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**The Third Sector and the Shaping of  
Services for Huntington's Disease in  
Scotland: Organisations, Boundary Work  
and Expertise.**

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# Declaration

This is to certify that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

Signed .....

Tirion Seymour

May 2016



## Abstract

Social science research on third sector organisations in the last two decades has emphasised their growing presence and importance in healthcare. This has occurred alongside significant reorganisation of health systems in the UK, including a continued policy emphasis on partnership-working between the public sector and the third sector. However, unanswered questions in the literature remain with regard to the specific roles that these organisations fulfil within partnership arrangements.

This thesis examines the role of third sector organisations within Scottish services for the chronic, neurodegenerative condition Huntington's disease (HD). The closely connected nature of Scottish healthcare and the multitude of professionals involved in HD mean these services are an important, but currently understudied, example of professional interaction around complexity. A multi-methods qualitative research framework was used to gather perspectives of key individuals working in the Scottish HD and wider health scene.

Making use of the key concepts of expertise and boundary work, this thesis argues that third sector organisations have an extensive shaping role in 1) the positioning of healthcare organisations, 2) the identities of healthcare professionals, and 3) the meanings around illness and the remit of support. The research findings revealed that organisations and professionals in HD partnership arrangements engaged in processes of boundary work in the negotiation of the roles of themselves and others. Third sector professionals occupied many positions within services, as both experts and supporters of patients. In the process they and other professionals often took on identities as 'key, committed professionals'. Understanding around HD was also shaped by these professionals as the wider aspects of illness and its support were brought into focus. Building on these findings, it is argued that third sector professionals in coordination roles are well placed to develop a type of expertise that I term 'aggregate know-how' (Pols 2014), based around both their professional skills and their extensive contact with patient experiential knowledge.

The research builds on and extends influential previous models of third sector 'partnership' in healthcare (Rabeharisoa 2003), emphasising the key role of third sector organisations in knowledge production. It also offers insights of both theoretical and practical use with regard to service delivery in healthcare, showing the potential for genuine third sector/public sector partnership around expertise when there is adequate cultural support and resources.



## Lay Summary

The modern Scottish healthcare landscape is populated by multiple interacting organisations and a large variety of individual professionals from different sectors. This research explored the role of ‘third sector’ health organisations – not-for-profit patient organisations – within the complex arrangements of healthcare service delivery in Scotland. In particular, it focused on the case of services for people with the neurodegenerative, genetic condition Huntington’s disease.

In a healthcare climate increasingly characterised by collaboration between sectors, a question emerges - what is happening to the relationships between the individuals and organisations within healthcare when third sector organisations become involved in the running of public sector-provided services? The data collection methods of semi-structured interview, participant observation and documentary analysis were used to gather perspectives of key individuals working in the Scottish HD and wider health scene.

The research reveals that third sector organisations within Scottish Huntington’s disease services have taken on extensive partnership roles. Alongside this, it is evident that important aspects of the healthcare scene are being shaped. Third sector organisations were found to have an extensive shaping role in 1) the positioning of healthcare organisations, 2) the identities of healthcare professionals, and 3) the meanings around illness and the remit of support. Based on these findings, it is argued that third sector professionals in coordination roles are well placed to develop a type of expertise that is termed by this thesis as ‘aggregate know-how’ (Pols 2014). This expertise is developed around both their professional skills and their considerable contact with patient knowledge about their own experiences.

The findings of this research build on and extend influential social science discussions about third sector ‘partnership’ in healthcare (Rabeharisoa 2003) by emphasising the key role of third sector organisations in knowledge production. The research also contributes to healthcare policy and practice by highlighting the ways in which the third sector can function as an expert resource and an asset in complex care coordination.





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## List of abbreviations used

AFM - (Association Française contre les Myopathies – French Muscular Dystrophy Association)

CHP – Community Health Partnership

HSCP – Health and Social Care Partnership

EHDN – European Huntington’s Disease Network

GP – General practitioner

HD – Huntington’s disease

HDA – The Huntington’s Disease Association (England and Wales)

HDAI - Huntington’s Disease Association of Ireland

HDANI – Huntington’s Disease Association of Northern Ireland

NCVO – National Centre for Voluntary Organisations

NHS – National Health Service

NPG – New Public Governance

NPM – New Public Management

SCVO – Scottish Council for Voluntary Organisations

SHA – The Scottish Huntington’s Association

SNP – Scottish National Party

STS – Science and Technology Studies

TSI – Third Sector Interface

## CHAPTER ONE: INTRODUCTION

The Scottish healthcare landscape in 2015 is populated by multiple interacting organisations and a large variety of individual professionals from different sectors. In this thesis I consider the role of the third sector – not-for-profit patient organisations - within the complex arrangements that constitute healthcare service delivery in Scotland. In particular, I explore the case of services for people with the neurodegenerative, genetic condition Huntington’s disease (HD) within this Scottish web of health care. This is an area where multi-professional, multi-sector services exist to provide clinical support and community care for people living with a complex, rare and currently incurable inherited condition, within a small and closely connected health system. As a result, it is a setting of key interest to sociological inquiry in the way that it involves the intersection of numerous types of specialist expertise, professional roles and organisational cultures under health policy that strongly encourages ‘partnership’. In a healthcare climate increasingly characterised by collaboration between sectors, a question emerges - what is happening to the relationships between the individuals and organisations within healthcare when third sector organisations become involved in the running of public sector-provided services?

I will argue in this thesis that in the process of establishing themselves within healthcare service delivery, third sector professionals articulate a form of expertise that is based on the combined experiential knowledge of multiple patients as well as the experience built up by professionals around this knowledge. I refer to this repository of expertise held by professional individuals as ‘aggregate know-how.’ In doing so, I draw on past theory by Pols about the situated nature of knowledge that patients might gather around their own condition (Pols 2014). I argue that being in a position to gather this aggregate know-how involves continuous boundary work by different professionals. They must maintain a position as individuals who belong in many different professional worlds, while at the same time emphasising their own



closeness to patient needs. This aggregate know-how, at the same time, operates as a legitimising and distinct form of expertise that third sector professions can draw upon in their interaction with colleagues and when supporting patients, as well something they could broadcast and share with others.

Uniting the rich literature on third sector activity in health with past work on the development of professions and expertise is something that has seldom been done in past literature. Following this path, however, allows the knowledge-producing and boundary-spanning roles of third sector professionals to be placed centre stage. In doing so, I contribute to the debates surrounding both professionalism and expertise. I do so through developing understanding of knowledge that is formulated around knowing a condition from first-hand experience by individuals in a coordination-focused professional role. This is something that third sector employed individuals are particularly well positioned to formulate from their role in partnerships, as revealed within the focus of my own research. However, I also argue that this knowledge is not necessarily exclusive to third sector professionals and might be something harnessed by others in boundary spanning and patient-focused professional roles.

In focusing on the cultivation of expertise by third sector professionals, my research contributes a new perspective on the role of the third sector as a resource and an asset in complex care coordination. I highlight an even more extensive and formative role for the third sector than has been put forward previously, building on models that suggest the third sector is an active player in healthcare, such as the 'partnership model' of Rabeharisoa (2003). This in turn allows me to contribute to ongoing discussions in policy-focused literature about the position of the third sector in service delivery in the UK in comparison to the state, showing the potential for genuine third sector/public sector healthcare partnership when there is adequate resourcing and organisational support.

In the chapters that follow, I draw on the data obtained from my qualitative fieldwork in the Scottish HD services to discuss the different ways in which partnership allows third sector specialists to build aggregate know-how. My three findings chapters present evidence that in the case of HD in Scotland, the third sector's involvement in partnership in service delivery is contributing to (a) a shaping of the organisations involved, (b) a shaping of professional identities, and (c) a shaping of the way in which the particular health condition is understood and treated.

I show that partnership arrangements around health conditions within Scotland have blurred organisational boundaries relating to the way in which different sectors, and individual professionals from these sectors, are viewed. Individual professional identities are shaped within these new arrangements, and certain individuals adopt a prominent and important role. The importance of what this thesis terms 'key, committed individuals' is also emphasised, again highlighting the complex relationship between the individual, organisation and condition within healthcare setups. It is argued that one of the main skills that these key, committed individuals acquire is an ability to overcome boundaries between organisations, while also highlighting the importance of certain types of expertise, most particularly that which champions the needs of the client group.

I also suggest that this transformation at the organisational and individual levels under partnership arrangements also contributes to the overall shaping of how a condition like HD is constructed and understood. The third sector services in my own research had a role in emphasising the social, material and psychological aspects of living with HD in addition to other symptoms of the condition. In line with highlighting such needs, different types of support - such as assistance with financial issues, or peer emotional support - were also made available by third sector organisations, or were something that these organisations campaigned for. In doing this, these third sector organisations are redrawing understandings of what support for a condition can and should entail, underpinning further service development. At all these different levels discussed within my findings - organisational culture,

individual professionalised identity and ideas of support - expertise was being developed and used by the third sector professionals involved through their work with patients and their families.

This chapter will now turn to examine the research question, aims and objectives that structured my enquiry. It will then explore in depth the rationale for developing the research within the area of the third sector and Scottish HD care.

## **Research question, aims and objectives**

My research is structured around the following research question:

**What is the role of third sector organisations, and of partnerships between these organisations and the public sector, within services for Huntington's disease (HD) in Scotland?**

I aim within the research to explore how the third sector is positioned within the context in which it is embedded. This includes exploration of how collaborations within and across sectors in the Scottish health arena might be used to achieve the successful delivery of services. I also aim to question the manner in which partnerships between organisations and professions develop within Scotland, and how such partnerships might connect to the experiences of the patients that are at the heart of the initiatives.

In order to achieve the aims listed above, several objectives emerged that examine how the third sector was shaping the arrangements in which it was embedded.

- To identify the nature and meaning of third sector 'partnership' in the case of Huntington's disease (HD) services in Scotland, through a multi-method qualitative approach.
- To determine what, if anything, is changing with regard to the professional health landscape as a result of these partnership processes.

- To consider how the existence of any engagement between partners might relate to the experience of the case condition Huntington's disease for the patients, carers and professionals involved.
- To analyse what the positioning of the third sector means for the further development of sociological theories of third sector engagement in health, and theories of collaborating across organisational boundaries.
- To suggest the practical implications of the above findings for developing effective partnership-working practices within collaborative working in healthcare.

## **Rationale for the research**

My own research focus on third sector partnership within service delivery arose out of a gap in social science research in the UK, including Scotland. In UK and Scottish governmental health policy documents, there has been a marked emphasis on the importance of forming partnerships across and within sectors to deliver services in governmental literature (Baggott 2013). Yet, despite this partnership role being depicted as a major function of the third sector in government literature, there is little analytical discussion within this grey literature about the dynamics of third sector service delivery for the organisations, healthcare professionals and patients involved.

There is also a paucity of sociological research that looks in-depth at the dynamics of third sector involvement alongside public sector NHS partners in the delivery of *services* – i.e. the provision of clinical treatment and other forms of medical and social support around health - as opposed to another aspect of third sector activity such as involvement in policy (Jones et al. 2004, Baggott et al. 2004a, Akrich et al. 2013, O'Donovan et al. 2013) or medical research (Rabeharisoa 2003, Epstein 1996, Epstein 1995). The work that has been attempted in this area of service provision from other social science disciplines, such as the science and technology studies research on HD clinical research in Japan and Canada by Nukaga (2002), draws attention to an important role for the third sector in shaping these services. Others

have indicated the importance of the third sector in support-focused activities, for example, researchers who have looked at the third sector's involvement in peer support provision (Mulcahy et al. 2010). Focusing on third sector activity in professionally-led service partnerships, as my own research does, allows me to build on the small selection of work about peer and professional support alike, and to consider what role third sector organisations and professionals adopt in the Scottish health context. It also allows me to develop the third sector literature about the 'partnership' role of patient organisations (Rabeharisoa 2003), in a service delivery setting in which third sector organisations are prominently cast in a collaborative role.

There is also a personal rationale for this thesis that comes from my own long-standing academic and personal interest in the experiences of people with long-term health conditions. The sociology of health and illness literature is rich in research on the healthcare journey as experienced by patients (Bury 1982,2001, Frank 1995, Hubbard et al. 2010, Locock and Brown 2010, Locock et al. 2009, Mazanderani et al. 2012, Radin 2006, Williams 2000) although this is an area for which additional work on different aspects of this journey remains vitally important. However, I argue here that the lack of work completed on professional partnership leaves a gap to be filled in understanding the totality of how services work. As my findings will highlight, the interaction between organisations and individuals that provide care and support and the patients is an important dimension of the illness experience, and it is also through these services that understandings of illness can be produced. My decision to concentrate my research focus on 'professional' individuals can therefore also feed into other literature that concentrates on patients and their families in practice. It will also build on prior work on third sector activity by looking at an example of service delivery involvement within one particular health condition. As discussed below, it is the close and collaborative aspects of Scottish healthcare practice, and the complexity involved in caring for HD due to the manifestation of the condition, that make the partnership practices in this area of particular interest.

Insights in this area are also a springboard for sociological examination around other complex neurological conditions such as stroke, multiple sclerosis and head injury.

### **Building on past work on third sector activity**

In recent decades, social scientists have been interested in the growing involvement of third sector groups within all aspects of health and health care in Western industrial nations (Hess et al. 2008, Epstein 2008, Brown and Zavestoski 2004). As will be elaborated upon below, the sociological interest in this phenomenon has come from the impact that these organisations are seen to have had in changing healthcare policy, transforming support and changing the possibilities of science. Third sector activity has also been considered to be of scholarly interest in light of the changing nature of healthcare in the UK and other developed health systems (Baggott and Forster 2008, Kelly 2007). Much of this change has taken place in areas in which the third sector is perceived to have a strong voice, such as around discourse to do with patient choice and involvement, and around the resourcing and design of healthcare services (Mold 2010).

The definition of third sector that I will be drawing upon throughout this thesis is the broad definition used by Lindsay et al. (2014) in their work on third sector organisations in the Scottish context. They define the third sector as: ‘any self-governing bodies that are formally organized, independent from the state, non-profit-distributing, and benefit from some sort of voluntarism in their activities’ (2014:195). This definition is particularly useful in including in its focus the non-profit and volunteerism aspects of an organisation’s activity while at the same time emphasising formal organisation.

It should be noted also that the very use of the term ‘third sector’ versus other potential options is in itself something that has been subject to much debate (Kelly 2007). In my own work, I chose to draw upon this specific term of third sector predominantly because of its common usage in Scotland, although the ‘voluntary

sector' and 'charity sector' are also commonly used. However, if entering into the wider debate, I would also argue that using the term 'third' before the 'sector' allows a different connotation than the older terminology of 'voluntary' or 'charity' which might over-emphasise the element of unpaid volunteering in an organisation rather than the paid staff present in many organisations. The same argument applies for the largely North American terminology of 'non-profits'/'not-for-profits'.

In social science and third sector literature concerning health, 'patient organisation' is sometimes also used as a description. Again, this has the potential to have issues in and of itself by obscuring the nuance that third sector provided services are often targeted at carers and family members of 'patients', as well as providing support for people without symptoms and/or who are not accessing formal medical services. Recent years have also seen the use of 'consumer' related organisation terminology - such as 'health consumer patient organisations' (Baggott and Forster 2008) and 'health consumer groups' (Baggott et al. 2004a,2004b, Allsop et al. 2004) in Baggott et al.'s work, and 'consumer groups' elsewhere (Loefgren et al. 2011, Sulik and Eich-Kroh 2008). Many authors seem to acknowledge the potential connotations of such terminology and often choose it even while they depict the commodification of health care as being a negative trend, but nonetheless want to emphasise the existence of the continued framing of patients as consumers in healthcare provision (Mold 2010). It is also the case that while 'consumerism' is particularly understandable as a description of patient behaviour under systems where healthcare is purchased from a provider, the activities it describes could occur, and do occur, within state funded systems of healthcare:

... 'consumers' actively seek optimal care by choosing providers, obtaining information, serving as their own advocates, engaging in collaborative decision-making with those who render care and participating in advocacy organizations (Chambre and Goldner 2008:xii).

Yet, while it is important to highlight this consumerism-influenced shift in the role of patients when discussing such activities as the above, there is a potential danger of framing groups in this way. It might have the function of attaching a positive value to

what I would argue is a negative aspect of consumerism in the sense of neoliberal, competition-centred influences in healthcare, alongside the more positive aspects such as patient-centred structures.

Finally, it must be acknowledged that for some, my own usage of the ‘third sector’ is potentially a contentious term also due to its origins in the UK with particular policy platforms implemented under New Labour (Alcock 2012, Alcock 2010a, Alcock 2010b), something that will be discussed in depth in Chapter Two. It also has the potential to include some organisations quite distinct from my own research’s not-for-profit focus, such as social enterprises and cooperatives (Alcock 2010b:2). The diversity within this area has also led to debates about the very idea of a unified ‘sector’, due to the way that the third sector is open to contestation in academic discourse and in the gap between state views of any ‘sector’ and the organisations themselves (Alcock and Kendall 2011).

While acknowledging these various critiques of the term ‘third sector’, my own research takes the same view as Brandsen (2008) that it does make analytical sense to talk of a third sector, albeit one that must be acknowledged to be internally diverse. While the origins of the term should be acknowledged, like much ‘third sector’ related policy itself, it has remained popular in Scotland beyond the New Labour era, and the changes in political administration in the Scottish Government. The third sector also exists as a ‘socially meaningful’ category (Brandsen 2008) to professionals in healthcare in Scotland – they understand which organisations are being discussed under this label. It is also the predominant term used when it comes to the classification and regulation of non-state and not-for-profit organisations in Scotland. While there might be debate to be had about the degree of overlap, the third sector is also depicted as an entity that is distinct from the state and distinct from private businesses within the everyday talk of individuals, as well as within health policy. Seeking to unpack different notions of the third sector – as I do with my own research to do with the Scottish Huntington’s Association – should be an aim of social science enquiry in this area.



### ***The phenomenon of third sector activity***

Third sector involvement in health is not a new phenomenon. A few of the groups present in the UK have a history going back to the Victorian era, and many proliferated in the second half of the twentieth century (Allsop et al. 2004:740). However, social policy research has charted the period between 1997 and the present as a time of particular change for the UK. This was a period of wide-ranging reforms of health care structures and third sector activity as implemented under the New Labour government from 1997 to 2007 (Alcock 2012). The process of reframing civil society's role also occurred alongside the devolution in 1998 of political power to a new Parliament in Scotland, and new Assemblies in Wales and Northern Ireland, opening up new opportunities for third sector activity at these levels of government.

A growing body of social science research has examined the scope of the presence and activities of third sector organisations in the UK health scene in the present day. The extensive UK work by Baggott and colleagues at De Montfort University (Baggott et al. 2004b, Baggott 2005, Jones et al. 2004) has emphasised the growth and importance of single-condition patient organisations in providing social support, research, political campaigning, and designing and delivering services. Recent research has built on these initial scoping studies by showing the role of third sector organisations in driving changes to healthcare systems across the UK and in other industrialised nations (Baggott and Jones 2011, Pestoff 2012, Rabeharisoa and O'Donovan 2014). This collection of research has both highlighted the sociological significance of third sector activity, and laid the groundwork for future research that unpacks specific aspects of healthcare involvement.

Partnership between third sector organisations and the state has also been a common theme in past empirical work. Looking at the promotion of research into muscular dystrophy in France, Rabeharisoa has identified useful typologies of patient organisation activism, by distinguishing between 'partnership', 'emancipatory' and 'auxiliary' groups (Rabeharisoa 2003). Such typologies are particularly useful for this

thesis when examining the changing modes of relationship between third sector organisations and public sector services. Recent work by Rabeharisoa and her colleagues (Rabeharisoa and O'Donovan 2014, Rabeharisoa et al. 2014a, Edwards et al. 2014) has also examined the knowledge production roles of patient organisations in the European context. I will be building on this research new and old, considering the extent to which service delivery might also be a context in which a phenomenon of partnership relations is occurring, and/or in which knowledge is being generated by patient organisations. In comparison to areas such as government policy or biomedical research, service delivery is an area in which the role of third sector organisations in partnership might be less immediately evident as distinct from their public sector partners. However, as my findings will go on to show, the potential for third sector organisations to develop their own expertise within this area, and actually widen the scope of what condition support entails, is extensive.

I suggest that further understanding within the specific area of service provision is valuable in order to comprehend how structural shifts in healthcare - enabled by policy shifts encouraging ever greater involvement from the third sector - are changing how these services and the professionals involved are understood. In my thesis I build on past literature by examining how models such as Rabeharisoa's partnership model (2003) function when the focus of the partnership is jointly delivering a service. Furthermore, I aim to unite discussion about models of third sector organisational activity with theorisation about the expertise that these third sector organisations possess, and the boundary work in which they engage during partnership arrangements.

### ***Defining partnership***

Partnership is a concept that is drawn upon often within discussions of healthcare, and heavily within discussions of the third sector, yet its meaning is often left undefined or merely assumed (Baggott 2007). It can be what Powell and Glendinning refer to as a 'Humpty Dumpty term', in reference to the circular style of definition

adopted by this character in the children's novel 'Alice Through the Looking Glass' – 'When I call something a partnership by definition it is one' (Powell and Glendinning 2002:2). It has been highlighted also that partnerships are often assumed to be an inherently good thing, so therefore are also talked about as a 'vague ideal' (Baggott 2007).

Powell and Glendinning attempt to break away from assumptions made in past work on partnerships and state that their own minimal definition for partnership would require:

...the involvement of at least two agents or agencies with at least some common interests of interdependencies; and would also probably require a relationship between them that involves a degree of trust, equality or reciprocity (2002:2).

A similar offering from Baggott's more recent work on partnerships in public health suggests a working definition of partnerships as:

...working arrangements, institutions and processes, involving organisations and individuals, that seek to improve the health and wellbeing of individuals and communities at various levels, nationally, locally and globally (2013:21).

I draw upon a combination of the two above definitions within my own research, combining the strengths of Baggott's description on the types of arrangement (2013) with Powell and Glendinning's emphasis on the relationship between actors that is required (2002). I define 'partnership' broadly as some sort of formalised arrangement between actors (individuals or organisations) that is oriented around some form of common goal or mutual benefit to do with improving health and wellbeing, and carried out with mutual respect for each other. Importantly within my definition, the arrangements that constitute partnerships in public services need not be subject to high levels of formality or structured agreement, but merely require to be agreed in some semi-formalised manner. However, as is often the case with partnerships in relation to service delivery, there might also be actual formal written agreements such as contracts or concordats in place also.

The partnership structures being discussed in my own thesis are service-related arrangements of both an informal and formal nature made between organisations around the complex condition of HD. These might range from occasional third sector input into medical and social care services, to extensive co-delivery of services via the presence of third sector specialists within teams. As I will discuss later in this chapter, one of the aims in my own research was to identify the nature and meaning of the various forms of multi-sector partnership that might be developed in healthcare, while paying close attention to the surrounding political and healthcare context. This is a particular apt topic to examine in devolved Scotland, where partnership remains a key word of health and third sector policy.

### **Third sector activity and healthcare in Scotland**

Past research such as the above on third sector activity situated with the UK or other western and publicly funded health systems provides a strong basis for examining shared themes about third sector activity across nations. However, there still remain uncharted areas of exploration about how the role of these organisations is understood within particular policy contexts. Sociological research on healthcare and third sector activity within Scotland is often subsumed within studies of ‘the UK’, despite the devolution of health and social care policies since the full establishment of the Scottish Parliament in 1999. The influential collection of social science research on third sector activity by Baggott and his colleagues Allsop and Jones (Allsop et al. 2004, Baggott 2004,2005, Baggott et al. 2004a, Baggott et al. 2004b, Baggott and Jones 2011), for example, refers to the UK but predominately focuses on the English NHS and English structures rather than the services in Scotland, Wales or Northern Ireland. Recognising this deficit in their more recent work, Baggott and Jones state:

...there has been no research into the impact of devolution on the representation of patient and public interests, and on health consumer groups in particular, something which needs urgent remedy (Jones and Baggott 2011:41).

Third sector organisations present in Scotland are very varied in size and income. As a report by SCVO reveals, they range from small organisations with a turnover of under £25,000 to larger organisations with a turnover of over £1 million (Scottish Council for Voluntary Organisations 2014:6). Some operate within one local area, while others have a Scotland-wide, UK wide or international presence. Organisations dealing with social care or health issues make up a significant proportion of the Scottish third sector (‘social care’ – 34% of organisations, ‘health’ – 4 % of organisations, SCVO 2014:14). When the share of the paid third sector workforce is broken down, the significance is even more apparent, with 42% of the paid third sector workforce working in ‘social care’ and 13% in ‘health’<sup>1</sup> (SCVO 2014:16). Some health or social care organisations focus on a single condition - such as the main organisation from which participants were drawn within my own research, the Scottish Huntington’s Association. Others have been formed for a particular group of people (such as carers, or patients from a single area). There also exist alliance organisations that are comprised of multiple third sector organisations united together around a common issue, such as long term conditions, rare diseases, or carers’ rights. Some of the participants of my own research were also individuals connected to such alliance organisations.

In structural terms, ‘NHS Scotland’ is a distinct organisation that follows policy objectives that differ from its counterparts in England and Wales, and the health service in Northern Ireland. However, there remain similarities across nations of the UK in many of the broader themes of health policy, such as the drive towards integration of services (Forbes et al. 2010), and rhetoric about patient ‘choice’ (Peckham et al. 2012). There are also still some areas of policy ‘reserved’ to the UK level rather than devolved to the regional Parliaments with either a direct or indirect relevance to the health experiences of people with conditions such as HD in

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<sup>1</sup> The only other area in which a greater share of the third sector workforce are based than ‘health’ is ‘housing’, at 17% of the workforce (SCVO 2014:16)

Scotland. These include the areas of medical ethics and welfare benefits. There has also been a Europe-wide climate of reduction in funding for public sector and third sector organisations, which have often in turn led to a drive from the governments of these nations to find new public and private solutions to meet increasing healthcare delivery challenges (Baggott and Forster 2008). Baggott suggests that the similarities between the pressures faced by health systems across Europe mean that the ‘menu of policy options’ for governments is ‘fairly restricted’, something which limits complete divergence between nations (Baggott 2007).

The contemporary structure of the health service in Scotland differs from that in England and the rest of the UK. Despite some remaining similarities, in recent years policy directions have emphasised the differences between the NHS in Scotland and England in particular. A greater degree of competition and private provision has entered the English NHS, particularly by following the wide ranging changes of *The Health and Social Care Act 2012* (NHS England 2014). Major provisions of the Act, including the establishment of budget-holding Clinical Commissioning Groups (CCGs) have not been replicated in the devolved nations of the UK. Scottish Government policy, in addition to regional and national Health Boards and the newly established Health and Social Care Partnerships, is responsible for much of the planning and delivery of Scottish services. The regional Boards in Scotland were established following devolution through the dissolution of the UK-wide NHS Trusts and therefore also the removal in Scotland of the purchaser-provider split in healthcare (Steel and Cylus 2012). It is also the case that even before the formalised process of devolution, Scotland had historically distinct public institutions (including the legal system and the church) and that distinct Scottish policy was produced in many areas including health and education (Steel and Cylus 2012:7).

As Chapter Two unpicks further, there are also particularities about Scotland when taken as a unit of exploration separately from the rest of the UK that are of relevance when considering how services would work. With a population of just over five million people, Scotland is a small nation, with a healthcare system that is closely

connected in number of different ways. For example, there is an internal flow of professionals within the third sector and the NHS, and the size and structuring of the health system also facilitates a close relationship between the small network of four medical schools and specialist services such as genetics clinics. The size and connectedness of the nation is also particularly important in situations like that of HD where the condition is classified as 'rare', as discussed later in this chapter.

Therefore, services must be developed that embrace both the severity and complexity of the condition, and also the differing densities of patients present in different parts of the same country. Other demographic factors, such as lower rates of outward migration compared to other areas of the UK, and a previous reputation of Scotland as the 'sick man of Europe' present their own healthcare challenges, alongside simultaneous opportunities for the development of health initiatives (Haddow et al. 2014).

The size of Scotland's population and services, as well as its continued theoretical and practical links with the wider UK, render it a useful backdrop against which to consider a particular condition in depth. Selecting Scotland as the setting for the research also allows inclusion of the added interesting features of it being a nation with a small overall population, but one in which there is a third sector that is seen to be strong and heavily involved in partnership working (Dacombe and Bach 2009). The combined features of this, yet the lack of Scotland-specific research on the third sector within it, has led some involved in third sector research, such as Dutton et al. (2013), to argue the following:

Recognition needs to be given to the excellent work of the third sector in delivering public services and a clearer understanding articulated of their unique contribution to service delivery across Scotland (Dutton et al. 2013:12).

In selecting third sector partnership as a focus, my research will build on past work to understand the nature of the third sector's 'unique' contribution to service delivery in healthcare from a sociological perspective. Scotland is a particularly apt context in which to look at third sector activity around a particular condition, especially one with the rarity and complexity of Huntington's disease, as will now be discussed.

## **Huntington's disease as an important and illustrative condition area**

The complex nature of the neurodegenerative and rare condition of Huntington's disease (HD) renders the condition a particularly compelling area of sociological exploration. HD is an example of a condition that poses multiple and significant challenges for patients and families. Related to this, it is also an area in which much professional interaction takes place, with the third sector adopting a prominent role in service delivery in the case of Scotland. As will be explained in greater detail in chapter Two when outlining the structure of HD care, the services I discuss here include multiple aspects: appointments with consultants in a dedicated HD clinic; appointments with particular health professionals from medicine, the allied health professions and social work; and a whole other range of life focused support surrounding including peer support, support for young people and so on.

The various forms of support for HD and the involvement of the third sector within this makes HD an insightful area in which to base research examining the dynamics that occur under partnership. It can also be argued that HD has largely been neglected in social science research in the past other than the considerable and important offerings from the literature on ethical decision-making and genetic risk, many of which are discussed in the literature chapter of this thesis. This present research is of value in adding in-depth work on HD, service delivery and the third sector to the existing sociology of health and illness canon. Work in this area also has the potential to be a model for understandings in this area around other complex neurological conditions.



## ***The features of HD***

When people ask us what Huntington’s disease is we say something like ‘Imagine the physical effects of Parkinson’s disease, mixed up with the mental deterioration of Alzheimer’s and you’re in roughly the right territory. It’s terminal, but it takes its time, decades sometimes. Oh, and it’s hereditary: each of your kids has a 50 per cent chance of inheriting it’ (Sulaiman 2007:9).

The most common, adult-onset form of HD on which this research is focused<sup>2</sup> is a neurodegenerative and currently incurable condition that is genetically passed from parent to child. Adult HD is a late-onset condition, with most adults first experiencing symptoms between the age of 35 and 55, although it is possible for them to develop at any age (NHS Choices 2015). The late age of onset in the majority of cases means that individuals have often already had children by the time their HD presents clinically. There is a 50% risk of the gene for HD being passed on from an affected parent. The gene that causes the condition has full penetrance, which means that if a person does inherit the gene they will be affected by the condition, while if they do not inherit the gene they will not develop symptoms (Myers 2004). In a small number of HD cases, up to 3%, there is no known history of HD in the family, either because individuals are not in contact with their blood relatives, or spontaneous genetic mutations have occurred (NHS Choices 2015).

HD causes the damage and death of nerve cells in certain brain areas leading to multiple and severe effects. The condition was formerly named ‘Huntington’s Chorea’ - after the Greek word *choreia* for dance – as well as ‘St Vitus Dance’, in reference to the involuntary jerky limb movements that are a prominent symptom of the condition (NHS Choices 2015, European Huntington's Disease Network 2015). HD has a major impact on motor skills and movement in both upper and lower limbs,

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<sup>2</sup> While this thesis explores activity around the adult-onset form of HD, it is important to note that there is a rarer, juvenile, form of the condition with an age of onset under 20 years and a different series of symptoms and experiences (NHS Choices 2015).

which leads to difficulties in walking, and completing everyday tasks, including washing, dressing, and swallowing food. Falls and accidents are commonplace. These profound physical effects are often combined with problems with cognition. The condition can also include significant problems with mental health including anger, depression, and anxiety (NHS Choices 2015).

Past research has also found that the risk of suicide attempts or suicidal thoughts is also higher for people with HD in comparison to those within the general population. This is particularly common in certain critical stages of the disease (Paulsen et al. 2005) and among people with the HD gene experiencing depression and/or on certain medication (Hubers et al. 2013). The combination of symptoms within HD means that as the illness progresses individuals will require round-the-clock physical care and emotional support. People with HD face an increasing severity in their symptoms over time, and the condition often leads to premature death within twenty years of the onset of symptoms from secondary causes related to the body's weakened condition, such as pneumonia and heart failure (Heemskerk and Roos 2010, Sorensen and Fenger 1992).

As this thesis will go on to discuss, it is not just the physical and mental health symptoms that people with HD face. HD, like all health conditions, is experienced within a social context in which the reaction of others to a condition plays a part. Personal accounts and media narratives of HD where they exist often discuss the stigma that can be experienced by individuals with symptoms of HD, or that can be felt by individuals themselves even where symptoms are not apparent (Tweedie 2012). Such stigma can lead to social exclusion as individuals lose friends and community networks due to fear or misunderstanding surrounding the condition and how to help with it.

The Scottish Huntington's Association have stated that there are approximately 1000 individuals in Scotland living with the condition, and a further 5000 potentially at risk (BBC News 2015). HD is classified as 'rare' based on the European Union

classification of a rare disease as one that affects less than 5 in 10,000 of the general population (Rare Disease UK 2015). However, the estimated prevalence of HD has increased from the years 1990 to 2010, with a recent high-profile study estimating as many as 12.3 per 100,000 (1.23 per 10,000) people might be affected across the wider UK as opposed to the previously estimated 5.4 per 100,000 people (0.54 per 10,000) (Evans et al. 2013). The same prevalence study also found that across the UK, rates of the condition are particularly high in certain areas, particularly in Scotland and the North East of England.

In addition to clinical diagnosis based on signs and symptoms, there are now a number of genetic diagnostic tests for HD (NHS Choices 2015). For adults there is a pre-symptomatic genetic test that involves taking a blood sample. This will inform an individual if they have the gene for HD or not and, therefore, if they will develop the condition or not. It is also possible to test a fetus prenatally and to use pre-implantation genetic diagnosis via IVF to test the embryos to be implanted for the presence of the gene (NHS Choices 2015). None of these tests will tell an individual with a positive test for HD when the onset of symptoms will occur. While there does exist medication and treatment to reduce the severity of some of the symptoms of HD, there is not yet a cure, or any treatment to slow the progression of the condition.

While the ethical aspects of HD have been the subject of considerable past research (Keenan et al. 2005, Keenan et al. 2007, Keenan et al. 2009, Huniche 2011, Leontini 2010) the condition has rarely been examined using a sociological lens in order to look at services and organisational arrangements. This is despite that fact that the very complexity of HD allows valuable insight into the structuring of services that must accommodate many symptoms, many professionals and many potential understandings of the condition.

### ***The delivery of HD care***

Depending on individual circumstances, people who are experiencing symptoms of HD are also likely to be attending numerous appointments with many different

organisations and professionals, a fact highlighted by many of the professional participants in the current thesis research. In her own autobiographical account of life with HD, the author Sandy Sulaiman playfully lists just a few of the large number of professionals in her life at various times, as this quotation demonstrates:

...ongoing trips to the family doctor (obviously); a dietician (half a dozen visits); a genetics counsellor (lots of visits); a physiotherapist (one visit was enough); a psychiatrist, an occupational therapist; several consultant doctors specializing in genetics; a movement disorder clinic; various voluntary agencies; social workers; two very nice social care assistants who came to the house wanting to give me a bath – I sent them packing; a neuropsychologist (I think, might have got that one wrong); a speech therapist whom I didn't actually get to meet but had several appointments made before she gave up and sent me a note saying I was no longer on her list... and lots of other people who have tried to intervene in one way or another with varying degrees of success....' (Sulaiman 2007:18).

Descriptions from medical literature - such as that referenced in previous sections of this chapter – give an indication of some of the many challenges faced by people living with HD, a fatal and currently incurable condition that causes severe disruption to the people whose lives it touches. However, it only goes so far in describing day-to-day life with the condition. It does not reveal how these facts of HD are experienced by those who face them, including the resilience of these patients and families living with HD.

There have been few famous figures who have publically talked about a diagnosis of HD, aside from the 20th century American folk music legend Woody Guthrie and the members of his family who are now heavily involved in organisational activity around research and services for HD in the USA (Huntington's Disease Society of America [HDSA] 2015) . As the literature chapter of this thesis (Chapter Three) discusses further, it has often been a long journey for activists in getting now widely-discussed conditions such as breast cancer and HIV/AIDS into the consciousness of the public, as well as on the radar of professionals and social science researchers. Huntington's disease, and rare diseases more widely, are perhaps only just beginning to gain such awareness.

It has been highlighted thus far that living with HD, whether as someone at risk, with symptoms and signs, or connected to someone who has the condition, brings challenges that are multifaceted, complicated, and that stem from medical, psychological and social sources. In addition to this, it has been highlighted that there are multiple forms of professional expertise that come together around the treatment of people with HD. This is therefore an important setting in which to examine what happens in the interaction of these different types of expertise around a complex condition area, and what this means for the professionals and, ultimately, the patients involved.

As the literature review chapter will explore, there is a wide range of social science research that looks in-depth at various aspects of health organisational work within condition contexts other than HD, much of which is relevant to this thesis. With regard to HD, recent qualitative research by Frich et al. (2015) developed from within a health services research framework has looked at the way in which rehabilitation services are structured specifically around HD needs. Their conclusion that services would benefit from greater input from HD patients is a valuable one. Their work adds to a much wider set of offerings from health services research about the degree of patient involvement in how services are run. Yet beyond this there is very little social scientific work that looks specifically at HD services, whether public, private or third sector services, and/or the extensive range of professionals that work within these services.

Research in the area of service delivery and the third sector therefore has the potential to shed further light on the role of third sector organisations in supporting a rare and complex condition like HD. Huntington's disease is a condition that affects multiple areas of the body, including having an effect on a person's movement and motor function, cognition and mental health. This means that it has commonalities with other conditions, such as stroke, multiple sclerosis and head injury, with regard to the symptoms experienced and the support that might be required. The combination of shared features and blurred lines with other condition areas gives

considerable scope for applying sociological insights gained in HD services to other conditions in which multiple professionals work together around a shared goal. At the same time, my research has the potential to provide insights into the mechanisms of how partnership is understood and carried out by those involved, something of future use to professionals involved in service delivery. As I turn to next, research in this area also has the potential to make important theoretical contributions to our understanding of concepts such as expertise and boundary work.

### ***Viewing third sector activity in Scottish HD services through the lens of boundary work and expertise***

In this thesis I contend that theories about boundaries and boundary work provide a useful framework by which to conceptualise the shaping processes that occur within health organisations. While the theoretical development around boundary work has its origins in science and technology studies (Gieryn 1986), the concept of boundary work is useful to sociological understanding in that it describes a process of a culture being subject to redefinition (Lamont and Molnar 2002, Lamont et al. 2015 (forthcoming)). Likely for such a reason, boundary work and related discussion around boundaries are conceptual areas that are increasingly drawn upon by social scientists when looking at multidisciplinary professional settings, especially in healthcare (Huby et al. 2014, Fournier 2000).

In my own research it was apparent from early on in the data collection process that different types of professional attitudes and knowledge were coexisting, and had the potential to work together, clash, or overlap. Taking this idea forward, the concept of boundary work emerged as a result of reviewing the extensive literature on how professional groupings come to work together. In this thesis I argue that using the concept of boundary work offers a useful way to examine the processes behind partnership across different professional cultures. My own work also seeks to build upon and expand this body of boundary literature, by highlighting the currency of this work to partnership activity across divides in healthcare. In particular it

emphasises the special role of particular type of boundary worker that I have identified as a ‘key, committed professional.’

Connected to the discussion on boundaries above, my research also contributes to the extensive literature on the role of professional expertise (Collins and Evans 2002, Collins and Evans 2007, Martin et al. 2009, Sanders and Harrison 2008) and individual and collective patient knowledge (Bourret 2005, Prior 2003, Petersen 2006a, Rabearisoa et al. 2014b, Thompson et al. 2012) within healthcare encounters. More specifically, it shows how expertise might be built and maintained in newly professionalised constituencies. It is suggested within this thesis that a particular type of expertise that might be seen as an aggregate, professional assembly of patient ‘know-how’ (Pols 2014) is built by third sector specialists involved in linking patients between the home and clinical settings. This is intimately connected to boundary work on the part of the third sector, as they must constantly maintain their professional status and span boundaries in order to demonstrate this expertise. My study of Scottish HD care also unpacks the different shaping processes at the level of healthcare organisations, individuals and ideas of the health condition, all of which contribute to the overall argument about the development of this aggregate know-how by third sector organisations. The organisation of the thesis is outlined below.

## **Organisation of this thesis**

Chapter Two of this thesis explores in depth the context of the research. I present an important aspect of the research by describing the historical backdrop to the key institutions under examination– the NHS in Scotland and the Scottish third sector. In so doing, I highlight the need for further social science enquiry on third sector/health activity in the Scottish setting in particular. Examining the continuities and differences between Scotland and the UK levels of policy, I emphasise the importance of paying attention to the specific features of Scottish healthcare that shape third sector activity. In connection to this, I highlight throughout this chapter

some of the relevant policy frameworks originating at the level of both the Scottish and UK Parliaments that have provided a framework for health and third sector activity in Scotland. These include documents that have created the overarching health policy structures (e.g. *Partnership for Care 2003*), reviewed health or care standards (e.g. the *Review of Genetics in Relation to Healthcare in Scotland 2006*), and have framed notions around the organisations working together in health (e.g. the '*Christie Commission*' Report 2011). I then go on to outline the way that care and support services are structured to support Huntington's disease patients and their families within Scotland, exploring the partnership arrangements involving the Scottish NHS and the main third sector organisation operational within this area, the Scottish Huntington's Association (SHA).

Chapter Three examines the social science literature of key relevance to this thesis and demonstrates how this thesis seeks to add to, and build upon, a number of bodies of work. This includes a rich set of literature on illness experiences, third sector organisations and healthcare professions, as well as theoretical development around expertise and boundary work. The first half of the literature chapter outlines some of the offerings from the sociology of health and illness literature on individual and collective patient experiences of illness (Locock et al. 2009, Locock and Brown 2010, Mazanderani et al. 2012, Mol 2002, Scambler 2009). I look specifically within this at research that has considered the impact of genetics and/or decision making around HD (Finkler 2000, Keenan et al. 2005,2007,2009). This illness literature is important even though my own research focuses on professionals rather than directly on patients. It offers insights into the different understandings and experiences of illness that professionals encounter in their daily work. This body of work that explores how a condition is experienced also leads into a discussion of the first of the two 'key concepts' of the literature, that of *expertise*. Expertise is outlined here as being something that exists in many different forms and with different individuals. The chapter examines literature about professional expertise in healthcare as well as that which different forms of experiential knowledge possessed by patients and



within third sector organisations (Collins and Evans 2002, Prior 2003, Rabeharisoa et al. 2014b, Taylor and Bury 2007).

The second half of Chapter Three begins by exploring in greater detail the work on third sector organisations that formed the starting point of my own research enquiry. As was mentioned earlier, notable empirical research within social science on third sector health activity has focused on a wide range of condition areas and national contexts. It has been suggested that that third sector organisations in health comprise a ‘social movement’ (Allsop et al. 2004, Brown et al. 2004) that organisations are increasingly taking on a ‘partnership’ role in policy and research structures (Rabeharisoa 2003, Baggott 2008, Bode and Brandsen 2014) and that organisations have been involved in the framing of ideas around conditions (Akrich et al. 2013, Edwards 2014, Edwards et al. 2014, Moreira et al. 2014, O'Donovan et al. 2013, Rabeharisoa and O'Donovan 2014) . While previous research is a vital backdrop to my own, I argue that a gap in much of the past third sector literature exists with regard to the specific roles that third sector organisations serve within healthcare arrangements, and especially in service delivery.

Also of relevance to my own focus on third sector roles is research - largely from the sociology of professions - that has concentrated on patterns of change within healthcare structures, particularly the changing roles of charitable organisations and the different established professions within healthcare (Huby et al. 2014, Nancarrow and Borthwick 2005). Finally, the literature chapter turns to the second of the two key concepts and explores past theorisation and research in the area of *boundary work* (Gieryn 1983, Fournier 2000, King et al. 2015, Star and Griesemer 1989, Star 2010). The offerings from this area present a theoretical background against which to understand the work that goes on to shape professional boundaries, and to establish remits of expertise.

Chapter Four of the thesis discusses the research design choices made over the course of the research, including some of the challenges encountered. I discuss the

logic behind selecting a research approach based on an inductive, interpretivist research design and outline how and why multiple methods of qualitative data collection were used. This chapter also explores ethical issues that were pertinent within the research and that demanded reflexivity and adaptability from myself as a researcher. These include the sampling of interviewees and the ethical treatment of data, argued further here as particularly important issues to consider within doing research in closely connected settings such as my own.

In chapters Five, Six and Seven of this thesis, I put forward the main substantive findings of this research, divided into three key themes. Namely, I argue that third sector organisations can have an active and extensive role in the shaping of 1) healthcare organisations, 2) healthcare professionals, and 3) HD support itself. Chapter Five focuses on this first dynamic of the shaping of healthcare organisations. It explores findings from research participants about the shifting boundaries of the organisations involved in HD services as third sector organisations take on more extensive, professionalised roles. This is not depicted as a passive process, but something with which organisations must actively engage by undertaking boundary work. This is something found to have a shaping function on all involved, but is particularly acute for the third sector itself when it takes on a status as a professional service partner.

In Chapter Six, discussion turns to findings from the data about the role of individual employees within the public and third sector organisations involved in partnership activities. I look at the new forms of expertise and status roles that emerge from a system of increased joint working and increased specialisation. In particular, I focus on how personal background and motivation is talked about alongside the label of being a ‘professional’, and discuss how the specific character of the ‘key, committed professional’ might emerge within collaborative working.

Chapter Seven builds on the findings of Chapter Five and Six further, and puts forward data to support the argument that the condition of HD is itself being shaped

by partnership activities. Drawing on themes from my data about understandings of HD and accompanying care and support, I suggest that the multiple types of expertise co-existing around HD contribute to multiple ideas of HD and what support for HD should entail. Notions of a condition can be extended through third sector workers' emphasis on the multiplicity of the medical condition as well as a role in bringing into focus the different areas of a person's life, such as finances, personal relationships, living conditions etc. This contributes to an undoing and re-stitching of previous ideas around a condition like HD, and the public sector and third sector support that can be provided. As a result of this process, the emergence the role of the third sector as a source of additional expertise becomes particularly apparent: third sector experts can adopt the role of not only a coordinator within complex care arrangements, but also become key architects of many of the notions of what support entails.

The final discussion chapter (Chapter Eight), makes further connections between the three previous chapter themes - the shaping of organisations, the shaping of individual professional identities and the shaping around the ideas of a condition. I present my overarching argument that, within the boundary work occurring at these different levels around HD services in Scotland, the third sector is establishing its role as an important partner with a particular and valuable type of expertise, *'aggregate know-how'*. The implications of this for past sociological models of third sector activity and of partnership around are examined. In particular, it confirms and extends the work of authors who have suggested a 'partnership' role for the third sector. It also suggests, in contrary to scepticism in some past literature, that it is possible to have genuine collaborative arrangements based around knowledge and expertise.

Finally, the concluding section argues for more academic work in this area. I make specific suggestions for further sociological research about third sector services, partnership in health services, and HD care. It is also revealed within Chapter Eight that findings about the changed nature of third sector involvement in Scottish care

services have practical as well as theoretical implications. My own research provides insights about successful practice that should help to create integrated services that are long lasting, run by dedicated professionals and, most importantly of all, appropriately serve the needs of people living with long term conditions.



# CHAPTER TWO: EXPLORING THE CONTEXT OF THE SCOTTISH HEALTHCARE SYSTEM AND THE THIRD SECTOR

## Introduction

This chapter outlines the key features of the wider field in which the current research took place, namely, at the intersections between the Scottish health system, and the third sector. It is not intended to be a comprehensive history of Scottish politics or Scottish healthcare, as there is a wealth of literature that discusses one or both of these topics (Davidson et al. 2010, Freeman 2007, Keating 2005, Maxwell 2007, Mooney et al. 2006). However, this chapter aims to place the sites in which I did my own data collection in their wider political and structural context. This is of key importance due to the distinct and interesting aspects of Scottish healthcare and the Scottish third sector scene.

The time period discussed in this chapter and for the majority of this thesis is from just before the millennium to the present year 2015. The reason for this is that the 1998 establishment (and 1999 opening) of the Scottish Parliament is an apt starting point from which to view the Scottish-specific policy that has emerged since powers were devolved. As the section below discusses, the 1997-2007 ‘New Labour’ administrations under Prime Minister Tony Blair has been viewed by social policy academics as an era that started considerable reform in health structures, particularly to do with ideas around ‘partnership’ and the ‘third way’ in healthcare. This is therefore an important policy context to discuss for my research.

While I emphasise the time period of 1997 to the present in this discussion, it is important to note that these changes did not occur in a political ‘vacuum’ (Baggott

2007:62) and that there is continuity between many elements of the late 1990s and what went before. While, at the UK level, the centrist New Labour era was one of rapid change in healthcare structures, many partnership-related reforms built on older changes made by the right-wing Conservative governments that were in power prior to this. In particular, 1980s marketization under Margaret Thatcher, and the purchaser/provider split that was introduced by the John Major Conservative government in the 1990s, are considered to be major moments in moving the NHS away from its original collective roots and opening the door to different modes of healthcare provision, including the later involvement of not-for-profit groups (Giarelli et al. 2014).

This chapter begins by examining Scotland as a political unit, including both the parliamentary structures present, and the key features of its health system. Within this, the growing difference between the health system in Scotland and its counterpart in England will be highlighted. Following this, certain UK and Scottish policy shifts that pertain to the third sector and healthcare are explored and the characteristics of the Scottish third sector outlined. Throughout this discussion, key government documents are highlighted in order to provide a background to the policy shifts and framing of the third sector. These documents include both policy guidance published directly by the Scottish Government, and Acts that have passed through the Scottish Parliament and that have been voted into law.

At the end of this chapter, the specific arrangements that exist for Huntington's disease care in Scotland will be outlined. I will conclude that Scotland is a unique place in terms of health care organisational structure. It is small and close-knit with its own policy directions and mix of relevant healthcare actors. However, it is also subject to other forms of national and international governance, and shares cultural commonalities and themes of policy with other nations. Research in Scotland focusing on professional interaction can allow a detailed study of how a rare condition such as HD is positioned, researched, experienced and supported.

## Scotland as a political unit

Scotland is a small nation in Northern Europe with a population of just over 5 million people. It is constitutionally part of the country of the United Kingdom of Britain and Northern Ireland, which has an overall population of 64.6 million people<sup>3</sup>. Since 1998, the nations of Scotland, Wales and Northern Ireland have each had a series of powers devolved to a government at the level of each nation, with Scotland's devolved structures being the most extensive of the three (Forbes et al. 2010:592). The devolved Scottish Parliament and its publicly elected Members of the Scottish Parliament (MSPs) have the power to make policy except in those areas which remain 'reserved' to the UK Parliament (Scottish Parliament 2015a). Some of the most relevant devolved areas include health and social care, housing, education and training, law and order and local government, as well as all aspects of regulation of the third sector. The 'reserved' (i.e. non-devolved) areas most relevant to a discussion of health and the third sector include social security, medical ethics, immigration and employment. A fuller list of both devolved and reserved areas is available on the Scottish Parliament website (Scottish Parliament 2015). In addition to MSPs, the Scotland also has publicly elected representatives in each constituency who are members of the UK Parliament (MPs) and deal with 'reserved' issues.

It also important to note that even before the establishment of the Scottish Parliament in 1998 there were long-standing distinct features of the political landscape of Scotland in comparison to England, Wales and Northern Ireland as a result of a historically separate church and legal system (Steel and Cylus 2012:7). The 'Scottish Office' of the UK government (established in 1885 and existing up until devolution) was responsible for producing Scottish-specific policy in many areas prior to devolution, including health, education, justice and fisheries. There are also

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<sup>3</sup> The Office for National Statistics estimated the 2014 population of Scotland to be 5,347,600, and that of the whole UK to be 64,596,800 (Office for National Statistics 2015).



geographical features and sociodemographic features of Scotland that differ from some areas of the UK, which are often highlighted as important when it comes to service planning. In particular, there is a lower population density in Scotland than in the UK as a whole (Steel and Cylus 2012:7). The distribution of the population within Scotland is also a challenge for healthcare provision, with there being large rural areas such as the Highlands with very low population density, and a much heavier concentration of the population in Glasgow and the capital city Edinburgh (Steel and Cylus 2012:2)<sup>4</sup>.

