugely discriminatory. If I could go into Specsavers and ask to change my name with no problem - why couldn’t they?” As Jeffrey Weeks (1998: 36) writes, genitalia assumes a certain ‘truth’ in society as an “undisputable biological fact” as medical institutions continue to classify people on the basis of their physicality. For Dorothy Smith, (1971) texts not only *represented* society but in fact brought subjectivities into existence by solidifying them through their embodied circulation. In this sense, institutional ideologies about the body are dependent upon communicative processes such as language, which act as “circuits” for the continual reproduction of discourse. (Biggs (2005: 269) By establishing a close

linguistic relationship between the 'heterosexual' and the 'donor' the language embodied in the IBTS' letter produced a subjectivity of the trans person as someone who the blood donor could never be; an abject and unrecognizable citizen.

Aoife's case was significant for two reasons. First, it demonstrated the continued pervasiveness of heteronormativity among medical establishments. Second, it revealed the reactionary and discriminatory nature of HIV/AIDS management, which continues to target and stigmatize non-normative subjects. The IBTS claimed to have an official policy on gender reassignment, which had not changed in recent years and which was simply to "accept whatever gender the person presented as when they attend donor clinics." However, Aoife insisted that "there [had been] no clear policy" before she had established contact with the Service. Pointing to her body in dismay she exclaimed: "they didn't know what to do with someone like me!" Medical staff from the IBTS later admitted to the Irish Times (2016) that they "hadn't seen a case of this before." This admission was significant for it made plain that the predominant cultural frame of sexuality in Ireland's blood donor service is that of "heterosexual" along with its constitutive opposite, the "homosexual"; staged oppositions which, as Hubbard (2008) argues, fail to take account of the multifarious forms of desire that exist in society. Prior to the removal of the MSM ban, the figure of the 'lesbian' had become a particularly culturally important one for the IBTS, as it served to discredit accusations that their MSM ban was discriminatory on the basis of sexual orientation: "there is no exclusion of ...women who have sex with women. The decision is not based on sexuality or orientation, only specific actions" (Give Blood.ie, 2016). But as Taylor (2007) has observed in her review of transgender policy-making in the US, despite attempts at objectivity and neutrality, public policy can still institute procedures that result in further discrimination towards non-normative subjects. The entire negation of the wide spectrum of genders and desires in blood donor policy demonstrates how the IBTS continues to recognise only three normative and essentialist understandings of bodily desire, which are arranged hierarchically: sex between a man and a woman (i.e. the most privileged among the hierarchy), sex between women, and sex between men. Danger is located entirely within these 'sexual' acts particularly when involving the 'male' body, which is then confused with notably fluid forms of gender that do not conform so readily to these socially fixed constructions of sexual orientation (Bennet 2015; Kitzinger, 2005).

It was beyond the scope and ethical remit of this thesis to qualitatively explore how trans people interpret and make sense of their own bodies and desire, but data collected from similar qualitative studies show that language is one of the societal systems which has consistently failed this collective. A trans woman informant in Hines' (2009) study for example, claimed that: "the objects of my desire are women. I don't know whether that makes me a female heterosexual or a male lesbian. I'm not quite sure [laughs]. I don't think it's either of those and again it's a lack of language." Roberto's (2011: 56) study of public library classification and cataloguing systems demonstrates further how such language codes, when

institutionalized, can contribute to the perpetuation of exclusionary violence by endorsing a ‘taken for granted’ boundary between normative sexualities and transgender identities. It is thus apparent that the knowledge which Aoife possessed about her own body and the language which she chose to adopt in relation to it, was undoubtedly entirely discredited by this public service, and was instead viewed with deception and suspicion once again providing confirmatory evidence of the reactionary and discriminatory practices embedded within their HIV/AIDS management.