A public referendum on Scottish independence took place in September 2014 with voters answering yes or no to the question ‘Should Scotland be an independent country?’ Approximately 55% of all voters voted ‘No’ and 45% of all voters voted ‘Yes’ (Electoral Commission 2014)<sup>5</sup>. Scotland therefore currently remains formally part of the UK. Scotland and the wider UK are also part of the European Union, which means that Scotland is also subject to legislation made at the level of the European Parliament. One example of policy at this level that is relevant to medicine is the *1999 EU Regulation* on orphan medicinal products, which provides incentives for drug development in what might be an otherwise low profit-making area of rare diseases (European Commission 2015). As well as national and supra-national political structures, there is also a system of local government in Scotland, mirroring that across the UK. The 32 Scottish council/local authority areas are each governed by councillors directly elected by the public, and who are responsible for provision

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<sup>4</sup> ONS (2011) reported Scottish population density as 67 people per square km compared to 225 per square km for the UK (Steel and Cylus 2012:2). The Highlands has a population density of 9 people per square km.

<sup>5</sup> The number of votes counted in the referendum was 3,623,344 (representing 84.6% of the electorate). There were an additional 3,429 ballots that were not counted (Electoral Commission 2014).

of a wide range of public services. These councils are financed via a block grant from the Scottish Government and from funds raised via local taxation such as council tax (Scottish Government 2015c).

The multi-level arrangements discussed above have many implications for the third sector and for other healthcare structures that will be unpacked throughout this thesis. For example, it means that a successful third sector organisation must be skilled at working across multiple different boundaries when it comes to different policy regimes and different funding sources. Social science work reports that for third sector organisations working around rare conditions in particular, there can be an advantage to working with others directly experiencing the condition in different locations in order to share condition specific knowledge and updates on medical developments (Baggott and Jones 2011, Hojnacki 1997, Jones 2007). The various levels of governments involved with different aspects of health mean that third sector professionals involved in partnership are subject to an array of policy influences that frame their role and the role of other professionals around them. They are also working with patients who are experiencing illness as citizens of different types of social policy – ‘devolved’ Scottish healthcare, ‘reserved’ UK welfare and cross-national policy such as the EU medicine directives highlighted above. Some of the specific features of the Scottish political, healthcare and third sector climate that relate to partnership are now discussed below.

## **The composition of the Scottish and UK Parliaments**

The voting systems used to elect MSPs/MPs differ between the Scottish and UK Parliaments, with the Scottish system incorporating proportional representation (Scottish Parliament 2015b). Table 1 below outlines the parties of government and their leaders at both the Scottish level and UK level since 1997. With regard to the political landscape of Scotland and the UK outlined within this table, there are several features that are particularly relevant to any discussion of healthcare and the third sector. Firstly, it highlights that there has been a shift in the political party in

control of the Scottish Government from a Labour-Liberal Democrat coalition, to a minority and then majority Scottish National Party government. This SNP government has positioned itself rhetorically in opposition to the former Labour administration in Scotland (who are the main opposition of the SNP in both the Scottish Parliament and individual parliamentary constituencies), as well as against the Conservative party in Westminster. The shift to an SNP majority government in Scotland has had a considerable effect in some political areas such as the constitution, with the SNP bringing about the referendum on Scottish independence in 2014. However, despite these changes, the wider themes of health policy have been analysed in the social science literature as remaining broadly similar across the different centre-left government administrations in Scotland (Alcock 2012). As will be returned to later in this chapter, there has been a consistent emphasis on the role of the third sector as ‘partner’ in healthcare in policy from all the governments that have controlled the Scottish Parliament.

<b>Table 1: Parties in government at the Scottish and UK levels since 1997 <sup>6</sup></b>		
<b><i>Scottish Government</i></b>		
<b>Parliamentary electoral term</b>	<b>Party/parties comprising the Scottish Government</b>	<b>Scottish First Minister</b>
2011-present	Scottish National Party (majority government)	Nicola Sturgeon ( <i>2014-present</i> )
		Alex Salmond ( <i>2011-2014</i> )
2007-2011	Scottish National Party (minority government)	Alex Salmond
2003-2007	Labour and Liberal Democrat coalition	Jack McConnell
1999-2003	Labour and Liberal Democrat coalition	Henry McLeish ( <i>2000-2001</i> )
		Jim Wallace ( <i>2000, 2001</i> )
		Donald Dewar ( <i>1999-2000</i> )
<b><i>UK Government</i></b>		
<b>Parliamentary electoral term</b>	<b>Party/parties comprising the UK Government</b>	<b>UK Prime Minister</b>
2015-present	Conservative	David Cameron
2010-2015	Conservative and Liberal Democrat coalition	David Cameron
2005-2010	Labour Party	Gordon Brown ( <i>2007-2010</i> )
		Tony Blair ( <i>2005-2007</i> )
2001-2005	Labour Party	Tony Blair
1997-2001	Labour Party	Tony Blair

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<sup>6</sup> Source – author’s own table. Information obtained from The Electoral Commission website, BBC website

## The structure of the Scottish NHS

The National Health Service in Scotland (NHS Scotland) operates as a separate organisation from its counterparts in England, Wales and Northern Ireland. However, the health system in all four areas has retained the NHS moniker that originated in 1948 when the health system across the UK was nationalised and made freely available to everyone by health secretary Aneurin Bevan (Our NHS Scotland 2015a). NHS Scotland is a large organisation and Scotland's largest employer (Baggott 2007), with over 160,000 staff<sup>7</sup>. It is the organisation responsible for delivering the majority of Scotland's health services, with the independent healthcare sector (profit and non-profit making) only having a small presence (Steel and Cylus 2012:17).

The Scottish Cabinet Secretary for Health, Wellbeing and Sport – currently Shona Robinson MSP - has responsibility for health and social care services in Scotland, and is also accountable to the Scottish Parliament in this role (Steel and Cylus 2012:17). At regional levels, the fourteen Scottish Health Boards (for example, NHS Lothian, NHS Grampian) have responsibility for health service delivery in hospitals and in the community. In addition to regional Health Boards there are also seven national 'special' Health Boards that provide national services such as the Scottish Ambulance Service and NHS 24, as well as the public health body Healthcare Improvement Scotland (Scottish Government 2015b).

Health boards have existed in Scotland since after devolution, with the merger of NHS trusts with Boards (Steel and Cylus 2012:17). This was set out in the Scottish Executive<sup>8</sup> White Paper *Partnership for Care* (2003), one of the early and major pieces of health policy to be delivered by the Labour/Liberal Democrat government

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<sup>7</sup> NHS Scotland had a headcount of 160,635 staff in June 2015 (ISD Scotland 2015).

<sup>8</sup> The Scottish Executive was renamed the Scottish Government by the SNP government on their election in 2007.

in the initial years of the devolved Scottish Parliament. It has been suggested that this is a particularly significant piece of Scottish health policy due to the structural changes in health organisation it brought about, which led to a Scottish NHS that was organised quite differently from the English NHS and which rejected the Blairite vision of ‘pro-market care’ (Beland and Lecours 2008). Bringing in the new system of locally organised Health Boards that were united under one national framework effectively abolished the internal market-driven NHS Trust system that existed elsewhere in Britain. *Partnership for Care* states the purpose of these changes to be the establishment of an NHS at local level that is ‘a single organisation with a common set of aims and values and clear lines of accountability’ (2003:57). This was also connected with an aim to enable greater autonomy at local level, devolving more responsibilities to frontline staff. Many of the Scottish health structures in place today – Community Health Partnerships (now becoming Health and Social Care Partnerships, as discussed below), the Scottish Health Council and the NHS 24 telephone helpline service – had their origins within this White Paper.

Many of the structures and values that were established in *Partnership for Care* were built upon in the SNP’s own flagship health policy ‘action plan’, *Better Health, Better Care* (2007). There was a similar focus on public health, regulatory standards and moving care to community settings. There was also a discussion of the need for integrated health and social care services, a topic discussed in more depth below. Within this document there was also a strong theme of the need for a ‘mutuality’ in the NHS, based on co-operation and collaboration between different professions and levels. There was also the explicit rejection of the idea of an internal market. The different dimensions of this particular partnership focus included workforce planning and the development of staff skills and experience. *Better Health, Better Care* also set out the expansion of the pre-existing Managed Clinical Networks as forums for networks of expertise between professionals and organisations around particular condition areas. Both *Better Health, Better Care* (2007) and *Partnership for Care* (2003) highlighted in general terms that the third sector was an important resource when developing partnerships in healthcare, particular at the level of communities.

Analysis of Scottish health policy by Stewart concludes that, while policy between Scotland and England had begun to diverge around public involvement since 2003, *Better Health, Better Care* represents a more rapid divergence, with professional, collective control re-emphasised in comparison to individual choice (2013).

Recent shifts have further integrated different elements of healthcare in Scotland. A formalised integration of adult health and social care structures in Scotland is currently underway as an outcome of the recent SNP-initiated *Public Bodies (Joint Working) (Scotland) Act* (2014). The joining together of many of the financing and planning structures of health and social care has been hailed by the Scottish Government themselves as being the following:

...the most substantial reform to the country's National Health Services in a generation, and will also radically transform the way social care services are provided too (Scottish Government 2014).

The Act has necessitated considerable reform of existing structures in order to implement the new measures. Formal integration means that, as of April 2015, each region of Scotland has put measures in place to form its own Health and Social Care Partnership (HSCP), replacing the aforementioned CHPs. The HSCPs are budget-holding committees of the NHS Boards and are responsible for making decisions about all adult<sup>9</sup> health and social care services for that region that are under devolved policy (Our NHS Scotland 2015). Individual health boards and local authorities must have the new structures for the HSCPs in place by April 2016 (Scottish Government 2015a).

Past social science and health services literature on health and social care would also indicate that the process of integration involves the combining of what might be seen historically as two very different organisational cultures (Bruce and Parry 2015). It is worth noting, however, that the formal integrating of commissioning structures has

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<sup>9</sup> There are some social care services, such as children's services, which the HSCPs do not cover (Our NHS Scotland 2015b)

not occurred out of the blue, and builds on what Ham and colleagues (Ham et al. 2013) explore in depth as an ongoing integration theme of past health policy from the Labour/Liberal Democrat coalition government and from the SNP government alike. The integration discourse has not been confined to health policy and has also featured in documents about wider public service delivery, such as the Christie Commission Report explored below (2013:31). The formal processes for health and social care integration nationwide have also been preceded by various measures to enable integration at a local level already, such as legislation allowing pooled budgets and the transfer of powers (Ham 2013:31).

Throughout the different stages of the *Public Bodies* Bill and the subsequent Act, and now in the ongoing development of these localised structures, there has been much debate about the role the third sector will play in health and social care integration. Since the initial framing of the Bill, the role of the third sector within the integration process has been strengthened, with the pre-existing Third Sector Interfaces – described more in the section below on the third sector – being positioned as a ‘conduit for the third sector in relation to integration activities’ (Scottish Government 2015d). There has also been £100 million in extra funding allocated to a dedicated ‘Integrated Care Fund’ in order to enable and speed up the integration process (Third Force News 2014).

Having outlined some of the past and current developments in the NHS in Scotland, this chapter will now explore some further aspects in which Scotland differs from England, before turning to a discussion of various aspects of third sector activity in the UK and in Scotland.

## **Current diversity between the Scottish and English healthcare contexts**

Some of the major points of difference between the Scottish and English systems have already been highlighted above when discussing the abolishing of the internal



market in healthcare in Scotland and the recent integration of health and social care structures. In more recent years, other structural differences to do with care organisation have emerged between Scottish healthcare and its counterpart in England. In fact, the English NHS is often used within literature as an exemplar of the marketization of a previously public health system (Giarelli et al. 2014:160). In particular, the Bill that led to the Health and Social Care Act (UK Parliament 2012) brought in by the Conservative-led coalition government in England, has been argued by academics such as Pollock and Price as representing a full-scale dismantling of the English NHS and its opening up to private market (2011). The most far-reaching and controversial element of this Act was the establishment of Clinical Commissioning Groups (CCGs). These CCGs are clinician-led regional bodies which control approximately two-thirds of the NHS's budget, and are encouraged to commission services from across the private, public and third sector, based on free-market principles of competition (Giarelli et al. 2014:160).

Scotland - alongside the other devolved nations - is not subject to the provisions of English *Health and Social Care Act 2012*, and therefore the public sector retains more governance over the healthcare system. However, as Scotland is still subject to other reserved policies and UK-wide economic issues, there exists a sociologically interesting variation in the structure of health systems across the UK. The continued wide-ranging marketization in England presents considerable challenges not only for those working within England, but also for both health professionals and third sector organisations working across UK internal borders. The variation also emphasises further the need for research that treats Scotland as its own area of enquiry when considering policy contexts that are on different journeys in the different nations of the UK.

## **The policy climate for healthcare and third sector activity in the UK**

The time period from 1997 onwards is seen by academics as a particularly important time for voluntary action in studies of the UK overall due to what will be discussed below as a mainstreaming of third sector activity across the UK. However, due to the establishment of the devolved Parliaments in Scotland, Wales and Northern Ireland in 1999, changes in ‘UK’ policy after this point are in fact only of direct relevance to the English context, something that Alcock (2012) discusses as often being lost within analyses of the third sector’s proliferation. There is a complicated relationship between the reforms in UK and those of the devolved nations, with some themes and structures being directly replicated in Scotland while others remain specific to England. Alcock’s conclusion, is that there has not been significant divergence in the policy drive towards mainstreaming of the third sector in public services across the different nations of the UK, and that the devolved structures might have in fact encouraged further proliferation of third sector engagement (2012:235). Therefore any discussion of third sector activity in Scotland often begins with reference to the policy developments at the UK level.

### **The mainstreaming of third sector activity across the UK**

The New Labour government that came into power in 1997 under Prime Minister Tony Blair has been credited with having ‘mainstreamed the voluntary sector as a policy actor’ (Kendall 2003:44). There is a great deal of literature about the policy-making of this era and the ‘Third Way’ ideology that underpinned it (Chadwick and Heffernan 2003, Giddens 1998, Giddens 2000, Glendinning et al. 2005, Hale et al. 2004), and I do not seek to cover this in full here. For the purposes of the discussion on the third sector and healthcare, however, there are a few important elements to highlight. Firstly, it has been discussed that while in opposition to the Conservative

in the 1990s, the UK Labour Party had made commitments about public health improvement upon gaining power (Baggott 2007:53). There was also a newly defined emphasis on overcoming ‘social exclusion’ of individuals within policy in areas such as unemployment, housing, skills and so on (Beland and Lecours 2008). Partnership working at a community level between the state and other bodies – patients, the NHS local government and ‘other agencies’ - was seen as a central element of the commitment to meet the considerable public health and social policy goals that had been set (Baggott 2007:53, Alcock 2012, Baggott 2013).

Partnership-working has also been explicitly linked to the Third Way ideals that underpinned the policy of this time period. Under this ideology, the state sought to implement a mixed provision of services and in doing so moved away from dominance either by the public sector, or by the economic market (Alcock 2010b:5). Therefore, as bodies that operate outside of the state or market, voluntary organisations were well placed to fulfil a function as partners under such Third Way ideals (Alcock 2010:5). Policy-making under the New Labour era – and, I would suggest, continuing in Westminster policy in the present day - has also been characterised within social science literature under the related governance theory of the ‘New Public Management’ (NPM or simply ‘managerialism’) (Kelly 2007, Pollock and Price 2011). Pollock and Price, taking a firmly critical stance to NPM, highlight that proponents of this theory argue that inefficiencies in the public sector arise from the presence of internal interests and a lack of financial incentives (2011). The contracting out of services to external, non-state providers and the ensuing competition between external providers is seen by NPM proponents as a way to drive down costs and to shift control from professionals to choice-oriented ‘consumers’ (2011:296). There has been a considerable and convincing body of work criticising NPM models, with critics such as Collyer and White concluding from their scrutiny of neo-liberalist approaches to healthcare there is ‘no evidence of cost efficiency, improved quality or greater equity, even according to the Government’s own costings agencies’ (Collyer and White 2011).

There is also a strong emphasis in managerialism approaches towards performance measurement as a basis for monitoring and financially rewarding services (Kelly 2007). It has been suggested that under the modified version of managerialism adopted by New Labour, policy surrounding partnership drew upon the above ideals of outside contracting yet at the same time a high degree of state control was maintained, with partnership functioning as an ‘explicit tool of central control and performance management’ (Baggott 2013:24). Investment in services and state regulation increased alongside many of the core neo-liberal tenets of NPM philosophy (Simonet 2015), and both ‘carrot and stick’ incentives were used to encourage partnership between sectors (Cameron and Lloyd 2011). The outcome of this New Labour partnership environment, Alcock argues, is a rise in the profile of voluntary organisations ‘to rival, if not outstrip, that at any point in the previous century’ (2010:2).

Alcock also emphasises that a particularly distinctive aspect of the New Labour era was the development of the discourse surrounding the ‘third sector’ itself in order to fit the aforementioned notion of provision from outside of the public or private sector (2010b:4). As a result, institutions such as the (now renamed<sup>10</sup>) Office of the Third Sector were formed at the UK level to directly encourage the involvement of these groups in public policy. A similar institution to the UK Office of the Third Sector was developed in Scotland in the form of the ‘Third Sector Division’ which was seen to have a similar focus on promoting social enterprise and overall encouraging the role of the third sector in policy (Alcock 2012:226). It is notable that such third sector terminology has survived in Scottish policy-making discourse even following the 2007 change in political administration at Holyrood from the Labour/Liberal Democrat coalition to the Scottish National Party (Scottish Government 2015f)

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<sup>10</sup> Reflecting what Alcock characterises as an attempt of the UK Conservative-Liberal Democrat coalition government of 2010-2014 to distance themselves from New Labour terminology, this was replaced by the ‘Office for Civil Society’ in 2010 (2012:231).

Various pieces of policy made in the UK Government and applying to England have been replicated in Scotland and the other devolved nations. These included changes to Charity Law and the establishment of a 'Compact' with the third sector (Alcock 2012:228, Fyfe et al. 2006). The role of 'Compacts' or other such concordats in formally acknowledging the value of collaborative relationships between the state and third sector has been discussed at some length in the literature (Kelly 2007, Fyfe et al. 2006). A Scottish Compact to mirror that developed at the UK level was developed in 1999, very early in the life of the Scottish Parliament. Fyfe et al. outline the mixed responses in academic literature about the role of such compacts, with the potential for them to be viewed as positive step towards champion the third sector, as merely 'platitudes', or, more negatively, as representing an 'incorporation' of the third sector into the public sector (2006:633).

Despite the similarities in arrangements such as the above, there are other policy agendas to do with third sector activity that have not been replicated in the devolved nations. Alcock highlights in particular that the much-criticised 'Big Society' agenda of the Conservative-Liberal Democrat Westminster coalition was not adopted by the governments of the devolved nations of the UK (2012:232) and became heavily associated with a version of third sector involvement where civil society at large was forced to pick up shortfalls in public sector provision. While the themes of third sector involvement extolling 'partnership-working' have largely been similar, there have can be seen to have been different agendas realised based on the political appetites of devolved governments and due to the nature of the health and social service structures in place to deliver policy (Forbes et al. 2010).

Sociological and social policy discussion has not been devoid of criticism when it comes to the idea of the 'third sector' in partnership with the state, with worries that such partnerships might merely co-opt or 'instrumentalize' the third sector in the interest of the public sector (Bode and Brandsen 2014). Talking predominantly about the English context, Carmel and Harlock state:

We argue that the discursive construction of VCOs as the third sector is embedded in a system of governance that tends to institute them as technocratic and generic service providers. In doing so, it renders their specific social origins, ethos and goals absent, as if these are politically and socially irrelevant to their activities and role in relation to the state. We argue that the partnership with VCOs, promoted since the late 1990s, has changed its meaning, since procurement has been adopted as the key mode of organising service delivery (2008).

While I agree that the scenario depicted above of the dilution of the social origins of ‘VCOs’ (Voluntary and Community Organisations) is negative, my own research seeks to show that there is hope that this is not inherently the case when organisations enter into partnership, especially outside of the procurement agenda. As even critics of the partnership discourse of the NPM era discuss, the impact of partnership is closely connected to the style of the governance arrangement chosen for the partnership (Bode and Brandsen 2014). While Bode and Brandsen are only cautiously optimistic, they allow that there could be situations within which partnerships are more socially embedded and where users and civic stakeholders have more of a direct role (2014:1063). Furthermore, as my own discussion of terminology in the introduction to this thesis explained, the ubiquitous modern usage of the term ‘third sector’ in contexts such as Scotland might be argued to have divorced it somewhat from its origins in the New Labour/New Public Management project.

### **Third sector partnership within a climate of ‘austerity’**

Another notable feature of the current political landscape is the continuing effect of the global economic crisis of 2008 on all the nations of the UK. In response to the national economic deficit, the last two UK governments have pursued cost-cutting ‘austerity’ measures that have entailed a severe reduction in spending on public services under its own remit. Cuts include decreased spending on the (English) NHS and other public services, the amount of money allocated to local government, as well as the amount of money directly allocated to voluntary organisations (NCVO 2013) The austerity measures also affect social policy in Scotland with relation to the decreased provision in reserved policy areas (e.g. welfare and employment support),

as well as in the amount allocated to Scotland in block grants from the UK. The welfare reforms in particular have been classed by the Scottish Council for Voluntary Organisations as already having the effect of ‘devastating families and communities across Scotland’(SCVO 2015).

While talking predominantly about England, recent work by Baggott and Jones examining the impact of post 2010 austerity measures on Health Consumer Patient Organisations (HCPOs) is insightful in revealing the multi-faceted effects of cuts in public spending:

As the capacity of health and social care systems is reduced, unmet needs are likely to increase and standards of care may fall. This is likely to increase demands on HCPOs for advice, information and assistance. Meanwhile, HCPOs that are funded by the state for services, advocacy and policy advice are being affected by budget cuts in the NHS and local government. Indeed across the voluntary sector, capacity is being adversely affected by the austerity programme (Baggott and Jones 2014:8).

The challenges discussed above are of central concern to third sector organisations that have become entrenched in the delivery of services, some of which are paid for out of the (reducing) public budget and some that are raised through separate fundraising. They also have analytical purchase within a contemporary Scottish context that has also seen direct and indirect austerity cuts. Baggott and Jones do highlight that there might be opportunities under austerity conditions for organisations to attract more membership/use from people in need, and possibly garner support from the public too for any anti-austerity service provision or campaigning in which they are involved (Baggott and Jones 2014). However, I would suggest that these opportunities might be overshadowed by the challenges of fulfilling such roles if funding is not available to meet increasing demand. Some of the Scottish specific features of the third sector are discussed below, followed by some of the empirical work that has been done on the opportunities and challenges for third sector organisations in Scotland.

## Third sector presence in Scotland

The third sector has had a long and important place in Scottish society, although, as outlined in the introduction (Chapter One), the way of describing it in popular terminology and in academic work alike is still subject to variation. The reasons behind my own use of the term ‘third sector’ are discussed in the introduction to this thesis (page 16 and 17). In short, the term has been chosen because it is widely used and understood within my research field of Scotland. It is also devoid of some of the etymological baggage of terms that are based on charity or volunteering, or alternatively, those that evoke consumerist practice. It is also the case, however, that many of these terms are often used interchangeably within conversation and policy in Scotland. Using both ‘third sector’ and ‘voluntary sector’ terminology, a 2014 ‘State of the Sector’ report by the umbrella organisation the Scottish Council for Voluntary Organisations (SCVO) estimated that in 2012/2013 there were 45,000 voluntary organisations in Scotland, employing approximately 138,000 people. The same report estimated that the income and spending of regulated third sector organisations overall in Scotland was 5 billion and 4.7 billion pounds respectively (2014:3).

In addition to the SCVO, there exist a large number of umbrella organisations, often also called alliance organisations, which aim to unite multiple third sector organisations around one common platform. Examples of alliance organisations that are particularly relevant to the focus of my own research on health and the third sector include: ‘The Alliance’ (also known as the Health and Social Care Alliance Scotland), ‘Voluntary Health Scotland’, ‘The Neurological Alliance of Scotland’, ‘The Genetic Alliance UK’ and the ‘Scottish Partnership for Palliative Care’.

Scotland also has a network of regional Third Sector Interfaces (TSIs) in each local authority area of Scotland that are funded and run by the Scottish Government. The purpose of these TSIs is to ‘provide a single point of access for support and advice for the third sector within the local area’ (Scottish Government 2015e). They are tasked with encouraging volunteering and social enterprise as well as strengthening



the third sector's role, especially within areas such as community planning. The name, structure and member composition of each TSI varies area by area - often building on previous voluntary and community structures existing in different regions - but all are subject to the same TSI Common Values and Services agreement. The outcomes expected from this agreement include third sector organisations that are 'well run and provide quality services', as well as those that 'understand each other better' and are able to 'influence and contribute to public policy' (Scottish Government 2013).

Alcock (2012) highlights that there are differences in the structure in the third sector within the different nations of the UK, again stressing the importance for research to examine these variations. He highlights the higher dependence of third sector organisations in the devolved nations on statutory funding, finding that this accounts for 39 percent of the sector's funding in Scotland, 44 percent in Wales and 61 percent in Northern Ireland – compared to the UK average of 36 percent (2012:224). While Alcock does not cite the comparative figures for England, a report by the National Council for Voluntary Organisations highlights the regional variation within England in the proportion of voluntary sector income received from local and central government (2015). Using data from 2012/2013, this NCVO report discusses a range from the area where this makes up the lowest proportion (London) at 27.9%, to the highest proportion in the East Midlands at 47%. These differences also exist alongside the fact that there many third sector organisations that operate across the whole of the UK, either working around shared issues across the different parliaments, or adjusting their work to different regions.

## **The opportunities and challenges for the third sector in Scotland**

Partnership working that involves the third sector has been a common theme of Scottish specific health policy. As the name of the 2003 White Paper *Partnership for Care* would suggest, there was also a continued emphasis on partnership working in

healthcare set out from the start of devolved health policy (Scottish Executive 2003:32). This partnership focus included more healthcare services provided at local level and strengthened relationships with local authorities and social care provision, and also work across the boundaries of NHS boards. The ‘voluntary sector’ is mentioned in several places throughout this paper, as useful partners at local level in particular service areas (e.g. integrated children’s services, health and homelessness) as well as an important partner in general for health improvement.

*Partnership for Care* (2003) also portrays the third sector as a route to accessing the patient voice as well as a service provider:

Sometimes the views and experience of patients can be expressed effectively through voluntary organisations. The health service does recognise the valuable role of the voluntary sector, not just as advocate, but in providing a range of services for patients and carers. We are supporting Voluntary Health Scotland and will continue to encourage NHS Boards to engage closely with the voluntary sector (2003:19).

The third sector is also actively referenced as a partner in later SNP policy documents such as the health action plan, *Better Health, Better Care*. Within this, it is stated that more needs to be done to foster the ‘important partnership’ with voluntary and community organisations, recognising their ‘value added contribution’ (Scottish Government 2007). The important impact of volunteering and the need to support this is also emphasised.

Throughout discussions of the framing of the role of the third sector in Scotland, the ‘Christie Commission Report’ is frequently highlighted as a pivotal document in setting the stage for increased third sector partnership in service delivery. ‘The Christie Commission’ is the name commonly given to the 2011 *Commission on the Future Delivery of Public Services*, work that was independently commissioned by the Scottish Government and authored by Dr Campbell Christie (Christie 2011). The key messages of this report are seen to be highly supportive of an increased and genuine partnership role for the third sector in public service provision. The report emphasises the need for radical solutions to overturn and prevent social inequalities, particularly (but not only) in times of financial strain. It calls for ‘bottom-up’

approaches to service delivery arising from communities - and that are characterised by collaboration - to become the norm (2011:18). The report specifically highlights the third sector's role in the above process in a number of different ways, including highlighting a role as 'experts':

Service providers often work in direct partnership with third sector organisations who have skills and expertise that mean they are able to recognise the very specific needs of individuals and work with them to achieve a positive outcome (Christie 2011:33).

A resource based argument is also evoked within the report, suggesting 'maximisation of scarce resources' involves drawing on 'all available' resources from the third sector, as well as resources of the private sector and communities (Christie 2011:ix).

The discussion thus far in this chapter about various policy changes within Scotland reveals that there has long existed a prevalent discourse of partnership working with the third sector in health policy and in social policy more widely. The third sector emerges in several different roles throughout even the small selection of government-produced documents discussed here. Third sector organisations are seen, among other roles, as advocates/voices for patients, as necessary resources for the provision of particular services, as links to expertise and access to particular issues and communities, as repositories of volunteers, and as checks and balances to the institutions of the public sector. These different discursive constructions of the third sector are particularly important for my own research when considering the possibilities for organisations and individuals to draw upon a role of an expert service provider. This way that the third sector is framed and understood by sectors is also a determinant of the opportunities and challenges presented for third sector activity. Some of the social science work that approached this topic within Scotland is explored below.

### ***Social science research on the Scottish third sector activity***

Dutton et al. (2013) discuss the results of a qualitative longitudinal study based in Scotland on changes in the public sector service delivery landscape, and the opportunities and challenges of this for the third sector. The time period that they tracked was 2009-2013. Although it draws partially on third sector activity outside of health, this work is illuminating in documenting what has been a rapidly changing public policy environment in Scotland in recent years. In particular the work highlights recent policy shifts such as (a) increased localism, (b) a move towards personalisation of services, (c) changes in funding availability and (d) a move towards different performance and outcome measures required. Dutton et al. conclude that there have been major impacts of such changes on third sector organisations, including challenges in keeping contact with multiple local authorities, maintaining partnerships, ensuring funding streams and maintaining staff morale (2013:10-11). The researchers also echo a conclusion of my own research in emphasising the need to examine how the third sector develops under public policy, especially in turbulent periods of change (2013:11).

There is hope from some quarters of the literature that, despite challenges such as the above, the third sector itself in Scotland might be able to sustain itself, as well as retaining an independent sense of identity and has a positive impact in service delivery. Drawing upon the same longitudinal research as Dutton et al. (2013), Lindsay et al. (2014) use the theoretical concept of 'New Public Governance' (NPG). Unlike the previously described, top-down 'New Public Management' (NPM) philosophies, the emphasis of NPG is the pluralistic nature of service delivery and co-production of services by users. This is seen to potentially allow for greater opportunities for third sector organisations to expand their own role (Lindsay et al. 2014:192). Lindsay et al.'s own work in the area of employability-focused third sector organisations in Scotland concluded that 'while there were themes of NPM styles of service delivery still present, there were increasing 'NPG-style relationships', including a move towards more holistic service systems (2014:205).

This is important because it reveals a continued emphasis on, and reliance on, incorporating the third sector in public service provision.

Having described some of the important features of the healthcare and third sector landscape in Scotland, this chapter will now turn to a particularly important aspect of the Scottish healthcare scene for my own research. Below, I examine the way that care and support services for people with Huntington's disease are structured in Scotland.

## **The structure of Huntington's disease care in Scotland**

As the previous chapter explored, HD is a condition that often requires the involvement of many types of professional expertise. The partnership structure that has been developed to run HD clinics in Scotland was featured in the 2006 Scottish Executive health publication the *Review of Genetics in Relation to Healthcare in Scotland* as an example for the setting up of other services for complex genetic conditions (Scottish Executive 2006). Third-sector-provided services in each area branch off from the NHS-run HD management clinics that exist in the major cities of Scotland. In the majority of areas across Scotland a Consultant doctor acts as a clinical lead for the HD management. These hospital-based Consultants are usually psychiatrists, neurologists or geneticists. This Consultant is likely to be just one of a large number of medical and social care professionals with whom someone living with HD is likely to interact with in the course of their care.

Within Scotland, HD clinical care and support also takes place within a framework that involves multiple sectors as well as different types of professional expertise. The three bodies at the core of the provision of Scottish HD services are 1) the public sector NHS, 2) public sector local government social care services and 3) the third sector organisation the Scottish Huntington's Association (described in greater depth

below). As the findings of this thesis reveal, at various times a host of other public sector and third sector organisations (e.g. housing services, benefits information services, alliance organisations engaged in campaigning) might also be relevant to somebody with Huntington's disease. While not addressed specifically in this thesis, the private sector is also involved in some aspects of the HD journey, especially when it comes to areas such as the provision of care in a person's home or in a private nursing home facility.

## **The Scottish Huntington's Association**

The Scottish Huntington's Association (SHA) was established in 1989 by a group of family members of people living with Huntington's disease. It currently exists as the only charitable organisation exclusively working with HD in Scotland. The SHA falls within SCVO's category of 'large' organisations i.e. those with an income over a million pounds (SCVO 2014:6). It reported an income last year of just over 1.3 million pounds.<sup>11</sup> The organisation employs over 40 paid staff located both in their head office in Paisley and in services across Scotland, and also liaises with a number of volunteers in local communities. The management structure is composed of a CEO and a separate Board headed by a chairperson.

On the SHA's website, it is stated that:

The charity exists to tackle the inequalities in health and social care provision, ensure families are better connected to support and services and increase the capacity of other agencies through training and education (Scottish Huntington's Association 2015c).

It should be noted that the usage of the word 'families' in the quotation above, or in the term 'HD families', encompasses both people with the condition *as well* as their kin with or without the condition. This is a common term used in HD support in Scotland. This more inclusive focus beyond solely 'patients' means that non-

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<sup>11</sup> Exact income reported was £1,326,810, for the accounting year until March 2014 (SHA 2015a:17).

biologically-related individuals such as carers (mainly partners and, to a lesser extent perhaps, friends) can and are included within the realm of HD support. It also is reflective of the discussion had in Chapter One around the many family dynamics involved in HD. For example, as a HD family member you might be a ‘pre-symptomatic person’ at risk but not yet affected (Konrad 2003), or know yourself to be a non-affected relative of somebody with HD. Individuals might also be seeking support specifically from their place in a non-patient role as a carer or advocate of somebody with the condition. This category of ‘HD families’ therefore allows for all these scenarios without pre-empting who is classified as a patient and who is not.

The organisation takes part in a wide range of activities connected to these goals depicted in the quotation above. The main area of the SHA’s work with which my own research is concerned is their Scotland-wide network of specialist services, discussed in more detail in the section below. However, there is also a wide range of other activities which the organisation organises or supports, as outlined in the recent annual report for 2014/2015 (Scottish Huntington's Association 2015a). It is also important to note that many of these activities overlap with the work being done by the SHA specialist services, as there is a great deal of interaction between the professionals in these services with the other groups, events and initiatives being carried out. This happens both in the form of referral between these different aspects of the organisation, as well as the way in which SHA specialists often directly take part in helping out with groups, running training, raising awareness and so on.

### ***Specialist services provided by the SHA***

The original family support services that were set up by the founding members of the SHA have now expanded to include an extensive network of SHA specialist services, which are the main aspect of third sector activity on which I have focused my research. Describing these services, the organisation’s 2014/2015 annual report states the following:

At the heart of the services provided by SHA are our dedicated team of HD Specialists who ensure that families get the support and services they need throughout their journey with HD (SHA 2015a:13).

Not to be confused with NHS hospital consultants, these HD Specialists are regionally located SHA-employed staff whose full time role is working with HD patients and families and doing other HD-related activities. The individuals that I encountered that fulfilled this role within my own research had largely come from a nursing background.

There are eight regionally located SHA services that employ HD Specialists as well as often employing administrative staff. The specialists employed within these services are involved in direct support with HD patients, their families and carers, as well as having interaction with public sector professionals providing care locally. As my research explores, there is a wide variety of support that these HD Specialists are seen to provide for clients of the service, including one-to-one home visits, attendance at important meetings such as clinics and case conferences, and providing information on all aspects of life with HD. These individuals are also involved in coordination of care with the public sector, with referral to other services, and in training such as that mentioned below. In the majority of cases, the specialist is based within a hospital within their support region (SHA 2015a).

### ***Other support for HD families at the national level***

Structural support such as organising help and funding is provided by the SHA for a network of family branches and support groups, which are run locally by individuals connected to the condition in five areas of Scotland. An annual conference also takes place specifically for people with HD and their families. Assistance for people with HD and their families is also provided at a national level via initiatives such as the provision of a 'Short Breaks Fund' and the recently developed Financial Wellbeing Service, which offers advice on issues such as welfare, benefits and financial planning (SHA 2015a). There also exists a partnership between the SHA and the mental health and wellbeing telephone support organisation Breathing Space,



allowing the development of specialist out-of-hours emotional support for people with HD (Breathing Space 2015).

For young people who have family with the condition and/or are at risk of HD themselves, there is a specialist Youth Service. This provides support at home as well as being involved with events such as yearly youth camps. The Youth Service was one of the first of its kind and has been used as a model for other countries looking to set up similar initiatives (notes from interviews A-N). The SHA is also one of many official supporters of the HD Youth Organisation (HDYO), which is an ‘international non-profit voluntary organisation set up to specifically provide support for young people around the world impacted by Huntington’s disease’ (Huntington's Disease Youth Organisation 2015). The English and Welsh Huntington’s Disease Association (HDA) is one of the premier supporters of this group.

### ***Involvement with awareness activities, policy and training***

Another type of SHA engagement is at the level of healthcare policy and other types of political engagement. Participation in awareness-raising activities is also something the family groups are involved in, but which takes place at a national level such as within parliamentary events or the media. The SHA has a close connection with the MSP Hugh Henry who has been involved in several parliamentary and other awareness events to do with HD. In 2015 he submitted a motion to the Parliament<sup>12</sup> and has been involved with a march alongside HD families and the SHA along Edinburgh’s Royal Mile, both activities as part of the SHA’s call for a national HD care strategy (Scottish Huntington's Association 2015b).

Another aspect of healthcare improvement activities that directly incorporates staff from the HD Specialist services discussed above includes their provision of training for professional groups involved in HD, such as staff within care homes or groups of

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<sup>12</sup> Motion S4M-13278, date lodged 26/05/2015. *Scottish Parliament Website*.

GPs. A recent initiative connected to training also involved a partnership with Stirling University to develop Continuous Professional Development Module in HD for practitioners. This in turn has led to the development of a Research Fellow Post funded by the Chief Scientist's Office and RS MacDonald Trust, which aims to contribute further to the evidence base on the needs of families with HD (SHA 2015b).

### ***International alliances***

A recent development in the history of the Scottish Huntington's Association has been the 2009 formation of the UK and Ireland HD Alliance. This arrangement exists to unite the four specialist third sector organisations concerned with HD across the different regions of the UK and in the Republic of Ireland: The Scottish Huntington's Association (SHA), The Huntington's Disease Association of England and Wales (HDA), The Huntington's Disease Association of Northern Ireland (HDANI), and the Huntington's Disease Association of Ireland (HDAI). A 2009 statement on the HDA website states the aim of this collaboration as 'to make as many people as possible aware of this rare disease and its devastating effect on whole families' (Huntington's Disease Association 2009). Although there are differences in the national structures in which the different organisations operate, there are shared goals around awareness. In the case of the three UK-based organisations, there will also be some shared policy issues. This again connects back to the earlier discussion of this chapter on the flows of activities and policies between different nations.

Another example of collaboration between nations around HD is the European Huntington's Disease Network (EHDN), of which the SHA and the other UK and Irish organisations are members. This is a predominantly medical research-related network, which links scientists working on HD across Europe. The SHA and the other third sector organisations maintain an active role in keeping up to date with the activities of this network.

## Conclusion

This chapter has explored some of the key aspects of the national, political and organisational setting in which the research is based. Understanding the specificities of political structures and service arrangements is particularly important in a context such as Scotland that has so often been subsumed in research under the label of ‘the UK’. However, as this chapter has shown, Scotland is an interesting example of a nation that has many of its own distinct public service structures and policy areas, but that also remains linked to past and current UK policy and agendas in many ways. Formal and direct links include Westminster-derived ‘reserved’ policy issues that cover all of the nations of the UK. However, there are also a multitude of informal or indirect links that have occurred over time, including shared themes of policy across the different nations. One such shared theme has been the enthusiasm for increasing involvement of the third sector in public services from the period of 1997 until the present.

While links on issues around the third sector might remain, some areas of policy - such as reform of healthcare structures - have been characterised by continuing divergence between Scotland and England. These facts once again highlight the need for sociological research around both third sector organisations and healthcare professions to pay attention to the devolved nations as their own unique contexts and important areas of study in and of themselves. Drawing on work that has been completed in this vein allows insight into some of the opportunities and challenges existing for the third sector in Scotland currently. Opportunities might be presented by a continuation of commitment to third sector involvement, but alongside challenges old and new to do with maintaining service relationships, securing long lasting funding and providing measurements of outcomes.

This chapter has also highlighted some of the documents – both policy and legislation that has been formalised into law – that frame the role of the third sector in healthcare in Scotland. As these documents show, the third sector emerges as a

‘partner’ in these documents, as well as one route for accessing the patient voice. The outline of the structure of HD care in Scotland sets the scene for my own research, and represents a prime example of partnership between the public and third sector in practice.

Building on the background discussion above, this thesis will now turn to examine the existing base of empirical and theoretical work surrounding the meanings of illness, third sector organisation activity, and changes in the organisation of healthcare. The broad selection of literature that I present here as relevant to my research reflects how discussions of third sector partnership necessarily raised questions about the patients, professionals and structures surrounding this activity. Within this, I will also tease out two key theoretical themes of key relevance to my own research: *expertise* and *boundary work*. These are concepts already pre-existing in the literature that my own research seeks to develop. It became evident to me that these were relevant and useful to the framing of my findings overall during the data collection and analysis stages of my research. In particular, boundary work was a useful tool by which to comprehend the processes of partnership and professional change. Alongside this, different notions of expertise emerged as central to understanding an important role for third sector organisations and individuals.



# CHAPTER THREE: A REVIEW OF THE LITERATURE

## Introduction

My research asks the question: what is the role of third sector organisations, and of partnerships between these organisations and the public sector, within services for Huntington's disease (HD) and similar conditions in Scotland? It examines how professional relationships work in practice within the context of HD, and suggests how this might shape the experience of services for all those involved. In so doing, this research aims to bridge a gap in past social science work, which has paid little attention to the dynamics of services involving partnership between multiple professionals from different sectors in relation to rare and/or complex health conditions.

From the outset, it was clear that the research would span multiple fields of social science enquiry around the topics of health and illness (including HD specifically) and work on organisational and professional activity. This chapter will begin by outlining some of the key literature - largely from social science work on health and illness - that looks at what can be broadly categorised as the *meanings* of illness. This literature is essential in providing a backdrop to the experiences and understandings surrounding illness that underlie the healthcare services that are the focus of my own research. Relevant work in this area includes that on the 'new genetics' and the understandings attached to genetic disease, as well as more recent work that looks at the different ways in which illness experience is understood, including the stigma that individuals might experience. There are many offerings from this area of illness-experience literature that have been based around HD directly, and these are highlighted throughout the discussion.

Tying into the discussion of illness experience, the chapter will then examine one of the key concepts of this research that links to this area, that of the *expertise* possessed by individuals about a health condition in a personal and professional capacity (Collins and Evans 2002, Pols 2014, Prior 2003, Rabeharisoa et al. 2014b, Taylor and Bury 2007). This theme, along with the concepts around *boundary work* (Fournier 2000, Gieryn 1983, King et al. 2015, Star 2010, Star and Griesemer 1989) that are discussed later in this chapter, emerged through an iterative approach within my own research, going back and forth between relevant past theoretical insights and the data that was collected. The notion of expertise and the understanding around expertise in the literature connect to a core finding of the overall research – the use by the third sector of particular forms of expert-based knowledge within partnership processes.

In the second half of this literature chapter, I explore recent work predominantly from the sociology of health and illness/medical sociology that has mapped the activity of the third sector (e.g. Baggott et al. 2004, 2005, Brown et al. 2004, Wood 2000), a literature which has been crucial in developing the focus of my own research. Related to this, I also examine work that has been done across the sociology of health and illness, the sociology of professions and organisational sociology, which examines the changing professional composition of healthcare structures (King et al. 2015, Nancarrow and Borthwick 2005). Across this literature, key themes have involved the changing status and professionalisation of charitable organisations and the changing roles of individuals working within healthcare structures. Related to both these processes are the changing professional identity roles available to individuals working within contemporary healthcare structures in the UK, again often discussed within the context of the broader, classic literature on professions (Freidson 1970, 1988, 2001; Abbott 1988, 1995).

Connected to the above, the final part of the chapter examines the second theoretical concept that frames the discussion of the findings of my research, ‘boundary work’ (Gieryn 1983). As this thesis will go on to discuss, key themes of my findings to

emerge around the shaping of 1) organisations, 2) identities and 3) conditions can be interpreted as being part of processes of boundary work between the different organisations in health. The constant boundary shaping and reshaping engaged in by the third sector is seen to bring about many different notions of expertise, many of which support arguments in the literature about the notion of expertise itself being transformed. These findings also suggest the need for continued theoretical attention towards third sector organisational activity - particularly around services - as an area where new knowledge is being produced.

## **Health and illness research after the ‘new genetics’**

The ‘new genetics’ is a term that has come to be used in social science literature to discuss the explosion of understanding, interest and hope surrounding genetic science and genetic medicine (Finkler et al. 2003, Kerr 2003,2004, Kerr et al. 1998). This literature predominantly discusses the two decades following the onset of the Human Genome Project in 1990. Considerable social scientific attention has been paid to the identity implications and power dynamics that might arise as genes are increasingly used as explanations of illness (Atkinson et al. 2006.). Scholars have also debated the extent to which the renewed interest in the new genetics departs from damaging ‘old eugenics’ ideas that took biological characteristics as the basis for social classification and stratification (Petersen 2006b, Petersen 2007).

The importance of the ‘new genetics’ literature for my own thesis is that, until recently, it has served as the main literary launching point for researchers interested in any aspect of a genetically inherited condition like Huntington’s disease. Lippman has developed the widely applied (and often depicted as negative) idea of ‘geneticization’ to describe a societal turn towards providing genetic solutions for human problems (Lippman 1992:1470). A major concern of critics is that high-tech research seeking the ‘gene for’ a condition may be prioritised over socio-economic



and/or environmental explanations for disease (Leatherman and Goodman 2005, de Melo-Martin 2008, Sulik 2011). However, literature also lends examples of ‘positive’ geneticization, whereby individuals and third sector organisations are hopeful that the new genetics will provide therapies and/or a cure for their condition (Bharadwaj et al. 2007, Gibbon 2008, Silverman 2008).

A ‘geneticization’ of sorts can also be seen within social science in general, and medical sociology in particular, as the social impact of genetics became a highly researched topic up until the most recent decade. Many scholars have highlighted what they consider to be novel features of genetic risk and genetic information when compared to other situations in health. In particular, social scientists have discussed the ethical dilemmas of risk/carrier status for a genetic condition when the information has implicit consequences for biologically related relatives (d’Agincourt-Canning 2001, Hallowell and Lawton 2002, Keenan et al. 2005, Leontini 2010).

However, as I will go on to show throughout this thesis, for patients and professional organisations alike, the implications of a ‘genetic’ condition are themselves complex, and combine aspects of familial relations – biologically related and not - as well as the symptoms and experiences of the condition. Within an editorial in a special issue of the journal *Sociology*, Hauskeller et al. (2013) stress that researchers engaging with the context of genetics – whether they are interested in medicine or other issues such as race/ethnicity - must recognise genetics as being part of a ‘multiplicity of identity engagements’. Past research that they bring together showing the complexity of how genetics connects to processes of identity leads them to argue that genetics should not be viewed as just an instrument of state power or a path to changing identity in a linear, deterministic way, but rather a type of knowledge that is used in many different ways. This is important within the context of my own research, as it highlights that the experience of genetics is mediated by the other ‘interests, expectations and power relations’ within the situation (Hauskeller et al. 2013:883), of which healthcare organisations are one component. Services that are providing support for genetic conditions, such as the HD services within my own research,

must be equipped to handle meanings that individuals bring to the condition, such as the decisions and relationships to do with their kin around them. Furthermore, as this thesis will go on to discuss, the different meanings around illness and care are also significant for the professionals and organisations involved in services as it makes many types of job roles and expertise important.

## **Genetic risk and the meanings around illness**

'Risk' is a frequent term throughout debates around the understanding of illness by patients and professionals within the context of the new genetics (Scott 2013, Scott et al. 2005). Genetic risk is depicted as something that can turn asymptomatic individuals into perpetually 'at-risk', self-monitoring subjects (Bharadwaj et al. 2007:120, Bharadwaj 2002, Braun 2007), potentially inviting negative psychological consequences. Several of these authors interested in risk have looked at the case of HD, which has often been regarded as a 'model' for ethical debates about new predictive technologies (Taylor 2004:137). For example, problems are posed concerning medical confidentiality and the right for individuals to know – and to not know – their genetic status (Chadwick et al. 1997, Chadwick 1997). The availability of a genetic test for HD combined with the fact that it has a clear-cut inheritance pattern for those who have the gene, is largely late-onset, and is currently incurable, means that it presents many ethical challenges related to the meaning of genetic information and the status of risk. Again, these types of ethical complexities form the context in which care and support services encounter patients. Risk is not the immediate symptom of a condition but remains part of the illness and its treatment. It is also one area of HD and other genetic diseases in which the social interventions around education, support and awareness raising can have a considerable impact.

The literature shows that lay interpretations of risk are constantly shifting, and that they are connected to the everyday lives of individuals rather than abstracted scientific frameworks (Cox and McKellin 1999). Psychological research has stressed the importance of lay beliefs and key life events and memories within the family in

triggering an individual's decision to get a test (Smith et al. 2002). This again connects such ethical decisions to a person's position in their kinship network. In the case of HD, even where individuals choose not to get a genetic test, they will still live with the knowledge that they have a 50% risk of fully developing the condition if one of their parents has the condition. Being in this position herself, the author Alice Wexler in her biography describes being in a 'third space', a place of uncertainty about one's own status and the future, not fully in one circumstance or another (1996).

As a consequence, there is potential for extreme anxiety on the part of individuals who have knowledge about their genetic status but can do little to alter the future, especially within a culture of healthcare that demands individual responsibility for healthcare (2003:152). As when Konrad was writing, HD still remains a suitable example of the prognostic gap as a condition for which there remains no cure, but yet was the one of the first genetic conditions to have a direct gene test developed following the mapping of the gene in 1993.

One area of research that looks at the interaction between ideas of genetics and *third sector organisations* specifically is that which has examined how third sector organisations negotiate complex kinship dynamics related to inheritable diseases. Finkler (2000) and others have explored how modern ideas about family and kin feed into understandings of genetic illness and inheritance (Atkinson et al. 2001, Featherstone et al. 2006, Latimer 2013, Rapp 2000). For inherited conditions – especially those like HD that are dominantly inherited and, as of yet, incurable – questions surrounding the existence of a gene in fellow kin (past, present, and those yet unborn) are particularly acute when it comes to decision-making to do with reproduction (Davis 2001, Leontini 2010). Reproductive decisions are a burden that research has additionally found to often be a gendered, as women of a family often bear the brunt of this decision making and/or of informing family members about risk (d'Agincourt-Canning 2001, Keenan et al. 2005, Mozersky 2012). This literature highlights further that experiential knowledge and beliefs, as in the case of risk

assessments, are central to the sense-making and decision-making processes about one's own health. For example, France et al. examine how real experiences of disability from their own life were drawn upon to make decisions about the termination of a pregnancy, through imagining the potential future for that child (France et al. 2012).

Several social scientists have focused on the enablers of and barriers to communication between individuals who find out about their own risk and that of potentially affected others in their family. The sociologist Keenan and her various collaborators (2005) have looked at communication between family members about HD risk and about breast cancer risk. They conclude that decisions about communication are influenced by multiple inter-personal factors. These include whether it is considered a family member's place to reveal another's risk, ideas about which particular family members hold responsibility for communication, and wider considerations of who actually counts as 'family' at all (Keenan et al. 2005).

### **Complexity and decision-making within HD kinship networks**

A recent study of the complete HD population in Northern Ireland explored uptake rates of predictive, pre-symptomatic tests for HD (Morrison et al. 2011). Echoing other research, it reveals that levels of uptake by people at 50% risk for such tests are low, at between 12.3% and 14.6% of individuals. Leontini's research (2010) exploring the reproductive decision-making of individuals who have HD shows further the complexity of the decision to get tested. There might be simultaneously multiple conflicting concerns relating to issues such as wishing to find out or not about own risk, versus the strong wish to have a child, or to protect future children from HD. As Downing explains within her own work on reproductive decision-making and HD, this protection might relate to both protection of these children from getting the gene, and protection of these children from seeing their parent develop the condition of HD (Downing 2005:220).

Keenan et al. (2007, 2009) have also carried out qualitative research into the experiences of young people growing up in a family affected by HD, and on the way that information about HD is communicated in couple relationships (2013).