Aoife’s desire to assume this hybrid identity as trans woman and blood donor is also particularly illuminating for it helps us to better understand how the MSM collective and indeed many other non-normative subjects are both perceived, and responded to by the IBTS. Especially revealing was Aoife’s admission that she had continued to be a blood donor after having received a blood transfusion as a newborn baby. In Ireland, as is the case in the United Kingdom and France, current blood donor regulations stipulate that individuals who have received a transfusion since 1980 (both in Ireland and internationally) are considered to be high at-risk of transmitting hepatitis or HIV and are therefore ineligible to donate on this basis. The ‘Give Blood’ website clearly states: “NEVER give blood if you have received a blood transfusion (other than an autologous transfusion) in the Republic of Ireland on or after the 1st January 1980” [emphasis in original]. Aoife was resolute however, that even when she had raised this matter with the blood service while presenting as a heterosexual *male*, she was still permitted to donate blood.

The inequitable flexibility that is applied to the blood donor rules demonstrate an uncompromising perception of trustworthiness in heterosexual males who are still prized and celebrated as the most culturally important contributor to the national blood supply. Dissenting or marginalized ‘bodies’ (including those of women) on the other hand, are viewed at best with immediate suspicion, or at worst, with outright fear and rejection. Again, the immediate and reactionary nature of the decision to remove Aoife from the donor registry without seeking her clarification, or indeed any other consultative knowledge, is illustrative of the ways in which *political* decisions are taken regarding certain collectives that cannot be reducible to scientific evidence or ‘blood security’ measures. Rather, they are premised on the fear and distrust of the political and cultural spaces in which these ‘panic figures’ move (Hubbard, 2008). Trans people, as with gay men, have endured an entire history of bodily pathologization in the field of psychiatry and medicine, and it would be a fallacy to believe that this institutional violence has simply disappeared overnight (Inch 2016; Taylor 2007). A category of people stigmatized with a mental health disorder since 1965, as Inch (2015) discusses, are only beginning to be understood and removed as a diagnostic category within recent years. Even when governments have not enacted direct violence upon their bodies (as is the case in some jurisdictions) mass media continue to depict them as “freakish objects” and “sexually deviant perverts.” Inch (2016: 197) One can therefore assume that despite some societal and legal advancements for LGBTI communities, heteronormativity continues to prevail in institutional

(and particularly medical) discourse. As Watney (1991: 172) has argued, sexual dissidents are still not granted a voice or space by the unforgiving “moral majority” that continues to retain control of the state machineries that formulate policies of inclusion and exclusion. Even so, and despite the discrimination she endured, Aoife hopes to continue donating blood: “their treatment hasn’t thrown me off [donating] entirely....I still want to help people.” However, her case with the IBTS is still on-going and remains to be resolved.

To conclude, the performative act of blood donation continues to serve as an important space of citizenship and governance, both for solidifying communities, and for drawing boundaries between them and others. Using the Republic of Ireland as a case study for my fieldwork, this chapter has attempted to conduct an institutional ethnography of the spatial tactics of the Irish Blood Transfusion Service that both produce, and further marginalise an already existing non-normative population. Drawing upon historical research and ethnographic observations, I have outlined two of these different spatial tactics, which are then juxtaposed with the ‘voices’ of those who have been directly affected by its exclusionary logic. As I outlined in my earlier ‘research design’ chapter, however, these exclusions and foreclosures cannot be understood as simply occurring within an institutional vacuum. We must conceive of them as occurring in tandem with multi-scalar forms of power, which I have discussed here in relation to international blood securitization. The legacy of securitizing blood during the AIDS crisis has undoubtedly manifested in a particular domestic type of blood governance that is still visible in transfusion services today.

CHAPTER 6: CONCLUDING REMARKS

Overall, this thesis has examined the political and organisational dimensions of the HIV/AIDS care and management sector in Ireland, with a particular focus on two embodied practices; AIDS quilting and blood donation and their relationship to the production of biopolitical precarity. My institutional ethnography (which consisted of participant observation, interviews and documentary research) was configured in such a way as to trace a landscape of HIV/AIDS care provision in Ireland and explore whether it had exposed marginalised bodies to heightened vulnerability during the AIDS crisis, or was seeking to bring a necessary visibility to the collective injustices which they had endured. There are two main findings of this thesis all of which have implications for understanding the lived realities of precarity in the Irish context, and which will be discussed further here.