Recognition that children and young people can be profoundly affected by having HD in the wider family has in recent years led to a number of third sector initiatives designed to support young people in this situation. When it came to how and when these young people found out about HD in their family (and in most cases, their own risk), Keenan et al.'s research concludes that young people who knew from a younger age seemed to cope with the information better, and that young children were able to process the information (2007, 2009). When it comes to communication about HD within couple relationships, non-disclosure about the condition to a partner was found to be often a contributing factor to relationship problems, and something that genetic counsellors needed to further take into account when supporting an individual with HD (Keenan 2013).

The literature above highlights that the classification of who is relevant to, or 'affected' by, a genetic condition at a service level - somebody experiencing symptoms, somebody known to be at risk, wider family members, carers and so on – both shapes and is shaped by common understandings of who is deemed to be 'kin' (Atkinson et al. 2001, 2013, Featherstone et al. 2006, Finkler 2000, Nukaga 2002, Latimer 2013). There has been discussion of the way that genetic practice can 'medicalise' (Finkler 2000) notions of kin and equate this with biologically-related individuals, as these are the people who are seen to possess the necessary biological information for certain genetic diagnosis and treatment (Atkinson et al. 2001, Dimond 2014). Yet, at the same time, social scientists have discussed how genetic disease, like all disease, is mediated in the everyday experience of individuals based on social constructed ideas of genes, inheritance and risk (Featherstone et al. 2006, Cox and McKellin 1999). Atkinson et al. have developed the useful concept of 'genescares' as a way of drawing together what are regarded as biological and cultural constructions of the gene alongside the further distinct category of inheritance (2001:1234). They highlight the importance of both social scientists and

clinicians acknowledging such multi-dimension genescapes when attempting to understand biographical experiences of illness (2001). However, there have been few examples from the literature that consider such social constructions or ‘genescapes’ through empirical examination of healthcare services, and fewer still that consider the third sector as having a role within this.

The changing dynamics of genetic disease and its interactions with kinship remains relevant to my own work when exploring exactly who is part of the ‘HD families’ around which inter-sectoral collaborations occur and the way this is open to redefinition. Likewise, when it comes to partnership around services for a genetic condition, it is the combination of the genetic aspects of the condition, in addition to the other experiences of a condition (physical disability, psychiatric problems, social exclusion and so on), that the professional encounters. Overall, this necessitates acknowledging both the ‘new genetics’ insights and wider sociological work on living with a chronic illness. Two other bodies of work that bring in an idea of the socially constructed understandings of illness experience are discussed below. I will firstly present insights from the literature on socially derived stigma and illness experience, before turning to work that has looked at the multiple ways in which ideas of illness might be constructed.

## **Stigma and the illness experience**

The theoretical concept of stigma is most closely associated with the work of Goffman, whose 1963 book *Stigma: Notes on the Management of Spoiled Identity* formed the foundations for much of the sociological work on stigma that has followed, including prominent work by Scambler and Hopkins (Scambler 2006,2009, Scambler and Hopkins 1986). Within his own work, Goffman suggests that people with identifiers of suffering from illness, or of being disabled, can become socially labelled as ‘abnormal’ and be discredited by those in the society around them. The stigma expressed by others might relate to the ‘enacted’ features of the condition, the

observed effect that it might have on a person's appearance or behaviour, or connotations associated with the condition in society (Goffman 1963).

Even in situations where the health condition might be invisible for some or all of the time, as is the case for some people with early or pre-symptomatic HD, individuals might still face the 'felt stigma' that comes with themselves knowing that they have a condition about which other people might have negative perceptions (Scambler and Hopkins 1986). It is discussed within literature that even where the exact diagnosis of a condition might be invisible, the manifestation of this condition within the behaviour of individuals can also render them visible in a way that might still yet prompt stigmatising reactions from others, as well as that felt by the individual.

It is also the case that many of the forms of stigma discussed in published personal accounts are attributed to a wider lack of awareness in society about the existence of HD and/or the symptoms and behaviours associated with it. The lack of other famous people with HD - other than the well-known example of Woody Guthrie (Buehler 2013) - has been highlighted in discussions in HD organisations as a difficulty for getting the name and the features of the condition widely known. This has recently led to individuals such as the former Olympic rower Sarah Winckless and her family making public their own experiences as people living with HD or HD risk in order to raise awareness (English 2014).

However, there still often exists a stark contrast in awareness between the public, who might not have heard of the condition at all, and a person with HD in their family. In the latter case, the individual might be fully aware of many of the future medical problems that they face. Talking about her HD-affected mother in her memoir, Alice Wexler talks of the condition's ability to function as a 'mirror', in which the experience of a family member you see suffering becomes visible as your own future or potential future experience (1996). Both the enacted and felt experiences of stigma discussed above view stigma largely at the level of individual interaction with societal perceptions, depicting it as a form of 'shame' that

individuals can internalise and incorporate into their identity. As will be discussed below, recent work on stigma has sought to highlight the wider social structuring of the experiences of stigma, as well as the way it interacts with or alongside social, political and economic inequality.

## **Updating understandings on stigma to incorporate systemic inequality**

It is also crucially important to recognise, as Scambler has done, that stigma has a very real interaction with other systemic oppression and exploitation, such as economic and class inequalities (Scambler 2006, Scambler 2009, Ridge and Ziebland 2012). Social science research and governmental research alike has discussed the comparative financial disadvantage and social exclusion faced by many people living with chronic illness (including mental illness) and/or who are disabled (Scottish Government 2015g, Burchardt et al. 2015) – both categories of which could apply to somebody with HD. Research has also shown how stigma around a condition, particularly where mental health is involved, can restrict access to what Schulze and Angermeyer call ‘social roles’, such as positions of employment, or personal relationships (Schulze and Angermeyer 2003). Fear of societal rejection might further isolate individuals from society and increase disadvantage – for example in the non-uptake of any services that do exist for fear of moral judgement about one’s status or behaviour (Rhodes et al. 2013).

Inadequate service provision for people with particular health or social care needs has also been highlighted as another problem within past literature that connects to disadvantage but goes beyond individual experiences of stigma. For example, Schulze and Angermeyer’s German-based research based on services for people with schizophrenia highlights that both gaps in care and poor quality care were interpreted by patients and professionals as relating to the societal and policy-based devaluing of the client group requiring the services (Schulze and Angermeyer 2003). In such circumstances, stigma might still exist, but takes the form of structural discrimination



through inequitable distribution of financial and human and organisational resources to a particular area. My own research proposes that the underlying disadvantages faced by individuals as well as the interaction with different types of stigma from different sources is something that successful services for people with conditions such as HD must acknowledge. Simply overcoming stigma alone will not ensure a good quality of life for individuals if underlying material and economic disadvantage still remains.

The discussion above on stigma, as well as inequality, highlights further the core tenet of the sociology of health and illness literature that disease can be experienced in many different ways. The literature that I turn to below is concerned with an area that might be broadly seen as the ‘construction of ideas around illness’, examining the multiple ideas that might circulate around a condition at both an individual level, and in wider framings of a condition.

## **The construction of ideas around illness**

### **Different meanings around illness and individual care**

A prominent social science text concerning different meanings of the body at an individual level has been *The Body Multiple* by Annemarie Mol (2002). In this work of ‘empirical philosophy’, Mol proposes that one condition can be enacted in multiple different ways by the different individuals who encounter it. Mol’s own focus on the ‘practices’ of disease - i.e. the actions that are taken by professionals and patients to do with disease - attempts to move away from the perspectives of individual patients and treatment providers in the assessment of a condition. Within her research into the condition of atherosclerosis, for example, Mol develops the argument that multiple versions of atherosclerosis coming in to existence in distinct scenarios surrounding treatment. There is considered to be a different ‘enactment’ of the condition within the story of an individual’s difficulty with climbing stairs, than to a physical examination of a leg by a surgeon, than to the cutting of amputated

tissue in a pathology lab (Mol 2002). She therefore claims that there is no single underlying condition called atherosclerosis beyond what is enacted within these different practices.

Through her observations of practices, Mol raises the important point that different individuals approaching disease from particular positions, e.g. as patient or as a clinician, might be understanding or experiencing different aspects of the disease. However, Mol's work can also be criticised in for its overly abstract nature and the limited implications beyond this point when comes to theory or practice about disease and multiplicity. Her emphasis on the disease being completely enacted by these experiences - and therefore not existing in a consistent form otherwise - means that the possibilities for applying this theorisation to professional practice are limited beyond the important task of recognising that there exist different perspectives. However, the core 'multiplicity' tenet of her work does provide a useful point of departure for researchers, including myself, who acknowledge that there are multiple meanings circulating around disease but seek to combine this with an ontological tenet that there are shared underlying realities of illness.

One set of authors who build on Mol's premise about multiplicity but with a theoretical and ontological approach closer to my own are Lerum et al (2015). These authors draw on 'social worlds' theory as an explanatory framework of how, under conditions of uncertainty, individuals might have different understandings and motives behind future prognosis in relation to the *same* biological condition. As Bowker and Star's work (1999) explains, social worlds are at their most basic groups or communities of people doing activities together, based on shared understandings of the world. Different sets of beliefs, knowledge systems and goals shape the way in which something is understood, even if the underlying physical characteristics of the object remain consistent.

Lerum et al.'s empirical research is based around the area of motor neurone disease (MND), and examines the way that the symptoms, trajectory and experience of the

condition means that it can simultaneously be understood by professionals as both chronic and terminal. As a result, there are shown to be real-world implications for the management of MND, as different medical advice might be offered by these different professionals depending on which aspect of the condition is being prioritised in communication and advice for patients. Ideas around the existence of MND as a condition in particular on a boundary between chronicity and terminality, and the resulting implications for patients, has also been discussed prior to Lerum et al. in the work of Locock et al. (2009). Their work highlights the identity implications for MND patients on receiving a diagnosis for a condition that is progressive and fatal, but where the speed of progression and length of survival is impossible to predict. Building on prior work on 'biographical disruption' and chronic illness, the theme of 'biographical abruption' emerges from the authors' data, highlighting the way that an MND diagnosis could be experienced as a 'sudden ending' for the patient (2009).

In both the examples above that draw on MND experiences, it is evident that the framing of the understandings behind a condition and its progression are important determinants of the response to it for professionals and patients alike. This is particularly important when a condition exists on a complex boundary between diagnostic categories. These examples therefore provide useful theoretical insights about managing illness at the boundaries of different categories, which are likely to translate to a condition like HD that is experienced in healthcare arrangements involving multiple perspectives. Like MND, HD might also be seen to exist specifically on the boundary between a diagnosis of chronic illness and progressive terminal illness, although the predicted length of survival following diagnosis between these two conditions differs considerably. As my research findings will go on to discuss, there are also other boundaries to do with the HD that emerge as relevant in a healthcare service context – the boundary between different specialist outlooks on the condition, the boundary between pre-symptomatic and symptomatic persons, and the boundary between clinical support and wider social support for the condition.

## Meanings of illness formed at the collective level

There also exist other offerings from social science literature that offer insight into the different ways a condition might be constructed on a collective, organisational level. Focusing on the case of Alzheimer's disease (AD) in the United States, Chaufan et al. discuss the 1970s medical reframing of AD as a biomedical condition and, simultaneously, the 'making' of it as a major health concern, overturning previous normalisations of dementia in old age as 'senility' (2012). Other research has focused on third sector-driven efforts to change understandings around conditions including autism (Chamak 2008) and ADHD (Edwards and Howlett 2013, Fuller 2011), further highlighting that disease classifications are not inherent but are subject to social interpretation of observed phenomena.

Chaufan et al. (2012) go on to propose that this biomedical classification for AD operates as a 'double-edged sword' for the AD organisations involved. While the medical label is seen to give legitimacy to the condition and allow for new types of activist expertise, there is the danger that the solution to AD becomes envisioned as a biomedical-based 'cure' rather than the social 'care' needs of current AD patients (2012). Other research has echoed this in showing the challenges faced by individuals when forced to fit themselves into categories not translatable to real experience, as in the example provided by Gillespie and Moore of the mismatch between people's own experiences of their disability and the questions on UK Disability Living Allowance (DLA) claim form (2015).

While categorisation is indeed being experienced in a negative way in the empirical examples of AD care and DLA claims form discussed above, there is hope offered by theoretical literature that by focusing on the boundary work going on about who is included and excluded we can be reminded that these conventions might have been 'otherwise' (Star 1990). As my own research findings go on to demonstrate, the existence of disease labels in and of themselves do not necessarily entail a polarisation of biomedical 'cure' versus social 'care.' Biomedical labels, and the

underlying understandings of a condition, are themselves questioned within the knowledge activities of third sector groups (Edwards et al. 2014).

The above work highlights that a fundamental role of some third sector organisations is the bringing together of different types of voices and expertise in the understanding of a condition. This in turn has the possibility of creating or undoing notions around a condition and its management, something of core relevance to my own research. Related to this, the chapter will now turn to a key concept of my own research in this regard, that of expertise.

## **Key concept one: Expertise**

The concept examined here, ‘expertise’, has been at the heart of a raft of scholarship, only some of which is directly related to my own sociological focus on the partnership work between different organisations in healthcare. For the purposes of my own work, two aspects of expertise as discussed in the literature are important: (a) the training and knowledge that people working in healthcare in various capacities bring to their professional role (Abbott 1988, Collins 2002, Martin 2009, Rabeharisoa 2014b, Sanders 2008, Yagil 2015) and (b) the knowledge and experience of both patients and other individuals involved with a condition, such as carers (Pols 2014, Prior 2003, Taylor and Bury 2007, Weiner 2009). While the empirical research that has addressed these two areas had often been done in isolation, I intend to show within my research the interaction that occurs between these bodies of knowledge, particularly when examining the work of specific boundary spanning individuals such as the third sector specialists as I do within my own research.

There also exists prominent work in the area of expertise which focuses on analysing the nature of expertise itself and the different forms of expertise claims that are articulated (Collins and Evans 2007). This focus on the micro-interactions of expertise is not something that is of central relevance to my present discussion of

expertise as a resource of professionals and patients. However, elements of this literature are incorporated into the discussion below as part of a wider focus on how expertise might be used.

## **Professional expertise in healthcare**

Rabeharisoa and colleagues in their recent work on third sector knowledge production define expertise as thus:

Expertise is the capacity of an individual or a group to produce propositions on whatever concerns the nature of the health issues at stake and on the way they should be dealt with. Those propositions are usually endowed with a degree of credibility underpinned by the recognised mastery of specific form of knowledge (2014b:115).

This approach is useful for opening up expertise to being a much more fluid notion that exists in networks and around certain issues rather than being attached to certain statuses only. Yet it does also highlight the credibility aspect of expert claims. This definition thus provides a useful, and suitably broad, base by which to consider the expertise that third sector organisations might hold.

Other work from the sociology of professions has examined how notions of professional and non-professional expertise are constructed and the role of technologies and structures within this (Korica and Molloy 2010). Of particular relevance to this thesis are the paths by which within these different networks of individuals develop professional identities of roles such as ‘doctor’, ‘social worker’, ‘nurse’, or the increasing number of intermediate professional roles (‘clinical champion’ for a condition, charity funded specialist nurse etc.). For the HD context, this has considerable relevance in light of the evolution of roles such as the (third sector funded) ‘HD specialists’ that are at the core of this research, as well as other titles conferred to clinical professionals informally such as ‘HD clinical champion’. These depart from previous professional labels such as ‘third sector professional’ or ‘hospital consultant.’

Classic sociological work on professional expertise within medicine has shown the potential for inequality between different professional groups in the medical arena – e.g. doctors and nurses - that can accompany privileged systems of expertise and other medical status markers. Ideas surrounding the ‘medical gaze’ and the control of individuals by surveillance of their bodies are discussed widely within the work of Foucault and those who have drawn upon his texts (Foucault 1973, Petersen and Bunton 1997). Building on this concept, other work has examined whether modern medical-scientific developments, including the Human Genome Project, might be seen through the surveillance lens that Foucault so strongly argued was a part of medical dominance (Bunton and Petersen 2005).

Recent empirical work has also sought to create a more up-to-date and nuanced picture of the blurred and frequently changing nature of power divisions within the medicine and healthcare landscape, often with a focus on both expertise and the other key concept of this thesis explored later in this chapter, boundary work. For example, attention has been directed towards exploring the processes of differentiation between different medical specialities, such as GPs and specialist hospital consultants (Martin et al. 2009), and the internal medicine specialists alongside other physicians (Oh 2014). Research in this area has examined how ideas of what constitutes expert knowledge, and processes of medical training, mean that some specialist areas such as neurology and cardiology are seen as holding a higher place in the medical hierarchy. Research has also sought to show that such hierarchies within medicine are plastic rather than fixed. Timmons’ work with his colleagues Tanner and Nairn (Timmons and Tanner 2004, Timmons and Nairn 2015) on the recent symbolic and formal recognition of emergency medicine as a medical speciality charts the rise of, and boundary work around, a new area of medical expertise.

As the section later in this chapter on the changing roles in healthcare will discuss, it is increasingly the norm for care to operate in multidisciplinary formats that draw on many different types of professional expertise. In their work on multi-disciplinary

meetings for cancer care in New Zealand, Dew et al. (2015) examine the different types of knowledge and authority that might be presented in such multidisciplinary forums. Several types of authority they describe pertain to the contact between an individual and the patient. 'Encountered authority' is based on a clinician's direct knowledge of patient, while the 'authority of lived experience' is based on knowledge from physical examination of the patient. The 'authority of clinical experience' draws on past experiences with the same type of condition more generally. Aside from these manifestations of authority, factors such as technology, evidence from research, and the position of those making referrals or viewing images are also presented as potentially of importance (Dew et al. 2015). It is therefore seen how even technical and elite knowledge becomes bound up with seeing or experiencing the life of the patient or multiple patients, and integrating this into specialised knowledge.

The work discussed above is therefore helpful in highlighting the professional 'knowing' of the patient and their experiences as a crucial component of professional expertise. Literature on professional expertise however rarely explores the form that the experiential knowledge possessed by patients might take. This is something of interest to my own research's focus which, while looking at professional experts, also explores the way that they draw upon and using experiential knowledge. As the section below discusses, there has been a wealth of work completed elsewhere in social science that has focused on the knowledge of those who have direct experience of living with a condition.

## **Knowledge and understanding from lived experience of a condition**

It has long been recognised in social science, and is increasingly recognised in governmental policy, that those possessing knowledge and/or expertise around a condition can extend far beyond the doctors, nurses and other professions in healthcare (Williams and Popay 1994). The potential for alternative, experience-



based forms of knowledge that might exist in health has been a regular feature of the sociology of illness literature (Arksey 1994, Gabe et al. 1994). First-hand knowledge of living with a condition has also been discussed as a route to collective action around a condition (Petersen 2006a, Raspberry and Skinner 2007, Akrich et al. 2013) a theme that will be returned to throughout this chapter when considering the role of third sector organisations.

### ***Debates about patient knowledge as ‘expertise’***

One of the first debates that emerges when understanding the role of knowledge from lived experience of a condition is the extent to which it might be regarded as ‘expertise’ in the way that it was categorised in the previous section about professionals. A review of past social science work by Prior (2003) seeks to trace in a critical fashion the emergence of the popular concept of the ‘lay expert’ within health and illness literature. Many aspects of this initial literature were useful for highlighting that there might be a particular quality to the knowledge derived from personal or ‘lay’ experience of illness or disease that both gives it value and that sets it apart from ‘professional’ expertise in some way (2003).

Prior suggests that within this literature there is firstly uncertainty about how this expertise arises, with patients seen to be experts by virtue of their experience alone in some accounts, and in others seen to be equated with individuals who have scientific training (2003). Overall, he finds the notion of patients as having ‘expertise’ problematic, arguing that while patients have ‘information and knowledge to impart’ and do have a form of expertise based in experience, their knowledge is ‘invariably limited, and idiosyncratic’ (Prior 2003:53). Therefore, according to Prior, patient knowledge should be regarded as vitally important and should be sought via participant and consultation, but it should not be seen as a form of ‘expertise’ in the sense of the diagnosis and management of illness.

In my own work I dispute Prior's latter point and take a stance more fitting with Collins and Evans (2002) in that I suggest a move away from the term 'lay expert' is useful, but that it is not necessary to abandon the idea of patient experience as constituting a form of expertise altogether. Collins and Evans make two arguments for moving away from the term 'lay expert.' Their first reason for doing so is, concurring with the above work of Prior (2003), they believe the term to be an oxymoron in the way that it combines 'expertise' with its opposite, 'being lay.' Secondly, and differing considerably from Prior, they suggest that that the 'lay experts' mentioned above should not be labelled as such because they are just experts whose expertise has not been recognised by certification, preferring their own term of 'experience-based experts' (Collins and Evans 2002).

Collins and Evans limit their 'experience-based experts' label to those only with 'specialist abilities' rather than just life experience alone to avoid what they fear is an extension of the label to all people (2002). However, I believe there is merit in suggesting that anybody experiencing a health condition has the potential to be an 'experience-based expert' related to that condition, with the points of differentiation then being about the nature of expertise that they might possess compared to others (e.g., those who have trained to work within a profession, or different patients), and the extent to which this expertise is made into a resource by the sharing of it by these patients with others. Furthermore, and fitting more closely with the topic my own research, the different experiences of patients might come to embody a collective form of expertise. This 'aggregate know-how' in turn becomes a resource on which other 'credentialised' experts – such as third sector professionals - might draw. There is a wealth of literature, a key selection of which will be described below, that unpacks the nature of patient knowledge, and the way this knowledge becomes used in healthcare.

### ***Experience and 'know-how'***

Pols begins within her own research with chronic obstructive pulmonary disease patients with the tenet that patient knowledge does exist as a 'particular kind of knowledge', although it is also depicted as linked to the medical practices in which patients are involved (Pols 2014). This highlights a crucial point when reviewing work on patient expertise that, even though the insights might largely be derived from personal experience and might often challenge biomedical understandings, individuals necessarily frame this within the surrounding medical and care context with which they are familiar (Nunes et al. 2014). In her own work, Pols (2014) aims to reveal the specific forms that patient knowledge might take and consider how it might be made transferable to science and used by others. This is particularly relevant to my own research as an area in which the translation of patient experience to practice is an important aspect of care. In her research, Pols presents a form of practical knowledge possessed by patients that she terms 'know-how', which is described as 'an activity of knowing that patients used to interpret new situations, to establish what might be the problem, and how they could act' (Pols 2014).

Know-how is explained to be a highly contextually-based type of knowledge that happens in the interaction with a situation by a person living with illness. Pols also presents know-how as something that might be undertaken within a community of people, within which patients use the experiences of others as a means to interpret their own situations (2014:81). She also goes on to explain how 'techniques' for living with disease might be developed from patient knowledge, and might in turn be something that other patients and professionals could draw upon and make available. It is also something that she suggests might be disseminated by patient organisations and through Internet communities (2014:90).

Work by Akrich on patient use of Internet health mailing lists shows the bridge between the shared experiences of a condition among patients and the potential political mobilisation of these patients when it came to future interactions with

professionals (Akrich 2010, Schaffer et al. 2008). She draws upon the notion of an ‘epistemic community’ to depict the shared understandings and goals existing within these online, knowledge-based communities. The use of such theory is in itself reflective of the credible status such knowledge has come to take. The original concept of epistemic community was developed as a political science concept in order to comprehend professional knowledge networks created around shared norms, shared beliefs about truth, and shared political goals (Haas 1992). However, such epistemic communities are something that particular groups of patients are now increasingly able to develop for themselves.

### ***Experiential knowledge as a resource***

Lived experience of a condition has been discussed throughout other literature also as a valuable resource that fellow people living with the condition might draw upon. Work by Mazanderani and colleagues in the areas of motor neurone disease (MND) and Parkinson’s disease explores how individuals turn the experiences of others into a source of knowledge for themselves (Mazanderani et al. 2012). Within this work, the face-to-face ‘seeing’ of another person like oneself with the same condition emerges as both a potential beneficial source of knowledge, and a potential source of distress if it leads to confronting one’s own future disease progression. The benefits and pitfalls of the comparison of one’s personal experience with the illness journey of others has also been explored in the work of Locock and Brown when considering why individuals living with MND might choose to attend or not attend peer support groups (Locock and Brown 2010).

In both the empirical examples by Mazanderani et al. (2012) and Locock and Brown (2010) discussed above, it was suggested that online communication offered support that involved less direct confrontation of the visual progression of a condition. However, this still did not mean avoidance of all the distressing realities of the condition, including the deaths of people contributing to internet forums (Locock and Brown 2010). One of the mechanisms by which individuals were found to manage

potential distress when interpreting the experiences of others was in emphasising the ‘differences’ as well as the features shared between individuals with the same condition (Mazanderani et al. 2012). This discussion of the use of other patients’ experiences is relevant to my own research in several ways. It highlights that both the visual and reported experiences of others might be regarded as an important resource by fellow patients. It also suggests that encounters with these experiences might be managed or psychologically filtered by people with the same condition when relating them to their own current and future experiences as a means for self-protection. These findings also suggest an important potential role for the third sector in providing accurate and honest ‘comparison’ information directly to patients about disease progression and expected symptoms, as well as providing means for patients to interact with fellow patients where this is desired.

It is also the case that, for some conditions, the involvement of individuals living with a condition directly in health services becomes a crucial part of the development of professional expertise. There is a large literature on patient participation in health that explores the merits yet challenges of ensuring there is meaningful patient input into the design and delivery of healthcare research and services (Dawes 2012, Frankish et al. 2002, Milewa et al. 2002, Locock et al. 2014, Thompson et al. 2012). Taking knowledge and expertise as a starting point, Caron-Flinterman et al. (2005) have discussed the potential for experiential knowledge to function as an important biomedical resource – for example within decision making about research and policy - if the correct structures are put in place to include this knowledge. Looking instead at the use of patient knowledge at the level of the individual clinical encounter, Dimond’s work reveals the multiple important roles taken on by parents of children who are patients in a genetics clinic, such as the narrator of the child’s experience and provider of information about biological inheritance (2014). This in turn illustrates an important point that important experiential knowledge around a condition might also reside with others close to a person with the condition, such as family, friends, spouses, informal carers and any other kin.

The examples above highlight that the nature of expertise, even that which is specifically based on an individual's lived experience, has diverse sources and might be drawn upon in a number of different ways. My own research is concerned with how the different types of expertise that might be articulated by patients and their families is evident in the work of professionals and, in particular, third sector professionals. This connects to a body of literature that looks at how knowledge is used and produced within the fora of third sector organisations.

### ***The production of knowledge within third sector organisations***

The next section of this literature chapter explores in depth the past literature on the third sector in health. However, for the purposes of the discussion on knowledge and expertise here, it is important to mention work that has been done on the relationship between third sector organisations and knowledge around a condition (Edwards and Howlett 2013, Weiner 2009). Although varied with regard to how they are composed, third sector organisations are frequently regarded as fora in which experiential knowledge is circulated and particular types of active patients are 'built' (Barbot 2006). The concept of 'evidence based activism' (EBA) is advanced by Rabeharisoa and colleagues in research arising from the EPOKS (European Patient Organizations in Knowledge Society) project, which examines how organisations become involved in the collection and production of knowledge around conditions (Moreira et al. 2014, Rabeharisoa et al. 2014b, O'Donovan et al. 2013, Akrich et al. 2013, Rabeharisoa and O'Donovan 2014, Edwards et al. 2014). It is further suggested across the literature that the 'production of knowledge' aspect relates to the fact that, for third sector organisations, knowledge is not just something they find, but something they 'contribute to and seek to shape with a view to expressing families' experiences and concerns' (Edwards et al. 2014:169).

'Evidence based activism' is also drawn upon in work by Moreira et al. to explore the way in which Alzheimer's disease (AD) organisations in Britain and Ireland mobilised the direct knowledge of people living with the disease using social

research techniques. They did this in order to challenge existing political structures of AD care and make AD into a ‘matter of concern’ (Moreira et al. 2014). It is shown that in mobilising this evidence based activism, these organisations were able to reinforce identities as ‘hybrid organisations’ through their ‘mediating between informal care, ‘grassroots’ networks and formal organisational formats and linking across lay, professional, expert and policy forms of knowledge’ (2014:175). Irwin and Michael also present the argument that patient organisations can exist as hybrid assemblages of knowledge, and also suggest that in so doing, the aforementioned dichotomy between ‘lay’ and ‘expert’ is made redundant (2003:142).

Within third sector activity in the area of health in particular there can, however, exist barriers to gaining a voice that are connected to the nature of the health condition itself. The sociologist Beard (2004) has traced the problems in providing true advocacy for patients who have Alzheimer’s disease, due to the condition’s effect on patient cognition combined with a lack of organisational structures that account for these added needs. In such situations, families and third sector organisations often become the default or ‘proxy’ voice for individuals, with problems therefore ensuing about the representativeness of this voice for patients themselves. Several studies have also shown that for people with a disabling condition and/or their full-time carers, time resources to provide input into organisational activity can be scarce (Fisher 2008).

When individuals are faced with a condition for which there is a contested or politicised basis, there might be limited routes to action (Dumit 2006), as Trundle and Scott find in their research with nuclear test facility war veterans (2013). Drawing on the case of what is often seen as an area of inter-professional contestation around ADHD diagnosis, work has also shown that support groups might be a forum by which the tactics for managing such contestation are shared (Fuller 2011). It is also the case that policy or healthcare initiatives to include experiential knowledge will only be successful in doing so if this is seen as a valid form of knowledge. O’Donovan talks of the failed project of Expert Advisory

Groups in Ireland, the main downfall of which was discursively placing ‘credentialized experts and scientific knowledge’ above what was seen as merely the ‘voices’ of patients rather than true expertise (2011:104)

The challenges discussed above suggest a more complex manifestation of the patient-expert relationship for many condition areas than the optimistic ‘hybrid assemblages’ role of patient organisations referenced previously (Moreira et al. 2014, Irwin and Michael 2003). Yet they also simultaneously show the importance of the third sector in shaping notions of where expertise can be found. In any of these situations where organisations come to speak on behalf of individuals, the role of the professionals within the organisation, and the way that the organisations depict themselves, is crucial. As this section has already mentioned, debates around expertise and identity are depicted in much of the literature as a process of drawing and redrawing distinctions between groups and knowledge. Theorisation around boundaries and boundary work, discussed later in this chapter, are suggested here as a fruitful way to explore the way the third sector emerges as its own source of expertise. Prior to this boundary work discussion, this chapter will first investigate the existing literature on third sector organisations in the health scene, followed by a discussion of the changing nature of professional structures in healthcare.

## **Mapping third sector organisations and health**

Past research on the involvement of third sector organisations in health and healthcare has been wide ranging, and much of it is relevant to my current exploration of the role of the third sector within partnership in the Scottish HD scene. Part of the difficulty with tracing relevant publications is the wide range of terminology used to describe such organisations with a presence in the health area. A huge variety of organisations can fall within the category of the ‘third sector’, encompassing everything from the smallest patient-led group in a single hospital, to a large and organised charitable organisation with a structure akin to a corporate business. Reflecting this variation and other discipline-based and nationally-based



influences, social scientists have employed a wide range of terminology and analytical approaches to explore different aspects of this third sector jigsaw.

When building a picture of past literature, it is therefore necessary to adapt to a constantly changing set of terms that can include ‘patient organisations’, ‘support groups’, ‘health consumer groups’, ‘patient advocacy organisations’, ‘health charities’, ‘not-for-profit organisations’, non-governmental organisations (NGOs), ‘the voluntary sector’, and so on. This different terminology often reflects everyday understandings of healthcare, the patient and civil society in different national and political settings (Baggott 2013:19). Furthermore, use of terminology by social science researchers is also often reflective of the normative judgements made about the nature of these groups, whether they agree with the policy directions behind these groups or not. For example, the recent proliferation of definitions involving the word ‘consumer’ – such as Baggott et al.’s use of the term ‘health consumer groups’ (HCGs) in their own UK research (2004,2005) - is drawing on market-related terminology to characterise the patient-healthcare relationship.

It is also notable that many of the prominent authors in the area of third sector organisation research have themselves drawn on different terminology at different times, reflective of their changing research foci as well as changing policy contexts. For example, Osborne, one of the main authors writing about ‘third sector’ organisational activity in Scotland from a business studies perspective, formerly drew upon the terminology of ‘voluntary and community organisations/VCOs’ (Osborne and McLaughlin 2004). In recent publications alone and with colleagues he now uses the terminology of ‘third sector’ (Osborne 2012, Dutton et al. 2013, Lindsay et al. 2014).

In the introduction to this thesis, I justified the use of the term ‘third sector’ in my own writing on the grounds that in the present day it might be seen as a relatively neutral and inclusive term. More importantly, it is also a term that has everyday recognition within my fieldwork setting of Scotland. It is also acknowledged that the

third sector is a general term that can also encompass a broad range of organisations that I do not directly address within this thesis, such as social enterprises and housing associations. However, I would suggest that it is possible that there might well exist a knowledge production role for these wider third sector groups also, something that would future research could do well to address.

## **The scope of third sector organisation involvement**

Since the late 1980s, the myriad of third sector organisations involved in various aspects of health and healthcare has been the focus of growing social science interest and investigation. Researchers have addressed changing facets of third sector activity against a backdrop of political and policy change, scientific developments, and the ever-increasing presence of internet technologies in all types of activism and support. Some scholars have chosen to trace in-depth the social and political conditions leading to the emergence of single or multiple organisations within particular condition areas. For example there has been work by Anionwu and Atkin (2001) on sickle cell disease and thalassemia, Eval et al. (2010) on autism; Epstein (1996) on HIV/AIDS, Klawiter (2008) on breast cancer, Rabeharisoa (2003) on muscular dystrophy and O'Donovan et al. (2013) on Alzheimer's disease. Others have chosen to focus on the macro level, examining multiple conditions and the way in which third sector organisations overall have gained presence within one country, such as Baggott et al.(2005) within the UK, Best (2012) within the US, Toiviainen et al. (2010) within Finland, and Wood (2000) within the US and UK by way of comparison.

For some scholars, research into the increasing influence of single-condition third sector organisations and multi-organisation alliances has led to the argument that this adds up to a significant, new, collective 'social movement' around health issues. This is most prominently argued by Baggott, Allsop and Jones in their wide range of collaborative work on third sector health organisations (Allsop et al. 2004, Baggott et al. 2005, 2004a, 2004b). Alongside this work there have also been a number of

review papers on health and third sector research from different social scientific perspectives, including those drawing on a social movement perspective (Brown et al. 2004) and science and technology studies (Epstein 2008, Hess et al. 2008). I concur with many of the above literature reviews in concluding that, despite the growing research base on third sector organisations, there remains much unanswered about how these groups work -and most importantly, interact - in practice. While the work of key authors such as Wood (2000) and Baggott and his collaborators (2004, 2005) has been insightful in describing the presence and activities of the third sector in health and healthcare, findings in this area have often been devoid of in-depth analysis about the sociological implications of the changing models of service provision and any impact this might have on the organisations, professionals and patients involved.

The focus on nation-wide, macro shifts in healthcare organisation by authors such as Baggott, Allsop and Jones (Baggott et al. 2004b, 2005), while important, has also entailed a lack of attention on how the interactions between third sector organisations and others within these professional setups relate to the particular condition or health context. Work that has looked at third sector organisations on the national level also requires updating in order to account for the constantly shifting nature of health policy. For example, Jones and Baggott update the stance of their earlier work in a recent book chapter, indicating that changed Public and Patient Involvement Structures and policy processes in England have altered the amount of political access by the health consumer groups that are the focus of their research (2011).

O'Donovan et al. (2013) advance the useful notion of 'cause regimes' as an explanatory framework in understanding the transformation of the remit of health social movement organisations over time. This cause regime of an organisation relates to the following:

..the public enunciations of the missions around which they are mobilised...that form an important part of organisations' patient identity work and can regulate their operation (O'Donovan et al. 2013:320).

Namely, this refers to the organisation's own depiction of who and/or what they are fighting for. Drawing on their own empirical example of the development of Alzheimer's disease (AD) movements across Britain and Ireland, they explore the changing cause regimes as the movements began to self-identify as organisations for people with AD, in addition to being organisations for carers of people with AD. Connecting to the earlier discussion of expertise held about a condition, this is useful for my own research in that it shows the different types of experiential knowledge that organisations might come to articulate over time. This research also highlights that both the scope and nature of third sector involvement is something that is subject to change under shifting notions of disease and the voices of patients/carers, and of where the third sector fits into this picture.

## **The nature of third sector involvement**

Across the micro and micro level approaches described above, research topics have included exploration of the activities and goals of groups. Wood's mixed-methods comparative research (2000) on what he terms 'patient association' activity in Greater Manchester in the UK and Metropolitan St. Louis in the USA remains a prominent comparative study of the different structural features that exist for organisations in these two contexts. For example, the US patient associations were seen to face far more competition, as well as having a greater emphasis on the use of paid staff than the mixed paid staff/volunteering model he reports as being often found in the UK. Furthermore, Wood also highlights the lack of political engagement by many of the groups in the UK and US alike. However, while the divergence of UK organisations with US models might remain, much of the empirical work explored below would suggest that in contrast to Wood's findings there does seem to be considerable political engagement undertaken by many patient organisations. As my own findings go on to show, it might also be the nature of political engagement that is changing also, as everyday support becomes a site for transforming policy and care around a condition.

Other studies have shown that it is the goal of many third sector organisations to address the sphere of politics itself, engaging with elected politicians and policy-makers (Baggott et al. 2005), although the degree of access and influence has been since argued to be contingent on the political structures present, as mentioned previously (Casey 2004, Jones and Baggott 2011). Researchers are also starting to take notice of the way in which third sector organisations are increasingly forming alliances with fellow third sector organisations as a strategy in order to present a stronger voice in political arenas (Jones 2007). However, such efforts are accompanied by challenges including inter-alliance differentiation and competition for scant resources (2007:524).

A recent edited collection of empirical work on ‘consumer groups’ across Europe questions the extent to which a possible ‘democratization of health’ is occurring as rights based health consumer organisations become more active on the policy scene across Europe (Loefgren et al. (eds.) 2011). The responses throughout the collection give mixed answers to this question, showing a wide range approaches to what counts as democratization, as well as variations in opinion as to the extent it has been achieved. The articles that were critical of new public management forms of governance were particularly sceptical of the extent of the impact of consumer groups in their respective arenas (Loefgren et al. 2011, Church and Armstrong 2011). Jones and Baggott’s own contribution suggests that UK health consumer groups do address a ‘democratic deficit’ in the form of lack of patient interests at policy level in the UK (2011). Yet they also express caution at the extent of the power that these organisations might have vis-à-vis other powerful state and private sector interests, and the potential for dilution of power of groups as they become more embedded in service delivery (Jones and Baggott 2011). This assertion about mainly English groups thus provides an excellent comparison by which to consider the power relations visible within service delivery of organisations working at the Scottish level.

Examples of third sector organisations fulfilling active roles in medical research are common throughout the literature (Allen 2003, Bourret 2005, Callon 2003, Taussig 2005). These examples show that collectives of organisations outside of industry and/or the state can contribute to defining the very possibilities of research or, as Novas phrases it, can become involved in the ‘governance of disease’ (2007:12). Epstein’s work on the scientific self-education of American HIV/AIDS activists (1995;1996) provides an earlier, but still useful, example of ‘partnership’ between activists with a condition and the researchers controlling cutting-edge clinical trials. It has been commented by Rabeharisoa in a brief essay within *Science* that the patient organisation involvement in medical research around genetics has had a ‘socialising’ effect, creating a sense of solidarity among individuals whose diseases were formerly perceived to be ‘shameful defects’ (Rabeharisoa 2011). While this is perhaps an optimistic simplification of the positive effects of something like research involvement, it does highlight the wider de-stigmatising function that collective action around a condition can potentially have.

Research has found that as well as the direct impact of an activity such as lobbying for research funding, there are potential ‘soft benefits’ for individuals and society that come from changing understandings - for example changing ideas about whether it is scientists or patients themselves who are the beneficiaries of medical research (Best 2012, Callon 2003). One author who has used a social science approach to look at healthcare services directly, and in the HD context too, is the science and technology studies scholar Nukaga (2002). His work involved a multi-methods qualitative approach using ethnography, interviews and archival data to explore the standardization of medical pedigrees as a form of medical knowledge practice in the countries of Canada and Japan. His main finding concerns the important role of traditional clinical tools such as family trees in the development of the ‘new genetics’ knowledge area discussed earlier in this chapter. However, with relation to my own research another important finding connected to this is that a third sector organisation the Hereditary Disease Foundation played an essential role as organisers and mediators in developing HD research collaborations between science laboratories,

the medical clinic and patients, particularly within North America (2002:59). While this is an example of third sector involvement in developing scientific research platforms, the continued relevance to my own work is twofold. Firstly, it once more highlights the important partner role of the third sector in interactions with other established institutions. Secondly, it suggests a potential boundary-related role for third sector organisations as mediators between the knowledge of the patient and the clinic, something that I discuss in connection with my own research findings.

The engagement of some third sector players within politicised clinical research arenas can be contrasted with other groups' more 'traditional' provision of support groups and direct healthcare and healthcare-related services. A large body of social science literature looks at the role of peer and professional support in providing personal benefits to patients as well as in the construction of their personal illness identity (Bar-Lev 2010, Greenspan and Handy 2008, Landzelius 2006, Schaffer et al. 2008). Baggott et al. (2004;2005 see also Allsop et al. 2004) among other authors make it evident that the domains of support for individual patients and political action are not mutually exclusive. Most of the British organisations in their qualitative research were classified as 'polyvalent', undertaking what could be regarded as both political and traditional activities (2004:319). Mulcahy et al.'s qualitative research into the Canadian cancer organisation Gilda's Club (2010) additionally points out that traditional activities can involve politicised engagement. For example, the 'support groups' within their study functioned as a forum for the exchange of information about health entitlements that patients could use as tools of advocacy in their interaction with medical professionals.

### ***The emergent 'partnership' model of third sector organisation engagement***

Moving towards an in-depth approach, the sociologist Rabeharisoa's extensive empirical work (2003;2006, see also Callon & Rabeharisoa 2008) tracing the French muscular dystrophy organisation, the AFM (Association Française contre les

Myopathies), is a much-cited research project about one organisation's growing involvement with the politicised arena of medical research. Rabeharisoa suggests that a new type of proactive cooperation – something she terms the 'partnership model' - is visible within the AFM's interactions with scientists (2003:2131). She contrasts this with organisations adopting either the more classic 'auxiliary' model or an 'emancipatory' model (2003:2129). The auxiliary model, as she describes based on the case of medical research involvement, involves the delegation of decision-making to specifically appointed 'experts' within their own organisation if possible, or those already in the scientific community. The emphasis is therefore on specialist expertise and existing knowledge structures (2003:2128). In contrast to this, the model that Rabeharisoa calls 'emancipatory' is focused instead on highlighting the experience of having a condition, often through the development of advocacy, experience led support and community services (2003:2129). This was seen to have arisen in direct contrast to former structures that were not seen to prioritise patient experience.

Finally, Rabeharisoa talks of the emergent 'partnership' model that she identifies in her own fieldwork with the AFM. She states that this model has two main characteristics: '(i) the patient organisation is master of its research policy; and (ii) patients are specialist' partners in their own right' (2003:2131). It is therefore seen to differ from the auxiliary model considerably in the way that the organisation and its patients have a direct say over activities. But it also is seen to diverge from the emancipatory model by having the goal of directly engaging with areas such as medical research, and directly shaping how these are run. Rabeharisoa discusses the role of the AFM as thus:

Not only does it have a say in a decision-making process co-ordinated with professionals; it is also an active player in that process, with the power to call on or even to invent forms of expertise and structures suited to its objectives (2003:2132).

The partnership model in Rabeharisoa's work might be seen to embody a new kind of relationship between professional structures and third sector organisations, in the way that it allows third sector organisations to be involved in the coproduction of



knowledge and services. Other research on third sector organisation influence would indicate that this ‘partnership’ model has not fully displaced all others, but is one that has emerged within specific circumstances. For instance, as discussed in the section below, important factors for third sector organisations controlling policy or for patients to emerge as partners include their ability to cultivate successful relationships (Epstein 1996, Panofsky 2011) and the range of cultural and social barriers that might be faced by the client group at the heart of third sector activities (Anionwu and Atkin 2001, Beard 2004, Dumit 2006, Best 2012, Nathanson 2010). In situations in which third sector organisations lack capacity or power to engage directly with institutional structures, an auxiliary presence, or starting their own initiatives as suggested by the emancipatory model, might be the only option for involvement and thus the enactment of change.

Within my own research, I also consider the applicability of Rabeharisoa’s own model (2003) outside of the specific context she examines, looking at the interactions within service provision around HD rather than biomedical research around muscular dystrophy. I also consider this from the perspective of the professionals that make up third sector organisations - such as the Scottish Huntington’s Association - as partners within service provision, who in turn are connected to their own patient constituencies.

## **Strategies and opportunities for third sector influence**

Other scholarship focusing on the specific dynamics of partnership suggests that third sector organisation involvement in politicised areas of health and medicine demands tailored alliance-management strategies. Panofsky’s qualitative research in the USA demonstrates how representatives from genetically-focused third sector organisations can build personal relationships with the researchers and biotechnology representatives that they hope to influence (2011:46). He concludes that generating such ‘sociability’ is as useful to non-statutory organisations as their formal networking processes. Such findings have potential transferability to my research as

Panofsky demonstrates the importance of individual professional relationships, in addition to organisational culture, in developing connections across boundaries.

However, it is important to note that Panofsky's American research, described above, in which such 'sociability' was generated occurred within a different type of relationship (i.e. between third sector organisations and profit-focused pharmaceutical companies, rather than between third sector organisations and the state-run NHS). It also occurred within a commercial setting in which the expectation that third sector organisations might treat potential partners to meals, events tickets and so on is far more commonplace than in interactions between third sector organisations and the NHS in the nations of the UK. Nonetheless, the tenet that there could exist informal channels between third sector organisations and other bodies that are supportive of partnership is a useful one, and is something that my own research has also addressed.

Epstein's work (1995; 1996), mentioned previously, highlighted that the successes of the HIV/AIDS movement arose out of both a long struggle by activists, and the impact of other social movements that had preceded HIV/AIDS activism late in the twentieth century, such as the gay rights movement and the women's health movement. Chambré and Goldner (2008) emphasise that 'activated' patients in the US might be found even further back in history. By way of example they cite the health reform and tuberculosis movements in the late nineteenth century, and the polio movement movements in the first half of the twentieth century (Chambre and Goldner 2008). Other research similarly explains the way that health movements and/or individual advocacy can succeed or fail depending on the political groundwork laid before them, and the ability of the individuals involved to articulate their cause in a way that those holding power understand (Anglin 1997, Fitzgerald 2008, Beckmann and Bujra 2010). For the purposes of my own research, this again highlights the importance of the wider context of third sector activity, and the way that current modes of organisation are bolstered by the past policy successes of other groups.

The notion of 'citizenship' has often been drawn upon by social scientists to discuss the way in which health activity might produce new forms of identity for patients (Whyte 2009, Renedo and Marston 2015). For the purpose of this thesis, citizenship is regarded as a useful way to frame the way in which illness - or ideas around illness - might relate to activity by organisations. For these reasons it is also a useful lens through which to explore how patients are constructed by third sector organisational activity, i.e. the way that third sector professionals and medical professionals come to view patient rights and roles within services. Recently, a host of new citizenship identities in health have been put forward, including those which examine individual identities that might develop surrounding access to pharmaceuticals and other forms of therapeutic treatment (Ecks 2008, Cataldo 2009, Nguyen 2005).

However, it should be noted that there can be limits to some expressions of citizenship around health that are not evident in the often optimistically framed third sector research discussed thus far. The social movement literature has a long tradition of exposing the barriers to health-related activism for particular client groups, with there being political and institutional obstacles in the way of collective movements by people in poverty, as well as difficulties for groups campaigning on their behalf (Nathanson 2010). Similarly, work has addressed the structural difficulties in translating expertise to policy faced by organisations concerned with health conditions primarily affecting people from a black or minority ethnic background (Anionwu and Atkin 2001) and/or those affecting women (Best 2012). Research has also reported the barriers that exist for collectivisation for health conditions in which a societally expressed or personally felt stigma is present, as discussed previously in this chapter. Such a stigma can from the outset prevent patients from acknowledgement of, or identification with a condition, limiting engagement in organisational activity (Clarke 2013, Rhodes et al. 2013, Ridge and Ziebland 2012).

The literature I have outlined above emphasises the growth in the number of third sector organisations and the scope of their activities. It also provides a window into the different type of activities in which third sector organisations might be involved.

These might include elements of support or service provision, direct campaigning against institutions, or working with them. Much of the literature has also shown that context does matter when determining the opportunities for organisational involvement, and that the level of institutional access or prejudice around a condition can also impact on involvement. This chapter will now turn to offerings from the sociology of organisations and sociology of professions that shed further light on the institutional dimension of third sector involvement in health.

## **Professions, health and the third sector**

Chapter Two of my thesis discussed specific aspects of the development of third sector policy in Scotland and the UK. I do not repeat this here, but seek rather to explore some of the more general offerings from the sociological literature around professions and the development of healthcare organisations. Since the development of the field of the sociology of the professions by Freidson (1970, 1988, 2001) and Abbott (1988, 1995), there has been a large and ever-growing selection of scholarly work on health professions and professions more widely (Muzio et al. 2013). In the section below, I intend to pinpoint what has been crucial literature for understanding the interaction between third sector organisations and individuals and the professional setups that surround them. At the crux of this discussion is an argument that professionalisation of the third sector does not occur in isolation, but happens against a backdrop of changing roles for the other professionals involved in healthcare, as well as against a backdrop of changing governmental policy (Harris 2001).

### **The nature of professionalism**

Classic work from the sociology of professions by Abbott (1988, 1995) and Freidson (1970, 1988, 2001) explores the mechanisms by which ‘professional’ groups come to take on this status and the resulting interactions with other occupational groups. Such work is important as a basis by which to understand the discussion of changing

healthcare professions that dominates contemporary discussion of healthcare partnership. For sociologists interested in health and illness it is of use and of academic interest that medicine has often been adopted within sociological work as an archetype of an occupation with a 'professional' status. As Freidson explains, this has not been the case because the professional characteristics of medicine are unique compared to other occupations. Rather, it offers a good starting point for analysis as a defined example of a high status role that is widely considered to be professional (Freidson 1970).

Freidson argues that at the core of what defines a profession in most prior explanations is the notion of 'autonomy' or 'self-direction', in which the occupation has freedom to control its own activities as well as potentially also directing those of others. He states:

From the single condition of self-direction or autonomy I believe we can deduce or derive virtually all the other institutional elements that are included in most definitions of professions. For example, an occupational group is more likely to be self-directing in its work when it has obtained a legal or political position of privilege that protects it from encroachment by other occupations (1970:93).

It is further argued by Freidson that any occupational groups might possess the autonomy required for professional status described above 'by default' through engaging in niche or unregulated work. However, it is being granted this autonomy by society as a result of perceived high status that makes some professions, such as medicine, emerge as dominant. This is also connected to the concept of expertise discussed previously, as dominant professions are able to make claims to their professionalism based on a 'hierarchy of institutional expertise' (1970:97). Freidson also emphasises that the perceived social worth of a profession is derived as much from their persuasion power and the perceived status than the actual underlying skill base of individuals within that organisation (Freidson 1970, see also Nancarrow and Borthwick 2005).

The sociologist Abbott in his own theoretical work does not seek to *define* a profession but instead provides an influential model of how a profession might strive

to maintain its autonomy. Abbott focuses in depth on the work that is done by different groups and their establishment of 'jurisdictions' as a result of this work:

To analyze professional development is to analyze how this link is created in work, how it is anchored by formal and informal social structure, and how the interplay of jurisdictional links between professions determines the history of the individual professions themselves (1988:32).

In both the characterisations of professionalism above, the structuring of the profession and its ability to assert a *boundary* between it and other areas of professional life is emphasised. Huby et al. in their summary of work by Abbott and other offerings from the professions literature, state that professional boundaries in particular contexts are 'created through a process of manoeuvre to expand and protect jurisdictional domains' (2014:412).

The work of both Abbott (1988) and Freidson (1970) indicate that social structures and values that ensure the dominance of certain groups run deep into institutions and resist instant alteration. However, their shared underlying premise that professionalisation is a socially structured and ongoing process highlights the possibility for both these structures and embedded constructions of what professions are to be redefined. Recent work on professions indicates that such a redefinition is currently going on in modern healthcare structures, in which growing involvement of newer professional groups has gone hand-in-hand with a decline in the dominance of the medical profession (Nancarrow and Borthwick 2005, Martin et al. 2015). Even in the accounts that are more sceptical about the actual extent of moves away from hierarchies in healthcare (Fournier 2000, Martin et al. 2009) the healthcare landscape in many industrialised nations is now seen to have moved at least away from medical dominance and increasingly towards healthcare pluralism within various public sector and private sector formats.

There is ubiquitous criticism of medical paternalism in sociological literature, and Freidson's work (1970, 1986) has been a prominent voice in exposing the problems with medical dominance. However, Freidson's most recent work (2001) contains a

warning over what he sees as growing criticism of the principles of ‘professionalism’ and therefore an erosion of its autonomous ‘soul’ (2001:221, see also Martin et al. 2015). In this work, he suggests such criticisms have often occurred when professionalism has been wrongly equated with the use and abuse of power within certain structures, or have occurred as a result of the devaluing of specialism or credentialism in favour of market-led choice or increasing bureaucracy. In line with Freidson’s 2001 argument, I would agree that specialised knowledge and the deliberate anti-competitive protection of certain, ideal-type professional values is indeed an asset in healthcare. However, it is also important to recognise that such professionalism is also located further beyond the elite groups such as doctors on which Freidson’s body of work has largely focused. As my research will go on to show, it might indeed be possible to preserve the ‘soul’ of professionalism within newer professional structures that are distinct from previous hierarchies. This classic literature further points to the utility of thinking of ongoing organisational jurisdiction negotiations in terms of boundary work, a key concept of this thesis that is discussed in the next chapter.

Nancarrow and Borthwick conclusion - that there has been a ‘growth and transformation of existing professions and the introduction of new workers’ in the past century (2005) - suggests that these changes have had a considerable impact on the healthcare workforce as a whole. Their research suggests several ways in which the boundaries between different professions are being redrawn, including practices of diversification and specialisation around tasks within professions, and the substitution of tasks from one profession to another (Nancarrow and Borthwick 2005, Nasir et al. 2013, King et al. 2015). There has also been much discussion throughout the literature of new types of role, or changed relationships between former roles, as discussed in the section below.

## Change across healthcare professions

There exists a large body of literature that unpacks the continually changing relationships between different types of professionals already working within the public sector in health (Nancarrow and Borthwick 2005, Fournier 2000). This literature is illuminating for providing insight into how and where third sector roles might fit in to the healthcare landscape alongside the other roles and professional identities already present. Fournier suggests that debates on professional change in healthcare have been ‘rife with contradictions and paradoxes’ (2000:68). She states that this literature has both simultaneously claimed that professions remain dominant and have been eroded, and that there also exists contradictory views as to the extent that the economic market has been responsible for healthcare changes (Fournier 2000). From her own viewpoint she does, however, suggest that there have been changes in the boundaries within professions, between professions and clients, and between professions and the market.

King et al.’s (2005) literature review of empirical work on boundary disputes across professions in healthcare suggests that the division of labour is based not on immovable professional boundaries, but on dynamic shifts influenced by forces such as the health policy agenda. It therefore might not always favour the traditionally most powerful professions. It may signal a reduction in professional power and autonomy by some of the professions, each of which is increasingly vulnerable to the vagaries of the healthcare market, and to the fiscal restraints imposed on healthcare budgets (King et al. 2015).

Other work has similarly focused on the role of the economic market in the ‘unmaking’ of the traditional professions in healthcare. For Fournier, this is due to what she sees as the logic of the economic market being about ‘boundarylessness’ between providers rather than set professional domains, and about performance according to best value and the satisfaction of empowered ‘consumers’ as patients (Fournier 2000). It should also be noted that Malin (2000), the editor of the same



volume within which Fournier is writing, also emphasises that pressure to erode hierarchical or closed off versions of professionalism has not just been due to the logic of the market. He highlights that this has also been due to other influences, such as pressures from movements of service users and the political Left (Malin 2000:262). Whether a result of what I would argue to be problematic market forces, or the more positive ideals around benefiting service users, an ‘unmaking’ of traditional hierarchies might actually open up space for new types of expertise and specialisms to move in and replace the ‘soul’ of professionalism lamented as being lost by Freidson (2001).

Overall, although complexities remain about the method and merit of healthcare professions change, the literature suggests that pluralistic professional healthcare delivery and multi-disciplinary working are in place. This has assisted in the emergence and cultivation of new types of professional groups, as discussed below.

### ***New expertise and specialisms***

Occupational areas such as nursing and those under the umbrella of the ‘allied health professions’ have been on a long trajectory to becoming defined as professions alongside the established specialisms of medicine. Empirical research has revealed the development of particular professional areas such as the formally unequal, but continually changing, relationship between medicine and nursing (Salmela et al. 2013, Salhani and Coulter 2009) and the growth and professionalisation of allied professions (Light 2000), such as occupational therapy, physiotherapy and podiatry. A specific example of this is present in the research by Bacon and Borthwick (2013) on the emergence of the role of ‘diabetes specialist podiatrist’. Social scientific research has also tracked the historical differences between the structure of social work and other health services, and the persisting perception of social work as possessing a different set of (altruistically focused) character traits (Abbott 1995). This is an area that is particularly current within Scotland in light of the recent establishment of formal Health and Social Care Partnerships. These mandate the

pooling of adult healthcare and social services budgets within each region of Scotland, as discussed in Chapter Two of this thesis. Alongside the expansion of the remits of health and social care expertise, the nature of what constitutes the medical profession, or indeed a 'profession' at all, can be seen as having altered substantially from previous hierarchical models.

As this thesis has discussed thus far with regard to third sector organisational activity, there exist a growing number of studies that depict third sector organisations as partners of some form within publicly provided social services (e.g. Baggott et al. 2004b, Brandsen 2008, Dutton 2013, Osborne 2004, Rabeharisoa 2003, 2006). This connects to a widely asserted claim across literature on professions, organisations and service delivery that suggests that many third sector organisations and their workers can undergo a process of 'professionalisation' as they become more embedded in formal service involvement (Carey et al. 2009). Academics have also started to examine how such processes of growing professionalisation for certain groups such as third sector professionals might in turn have an impact on how an individual's own work identity is viewed. For example, Roth's recent work (2015) examines the job satisfaction of individuals working in international aid organisations under changing organisational structures, as well as other challenging emotional features that are associated with an identity as a professional aid worker. These important aspects of professional role-bearing - identity and emotions - are explored later in this chapter.

### ***Teamwork in healthcare***

The changing nature of roles within healthcare and how they come to interact is also of interest to academic work looking at 'teamwork' among professions in healthcare. Much of the work in this area has taken on a critical slant, juxtaposing what is often seen as 'inherently positive' (Finn et al. 2010) discourse about the existence of teamwork with a reality in which inter-professional hierarchies often remain (Finn et al. 2010, Martin and Finn 2011). Finn et al.'s research (2010) in two hospital

teamwork settings also found that there can also be considerable ambiguity from individuals around what the discourse of teamwork means in practice, even if the underlying principle is widely accepted.

However, other empirical work has shown the successes of teamwork in healthcare settings. Research by Garrino and colleagues in a Northern Italian rare diseases centre - has shown that successful multidisciplinary working is both possible and important for care around conditions presenting many different complex elements (2015). Likewise, rather than just being something which maintains some individuals in a higher status, teamwork has also been found to be a useful resource by which some 'lower status roles', such as health care assistants can assert themselves as members of a team (Bach et al. 2012). The existence of these competing sources of evidence about the extent that teamwork is achievable or desirable highlight the need for further scrutiny of the roles of the individuals placed into different types of teamwork situations in health.

## **Professional roles and identity**

There is a growing body of work that examines the impact of changing occupational roles and team composition on the individual identities of people working in healthcare. Identity is an important concept within my research, particularly when discussing my findings around professional identity in Chapter Six. It is a concept that is employed frequently by social scientists, but often without definition. For the purpose of this thesis, a working definition of identity developed by social identity researcher Manuel Castells is utilised:

..the process of construction of meaning on the basis of a cultural attribute, or a related set of cultural attributes, that is given priority over other sources of meaning (Castells 2004:6).

Identity as defined by Castells above is seen as something that is a process of meaning-making rather than something fixed (2004). It is also able to exist concurrently in a number of forms. This idea of a changeable, plurality of identities

is important for this research because I am here regarding professional identity as merely one aspect of an individual's life, even if it happens to be the area of their life that my own research is most focused upon. Furthermore, Castells' flexible approach allows a recognition that different influences on identity, such as the personal and professional lives of an individual, might overlap.

Much of this work completed on identity discusses the multiplicity of identities that an individual professional such as a clinician might experience, as their position as 'clinical expert' becomes combined also with roles as a 'service provider' or 'resource allocator' (Yagil and Medler-Liraz 2015). Another aspect of professional identity is the emotional dimension of providing healthcare support under a 'caretaker' identity (Yagil and Medler-Liraz 2015).

There is also evidence throughout the literature of professionals having to go 'above and beyond' their own basic role in order to fulfil the changing expectations of both others and themselves about who will address health and social care needs. Hanlon and colleagues, drawing on their research in rural Canada, suggest a phenomenon of 'stealth volunteerism' taking place among health and social care professionals in this context (Hanlon et al. 2011). This involved professionals getting involved in their own time with activities to benefit the users of services, such as running support groups and providing individual advocacy and care coordination. Personal commitment to their helping role, and a sense of belonging to the local place, are depicted as motivators for this activity, in addition to professionals fearing a lack of support being available to the service users otherwise due to welfare retrenchment (Hanlon et al. 2011).

### ***The emotional dimension of professional activity***

Fisher and Byrne (2012) explore the challenges surrounding the emotional aspect of professional identity within their own research, which was focused on care-workers in Manchester who support people with learning disabilities. The researchers develop a distinction between the rewarding, internal 'goods' of these professionals when it

comes to them ‘doing good’ for their client group, and the tension that can exist between these goods and the ‘external goods’ of outputs and targets that are required by the services (Fisher and Byrne 2012). Various strategies used by individuals at different times to reconcile what might be clashing demands on professional identity are put forward in these research findings and across the literature. For example, professionals might choose to privilege what they see as their core identity in response to challenges (Yagil and Medler-Liraz 2015, Fisher and Byrne 2012), or integrate or incorporate other identities – such as the aforementioned ‘caretaking’ identity – into part of the expert role (Yagil and Medler-Liraz 2015).

Connecting to the professional strategies employed by individuals to manage different roles, ‘emotional labour’ (Hochschild 2012) in the face of difficult decisions and work practices is a prominent theme within literature on work and emotions (Lewis 2005, Bolton 2000, Hochschild 2012). An empirical example of emotional labour is provided by Lewis (2005), who examined the way that nurses in a special care baby unit constantly managed their emotions at times where a personal connection with families went alongside a need to maintain a professional persona. The creation of ‘communities of coping’ with fellow professionals is suggested by Lewis as an important aspect of maintaining this personal/professional emotional balance (2005). Emotional management has also been depicted a key aspect of team working in healthcare situations in other research, as Henckes and Nurok find in their own example of support among paramedic teams (2015).

Research by Bolton on emotional labour in gynaecological nursing (Bolton 2000) suggests that personal emotional labour might also be offered altruistically as a ‘gift’ to patients as part of the nurses’ caring role. The establishment of a ‘human connection’ through a provider taking interest in the patient’s wider life, hobbies and so on has been reported as integral to shared decision making elsewhere in the literature too, such as in Eliacin et al.’s own work in the area of mental health (2015).

The different aspects of emotional management and connection to patients are of key relevance to my own research when considering the overlapping relationship between professional roles and the personal background and motivations of individual workers. As will be developed in Chapter Six, this connects to a theme within my own research about individual professional identity and performance, and the connection of this with being perceived by oneself and others to be a good professional. I will argue within my own research that emotional work is a feature of professional identity formation within what can be challenging but also rewarding professional contexts such as HD service provision.

Building on the above discussion on the changing relationships between different organisations and different individual roles, this chapter turn to what is a second key concept in developing the argument of this thesis research. Below, I outline the concept of ‘boundary work’ as a way of understanding the way in which individuals and organisations define themselves within healthcare.

## **Key concept two: Boundary work**

In this section I will summarise conceptual work that has been done around ‘boundary work’ and its close relative, ‘boundaries’. Prominent research within the area of boundaries and boundary work has taken place outside the context of health and illness - for example within the aforementioned area of the sociology of professions (Hunter and Segrott 2014, Huby et al. 2014, Martin et al. 2009), or in research in the social science sub-discipline of science and technology studies (Fox 2011, Gieryn 1983, Ramirez-i-Olle 2015). However, the ‘plethora’ of different occupations in the health landscape (Bach et al. 2012) has meant that considering these changes in boundary terms has often been of use in sociological work around organisational change (Fournier 2000).

It is argued here that viewing interactions (between professionals from the third sector and other organisations) through a ‘boundary’ lens is a useful way to explain

the third sector's role within partnership around conditions like HD. It is also a concept that directly connects to notions around expertise, in that the boundary work being discussed here is all about the construction of ideas about different groups of expertise. As with the aforementioned notion of 'expertise', 'boundaries'/'boundary work emerged as key themes when looking at my data alongside prior theory. As this thesis will go on to develop further, these ideas of boundary and expertise together help us to understand the new types of knowledge that third sector individuals might make claim to when the borders between healthcare services are moved to make way for partnership.

This thesis adopts the definition of a 'symbolic boundary' as advanced by cultural sociologist Michèle Lamont, who along with colleagues has charted the history of the concept:

"Symbolic Boundaries" are the lines that include and define some people, groups and things while excluding others (Epstein 1992, p. 232). These distinctions can be expressed through normative interdictions (taboos), cultural attitudes and practices, and more generally through patterns of likes and dislikes. They play an important role in the creation of inequality and the exercise of power. The term "symbolic boundaries" is also used to refer to the internal distinctions of classification systems and to temporal, spatial, and visual cognitive distinctions in particular.

(Lamont et al. 2015 (forthcoming))

Lamont and Molnar's review (2002) of boundary-related literature in the sub-area of the professions, science and knowledge highlights the way in which this concept brings together a diverse selection of literature. This has included studies of social and collective identity, work on inequality across lines such as class, ethnicity and gender, research on communities and national identity and, finally, scholarship that examines issues around professional status and knowledge. As Lamont and Molnar point out, while there is a current enthusiasm for adopting boundary terminology, there is a much older social scientific foundation in this area, with concepts about the processes of boundary-making being developed as early as the work of Durkheim, Marx and Weber (Lamont and Molnar 2002).

One of the most influential notions drawn upon in the area of boundary theory is that developed by Gieryn on 'boundary work' (1983), from his work on scientific authority. In his article 'Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists', he argues that scientists consciously demarcate themselves from others as a 'stylistic resource' to separate themselves from, and elevate their status above, what they define to be an opposing group of non-scientists. Such boundary-work is regarded as:

..a sociological parallel to the familiar literary device of the "foil." Just as readers come to know Holmes better through contrasts to his foil Watson, so does the public better learn about "science" through contrasts to "non-science." (Gieryn 1983: 791)

Gieryn argues that there are a number of likely reasons why a group such as his own exemplar of scientists might come to engage in boundary work. In summary, the three main reasons he cites for groups doing this are the 1) expansion into other remits, 2) the monopolisation of resources, and 3) the protection of professional autonomy against others (1983:792). In this light, he argues that boundaries become a consciously and subconsciously used tool by which professional status can be guarded or enhanced. Gieryn also highlights that these three reasons for boundary work listed above are connected to processes of 'professionalisation' of knowledge areas.

An empirical example of work completed in this area of boundary work and professionalisation is Bach et al.'s work on the relationship between nurses and healthcare assistants (HCAs) (Bach et al. 2012). This was a focus that was taken deliberately to add a different dimension to past work, mentioned earlier in this chapter, that considered the changing boundaries between nursing and medicine (Bach et al. 2012:206). This UK-based research suggested that as HCAs take on more of the direct patient caregiving work formerly done by nurses, in turn, these nurses were often taking on more administrative, care management and prescribing roles formally the domain of medicine. As a result, both sets of occupations were engaged in boundary work to assert their newer status to each other and to others in the healthcare hierarchy.



For the HCAs of Bach et al.'s research (2012), their comparatively 'lower' status compared to the nurses mean the boundary work partially involved showing where boundaries did *not exist*. They did this through evoking the similarity of their caregiving to the holistic and caring philosophy of nursing, and therefore the value of their work. However, at the same time, the HCAs were found to differentiate themselves in order to justify the unique contribution they were making to care, as well as to highlight negative issues such as the comparatively lower pay and status accorded to them (Bach et al. 2012). This example works well to highlight that boundary work is multifaceted, and the types of boundary work that exist are constantly changing in light of new processes of professionalisation. Change in healthcare structure is also complex, and as one profession gains different remits (e.g. nurses), this is also likely to have an impact on the boundaries set for other professions (e.g. HCAs).

The discourses that are employed by different specialities in asserting their occupational boundaries might be seen as another form of boundary work, and is something that Sanders and Harrison (2008) examine with their own work on heart failure care in the UK. They show that at different times professional groups might evoke particular discourses as a means of 'establishing professional legitimacy' (2008:303). For example, reflecting the expertise discussion earlier in this chapter, professionals of various types might draw upon a discourse of 'specialised expertise' to demonstrate their own authority to make claims over others, or at the very least display a discourse of 'competence' to show that their expertise was valid. Individuals that were operating across boundaries –in Sanders and Harrison's study, specialist nurses – also drew upon a discourse of 'organisational efficiency' to show the value of their own role (2008). Finally, a discourse of 'patient centred-ness' was used by individuals to present holistic care as both a need of the patient group, and something that they in their own professional role were well placed to bring.

While some authors have focused on the ways in which boundaries are drawn and redrawn, with different degrees of optimism (Fournier 2000, Huby et al. 2014, King

et al. 2015, Lamont and Molnar 2002, Martin et al. 2009) others have looked at some of the mechanisms by which boundaries might be crossed (Cameron and Lloyd 2011, Star 2010, Star and Griesemer 2007, Williams 2002). Two of the most applied concepts in this latter area have been the concept of the ‘boundary object’ and that of the ‘boundary spanner’, as I discuss below.

### ***Strategies for boundary crossing – boundary objects and boundary spanners***

#### **Boundary objects**

Originating within the work of Star and Griesemer (1989) and further developed by Bowker and Star (1999, Star 2010), the notion of a boundary object has gained considerable traction in social scientific literature. A boundary object is something that might be material or abstract in nature, which functions as a communication bridge across different ‘social worlds’ (Star Griesemer 1989), allowing cooperation in the absence of consensus (Star 2010:602). In recent social scientific work around health and illness, the idea of a boundary object has been applied to a range of phenomena, from care pathways (Håland et al. 2015) to the category of ‘rare diseases’ (Huyard 2009) and even to patients themselves (Lindberg et al. 2012).

The context within which Star and Griesemer’s original 1989 research was based was within the research department of a zoological museum. This is an environment in which there exists simultaneously a diverse range of informed viewpoints, alongside a need for cooperation and scientifically rigorous results. Within their research, the authors defined a boundary object as needing to be ‘both plastic enough to adapt to local needs and the constraints of several parties employing them, yet robust enough to maintain a common identity across sites’ (1989:393). In recent years, use of the concept has in fact become so widespread that in a recent article, Star reaffirms the three core criteria that must be considered when determining what

is a boundary object: interpretative flexibility, the organisation of the object and the scale to which it applies (Star 2010:602).

Star and Griesemer provide a list of examples of various systems of boundary objects from their original research context (1989: 410-411). This list includes repositories of objects for shared use such as those you might find in a library or museum, as well as 'ideal type' objects that provide an abstract idea that multiple groups can work with, such as a map, or a shared working idea such as that of a 'species.' Another example comes from systems of objects that provide a fixed common reference but are used in different ways, for example a map of a country or state having different markings and functions depending on its user (a member of a public, compared to a conservationist, compared to a biologist etc.). A further example given of a type of boundary object is something that allows standardized communication across the different social worlds, for example, a written document in the museum that amateur collectors have to complete for each specimen to be indexed (1989:410-411).

This idea of a boundary object as discussed above is something that would seem to have considerable import to a healthcare context in which, as described previously, there are many different professions and forms of expertise crucial to care. Reaching enough common understanding across these social worlds for healthcare to be practiced effectively would appear to be vital in such a multi-disciplinary setting. My own research sees this occurring in a number of ways, including through understanding converging around objects in this manner. Furthermore, the role of the people involved in making and crossing – or 'spanning' these boundaries, sometimes alongside such objects, is also something of key relevance to my own healthcare coordination focus.

### **Boundary spanners**

The notion of a person who functions as a 'boundary spanner' is another concept that has had particular attention in research around healthcare. Lindsay and Dutton

suggest the role of boundary spanning individuals within professional settings as including the following aspects:

...providing local coordination as an 'anchor point' between collaborating agencies; linking stakeholder groups within and beyond the boundary spanner's own organization; managing tensions and conflicts between partners; building trust and shared values; demonstrating leadership in pursuing the partnership's goals; promoting innovation in policy solutions that reflect inter-disciplinary approaches; and (crucially) networking to share information and practice (2012:514).

Individuals who are able to span boundaries are of key interest to scholars interested in collaboration in public services.

Williams (2011, see also 2002 and 2013) has undertaken a wide-ranging literature review on the individual roles and competencies of the individuals involved in boundary spanning within their job. One of the central roles he puts forward for the boundary spanner is as a 'reticulist.' This somebody who can link and communicate across many social networks and 'deal in the creation and brokerage of social capital' (2011:27). Connected to this are other roles of the boundary spanner as an 'entrepreneur' of solutions within these networks, as well as a 'manager' of the relationships within collaborative environments. Finally, on a practical level, the boundary spanner is also involved as a practical 'organiser' of the underlying collaborative machinery (2011).

All of these roles are seen to demand knowledge not only of the context in which they are involved (e.g. the particular public service), but also a wider understanding of collaboration processes, organisational systems and so on. Williams identifies a suggestion within some of the literature, some of which is outlined below, that particular charismatic, trustworthy and communicative personality traits are also connected to this role (2011:29). Bacon and Borthwick build on Weber's classic theories around 'charismatic authority' (Eisenstadt 1968) within their own research to highlight the major role of motivated and amiable leaders advocating for, and providing justification for, the new area of expertise connected to the role of 'diabetes specialist podiatrist' (2013). They argue that those who embody

charismatic authority are found to have a prominent, and even vital, role in the professionalisation and status building of professions.

A recent article by Nasir et al (2013) focuses on the role of boundary spanning individuals in both facilitating integration in health services and on improving patient outcomes, both areas they found to be lacking in past research. Their research involved both a 'meta-ethnography for evidence synthesis' approach to find international empirical literature on boundary spanning, and an evaluation of a particular initiative within one area of England. Within this, they identify two types of integration that policy makers are often seeking to achieve through boundary spanning initiatives. 'Horizontal integration', as they use it, refers to connections between 'similar levels of care', such as in multi-professional teams, while 'vertical integration' refers to 'care pathways between generalists and specialists for named conditions' (2013:4). Both these types of integration process appear within my own research, although the latter - vertical integration - is more squarely my focus when it comes to coordinating HD support and care.

The meta-ethnography for evidence synthesis within Nasir et al. revealed four themes from previous boundary-spanning literature. The first theme was that a wide range of communication skills were required for successful boundary spanning (2013:8), connecting to the discussion above concerning the attributes of these individuals. The second theme they uncovered was that there was a need for constant formal and informal role negotiation for boundary spanning professionals (2013:9). This is something reflected throughout my own findings within this thesis. Thirdly, Nasir et al uncover the importance of the social and political context of professions and organisational cultures on the way in which knowledge is shared (2013:11), again something of key relevance to my own research's focus on inter-sectoral collaboration. Finally, they suggest there has been little discussion of boundary spanning processes or evidence around patient outcomes within the prior literature (2013:13). This fourth theme is an area that their own case study research of a particular health service initiative went on to address. The overall finding of this

research is the importance of context for successful boundary spanning, both in the sense of shared knowledge frameworks across teams, but also in the sense of the availability of suitable resources and structures to facilitate the process (2013:92).

Other work has similarly highlighted the importance of the wider social structures and interaction between key individuals and others rather than merely focusing on the qualities of individuals alone. For example, work by Locock et al. on evidence based medicine suggests that the effectiveness of ‘opinion leaders’ or ‘project champions’ is connected to the contextual factors surrounding these individuals, such as receptiveness to opinion leader viewpoints, as well as who is perceived to be an opinion leader in the first place (Locock et al. 2001). Williams himself argues that the roles, skills and attributes of boundary spanners are accompanied by the tensions that come with being involved at the juncture of many competing interests, cultures and personal relationships, as well as the need to exert collaborative leadership rather than hold direct power (2011).

Boundary spanner is not a job title in and of itself but rather something that people take on in addition to/as part of another role. Enabling existing professionals to be boundary spanners within complex health and social care situations therefore appears to be connected to the degree of investment in training and supporting these individuals, something of central relevance to my own research. The literature indicates that boundary spanners have a distinct role to play in managing the highly interdependent and collaborative arenas that are designed to manage health and social care, and they undertake this by deploying a range of competencies, supported by relevant knowledge, experience and personal attributes.

Furthermore, when it comes to where boundary spanning individuals might be located in an organisation, more recent work by Williams (2013) has highlighted that it is important to recognise that boundary spanners can include chief executives, directors and others at the head of organisations, as well as managers at different levels. However, the concept can also embrace front line staff involved in service

delivery and interactions with staff across other agencies. The ability for boundary spanning to occur in many places in an organisation does not, however, mean that all staff can, or should be, boundary spanners:

Many professional staff will continue to work primarily within their particular areas of specialized knowledge, expertise and profession, and their roles and competencies need to be differentiated (Williams 2013:27).

When reporting the findings of my own research, I discuss the possibility of boundary spanning existing as a form of expertise that might combine personal attributes with skills acquired through training and/or being in particular roles. Some individuals seem to be particularly well equipped to emerge as what my research will call 'key, committed individuals.' This is not a process that is simply down to the charisma possessed by the individual but also something that can and must be nurtured by the surrounding context.

Another important point highlighted by Williams (2013) connects to the discussion in the previous chapter with regard to policy making under conditions of financial restraint. He highlights the potential for dedicated boundary spanning roles in the public sector to be 'axed' in such situations as a way to release the state from important (and costly) statutory responsibilities. However, this type of cost-cutting by removing expertise is likely to have a negative impact in the long term:

...threatening the collaborative infrastructure of personal and professional relationships so painstakingly built up over time might be seen as extremely short-sighted and counterproductive to co-operation in the future (2013:27).

While third sector organisations and third sector boundary spanning individuals might actually be the ones brought in to fill the gaps in such situations, they can also be the ones subject to having statutory funding removed. Boundary spanners from all sectors will in these circumstances need to convince others that their role is a valuable and cost-effective one (Williams 2013:28). This example from Williams highlights that it is important for there to be awareness of the way that the skills and attributes of individuals are also subject to the trends and decisions from the surrounding policy environment.

## **Conclusion**

The location of my research topic within the overlapping areas of (genetic/HD) illness experience, third sector activity and professions in healthcare renders a large array of literature of relevance to my own research. My own research highlights the sociological benefit of bringing together these bodies of work alongside theoretical development around boundaries and expertise.

### **The experiences of, and meanings around, illness**

Relevant empirical work under the banner of the ‘new genetics’ has focused on the social aspects of genetic disease (Kerr 2004, Atkinson et al. 2006), while other research has focused specifically on different aspects of illness experience, including kinship dynamics (Finkler 2000), stigma (Scambler 2009) and the way that patients and professionals deal with the different meanings around illness (Lerum et al. 2015, Locock et al 2009). Any third sector activity and inter-sector collaboration around HD occurs within a process of shifting complexity and uncertainty. While the different facets of HD (the neurological aspects, psychiatric aspects, genetic aspects and so on) means that there is a wealth of social science literature on other conditions which is relevant to my own research, the very nature of this complexity around HD demands further sociological insight on the care and support for the condition. Taking a sociological approach would mean focusing on the perspectives and processes involved in HD services, in addition to other important aspects of the context such as the wider policy trends. Looking in-depth at HD as a single condition, as this thesis does, highlights the challenges and opportunities of a context in which multiple devastating symptoms are combined.

Furthermore, while social science research has explored the ethical issues around genetic risk, testing, and kinship relationships that HD presents (Hunniche 2011, Keenan et al. 2005), there is a lack of work elsewhere that looks at the complex support needs and services for people with HD. Part of the reason for a continued



focus on ethical debates around HD and genetic testing has been the status it has come to take as a ‘model’ for other conditions around these ethical issues to do with diagnosis, risk communication and so on. However, this thesis will go on to show that direct research on services and partnership around HD could fulfil a similar function of promoting good practice in service provision outside the field of genetics too.

Expertise is used as a key concept in this thesis and is at the crux of forming the overall argument presented about aggregate know-how (Pols 2014). Previous literature in the area of the sociology health and illness and in STS has already emphasised the importance of different types of expertise and knowledge to health and healthcare, looking at knowledge possessed by professionals, the third sector and by people living with illness or disease (Collins and Evans 2002, Rabeharisoa 2014b). There have been numerous scholarly debates with regard to how the different knowledges of these three ‘groups’ overlap (Prior 2003). My own research builds on this literature and shows the continued relevance of such an expertise focus, especially where third sector and services are concerned. Furthermore, it seeks to show where the overlapping and blurring of these types of expertise occurs, and the new forms of expertise this might produce.

### **Third sector organisations in health and healthcare**

Highly useful to my past empirical work on third sector organisations have been attempts by scholars have to map the origins and scope of activity around specific individual health conditions, and across nations. Past macro scholarship on third sector health organisations reveals that these organisations are growing in both numbers and strength (Brown et al. 2004, Baggott et al. 2004b, Rabeharisoa 2014a, Wood 2000). Work highlights that some groups choose an exclusively ‘political’ focus, such as campaigning for change in laws or changes to health service provision, while others focus solely on the individual care and support needs of patients and carers. Research has also shown that many third sector organisations combine these

goals, demonstrating the overlapping nature of the categories of campaigning and traditional support.

Empirical work from sociology and science and technology studies has also sought to tease out the different types of partnerships that third sector organisations can enter into, creating connections between themselves and scientific and medical research (Nukaga 2002, Epstein 1995;1996), policy-making institutions (Baggott and Jones 2011, Rabeharisoa and Donovan 2014, Best 2012) and, explored in a small selection of research, service delivery partnerships (Dutton et al. 2013). Some individuals have focused on aspects of this activity, such as the strategies employed by groups (Panofsky 2011), or what this might mean for social movement theory (Brown et al. 2004). Jones (2007) has returned to research conducted previously with colleagues Baggott and Allsop (Baggott et al. 2004a, 2004b, 2005) examining third sector organisational partnership with fellow third sector organisations in the UK. While focusing more on the case of England, this research has, like much other work, underscored the importance of third sector involvement with healthcare in the UK context. Those who have done important work tracing third sector collaboration around one condition, such as Rabeharisoa in the French muscular dystrophy context (2003, 2006 ; Rabeharisoa and Callon 2002; 2008), have suggested that an increasingly definitional ‘partnership’ role is emerging for organisations in their interaction with the State as opposed to their former auxiliary or emancipatory roles.

## **The changing boundaries in healthcare organisations and among healthcare professions**

This literature review has also explored an ever-growing literature on the changing shape of healthcare organisations. Work in the area of professional change has often been focused on systems of healthcare as an area of professional activity that is characterised by multiplicity in roles, perspectives and expertise (Nancarrow and Borthwick 2005). The development of new and hybrid professions, including the

involvement of the third sector, has been the subject of empirical research of key relevance here.

A central point to emerge from both Fournier (2000) and Malin's (2000) work is the assertion that even in light of professional changes, boundaries and the professions within them can be 'remade'. It is a matter of professionalism being a shifting phenomenon, rather than a case of the elimination of professionalism overall (Malin 2000).

Connecting directly then to these processes of professional change, this chapter has also explored some of the many academic offerings around the concept of boundary work (Gieryn 1983, Lamont and Molner 2002). Discussion in this area has revealed the utility in looking at the negotiating of different cultures in healthcare through such as boundary lens. It allows consideration of how third sector professionals positioned in the intersections of healthcare services handle the existing and changing constructions within organisations around the status of expertise, the remit of different professions and the appropriate format for service delivery.

## **Addressing gaps in the literature**

The literature surveyed in the present chapter has shown a paucity of research on the role that is taken on by third sector organisations when they become involved in delivering services jointly with the public sector. Yet the existing literature indicates that this is an important and timely area of research, thus justifying my own research focus on this area. This topic stands at the intersection between work on third sector involvement, professional identities in healthcare and the experience of people with complex conditions. It allows consideration of how third sector involvement is transforming healthcare in a service-delivery area heavily promoted in health policy literature, and in which addressing the complex needs of patients is fundamental. In this thesis I consider whether a form of the 'partnership model' that Rabearisoa (2003) describes is readily visible within the Scottish HD service landscape. If it is,

how might it be altered from Rabearisoa's original formulation to adapt to a service provision context, and in a partnership setup involving professional individuals?

It is also relevant to this thesis that the previous UK empirical research directly on third sector partnership (e.g. Jones 2007) has largely focused on England and the English National Health Service, rather than the separate devolved political units of Wales, Northern Ireland and Scotland. As discussed in more detail in the previous chapter (Chapter Two), the devolved systems of healthcare, charity regulation and social policy that are present in Scotland means that the nation is worthy of academic attention by itself as well as within 'UK' studies. This is particularly relevant following the increased attention paid to Scotland in recent years following political developments such as the 2014 referendum on Scottish independence. It is also timely in light of the divergence between Scotland and England in key areas such as the structure of the NHS, and constantly changing alongside financial pressures for the Scottish health system and third sector. Many of the insights from English/UK and other global studies have theoretical transferability to research such as my own due to similar aspects of the HD experience, or shared themes around service delivery or multi-sector working. However, added depth is gained from looking specifically at the HD scene in Scotland and paying close attention to the details of the surrounding context.

Aiming to build on work about the third sector, professions and healthcare, this thesis examines partnership activities between HD professionals and its organisational and individual impact. It does this within the currently under-addressed Scottish context. The specific context being explored is partnership around Huntington's disease, a condition that has gained considerable research attention in terms of the ethical and experiential issues surrounding the condition, but for which attention on organisational activity has been almost completely absent. This is despite the interesting and important insights about expertise and organisational culture that might be derived from exploration of partnership around a condition whose very complexity means that there are multiple different ways it might be constructed and

acted upon. For example, it allows consideration of how clashing professional remits are managed in such a situation, and how the experience of working with others is viewed. Through use of the added theoretical lenses of boundaries and expertise, this research develops the core argument that a form of expertise is developed within the partnerships I examine, and that this is connected to the processes of boundary work that go on between the third sector and their public sector partners.

This thesis will now turn to a discussion of the methodological choices made within my research, from the underlying research strategy to the process of collecting and analysing data.

## CHAPTER FOUR: METHODOLOGY

### Introduction

This chapter examines the methodology that underpins the research. An inductive and interpretivist research strategy was used, drawing upon qualitative methods of data collection to conduct primary research. As the previous chapters have outlined, HD services, the third sector and healthcare in Scotland is a context that continues to undergo change, due to factors such as shifts in health policy and structural changes in healthcare organisations. The research design and methods therefore had to be responsive to the dynamic field in which the research was taking place. This chapter begins by outlining the research design, including the underlying strategy used, the ontological and epistemological position that I adopted, and my approach to using past theory within the research.

Following this discussion of my research design, I then go on to examine the processes of data collection and analysis. This begins with a discussion of the sampling processes that led to the selection and recruitment of key individuals and sites. I also outline the two main methods of data collection that I drew upon to create this data – semi structured interview, and observations and discussions at events. I also discuss the way in which the rich data subsequently created was handled and analysed using a thematic networks approach (Attride-Stirling 2001).

The final section of the chapter discusses the pertinent methodological challenges that were dealt with over the course of the research. It explores how an ethically-aware and reflexive approach was needed to manage emergent issues. Some of the ethical challenges were those common to much qualitative research, such as managing the confidentiality of data. Others were more directly a product of the research's thematic and methodological context, such as the specific participant anonymisation challenges that arise within close-knit networks made up of 'elites',

or the need to gain research access to particular patient groups. In relation to the interconnected nature of the field, it is also suggested that my research contributes to a wider discussion occurring in methodological literature about conducting research within ‘small connected communities’ (Damianakis and Woodford 2012).

## Development of the research topic

As stated in the introduction chapter to this thesis, the research objectives developed out of a personal interest in the mechanisms of providing practical and emotional support for people with long term and chronic conditions. This was combined with what I perceived as a need for further work on multi-organisational interaction in healthcare. Early on in the research process, I undertook a review of past social science literature surrounding third sector organisations – under their many synonyms - as well as that surrounding healthcare and organisational collaboration. This review involved searching for key terms such as ‘partnership’, ‘healthcare’ and ‘charity’ on academic databases, particularly ‘Web of Science’ and the University of Edinburgh’s online library database ‘DiscoverEd’. A table containing examples of the search terms that were used in various combinations is provided in Appendix A. In light of the many possible search terms, another valuable method to scope out previous literature was through the citation mapping functions available on databases such as Web of Science and Google scholar. This allowed me to take articles that were important and relevant to my research topic - such as the work of Baggott (2004a) or Rabeharisoa (2003) - and to view both the work the article had referenced, as well as highlighting where it was now cited.

As is discussed in Chapter Three, my review of the literature revealed there to be great potential in further research exploring in-depth of third sector organisation partnership in service delivery. Thinking of the third sectors in terms of partners in healthcare brings to the forefront questions about the changing nature of healthcare professions, and what partnership means to the different organisations and patients involved. In this way, the central concern of the research as the *role* of the third

sector organisations involved specifically in service provision in partnership with others was developed.

### ***Focusing on the case of the condition Huntington's disease***

Across prominent research that examines third sector activity around a single condition (Rabeharisoa 2003, 2006, Beard 2004, Epstein 1996, Weiner 2009, O'Donovan et al. 2013, Edwards et al. 2014), it is rare for the focus to be the actual provision of services, rather than other third sector areas (such as influencing clinical research, shaping policy, or providing more informal social support). Therefore, from the early stages of the research design process, it was decided that an approach that looked at the partnership activity in one health condition area across the different sites within Scotland was a useful way to examine the third sector's role. Such an approach would sufficiently allow the important contextual factors around a condition and the support that existed in this area to be explored in depth. In so doing it should also achieve the aim of providing theoretical insight about third sector partnership that was relevant to other condition areas.

After initial internet research and discussion with key individuals within healthcare and the third sector in Scotland, I opted to focus on the genetic, neurological condition Huntington's disease (hereafter HD). This research decision arose from initial investigations that revealed that while HD as a 'rare' condition directly affected relatively small numbers of the Scottish population<sup>13</sup>, the clinical and other organisational activity in this area was (a) considerable, (b) had a strong third sector presence, and (c) was undertaken across many professional boundaries. As described in the introduction chapter, HD is also a condition with no current cure that has a devastating impact on those whose lives it touches, with there being multiple effects on an individual. These facts, combined with what was still regarded by professionals as a lack of awareness of HD across the wider UK, meant that

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<sup>13</sup> HD is classified as a rare condition based on the based on the European Union classification of affecting less than 5 in 10,000 of the general population (Rare Disease UK 2015)



increased attention upon HD initiatives would be welcomed by many stakeholders. Previous social scientific work on various aspects of HD (Nukaga 2002, Leontini 2010, Keenan et al. 2005, Keenan et al. 2007, Keenan et al. 2009, Huniche 2011) has looked at important aspects of individual experiences but has seldom addressed organisational activity around HD. Using HD as a case condition therefore simultaneously had theoretical justification, methodological justification and knowledge exchange potential. The particular condition would form a focal point, but would not preclude discussion of how partnership was occurring in other surrounding health contexts.

### ***Scotland as a research setting***

As Chapter Two describes, Scotland is a fascinating setting within which to examine healthcare and third sector activity. While Scottish healthcare has some cultural similarities with the other nations of the UK, within recent times Scotland has carved out an increasingly distinct healthcare and social care system that in particular displays less marketization and more integration than its English equivalent. The core themes of partnership in healthcare and the role of the third sector have been prominent since the Scottish Parliament was established, as well as across the whole UK. Scotland is therefore a nation that has similarities in terms of policy themes to the rest of the UK (especially where the third sector is concerned) but which is increasingly evolving different healthcare structures. Previous empirical and theoretical work on healthcare partnership in nations of the UK and about other similar health systems has considerable relevance to the Scottish setting, but there is much to be gained from taking a Scotland-specific focus.

However, the small and separate Scottish context also presents its own challenges related to issues such as the health of the Scottish population, the budget available for services, and geographical logistics that any government must tackle. As the findings will discuss, partnership and access in a unit that is small and theoretically welcoming to partnership is likely to provide better access opportunities for

professionals and organisations than in other national setups. This small and highly connected Scottish context resulted in both benefits and challenges in my own research, as this chapter will go on to explain.

## **The methodological framework of the research**

Once the research problem and overall framing research question had been identified, I required a research strategy that would examine in depth the experiences of the individuals involved, within a context in which very little detailed social science data existed. Scholarship from across the large corpus of sociological literature was influential upon this research, and led to the development of an inductive and interpretivist research design.

### **The ontological and epistemological assumptions of the research design**

Williams broadly defines ‘interpretivist’ strategies as those which ‘interpret the meaning and action of actors according to their own frames of reference’ (2000:210). Interpretivist philosophy in this way contrasts with social science research designs that use a positivist framed approach to enquiry influenced by methodology from natural science. Broadly, positivist strategies have the underlying philosophy that there exist objective facts that can be observed and measured using standardised research techniques (Bowling 2002:126). Departing from this idea, in my own research, the underlying, epistemological assumption that knowledge is filtered through cultural practices meant developing an interpretivist research design that explored social phenomena through the understandings of the individuals and groups involved. This was something of key relevance to my research question’s focus on the *roles* and *meanings* within healthcare. In line with this epistemological approach, I used qualitative methods of data collection – semi-structured interview and

observation at events - that allowed access to the understandings and practices surrounding third sector involvement in the Scottish HD scene.

I was interested in obtaining insights about how the experience of partnership and the relationships between organisations are constructed through the perspectives of the individuals involved. However, I also embarked upon the research with a keen awareness that there is much evidence in accounts of the pain and disadvantage present for people living with illness, especially when living daily with a condition like Huntington's disease. As my own research findings show, the fact that external reality is subject to different types of understandings on the part of individuals, does not make the underlying circumstances less real. In fact, it renders investigation of these differing understandings by groups such as professionals all the more important, in order to uncover how cultural assumptions enter into service delivery.

The underlying ontological position that I took in approaching the research as described above can be seen to align closely to what Blaikie has characterised as 'subtle realism'(2010). This claim about the underlying nature of knowledge sits within a wide range of research paradigms that have suggested an intermediate position for researchers between the argument that there are objective, 'knowable' criteria and the opposing argument that all social phenomena are constructed. This range of approaches is generally labelled throughout methodological literature under the terms critical realism, as well as Blaikie's own suggested definition of social realism. The particular emphasis in 'subtle realism' is on individuals knowing the world through perspectives. It is held that 'an independent, knowable reality exists independently of social scientists' (2010:94). Importantly, however, this position acknowledges that how we come to understand this reality is mediated by cultural assumptions. As a result, 'as all knowledge is based on assumptions and purposes, and is therefore a human construction, it is not certain.' (Blaikie 2010:94).

The social anthropologist Hammersley, one of the earlier proponents of taking a subtle realist position, suggests that the practical implications for ethnography (and

indeed, all qualitative research) are that researchers must take heed of the different ways that they can analyse the accounts given by research participants (1992). He suggests that it is possible to analyse participant accounts as social phenomena or examples of cultural beliefs, but it is also possible to use participant accounts as sources of information about phenomena (1992:53). In the latter use, Hammersley suggests these accounts must be subject to checks against other sources of knowledge and subject to question about potential error, an approach I took within my own analysis.

The constructivist aspect still present in subtle realist ontology also allowed me to recognise the way in which understandings about real-world phenomena are jointly constructed by the different actors involved (Moses and Knutsen 2007:11). This was particularly important for my own research's focus on the different constructions that might emerge around a single condition such as HD. A key finding of the research, explored in Chapter Seven, is that there are competing understandings of HD present in professional interactions around HD but that they occur around certain shared knowledge frameworks. This builds on and critiques prior work, such as that by Mol (2002), which has suggested a more completely constructed nature of disease. Furthermore, as the overall findings of the research emphasise, successful partnership working and the crafting of professional identities and professional expertise can be seen to be a mutually shaping processes within the research. An ontological position that captured the complexity of these constructed understandings around certain shared experiences was vital for the purposes of my own enquiry.

## **The use of theory within the research**

As highlighted above, the research strategy used was inductive in nature. The research problem was the starting point for investigation, and theory was developed from thematic analysis of the findings of data collection. As Blaikie discusses, an inductive research strategy is useful to 'establish descriptions of characteristics and patterns' around a research question concerned with 'what' is happening in a

situation (2010:83-84). At the crux of my own research was a question concerning (a) what was the role of third sector organisations when they became embedded in services (b) and what this meant for the professionals and organisations involved.

While the research did not begin with the intention of testing a specific hypothesis, theoretical concepts were drawn upon at all stages. Following what Blaikie calls a 'sensitizing' tradition of concept use, research-generated concepts based on prior theory were used initially to provide different ideas of what to look for, which then became subject to change as the research progressed (2010:118). As data emerged, new directions in which to develop the theory became apparent. For example, the relevance of the concept of boundaries and boundary work increased as the data analysis unfolded. The approach taken fits closely with what Layder has classified as 'adaptive theory', which he describes as being produced within the 'interchange and dialogue between prior theory...and emergent theory' (1998:27).

## **Generalizability and the research**

There have been many debates in methods literature about the degree to which the findings of qualitative research might be generalizable to other contexts (Groleau et al. 2009). Throughout my own research, the intention was to produce theoretical insights that would be useful to social science theory as well as have relevance to the everyday practice of individuals working within health settings. The wish to achieve the latter goal of real-world application was also enhanced by the fact that my research was funded by public money in the form of an Economic and Social Research Council grant.

As has been discussed previously, the context of Scotland and of Huntington's disease were both chosen for the suitability of this field in allowing a window into the wider national and international contexts to which they bore similarities, while also exploring their specific features. The design was intended therefore to allow what I argue is much need theoretical transferability from the specific context of

Scottish HD care, to other types of care that was collaborative and/or involved long-term conditions. The role of theory was once again important in allowing for this, as it allowed the development of concepts about third sector organisation practice which could be tested in other, diverse, contexts.

I will now turn to discuss specific aspects of the research methodology itself, starting with the sampling and recruitment processes.

## **Sampling and recruitment**

Table two below outlines the types of data collected for this research including the data collection method and the characteristics of site or individuals involved.

Sampling took place continuously throughout the fieldwork process rather than just during the initial design of the research, reflecting the dynamic nature of the research field.

The initial gatekeeper for the research - the organisation the Scottish Huntington's Association (SHA) - was the starting point of the research sampling process. It was intended that HD and third sector activity around this condition was the prime focus of my research rather than a specific organisation. This recognised that there were multiple third sector organisations that might be relevant to some aspect of the HD journey. However, where specialist HD services were concerned, third sector support within the Scottish context was almost synonymous with the SHA as it is the only third sector organisation focusing exclusively on HD.

After identifying that HD would be a suitable and important condition area in which to examine third sector activity, I got in touch with the SHA's head office, and subsequently secured their help in recruiting participants. This organisation was highly important to the sampling process due to their location at the very heart of the network being explored. It therefore had the ability to provide me with valuable contacts of people with whom they had actively been engaged in service partnerships

in and around HD. In turn, these contacts allowed me to pursue my research objectives. For example, in reference to my first research objective, I was able to set up interviews and meetings with professionals who could talk about the nature and meaning of third sector ‘partnership’ from their own direct experience.

<b>Table 2 – Data collection sample<sup>14</sup></b>	
<b><i>Semi-structured interviews</i></b>	
<b>Professional area of interviewee</b>	<b>Number of interviewees (Total n = 14)</b>
Third sector HD professional	6
Third sector alliance organisation professional	3
NHS clinical professional	2
NHS non-clinical professional	2
Individual with personal connection to HD context	1
<b><i>Informal meetings</i></b>	
<b>Professional area of individual or individuals</b>	<b>Numbers of meetings (Total n = 4)</b>
Professional team meeting (group meeting)	1
Non-NHS care professional	1
Policymaker	1
Third sector professional (outside of HD)	1
<b><i>Events attended</i></b>	
<b>Type of event</b>	<b>Number of events attended (Total n = 8)</b>
Scottish Parliament reception	4
Community events around HD	2
Third sector conference	2

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<sup>14</sup> Data collection took place between 2012 and 2014. Of the fourteen interviews, eleven interviewees were based in Scotland, and three were based elsewhere in the UK. All informal meetings and events were based in Scotland.

## **The sampling of individuals and sites**

Participants from the research connected to the SHA assisted with identifying and contacting a number of colleagues within the SHA who were willing to participate in the research. SHA staff members also agreed to contact individuals with a personal connection to HD who would be capable and willing to participate, and informed them that my research was taking place. These ‘family’ (patient, family and carer) individuals were then able to contact me as the researcher if they were interested in taking part. Due to the extensive nature of ethical review in the NHS, this type of recruitment is something that would have been far more difficult and lengthy as a process if I had sought to do it via public health structures rather than through a gatekeeper based externally to the NHS. This assistance led to an interview with one individual who had experience in their family of HD, who had also been involved with third sector HD initiatives on a volunteer basis. The same interviewee with family experience also acted as a means to access other sites useful for the research in the form of local community events raising awareness of HD.

The initial SHA interviewees were also a key source for suggestions of other professionals in a wide range of occupations that were likely to be willing to participate in the research. Subsequent individual interview participants, in turn, provided recommendations about future people that might be relevant to, and/or interested in, the research. The strategy amounted to what is often termed ‘snowball sampling’ due to the way that respondent referrals resulted in further leads, escalating the number of contacts for the research (Atkinson and Flint 2007). This sampling technique fitted closely with the methodological goal of accessing the perspectives of potentially hard to reach individuals directly involved with the research context, as the participants who were identified as relevant by fellow professionals were all highly involved in HD services and/or the Scottish health scene.



Furthermore, the selections individuals made in giving me recommendations were also indicative of the network relationships that were necessary to the nature and quality of partnership. Who knew who, and how they knew each other in the HD and wider field, provided an early contextual backdrop of where potential partnership resided. For example, I was made aware of particular links between the Scottish setting and elsewhere (the UK and Ireland HD Alliance, the European Huntington's Disease Network) only as a result of directly talking to participants about their relevant network participation.

While snowball sampling was central to the research, there was also a degree of independent, purposive recruitment undertaken in order to incorporate the views of individuals within the network who had not been reached by snowball sampling. This predominantly involved using internet research and my own attendance at conferences and meetings to identify key individuals involved in engagement around health in Scotland. Identifying these individuals involved reflecting on the questions of 'who was talking' and 'who was being talked about'. My approach to sampling was also influenced by the work on multi-sited ethnography by Marcus (1995), which has a core tenet of 'following' something from site to site in sampling. This might be a physical object or, as in my own case, be something more abstract such as the 'signs, symbols and metaphors' present in a situation (Marcus 1995:108) Although my own research was not conducted according to this particular research strategy, multi-sited ethnography was influential in identifying suitable research sites and potential research participants. Throughout the process of snowball sampling and purposive sampling alike, participants and sites that were identified as suitable for the research were checked against a rationale of whether the connection being followed might be regarded as representing a situation of interviewee-defined or researcher-defined 'partnership' between the referring interviewee and the subsequent new interviewee/ site.

There is a growing interest in methodological literature around issues that might occur when conducting research with participants that might be considered 'elites'

(Aldred 2008, Conti and O'Neil 2007, Harvey 2010, Puwar 1997). Broadly, elite interviewees or other research participants might be characterised as individuals with a higher societal or professional status than the researcher. By this criterion, the majority of my own research could be considered to involve such elites, as the majority of participants were individuals in job roles that were both professionalised and likely to confer a higher status than myself as a doctoral researcher. Despite this, there were few of the interactional challenges that have been reported in other research on elite professionals, such as Conti and O'Neil's stark description of the control and authority exhibited by Conti's own interviewees who were connected to the World Trade Organisation (2007).

The ease in talking with my own 'elite' participants might be a reflection of the fact that they were all individuals involved in third sector or healthcare roles that demand good communication skills and a sense of equality among individuals. As my research will go on to show, these qualities were actually core to the professional identity and role positioning of the partnership-engaged individuals that were the focus. Rapport was also assisted by the fact that the participants of my research appeared genuinely interested in my research topic and keen to be of use to me and to the project. It might be speculated that there might be something quite different in interactional terms in talking to 'caring elites' as I did within my own research, rather than elites who hold power in other spheres of professional spheres of life such as politics or finance. As Smith has argued, is also the case that the very notion of a distinction between 'elite' interviewees versus others might itself be somewhat misleading, with potential issues brought up around elite interviewing and power dynamics having the potential to arise in all interviews (Smith 2006).