In the first instance we can see that the cultural memory of Ireland's AIDS crisis is vastly different from that of the US. Chapter 4 sought to encounter and interpret the aesthetic properties of Ireland's AIDS Quilts as a medium through which the cultural memory of Ireland's AIDS crisis has largely been refracted. As a profoundly significant cultural marker of the AIDS crisis, the NAMES project has been an important object of our material culture for producing a "mourned-subject position" (Rand, 2007) of the gay male collective who found themselves disproportionately affected by the crisis. Cultural theorists of the NAMES memorial quilt in the US, which I primarily drew upon in the thesis such as Sturkan, JHunge, Hawkins and others have all demonstrated the significance of the 'name' for marking and memorializing the deceased. However, drawing upon Judith Butler's theories of mourning and melancholia, I argued that what we include on the NAMES Quilt is just as important as having an AIDS Quilt, for politicized messages, photographs, family names and other personal memorabilia function as the disembodied 'face' of the other, or the paradigmatic call to peace during regimes characterised by unpredictability. However, Ireland's quilt panels demonstrate that the ethical impulse to respond to these AIDS deaths has in many ways been negated, by virtue of the intense moralization and stigmatization which resulted in the material occlusion of the name from the Quilt, and the failure to include any politically insurgent communication upon the panels. In Ireland, HIV/AIDS voluntary organisation tended to work predominantly with families of the victims, rather than lovers, and as such, the families wishes to maintain anonymity given the pervasive influence of the teaching of the Roman Catholic Church were often adhered to over and above the desire to incite change. The caution that has been exhibited in much of these panels along with the illegality of homosexuality during much of this period, evidently demonstrates a cultural denial of the Irish homosexual figure. The gay figure with AIDS, represented what Conrad (2001) has referred to as "the cultural limits of Irishness" and as a result, had been largely negated, occluded or geographically excluded from our national remembrance.

Secondly, we can see that ‘bodies’ as they have been theorised in the performative turn as sites of inscription where power regimes to be inscribed, simply cannot be conceived as having ‘materialized’ within a spatial vacuum, but must be understood instead as co-constitutive of the places, space and environments which produce and sustain them. The production of community AIDS Quilts demonstrates first and foremost, the way in which bodies and their exposure to vulnerability is sustained within and through place, but that the inter-generational connections of place brought together by voluntary HIV/AIDS organisations, has also facilitated with the process of healing. This thesis has also shown that while the US NAMES Quilt has to some degree claimed legitimacy as to the appropriate way in which to memorialize lives lost to AIDS, its focus on the ‘bodies’ of those who have been lost across vast spatial scales, has in fact been challenged and subverted among small communities in the Irish context, through the practice of their own place-based AIDS Quilt which was carried out in conjunction with members of an inner city AIDS organisation. These findings are important, for they demonstrate the cultural limitations of the NAMES project as the perceived orthodox way in which to memorialize lives lost to AIDS. Furthermore, the findings have been significant as conversations with members of the voluntary and community organisations with whom I was engaged with have already begun in order to begin a project to digitize Ireland’s AIDS quilts. This could potentially be the first time that members of Ireland’s voluntary HIV/AIDS organisations will be brought together, in an effort to preserve and restore this important part of Ireland’s queer history.

Methodologically, this institutional ethnography has also built on the embodied research methods of Parr (2000) and Hiemstra (2012) in order to consider the effectiveness of a situated praxis for investigating these lived experiences of vulnerability. However, as my research design chapter has shown, this ethnographic study also required me to become more fully aware of my own positionality as a white 20 - 23 year old female who was not part of the collectives especially impacted by the AIDS crisis and which undoubtedly resulted in some limitation in terms of the participants who were willing to partake in this study. Through my embodied presence within and through the Irish Blood Transfusion Service for example, I was able to effectively illustrate how the precarity that is induced on non-normative bodies, is effectuated only within a particular form of spatial encounter with service that has been amplified in the aftermath of the AIDS crisis. In chapter 5, I demonstrated how the governmentality of blood has its own distinct political geography which is organized across the national scale, but which is connected with extra-local modes of governing beyond Ireland’s borders. For example, the wording of Ireland’s blood donor questionnaire which functions as a particular form of spatial regulatory device, cannot be understood without considering its geopolitical influences in the form of law, economics and geographical-political histories from other jurisdictions where blood ban exclusions have become a norm. Findings from the state-based service sector therefore demonstrate that these domestic institutions