However, there did remain some insights from past social science research about conducting interviewees with individuals in elite positions that were pertinent to my own research. As discussed below, in my own work this had most relevance when attempting to gain initial access to some individuals, as well as when discussing the anonymisation options for any data they provided. Furthermore, there were also

some aspects of interviews that also related to the setting of the encounter being at a workplace.

## **Reflections on the sampling strategy used**

There were both benefits and challenges associated in with the predominately snowball sampling method, supplemented by some purposive sampling. Where snowball recommendations were given rather than interviewees identified through researcher investigation alone, there appeared to be a greater willingness on behalf of the recommended interviewee to participate. Based on the small and close-knit nature of the environment, having past interviewee permission to ‘name-drop’ when sampling their recommended contacts was an asset for building trust between researcher and interviewee. The ability of influential gatekeepers to ‘open doors’ as well as to keep them closed is something that has also been suggested in other literature on interviewing elites in particular (Harvey 2010).

The extensive methodological literature on social network analysis emphasises the analytical value of ‘relational data’ on the ‘contacts, ties and connections, and the group attachments and meetings’ between interacting agents (Scott 2013). Although I did not analyse the network connections themselves as data, having this insight into the interconnectedness of the field was valuable when talking to participants of the research and ensuring that I asked the relevant questions of them. For example, I was able to direct questions about key conferences, meetings, and other events related to third sector partnership having been made aware of these by previous respondents. It was also important to have an understanding of the scope and limit of the relevant network in order to know the extent to which recruitment might be required to obtain an adequate range of perspectives. The overall goal with the eventual sampling network, however, was to achieve ‘theoretical saturation’ in the data. The broad definition of theoretical saturation provided in the work of Guest et al. was useful as a guide on this issue: ‘the point in data collection and analysis when new information produces little or no change to the codebook’ (2006:65). After initial data collection

via interviews and observations, and then several additional interviews, I was able to identify theoretical saturation along these lines that Guest et al. (2006) describe, and cease further recruitment.

There did exist what might be regarded as inevitable but frustrating challenges of the mainly respondent-dependent sampling style chosen. One such issue involved the time it could take to secure new interviews through a predominantly recommendation-based method as there was, predictably, a lag between talking to one interviewee and the meeting with the person they had recommended. Partly responsible for delays was the fact that recommended figures were often committed to a considerable level of activity around HD and often other health conditions or initiatives, meaning that they had limited time resources.

There was also a limit to how much snowball recommendations could guarantee future interviews, if the potential interviewees saw themselves as having too many other commitments to participate. The reason most frequently cited for non-participation for those that responded was lack of time. This happened on five occasions when initially recruiting participants. In the smaller number of circumstances where the concern about participation related to the wish to only speak more informally 'off the record', a meeting was offered instead of a formal interview. Nonetheless, the majority of individuals approached, were happy to be of assistance to the research despite their busy schedules, and were also forthcoming with useful suggestions of whom to interview next. In fact, the involved and active nature of many potential interviews only sought to highlight further a level of commitment to their work or voluntary activity, which was largely why others saw them as a key figure in the first place.

The sampling process also revealed just how small and close the different individuals and 'sites' actually were in terms of location, and how mobile individuals could be within the different organisations within the field. For example, within both their discussion and their snowball recommendations, interviewees often unknowingly

referenced other individuals who had already participated in part of the research. A considerable flow of individuals between job roles, i.e. from third organisations to NHS and local authority positions - and vice versa - was also evident. As will be discussed in more depth later in this chapter, the emergent fact that the research field was a 'small connected community' (Damianakis and Woodford 2012) posed a number of ethical complications, particular around preserving interviewee anonymity and negotiating my own positionality as a researcher.

## **Methods of data collection and analysis**

As discussed above, primary research utilising qualitative data-collection methods was considered the most appropriate way to engage with important voices in the Scottish health scene interacting around Huntington's disease initiatives. Quantitative and qualitative mapping of networks as used in approaches such as Social Network Analysis has become particularly popular in recent years (Scott 2013). However, while these techniques measure connections and, in some cases, the strength of connections, I was looking to uncover the perspectives and understandings of individuals about the third sector and healthcare partnership. For this, methods that allowed me to hear, see and read about how the role of the third sector was understood were important.

While presented as three different methods below – semi structured interview, non-participant observation at events and examination of key documents - in practice, the different elements of data collection were overlapping and interactive. Interviews with participants of the research contributed to the largest bulk of the body of data and thus will be discussed in the most depth below. However, valuable contributions were gained from setting the interview data in context with other sources of data from meetings, observations and analysis of key documents. Data collection was an ongoing and overlapping process, as might be expected from the multi method research design.

## Semi structured interview

Semi-structured, qualitative interviews were the predominant method of data collection and were considered to be the most suitable way to get to the heart of my research question and objectives. The greatest asset of qualitative interviews, as Seidman contends, is that they can be a route to ‘understanding the experience of other people and the meaning they make of that experience’ (1998:3). This focus on people’s *talk* allows interviews to be used to uncover emotional dimensions of people’s lives, and their self-conceptualisation, which would not necessarily be evident through studying their behaviour (Lamont and Swidler 2014:159). The format of semi-structured interviews also had the benefit of allowing for in-depth and interviewee-directed discussion, while at the same time permitting the conversation to be guided to cover certain topics (Rubin and Rubin 1995). For the purposes of this research, talking directly to these individuals was deemed to be the most appropriate way to explore their experiences of their organisation’s engagement and alliance-building activities, as well as what these representatives perceived to be the role of themselves, their organisation, and others involved.

As outlined in Table 2 earlier in this chapter (page 144), thirteen semi-structured interviews (twelve in person, and one over the telephone) were carried out with individuals from a range of what will loosely be termed here as ‘professional’ roles. One additional face-to-face interview and a series of meetings were also carried out with one individual with a family connection to HD. In addition to formal interviews, four informal meetings took place. Three of these meetings were ‘one-to-one’, while the fourth was a highly insightful, group meeting. This was carried out at as part of a weekly team meeting for a group of professionals from the third sector and the NHS who were involved in HD care in one region.

The meeting-only (rather than interview) data collection that took place served a number of purposes. In some cases the meetings occurred because the potential interviewee approached did not want to participate formally in the research, but did

want to contribute in some form. In other instances, meetings were set up from the outset as a networking opportunity or to elucidate information on the wider context rather than to create data. Where the group meeting was concerned, this had been arranged with one of the meeting participants as an individual interview. However, the resulting opportunity to attend a meeting with both this individual and a local clinical group meant that a wider set of topics could be explored. It did, however, have the consequence that it was not possible to use the meeting data in quite the same way as one would an interview, due to the fact that not all participants in the conversation had been given the opportunity to give prior consent to a recorded interview, but had fully welcomed me in to be part of the existing meeting and to take notes. This experience emphasises the unpredictable nature of research with people and the need to adapt when in the field. It also illustrates the need to pay attention to the different shape that ensuring informed consent might take when conducting research in a group context.

### ***Preparing and conducting interviews***

Preparing schedules for the interviews required a large degree of flexibility in order to keep consistency in the broad topics being discussed, while also allowing for discussion of specific experiences of interviewees from a wide range of roles. Broadly, the topics of questions included those about experiences of partnership arrangements between voluntary sector organisations and other organisations in health, the role of alliance organisations in supporting and uniting people and organisations, the involvement of patient perspectives in organisational activity, and other themes such as this relevant to particular interviewees. An example schedule of the questions and themes that formed the base of discussions within interviews is provided in Appendix B of this thesis.

Prior to all interviews, participant information sheets and informed consent forms were distributed to interviewees to check and sign before the interview began. A copy of a combined information sheet and consent form can be found in Appendix D.

This document outlined key elements of ethical research practice, including a reminder to the participant that they had the right to withdraw their data any time without having to give a reason, as well as outlining their various options concerning anonymisation, potential banking of their data, and preferences to do with access to future stakeholder reports. I signed a copy of the participant consent form and gave one to each participant for them to keep. Following each interview, interviewees had the opportunity to provide feedback on their experience of being interviewed. This feedback, in addition to reflection on the part of myself as a researcher on the progress of the interview, worked to inform the revision and development of future data collection materials.

The interviews ranged in length from one interview that was cut short due to working day time constraints at seventeen minutes, to the lengthiest individual interview at two hours and forty minutes, with the majority of interviews between one hour and two hours long. Where permitted by interviewees, interviews were digitally recorded and then transcribed verbatim. This was the case for all interviews apart from the one professional interview conducted over the telephone, for which copious hand-written notes were taken.

### ***Managing the interview encounter***

The work of Mason (2002) has extensively discussed the effect that the choice of interview setting can have on data collection. This is seen as particularly pertinent in research involving elite participants, whereby the interviewee being within their own known environment allows for a greater sense of ease. In the cases of all the face-to-face interviews and informal meetings with professional interviewees, the location for the meeting was the workplace of the professional individual. In some cases this location was the private office of the interviewee, and at other occasions it was a booked meeting room or coffee area within the building of the organisation. The rationale for the locations chosen was that it allowed maximum convenience for the busy professional individuals, and in most cases allowed for a quiet and undisturbed



meeting space. This was not true in all cases, with there being occasional interruptions related to the interviewee receiving phone calls or being approached by a colleague during the course of the interview.

Another unavoidable effect of the location was that was perhaps more possible for the interviewee to halt the interview when they chose to do so, for example, to attend another meeting, or to head home after only a short period of time. This was prominent in two of my thirteen interviews. While it curtailed the amount of data collected from these particular interviews, it was not a problem across the body of data overall. The sociologist Puwar's research interviewing female MPs - a group who undeniably carry an 'elite' status – highlights the reduced control for the interviewer in non-private interview settings that feature constant work-related interruptions, as well as those which take place within rushed circumstances (Puwar 1997). While my own experience of this was nowhere near as challenging as the rushed and exposed interview encounters Puwar describes, her experience and my own both serve to highlight the importance of researcher flexibility in the process of collecting data. This might entail a researcher adjusting to the interview happening at a different pace than expected, and adapting to settings that are an unexpectedly public in nature, or that are beset by interruptions.

## **Observation at events**

Observational methods enable a researcher to explore real-life patterns of interaction from the standpoint of the participants inside a situation (Jorgensen 1989:12). For my own research, the value of engaging in non-participant observation was that it allowed engagement practices to be tracked and observed within the different sites in which they circulate, and in a largely unobtrusive manner (Rice and Ezzy 1999). In all the locations where observations took place, there was the opportunity to examine the ways in which practices surrounding 1) voluntary sector involvement, 2) collaborative activity, and 3) patient and professional understandings about HD and other conditions, were understood and enacted within everyday practice. While

the events were considered non-participatory in the sense that I as a researcher was not involved in organising or running the event, in some elements I was observing the event in a more active capacity, for example, within discussion groups at conferences.

Informal, open observations were conducted at events involving various aspects of third sector collaboration in healthcare. As detailed in Table 2 previously (page 144), the sites included grassroots events run by local third sector organisations involved in raising awareness about HD specifically, and Parliamentary receptions raising awareness for a range of different causes. Two third sector conferences were also attended, again in a non-participant capacity.

Discussion about potential ethical issues about privacy arising from covert research has been a feature of social science research and of research regulation, and are usually applicable even when research is taking place in an otherwise 'public' setting (Spicker 2011). However, this has been disputed by some such as Spicker himself, for confusing such research with 'deception' of individuals and distorted ideas of participant protection. Instead, he emphasises that there is an academic need for appropriately regulated (and covert) observational research in various informal settings (Spicker 2011).

In my own research practice, I was first and foremost keen not to end up collecting what might be considered as private data, especially in light of the fact that I primarily intended to these sites for information for background context rather than primary data collection. As a result, I took steps to ensure that the events that I attended and the way that I accessed them limited any ethical problems, In the case of all events that I attended throughout my fieldwork, attendance was fully open to any interested members of the public, although a registration to attend was required for the more formal events such as conferences and Scottish Parliament receptions. In many of the situations I had actually been directly invited by a participant of my research, such as for the two local HD awareness events and one of the Scottish

Parliament receptions. Where possible, my role as a researcher was openly disclosed to the organisers of the event during any sign-up procedures for the more formalised events such as conferences.

Over the course of attending these events I met a wide range of individuals who were fellow attendees. They included families with direct experience of a wide range of health conditions, health professionals, third sector professionals, MSPs, academics, and other members of the public. I ensured that if any fellow event attendees asked conversationally in what capacity I was attending the event, I was fully honest about the fact that I was a sociological researcher interested in third sector and public sector collaboration around conditions such as HD. The reactions I received from others about my own role were wholly positive, and often led to individuals asking further questions or suggesting individuals of whom they were aware that might be of relevance to the research.

Conversations with fellow attendees at events were also often insightful methodologically, in that I discovered that they had often assumed I was attending the event as a patient with a particular condition. This further highlighted the need for any data that I recorded to also be sensitive to the fact that there were expectations about who would likely attend these events, even where I myself was as overt as possible about being a researcher. Therefore, while written field notes about my general impression of events were recorded following the event, no audio recordings or pictures were taken at the events themselves in order to preserve the privacy and anonymity of any attendees not aware of my own role. Similarly, the field notes only discuss the interactions at the event and the themes of discussions rather than mentioning any particular individuals or conversations.

## **Analysis of key documents**

In addition to the interview and observational fieldwork that took place, I also completed an initial scoping analysis on a selection of key policy documents from

the Scottish and UK Governments to provide background information on the fields of healthcare and /or the third sector. Some of these documents were discussed earlier in this thesis in the chapter looking at the Scottish healthcare/third sector context (Chapter Two). The purpose of examining these documents was twofold. It was, firstly, intended to provide background reference that I myself as a researcher could use to understand the wider healthcare context in which third sector groups for HD were presented. Secondly, it helped to orientate both the interview schedules and useful themes to pick up on during observational work. A more extensive content analysis of the themes of health policy around third sector partnership – such as that which has been done by Stewart (2013) - was outside of the scope of this study. However, the limited use that I did make of these documents indicates that documentary analysis would also be a fruitful direction of enquiry for future researchers interested in the framing of third sector activity.

## **Analysing the data**

A large body of data was created in the combination of the different methods of qualitative data collection, which were combined to form the basis for analysis. This entailed the identification of common themes across the data as well as identifying where there existed tensions, differences, or other points of interest. The rich, qualitative data was taken to be a situated description of experience and was analysed for both literal content and bearing in mind the situated context. It was also considered reflexively for the way it constructed the interviewee, myself as the interviewer and categories like ‘professional’ and ‘patient’.

While analysis is discussed here as a distinct stage, in reality, analysis occurred during data collection as well as afterwards. Initial analytical categories assisted in the formation of later data instruments such as interview schedules and topic guides for observation at events. Following data collection, a systematic process of coding allowed for key themes to be identified within the data. Written transcripts from audios were combined with written field notes from events and organised within the

qualitative data analysis computer software NVivo 9. I did several readings of this data, noting down key aspects of the data as well as my own thoughts and reactions to what it contained. Following this I embarked upon the formalised aspect of analysis in the form of coding the data by themes, organised into 'nodes' within the programme NVivo.

In the process of coding themes within the research, the 'thematic networks' approach to analysis - described in some detail by Attride-Stirling (2009) - was of great use. It is also a rare example of an in-depth discussion of the mechanisms of carrying out a thematic analysis on qualitative data. Using thematic networks in analysis is an approach that has drawn on other methods of qualitative analysis based on seeking themes within data, such as grounded theory. The core tenet within this approach is the identification of key themes using a thematic analysis, and then the connecting of these themes in networks in order to 'facilitate the structuring and depiction of these themes' (2009:388). The resulting codes produced are at different levels. Initially, codes correspond to 'basic themes', groups of which are then linked to 'organising themes' and then the network joined by an overall 'global theme' (2009:388).

My own data and the underlying ontological and epistemological premise of my own research meant that a thematically-based approach to analysis was suitable. It was a way to both identify emerging themes and to examine the fit between these themes and prior concepts from the literature. Using this template was also useful when it came to thinking of the connections between the themes that emerged from the data. While I did not aim to produce a map of my resulting network as data in itself, this formed the basis of thinking about the levels. So, for example, over the course of analysis I was able to identify the base themes that emerged from the data – for example 'communication between professional individuals', 'training development', 'patient voice' or 'professional conduct'. I was then able to organise groups of these themes around broader 'organizing themes', such as 'knowledge bases' or 'patient-professional interaction.'

The organising themes produced from analysis in turn formed the foundation of the findings chapters and central argument of this thesis. For example, the three themes of findings that structure the data chapters Five, Six and Seven of this thesis emerged from a combination of the generated organising themes. These themes were also developed further in the comparison between these emergent themes and the prior literature on areas of theoretical relevance, such as third sector partnership, professional identity, and constructions around illness. The overarching argument presented in this thesis with regard to ‘aggregate know-how’ as possessed by the third sector was a theme that emerged when looking across the other themes generated and considering how they related to my initial main research question about the role of third sector organisations. This overall linking argument about expertise was developed from the dominant theme that linked across the others – this was my own version of what Attride-Stirling calls a ‘global theme’ (2009:388).

## **Ethical considerations**

Prior to the beginning of data creation, a University of Edinburgh internal ethical review was conducted. The research using the methodology discussed here was not deemed to present a physical or psychological risk to the potential participants, especially with the focus of questions being mainly about professional partnership practice rather than personal experience. However, I was aware that this topic was unlikely to be separated entirely from interviewees’ experiences and emotions around their own professional identity and/or connection with people with HD and other long-term conditions. Therefore, certain safeguards for the research were put in place in case the semi-structured conversations led to interviewees themselves bringing in topics of discussion they found distressing. For example, contact details of support services were taken to interviews in the case they were required. I was also ready to draw on my knowledge of trauma support - which I had been trained for in contexts outside of my own doctoral studies - if a situation arose where emotional reassurance of an interviewee was required.

While a situation did not arise during data collection where I needed to draw upon the particular support provisions highlighted above, several of the interviewees did disclose considerably more personal and emotionally sensitive information than had been originally expected. This occurred both within the interview encounter and in the discussion before and after data recording began. It emphasises the need for a constantly reflexive approach to ethical review, and that while the underlying principles of ‘procedural ethics’ such as ethical reviews are important, further issues might arise during data collection during ‘ethics in practice’ (2004). Guillemin and Gillam discuss the significance of ‘ethically important moments’ in research where there is a possibility of handling the situation in a ‘wrong’ way, during situations such as interviewee discomfort being expressed or in the decisions by researchers as to how far to probe a topic (2004). I would also add to this by suggesting that it is important to acknowledge that such sensitive moments might arise over the course of any research topic or when talking to any type of interviewee.

### **Ethical handling of the data created**

In order to uphold the commitments both to the participants of the research and the funding body the ESRC, steps were taken to ensure all data was handled in an ethically robust way. MP3 audio recordings of interviews and the subsequent typed transcripts were stored on password protected computers and in locked filing cabinets. The names and other identifying details of participants (location, contact details) were also kept separately from this data and were themselves subject to being kept in locked drawers and/or on password protected computers. The interviews and field notes were all transcribed by myself only.

### **Anonymisation of interview data**

Prior to all formal interviews, a discussion was held with interviewees about whether they wished for their names to be changed and identity concealed in this thesis and any other outputs to do with the research. The aforementioned information sheet and

consent form (available in Appendix D) outlines the options from interview participants selected.

Initially, the possibility of being named was offered to participants as an option because even though anonymisation remains the ethical standard for social science research (Saunders et al. 2015, Tilley and Woodthorpe 2011), it is suggested by some authors that giving participants the option to individuals to use their own name in research and speak ‘on the record’ can increase their voice and autonomy in research (Tilley and Woodthorpe 2011, Giordano et al. 2007). Giving participants this choice would also seem to fit with some research council ethical guidelines such as the following statement in the ESRC’s Framework for Research Ethics, which occurs alongside discussion of confidentiality and anonymity in research practice: ‘individual research participant and group preferences regarding anonymity should be respected’ (Economic and Social Research Council (ESRC) 2015).

Full identification of participants also overcomes some of the practical difficulties with promising full anonymisation when conducting in-depth research. As previous research has highlighted, there can exist a ‘balancing act’ between the protection of the identity of participants and maintaining integrity of the data as identifying details can extend far beyond a name and location (Saunders et al. 2013:3). Saunders et al. also draw upon their own research about people with brain injury and their families to highlight that even when a participant population is ‘geographically dispersed’ individuals might be identifiable through ‘unusual characteristics’, especially if the participants of research are likely to know each other (2013:4). Within my own research field, particular professional roles - and the naming of particular organisations - could mean that even pseudonym use is not enough to fully conceal identity. It was therefore necessary to highlight to my participants both verbally and in the consent form that the identification of the organisation the Scottish Huntington’s Association and the basing of the research in Scotland meant that, although individual names could be concealed as much as possible, a full guarantee of anonymity could not be given.



When offering the different options to do with anonymisation, it was also highlighted, however, that where interviewees actually elected for their name to be *used*, this could only occur if there was not an indirect effect of this revealing the identity of other, non-consenting participants. As my own research found, the HD services field in which the research was conducted is a small and closely connected one in which good relationships between professionals are key, and there was potential to cause distress to individuals or to organisations if names and information were not handled correctly. There was also the problem that, within a small context, if many participants of the research were named, those that were anonymised might be identifiable by a process of elimination.

Furthermore, while maintaining anonymity of others who are connected to a research participant can be an issue where there are associations between individuals, the anonymity issue is even more pertinent when it comes to research in the area of HD. As a genetic condition with particularly defined patterns of inheritance and risk, it is an added ethical requirement of researchers working with conditions such as Huntington's disease that they do not unwittingly reveal the genetic information of individuals past or present – or any future children they might have - through the identification of one individual. This was most relevant for the HD family member interview and the multiple other encounters I had throughout the research with people with a personal connection to HD and other conditions.

Following discussions with all participants, it was decided that the most ethical and consistent way to approach anonymisation was to attach a pseudonym label to *all* participants of the research. Within this thesis, the letters used in labels under quotations are also encoded so as to mask the order in which individuals were interviewed. Basic descriptions of job roles are given in order to allow for enough reader understanding of the professional interviewee's work role, and wherever possible other identifying information on location, background and the names of initiatives are removed. However, even though I opted to use anonymisation of the aforementioned type in my thesis, it also had to be highlighted to participants at the

data collection stage that the ability for the research to fully anonymise an interviewee also had context-dependent limits. There were also data-related implications of attempting to achieve anonymity for participants. My commitment to removing identifying information as much as possible also meant that large amounts of data that contained identifying information was unusable within direct quotation.

## **Researcher positioning and values**

Some methodology scholars have suggested that the credibility of research findings can be enhanced by researchers reflexively examining how their own position in the research field might influence the conduct of research (Cutcliffe 2003) Indeed, it has become increasingly common in what is now becoming known as the ‘reflexivity’ literature for researchers to ‘out’ their own practice (Finlay 2002), and to feel confident in discussing their failures as well as successes.

Although I was not directly employed by any of the public sector or third sector organisations from which my participants were drawn, I constituted what methodological research might call a partial ‘insider’ in the field (Harvey 2010) to the extent that I am a life-long citizen of the country in which they function (Scotland/the UK), and have previously been a recipient and/or supporter of their services. Such an insider status is often regarded to have advantages when it comes to establishing a shared sense of belonging with participants (Harvey 2010). However, it might come with its own pitfalls if respondents make assumptions about what a researcher knows about a situation, or if the researcher themselves assumes too much without knowing the ‘subtext’ of a context (Dwyer et al. 2009:55). When carrying out my own research I was aware that I had experience of my research field from certain professional and personal angles and shared values only, and did not have in-depth knowledge of the roles of daily work of my researcher participants as medical or third sector professionals. In line with this, the insider/outsider divide has in itself been discussed by authors such as Dwyer et al. (2010) as being far more blurred than the literature often suggests, presenting an alternative to this dichotomy

in the form of there being a 'space between' being similar and being different to a research population.

In addition to the above quasi-insider or 'space between' status, I entered the research with the goal of knowledge exchange and the production of insights of relevance to policy and practice. Throughout the research, I was also acutely aware throughout of my own role as a node within the network that I was examining, and the way that collaborative activities between interviewees and myself in the research might be considered as a function of their enthusiasm for partnership working. Early on in the research, it was supposed that by maintaining an acute self-awareness about my positionality, I would be able to 'bracket' my beliefs somewhat, and thus approach the research field with fresh eyes (Finlay 2002:537). Despite this, the research field still entailed a constant process of negotiation of my own position in the field and the outputs that I could deliver to my participating individuals and organisations. For example, encountering the challenges that people with HD faced gave me a strong desire to produce work of benefit to these patients and families – something akin to professionals getting 'hooked' on providing help for the condition as I discuss in my findings in Chapter Six of this thesis. However, I had to balance this wish with a realistic assessment of the time the research would take, and the nature of the impact that sociological research would bring.

I also took steps to prevent misapprehension about my role within the organisations in which I was doing research, something that has been suggested as key in methodology literature (Harvey 2010). I was fully transparent with participants and end-users from the outset that I was carrying out this research as a sociologist interested in health engagement, rather than as an evaluator, a critic or an employee of any of the organisations involved. This still required constant reassessment and reinforcement, especially in light of the fact that there was indeed a degree of reliance on the gatekeeper organisation, the SHA, and the subsequent interviewees, even though the research was independently designed and independently funded.

## Doing research in small, connected communities

Many of the issues experienced in my own research – such as the aforementioned issues with anonymity being preserved at the loss of other data - are highlighted by Damianakis and Woodford as particular challenges of research in what they have termed ‘small connected communities’ (2009). They discuss that it might become evident to the researcher at different stages that their participants are likely to know each other. These stages occur when planning the research, during recruitment when participants are recommending other participants, and in data collection when participants are talking about other people in their field (2009:716). The challenges of research in ‘small, connected communities’ are seen to require extra reflexive attention on the part of researchers to adjust research procedures in light of the context. For example, it might be necessary to alter the way that participants and their data are labelled in outputs (2009:716). However, I would argue that in addition to this, acknowledging these potential issues is also something from which any project involving primary research with people would benefit. It is also the case that the very revealing of a research context as a ‘small, connected community’, especially if this is dissipated across geographical boundaries, indicates it might be of sociological interest to uncover these network relationships.

## Conclusion

This chapter has discussed the methodological choices made throughout this research. The original research problem and research question arose from what I perceived to be a gap in the literature, combined with an interesting and suitable context in which to do the research. Review of the empirical and theoretical social science literature in health indicated that organisations from the third sector are increasingly involved in all aspects of support around these conditions. Furthermore, the policy literature and social science literature alike stressed the importance of ‘partnership’ and ‘collaboration’ in a number of forms as a solution to increasing

health service demand. Partnership in services provision, one of the main elements of the research question, is also an apt topic for sociological research as it returns to a core theme of sociology by examining why organisations in society function as they do. A research design was accordingly composed to fit my central question around the role of third sector organisations and their partnership with other organisations in service delivery in Scotland. My research design was built on interpretivist and inductive research strategies and what might be classed as a 'subtle realist' approach to the status of knowledge.

Sampling, data collection and analysis were continuous processes that demanded that I exercised constant methodological and ethical reflexivity. In particular, challenges were encountered to do with arranging and managing interviews with professional individuals who had extremely busy schedules. Serious consideration also had to be given as to the way in which anonymity would be handled within a research context that was both small and connected, and that also included some individuals whose association with others might unwittingly reveal personal genetic information. Furthermore, in common with many sociological researchers engaged in field work, I had to manage my own position in a research field in which I was personally invested. These experiences from my own research connect to many themes of the methodological literature. In particular, I argue that insights from my own research experience show the need for continued debate around when anonymisation is or is not possible. Like others have found (Aldred 2008), my own research showed a situation where waiving anonymisation might be desirable but was not completely possible. I also suggest that the closely connected nature of many situations - while presenting potential challenges around anonymisation, sampling and researcher positionality – represent fascinating areas of study because of their very closeness and network properties (Damianakis and Woodford 2009).

Having discussed the way the research was planned and carried out, this thesis will now turn in the next three chapters to discuss the major substantive findings of my research. This begins in the next chapter, Chapter Five, with a discussion of the way

in which third sector partnership is shaping the organisations involved in the delivery of HD services in Scotland.



# **CHAPTER FIVE: PARTNERSHIP AND THE SHAPING OF THIRD SECTOR HEALTH ORGANISATIONS**

## **Introduction**

In this chapter I will explore the way that third sector organisations, particularly those concerned with the condition Huntington's disease (HD), are shaped by, and are shaping of, multi-organisation partnership arrangements. Findings in this area relate to the core aims of the research. They allow the unpacking of the role of third sector organisations in service delivery, and of partnerships between these organisations and others, in shaping the experience of HD and other long term conditions in Scotland. These findings also relate to the way in which individuals within these organisations interact. This is built upon in the subsequent chapter on individual professional identities.

The interview and observation data that I collected with a range of professionals across the Scottish health scene - see Table 2, page 144- allows insight into what can be considered major enabling and constraining factors when it comes to working across professional boundaries in healthcare. In order to explain how professional and organisational symbolic boundaries were engaged with by individuals involved in service collaboration around HD, I draw upon the rich literature from sociology and STS that develops the idea of boundary and boundary work. Developing these insights, I will argue that when asking professionals about the service arrangements in which they are involved around HD, the drawing and redrawing of boundaries between different groups of professionals in their daily work becomes visible. This argument will be further developed in the subsequent findings chapters. In these two subsequent chapters (Chapters Six and Seven of this thesis), I discuss how new



organisational partnerships shift the boundaries of how individual professional identity roles are formed, and also how they shape the way in which in daily experiences of patients and families are brought in to services.

## **Boundaries within health services**

As the literature review chapter of this thesis explores, in social scientific literature from the second half of the twentieth century, theoretical development around the concept of a symbolic 'boundary' or 'boundaries' has been a popular enterprise (Lamont & Molnar 2002). The appeal of adopting the lens of 'boundaries' is that it helps to expose how, where, and why demarcations of both a physical and symbolic nature between individuals, groups and other entities occur, and their very real material effects. This theoretical lens remains useful regardless of what is being separated by the dividing line that is the subject of the research. For example, particular individuals from groups, one nation from another, two bodies of professional expertise, and so on, can all be analysed in this way.

For researchers working in the field of health and illness the professions literature has cast regular spotlights on boundaries within medicine and associated health and social care systems as an area populated by a multitude of different cultures, or 'turfs' to use Abbott's terminology (1995:552). However, much of this research has developed theory around boundaries within the health field where the roles are relatively well-defined, such as 1) between medical specialities, 2) between doctors and others professions such as nurses, people in the allied health professions or social workers, or 3) between the professional and the patient. While this past research on professional differences, organisational differences or experiential differences remains useful for this current discussion, somewhat lacking has been the application of boundary-related concepts to third sector presence and activity within a health setting. This is fertile ground for research focusing on the potential boundaries that might arise when two distinct sectors, such as the public sector and the third sector, encounter each other.

When presenting the findings about organisations below, I recap firstly the types of collaboration in which participants were involved, and then go on to discuss themes from my data concerning the organisational challenges of partnership. These themes include the position of the third sector vis-à-vis other organisations. This was something that both functioned as an enabler of partnership arrangements and something that was constantly being re-interpreted as a result of new arrangements. Following this I will examine the role of collaborative ‘work’ taking place and the way that organisational difference as a feature of collaboration entered working practice. I will then go on to illustrate some of the strategies by which organisational boundaries were crossed within my research area, exploring the functions of boundary spanning individuals and boundary objects. Finally, the chapter turns to the way in which collaborative working is shaping a sense of professional community in the organisations participating in the process, and what this might imply for current sociological ideas about boundaries in healthcare.

## **Positioning the third sector within the Scottish HD/health scene**

During qualitative interviews and meetings, the various participants of the research were invited to reflect on the third sector’s role as a whole vis-à-vis other organisations in the health landscape. When asked for examples of collaboration in which third sector organisations in health were involved, the research participants highlighted a wide range of activities. Within the HD context, the majority of these collaborations focus on delivery of a support service of some type. This comprises clinical support, as well as social support such as the facilitating of patient and carer support groups, youth retreats and so on (notes from all interviews and meetings). The only organisation directly working with HD services in Scotland is the Scottish Huntington’s Association (SHA), an organisation that was invaluable to this

research. Their own website lists some of the wide range of ways in which they support individuals with HD alongside the public sector in Scotland:

There are currently nine specialist HD services in Scotland; Highland, Grampian, Tayside, Angus, Fife, Lothian, Lanarkshire, Glasgow and Ayrshire. We also have three specialist youth advisors; one covering the North East, based in Aberdeen, and two the South West, based in Glasgow.

SHA also supports a network of family branches which are run by family members for family members and provide information and peer support. The groups also fundraise, are able to help people in practical ways by providing welfare grants and provide fun social opportunities. There are currently groups in Tayside, Fife, Lothian, Forth Valley, Lanarkshire, Aberdeen, Elgin, Glasgow and Ayrshire (SHA 2015).

Where public sector-third sector partnerships around HD are concerned, these are seen to occur at a number of levels within the public sector: with the Scottish Government, with local council authorities and with NHS Boards across Scotland. At the level of individual health there exist clinical partnerships - described in full in the chapter that discusses Scottish aspects healthcare (Chapter Two) - between NHS boards and the Scottish Huntington's Association. This model involves clinics being run by hospital Consultants from different medical specialities - normally psychiatry, genetics or neurology - in different areas. These consultants have a link to health and social care in the community via the regional HD Specialists, who are employed by the third sector group the Scottish Huntington's Association. A quotation from a clinician in a HD clinic provides a backdrop to the way such services function:

...it was a joint partnership clinic. I was bringing to the table my [medical] experience and the Scottish Huntington's Association were also bringing an awareness of the specific condition and its complexities. So it was a partnership clinic in which we both brought our individual knowledge and experience and specialist skills.

Interview with NHS clinical professional (Int-C)

The scope of collaborative endeavours between the third sector and public sector in Scotland also encompasses informal arrangements with fellow third sector organisations to develop joint support and educational initiatives, exchange ideas, and share resources. This involves everything from informal contact being made between professionals over the phone etc., to more formally co-organised mutual events such as third sector conferences and learning sessions (notes from observation at events).

Another aspect of collaborative working for third sector organisations is within alliances with other third sector organisations. Within these alliances, third sector organisations can unite with a common voice and provide mutual support. Such alliances often have a political function as well when it comes to exerting collective pressure on the government or health service for policy issues such as patient access to treatment, or on wider awareness-raising around a condition or group of conditions. The benefits of joining an alliance were summarised by one interviewee who worked for such an alliance organisation as including the following:

...having the opportunity to engage with things that they wouldn't necessarily be able to engage with. When it comes to the Scottish Government particularly, they like to be able to have an umbrella organisation, because they can come to us and say 'we've got this group starting up, we'd like some representation, can you get that for us'... So we have a lot of different member organisations who have agreed to become representatives. They then get the chance to get involved in national strategic work which wouldn't necessarily be something that they would be approached to do as an individual organisation. But because they are the member of the alliance organisation, they can get involved in that.

Interview with third sector alliance organisation professional (Int-E)

As outlined in Chapter Two, in the case of Huntington's disease there are many different types of alliance that might emerge based on the different symptoms of the condition. For example, some Scottish alliances cover neurological conditions (e.g. the Neurological Alliance Scotland), while others have a connection to palliative care (Palliative Care Alliance Scotland). There are also numerous alliance organisations that enrich care through bringing together organisations under a more general third sector and/or health focus - such as the Scottish Council for Voluntary Organisations,

and Voluntary Health Scotland - and those that bring together carers of people with long term conditions, such as 'The Alliance'.

An important finding that emerged from my research into the activities of the third sector in Scottish healthcare was that constant renegotiation took place about how these organisations were positioned in comparison to other third sector and public sector organisations, as well as patients and the public. While many of the topics below relate to third sector activity which is not exclusive to HD, I argue that they are of relevance to the specific research context. The reflections offered from participants in the research shed light on the wider position of the third sector in Scotland, which forms the backdrop against which HD organisations operate. As will now be explored, one of the main organisational aspects discussed was the variation present within the third sector, and what this meant for third sector interaction.

### **Variation in the third sector's remit in Scotland**

The majority of organisations involved in this research or discussed by participants aimed to provide direct support or advocacy services in a professional manner and to the same standards as the public sector. When talking about the third sector in the present day, many participants highlighted the sheer diversity of these organisations even within the subfield of third sector organisation activity in health. There were seen to be sizable differences between third sector organisations along capacity lines, including size, budget, level of activity and remit:

And the third sector is difficult to understand because it's not a simple thing and it appears anarchic and diverse... within the third sector as well, projects and organisations come and go.

Interview with NHS non-clinical professional (Int-J)

In part connected to this varying capacity, there were also perceived to be considerable variation in the goals and intentions of third sector organisations across health:

So that interface between health professionals attempting to support and advise their patients and the rich resource that is the voluntary sector appears to be chaotic and difficult to access... for those looking in, who aren't of the sector.

Interview with third sector alliance organisation professional (Int-K)

As the quotation above indicates, the variety of organisations was also talked about as a potential barrier to non-third sector individuals understanding the third sector, which could appear to be a chaotic array of different organisations set against a moving background of changing priorities, personnel and so on.

In many cases, it was individuals who had worked, or were currently working, within the third sector who emphasised this level of diversity across the sector. The 'variability' and therefore 'unpredictability' of third sector organisations compared to more well-understood public sector services was put forward as a type of boundary work that individuals in organisations such as the NHS or local authorities drew upon. Most relevant to my research's focus on the role of the third sector was the worry articulated by participants that some individuals within public sector organisations, including both the NHS in Scotland and local government social care, still do not fully understand or appreciate the role of the third sector:

I think sometimes the fact that we are a voluntary organisation does kind of mean that people don't often know what you are about. So, if we were employed as part of the health service as a specialist nurse, for example, I think that would be easier for people to understand what our role was... and I think because we are employed by a charity and part of the third sector, it's maybe not as clear what the role actually is and what we can provide.

Interview with third sector HD professional (Int-N)

While a lack of understanding was seen as something that is becoming less common, particularly in light of the partnership emphasis within policy documents, it was still seen as a potential barrier to full inclusion of third sector expertise. Related to this, NHS and third sector professionals alike mentioned that the sheer range of third sector organisations, with their considerable variation with regard to resources, communication strategies and service style, could make it difficult for public sector agencies to identify appropriate third sector partners.

### ***Tea and sympathy***

For most organisations involved in my own research, the priority of facilitating softer support - i.e. non-formalised emotional support such as peer discussion groups - still formed an important part of their role, but their focus was seen to have become extended beyond this as the priorities and resources of the organisation changed. As one third sector interviewee phrased it, many organisations had been built on what many saw as a historical remit of ‘tea and sympathy’ (Interview with third sector representative Int-G). The exact phrase of ‘tea and sympathy’, or a variation on this term, also arose several times throughout interviews and in observations at events:

I think there are some who haven’t come across us in the past, and they go, ‘oh, here’s the sort of ‘tea and cake’ brigade, coming along, the nicey nicey people’. But I think actually when we get involved in certain aspects of work, I think they realise that actually our staff are from health and social care backgrounds. Most of them are nurses or social workers.... So we do have quite a good selection of backgrounds and professional backgrounds.

Interview with third sector HD professional (Int-F)

I think to other professionals and the media it was about making a cup of tea and a chocolate biscuit, they were always pretty shocked that we could be professional... and be paid! The amount of people who said to me when I first started working at the voluntary sector, ‘Do you get paid for that?’ Yeah! I’ve got a mortgage to pay, and a family to raise.

Interview with third sector HD professional (Int-G)

In all cases, this metaphor of ‘tea and sympathy’ was being employed to retrospectively describe a previously lower status ascribed to third sector organisations, whereby it was perceived that emotional support was the main or only remit of the sector. It was still possible for this important function of emotional support to be portrayed by others not in the third sector in the sort of way experienced by the interviewees in the quotations above.

Third sector organisation professionals involved in professionalised services often used the tea and sympathy idea as a form of boundary work in order to draw a contrast between the current professional nature of third sector support and what had been labelled by others to be a less professionalised support remit of the past. This in turn could allow a strengthening of their current position by emphasising the change and evolution that had occurred. At the same time however, such necessary boundary work to assert current professionalism might also have the undesirable consequence of simplifying an organisation’s historical development, in which both emotional support and more politically important activity could be important features both then and now.

There was, however, a dual aspect to boundary work around this issue. It was also used at other times, and sometimes at the same time, to remodel ideas of what much of the friendly, informal support that others had labelled as ‘tea and sympathy’ was achieving. In doing so, it was used to show that no setting was ever ‘solely’ just providing comfort. The interviewee in the second quotation above had described at length a radical third sector initiative they had been involved in within a previous role. This involved providing emotional and practical support to individuals in a drop-in centre and café, but that allowed them to gain further information about, and links to clinical and social care services (Notes from interview with third sector HD professional, Int-G). Likewise, the important role of family peer support branches for HD and other conditions was also emphasised throughout interviews (Notes from interviews A-N). Past research has identified that such informal and supportive settings can provide important functions in themselves as well as providing spaces



for professionalised support, advocacy, or political collectivisation (Mulcahy et al. 2010). This also connects to a theme that will be returned to again in both Chapter Six and Seven: the building up of rapport by professionals through informal support as both important to good professional/patient interaction, and a route to understanding the totality of a condition.

### ***Different structural organisation between sectors***

Another type of division often highlighted by participants was that the third sector was subject to less regulation and did not bear the statutory responsibilities of organisations such as social work and the NHS. Although there were perceived to be some actual benefits to this, as elaborated upon below, it was also thought that this resulted in the third sector sometimes being taken less seriously as a partner in service planning and delivery:

The power balance is always a challenging one, because local authorities and health boards have statutory functions and responsibilities and legal duties and so on whereas the voluntary sector doesn't...that's sometimes used as a barrier or as an excuse for excluding the third sector.

Interview with third sector alliance organisation professional (Int-K)

At the same time, individual staff in third sector organisations were perceived to shoulder more personal responsibility for their decision-making and for specialist tasks due to the lack of set bureaucratic structures and support. This could lead to individual 'burnout' for leaders.

At the core of the third sector it would be fantastic if you had a HR department...or maybe it wouldn't? I don't know. But a lead HR person to do that stuff, a finance person to do that stuff, a legal person to do that stuff. Sometimes they don't have that resource, and sometimes the leads are kind of exhausted by the level and amount of responsibility they have. However, I am not saying that the public sector model is any better because it really has its downfalls as well.

Interview with NHS non-clinical staff member (Int-J)

Connecting to the previous discussion around ‘tea and sympathy’, participants in the research frequently stated that individual third sector organisations felt it important, and even necessary, to emphasise the ‘professional’ nature of their work in order to be measured solely by the public sector yardstick of what constitutes a professional service. They often felt the need to emphasise what they had in common with statutory services when it came to regulation and so on:

We want to be seen to be professional. And what keeps coming back to me is that people are congratulating [our management staff] as an organisation about how well we’re doing... comparing [us] to the bigger organisations, voluntary organisations, charity organisations. So that obviously comes down to the fact that we’ve got lots of good policies in place. We actually keep abreast of contemporary legislation and keep... moving forward really.

Interview with third sector HD professional (Int-F)

Through discussion around policy awareness such as that featured in the quotation above, participants were able to discursively challenge the existence of such a boundary between themselves and professional services, or redraw to include their own practice as within the realm what constitutes a professional service. Above and beyond mere resources, it becomes about the ability of third sector organisations to present an authoritative voice, as the following quotation highlights:

The ability of the patient organisations to advocate for those service improvements, is not contingent on the severity of the condition or on the availability of interventions that will change the trajectory. It is also, to some extent, very dependent on the ability of the patient support organisations to articulate a case for intervention that the health service can recognise and respond to.

Interview with third sector alliance organisation representative (Int-M)

Findings from the data such as that above revealed how both positive and negative ideas of the third sector could be drawn upon to explain the relationships across different organisations and sectors. Participants of my research suggested that notions of the third sector also evolved in practice during collaborative working. In relation to this, in the section below I will now examine the boundary work that

emerged from my data, and particularly the way in which the role of organisational culture within or between sectors was discussed by the participants of the research.

### ***The third sector and political accessibility in Scotland***

Comparisons were made by participants in the findings about the situation in Scotland versus the rest of the UK and beyond when it came to the third sector's access to public sector engagement, particularly in regard to policy-making. A theme of 'Scottishness' and 'Scottish public services' emerged from these discussions. It was put forward by several interviewees, referring to mainly the Scottish Government and Scottish Parliament, that Scotland was more open and accessible to third sector groups, patients or medical professionals in comparison to other similar national parliaments. This was perceived to be an advantage for third sector organisations who wished to have input into policy making and the structuring of services:

I think it has been considerably easier [in Scotland], whether it's accessing MSPs, or getting a reception organised at the Scottish Parliament and influencing MSPs and having conversations with ministers... or whether it is, quite literally, going to the minister's office and saying these are the issues for families... It's a much more immediate and accessible form of government I think - that's my impression - than in other parts of the UK and Ireland.

Interview with third sector HD professional (Int-H)

The size of Scotland was often mentioned when talking about issues such as the accessibility of Scotland, as in the above quotation. Participants highlighted that being on a smaller political playing field, compared to say England, gave them more opportunities to approach individual MSPs, as well as to attend events to do with government and parliament:

I think it's much easier to work in health in Scotland than it would be in England just because it's quite small... and the Scottish Government I feel are quite responsive, so it's pretty easy to engage with them compared to what I would imagine [it would be] to engage with Westminster.

Interview with third sector HD professional (Int-E)

The remit or reach of third sector organisations then, was not something solely determined by their own capacity or drive, but by what was perceived to be greater openness in access given to the sector by wider Scottish policy structures. This same comment about the comparative accessibility of the Scottish political setting was also highlighted by individuals from outside of Scotland.

However, participants also highlighted that even in comparison to other political units smaller than England such as Wales, the Republic of Ireland and Northern Ireland, Scotland might have a greater *proportion* of third sector resources to draw upon as a small nation, particular in the area of HD. Participants cited the active nature of patient and professional communities as well as the engagement capacity of individual third sector organisations and alliance organisations in Scotland as contributing to a climate that was positive for third sector engagement (notes, Interview with non-clinical professional Int-I). Scottish health policy arising from successive governing Scottish administrations that has been supportive of third sector presence was another major aspect of this, as will be discussed later in this chapter in light of ‘boundary objects.’

It is, of course, possibly the case that the situation in Scotland described above is one in which there is a *perception* of greater influence resulting from the small size and particular structures rather than an actual increased influence. Having not set out to measure the causal aspects of influence in my own research it is not directly possible for me to make a claim to this. However, it can be said that even the widespread perception of third sector importance and influence might be seen as a driving force for third sector access, as it was used by third sector organisations as a tool in claiming their role at policy tables. For example, third sector organisations from within and beyond HD care stressed the important role of the third sector in past policy when making the argument that the third sector should be more formally involved in the ongoing process of the integration of health and social care following the *Public Bodies (Joint Working) (Scotland) Bill*. This is highlighted in the

quotations below, taken from data collection while the Bill was still in its initial stages in the Scottish Parliament:

With health and social care integration it's going to be interesting because one of the things that might have initially not been a sort of feature in the proposals was the value of having the third sector on the committees that were set up to allocate the funding and the budget and stuff...and that's something that I know [other third sector organisation] has done a lot of work on, lobbying for third sector organisations to be key in that.

Interview with third sector alliance organisation professional (Int-E)

The next three years we will see huge changes in terms of the integration of health and social care and I would like to believe the third sector will be seen as an important partner in that whole process... I think that has to be safeguarded and promoted effectively... because the sector in Scotland has got a phenomenal contribution to make.

Interview with third sector HD professional (Int-H)

As was discussed in Chapter Two, one of more recent additions to the health and social care integration process has been formal measures to include the third sector in the newly created integrated structures. These measures have included increased funding to support this as well as guidance about how the existing regional Third Sector Interfaces will form part of the new Health and Social Care Partnerships (Scottish Government 2015d). This might be taken as tentative evidence that there might be areas in which the third sector is still not yet fully integrated into policy. At the same time, the measures provide opportunities for the third sector as a whole to increase its presence and influence further.

## **Boundary work and the role of organisational culture**

Various aspects of ‘organisational culture’ were frequently discussed in interviews as major facilitators of understanding and collaboration between organisations and sectors. The concept was particularly prominent in light of the aforementioned process of the integration of health and social care, and with regard to the distinct cultures of these respective institutions as well as the further distinct focus of the third sector:

Certainly it’s not going to be easy to integrate two very different cultures [health and social care] and two very different organisations into one. I kind of think, in some ways, that the benefit of involving the third sector is that a lot of third sector organisations have a uniquely person-centred focus. I kind of have this vision about the third sector actually enabling the process of integration because it would help everyone keep their eye on the ball, which is ultimately to provide better services for people.

Interview with third sector HD professional (Int-H)

When reflecting on the role of their own and other organisations within the health scene in Scotland, it was often mentioned by interviewees and discussants at events that there did exist shared practices, norms and guidelines between the public and third sector, and between different individual organisations. Successful instances where different cultures existed but were seen to agree or combine around a common platform were highlighted. For example, the Getting it Right for Every Child (GIRFEC) governmental framework was mentioned by two separate interviewees as an example of something that united different organisational cultures around the issue of the wellbeing of young people:

The GIRFEC approach says shared values and principles are the way that the needs of the child are approached. So the child's at the centre and the world around the child is looked at...the approach is so that you've got across organisations and sectors some framework of shared values and principles. I think that helps.

Interview with third sector alliance organisation professional (Int-K)

As reflected in the quotation above, shared values across cultures and achieving organisational goals were often seen to be directly related. However, at the same time, there was mention of the potential existence of organisational cultures in the form of creating particular 'tribes' that might physically or metaphorically exclude other groups from organisational settings. As discussed below, this is something that needed to be overcome if service collaboration was to occur.

### **'Siloed' practices within organisations as a potential barrier to collaboration**

One prominent idea that arose within observations at events was the shared belief that there could exist organisational and sectoral 'silos' within the health scene in Scotland and the wider U.K. This term of 'silo' draws on the metaphor of agricultural storage containers, where each container of the stored substance, such as grain, remains isolated from the other containers. Siloed practices were considered to be less prominent in the present day, or more deliberately avoided by the organisations involved, although they were still discussed as posing a danger to successful joint working across boundaries. Thinking in siloed ways was attributed by some participants to the past cultures of entire sectors or parts of sectors, rather than being something that participants of the research believed that they themselves or colleagues adhered to. For example, the refusal to communicate or understand perspectives other than within one's own professional area (e.g. nursing, social work, medicine, third sector support) was frequently referred to as a form of organisational siloing (Fieldnotes of observation at third sector conference Obs-B).

Siloed thinking was also cited as existing at the level of individual professionals and the provision of services. It was seen as something that might exist around an understanding of the patient or the most appropriate way to address their needs. For example the interviewee who had a personal connection to HD highlighted that if a professional outlook entailed too much rigidity, and was closed off to other sources of information, then there was the potential for certain needs to be overlooked:

A lot of ‘professionals’ feel as if they know and they don’t need to be told any more... but with the complex needs of somebody with HD, if you don’t know, then you’re not giving that person the support they need.

Interview with individual with personal connection to HD context (Int-A)

In the above quotation, the interviewee is depicting a potential problem as being rigidity in outlook from selected professionals. As the following chapter on professional identity will discuss, preventing this from occurring was to have much to do with the time, resources and dedication of particular individuals who worked in a flexible manner that truly heard patient needs.

While siloed practices were seen as the negative aspect of different types of knowledge and experience co-existing in the healthcare settings, that difference in itself was not necessarily portrayed as wholly negative. As I will discuss below, there was seen to be positive ways to cope with, or even to embrace, differences between organisational culture and outlooks that might prove beneficial.

### **Organisational difference as a positive attribute**

While exclusionary boundary work was often talked about as a source of inequality in collaborative settings between the third sector and other organisations, there were situations in which the perceived difference of the third sector was actually put forward as a positive resource. This was especially relevant in times of service pressure. Despite assertions of how varied the sector was, as discussed earlier in this chapter, there were seen to be some values that the third sector embodied as a whole that it was important to preserve. First and foremost, the idea of a person-centred



view of both issues and methods of working was talked about by participants as a prime function of the third sector, as well as something that the government and health service were striving to do in policy:

Obviously there's a huge focus on person-centred care from the Scottish Government. It's what the NHS Quality Strategy sets out that services should be: the person should be in the centre of all that. So we can help the Scottish Government by providing that.

Interview with third sector alliance organisation professional (Int-E)

In the above quotation, the interviewee is talking about specific initiatives in which their own third sector alliance organisation was involved in order to increase patient input into services and therefore make services more responsive to the needs of patients. This was one manifestation of person-centred care. However, there was also a slightly different depiction of the third sector's person-centred practice within other interviews that was expressed more in terms of 'holism' or 'holistic practice'. While sometimes used interchangeably with the term 'person-centred', 'holism' was often advanced as a value that could and should be possessed by professionals or services. By this it was meant the ability to focus on many aspects of life with a condition rather than just one particular aspect of the symptoms or social needs etc.

Operating as a linking point of many services was one way that holistic practice was perceived to provide benefit:

The aim is really to make sure that the person and their family receive the best possible service. So the link would actually be from the clinic through the third sector support worker, and maybe to their GP or other community services. It might be that social work gets involved, or it could be a dietician or a speech and language therapist. So it's really a holistic approach to get the best possible service for the individuals and their carers.

Interview with third sector HD professional (Int-F)

As will be explored further in the subsequent chapter on individual professional identity, the ability individuals in the third sector to spend time listening to needs was also considered part of this holism.

It should be noted that it was clear from the research that the ideal of taking a holistic approach was by no means *limited* to the third sector, and was also something that public sector participants often also aspired to do, either through flexibility in their own practice, or using collaboration and referral with other professionals to address the multiplicity of needs. It was also seen to be embedded in policy (as mentioned above) as well as in other, public sector services deliberately set up to provide a person-centred service. These included the many NHS-funded specialist nurse posts and coordination-focused services such as the Single Gene Service in the Lothians (notes from Interviews A-N). Holism was, however, often portrayed as something *particularly* embedded in the ideals of the individual third sector organisations and also surrounding wider third sector culture, and therefore something that could be readily achieved within third sector structures:

If a patient organisation is good then they will have insights into the condition, and the care and management of the condition, and the needs of those affected... which can be communicated to professionals in a way that resonates with professional expectations and translates into a better organised, planned and delivered package of care.

Interview with third sector alliance organisation professional (Int-M)

However, throughout data collection it was also seen that a specific focus on one part of the patient was *not* something that was seen as inherently negative, as there was considered to be a definite need for specialist pockets of knowledge in health care. Indeed, pockets of specialist knowledge were seen as particularly important for the care of a condition such as Huntington's disease with multiple physical and psychological aspects. In this case, the important aspect was to make sure that the different types of expertise were suitable for their own purpose:

In terms of mental health staff, obviously if people were interested in mental health aspects they'll also be quite au fait and knowledgeable about medications that are often used in Huntington's disease. Whereas staff in the general hospital they may be more interested in physical aspects. However we always make sure that training is sufficient, that it educates and upskills people no matter what starting point they have.

Interview with NHS clinical professional (Int-C)

While specialist knowledge was in itself useful, it was the inability to see how this might fit into a wider picture that might end up as negative use of this specialist knowledge. It was in these circumstances where communication did not occur that specialist knowledge became a form of ‘siloes’ knowledge. The third sector’s shared value of a holistic approach was seen to be a way to transcend any jurisdictional boundaries in actual service provision, either through advocating that professionals worked across these, or by actually being the coordination point for this joint working. In the case of HD care in the UK, third sector-employed staff members (HD Specialists in Scotland, Regional Care Advisors in England and Wales) provide the linking point across multiple bodies of expertise. In Scotland, regionally based clinics that run in collaboration with a hospital consultant, the Scottish Huntington’s Association HD specialist and a host of other professionals provide what can be described as a ‘hub and spoke model’ of service delivery:

The unusual thing about this clinic is that it is a partnership. It is fairly unique in one sense. It involves specialist doctors, a specialist nurse... It doesn’t allow us to do everything for the patient. It allows us to make an assessment of needs and refer people on to different specialists, different social services and other services that are required. So it is an avenue in which to coordinate their care, which in the case of Huntington’s patients is very complex, requiring as it does many different professionals. So it seems to work well on that basis.

Interview with NHS clinical professional (Int-C)

When brought together successfully, the combination of multiple groups of bounded knowledge from across medicine and social care was seen to actually be a positive thing:

Thinking of my own experience... it’s impossible to provide a service in isolation. And people get the best deal with multi-disciplinary working. So somebody with dementia comes along then, yes, I can diagnose dementia...and I can provide medication and I can give them information or direct them to information. But I couldn’t work without the CPNs [Community Psychiatric Nurses] in terms of challenging behaviours at home, supporting spouses... [or] occupational therapists, doing their specialist home environments, adapting things so that they can function to their highest ability within that... [or] social work department in terms of home carers, in terms of supporting the activities of daily living...[or] day care services,

respite services. So... without a multi-disciplinary input people suffer. Or people don't get the best service.

Interview with NHS clinical professional (Int-D)

Staff in the statutory services are under increasing pressure and people can't know everything all the time. A general nurse is a general nurse, a mental health nurse is a mental health nurse. They can't know everything...I think people now are actually only too glad that, if you see someone that's got a specialism, it's one that you can pass on to them [the specialist].

Interview with third sector HD professional (Int-G)

There were also seen to be many medical conditions outside of purely the context of HD for which the third sector was a vital component to the existence of the service, which in turn strengthened their standing as an equal partner. One of the ways the third sector had developed credibility as a provider of services across many conditions was via the funding of specialist nurses, even if the individual nurses were themselves trained within public sector settings:

We know that specialist nurses are vital. They are so, so important for people with conditions, particularly a condition like MND [motor neurone disease] which is very rapidly progressive and a terminal illness. So I think the third sector are being seen as legitimate, very valuable, providers of services as well...

Interview with third sector alliance organisation professional (Int-E)

It was also highlighted by participants from across different roles that the multiple types of professionals involved in a situation such as HD care also function to provide multiple entry points for a specialist organisation to engage:

Because it is such a complex condition it can sit within mental health, it can sit within physical disability. It obviously sits within long term conditions, it sits within neurology, it sits within palliative care. So in some senses that's a strength, because it gives you a whole range of avenues in which you can access support or get your voice heard.

Interview with third sector HD professional (Int-H)

As the above quotation indicates, the complexity of HD means that it shares symptoms with many other conditions. The existence of many possible relevant alliance organisations which an organisation working with HD might join also worked as an asset in order to engage in a wide range of issues. There were many different organisational allies possible, and, as this thesis will go on to explore further, many different ways that the condition of HD could be articulated. At times, this involved a deliberate narrow focus on specific medical aspects of the body too, in order to see HD in some of the ways suggested in the quotation above (a disability, a neurological condition, and so on). However, this also occurred alongside a process of widening and changing definitions around issues such as stigma and support for other wider life-related issues, as will be discussed in depth in Chapter Seven.

### ***Independence from the state, and addressing client need***

Another positive organisational norm difference that was often identified was the independence of the third sector from the State. By being independent from the NHS, and by having a focus on a certain condition, or group of conditions, third sector organisations were often described as closer in position to their client group. Even if they were a professional service provider or policy voice, for many of the third sector organisations it was important that they had an independent voice and emphasised that they were first and foremost about the client group. As one interviewee phrased it: ‘Families are at the heart of all we do.’ (Interview with third sector HD professional Int-H).

For third sector organisations that provided professional services, the fact that they combined this partnership with remaining independent was a key point that they emphasised:

I think one of the biggest things that we try to get across is that we are independent... We do work with the statutory sector all the time. We are actually sitting in the same offices very often... in clinics, and things like that... or at review meetings, or at case conferences and that sort of thing. But actually... we oppose some of the things that the statutory sector try to impose on families and actually

battle with them all the time...and that actually is because we are independent of the statutory services. So I think that's a great strength that we have.

Interview with third sector HD professional (Int-F)

As reflected in the discussion about variability among organisations earlier in this chapter, some organisations were seen as being true experts in the particular medical condition, and were called upon by the NHS and local authorities because of this expertise:

There's one organisation... If we have any, patients referred who have [the particular condition] they are my first port of call. They are absolutely fabulous in terms of their quality clinical governance. We just can't get that quality of information from any other source, in my opinion. So there are some really brilliant, third sector organisations that I would, before any NHS organisation, get in touch with first.

Interview with NHS non-clinical professional (Int-J)

For example, the fact that their own third sector organisation was independent from the state was put forward by a representative of this organisation as giving more scope for advocating for their client group while still remaining a professional service provider:

And some organisations start out as an expression on the aspiration on the part of a patient - or a parent, or a carer - to make a difference. Some organisations grow through that... to highly professional, highly skilled organisations who are able to advocate strategically on behalf of their members and the families they support.

Interview with third sector alliance organisation professional (Int-M)

In the above quotation, there is further indication that the rhetorical boundary often drawn between the 'tea and sympathy' and a current climate of professionalism is not a clear-cut dichotomy. An organisation in the early stages of development could still serve a political function of articulating injustice, and also provided the necessary

motivation for groups to build resources to become a modern-day ‘expert’ organisation.

Retaining independence from the state was also discussed as something that organisations were well positioned to do due to their structures allowing them to maintain this distance and use this as an asset. It has been frequently highlighted in the social science literature that for rare diseases in particular, single condition third sector organisations can often be better repositories of knowledge about patient numbers, recruiting participants for trials and so on than mainstream health services (Raspberry and Skinner 2007). Similarly, many third sector organisations are in a position to act as a direct interface between their client group and the state through their advocacy or support services.

There is also a state that is going to be constrained for the foreseeable future. So I think there’s particular recognition from the public sector that the public sector needs to join up more, but the third sector also needs to be independent. I mean if we look at people’s demographics – we’ve got an ageing population.

Interview with third sector alliance organisation professional (Int-K)

In the above quotation, stressing the retained independence for the third sector is presented as an asset to preserve the services it provides in the long run, in order to address future health challenges. A different interviewee, in the quotation below, also highlights the way that the third sector is brought in to fill gaps both for everyday needs and in times of crisis. This too validates the need for third sector organisations being brought in as partners, while also demonstrating they can carve out their own independent professional territory:

...and then when you’ve got a change in welfare reforms, or something like that, it’s the third sector that pick all of that up. So you know people who have got huge concerns about access to benefits, or assessment processes for benefits, they really are being supported by the third sector. So there’s huge value there as well... I think that there is just the perception that the third sector is very professional and very vital in filling those gaps. So they are becoming true partners at the table, I think.

Interview with third sector alliance organisation professional (Int-E)

A potential for the third sector to be in complex and potentially even competing roles is revealed throughout the discussion of this section. Boundary work is drawn upon by organisations themselves to cast third sector services as similar to the state in professional quality, but with particularly strong values around person-centred and holistic care. However, they are sometimes, as in the above quotations, portrayed as being an ‘opposition’ to the state, or else acting as a respected substitute, in times of austerity programmes, welfare cuts and so on.

A question emerges from this discussion about whether, in times of austerity, the third sector and its constitutive staff and volunteers ends up in a subordinate role to the state or instead becomes a more valuable and powerful resource in response to increased need. As the findings in Chapters Seven and the discussion in Eight of this thesis will explore further, the valuing of the expertise of organisations in my own research case tended to result in the latter, more positive, scenario. However, funding for services needs to reflect this valuing of expertise in order to prevent a decreased remit for third sector services.

## **The necessity of collaboration**

In terms of collaboration as a means to other benefits, there was much discussion, particularly from the third sector representatives, of the strict criteria needed to work out whether collaboration was ‘worth’ the considerable time investment it often required. The fact that duplicate or unnecessary initiatives were talked about as wastes of organisational time highlighted the fact that collaboration was not always seen as an unlimited ‘good thing.’ For example, a collaboration might be regarded as not worthwhile if the effort that was required to sustain it was disproportionately greater than the benefits that it might bring to the organisation or client group.

It’s principally about two organisations or more deciding that there is a goal or goals that they want to achieve, and that that can be achieved more effectively by combining the resources of all the different partners.

Interview with third sector HD professional (Int-H)



In some cases collaboration was necessarily strategic in nature as individuals identified a need they could not address alone. For example, partnerships between multiple small health-related charities in Scotland - including the SHA - and the pre-existing charity telephone support service Breathing Space overcomes the need for individual charities to develop their own costly equivalent services (notes from Interview with third sector HD professional). Instead, individual third sector health organisations could bring their own expertise about a particular client group to provide training to a developed and professional telephone helpline service. This had the secondary benefit of at the same time raising awareness for both organisations about one other, as well as leading to wider contacts.

Many of the participants involved in HD care and support – individuals from the SHA, clinicians, allied health professionals such as physiotherapists, and so on - also discussed collaboration across geographical boundaries for maximum influence. While collaboration was often seen as a means to achieving an end as in the example of a dedicated telephone support service just given, it also was depicted as being potentially a ‘good’ in itself. The mutual support and personal relationships that arose from collaboration could be regarded as both a means to further outcomes, and also a good in itself:

When I talk to my colleagues in the other [partner organisations] I’ve got a really good reference point, and I can see that they’re struggling with the same sorts of issues that we are struggling with, and that really helps. Equally, you can both give and receive advice from each other about how to deal with some of these things.

Interview with third sector HD professional (Int-H)

As the quotation above indicates, for alliances between third sector organisations with a very similar client group, such as in the case of the UK and Ireland HD alliance, benefit could be obtained from the raised awareness of HD across the nations, as well as mutual support obtained from liaising with organisations that were in the ‘same boat’ concerning the challenges of being a rare disease organisation.

### ***Working around complexity in HD***

The complexity presented by the multiple needs and medical symptoms of HD and therefore the complexity of support and care required was frequently discussed by interviewees directly involved with this condition, particularly those involved in the area of clinical care. As described in the chapter discussing the medical, social and psychological aspects of HD (Chapter Two), the condition can encompass movement disorders, neurological difficulties and psychological difficulties, and patients often face stigma and social problems in addition to these other issues. The multi-faceted nature of the condition was perceived by many participants of the research to necessitate certain forms of collaboration in the sense that the sheer number of professionals involved required at least a basic degree of communication with, and referral on, from other professionals:

In comparison to someone with another illness, you can be looking at a big team to support someone with Huntington's. You want a massive team of people regularly in to make a big difference to their quality of life.

Interview with third sector HD professional (Int-G)

Referrals to other services as an expected practice often meant ceding organisational or departmental 'ownership' over the patient's care. This meant the overcoming and prevention of organisational silos in the way described previously in this chapter.

Even if the overall condition was complex, a few of the interviewees commented that there were sometimes deceptively simple answers to the problems affecting patients with conditions such as HD. A common experience cited for HD patients was the societal stigma that could be connected to the direct disease symptoms, and the social and financial exclusion that could be faced by patients and carers. The complexity in solving this, again, often came from the need for multiple agencies to seamlessly work together to mitigate these social pressures:

We work with a group of people who have immense needs, and it's unrealistic to think that you can achieve all the things that you need to be achieved on your own.... Partnership working can be an extremely effective route to achieve those aims.

Interview with third sector HD professional (Int-H)

It has been discussed in the chapter thus far that there are many examples of boundary work present within the HD service and wider health services in Scotland. Below, I will discuss some of the ways in which the crossing of boundaries was facilitated, using notions from previous boundary literature about boundary spanning individuals and boundary objects.

## **Facilitators of boundary crossing**

### **The creation of, and contribution of, boundary spanning individuals**

Discussion of how boundary spanning individuals operate ties in closely with many of the findings about individual professional identity discussed in the subsequent chapter. My interviews and observations revealed a key role for certain individuals in driving forward health and social care initiatives, something which was often closely intertwined with their personal background, beliefs and motivation. It was not difficult to identify individuals who have been termed 'anchor points' between organisations, and who link and lead others (Lindsay and Dutton 2012:514).

Participants named specific people, including themselves, who consciously tried to bridge communication gaps that they saw between organisations and sectors:

I don't actually work in these teams, I liaise with them. I feel that you need to work at that... For example, when I first started in this job I made a point of going and meeting with the teams. And I do now still try to kind of make sure that the teams know where we are. So I think there's a bit of work on our part to make sure that people know where we are and that we kind of regularly remind the teams of what we're about.

Interview with third sector HD professional (Int-N)

When it came to the enablement of *non*-third sector professionals to span boundaries and work with the third sector, it was highlighted that suitable time and resources needed to be invested. Professionals firstly needed to be given education on the need to engage with the third sector, and then also given the time away from other immediate statutory responsibilities to participate in cooperative activities with the third sector, and patients:

What works best as well is a recognition that people actually invest and resource their time to get it right... That often doesn't happen either, because people will rush in and rush out and don't spend the time to get it right, and I think that would save vast amounts of resources if we actually get that bit.

Interview with NHS non-clinical professional (Int-J)

The concept of boundary spanning was important to the findings of my research on a number of levels. Above it is depicted as a useful organisational resource. The work of boundary spanning individuals will also be developed further in the next chapter when looking at the *identities* that also emerged within these partnership processes. Below, I will now explore how findings from the data might connect to another theoretical concept concerning boundaries and the overcoming of boundaries – the role of boundary objects.

### **Boundary objects within the HD collaboration context**

This chapter has thus far has highlighted some of the problems that could occur for collaborative action when boundaries are present. The role of boundary objects in overcoming such situations has been frequently discussed in the literature. As outlined previously, the original authors of the concept, Star and Griesemer (1989), describe such objects as those that can form a bridging role and allow collaboration between diverse groups when consensus is absent. This is something of relevance to the current research, where at any one point any combination of relevant professional stakeholders (third sector staff, clinical professionals, health managers, social

workers, local and national government staff, policymakers etc.) might agree on a number of factors. Points of disagreement might include such things as which organisations and sectors should be involved in an initiative, different medical and social approaches to patient care, what aspects of a condition should be prioritised, and many others.

In my own research, the objects that appeared to function most as boundary objects were health policy documents. Throughout interviews and other meetings with third sector representatives, collaboration and the factors that enabled it was a frequently discussed topic of conversation. When asked about helpful tools when it came to collaboration around services between third sector organisations and other organisations, particular informal Scottish Government policy documents were frequently highlighted as useful. This was something that was echoed by professionals working in the NHS when it came to their own reflections on how they managed to work alongside organisations with different experience bases and remits. Several participants of the research also highlighted how useful certain government documents were in acknowledging the importance of the third sector, and laying the foundations for collaborative activity (notes from interview with third sector alliance organisation professional Int-K).

As Chapter Two explored, terms such as partnership, joint working, and engagement have been a prominent feature of the government documentation about health and welfare-related services in post-devolution Scotland (Tannahill 2005). It is within this context that the third sector and public organisation participants that were part of my research measured their own professional roles.

Of the possible Scottish Government documents, the two that were most commonly mentioned by research participants were the 1) Report on the Future Delivery of Public Services more widely known as the Christie Commission (Christie 2011), and 2) NHS Quality Strategy (Scottish Government 2010).

While not elaborated upon further here, discussions revealed that other more condition-specific documents might also be regarded to allow a different type of boundary work. For example, the Clinical Standards for Neurological Services (Scotland 2009) and the UK Strategy for Rare Diseases (UK Department of Health 2013) both have a function in ensuring that certain conditions receive recognition in the wider health field, and that there is a degree of uniformity in services across regions.

### ***The Christie Commission report as a boundary object***

The *Commission on the Future Delivery of Public Services* (Christie 2011) is widely known as the ‘Christie Commission’ after the author. As outlined in Chapter Three, The Christie Commission report is an independently commissioned piece of work that set out a vision for joint working between the public sector and the third sector in Scotland around public services. It was particularly commended by my own research participants for the way it underscored the importance of including the third sector as partners within public service planning and delivery. As a result, it continued to stand out as one of the main Scottish policy documents that spotlighted the third sector’s role in partnership and service delivery. It was often put forward by third sector representatives as an example of a document that gives credence and strength to their partnership activities, as one interviewee highlighted:

Of course... everyone still talks about Christie. If Christie was to be implemented in full with its focus on much more joint partnerships across sectors and a much more preventative approach, and they observe the intervention - person centred - then I think the third sector would say that all the boxes have been ticked. I don’t think I’d call the Christie report recommendations a framework, but certainly those different elements, in terms of what it was asking for, I don’t think I’ve heard anybody in the third sector - or actually now you say it, in the public sector - criticise it for how to get from here to there.

Interview with third sector alliance organisation professional (Int-K)

The Christie Report can be regarded to have achieved a great deal of boundary work for third sector organisations, by positioning them in the realm of professional actors. For third sector organisations and public sector organisations alike, documents such as the Christie Report and the Quality Strategy outlined below also served as a reminder of a promise to be fulfilled, even if the individual work to achieve this goal was different. In this way they partially functioned as a boundary object, but also partly as a strategy for creating shared values and shared understanding of remits, that later enabled boundary spanning by individuals also.

### ***The Quality Strategy as a boundary object***

The NHS Quality Strategy is a Scottish Government-produced document that is part of a wider '2020 vision' reform agenda for public services across Scotland. It aims to establish a core set of priorities and values for the NHS in Scotland.

The Quality Strategy was frequently mentioned for being a document that provided a focused framework for action across sectors, medical specialities, and other dividing roles.

We are very aware of lots of the other policy documents, but you could get so bogged down and confused by them all. Because these people - the people that we work with - have mental health and capacity issues, they have cognitive challenges, they could have learning disabilities. Some are children, some are adults. So they cover the whole gambit...Actually you could drown in policy, so the Healthcare Quality Strategy is our focus really.

Interview with NHS clinical professional (Int-C)

Reflected in the quotation above is the sheer volume of policy and guidance documents present that any professional working in the NHS or voluntary sector might find relevant to their work. More abstract, generalised and concise documents such as the Quality Strategy and the Christie Commission's Report can therefore serve as a useful base for activity. They work as boundary objects by depicting certain organisational barriers as traversable. Even more so, they give support to the

idea that traversing barriers can be for the common good, which in this case, entails better patient care. Such documents also establish a common language between groups, in which notions used throughout this thesis such as collaboration and partnership become commonplace:

Because the NHS Quality Strategy was launched, and I read it, and we completely align with what it said.

Interview with NHS non-clinical professional (Int-J)

Shared standards of governance and shared goals were frequently referred to throughout data collection as being communication bridges across boundaries, and documents often seen as one formal way to set out these.

### ***The limits of documents as boundary objects***

In discussing documents as boundary objects it should be noted that there was a limit to how much they alone could achieve. Alongside a widespread appreciation for many of the sentiments of document such as the Christie Commission it was debated to what extent such terminology in documents sometimes functioned as anything more than rhetoric. It was agreed across participants in third sector organisations, third sector intermediaries and public sector organisations alike that policy documents and strategic frameworks were not enough on their own to activate collaboration. They needed to be backed up by the commitment that comes with resources, training, and an embedded organisational culture that appreciated the value of the documents and actioned their messages:

If all that happens is that you produce documents and nothing changes then you can feel kind of pleasantly smug [about having produced a document]... But then if nothing changes, so what? So it's not just about producing the policy documents and policy frameworks and what have you. It's about working with people who will be charged with the implementation of those commitments on the ground.

Interview with third sector alliance organisation professional (Int-M)



Another aspect relevant to major health documents was that there was also a considerable blurring when it came to the role of patients within organisations and how they factored into ‘partnership’ ideas. Much of the previously mentioned literature discussed partnership between the third sector and other agencies as a route for incorporating patient experience, an issue that I will readdress in the next two chapters (Six and Seven) when looking at the development and use of expertise. However, direct engagement with patients and carers was not always easy. The interviewee in the quotation below describes an official forum set up in an area of healthcare outside of HD for patients to have input into the design and delivery of a care service related to their condition:

Obviously nobody knows what it’s like to receive a service better than the person receiving the service, and I think that traditionally it’s been very paternalistic. You go along as a patient and you do what you’re told to do... That has really shifted now to patients being much more involved in their care... and self- management and that kind of thing to try and cope with their conditions. We’ve heard stories of people who were diagnosed with a brain tumour and then sent off without any information, or without being signposted to any other organisations, and there’s a real need to change that... It is changing, but the best way to change that is to have people involved who can say: ‘well, actually, this would have made my journey a hell of a lot easier. This is what would’ve really helped me’. So I think it is really important to have patients involved in that.

Interview with third sector alliance organisation professional (Int-E)

Several interviewees argued that there must be a will on the part of organisations to effectively capture and include such patient experience, something, again seen to be connected to the underlying belief and culture of the organisations involved.

## **Organisational collaboration and the creation of professional communities**

As will be discussed in the next chapter, it was seen in the current research that clinicians, third sector staff and patients can draw upon professional identities and

practices based on their connection to certain disease communities. In this way a health condition might be seen to help create and build communities other than in the direct way of creating patients with a ‘HD identity.’ Such a community for HD, or any other condition, might emerge around the professionals who collaborate around the condition. One clinical professional talked of the small and closely knit context that helped to bind the (clinical) professionals together:

Things work well if people have good working relationships, and in small numbers you can do that. You can forge relationships in that. In fact, for the most of Britain I know the HD clinicians... because it is a very small world, HD research... We have an annual meeting [for] sharing ideas.

Interview with NHS clinical professional (Int-D)

Yet this community was not limited to clinicians alone and came to encompass all those working around HD. Indeed, my data findings point to the possible existence of ‘professional communities’, comprised of multiple individuals working together around the same or similar conditions. These professional communities were found to expand, contract and change in their memberships and identities according to how various professionals were positioned within health services, and the wider health sector.

A sense of professional community was seen as inherently bound in to the factors discussed throughout this chapter – a sense of understanding and acceptance of the purpose of organisations of different norms from one’s own, the overcoming of structural barriers to collaboration, the presence of key facilitating individuals and frameworks. Altogether this led to the development of a sense of mutual respect, as one interviewee commented:

...[the service is about] supporting people to walk in other people’s shoes. It is supporting people to get under the skin of the organisation that they are trying to work with and to understand what are the challenges as well as the opportunities. So I think tied up with that is mutual respect.

Interview with third sector alliance organisation professional (Int-K)

The structuring of partnership around HD in Scotland between the health service and third sector has been adopted as a model of excellence by other nations and in European guidelines. This might well bolster the identity attached to these temporary professional HD communities as their activity becomes taken as a source of pride. In this way, the creation of professional communities become less a form of boundary crossing, as a form of boundary redrawing to deliberately create new formations of care and support.

## **Conclusion: Working with boundary work**

Using data collected from participants working in the context of HD and other related third sector organisations in the Scottish health scene, this chapter has sought to illustrate that boundaries between third sector organisations and other organisations are blurred and unfixed.

### **Boundary work in the positioning of the third sector**

It is widely acknowledged by professionals within the health scene that the third sector is internally diverse along the lines of size, resources, capacity, skills and goals. While research has revealed a growing strength in professional identity for vocations such as social work or nursing, the claim to a unified body of expertise or common mode of working is not possible across the whole third sector. Boundaries are instead drawn differently based on judgements of individual organisations in addition to wider underlying idea of what constitutes ‘third sector’ culture. One of the key differences between the third sector and public sector highlighted within the literature and everyday professional understandings is the lower amount of regulation of the third sector overall. This is notwithstanding the fact that some individual organisations have a high degree of internal training and regulation.

An organisation wishing to be regarded as a professional institution must contend with prior conceptions such as the third sector remit being solely of ‘tea and

sympathy.’ Yet there is also often currency in maintaining a degree of separate identity for these organisations that stresses a different set of unique third sector values. Pre-existing ideas of the third sector were used in a both a positive and negative light to explain relationships across different organisations and sectors. It was also the case that involvement of the third sector also led the other professionals present within partnerships to consider their own practice. Gieryn’s (1983) discussion of boundary work, as explored in the literature chapter (Chapter Three), described organisations operating as ‘foils’ – i.e. comparison points - for one another. It can therefore be argued that if the ‘foil’ that is a third sector organisation takes on a new and professionalised role, then that correspondingly has consequences for perceptions of the existing services.

Work around boundaries was evident in multiple different forms in the data. Drawing on widely perceived notions of the third sector as holistic in their working practice, third sector organisations demarcated their own boundaries. It was suggested by the third sector and others that they could provide a route to connect to a client group, or to have the ability to plug ‘gaps’ in public sector provision and thus act as enablers of collaborative working. Yet, I have also explored in this chapter how the data reports the threat to collaboration if other boundaries emerged that in the form of silos in which the different organisations could not or would not interact with each other. Organisational remits must be flexible enough, therefore, to allow interaction between these other groupings and with other types of knowledge and cultural practices. My data identifies that the understanding held by other organisations is something that therefore both enables partnership and is strengthened when partnership is in place. Individuals and objects that allow the bridging of worlds become vital within a partnership-oriented context such as the Scottish health scene.

The choice of the medical condition of HD as the focus for my research is likely to highlight some features that differ from those of other illnesses. I also acknowledge throughout this thesis that the specific features of HD are likely to shape the corresponding organisational culture, behaviour and opportunities. One theme to

emerge from discussion surrounding collaboration around HD was that partnership was fostered when conditions were ‘complex’ in the sense that they required interaction and input from a wide variety of different professionals. The very factors described here – that the third sector is diffuse, varied and possesses a range of expertise – have the effect that boundary-work is something constantly engaged in by and for individuals working in and with this sector. In order to present the desired image out of many possibilities and some persistent pre-conceptions, organisations must seek to shape their own role in the wider health landscape.

### **Boundary crossing**

One of the facilitators of the crossing of boundaries discussed in the literature and visible in the current research is the figure of a boundary spanning individual. As the next chapter will discuss further, these key individuals take on a role of ‘translation’ across different social norms and structures. The concept of a boundary object also has relevance and use in the current context. Particularly apparent boundary objects identified in the current research were government documents that provided a common framework around which diverse groups could orient shared goals and different types of activity.

In the next chapter, I will turn to another, related aspect of the shaping of organisations under collaborative service arrangements. There, I will examine the way in which the identity of individuals working as professionals within collaborative services becomes developed, and in turn is a perpetuating factor of multi-sector partnership.

# CHAPTER SIX: THE SHAPING OF PROFESSIONAL IDENTITY WITHIN THE LANDSCAPE OF PARTNERSHIP

## Introduction

In the initial aims of this research, I set out to examine the role of third sector organisations, and of partnerships between these organisations and other professional groups, with respect to Scottish services for Huntington's disease (HD). My work did not set out explicitly to examine the identity processes of the professional actors involved in various aspects of healthcare services. The point of departure was instead established bodies of work that looked at the organisational dynamics of partnership and third sector activity. Through this, I considered the consequences of partnerships in services for patients and families living with complicated conditions such as HD. However, when formally and informally talking to individuals in a number of roles as part of this research, it rapidly became apparent that the formation of collaborative identities for third sector and public sector professionals was central to partnership working. In this chapter, I will examine the impact that partnership arrangements are having on the working practices, and the ensuing professional identity, of professionals working in and with the third sector. In particular, this chapter will argue that amidst dedicated, personally-invested activity around complex conditions such as HD, a plurality of identities emerge for the professionals involved. Overlapping identities as a 'good professional', as a 'key, committed professional' and as a purveyor of 'aggregate know-how' are all identifiable and are connected to new, hybrid professional job roles.

## Professional identities in the health landscape

The professionals who participated in my research held several types of job role across different sectors. These professionals included, but were not solely limited to: individuals working in third sector organisations under a variety of management, service delivery and administrative roles; clinical and non-clinical staff in the NHS (including allied health professions as well as hospital and community staff); local authority-employed social care staff; policy makers including councillors, MSPs and MPs; and civil servants. Table 2 in this thesis (page 144) outlines the specific professions and sectors of individuals who formally contributed data to this research. While the majority of professionals that I have quoted as interviewees are paid staff, there were a few individuals who were encountered in the observational data collection – particularly in the third sector – who were giving their time on an unpaid basis as volunteers or board members. Likewise, several of the paid professionals in the third sector had at one point been involved with a service as a user/family member.

As both the context chapter (Chapter Two) and the former substantive chapter (Chapter Five) have explored, there has also been increasing involvement and professionalisation of third sector organisational activity within Scotland and across the UK, especially over the last twenty years. Post-devolution policy and legislation in Scotland surrounding public services has contained the rhetoric of a strengthened third sector (Christie 2011, Scottish Executive 2004). This has been accompanied by a lengthy policy discourse around placing patients and communities more squarely at the centre of public services (Scottish Executive 2003). It has meant that there is a greater involvement of third sector organisation individuals in new professional roles that are accompanied by their own systems of regulation and audit. The professionalisation of third sector roles is depicted within the literature as having implications for the self-perception of employees, as they tussle with the new obligations and opportunities of their work (Carey et al. 2009, Roth 2015).

This chapter examines key findings from my own data about the formation of individual professional identities within collaborative structures for HD. I will explore how the perception of job roles interacts with the biography of individual employees – both with regard to their personal biography and their professional biography. Expectations about what constitute ‘professional’ status, attitudes and knowledge is also examined, as is the role of expertise within these various identity constructions. Finally, I identify the figure of the ‘key, committed professional’ as a central identity to emerge within the area of multi-organisation and multi-sector partnership, and one which connects to the notions of boundary redrawing and professional community that are proposed throughout this thesis.

## **The intersection of biography and professional identity**

As explored in various points throughout the literature review (Chapter Three), experiences from the daily life of individuals have often been researched in order to understand how people living with health conditions manage their illness and the ensuing consequences for patient and carer identities (Bury 1982, Hubbard et al. 2010, Locock et al. 2009, Locock and Brown 2010, Mazanderani et al. 2012, Williams 2000). When discussing the issue of partnership around HD with participants of the current research, it was their personal and professional biographies that often came to the fore. Experiences drawn from the personal lives as well as the professional lives of staff employed by the NHS or third sector were used as explanatory frameworks by these participants in describing their career trajectory. While the sections below discuss each of these categories in turn, the overlap between these two categories was also apparent.



## Personal biographies

For several of the professional individuals who I encountered in my research, direct personal experience of HD or another medical condition was what had led them to their current work role. This was true for individuals who held professional positions within the third sector as well as those who undertook more grassroots third sector activity (notes from interviews A-N). For those individuals who were directly involved in a caring role, personal experience was a motivator to get involved in a more formal capacity. This motivating force could sometimes be a somewhat negative one, in that the drive to get involved connected to a wish to prevent others from experiencing the barriers to support, or personal trauma that they themselves had experienced as someone with HD in their family (notes from interview with third sector HD professional).

Even beyond the HD context, other professional individuals with personal backgrounds as patients or carers, even if the medical context was something other than HD, talked about this as background as allowing them to bring greater understanding or empathy to the role as a result of these experiences. This perception helped to cement relationships between professionals and people living with HD. The quotation below, in which a family member of someone with HD talks about a contact of theirs involved in the area of policymaking, illustrates this:

Their relative has got a learning disability. So they met my relative and there were a lot of traits that they could relate to... So when I'm talking away there, they totally understand. Their background is in social work.

Interview with individual with personal connection to HD context (Int-A)

A person's background in caring and empathetic roles functions is discussed here as evidence of person-centred practice within both past and current work roles.

Professionals were also attributed with having gained skills in empathy due to prior

experiences in their own personal lives. This also seemed to be relevant to the ideas of what made a ‘good professional’, as discussed later in this chapter.

Another emergent theme concerning the identity of those that became involved with third sector more widely was the achievements that could be attained by people from a completely untrained, non-medically related professional background. My research did not aim to focus on patient and family activism. However, the overlap between the activities of paid staff in services and the involvement of families connected to the condition meant that it was a topic that arose within interviews and other discussions. The challenge of running an event as someone from a background where they had received no professional training was a prominent topic in the interview with the individual personally connected to HD. In the following quotation, they discuss some feedback they received about their involvement in organising a local event:

‘Look what that person pulled off. That event was pretty amazing. [Look] what they have done, considering that none of this is their background, you know what I mean?’

Interview with individual with personal connection to HD context (Int-A)

An emphasis on the success of these events - despite the fact that none of the people involved in these events had formal charity training - was used by participants of the research to highlight further the effort and commitment of non-professionalised individuals. The interviewee quoted above frequently expressed surprise that they, as somebody without formal training or education, could achieve all that they had for awareness and fundraising through holding community events.

The unexpected personal benefits of involvement with HD support of any type beyond the actual goals of the paid or volunteer position was also emphasised by many of the participants. This was particularly true for individuals who could be regarded to occupy the space between ‘family member’ and ‘professional’, in that

they were individuals taking on grassroots awareness raising and fundraising around HD at a community level, and were not formally employed to do this. For many of these individuals connected to the condition by personal experience and using their own personal time to engage in this activity, one unexpected benefit was a sense of support and wellbeing that came from attempting to change the situation that had blighted their own lives. This is described in the following quotation:

It just astounds me that it is kind of happening. That something so negative can be so positive.

Interview with individual with personal connection to HD context (Int-A)

There were also a number of practical benefits that emerged for those involved in running community events. The unpaid work that they had engaged in due to the personal connection to the condition had bestowed on them the status of a fundraiser that might have otherwise been developed only by working directly in the third sector. In turn, part of the goal of local events was to involve other people connected to the condition. This was especially the case when it came to local awareness events involving young people connected to the condition. Benefits cited included gaining skills and experience, and in some cases direct rewards such as volunteering awards, or even just the chance to travel:

We're involving teenagers - young adults - from HD families, and if we're going to different places in Scotland we're giving them the urge to travel when they're older. Okay it's just a short ride up the motorway or wherever, but you're still helping them shape their own futures as well.

Interview with individual with personal connection to HD context (Int-A)

For individuals connected to the condition doing unpaid fundraising and awareness work, their personal biographies became aligned to a professional status, while at the same time retaining their lived connection to the condition. This was a different route from other participants in the research for whom their journey to working with HD or

similar conditions had been part of a professional journey, as will now be discussed below.

## **Professional biographies**

It was evident within the data collected for this research that previous job roles of professionals involved in services were also used in addition to personal experiences to explain why particular people and approaches were suited for working in the field of HD/ in a collaborative or ‘person-centred’ way. Professionals often mentioned particular career backgrounds as evidence of their suitability for current caring or support roles. Examples that were given of suitable experience by participants of my research involved a social work or nursing background, or work with other vulnerable groups such as people with mental health problems or victims of domestic violence (notes from interviews A-N). Professional identity was therefore depicted to emerge from a complex mix of different types of experience and expertise, some of which had direct relevance to HD, while others were related to more general social issues. Particular empathetic disciplinary outlooks, such as a palliative care approach, or the ‘Care Programme Approach’ in psychiatry, were also mentioned in terms of background, equipping clinical and non-clinical individuals with suitable knowledge, understanding and ideals.

It’s a very complex condition. It covers a broad range in terms of the types of difficulties and symptoms that people can have and I think you can draw on your experience... from a combination of the physical way that it can affect people but also on the emotional and psychological impact of the disease... Certainly from my [professional] background I think that’s really helped with being able to look at all that with people.

Interview with third sector HD professional (Int-N)

Within discussions with family members in particular, the involvement of service managers in caring jobs currently or in the past was seen to demonstrate an understanding and ‘down-to-earth’ quality that made the distinction between the

professional and those they were supporting increasingly blurred. There was also considerable self-reflection on the part of many of the interviewees about how their career choices had shaped their skills and had been shaped in return. The need to constantly refine and develop skills was also perceived as important:

I get in to a job and I see deficits in my skill set and I think ‘gosh, I really need to...’  
So I love studying but it’s always really relevant to what I am doing.

Interview with NHS non-clinical professional (Int-J)

Discussions of background also provided insight into the paths by which some professionals ended up undertaking specialist roles. It highlighted the importance of encounters with key individuals who themselves were ‘champions’ for a particular condition such as HD in sparking initial individual interest in the condition, as in the following example:

As part of my training I got to do special interest sessions. So I was inspired by a previous talk - that was the year before I think - by a well-known person within the HD world. And they’d come up to do an education session... That kind of sparked my interest... I was thinking what would I like to do for special interest? And I had done some special interest things, but I thought; I will maybe find out a bit more about Huntington’s...

Interview with NHS clinical professional (Int-D)

For many of the third sector and public sector professionals who were interviewed or who participated in informal meetings as part of my research, their work in the area of HD or other health conditions had led them to gain the status of being a key individual in that area. This had the potential to generate benefits with regard to both job satisfaction and job advancement opportunities. Being asked to become the clinical lead for a particular condition area, to chair key committees, and to attend important conferences were just some of the outcomes related to the status of participants involved in the research (notes from interviews A-N).

Another third sector professional participant talked of the ‘personal pride’ in producing guidance that was to be used as a model of best practice (Interview with third sector HD professional Int-H). Other interviewees directly or indirectly conveyed their status as a ‘go-to’ person. The following quotation conveys this as a participant mentions their role in giving advice to fellow professionals in the same clinical area within their own region of Scotland:

If you said my name people would say ‘they do HD’. So it’s quite good in terms of raised awareness... I regularly get phone calls from other clinicians saying, ‘somebody’s come up with HD... can I get some advice’.

Interview with NHS clinical professional (Int-C)

Across the research data, it was also highlighted as crucially important that there existed individuals prepared to act as ‘champions’ for a rarer and less well-known condition like HD:

Because, you know, everybody’s heard of a condition like MND [motor neurone disease]... Huntington’s is not a condition that a lot of people have heard of. We try our best to educate people, to raise awareness.

Interview with third sector HD professional (Int-G)

Advocating on behalf of HD was seen as important in order to enhance the wellbeing of individuals connected to this condition through enacting wider policy change, delivering appropriate treatment and continuing to spread awareness throughout services, professional communities and the public. The importance of awareness as an organisational resource is returned to in the subsequent chapter on the shaping of conditions.

## **HD as a ‘hook’**

Another aspect of working around HD in particular was mentioned frequently by the participants of the research. Many directly connected to HD highlighted the way in which the condition tended to have a particular emotional pull on professionals. The

metaphor of a ‘hook’ was used by one professional to describe the way that professionals became dedicated to giving up their time for HD:

And it’s when you go in and do the training with them [professionals] and people are genuinely shocked and horrified... people will sometimes come out after training and say: ‘I had no idea. I remember seeing someone years ago, but I had no idea it had that effect on their life, that it could have that effect on their life’... It sort of *hooks* people. Huntington’s does hook people. If caring for people it hooks you because you think ‘these people are struggling with the most awful condition’... and people want to do their best.

Interview with third sector HD professional (Int-G) (emphasis added)

This adds another dimension to the way in which the reasons for an individual’s personal and professional motivation for their work was formed. It was reflected throughout the data collected that there was something particularly emotive about seeing a condition, like HD, which had many complicated elements, was less well known, and that had a considerable effect on those whose lives it touched. These factors together solidified a commitment by professionals to help patients and families to the best of their ability:

Everyone who works with HD; when they are committed they are really committed. It’s down to meeting people with the condition and having understanding and a connection.

Interview with third sector HD professional (Int-L)

There were several occasions where interviewees reported on the positive impact on professionals of direct patient narratives, at training sessions or public events:

You can use the best English that you like but nothing hits home like hearing people’s stories.

Interview with third sector HD professional (Int-L)

*(Interviewee is talking about written feedback received from a HD training event)*

So we had a workshop for instance that was about understanding changes in behaviour that come with Huntington's disease...and we had a family member whose husband was in nursing care... You can very quickly get a sense that, for the people who attended that event, their contact with [the family member] was really powerful and they go away with having learned a great deal.

Interview with third sector HD professional (Int-H)

A further interviewee discussed somebody from a governmental agency attending a support meeting of HD patients that turned out to be 'particularly poignant' for her, and led to her lobbying to get additional services that were lacking for this particular group (Interview with third sector HD professional, Int-L). It might be said, then, that the 'hook' functioned to unite the skills that individuals might have gained from past experiences with an opportunity to have an impact in alleviating patient support needs. These needs include financial and social needs as well as disease symptoms. I will explore this in more depth in the next chapter.

The notion of HD as a condition 'hooking' the interest of individuals also applies to others outside the area of clinical services. I myself became acutely aware of having been 'hooked' on exploring the case of HD within my own research. The complex and often devastating nature of the condition presented a sociologically interesting puzzle but over and above this called for human compassion and an increased inner pressure to make life better for people affected by HD.

Another relevant factor to the formation of professional identities around a condition was the way in which the expectations, and in some cases limitations, of certain job roles framed the identity options available to professionals. As will be discussed below, this was also an area in which considerable blurring could be found in the areas where 'expert' knowledge started and other types of experiential knowledge began.



## The expectation of professional roles

For individual third sector actors, the negotiation of individual professional identities is part of a backdrop of the negotiating and strengthening of the sector's overall identity. This was also a context in which the other, public sector health and social care employees of collaborative health care settings had to renegotiate their own identity.

### Defining the role of a 'good professional'

Throughout all the interviews and meetings, discussion arose about what being 'professional' actually entailed and the qualities needed to do a job well. This was also a topic regularly brought up at public events such as third sector conferences and Scottish Parliamentary receptions about health issues other than HD (notes from fieldwork Obs-A). For example, talks in the form of patient and family testimonies about their own illness journey around a particular condition - a common occurrence in Parliamentary events - often centred on their experience with health services and the (helpful and unhelpful) professionals whom they had encountered.

A prominent theme to emerge particularly from the family member interview and fieldwork events that I attended was that those professionals perceived as being excellent went 'above and beyond' their role to help their patients/constituents/clients. One of the third sector individuals gave an example of the assistance one of their HD clients had received from a worker at a Citizen's Advice Bureau:

She actually went out in her own time - I think at 6 or 7 o'clock at night - to see the person. After she finished her work she drove thirty miles to go and see the client after her work because the client works 12 hour shifts in a shop. So she could tell them their employer rights and so on. So they could have rights run by them and get it sorted out.

Interview with third sector HD professional (Int-G)

Good professional service therefore involved going over and above the service that was expected of somebody in their position by committing extra time and effort to HD (or any other condition with such a degree of complexity). The following quotation is taken from a participant of the research with a family connection to HD, who was discussing a clinician with considerable dedication to the HD cause:

Their life was studying HD... supporting people's families, supporting people with HD... Their house, for a doctor of their standard, for how high they were up in their profession... [was a regular, small house]. From floor to ceiling windows - and we're talking like three to four feet high - every single window was just full of files.

Interview with individual with personal connection to HD context (Int-A)

As demonstrated in the quotation above, participant illustration of personally dedicated professional individuals often referred to the visual demonstration by these professionals of their level of commitment. In the above quotation a well-rated individual in a professional role appeared more down-to-earth and less status-focused than would be expected, and this was taken as partial evidence of their commitment to their work. Suitably-experienced backgrounds as well as the personal characteristics of an individual were also discussed when talking about what I term here to be *'key, committed professionals'*. As I use it here, this refers to individuals who were regarded not only as important experts in their role, but were also seen to exhibit a personal commitment and boundary crossing ability around the cause of HD or the other condition(s) around which they worked.

### **Bridging – or blurring –professional and patient experience**

The role of a personal connection between professionals involved in clinical and non-clinical support and the users of services was discussed by a range of participants. This situation involved the building of a service relationship whereby key individuals became a consistent source of support:

If it's the first time that the client's meeting with a speech and language therapist, or the first assessment of that type, it's quite nice if we are able to be there to introduce them to what that means. Sometimes it just makes it easier for the client if you're there – familiar - and it's a new member of staff being introduced to them. We don't always go together. For some people there would be no need for that. The speech and language therapist, or whatever profession, would just go out on their own. But our role is really from the point of view of having that experience of, Huntington's disease itself and being able to offer that more disease specific information. Because sometimes the other professionals maybe haven't had that same level of experience.

Interview with third sector HD professional (Int-N)

Being able to understand the complexities of a condition in depth, as discussed in the above quotation, was discussed by research participants as connected to the way that services got to know HD families personally over time. Professionals from both the third sector and public sector working in HD in one region of Scotland for a long time meant there was both continuity in knowledge of the condition, and of the HD families being supported:

I've had lots of patients who have subsequently died, or I've got lots of patients where I am now seeing their children. You do get to know the families very, very well, and it's on quite a personal level... I suppose it's almost like a GP in that the families come up with the patient, and just with the genetic aspect of it then the children get it. So it does become quite personal.

Interview with NHS clinical professional (Int-D)

The quotations above indicate a further blurring between ideas of patient experience and professional expertise. A more knowledgeable and skilled professional was identified in both participant discussion and in policy frameworks as one who was increasingly in tune with the everyday needs of people experiencing the condition and who listened to and understood the challenges being faced by patients:

A lot of 'professionals' feel as if they know and they don't need to be told any more, you know what I mean. But with the complex needs of somebody with HD, if you don't know, then you're not giving that person the support they need.

Interview with individual with personal connection to HD context (Int-A)

*(Interviewee below is discussing the characteristics of a good professional)*

They use a language that patients understand, they work with that patient on an equal playing field... They are empathetic and they 'get it'. They absolutely realise how challenging it is for that patient, so they get it. I think they're influencers as well. They have a really strong skill set to be able to manage to work in that way and to actually communicate with their team about why that's important.

Interview with NHS non-clinical professional (Int-J)

The concept that understanding and trust over time could add to one's expertise was not restricted to discussions with third sector professionals, appearing also in the discussion of one interviewee who is an NHS clinician:

But what I am getting is the grown up children of patients that I've seen... Often I have seen them as they accompanied their parent to clinic. And now they're presenting with illness themselves... That's quite good because you can build a professional relationship in terms of trust. Because you've cared for their parents - you might still be caring for their parents. And now they're presenting with the illness.

Interview with NHS clinical professional (Int-D)

It is revealed in the paragraphs above that negotiating a stance as a good professional was complex territory in which there were competing demands. For example, there was the expectation that individuals should possess a down-to-earth manner, but also have a willingness to go above and beyond their role, in order to provide a high quality, respected and sustainable service. These competing demands might be seen as particularly acute for third sector actors in less defined roles than their public sector counterparts, although this is also likely to allow a greater degree of flexibility in the definition of them by others.

It emerged throughout the data that the ability to bridge the divide between everyday experience of a disease and professional services did not, however, mean that professionals could take on the patient's role entirely. One interviewee highlighted this clearly in the following quotation, when discussing the issue of choice and an individual's connection to a condition:

First of all, as a professional you have to some extent made a choice: ‘I think I would like to be a doctor, a nurse, an academic, a whatever’ ... as opposed to being a merchant banker, or a binman, or some other form of way of filling in the otherwise idle hours. But patients, particularly those with life limiting diseases and those that have got familial implications and so on, are not there voluntarily. They are there because of a crap hand that has been dealt to them as a result of their biology or their exposure to external circumstances.

Interview with third sector alliance organisation professional (Int-M)

As indicated above, while the professional and patient role might be equated as similar in the way that individuals talked about establishing expertise, it was always the case that the taking on of a professional role involved an individual decision to do so. This is even the case in situations in which it was somebody’s own personal connection to the condition that led them to take on the role.

This element of ‘choice’ in a profession also means that roles and services are not automatically permanent. They depend on both the continued desire and ability of individual professionals to stay in post, plus the continued resourcing of these positions. One of the assets of third sector services for HD in Scotland in particular was that there was low turnover of staff:

I just see a lot of very dedicated staff. Turnover I don’t think is that high and from what I see people are still working extremely hard to do as much as they can for patients.

Interview with NHS non-clinical professional (Int-I)

The longevity of being in their particular role was also something that I encountered among the participants in my own research in both the third sector and NHS services, many of whom had worked in the area for over a decade.

Another theme that emerged in relation to consistency in professional services was that keeping people within their roles, as well as plugging unfilled gaps, also required adequate resourcing. While financial constraints are discussed in more depth in the previous chapter as an organisational challenge, there were other related resource issues directly experienced on the individual level. One such resource discussed below is that of the ‘time’ available to give to different tasks.

## Time as both resource and attribute

The theme of ‘time’ emerged in a number of different forms through the research. It appeared frequently when individuals were talking about what constitutes a ‘good professional’ as mentioned above. The most understanding and effective of professional staff were considered to be those that actually give their time to listen to particularly patient stories, as the following quotation addresses:

But I think what’s more important is that we all appreciate that people are individuals. Their condition is subjective to them, it’s their experience... Their knowledge or skill set, should they wish for that to be built, they should have that opportunity. But we have to work with the individual... I’ve talked a lot about the disease but it’s working with the individual and it’s trying to gauge what will maximise their outcomes.

Interview with NHS non-clinical professional (Int-J)

The experience of having adequate time ‘given’ to you as a patient or carer was also frequently mentioned in the family member interview as something that in itself appeared supportive, with the opposite situation considered highly upsetting. Time spent getting to know someone was also seen as an asset from a professional point of view by almost all of the professionals interviewed. Giving adequate time to listen was regarded as key to properly understanding the needs of individual patients/clients, as well as the more general impact of a condition like HD. In both these formulations, time is seen as a skill, something that can be shown and given by one professional to a client, as well as to fellow colleagues within organisations. However, professionals constantly highlighted the pressures that existed in allowing this time to be fully given to the patient, even when they were fully committed to doing so, due to overall workload (notes from interview with third sector HD professional Int-L).