continue to function as important actors for the profuse effects of governmentality but which are nevertheless connected into a global assemblage of other multi-scalar forms of power. These findings have opened up a new line of inquiry into the geopolitics of blood on a global scale, and the cross-border institutional practices that may govern and securitize blood between West and global South. In order to do this, one could conduct an IE of medical and pharmaceutical establishments that govern the regulations of blood in order to determine how this cultural fluid is caught in distinct geopolitical power- plays with impacts for HIV/AIDS securitization in affected regions of the global South.

The findings of this thesis also leave us with other questions of how we, as researchers, might advance the study of geopolitics through a more explicitly context-specific cultural project - one which, to follow Gregory (2004) would engage us for enriching the locally based forms of counter-narrative and experiential knowledges that are lost in these grande and totalizing organisation practices, and which would enable us to begin insisting instead upon a dialogue of locally based hope and justice.

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Appendices

Appendix 1. Interview Questions for Quilters.

*Interviews with quilt founders and organisation representatives were all very different and tended to follow a conversational narrative that in many cases, diverted considerably from pre-prepared questions. Interviews were typically over an hour and in-depth being primarily led from the perspectives of participants themselves. However, some questions which guided discussion have been included here:

Theme 1 – Personal Involvement

1. Tell me a bit about yourself and how you began getting involved with AIDS activism. What year was it and what was happening at the time?
2. Where did you first hear about the quilt? *Were you inspired by America and if so, why?
3. Where did your interest in the project come from?
4. Was it just yourself or were there others involved? How and when did you all meet and coordinate?
5. Did you know any of the other volunteers prior to the quilts creation?
6. What was the significance for you in meeting as a group?
7. Can you tell me a bit about the group – is it still on the go? If not, when did it disband and why?
8. What was the gender and age composition of the group?
9. What is the nature of their involvement?
10. When everyone meets (or used to meet) what happens? Can you give me a run through of a typical meeting?
11. What kind of space is created in your opinion?

Theme 2 – Connections with Statutory, Voluntary Organisations and Wider Society

1. Were you also involved or active in any voluntary HIV/AIDS organisations?
2. What kind of support for people with HIV was being provided by voluntary and/or charitable sector's?
3. How would you compare it with the government/ statutory sector?
4. Were there any organisations that typically stood out for you in terms of their support and why?
5. How did you inform the general public about your activities?
6. What kind of support did you get from the general public?
7. Can you describe the impact or influence of the Catholic Church during this period?
8. 8) How has the media portrayed the quilt project?

Theme 3- The Quilt Display

1. Can you tell me a bit about the quilt and what it shows?
2. Why did you decide on that theme?
3. Do you believe that it is important to include names on the quilt? If so, why?*
4. Has it been a challenge to get permission for full names? If so, why?*
5. What is the significance of the quilt to you?
6. Has the project changed you or the participants in any way? If so, how?
7. Would you describe it as a therapeutic or healing practice?
8. What is your favourite aspect of the quilting?
9. What has been your proudest moment undertaking the quilt work?
10. What are the more difficult aspects of undertaking a project such as this?
11. Who were the main client group represented in the quilt? And why?*
12. Where have the quilts been displayed? Has it been difficult to gain access to these venues? If so, why?*
13. What is the significance of these displays and ceremonies?
14. Is there anything you regret or would have changed about the quilt project with hindsight?