Time was also not seen as something that all organisations were able to provide equally, with the third sector often being better placed to afford this time if their services were structured appropriately:

[As a specialist] with HD you can't just rush into a house for ten minutes and out. CPNs (Community Psychiatric Nurses) [have to] do that, fifteen minutes... Sometimes you have got to be in there for half an hour to an hour, sometimes it can be three hours. You just don't know how it's going to be when you do that visit.

Interview with third sector HD professional (Int-G)

The third sector interviewee speaking in the quotation above also provided an example of an individual patient who was only intermittently taking essential medication provided by their CPN. It was the ability to have a longer time with this patient as a visiting HD Specialist that allowed a sufficient personal and trusting relationship to develop for them to discuss their feelings about the medication in depth (Interview with third sector HD professional Int-G). A similar example was given to me when conducting fieldwork with participants in a group meeting in a different region. In this situation the HD Specialists were talking about the need to build up a relationship over time with many clients before they might feel comfortable talking about the wider issues they might be having, for example, to do with financial debt (notes, group meeting GM1).

The concept of time spent with someone by a professional connects to a theme that will be discussed more in the next chapter of this thesis with regard to the multiple ways in which a condition might be 'known' or accessed. Getting to know certain details of a person's life as depicted in the examples above took time, mainly due to the need to build adequate trust and rapport. Before this point, the full details of the condition or that person's particular experience might not emerge, meaning that only a partial understanding of the lived experience of the person with HD was known or subject to professional intervention:

A half hour chat here and there gave you one kind of level. But when you spent more time with people... overhearing them talk about being anxious about mum or dad being at home and just being part of those conversations. Not a 'fly on the wall', just seeing the real side of things.

Interview with NHS non-clinical professional (Int-I)

However, time-giving existed as a resource that could be curtailed externally by restrictive targets that did not see the importance of certain types of work. The question of how target cultures and cuts in healthcare resources have perhaps encouraged staff to 'go beyond' their duties is also relevant here. Administrative responsibilities were also frequently discussed as something that took extra time away from tasks that would have fallen within original job roles, such as face-to-face contact with clients. Participants employed by the third sector in particular highlighted the increasing level of administrative work they were required to do as services became increasingly subject to more routine recording and audit:

We've got our own database, and we've got our notes to do, and we've got our client assessments to do. And we've got the following assessments. You've got your outcomes and your risks and you've got to score each risk and each outcome for each client... It's putting down on paper justifying what you do. That sometimes takes longer than actually doing the job... If you had someone dead simple it could be half an hour... [But it could be] up to two hours, by the time you write it all in, depending on how many problems they've got and what the risks are.

Interview with third sector HD professional (Int-G)

Connecting back to the previous chapter, these administrative tasks were perceived as important by organisations and often the individuals themselves too, due to the way that they allowed a record to be kept of the impact of their service. Increasing paperwork demands were also seen as something that was a feature of modern professional working whatever sector or profession one worked in. For example, the administrative burdens of NHS-employed individuals such as district nurses or social workers were mentioned by several interviewees (notes from interviews A-N). However, for third sector staff in more managerial roles the daily paperwork was also combined with regular rounds of applying for funding at an organisational level, something that could be extremely time-consuming as a process (notes, group meeting GM1).



In these situations, time becomes a valuable and finite resource that has to be managed carefully in order to produce the type of service desired:

Maybe you have to look at having one or two days in the office and three days on the road. Instead of it just being one morning in the office... that's enough to do my admin.

Interview with third sector HD professional (Int-G)

This discussion above also highlights the vital importance of adequate resources for staffing in order to be able to strike a balance between direct support and reporting activities. In particular, the value of being able to employ administrative staff in order to divide the burden of this work was emphasised (Interview with third sector HD professional (Int-L)).

Over and above the resourcing elements, the ability to coordinate one's own work effectively was also seen as connected to personal skill. Within such discussions in my research the figure of a dedicated individual, here termed a 'key, committed professional', became evident, as will now be discussed in depth below.

## **The figure of the key, committed professional**

The relationship between the work completed by third sector representatives and the creation of new spaces for third sector leverage was frequently highlighted by participants of the research. Third sector influence was portrayed as connected to the recognition - by other third sector and public sector forces - of the work that these individuals and groups have completed. However, the ability to carry out such work on behalf of the third sector was also strengthened where there existed trust on behalf of statutory and fellow third sector bodies in the quality and suitability of such work, creating a positive relationship between past work and organisational reputation. Many of the interviews connected reputation closely to the characteristics and performance of key individuals who came to represent the partnerships within and between sectors.

Various characteristics of professional individuals have been explored throughout this chapter – their connection to and understanding of patients, their ability and willingness to give adequate time, and their personable manner. It was also highlighted in the data that it was often such ‘key’ individuals that had driven initiatives forward:

Early evolution [of third sector organisations] is to some extent contingent on key individuals...Having the right person in place at the point at which the organisation is hitting those, step-change opportunities. Who has both got the ability to persuade and the willingness to take the risk.

Interview with third sector alliance organisation professional (Int-M)

In theorising the idea of a key, committed professional, I suggest this overlaps with the aforementioned category of boundary spanner, but is not exactly coterminous. As the previous chapter discussed, boundary spanners were seen to be people who were able to translate expertise across different organisational cultures. By contrast, the main characteristic that I suggest is manifested by key, committed professionals is a motivated, personal dedication to a particular cause in the course of their work role. For many individuals, and particular those in third sector organisations in partnership roles, the enactment of this involved acting as a coordinator of services that would entirely fit with ‘boundary spanning’ criteria. For others such as clinicians, it involved establishing one’s own expertise in a particular niche, but ensuring that this coordination took place through connecting to fellow boundary spanning professionals. In either version, the key, committed professional is connected to a wider system of person centred, holistic care while also emphasising the value of specialist expertise around health and illness.

## **Conclusion: Partnership and the development of professional identities**

The growing institutionalisation and professionalisation of the third sector as a support provider is a topic that social science research has started to address (Bode

and Brandsen 2014, Carey et al. 2009, O'Donovan et al. 2013, Rabeharisoa 2003). It is also something that is frequently mentioned within government and third sector literature, both in Scotland and across the wider UK. As I discussed in the previous chapter, the work of the third sector has also informally been shaped by perceptions of the individuals within these organisations as trusted, professional providers of services and/or information.

I have argued within this chapter that individuals working in partnership roles within a complex condition area such as HD draw from many different aspects of their personal and professional lives in order to construct complex professional identities. Professional identities and past roles come to be regarded as connected to the personal experience and understanding of the staff themselves. This is especially true if they had, or continued to have, direct experience of living with or caring for someone with a condition, but also remained the case even if they have not.

In my research, successful partnership working and the crafting of positive and collaborative individual professional identities emerged as a mutually shaping process. Namely, certain professionalised organisational identities were seen to be a key part of partnership in the context being researched, and these also flourished within such a context. For third sector organisations this had relevance to not only partnerships formed within the same sector (i.e. with fellow single condition third sector organisations or alliance organisations), but also those between themselves and statutory organisations (including the NHS, and local authority functions such as social care). The ability to truly understand and listen to patients and families can be regarded as much of a mark of a 'good' professional as one of the classic markers of professionalism (knowledge, adherence to rules etc.). In this way, it is shown once more how the boundaries between the concepts of patient knowledge and experiences, and professionalised expertise are blurred. Indeed, the way such biographies were shaped complicated the notion of there being any type of professional expertise that was not experience-related in some form. Instead, a more meaningful conceptual distinction might be suggested that on one hand there are

those who have access to knowledge of a condition as a result of direct experience, and on the other hand those who have built up a body of knowledge from professional experience and training. These, however, are also not mutually exclusive categories, and one person themselves could have direct experience of both categories. My own research seeks to show that a positive professional identity can also be bound up with the goal of accessing or demonstrating experience based knowledge.

Within a condition area such as HD that demands input and cooperation from a wide range of services across health, a newer range of specialised roles and professional identities can be opened up to the individual, allowing them to become a distinct specialist or ‘champion’ within their own job area. The necessity of collaboration across disciplinary and sector-based boundaries also opens up spaces for individuals to develop identities based on collaboration itself, as the literature on ‘boundary spanners’ has long discussed. For individuals who are both recognised as expert and personally driven in some form, it is argued here that an additional identity of a ‘key, committed’ professional can become available as both a self-ascribed identity and as a label attributed to them by others. With key, committed professionals involved, awareness continues to be spread and the cycle of increased interest in a particular condition or cause continues. Awareness of a condition interplays with motivation on the part of individual workforce staff, and they come to form the resources behind effective collaboration, even when organisational divides must be traversed.

From the data, it appears that boundary spanning ability is largely thought of as an attribute strongly possessed by some people. These are often particular professionals or expert patients who have a suitable skill base combined with a personal conviction that gaps in communication or knowledge should be bridged. However, while this individualised skill element is important, highly successful boundary spanning requires that the professional roles have the mechanisms built in to avoid individual professional burnout. These include adequate time and resources to continue within their role, as well as the support and knowledge of others. The presence of these

boundary spanning individuals also helps offer to offer some conceptual clarity on the nature of the boundaries that exist in healthcare organisations. In my own case, the boundaries encountered seemed to mainly exist as symbolic boundaries around different professions linked to ideas around status and values, also seen as increasingly open to being undone and remade.

Overlapping new identities might be regarded to have implications for many aspects of health activity. While there is evidence of increasing specialisation towards new hybridised roles, the fact that flexible professional identities are now being derived from multiple professional cultures and are being formed amidst collaborative activity actually increases the potential for collaboration between different sectors (with the public and third sectors almost exclusively focused upon here). With such collaborative identities it might be argued there exists potential to overcome the challenges of cultural clashes and professional siloisation that are presented as key reasons for lack of cooperation across health overall, as was discussed in the previous chapter.

I have argued thus far that the shaping of organisations and individuals within these partnership formulations is a phenomenon, and is a process that feeds back into future ideas of service provision and organisational setup. Within this chapter, I have also aimed to demonstrate that the identity of professionals within organisations is an area worthy of examination, as it is yet another window on to how wider organisational processes around these individuals are changing, and of future prospects for these organisations. In turn, the framing of these organisations and the professionals that work within them is one important determinative of the way that patients experience the services available to them. In the next chapter, I will turn my attention to the way that changing collaborative structures are shaping underlying ideas of medical conditions such as HD, and of the support and care that can or should be available.

# CHAPTER SEVEN: THE SHAPING OF HEALTH CONDITIONS AMID PARTNERSHIP

## Introduction

This thesis has thus far focused on two aspects of collaboration in services for people with Huntington's disease in Scotland. It has examined the shifting in positions and blurring of roles of (a) the organisations, and (b) the individuals, involved in service provision around HD in comparison with other conditions. I have argued in these previous chapters that the third sector organisations and the individuals they employ operate as key actors within a multi-sector and multi-disciplinary network. Strong organisational and individual professional identities specialised around certain types of work and attitudes also become developed within these structures. This includes the particular role – referred to by myself as a 'key, committed professional' – which some individuals adopt. Such practitioners are widely viewed to have a unique body of expertise and can function as trusted coordinators across a range of services. These findings build on previous social science work that proposes a more proactive partnership role for third sector organisations (Allsop et al. 2004, Baggott et al. 2004b, Rabeharisoa 2003, Rabeharisoa et al. 2014b) and show that paying research attention to these organisations is particularly important in the multi-sector Scottish context. This is a distinct setting in which third sector partnership is set to continue to increase within a climate also characterised by growing integration of health structures, something of particular importance where rare and complex conditions such as HD are concerned.

The previous findings prompt a further question - what do these partnership configurations mean for understandings of the actual medical conditions at the heart of care and support initiatives? In this chapter, I will present findings about the meanings that are embodied within the support provided by public sector and third

sector partners, looking in particular at the case of Huntington's disease. HD is often depicted by those involved in care as necessarily spanning many medical professional remits. Building on these findings, I will argue that such a variety of input leads to HD being seen in entirely different ways, on different occasions, by different people. As this chapter will go on to show, this arises from the involvement of multiple types of expertise combined with the emergence of different types of need at different times. For example, while at certain stages the diagnosis and management of the genetic inheritance patterns of the condition are the key focus of clinical attention, on other occasions it might be an issue such as physical care needs, or financial circumstances, that are the most prominent concerns for patients and families. This chapter begins with a discussion of how multiple forms of HD might emerge within clinical services, and the role of the third sector within this. While I take HD as the case condition within this chapter, I conclude that the processes that are being discussed here could also apply to other conditions. This is especially true for conditions, like HD - multiple sclerosis or head injury - where multiple complex care needs are present.

This chapter explores how the idea of what HD 'is' becomes shaped both within the clinical encounter, and the support services beyond this. Drawing on the research data, I explore the ways in which third sector organisations carve out specific roles for themselves in areas such as combating stigma and influencing what falls within the confines of HD support. This chapter revisits several of the key concepts outlined in the literature chapter of this thesis. Most notably the themes of boundary and expertise are once again returned to. I use these concepts to explore how ideas about what constitutes appropriate HD support are being remade and expanded by individuals and groups bringing in different types of support. This shaping of the boundaries of HD by the third sector presence, both in and out of the clinic, is argued here to have an impact on how current and future HD families experience support for the condition. Furthermore, this contributes further to the overall argument of this thesis that within these partnership arrangements, individuals such as third sector

specialists are drawing on a knowledge base rooted in patient experience while shaping support structures.

## **Key concepts in understanding the shaping of conditions**

As the literature review highlights, Mol's work (2002) on the shaping of disease has been a key text on the construction of conditions. She puts forward the notion that different versions of the diseased body arise through different medical practices. The reasoning behind Mol's approach connects to her own goal of focusing on multiple forms of disease through observing 'practices' rather than perspectives. However, an important aspect of my own research was to pay attention to the *perspectives* of individuals working within an area as an insight into the roles of the different organisations involved in care and support. Following on from this, I argue here that the partnership that is the focus of my work relies on there being a single diagnostic entity present around which the different perspectives work.

Unlike Mol (2002), I therefore, in this research, begin from a position of there being a single unified condition, i.e. Huntington's disease, but I pay attention to the different *perspectives* on the condition and its treatment. I will illustrate how the presence of different perspectives – of 'multiple HDs' - in turn impact on the way that people experience life with the condition. The reasons for my departure from Mol and the argument that multiple bodies exist are twofold. Firstly, I adhere to a core ontological tenet of my research that underlying realities about the body and illness exist, but that these are importantly mediated by the perspectives and understandings of individuals. Furthermore, my own research supports an overall point that HD itself is not a contested underlying category for the participants of my research, in the sense that it was widely agreed to be a real condition with multiple and significant effects on a person's life. The differences in perspectives that arose



were to do with understanding around how to best support people with the condition and the roles of the different people involved in the HD journey.

Work that looks at different social perspectives and the way these enter medical experiences, such as that of Lerum et al. (2015), is useful in this regard as it focuses on the cultural differences between different ‘social worlds’ and how they interact. The divisions between individuals inhabiting distinct social worlds again brings the discussion back to the role of boundaries in organisational settings, and how these are negotiated when treating a condition. The suggestion that there are ‘multiple HDs’ in the form of different *perspectives* on care also returns to an underlying question of this thesis, namely, the role of the third sector within services.

When it comes to thinking about an extended role for third sector services the notion of ‘life costs’ put forward in book chapter by Mikami et al. (2014) is a useful one by which to understand a wider idea of the impact of a condition like HD. This work has explored standard quality of life indicators but has expanded upon these to show the way that daily living is impacted on by factors beyond the direct effects of illness. In my own research, I have focused on professionals and therefore do not claim to present the patient perspective on living with a condition such as HD. However, by taking into account issues such as life costs as discussed by professionals running services, it is possible to shed some light on how the care and support experienced by patients might take into account a range of health and social needs.

## **Constructing an understanding of HD**

People living with Huntington’s disease bring to the clinic the challenges they face concerning their physical and mental health. Depending on the type of professional sitting in front of them – a psychiatrist, neurologist, physiotherapist or so on – an individual patient might be discussing anything from their mood, to pain, to swallowing difficulties. A host of individual professions has been mentioned throughout this thesis, each with their own remit of expertise. The quotation below

from one of the interviewees of my own research also provides a snapshot of the myriad of health and social care departments that a patient might encounter:

There are so many professional groups involved in any one person with Huntington's. Not necessarily at any one time, but over what can be a relatively short period of time. It can be neurology, genetics, medicine, psychiatry, general practice, OT, dietetics, physiotherapy, speech and language therapy, core day health care, day services, social work, mental health officers....

Interview with NHS clinical professional (Int-D)

As previous chapters of this thesis have explored, the challenges for people with a condition such as HD may extend far beyond the physical symptoms described above. Social and economic factors, including issues to do with day-to-day care, finances, housing and employment, are all potentially relevant to the HD experience.

In this section, I draw upon data from the research that illustrates the different ways that the same biological condition of HD is approached when encountered by different professionals across the healthcare spectrum. The data from interviews, meetings and attendance of events reveals how different ideas of what HD 'was' were constructed within support services, and how these differences were perhaps even enhanced further by a partnership structure which involved multiple experts working together. This partnership structure, while potentially presenting organisational challenges, was also important in ensuring a comprehensive and coordinated service. In turn, such smooth running of services was something widely depicted by participants of the research as being of key benefit to the patients and carers themselves, who existed as the important, uniting element across the multiple versions of HD.

### **Structuring professional support around HD in Scotland**

Regional HD management clinics based in NHS premises exist across almost all of the fourteen Scottish NHS health board regions. At the same time, the third sector

Scottish Huntington's Association specialists are also present in almost every region and have an involvement with these NHS clinics as well as having a wider continuing involvement through their own interactions and appointments with clients, involvement with family groups and so on.

In most parts of Scotland a hospital consultant acts as a clinical lead for the HD management clinic in their own area. These consultants are largely psychiatrists, neurologists or geneticists. In some areas of Scotland there is no permanent clinical lead but rather a connection to the clinical lead of a different region. In other areas with no clinical lead there exists a range of professionals who manage individual patients within the remits of their own services, e.g. neurology, or psychiatry, and refer on to other services as required (notes from interviews with third sector HD professionals).

## **Diverse perspectives around the condition of HD**

As the in-depth discussion of HD earlier in this thesis explained, HD is known to be a genetically inherited condition with a documented pattern of onset once symptoms begin. The multiple symptoms that are connected to the condition, including movement issues, and cognitive and psychiatric issues, are well recognised.

As previously discussed, the adult form of Huntington's disease on which this research is based is genetically inherited. Indeed, it was one of the first conditions for which a genetic test was developed as a consequence of the HD gene being found as part of the Human Genome Project, in 1993. Research such as that by Nukaga (2002) traces how genetic work in the area of HD and involving medical pedigrees, has played a key role in the development of the new genetics research programmes which followed.

In previous social science scholarship, HD is often discussed for its features as a *genetic* condition, partially due to the considerable personal and ethical challenges it can indeed pose for patients, families, carers and professionals (Hunniche 2011,

Keenan et al. 2005, 2007, 2009, 2013). Yet, it was found rapidly within the data collection of this research that the inherited or genetic nature of the condition was not always the most dominant frame employed in the healthcare context. While the features of the condition remained widely agreed upon, discussion of HD by the myriad of health service and third sector professionals in my own research showed that different aspects of the condition became more important at certain times when it came to providing services to patients. It also emerged that none of these approaches to the condition existed in isolation from each other – it was never a case of HD being solely a genetic condition or solely a neurological condition, but rather something for which the focus shifted at different points in the clinical journey.

The multiple manifestations of genetics and ideas around genetic medicine were seen to emerge as the crucial feature of care at times, most particularly when it came to discussions about the implications of getting tested for the gene, or having children. However, it was not something used as a dominant frame throughout discussion of HD at other moments. When other types of symptoms or life issues required prioritisation, or a different type of expertise (such as that of a neurologist) was often given precedence. Furthermore, it was often the case that genetics did not emerge as ‘genetics’ per se, in the sense of directly inherited genes at the level of an individual’s DNA, but in a much more open idea of kinship:

On a day to day basis our role is varied. So we provide support and information for people who are maybe considering being tested. We supply information about maybe talking about other members of the family if they have concerns. If they are planning on being tested - or if they have children - we can maybe refer them on to our youth service. But we might be the first point of call when someone says ‘I’m worried about my children, how do I tell them?’

Interview with third sector HD professional (Int-G)

While the biological inheritance was important, discussions were predominantly framed in terms of the impact on the family (direct blood relations and others) and

the need to support one another through the situation, as exemplified by the following quotation:

Things like cancers are awful as well, and things like that. But it's this whole family aspect [in HD] and the big impact... I think as well professionals probably realise that this person has been surrounded by Huntington's since they were a small child and they have grown up seeing this and knowing what is ahead of them... That does affect them. There's very few people that I've come across that have remained aloof about Huntington's when they've started working with patients.

Interview with third sector HD professional (Int-G)

As shown in the literature review, the relationship between genes and notions of kinship has been a popular topic of past research (Finkler 2000, Atkinson et al. 2013, Latimer 2013). Within my own research, when HD professionals discussed aspects of kinship in HD, their discussions embraced blood relatives of the past and present, as well as often including any future children that might be born. Yet they also acknowledged the importance of the experiences of non-blood relatives within HD experiences, including most prominently partners and other close carers of people with HD.

As a single-gene, dominantly-inherited genetic condition passed from parent to child, HD spreads down and throughout family trees, with each child of someone with the gene being at 50% risk themselves. The late onset nature of HD means that in many cases, at-risk individuals will have seen the often devastating effect of HD on other family members. Indeed, as has been already stated, viewing this other person's journey might have been what alerted them to their own risk to HD, or what gave them an indication of what symptoms they might expect to develop themselves.

It is also the case that where individuals find that they are the 'lucky' ones that have not inherited the gene, they might face the guilt of escaping the fate of fellow relatives, as well as the distressing knowledge that their relatives face the condition. Sandy Sulaiman's sister Wendy, who found out that unlike her father, sister and

brother she does not possess the HD gene, discusses her own position in her own chapter in their family's book about living with the condition:

No one escapes the illness. No one is exempt. There is no free pass allowing you out of the Huntington's club. We all have to deal with it in one way or another. (Sulaiman 2007: 44).

Although HD medically can be correctly diagnosed to be a 'genetic' condition, other aspects of the condition were often the important focus of medical care at particular times. The *psychiatric* symptoms of HD were often stressed by interviewees involved in HD clinical care as something that was commonly misunderstood or overlooked by professionals not acquainted with the condition. In contrast, for those such as consultant psychiatrists who encountered HD first and foremost from a psychiatric approach, this entailed a different way of looking at the condition. It was seen to prioritise some of the most distressing features of HD not just for patients but also for those kin around them. The following interviewee in a clinical role highlighted the benefit of viewing HD under a mental health approach in terms of both the clinical skills this could bring and the ease of community referral:

There's a high level of psychiatric morbidity with Huntington's disease. It's the cognitive impairment aspect as well. The neurology bit, whether it's a psychiatrist or a geneticist I don't think it matters. So the cognitive impairment and the psychiatric bit, then, I think you are better doing the whole thing in very close contact with the community, in terms of where the patient lives.

Interview with NHS clinical professional (Int-D)

In the services that were the subject of my research, I also found that there was shared agreement around achieving specific outcomes for people with HD – getting them access to the 'appropriate services' and at the 'right time' (notes from interviews A-N) - even in light of different professional approaches. I therefore argue here that while 'multiple HDs' might have become visible, this tended to happen within an overarching shared understanding of HD and its basic scientific causes and treatments, on which all professionals agreed. The fact that this is not a

matter of dispute binds multiple understandings of the condition together and allows for care to take place in an organised fashion.

As has been discussed throughout this chapter so far, there are multiple types of professionals involved in HD, bringing multiple perspectives on care. There are benefits and challenges to this multiplicity, as discussed below.

## **Benefits and challenges of multiple perspectives on HD**

In relation to the topic of different professional remits, interviewees spoke of potential issues to do with inflexible applications of specialist expertise, drawing largely on examples of situations in areas other than HD. They described how barriers could also be created when it came to care for HD or other conditions within services where a condition was not able to be classified within a certain remit. This was seen as something fortunately now more a problem of the past where HD was concerned. One third sector representative discussed a historical situation in which they were in a discussion with a mental health team who were unsure whether a person with HD admitted to hospital belonged in a mental health remit despite their simultaneous physical needs, as described in the following quotation from a third sector staff member:

But sometimes it's the ward staff saying, 'this person shouldn't be on our ward. This is an acute [mental health] admissions ward. We are not supposed to spoon feed someone, we are not supposed to liquidise food'.

Interview with third sector HD professional (Int-G)

While the staff members who are being described in the above quotation were operating within the same mental health outlook as the psychiatrist above, HD here was seen in an entirely different way in which the presence of physical disability was regarded as a priority by this particular mental health professional. The interpretation of the individual mental health members about where a HD patient 'belonged' drew on their professional background, but also their knowledge of what HD was, at this particular time. As a result of the remit discussion, the third sector professional in

this instance was involved in offering their own expertise about the overlap between both the psychiatric needs and physical needs in HD care, and what the key priority for the particular patient was at that particular time if they needed a placement under psychiatric care.

Having a formalised clinical lead in place was seen as a valuable asset and a way of helping to clarify remits in situations such as the above. These individuals, normally consultant doctors, have a role not merely to provide their own specialist care, but also to refer on to other medical specialties and care teams. It was having this expert anchor point that was often valued even more than the particular medical approach they had arrived from, as it was known that by having such an anchor, routes to other types of medical specialist knowledge could be coordinated.

Tying in to the idea of multiple HDs, each type of clinical lead could approach the condition using different types of expertise and contribute greatly in their own particular area. The exact medical background to their expertise was thought less important than their ability to successfully connect this expertise with other key professionals with other types of knowledge. Most prominently in relation to their lead capacity, acting as a central node allowed them to have an overview of the condition that would allow other services to be coordinated around this, as one interviewee in an area *without* a lead clinician explained:

It would make a difference if there was one [a lead clinician], we had access to. If there were medical staff for whom HD was part of their remit... Obviously, it is part of lots of doctors' remits. If the GPs have a patient with HD, it is part of their remit, I don't mean it in that way. What I am meaning is that if we had an overseeing consultant as such that would make a huge difference. That would kind of help streamline and focus.

Interview with third sector HD professional (Int-N)

One of the main perceived values of having a single clinical lead was the way in which such an individual was able to provide consistency in management, to champion the existence of the service and to coordinate overall care.



Additional coordinating figures in this context arose in the form of boundary spanning individuals such as the third sector-employed HD Specialists, or public sector or third sector professionals who adopted a culture of partnership working. The following quotation from an NHS clinician details the benefits of this relationship further:

It's very time consuming liaising with all these people [in different professions]. If, Huntington's disease was my full time job then I could dedicate a lot more time. So it's fabulous having the SHA (Scottish Huntington's Association). I see the patients with regard to the neurological assessment, making sure that their medication's right, doing that bit, and the SHA provide the support... Between us we make sure. We're in almost daily contact by email with the HD Specialists. So they make sure that people are referred at appropriate times.

Interview with NHS clinical professional (Int-D)

The clinician in the example above is adopting the aforementioned role of an anchor point from which other services could be referred, as well as being an expert in their own medical field. Building on the discussion of 'key, committed professionals' in the previous chapter, such a clinician can be seen to have an indispensable and patient-focused place in care, without necessarily taking on boundary spanning roles themselves. The third sector individuals in this partnership arrangement are in a better position to span boundaries, adopting a valuable coordination role and linking their expertise to other services. However, as the quotation above also hints, the coordinating individuals also provide their own type of expertise and 'support' beyond this. The section below will now discuss how this wider support function related to the shaping of HD services and the condition of HD itself.

## **Services and the power to define HD needs and support**

As discussed in chapter three, the literature on third sector organisations in health more broadly across the UK discusses the way in which these organisations attempt to bring a variety of different support needs into the existing care provided by state health services, or into other public and private institutions (Baggott 2004b, Kelly 2007, Wood 2000). The support provided by third sector organisations is not limited to the clinic, but also takes place outside it through community resources, or in other locations towards which third sector organisations signpost their clients. There are a range of services provided by the Scottish Huntington's Association (SHA) for people with HD in Scotland, and equivalent services across the UK. These include (a) the link between the clinic and the community/home provided by the HD Specialists, (b) the events, conferences and specialist resources such as the youth service provided by the national organisation, and c) the local events and peer support going on via regional family branches. In addition to this further advice on issues such as housing, employment, support for carers and so on are provided both by the SHA and by other third sector and public sector organisations, to which individuals might be signposted by the SHA.

I argue here that through extending the types of support available, third sector organisations have a role in defining the remit of needs and therefore the boundaries within which the condition lies. I first discuss the way in which organisations aim to acknowledge and overcome the stigma associated with a condition.

### ***Acknowledging and overcoming stigma***

As highlighted earlier in this thesis, stigma is something widely discussed in accounts of life with HD and other long term conditions. Stigma was also a term frequently mentioned in interviews, or introduced conceptually as a major factor that

affected how people with HD lived their lives. It was not just the medical features of the condition that were seen to be of importance, but the way in which these were interpreted and reacted upon by people around the person with HD. The view of HD as a stigmatising force could be seen as an extremely damaging form of the multiple ‘versions’ of HD that this chapter discusses. Indeed, as the quotation below describes, the other multiple aspects of HD described earlier in this chapter could each be a source of stigma in their own right:

Huntington’s has got a triple stigma. It’s the stigma of being a genetic condition, of having a significant mental health component, and a physical disability. So what we have to do is acknowledge the huge challenges that Huntington’s creates for people.

Interview with third sector HD professional (Int-H)

A basic sociological point, but one that is important to acknowledge to do with the current discussion, is that stigma is societally constructed and perpetuated, and is not inherent to people with HD or HD as a condition (Goffman 1963). Indeed, it is due to the social nature of the stigma surrounding different aspects of HD experience that it is something that can be potentially mitigated or eradicated through awareness and education initiatives. It is also the case that social stigma is not at all limited to the experience of people with HD and their kin. As the quotation above indicates, the potential for facing stigma from society for people with HD might be *particularly* acute because of the way the condition combines multiple aspects of different health conditions. Individuals with conditions other than HD living with any and all of these elements – genetically inherited disease, mental health challenges, disability – could be subject to social stigma for similar reasons as people with HD.

### ***The manifestation of social stigma***

Data obtained from both my interview and observational research with professionals and people personally connected to HD reveals that there might be many manifestations to social stigma where HD is concerned. For example, people exhibiting the movement symptoms of HD can face enacted stigma from members of

the public who misinterpret such movements as being to do with the influence of alcohol or drugs:

I think stigma's still a big issue. I think that people with Huntington's disease are stigmatised because of their mental health problems and because of their sometimes 'weird' appearance, in inverted commas... and that the public might perceive them as intoxicated at times or just 'odd' people, and therefore they don't get the attention they deserve.

Interview with NHS clinical professional (Int-C)

The way it affects people is they stay in. If someone notices them walking down the street funny, they tend to stay in after that, because they don't want to be accused that they're drunk or they're on drugs or something. So this then isolates them, which then leads to their whole family being isolated.

Interview with individual with personal connection to HD context (Int-A)

Participants of the research involved in HD support also discussed how stigma might extend beyond the physical markers of the condition, with individuals also describing the way that HD had in historical terminology been discussed in rather medieval-sounding terms of a 'shame' of a family or a community (Interview with third sector HD professional, Int-G).

Negative attitudes about symptoms or the meanings of a diagnosis could also impinge on people who were partners, carers or kin of people with HD too. As the second of the two quotations above highlights, adverse judgements by strangers might not only be experienced and internalised by the person with HD themselves, but might also be something that carers or other people close to this individual also experienced. It was highlighted in my data that family members might avoid talking about the presence of HD in the family as a strategy for self-protection. The quotation below illustrates one such situation in which a third sector worker is talking about one HD family's experience with the reactions of extended relatives:

From a family perspective the stigma is very high. In a lot of families and in a lot of areas, they just don't talk about it... Two clients of mine said, 'we've got relatives who cross the street when they see us coming, because they know we go to the conferences and they want to live their life never hearing the word HD... They are worried that we might stop them and say, "did you hear this about HD, this new drug", and they don't want to hear that, so they'll cross the road when they see us coming.'

Interview with third sector HD professional (Int-G)

For some people, the effect of felt stigma might be heightened by having seen previous generations of their own family living and dying with HD and thus knowing what to expect from both the symptoms and the reactions of society. However, as will be discussed below in relation to ways to overcome stigma, this experiential knowledge of HD could also be a factor in the overcoming of stigma.

### ***The de-stigmatising role of services***

When it came to the role of the services that I explored in this research, stigma entered considerations in two main ways – 1) as something to be acknowledged when working out how to tailor support appropriately and 2) as something that successful services could help to overcome. The process of acknowledging stigma entailed services adapting to individual patient and client preferences to do with maintaining confidentiality. One third sector service professional discussed the need to sometimes meet clients in confidential locations of their choosing if they were not prepared for family or friends to find out that they had HD and/or that they were accessing support services:

There's this girl, [she asked] 'can I meet you, but we can't stay in the carpark, somebody will see me'. So she'll pick me up from work and we'll drive up this alley somewhere and do all this stuff about testing, and whether she wanted to go and do testing... because nobody in her family knows, nobody had to know.

Interview with third sector HD professional (Int-G)

Preparing individuals for the potential consequences of their condition becoming widely known was also something considered to be essential when supporting individuals through processes such as publicly talking about their condition. This included contributions within participation such as talking to the media or speaking at an event, as discussed in the following quotation:

So I guess stage one is working with families and identifying families who felt that they could go public with their stories... That's a big challenge for people with Huntington's disease, lots of considerations around that. Because you are in effect revealing your genetics data, but also other people's genetics data as well. So it requires a lot of discussion, sensitive discussion, with informants. But we were able to identify a lot of families. There are a lot of people living with Huntington's who I think burn with the desire to change things so that their children, and their extended family, don't have to grow up with the same stigma.

Interview with third sector HD professional (Int-H)

The fears of some patients that they might face discrimination once their connection to the condition was revealed were all potential considerations when talking on a public stage. Employers, insurance companies, wider family or even just people they knew were some of those from whom they potentially wished to hide their experience of or risk of HD. Again, the relevance of genetics and kinship relations emerged here, as one person publicly discussing having the HD gene in their family could also reveal this information about a host of others.

Successful services also were seen to be those that went further than merely adjusting to minimise the stigma that already existed. Patterns of service delivery involving collaboration and a diversity of services that brought in social and other aspects of life with the condition appeared to help to overcome some of the multi-faceted issues for people with HD and their families in the long term. Certainly in relation to stigma felt by patients and their families themselves, a key goal of clinical support was to inform individuals about what was normal for their condition and in doing this reduce self-blame. Restoring the confidence of individuals that any difference was not a mark of shame was to do with this:

[as an organisation we must]... promote understanding that people that are living with Huntington's are the same as everybody else - want the same things, need the same things as everybody else, and that they deserve as much a place in the world as people living with any other condition... Then I think probably what sits alongside that is, in the process of doing that, you are improving the level of social inclusion. I think maybe what you are changing more than anything else is the confidence that people have.

Interview with third sector HD professional (Int-H)

Likewise, local groups which connected individuals with other people affected by HD, or fellow carers, were forums in which stigma could be reduced through seeing others in the same situation and exchanging information and advice. In some cases these forums had a large social support function also, as the following quotation highlights.

I mean some are there for peer support. Some just have fundraising events, others have... coffee mornings, or cheese and wine evenings. But they have the sort of common aim to support each other.

Interview with third sector HD professional (Int-F)

In all the activities discussed above, raising *awareness* about what HD was –among professionals, the public, carers and patients themselves - was frequently mentioned as something that was an important, de-stigmatising force. Raising awareness by the third sector was seen as a route by which to undo and counter particular negative or incorrect perspectives that might be held by individuals, whether these were members of the public, professionals or people with HD themselves. The next section will examine how different aspects of raising awareness of the condition of HD became a central feature of partnership working involving the third sector, acting as both a facilitator of collaboration, and an end goal in itself.

## **Raising awareness**

The topic of 'raising awareness' directly connects to the theme of the reduction of stigma. As discussed above, it was frequently suggested by participants in the research that raising awareness of the condition to members of the public, and fully

informing HD families and carers on expected symptoms, were key methods for reducing stigma. However, raising awareness was also put forward as something even broader. It was depicted as a resource that third sector organisations could use to achieve a wide range of goals. Heightened awareness of the condition in the minds of the professionals and people living with HD were all seen as leading to improved service provision through more appropriate understanding and treatment (notes from event observation Obs-C). Similarly, greater awareness of the role of organisations in supporting people was also seen as a route to ensure that people with the condition got the support they required. These two aspects of awareness – awareness of HD, and awareness of the organisations and services available to support HD – are discussed in turn below.

### ***The goal of raising awareness about the condition of HD***

‘Awareness raising’ about the condition of HD directed at the public and professionals not directly involved with treating patients (such as politicians including MSPs and MPs) was discussed in a number of different ways by participants of the research. This is reflective of the fact that there are many different forms of awareness-raising activities in which third sector organisations participate. In the case of HD in Scotland, the Scottish Huntington’s Association cites awareness-raising about HD and HD services as a key goal, and one that is achieved through a mixture of year-round events. An annual awareness-raising week is also held by the SHA in conjunction with its fellow organisations that form the UK and Ireland HD Alliance: The Huntington’s Disease Association (England and Wales), The Huntington’s Disease Association of Northern Ireland, and the Huntington’s Disease Association of Ireland. This alliance was developed in order to increase the profile of the condition by coordinating efforts:

It occurred to me that if we were ever going to try and make an impact on levels of awareness that working collectively had so many advantages, and that a sort of fundamental thing would be just to have a single awareness week that we were all agreed on.

Interview with third sector HD professional (Int-H)



The lack of awareness of the condition HD among the public (and, to some extent, among professionals) was something frequently discussed by interviewees and also mentioned in other meetings and specific awareness-raising events. There was a feeling from participants that HD as a condition suffered from a lack of widespread awareness even in comparison to other conditions also classed as rare in the UK, for example motor neurone disease. One third sector interviewee discussed a situation in which a Member of the Scottish Parliament aptly summarised the situation when it came to public awareness of HD:

[A particular MSP] very famously said that Huntington's needed to be 'rescued' from the lack of awareness in society. And it was just one of those things that - I don't think they were aware - it just had such huge resonance across the charity. Not just with me, but with families, who all kind of recognised that that was true.

Interview with third sector HD professional (Int-H)

A major goal of awareness-raising achieved by organisations was overturning 'wrong' conceptions of HD. This firstly includes judgements from members of the public who regard a person with HD as having some other illness or issue or who fail to recognise HD at all. It also, secondly, attempts to correct viewpoints that misunderstand the causes or symptoms of HD. Awareness was also used as an educational tool to overturn misunderstandings that might occur about where HD sits within care. For example, information that HD had both physical and psychiatric elements would be information that would overcome the mental-health based remit dispute discussed earlier in this chapter, as the following quotation illustrates:

If you're talking to mental health teams - community mental health teams for example - they will come to the training thinking, 'well HD, there's no mental health involved because it's organic. We don't deal with organic illnesses'. And then we talk about actually how the psychiatric symptoms manifest within HD. And they go away thinking 'yes this is something we can work with'. So it does have its benefits ultimately for the individuals and their families, and it's really just about educating people. You know, there's a lot of misinformation out there - certainly on the Internet as well - and we do try to set that straight.

Interview with third sector HD professional (Int-F)

Within their educational activities, third sector organisations might draw on one or all the different framings of HD outlined earlier, in order to gain understanding from the particular audience being trained. The training would be tailored to the knowledge base and information needs of the particular audience, as the following quotation discusses:

We also do more focused training. For example, for a group of carers... If they are looking after a family and there are particular difficulties we would do training for that group of carers. So it's individualised, as well...

Interview with third sector HD professional (Int-N)

Raising awareness among professionals of the how the condition manifests was also talked about as something that was a possible (or at times necessary) means to other goals. Lack of awareness on the part of medical professionals about HD needs had significant implications concerning the appropriate treatment and support of people with HD and their families, connecting back to the discussion of professional 'silos' earlier in this thesis. Professional awareness of the trajectory of the condition, the needs associated with it and the measures that could be put in place could mitigate some of the difficulties a person living with condition might face. A whole new type of 'knowing' was seen to emerge when professionals individuals got to know HD patients more closely through increased information, or even more so, through direct experience with patients, as depicted in the following quotation:

For professionals I suppose, it's not until you are involved with the family that then you begin to find out more and really know what the disease is. And I suppose that's the step... Directly working with the family is when people try and access that more specific knowledge. Because that's when you need it...

Interview with third sector HD professional (Int-N)

While it was professionals who were the participants in this research, the findings also reveal how awareness of what might be expected from living with the condition for HD families themselves was also seen as something that could benefit individuals directly experiencing the condition. This was due to the way that it allowed these individuals to gain recognition of the experiences they were going through, or what

was 'normal' for their conditions at different times. It also importantly allowed for individuals and their families to plan for the future and, in doing so, have some added control over life with the condition. Honesty and clarity in how the disease was conveyed was seen as central to this process:

I think that if you are honest from the start. Because we always are with HD, and we talk about the disease. When it's appropriate we talk about how bad the disease can be. But what we can do is give clients the power of control over that such as advanced directives, giving them the voice. But it's getting the right times to do that. When you feel that the relationship is strong enough that you can do that... I always say to people, 'I'll always be honest with you, if you ask me anything, I will always tell you the truth'.

Interview with third sector HD professional (Int-G)

The findings also show that awareness of the symptoms of the condition were seen as an important thing for people to know, whether connected to the condition or not. However, awareness of what might be expected from the condition was also seen to be important in order to understand their prospects of life with HD. In doing so, it also had the function of striking a balance between realism and hope. This is something of relevance to all, but is particularly relevant to those whose life is directly affected by HD as a person with the condition or a family member or carer. Through emphasising the correct information about HD and the availability of support services and ongoing research, services aimed to ensure a realistic, but where possible hopeful, understanding of HD:

[The support aims] to keep the carer mentally and physically well so they can feel comfortable supporting the person with Huntington's... We try to make that happen over a period of time so it's a lot easier for people, with the caveat that... we are honest with our clients, with our families. We cannot promise to keep people at home forever because of what the disease is and we're always very open, quite early on, about what the disease is and what the journey might be.

Interview with third sector HD professional (Int-G)

Connecting back to the discussion of stigma above, increased awareness was also frequently mentioned as something that would benefit the HD community more

widely, through improved social understanding and the associated goal of better social inclusion for individuals. This was in turn seen as something that would be good for entire communities, not just for those who had the condition themselves or had it in their family.

***The goal of raising awareness of available HD support and change perspectives***

In connection to the findings above, a prominent theme to emerge from the research was that ‘awareness’ was not merely limited to ‘knowing’ HD as a medical condition. It was also the case that awareness-raising was sometimes about raising awareness of HD support, i.e., the services provided by the public and third sector within Scotland. These goals often went hand in hand, in that any activity designed to highlight condition needs almost inevitably mentioned this support available, and vice versa.

Gaining heightened awareness as an organisation includes gaining recognition of an organisation as a valid service provider. The intended result of this for the SHA was for patients to receive the referrals to services to which they were entitled. This connects to my own previous discussion of the positioning of the third sector in Chapter Six of this thesis. Awareness was tied to recognition and credibility that allowed third sector services to be positioned within the boundaries of appropriate support. This was also a factor when it came to building the trust of potential patient and family users of the service, as the following quotation explains:

The more collection cans that we have out in shop counters, the more people see our logo about the place: it will increase awareness. Folk know that they can trust you or you build some form of recognition and that in turn brings trust, I suppose.

Interview with third sector HD professional (Int-B)

Similarly when it came to the initial development of services or policy, recognition in political arenas was regarded as vital in order to build the contacts and influence needed. Events such as Parliamentary receptions are used by charities in Scotland,

including the Scottish Huntington's Association, as a way to engage with MSPs directly about their cause. They are hosted by the charitable organisation and 'sponsored' by a particular MSP. Other MSPs are then invited to join, as are other invited guests and sometimes wider members of the public too. A third sector professional involved with HD talked about being able to measure the positive effect of such awareness raising about HD and HD services among these Scottish politicians:

We did a 'Survey Monkey' survey of MSPs' level of awareness of Huntington's and it's very high. About seventy percent of MSPs know about Huntington's disease... I think there's been the opportunity to influence strategies, or policies. Things like the neurology standards are good examples of that... Certainly it's helped us to attract funding from the Scottish Government as well, without a shadow of doubt.

Interview with third sector HD professional (Int-H)

As the above quotation highlights, as charitable organisations are dependent on raising funds, raising awareness of their own presence was further a vital tool for organisations like the SHA in order to raise money to fund their care and support activities. This fundraising includes both public donations and charity and governmental grants. In these ways, awareness can be seen as a form of capital that operated on a number of interacting levels, all of which led to greater opportunities for organisations such as third sector organisations and services for patients and families affected by conditions like HD.

Again connecting back to the initial discussion of awareness as a resource to break stigma, participants of the research discussed that alerting individuals to the presence of services also itself had a wider, destigmatising function. Interviewees highlighted that the long-term presence of HD Specialists and regional arms of organisations such as the Scottish Huntington's Association within communities was in itself seen to have a potentially positive effect on awareness-raising for the condition, at least to a degree:

People will have heard of Huntington's. I'd say that mostly when I go out to do awareness-raising now having been in this job for, you know... But maybe that's because in this area there's been this service for such a long time. Maybe that has something to do with it. But, like I say, it doesn't mean that people fully understand what it's all about.

Interview with third sector HD professional (Int-N)

The fact that the Scottish Huntington's Association specialists were part of the local service infrastructure, for example, was often the way that public sector services came to know about them, and remained aware of both the condition and services available.

## **Collective work within alliances and at community level**

As I explored in Chapter Five when outlining the shaping of organisations, the climate of partnership around single conditions in Scotland is not confined to just the relationship between a single specialist third sector organisation and the relevant NHS and social care services. It is also a climate of alliance between multiple third sector organisations with differing purposes. Several of the interviewees that took part in the research were individuals from large, nationwide alliance organisations working in areas directly relevant to HD. Data from interviews with individuals in alliance organisations as well as other health and third sector professionals show another level at which constructs of HD emerge. Bringing in one third sector organisation to a partnership brings in others in the forms of alliances, and these operate within a wider awareness-raising framework. The wider goals of alliances involve highlighting problems accessing specific services/medical treatment, problems with poverty, problems with suitable services for disabled people, and so on. The benefits of this collective voice were often pointed out by organisations themselves:

I think because they are talking as a collective group of charities as opposed to just a one condition charity. So I think that's a huge benefit... I think just the chance to get access to MSPs and access to Parliament.

Interview with third sector alliance organisation professional (Int-E)

Alliance work was in turn depicted to have a de-stigmatising function in that it emphasises wider issues with societal structures that affected even larger groups of individuals than patients within a particular condition area. Campaigning as part of a wider collective also often involved a public articulation of the rights of individuals in particular groups, such as people who are disabled, or people who are patients of certain services.

As well as the work of the Scottish Huntington's Association (SHA), in the HD context in Scotland there also exists a family-run HD awareness raising charity called the Live for Life Foundation (LFLF). This group had close links to the SHA and was supported by it in getting started and advertising its events to the HD community. The group focuses on awareness-raising through arranging events such as music events and sports tournaments in local communities at which the goal is to raise awareness of HD, while also providing an enjoyable night out for that community. Like the other forms of awareness-raising discussed above a major contribution of the LFLF was seen to be in terms of spreading accurate information and breaking stigma. There was also seen to be a focus on fun and enjoyment for people from the local communities attending the event, some of whom included HD families (notes from events observation Obs-D).

Similarly, the family branches of the SHA and their equivalent organisations across the UK are involved in running their own activities around awareness-raising and peer support of fellow HD families. This was another way in which support for HD for widen, and came to encompass other activities to do with recreation and social support. In a local community event that I attended one of the organisers talked of the feedback they had received after a social event in a local community:

...[the person said] the mix of people you've got here is something to celebrate, that's amazing what you have pulled off here. And I thought, 'I'm sort of bringing communities together for HD awareness, this is what the whole thing is all about'.

Community events organiser

The HD work undertaken at both an alliance level and a community level ties in with much of the discussion throughout this chapter when it comes to the emergence of 'multiple HDs'. HD was something represented differently at each of these interactions as the type of rights being promoted changed, and new types of alliance were prioritised. As discussed in Chapter Five, multiple types of organisational alliance were made possible because of the multiple ways that HD could be framed.

Part of the work being accomplished at these events also involved changing individual *outlooks* upon HD, rather than attempting to shift any sort of medical opinion. Groups with an advocacy focus had a role in installing realistic attitudes, but also promoting hopefulness and/or autonomy where possible within the groups affected by a condition. Giving back a degree of control to patients and families in articulating the realities of life with the condition was part of this.

## **Extending HD support, and incorporating a 'life costs' approach**

Building on the findings explored throughout this chapter, I argue here that care and support service partners such as third sector patient organisations are involved in extending the remit of HD care itself to also include a wider notion of support. This occurs within their activities designed to overcome stigma, raise awareness and communicate across services. Throughout my research with professionals, it was evident that the people with HD and their families faced challenges beyond even the vast impact of the symptoms of the condition. Data collected from interviews and meetings more widely as part of the research highlighted issues including unemployment, poverty and financial exclusion, unsuitable housing, and relationship



breakdown, in addition to the stigma attached to these experiences. The practical mental health needs of carers and family members, some of whom might themselves be at 50% risk of developing the condition, were also often highlighted. Below are two quotations that highlight these kind of issues when discussing support for people with HD and for other conditions also:

[it is about]... the stuff that is really impacting on that person in terms of their quality of life. Like: 'I've no money... I'm in a seventh floor flat, and I actually can't manage the stairs'.

Interview with NHS non-clinical professional (Int-J)

But it's being that access for the carers. I mean that's a big part of the job... someone they can talk to. Someone who understands what they are in.

Interview with third sector alliance organisation professional (Int-M)

Part of the way the partnership role of the third sector was depicted again, then, was to shape the idea of the condition and what support should entail to encompass assistance with social needs, psychological needs and other non-medical practical needs. This was achieved partially through the assistance that the Scottish Huntington's Association themselves provided, for example, through running a carers support group, or liaising directly with a relevant agency such as a housing authority (notes from interviews A-N). The remit was also shaped in the way in which they had a function in signposting individuals and families to suitable places to address this extended range of needs.

Practical assistance with matters such as completion of a highly complex welfare benefits form was something that the HD Specialists also mentioned. They discussed such assistance as something that fell within their own role, or something with which they regularly consulted other expert third sector organisations (for example, Citizen's Advice Scotland and their network of regional Bureaux). In such a scenario the professional facilitating the financial assistance was operating within a role as

somebody assisting someone with their needs around HD, which includes the financial circumstances a person might face. Further evidence of the third sector's role in the extension of HD support to incorporate such important material needs is provided by the recent employment by the Scottish Huntington's Association of a specific Financial Wellbeing Officer to offer this kind of support nationwide. One interviewee discussed the importance of assistance of this type:

It's just one of those cornerstones of good support for people if you can help them navigate their way through a very complicated welfare benefit system... Maximise their income, or help them deal with debt issues, or work out how to get life insurance. All these huge financial things. How to plan for the future. Then you can dramatically reduce the stress that families are living under.

Interview with third sector HD professional (Int-H)

A further way in which HD Specialists assisted in advocating for families included taking a long term and preventative outlook to the provision of services such as local authority care and support. They were able to draw on their experience of working directly with HD families in the past to 'predict' future outcomes and trajectories for HD. In this way the HD Specialists were able to both emphasise projected quality of life for their client groups as well as drawing on cost justifications:

I'll give an example of an OT. If they didn't know Huntington's they'd fit an upstairs bedroom shower. This happened to a client of mine and then I got involved. After a period the shower gets ripped out and put in downstairs in a small cupboard, and it's an inappropriate shower base/shower cubicle...Then two or three years later they had to rip it out and put in a wet floor. And I say to them if they'd just put in a wet floor downstairs in the first place, that would have saved you money.

Interview with third sector HD professional (Int-G)

The concept of 'life costs' (Mikami et al. Forthcoming) and health is once again revealed to be useful here as a way to conceptualise a person-focused way of viewing the impact of illness that often extends far beyond the symptoms of the disease itself. It puts forward the argument that material conditions such as financial means and the

suitable of housing are indicators of quality of life with direct relevance to support around a medical condition, rather than just related to illness in an indirect sense.

Within my own research field, the voices of third sector organisations were often key to making all aware of such 'life costs', and undoing previous notions of where the clinic might end.

## **Conclusion: The shaping of HD and HD support**

It has been argued within this chapter that different ideas of HD can emerge both within professional approaches, and also in forms such as the stigmatised HD patient. It is completely possible for many of these versions of HD to exist at the same time. The need to deal with this multiplicity is something that all people living and working with HD must contend with, and something that individuals devoted professionally to working with HD full time are in a prime position to highlight. I have illustrated within this chapter that it is possible to have these multiple meanings of a condition such as HD while still retaining an idea of one body and one condition connecting these different approaches.