Appendix 2. Interview Questions on Blood Donation and the IBTS

Theme : Donation and Citizenship

1. You describe blood donation as a “civic duty” and you began doing so from the age of 18. Can you tell me a bit about why you first started donating blood and what it means to you donate?
2. How do you prepare both physically and mentally for blood donation?
3. Do you think more people should donate blood? If so, why?
4. Though we will discuss in more detail the role of the deferrals, why do you think more people in generally less inclined to donate blood?
5. In your opinion, what do you think might be the symbolisms of blood donation for Irish people?
6. Why do you think the State might want to promote blood donation?
7. What kind of people (should) donate blood?

Theme 2: Virtues of Blood Donation: Altruism and Honesty

1. Do you think donors should be paid? Why/ Why not?
2. What makes blood donation ‘safe’?
3. Blood donation typically relies on honesty. Why do you think this might be an important element as part of national screening efforts?
4. In what ways do people will feel morally obliged to be honest and upfront with medical staff?

5. You mentioned in the media having been with other men, testing negative for infection and yet still having to conceal your sexual orientation. Why did you make this decision, and how did it have an impact on you?
6. Did the act of lying become more oppressive or empowering for you?
7. At what point did you decide to be 'honest' with the IBTS about all of this? And why?

Theme 3: The Donor Questionnaire

1. Where did you regularly give blood?
2. So walk me through what happens when you present to donate. Who do you meet, what do you see, what are the surroundings and staff like?
3. How does it feel to have a doctor observe you?
4. You hadn't donated in a year and when you went back, you were presented with a first time donor's questionnaire.
5. What do you think is the importance of having this questionnaire? Do you believe it to be worthwhile? If so, why? If not, why not?
6. What were the questions on it which most affected you? In what ways did they impact on you reading them? [copy of questionnaire provided for recollection purposes]
7. Can you elaborate a little bit more on how you felt reading the wording of the questions?

Theme 4: Towards Change – Questions for Tomas specifically

1. How did the process become so stigmatizing for you that you decided you wanted to bring about change to this matter?
2. It is interesting for me that instead of forming an activist or lobby group on the issue of blood donation, you sought redress instead through formal legal structures and mechanisms. Was there any particular reason why this was so?
3. Had you been aware of any activism happening internationally on this matter? If so, how did this impact or guide your decision?
4. Did the recent success of the Marriage Referendum here have any bearing on your decision to take
5. this legal challenge? If so, in what way(s)?
6. You had been sending personal lobby letters to the IBTS. What kind of things were included in these letters? What was the response? Do you happen to have any examples of either that you wouldn't mind sharing?
7. At the time you sought legal counsel, had you been aware of any changes happening to the deferral policy internationally? In what ways did this give your own case more impetus?
8. Your legal team took the case on pro bono. What were their backgrounds? Was there a general sense of confidence that this case could win?
9. Had you been aware of the recent outcomes of international ECJ decisions such as the French Case on discrimination if not proportional? If so, how did this affect your own legal challenge?
10. What did you find was the particular problem with the European 'proportionality' principle?
11. The European Directive on Blood Safety and Quality draws an arbitrary distinction between someone who is "at risk" or "can be put at risk" of infection, with two very different outcomes in terms of deferral. Did you come across this and or discuss this in the process of your legal hearings?
12. Are you able to elaborate a bit more on your hearing where Justice Seamus Noonan granted you Judicial Review? What were the key finding of the day?
13. When the IBTS confirmed they would review the policy, you retracted the legal challenge. Was this a kind of success for you? If so, why?
14. Did the IBTS invite your submissions or any other LGBT groups?
15. Is the new change enough in your opinion? What more do we still need to do?
16. Did you face any further stigma or discrimination by virtue of bringing this legal challenge about?
17. You describe the whole process as a "lonely road" that not many people will understand. Can you describe how the legal challenge has had an impact on you as a young gay man in Ireland and for your family back in Galway? Has it changed you in any way?

Appendix 3 : Revised Freedom of Information Letter sent to the Irish Blood Transfusion Service

Gisele Eugenia O'Connell
Department of Geography,
Spatial Analysis Lab,
Rhetoric House,
Maynooth University,
Co. Kildare.
07th September 2016

Ms [REDACTED]
Freedom of Information Officer,
Irish Blood Transfusion Service,
St James Street,
Dublin 8.

Re: Freedom of Information Act Request

Dear Ms [REDACTED]
Freedom of Information Officer,

My name is Gisele O'Connell, I am a research postgraduate student leading an investigative project on politically- induced vulnerability, HIV/AIDS and blood donation in the Geography Department of Maynooth University. I write, with academic supervisory support, in request of Irish blood transfusion documentation pursuant to Section 15 of the Freedom of Information Acts, 1997 and 2003.

Following a meeting with [REDACTED]
[REDACTED] James Street, Dublin, Monday 5th of September 2016 at 11:00am, I wish to review my initial Freedom of Information Request submitted on the 15th August, 2016. Having discussed my research more in- depth with [REDACTED] on the aforementioned date, it became clear that it would be necessary to submit a new Freedom of Information request. This updated request seeks the minutes of Medical Committee meetings and associated correspondence from circa 1984- 1990 when a blood donation advisory and/or subsequent questionnaire would have been first implemented in order to screen out potential donors. It was at this time, it is believed, that decisions taken by the Medical Committee would have passed through the Board and would thus be included in Board meetings. Of interest in this context, is how blood donor screening evolved from an advisory into a donor questionnaire

as a more specific form of disciplinary instrument. What also emerged during this meeting was whether the first advisory information leaflet that was circulated by the Service in the context of an HIV/AIDS crisis, would perhaps still be available for review? Other documents that would be incredibly useful to the nature of this research are publications produced by the Service that specifically address donor selection, and lifting the lifetime deferral on MSM donation (presentations and publications from the April 2016 International Conference on lifting the ban have been very graciously provided directly by Dr William Murphy [REDACTED] Given the *recent* shift towards lifting the ban, I wish to learn of the engagements and relations between organisations such as ‘Transfusion Positive’ and the ‘Irish Haemophilia Society’ (if any) with this shift in practice, and whether any submissions would have been made on behalf of these organisations to the Blood Transfusion Service, in respect of the new proposed policy. Perhaps this is something that I could later follow up with the individual organisations themselves, and/or with [REDACTED] [REDACTED] I am of course incredibly grateful for any documentation that could be potentially made available, in light of the above. I am incredibly appreciative of the personal time needed to retrieve this information and please note that I am willing to offer my own time and money where necessary also, if this could additionally help with the request in any way. It is certainly hoped that through this mutual productive collaboration, a substantive piece of knowledge production will be to many people’s mutual benefit and interest.

Disclosure of this requested information, I believe, is in the public interest, as it is likely to contribute substantially to public understandings of the operations and activities of Ireland’s Blood Transfusion Service, as well as assessing how decisions are taken to safeguard a blood supply, both at, and beyond a time of national crisis. Given my affiliation with an educational institution, this request is being made solely for scholarly and/or scientific purpose, and is not for commercial use. Ethical clearance for the wider project on the political-geography of Ireland’s HIV/AIDS service provision was secured from Maynooth’s University’s Social Research Ethics Committee on the 8th February 2016 of which copies can be provided on request. Results of this study will be used as part of a research dissertation and potentially any additional scholarly and policy/report outputs. Respect for anonymity and confidentiality is of utmost importance to this research. I foresee no risks to your organisation, or the general public during the process of this study, as no personal identifiers will be used in research outputs.

I am willing to pay associated fees for this request, up to a maximum of **600 euro**. If you estimate that the fees for accessing this documentation will exceed that limit, please inform me first.

Thank you for your kind consideration of this request.

Sincerely,

Gisele Eugenia O'Connell, BA (Pol Sc)

Gisele Eugenia O'Connell

Endorsed by Supervisor:

Professor Gerry Kearns,

G. Kearns

Appendix 4. Decision Letter on the Freedom of Information Request from the Irish Blood Transfusion Service.