While different professional outlooks are something that might be expected in any situation involving multiple professionals or symptoms, these differences should not be taken for granted. The differing frames are what lead to different understandings of the condition, as well as the scope for partnership working. They are also a key area where the third sector enters the healthcare landscape. HD is notable as a condition in which third sector activity has been embedded at the service delivery level for several decades. This makes it an example of long-standing cross-sectoral partnership. Practitioners such as the HD Specialists and clinicians involved in my research have also highlighted that HD is a condition that continues to suffer from a lack of public and professional awareness, even compared to other rare conditions, such as motor neurone disease. Many factors for this are identified within my own research findings – the potential for stigma from others in society, a lack of high-profile advocates for the condition, the clustering of HD patients in certain areas, and

the complexity that professionals must take on board to understand and tackle the condition.

A key factor to ensure consistency across the multiple HDs that emerge is the acknowledgement by individual professionals and organisations of each other's areas of expertise, even if it is recognised that there are differences in knowledge and outlook. Therefore, where services work best, the appropriate person is available to provide their expertise at the time the different aspects of the condition become most relevant. In such a successful context, individuals are also willing and able to consult, and refer to, other experts where necessary.

### **Understanding HD across different social worlds**

Returning to the idea of co-existing social worlds as discussed by Bowker and Star (1999) appears to be a useful way of understanding how remits of professional jurisdiction get defined and re-defined, with boundary spanners aiming to function as a bridge across these distinct views of HD. While, as my previous chapters illustrate, the role of boundary spanner is not limited solely to the third sector, this is often a position occupied by individuals from the third sector, or somebody with whom third sector services are designed to liaise. Other than a disease specific remit, the third sector actors in my own research embodied a commitment to working across all other professional boundaries and could thus demonstrate that HD was within the remit of certain professionals at certain times. This, again, connects to theoretical discussion in previous chapters about how boundary work and boundary spanning individuals are key ways to understand how different actors are shaping healthcare.

The findings showed that coordinating individuals were important in the smooth flow of the treatment process. Their expertise was rooted in this cross-cutting ability and the prime focus on the condition itself. HD remained a consistent whole, while at the same time different understandings and approaches to the condition were applied where necessary. Most importantly, this also entails a smooth pathway for the patient

in the process of having their different needs met ‘at the appropriate time’, a phrase frequently found within the data.

## **Shifting the boundaries of HD services**

The data further highlights that collaborative third sector/public sector support services create a space to acknowledge the multiple needs of people with HD and their family including the social, psychological and material aspects of life with the condition. This shifts the boundaries of what the condition of HD ‘is’ for those who experience it, and shapes notions about what HD support should be. In addition to this, within fora such as alliances, single condition organisations become focused on more than just their own condition and unite under banners such as rare disease organisations, neurological organisations or, even more broadly, charities concerned with health. This again allows for HD to simultaneously have multiple meanings, yet retain integrity in order to receive the specialist support required. Awareness of both the condition itself and the services available might be regarded as a good that operates in a number of interconnected ways. It could impact on both direct individual knowing of the HD, as well as organisational possibilities.

Collaborative services involving third sector partners such as those seen in HD go beyond just defining what HD is and how it will be treated, but also help to shape attitudes about life with the condition and future prospects. Hope around a condition can be advanced in subtle but important ways within forms of service provision. In my research findings I have suggested that the third sector organisations that were involved in my research adopted a prominent role in aiming to reduce the stigma personally felt by people with HD and/or experienced as a result of the reactions of others. Through the interconnected processes of acknowledging and attempting to combat this social stigma current and future quality of life for people with HD is enhanced. Raising awareness about the condition is a key element of this de-stigmatising function. Furthermore, it could be suggested that any decreasing of stigma in one aspect of life with HD is likely to have a similar de-stigmatising effect

for others in different medical contexts facing similar challenges, and vice versa in the case of successes outside the HD context. A legacy is left of greater awareness as well as access to support services that are inclusive of a wide range of medical and support needs.

The discussion chapter that follows builds on the findings within this chapter and the previous two chapters, and presents my overall argument about the formation of a particular type of expertise by professionals within third sector roles in HD service partnerships. The implications of the findings for sociological understandings of the role of the third sector in healthcare and of the development of professions in healthcare will be explored, as will suggestions for future social science research and for the future application of these insights to policy and practice.



# **CHAPTER EIGHT: DISCUSSION OF FINDINGS AND THE IMPLICATIONS FOR RESEARCH AND PRACTICE**

## **Introduction**

In this chapter, I will return to the central arguments that I have advanced throughout this thesis regarding the role of the third sector in Huntington's disease (HD) support and care in Scotland, and I will discuss their implications for sociological understandings of the third sector in healthcare. I begin with a discussion of the central research question that framed my sociological enquiry, and then consider the three key themes that were presented in the substantive chapters of this thesis. I then move on to present my core argument that extends across these findings, exploring the development and use of a particular type of expertise by third sector professionals. Connected to this argument, I will show how my findings contribute to the literature in the area of third sector activity and health, as well as how they inform theoretical concepts about boundaries, expertise and the development of professions. Like all research projects, there were limitations to my research design, and these will also be explored.

I suggest in this chapter that the findings of my research demonstrate the continuing importance of paying sociological attention to the service role of the third sector in health settings, and I make specific suggestions for future social science research within the Scottish HD context and in other settings beyond this field. There are also potential implications of my work for future policy and practice. This chapter concludes by offering insights that pertain to future positioning of the third sector in healthcare policy, and that are likely to impact on the future structuring and delivery of services in Scotland around HD and other long term conditions.



## Summary of the research questions and aims

The research set out to answer the following original research question:

**What is the role of third sector organisations, and of partnerships between these organisations and the public sector, within services for Huntington's disease (HD) in Scotland?**

The above research question emerged out of a gap within social science research around the third sector in healthcare. There is much social science and policy interest concerning broad trends around the third sector and around cross-sector partnership. However, there is little research on the actual delivery of health services, particularly when a specific client group (such as people with HD) are involved. It follows that little is known about the dynamics of third sector involvement in this area.

Furthermore, while Scotland as a separate nation and health system constitutes what might be seen as a fascinating microcosm of multi-sector partnership arrangements, it has rarely been given space of its own in third sector or healthcare organisations literature. The closeness in the connections within and between the third sector and the Scottish NHS meant that the context was an interesting and accessible one within which to embark upon my in-depth research. In identifying Huntington's disease services as an important example of modern partnership arrangements, this research explicitly began from a focus on one health condition in one healthcare setting, with a deliberate aim to examine this activity in depth.

The research question itself was built on a legacy of prominent past research on third sector organisations in health. Particularly useful in framing my research was social science work outlining third sector organisation activities in the UK by Baggott and colleagues (Allsop et al. 2004, Baggott et al. 2004a;2004b, Baggott and Jones 2014, Jones et al. 2004, Jones and Baggott 2011) and by other notable scholars in this area (Beard 2004, Dutton et al. 2013, O'Donovan et al. 2013, Osborne and McLaughlin 2004, Wood 2000). This prior research has laid the foundations for widespread

interest in third sector activity, especially through underscoring the importance of these organisations to healthcare in the UK. Furthermore, the wealth of literature tracing developments in health policy in Scotland and the UK over the last twenty years (Alcock 2012, Alcock and Kendall 2011, Carmel and Harlock 2008, Forbes et al. 2010, Fyfe et al. 2006, Kendall 2003) has also underscored the notion of ‘partnership’ in framing third sector activity. Models of third sector organisation activity such as those developed by Rabeharisoa and colleagues were also useful in the way that they depicted a ‘partnership model’ for patient organisations that involved engagement on their own terms and using their own knowledge (Rabeharisoa 2006, Callon and Rabeharisoa 2008, Rabeharisoa 2003, Rabeharisoa et al. 2014b). However, my review of the past literature highlighted the dearth of work in the area of *service provision* involving third sector organisations, and therefore left an opportunity to investigate this area while drawing on these relevant past insights.

The multi-method qualitative research strategy used to fulfil the objectives of the research was found to be a suitable approach. It predominantly involved using interview data – while also incorporating insights obtained from observations, meetings and documents – in order to tap into the perspectives of individuals within my chosen field. It demanded a degree of flexibility and ethical awareness in order to manage the issues that arose over the course of data collection and analysis. In particular, managing anonymity and confidentiality in order to safeguard the reputations of my participants was important in a field that was small in size and in which the potential participants were closely connected to each other.

## **Summary of the key findings of the research**

My research reveals that third sector organisations within Scottish HD services have taken on extensive partnership roles, and that alongside this it is evident that important aspects of the healthcare scene are being shaped. The three main themes of the research findings that were each explored in the substantive chapters of this thesis are as follows:

### ***1) Partnership is shaping third sector organisations***

The coming together of different organisations and sectors within partnership structures involves necessary reflection on the part of the professionals involved on the cultures and positions of the organisations, and most particularly the role of the third sector. My study of HD services in Scotland reveals that the perceptions of individuals in the third sector are formed through interactions between third sector organisations and their public sector colleagues within these partnerships. Those in third sector organisations engage in a range of work which justifies their organisation being regarded a credible professional group, while at the same time emphasising values that the third sector is seen to embody, such as holistic working.

### ***2) Partnership is shaping professional identity***

Within partnership structures such as HD services there is also space for new and/or partnership-related identities to emerge that focus on the newly professionalised nature of third sector roles. Professionals from the public sector and third sector alike draw upon past and present examples of collaborative, caring styles of working when forming perceptions of their own role. It is also possible to identify within this the emergence of ‘key, committed professionals’ from many professions who are particularly dedicated to an area of service provision and are core to the organisation of care. The third sector specialists within my research were often in both this position and in a boundary spanning role.

### ***3) Partnership is shaping ideas around health conditions***

Partnership arrangements such as those within Scottish HD services are also shaping health conditions themselves, through changing and expanding the way that conditions are defined. The combination of different types of expertise, a common feature within care for complex conditions such as HD, leads to multiple viewpoints of the same condition and the way it should be managed. The involvement of partners who have a wider remit and understanding of a particular condition – such

as the third sector HD specialists within my own research – allows these individuals expand and inform the realm of needs and support for people with that condition. This in turn is likely to affect some aspects of patient and family experience of an illness, through changing the nature of their encounter with care and support services.

My findings also underscore a basic sociological argument - articulated in much third sector organisation activity - that the wider context of illness experience matters. When living life with a potentially devastating condition like HD, many aspects of life are relevant to the HD experience beyond the already considerable symptoms affecting physical and mental health. Relationships with kin, an important feature of much illness experience, can be extremely pertinent in light of the genetically inherited nature of the condition. Stigma and social exclusion often enter people's daily experience and their self-perception, as can wider social factors such as economic stability and the suitability of housing. Emphasising this wider social context around a condition was something that was at the core of the Scottish Huntington's Association work, including their partnership within services.

This chapter will now turn to the central argument emerging from the thesis, advancing the suggestion that there exists a particular type of expertise exhibited by third sector professionals in the partnership arrangements that were researched. I also explore some of the other key messages that cut across the findings of the research that relate to this discussion of expertise, and explore in turn how these relate to the current body of knowledge on the third sector, partnership and healthcare professions.

## **Third sector professionals and the development and use of new forms of expertise**

In response to the research question, it can be said that the three themes of the findings chapters (Chapters Five, Six and Seven) discussed above point to many important and interconnected roles for third sector organisations within the delivery of HD services. They highlight roles for third sector organisations and their composite professional staff as important links between the formal healthcare structures and the patient at home. This occurred in a direct capacity in which third sector specialists based within services functioned as valued coordinators or facilitators of services. Individual third sector staff members acting as what I have here termed ‘key, committed professionals’ were often central to this coordinating function. The third sector professionals with job roles based largely on coordination and working across boundaries were able to emphasise this boundary spanning skill as something valuable that they and/or the third sector could contribute. Third sector organisations also more widely helped to construct the overall appearance of care and support through their role as trainers of other professionals about HD needs. In addition, their advocacy and awareness work was able to expand the ideas of other professionals about the support that HD families required.

### **Cultivating ‘aggregate know-how’**

I have come to the conclusion that the uniting feature across the different roles highlighted above is the nature of the expertise that the third sector organisations and their professional staff could claim to possess within their work in HD service partnership. All the professionals who participated in my research, as well as the few HD family members whom I encountered, could credibly claim to have bodies of specialist knowledge about HD and/or other health conditions. Most, if not all, the participants in my research across different professions and sectors were also visibly

committed to providing caring and holistically focused support in a way that corresponds with my categorisation of a ‘key, committed professional.’ They were aware of the way in which the experience of illness went beyond the mere biomedical definition of a condition and how it incorporated understandings around the ‘life costs’ experienced by individuals (Mikami et al. Forthcoming).

However, despite the similarities in characteristics to do with attitude with the other participants of my research discussed above, third sector knowledge around HD was perceived as being expertise in HD *as a condition overall*. This knowledge draws on the wealth of professional experience that the HD specialists and other third sector professionals gained from working exclusively with HD and HD families. This was also combined with the third sector being positioned closer to the HD families at the heart of activities. This happened in a literal sense when third sector specialists were involved as a support to families and a coordinating point between families and other services and therefore got to know various things very well: individuals and families, the local community, and the features of the condition. Furthermore, in a metaphorical sense these third sector specialists were seen to be positioned closer to HD families due to widespread beliefs from patients, the public, professionals and policy about the holism and patient-centred values at the core of third sector. The third sector professionals were therefore seen as being able to access and understand the complexity of HD in a different way from individuals with other professional remits.

I suggest that the best way to characterise this third sector expertise discussed throughout this thesis is as a form of ‘aggregate know-know’, drawing on work around the idea of situationally focused patient ‘know-how’ developed by Pols (2014). As explored within the literature chapter, know-how is described as more than just patient knowledge of a condition, anchoring instead on the experience of the condition in combination with the strategies used to react and self-manage illness within particular situations. For third sector specialists working with HD patients, the cultivation of individual patient know-how can be seen as core to their individual

interactions with patients and families within the mutual exchanging of information between specialist and patient. I suggest that the building of 'aggregate know-how' by professionals occurs through the accumulation of the knowledge and experience of working with, and listening to, individual HD patients over time. It also involves learning the various tricks of the trade of providing HD support. As has been discussed throughout the findings chapters of this thesis, this knowledge involves understanding the likely current and future needs of patients based on past experience, as well as having an understanding of the resources and options available to them within a particular area. It is also something that was seen to be both collected and enacted as a result of the boundary spanning remits and the skills of individuals, such as the third sector HD specialists that were the primary focus of my research.

Aggregate know-how is by no means being discussed here as an unproblematic representation of genuine patient experience, or a direct means by which individual experiences affected professional practice or wider organisational change. Nor is it argued that it is, or that it should ever be, a replacement for the meaningful involvement of patients and families in their own healthcare and wider service design. My own research was concerned with the work undertaken by professionals from the third sector in their interactions with others. My findings suggest that drawing on expertise that referred to patient experiences was part of the work done by these professionals in their interaction within clinicians and other healthcare professionals. This expertise was also seen to become part of the ongoing boundary work of the third sector as the professionals legitimised their unique and important role in service delivery, emphasising both their closeness to patients and their skill set in working across organisational divides.

To clarify further, I am also not arguing here that the aggregate know-how - or any other related collective notion of professional knowledge based on patient interaction and experience - is something that only the third sector professionals are able to possess. There is nothing intrinsic about its qualities that limit it to these groups, and

it might be something that people working in NHS services or other public sector settings can and should seek to cultivate. It is also something that people with direct experience of the condition as patients, carers or kin might develop if they enter into particular roles as advocates and supporters of others with the same condition. I do, however, argue that within my own research it was evident that the third sector individuals who took on roles as full time supporters of HD families, and as coordinators and communicators across professional boundaries, are particularly well placed to develop and use this type of expertise.

The argument that I present here, emerging out of my research about third sector professionals exhibiting patient-focused expertise, has considerable implications for sociological understanding of the role of the third sector in healthcare. It shows a more extensive, formative role for the third sector, and the opportunity for third-sector partnerships to be structured around expertise as a central quality. It also contributes further understanding to literature that examines the overlapping areas of the development of health professions, and of the nature of expertise and of boundary work.

## **The extensive ‘partnership’ role of the third sector**

I embarked upon this research with an awareness of the wealth of past literature discussing different aspects of third sector involvement in health that might be theoretically transferable to collaborative service provision in Scotland (Akrich et al. 2013, Allsop et al. 2004, Baggott et al. 2004b, Jones and Baggott 2011, O'Donovan et al. 2013, Rabeharisoa 2003,2006, Wood 2000). In particular, I drew on the influential sociological work of Rabeharisoa (Callon and Rabeharisoa 2008, Rabeharisoa 2003, Rabeharisoa 2006), which suggests there has emerged a ‘partnership’ model of third sector interaction with medical research. I believed this could form a potentially useful insight into the dynamics of third sector involvement



elsewhere. Rabeharisoa's own work in the area of French muscular dystrophy organisations' involvement with medical research discusses the active rather than passive nature of organisations operating under this partnership model. An organisation under this model is a 'master' of its (research) policy, and has an ability to 'call on or even to invent forms of expertise and structures suited to its objectives' (2003:2132). It can be said that the findings of my research do lend further support to Rabeharisoa's (2003) theory, and suggest that such a partnership model can be found within the slightly different context of joint third sector-public sector service provision in Scotland.

With relation to the first point about mastery of one's own policy, a core message of my own research has been that the specific nature of the 'partnership' present in HD specialist services is one in which the third sector has been positioned as a necessary and equal partner, who is able to sculpt and define the nature of the services offered by itself and offered jointly with other organisations such as the NHS. In fact, it is only due to the presence of the Scottish Huntington's Association that much of the support - such as the connection from clinic to community, or special initiatives such as the youth service - is provided. In the day-to-day running of the partnership-delivered services, the articulation of the third sector about patient needs is also essential in widening the scope of other expert understandings. Some of the subsequent consequences of this equal partner role for other writings in the wider canon about state-third sector partnership are discussed in the next section below.

With regard to the ability of partner organisations to 'call on or even to invent' forms of expertise and structures (Rabeharisoa 2003), my own findings about third sector expertise based on professional experience with patients and their knowledge – here termed as 'aggregate know-how' – can also be claimed to fulfil this function. The third sector organisations can come to be regarded as professionals and experts by the public sector partners involved with them. My research therefore supports further a longstanding argument of much social science work that the third sector should be taken seriously as both a partner in service delivery and a subject of social

science enquiry (Baggott and Forster 2008, Baggott and Jones 2014, Epstein 2008). I argue below, however, that my contribution extends further than just confirming Rabeharisoa's insights about partnership (2003) and highlighting the third sector's importance, by showing an active role for organisations in the production of knowledge around illness, disease and support.

### **Third sector organisations and the active production of knowledge**

As has been explored throughout this thesis, and particularly in Chapter Seven, my research contributes evidence that the third sector can be formative of care and support structures, and have an active role in the production of knowledge. The knowledge-producing aspect of the third sector is something that some academics, particularly those working with Rabeharisoa within the *European Patient Organizations in Knowledge Society* (EPOKS) body of work have written about in some depth (Akrich et al. 2013, Edwards et al. 2014, Moreira et al. 2014, O'Donovan et al. 2013, Rabeharisoa et al. 2014b, 2014a, Rabeharisoa and O'Donovan 2014). I contribute to this growing literature by suggesting that one such knowledge producing activity is visible within the afore-described form of 'aggregate know-how' manifestation of expertise, which is developed at the level of third sector care and support and then collected as a resource to be used by third sector organisations more widely.

It has been seen in past literature that third sector organisations have had a role in transforming ideas around an illness, legitimising it in the eyes of others (Fuller 2011), and/or contributing to changing notions about what it entails (Chamak 2008, Chaufan et al. 2012, Edwards and Howlett 2013). Adding further evidence to this 'knowledge production' literature outlined above, my own research findings highlight that the repository of expertise upon which third sector HD professionals draw can be seen in a similar way.

Among other functions, third sector organisations have used this body of knowledge obtained from working with patients (a) as a resource to emphasise the wide range of medical, social and psychological needs of HD patients, (b) to highlight the existence of stigma, and to (c) present data on the prevalence of the condition in Scotland. My own work therefore supports the notion of third sector organisations as engaging in ‘evidence-based activism’ (EBA) that has been developed by many of the EPOKS academics discussed above (Rabeharisoa et al. 2014b). I also suggest that this same EBA is intimately related to the simple, day-to-day evidence-based practice of third sector individuals engaged in direct care and support work with patients.

The discussion around the use of knowledge for changing ideas around a condition speaks to some of the other questions that have been posed across both illness experience and knowledge expertise literature. For example, scholars have been interested in the way that patient experiences might be interpreted and come to be used in a collective form by other patients and professionals (Pols 2014, Locock and Brown 2010, Mazanderani et al. 2012). Two broad answers that might be offered to this question from my own research is that an assemblage of patient experiences as communicated to specialists by patients might be used as a basis for professional practice with other patients. For example, when supporting a patient with a particular issue – e.g. finding a way to access respite care, or advice about communicating about HD to their children – the know-how of the professional in conjunction with the know-how of the past patients whom they have encountered is a vital resource. While the policy input aspect of third sector organisations is not the main focus of this thesis, this research also indicates that patient experiences in an aggregate form are also likely to be of prime relevance to how third sector organisations develop agendas for political campaigning, awareness raising and other types of third sector involvement (e.g. partnership scientific research). Information around condition needs and issues assembled by individuals in an aggregate form can be a resource for these activities in addition to the other vitally important input obtained directly from patients and carers.

Related to the above point, however, is the aspect of Rabeharisoa's work on the partnership model (2003) of patient organisation activity with which this research is not yet able to fully concur. This is with regard to the actual nature of the involvement of *patients* within these partnership activities. In Rabeharisoa's own discussion of the partnership model, she suggests that patients become 'specialist partners in their own right' through the involvement of organisations of which they are a part (2003:2131). My research deliberately focused on the arrangements between the professionals that deliver Scottish HD services as an important and understudied area of research. It did not, however, directly examine the interaction between third sector organisations and their patient client group, and is therefore only able to talk of the 'patient' perspective only from the way this was brought into conversations by these professionals and any other research participants. It follows from this that there might exist questions that past research has also raised (Beard 2004, Fisher and Owen 2008, , Fitzgerald 2008, Nelis et al. 2007, O'Donovan 2007, Raspberry and Skinner 2007) about the representativeness of such aggregate and professionally held knowledge about patients, which my research was not able to address in full due to the focus oriented towards professionals.

It can be said from my own data analysis that bringing the patient perspective into services is something that the professionals from across the organisations that I encountered did indeed strive to do in their daily practice. They did this through listening to patients and families, developing patient-focused initiatives and by involving patients and families in many aspects of service design and awareness-raising. Connecting to past empirical work, it can also be said that the involvement of the third sector in Scotland is often seen in itself to be a step towards involving (at least some) patients further in the planning and delivery of services (Dutton et al. 2013). Furthermore, research participants involved with the Scottish Huntington's Association, the NHS, and other third sector and public services all emphasised the centrality of patient perspectives in their activities. Therefore, while the organisations of my own research could certainly be found to exhibit their own 'hybrid identities' as experts existing between patient and other professional knowledge (Moreira et al.

2014), the extent to which their knowledge might be seen as a true ‘hybrid assemblage’ (Irwin and Michael 2003) of patient and professional knowledge would rely on further research from the patient perspective. As the section below suggests, additional research directly with HD patients and families would be valuable in order to develop insights on the degree of ‘partnership’ in which patients feel they are engaged and to explore the mechanisms by which patient knowledge is communicated to service providers.

## **The potential for genuine third sector-public sector partnership**

As highlighted in this chapter already, as a broad category partnership has been central to the framing of third sector activity in UK public policy in the last two decades (Baggott 2013, Powell and Glendinning 2002) and has also been of key interest to social scientists interested in the third sector’s involvement in healthcare (Baggott et al. 2004b, Baggott and Jones 2014, Bode and Brandsen 2014). Whether they are actively engaged in cross-sectoral service partnership or not, the wider policy climate in Scotland and the UK is something from which third sector organisations and the NHS cannot escape. As the discussion throughout this thesis reveals, the discourses surrounding partnership have already been influential in transforming ideas of the third sector and its professionals, and are continuing to form the backbone of current developments around Scottish health and social care integration.

One of the core debates within social policy-focused work on partnership is the extent to which the third sector in the UK, and particularly in my own context of Scotland, can operate as an independent and equal partner in third sector-public sector service arrangements. Many suggest that this can indeed be the case, at least in certain circumstances (Baggott 2007, Dutton et al. 2013). Alternatively, it is suggested by critics that bringing third sector organisations into partnership with the state, especially from the partnership emphasis of the New Labour era onwards, has

simply been a way for public sector to co-opt the values of not-for-profit groups as a means for ‘instrumentalizing’ (Bode and Brandsen 2014) the free services of the third sector (Carmel and Harlock 2008). This debate has become all the more important recently in light of shrinking public service provision and welfare provision at the hands of the UK government. This has occurred alongside government policy affecting mainly just England that has suggested that it would be the task of the civil society – formally branded ‘the Big Society’ by the Conservative government – to overcome welfare shortfalls (Alcock 2010a).

My own research contributes to the above debate by suggesting that while the origins of modern service partnership may have been skewed towards public sector dominance and a new managerialist framework, there is evidence from the present situation in Scotland that there is space for what might be seen as a genuine partnership of equals between the third and public sector within services. Connecting back to the core argument of this thesis, I would suggest that the possession of unique expertise that has been built over time functions as one of the equalisers within this relationship. Third sector services – in my own research, those provided by the SHA around HD – are providing a complex, disease-specific and patient-centred service that would be difficult, if not impossible, for the state to provide straight away for a rare and complex disease like HD without the aggregate knowledge of the third sector being involved.

Even in the circumstances where these third sector services are funded directly or indirectly by public sector money, the expertise, disease-related commitment and degree of independence of third sector organisations exist as valuable resources. The system of NHS provided specialist nurses, especially recent additions such as the motor neurone disease (MND) specialist nurses, show that it is indeed possible to provide valuable, coordination-focused services from within the NHS. However, as was especially the case with the MND nurses, this has also often been as a result of public and third sector campaigning for and input into services where the roles and expertise previously did not exist (Scottish Government 2015h). Scotland is also not

seen to be moving towards a neoliberal healthcare market in the same way as health policy in England. However, it can be speculated that any possible private sector alternatives to the third sector or public sector provision described above, in which there existed competition between multiple providers, would also be even *less* conducive to the building up of aggregate know-how and the stability of services.

The policy regimes that have allowed third sector organisations to flourish and enter partnership have been argued by some to have been predicated on burdening the third sector while maintaining state power (Bode and Brandsen 2014, Carmel and Harlock 2008). However, I argue that my own case of HD services provides evidence of organisations that are able to assert expertise-based power from within partnership structures. In this way, they are able provide resistance to systems of either managerialism *or* the potential alternative of historical medical dominance. Furthermore, as this thesis has outlined, even service-delivery-centred organisations can have a degree of a campaigning function, through directly or indirectly highlighting the need to increase welfare services to address the needs of their client group. However, while the power of organisations in comparison to their state partners might well be greater than has sometimes been portrayed in past literature, their activity might still be limited by a lack of financial resources, which might include a lack of funding from the state. Decreasing government spending on services and welfare might be used as a reason for decreased third sector support. However, in times of brutal austerity measures from different levels of local and national government, the expertise and services of third sector organisations are all the more important so that they can assist individuals who require services more in times of poverty.

My suggestion here that organisations might be valuable partners by virtue of their expertise has the potential to move along the academic conversation about third sector and public sector engagement. This conversation is often more concerned with what scholars view to be the many problematic origins of partnership discourses, rather than focus on the analysis of positive examples of service delivery

relationships such as that I found within my own research. I suggest that the claims to expertise that third sector organisations can make render them more powerful or resistant to existing structures through everyday practices than much of the literature has acknowledged. Yet there is still the need for critical attention on the difficulties that organisations might have in maintaining this role as a subtly critical partner if they face cuts to their funding streams.

## **Expertise and boundary work in the development of healthcare professions**

My research findings also contribute to current debates about the development and direction of travel of the healthcare professions. Within the sociology of professions field, there have been many debates about the precise professional restructuring processes that have occurred in healthcare systems (Fournier 2000). Overall there has been a broad consensus that there has been a decline in the former system of medical dominance, as well as a rising development of new professional roles within and across healthcare structures (Nancarrow and Borthwick 2005). Beyond this consensus, there remains much debate about the nature of the altered relationships between healthcare professions and whether old hierarchies are indeed being remade as professional boundaries shift (King et al. 2015).

The findings of this thesis about the shaping role of the third sector in HD care and, crucially, the positioning of certain third sector professionals as a type of expert, might be seen to contribute useful insights to the overall healthcare professions debate. Firstly, the findings add weight to analytical work discussing the ‘professionalisation’ of the third sector in healthcare (Carey et al. 2009, Malin 2000), by showing a clear example of the third sector as a partner and expert within a formalised service provision context.



However, the findings at the same time also trouble some of the classic ideas presented by professions literature stalwarts such as Freidson (1970, 1986) and Abbott (1995, 1988) around 'professionalism' being about occupations attempting to create barriers between themselves and others in the establishment of a superior and inaccessible professional realm. Conversely, my research reveals that performance as a 'good professional' from a position in the third sector and public sector alike involves exhibiting what might within these past characterisations be traditionally seen as 'unprofessional' qualities, such as flexibility across organisational cultures, and knowledge based on experience as well as formal training from within a particular group. It is also important that discussions of professionalism and expertise also draw on a growing area of sociological enquiry that addresses the emotional aspect of healthcare work (Bolton 2000, Lewis 2005). This is a body of literature that this thesis was able to only partially dip into within my discussion on professional identity, but that is becoming even more relevant to discussions of professionalism within multi-professional climates where emotional management is key.

My own research findings also speak further to the ever-continuing debate on the level of dominance held by the medical profession, providing further evidence that doctor protectionism concerning their remit over individual patients is declining within a health climate characterised first and foremost by multi-professional working (Martin et al. 2009, Martin and Finn 2011). As the findings of my own research suggest, professionals from within the traditional higher status roles in medicine are acknowledging the importance of including different types of expertise of their colleagues in care and support. This has gone hand in hand with the emergence of many types of roles and remit restructuring in-between and across organisational boundaries (Bacon and Borthwick 2013, Nancarrow and Borthwick 2005), a phenomenon of which my own depiction of third sector experts can be regarded to be a part.

As partly discussed above when talking about models of third sector care and partnership my research also suggests it might be possible for a decline in medical

paternalism to occur without reverting to a potential opposite, i.e. a scene of multiple competing healthcare providers who are not experts in their own right, but merely offer the most competitive service. I propose that my work builds on the literature about the different modes of healthcare organisation by suggesting that expert roles that fulfil a coordinating function - such as the holders of aggregate know-how that I present within my own findings - might exist as a bridge between different pockets of specialist knowledge. If successfully delivered, the resulting situation allows patient needs to be addressed appropriately by particular experts, but with the added value of patient-centred coordination between these elements.

While third sector organisations might have often been characterised as being part of growing consumerist influences and de-professionalisation in health, my own findings suggest they actually might be part of a novel variety of professionalism that has often made use of these new access opportunities. Their own professional status is based around flexibility in occupational boundaries and a re-imagining of what passes to be credible expertise. They could therefore be the answer to the plea of Freidson that the 'soul of professionalism' must be saved from the negative trends of both marketization and of bureaucratization in healthcare (2001).

My research also speaks to the continued utility of ideas around boundary work in the version originally developed by Gieryn (1983) when understanding complex organisational situations such as partnership arrangements. Recognition of the work of the third sector and other actors as forms of boundary work brings the understandings that the participants of my research held about different professions and organisations to the forefront of analysis. Furthermore, my research reveals that there is benefit in uniting what curiously has often been in the past two mainly distinct areas of literature – 1) work on third sector organisation activity, and 2) work around professions and organisational boundaries. Uniting these literatures, I argue, provides a means by which to analyse the role of third sector organisations within healthcare systems in more depth. The very insertion of the third sector into public service delivery structures involves a combining (and sometimes clashing) together

of what participants of my research often described as different sector cultures. This in turn requires those in different sectors to work across these cultural divides, which they might regard as a positive or negative feature of partnership. Such situations are made more complex by the existence of different types of symbolic hierarchies and divides that often have to be negotiated and the expertise of individuals asserted within these.

Following on from the above discussion of core arguments of the research and the contributions they make to existing understandings in social science, I will now explore some of the limitations of my own research. I will then suggest what directions might be pursued by social science research in the future, and put forward the potential implications of my own findings for policy and practice.

## **The limitations of my own research**

My research examined the role of third sector organisations, and of partnerships between these organisations and the public sector, within HD services in Scotland. One of the limitations, as mentioned when discussing partnership above, was that this research only focused on the *professional* dynamic of service partnership, and did not aim to uncover in-depth interaction of patients within services. This was a deliberate decision in order to limit the scope of the study and plug a previously unfilled gap to do with professional partnership, the third sector and service delivery. However, it is acknowledged that this limits the findings of my research to discussion of the professional dimension of service provision only. Patients, families and carers are evidently extremely important to the findings of my research, particularly within my overall claim that an aggregate form of patient knowledge and experiences is central to third sector professionals' expertise. Further research from the perspective of HD patients about their knowledge, and about other aspects of healthcare, is suggested as a potential future direction below.

In addition to patients, there are other individuals and groups whose input would potentially enhance the research findings. The viewpoints of individuals involved with policy making (civil servants and elected politicians at all levels), and professionals from other service delivery areas such as social work, would add an extra perspective on the place of the third sector. The predominant reliance on respondent-led sampling techniques, as well as fieldwork time constraints, resulted in a sample that did not include individuals from these professional areas. HD is not something that every doctor, social worker or policymaker is familiar with, so accessing suitable individuals from these groups requires added background knowledge and/or direct respondent referral. Further research in the same area might aim to specifically target these groups by directly asking those in HD field to identify key individuals from policy and social work and/or recruiting more widely. Views from a social work perspective about partnership would be likely to be particularly enlightening considering the ongoing integration of health and social care structures in Scotland.

It is further acknowledged that the research methods used within my own research, while allowing me to explore a context in depth, permitted only certain types of transferability of the findings to other settings. The research was undertaken using a qualitative and adaptable flexible design. While some standardising methods such as base interview schedules and coding schemes were used, there was considerable adaptation of approach within the data collection setting. This occurred in order to account for emerging topics, overcome unexpected interruptions and to maintain rapport between myself and the participants of the research. As with much qualitative research, the various non-standardised and non-replicable features of the research design mean direct statistical generalisability is not possible.

The emphasis on both the complex, unusual nature of the condition of HD and the small and understudied Scottish healthcare system might beg the question of whether HD is perhaps unique in the way that the multiple organisations work together and therefore my findings about the way that particular types of third sector expertise emerge are also unique. The findings do suggest that the complexity of the condition

makes it arguably *more* necessary for people with HD and their families to be provided with support that is flexible, communicative and extended. However, the findings also indicate that the model of interconnected, expert services with a coordinator, with an added focus on wider life-related support, would be desirable for many conditions, complex and otherwise. The important factor is the way in which different understandings of a condition are incorporated into care.

Through looking at the experience of someone with a condition like HD, as social scientists we are provided with an analytical window on to the structural arrangements of health services more broadly within societies such as the UK. With respect to other aspects of the research, the potential for theoretical transferability is high, and means that the research is likely to be of considerable relevance to other condition areas and national contexts. In particular, the overall findings around third sector organisational involvement shaping public healthcare settings are likely to be of prime relevance in other developed nations. This is particularly true for the other nations of the UK that share common histories and policy trajectories with Scotland. However, it is also potentially the case within other nations with largely universal health systems in which the third sector has a sizeable presence, for example Ireland, France, Australia, New Zealand and Canada.

## **Directions for future social science research**

### **Sociological exploration of patient views on patient experience and service provision**

As discussed above, one area of future research that this research indicates would be an important addition to current literature would be work directly involving patients (those who have HD as well as other conditions) which could explore various aspects of their experience of services delivered in partnership. Work with patients might be centred on how they perceived the different sectors and professionals involved in

their care, or might be focused more squarely on the role of patients, families and carers within these services. In light of this thesis's central claim about aggregate know-how, further sociological research in the manner of Pols (2014) about the nature of patient knowledge, experience and expertise would provide valuable additional insight to my own findings. In particular, the way that patients might communicate their know-how in encounters with professionals, particularly professionals in coordination-oriented roles such as third sector employed specialists, would provide added analytical clout to my own research. One might ask, if aggregate know-how gathered on the part of professionals is crucial to their own work practices, how representative is the collective form of such expertise to particular patient experiences? Furthermore, from a practical perspective, what might be done to ensure that patients (plus families and carers) can have a genuine input into the structuring of service provision?

Research with patients might be carried out through interviewing patients, or through ethnographic work in hospital clinics, peer support groups and other community support settings. Another interesting sociological issue concerning the level of input that patients have into the organisational agendas of third sector groups is also something that research has begun to address (Beard 2004, O'Donovan et al. 2013) but that has not yet been attempted with a focus on HD and/or the Scottish third sector. Although there are potential ethical challenges when gaining access to patients perceived to be vulnerable, the current research reveals much potential for future work with HD patients in regard to third sector engagement, and on wider issues.

## **National level and comparative research on third sector organisation involvement in health service provision**

Following my own findings, I also join others in suggesting that comparative research on third sector organisation engagement in different national health systems would be useful (Baggott and Forster 2008, Epstein 2008). In particular, research

tracing the similarities and differences between health partnership in Scotland and England would be timely in light of increasing divergence across the nations of the UK (Jones and Baggott 2011). Possible methods for such research could take the form of documentary analysis of major policy shifts, and/or interviewing key individuals across both contexts.

There is also much scope for up-to-date, macro-level analysis of third sector activity in health across the UK that looks in detail at the devolved nations in addition to England. As well as survey methods, social network analysis methods would prove useful to trace the professional communities formed around one condition such as HD. Within Scotland, insights about the knowledge and expertise that might be offered by different organisational cultures, as well as their ability to work together, are particularly timely in light of the ongoing integration of health and social care structures following the *Public Bodies (Joint Working) (Scotland) Act 2014*. It is also the case that practical insights about third sector partnership in services are likely to also be of relevance to other nations where exact policy might be different but, as highlighted above, some of the themes of policy are similar.

## **Exploration of the interactional aspects of partnership arrangements**

The findings from my own research in the HD services context reaffirm the value of examining the underlying interactions around partnership arrangements when examining processes of change in healthcare. Overall, my research highlights the benefit of sociologically examining ‘partnership’ in both a general and specific sense. While partnership works generally at one level as a policy discourse, it also defines and characterises a specific arrangement ‘on the ground’ in healthcare. The interplay between these two levels is an important area for sociological enquiry. My own research case provides an example of where the work on the ground largely matches the more abstract intentions of policy. Such specific examples are important going forward when attempting to define what is meant by successful ‘partnership’

in the future. Much of the previous research in the area of partnership derives from a functionally focused management literature or a social policy literature interested in broader shifts in health policy but which could benefit from more examples of partnership in practice.

Focusing instead on the micro dynamics of partnership, further sociological research might also seek to look at some of the everyday strategies and practices involved in maintaining positive partnerships around healthcare services. Connecting to another area of findings within my own research, the impact of partnership on the professional identity and emotions of professionals involved in collaborative working is something that warrants further development. This is likely to be of considerable practical use to health and third sector professionals, as well as being of interest to social scientists studying professional interaction. The Scottish context offers a rich backdrop against which to explore such dynamics. Alongside third sector organisation services, ongoing developments such as the new integrated Health and Social Care Partnership structures would present a suitable context in which to carry out ethnographic research or to use as a field setting for interview-based research.

## **Implications for future policy and practice**

My own work also points to potential implications for policy and practice in the area of third sector involvement in health. First and foremost, it indicates a need for those planning healthcare structures to fully acknowledge the challenges experienced by those working across professional boundaries. The participants of my research in both the third sector and public sector were often fully supportive of the practice of working together. However, they were also aware of barriers to communication that existed, or the inadequate time or funding allocated to partnership initiatives.

Architects of health policy and service infrastructures would therefore potentially benefit from researching the best way to fully achieve the claims about partnership working already widely discussed in documents such as the Christie Commission Report (Christie 2011). In order to do this, drawing on lessons learned from



successful existing partnerships – such as those around HD in Scotland – would be a positive step. It is also vital that, in devising future models of partnership, policy makers pay attention to a constantly growing social science literature on third sector activity around healthcare.

The findings of my own research also support another long-standing discourse of policy in Scotland concerning ‘holistic’ ways of working. My research indicates that discussions of holism and person-centredness can, and should, be more than just a hollow sentiment of policy. Seeing the whole person and ensuring that they are receiving support for their needs in many aspects of their life is portrayed by experts in the HD area as vital to quality support. The findings of the research, however, reveal that this does not entail that everyone must be knowledgeable about all aspects of care. Rather, holistic working also includes professionals recognising their job remit and embracing both referral to other experts and the importance of coordination roles. The complexities in achieving holistic working across boundaries are also relevant to multi-professional support in areas other than healthcare: homelessness, youth support, addiction, supporting victims of crime, supporting older people in the community, and so on.

Another important implication is tied to both the points made above concerning building collaborative infrastructures and supporting holistic working. If third sector organisations, or indeed public sector organisations, are going to achieve their partnership-focused goals, there needs to be sufficient public sector resourcing allocated to specialist and coordination-related services. This sufficiency of resourcing relates both to having adequate amounts of funding given, and also longevity in funding streams. Without such support, organisations that might be well placed to ensure holistic services - such as specialist third sector organisations like the Scottish Huntington’s Association – will have reduced or no capacity to provide their expertise. While a strained financial climate is often used as the reason for depletion of funds for services at the level of UK, Scottish and local government, it is in these times of austerity that health and social support is arguably most important.

Simultaneous cuts to other public services and reduction in the accessibility of welfare benefits places extra weight on crisis services and support services more generally. In such a circumstance, continuing financial and logistic support from the State for third sector services is needed, in addition to what has been pledged over twenty years of past policy.

## Concluding thoughts

I have argued in this thesis that there exists an extensive role for third sector organisational activity in my own research field of Scottish HD services. The ‘shaping’ processes of which third sector organisations are a part are transforming (a) the organisations involved in healthcare, (b) ideas around professions and identity, and (c) constructions of HD and HD support. Within this, it can be argued that a particular type of expertise formulated around aggregation of patient experiences is developed by third sector organisations and continually used to assert their legitimacy as partners in services. The shifts in third sector positioning that I have depicted throughout this thesis look set to continue amid an ever-present Scottish and UK policy emphasis on the role of the third sector in service delivery. These factors highlight the continued importance of social science researchers keeping their attention focused on third sector organisation activity in healthcare.

Service delivery, the Scottish healthcare system and the condition of Huntington’s disease are all also previously untapped and important areas for research within which there is much left to explore. My own research serves as a building block for future exploration in these areas, as well as a call for social scientists to appreciate the boundary work and expertise articulations going on behind the scenes. However, the important gathering of theoretical knowledge about third sector organisations should be ever mindful of a key asset of any such research – the ability to provide insights that could improve essential healthcare services for people living with long term conditions like HD.



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## Appendices

### Appendix A: Literature review search terms

Health/ healthcare	Third sector
Illness	Health charity
Disease	Voluntary
Medical/medicine	Community
Huntington's disease/HD	Voluntary and Community Organisation (VCO)
Huntington's chorea	Patient organisation
Genetic(s)	Health consumer group (HCG)
Care/ social care	Health care patient organisation (HCPO)
Support	Not-for-profit
Service delivery	Non-profit
Welfare	Advocacy
Public sector	Patient advocacy organisation (PAO)
State	Carer organisation
NHS	
Scotland	
UK	
Partnership/ Partnership-working	Organisation
Collaboration	Group
Co-production	Charity
Relationship	Sector
Alliance	Association

## **Appendix B: Sample themes and question prompts for interviews**

### **1) Interviewee background**

- Job title and outline of roles involved for info only
- Time working for organisation
- Past experience of similar
- Idea of the structure of the organisation

### **2) Could you please give me an idea of the main networking activities that you are involved in within your role? (for example, within the last year)**

- with other voluntary sector organisations?
- with medical professionals/ allied health professionals/ social care professionals?
- with politicians and/or policy makers (civil servants, councillors, MSPs, MPs, MEPs...)?
- with medical researchers?

2.1) (For any or each of the above) When it comes to collaborations with...

- what are the main outcomes of these partnerships?
- how are initiatives first developed

2.2) What are the tools that help engagement like that... you have described?

2.3) In what ways do you think there have been any changes in how links are developed and maintained in the time you have been in the organisation?

### **3) Can you elaborate on any professional collaborations you have been involved in where awareness-raising is a key outcome?**

**4) Could you please tell me about the practicalities of working with other organisations?**

4.1) What conditions/factors help with the maintaining of partnerships (like those described)?

-what is helpful or not helpful

-what is involved in *maintaining* links

4.2) Could you please tell me a bit about the partnership with...[organisation]

**5) In what ways does the organisation bring in the everyday experience of living with HD (or other conditions) into activities?**

5.1) what is the place (if any) of these family stories?

-are there challenges presented when it comes to involving families?

-what are the important factors when it comes to representing families with HD?

-how are views canvassed?

**6) What do you see as future directions for models of engagement:**

-around HD (or other conditions)?

-for your organisation?

-for the voluntary sector in health overall – in Scotland, in the UK?

-what do you think will be most influential on shaping engagement in the future?

6.1) Has anything happened that you didn't expect with regard to the direction of the organisation?

6.2) What are your hopes for future practice around HD (or other conditions)?

-in health

-in politics

-in medical research

**Any other comments, questions etc.?**

## Appendix C: Example research outline for recruitment

E·S·R·C  
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### Research Project Outline

**Professionals involved in healthcare delivery, policy and campaigning in Scotland invited to take part in a research project on professional collaboration**

**'Community building around health conditions in Scotland'**

**Tirion Julia Seymour, PhD researcher in Sociology, University of Edinburgh**

*Supervisors: Dr Angus Bancroft and Dr Gillian Haddow*

*Project funded by the Economic and Social Research Council*

#### The research

Individuals working in a range of professional roles are warmly invited to take part in qualitative research exploring how voluntary sector organisations for people with complex health conditions might form collaborations in order to achieve goals like raising awareness. I am particularly interested in issues such as how 'professional partnerships' with other organisations and professions might develop in Scotland. As a result, I will be talking to health charities concerned with specific health conditions as well as the other professionals with whom they might form collaborative partnerships. I seek to look at activity around the genetic condition Huntington's disease (HD) in particular as a 'case study' of collaboration in light of a specific context, and have already had involvement with the Scottish Huntington's Association.

The intended outcome of this research is to gain greater insight into models of professional engagement around health conditions, and, in particular, long-term and complex health conditions like HD. Importantly, the research is also a chance for professionals in a range of contexts who want to raise awareness of their work to have their say on what partnership means to them and how it should take place.

#### What participation will involve

Participation will consist of taking part in an informal one-to-one interview. Broad topics being addressed will include the interviewee's own experience of partnership arrangements with other organisations, the different strategies being developed to raise awareness of complex conditions and the different people involved in setting up and maintaining professional partnerships.

Taking part in an initial one-off interview would take no more than a maximum of 1.5 hours of an interviewee's time. The date and location of the interview would be arranged in accordance with what was most convenient for the interviewee. Any travel costs incurred as a result of taking part in the research will be fully reimbursed.

There will also be considerable opportunity for all participants to comment on initial findings of the research during a consultation period following each stage of data collection. Additional comments on the research will also be welcomed throughout. Research protocols surrounding anonymity, data banking and the right to withdraw from the research will be thoroughly addressed in a research briefing prior to the interview, and any questions about these ahead of the interview are also welcomed at the contact details below.

#### Getting involved

Any individuals who might want to participate in this research are very much welcome to get in touch with me as soon as is convenient for yourself in order for a date and location for an interview to be arranged. If you have any questions or comments, please do not hesitate to get in touch with me by email or telephone – my contact details are provided below.

Many thanks for taking the time to read this information sheet. I look forward to hearing from you.

Tirion Julia Seymour

Email contact: ----- Telephone contact:----- Address: -----

12<sup>th</sup> December 2013

## Appendix D: Participant information leaflet and consent form

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THE UNIVERSITY  
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**Research participant information sheet and consent form**  
**‘Community-building around genetic conditions in Scotland’**  
**Tirion Julia Seymour, PhD researcher in Sociology, University of Edinburgh**

*Supervisors: Dr Angus Bancroft and Dr Gill Haddow*  
*Project funded by the Economic and Social Research Council*

### **The purpose of this information sheet**

This information sheet explains your rights as a participant so that you feel fully informed before taking part in the current research.

**Please read this information sheet, the consent form and the accompanying documents carefully and do not hesitate to ask questions about anything that you do not fully understand.**

The signature at the end of the consent form confirms that you understand the contents of this information sheet and consent form and that you consent to having your data collected and used in the ways outlined.

**You should remember that participation in this research is entirely optional and you have the right to withdraw your participation in this research at any time before, during or after taking part in the research and without having to give a reason. The signing of this consent form does not affect that right.**

### **The purpose of the research**

The research being conducted is for an ESRC-funded doctoral research project on professional engagement by patient organisations in Scotland concerned with genetic conditions. Interviews are being conducted for this research in order to seek the views of individuals who are involved directly or indirectly in patient organisation activity.

By taking part in this research, participants will contribute to academic knowledge about patient organisation engagement around genetic conditions. It is hoped that the end-product of the research will be beneficial to future understanding and knowledge of community building and to political and healthcare practice. Please refer to the *Research Project Outline* sheet for further information about the purpose of this study.

### **Uses of the research**

The final product of this research will be a PhD thesis that will be publicly available online and in hard copy format through the University of Edinburgh library and the British Library’s EThOS initiative<sup>1</sup>. Reports containing analysis of the research findings will also be widely disseminated to academic and public audiences. Within this thesis and in research reports, direct quotation and/or

<sup>1</sup> Electronic Thesis Online Service. Available at <http://ethos.bl.uk:8080>

paraphrasing of interviews will be used with the permission of the person who was interviewed (see section below on 'Participant Access to Own Data').

Where permitted by individual participants, the data collected during the research process in the form of fully anonymised written interview transcripts may also be 'archived' in the UK Data Archive<sup>2</sup> to benefit future academic and not-for-profit researchers. Please see the additional information sheet *Data Archiving Procedures* if you would like information about how data is stored and used in this archive.

### **Data confidentiality**

Any audio or written data collected during this interview will be stored safely, securely and anonymously by the current researcher in line with the UK Data Protection Act 1998 and guidelines issued by the Economic and Social Research Council and the University of Edinburgh.

As a solo PhD project, the primary researcher involved in handling the raw data is the researcher, Tirion Seymour. Any research assistants employed to transcribe interview materials will also be subject to stringent confidentiality agreements. Any data collected as part of this research, including audio recordings, will be kept separately from names of participants and destroyed after the completion of the doctoral research and depositing of any data in the UK Data Archive.

### **Participant anonymity**

In the PhD thesis and in any other research reports, all individual participant names will be automatically changed to a different name unless participants wish otherwise. If interviewees have a particular preference about what their pseudonym will be, they are welcome to inform the researcher of this name. The option to waive anonymity will be discussed within the interview itself during completion of the 'Participant Confirmation and Consent' section of the attached consent form.

**Participants should note that the Scottish Huntington's Association will be freely named within the research. Therefore even participants who have had their names changed might be identifiable to some degree, especially to those working within this organisation or by individuals who are closely connected to the SHA.**

### **Participant access to own data**

As a participant of this research, you will be consulted about any direct quotes to be used from your own data in the current thesis or other reports and articles related to the current research. Where an audio recording has been taken, participants will also have the opportunity to view and comment on a copy of their transcript if they wish to do so. Participants have the right to withdraw their data at any time in the process of the current research without having to give a reason. Once data is withdrawn, no extracts from this data will be used within any talks or papers that are produced from the point of withdrawal onwards. For discussion of withdrawal of data in relation to the archiving of data in the UK Data Archive, please see the accompanying sheet *Data Archiving Procedures*.

It should be noted that participants who have consented to have their data archived in the UK Data Archive *will not be consulted by any secondary researchers* in the future about use of their data. This is in order to protect participant anonymity, as all data in the UK Data Archive is anonymous.

<sup>2</sup> <http://www.data-archive.ac.uk/>

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## Research Participant Consent Form

The Economic and Social Research Council (ESRC), the researcher Tirion Seymour and the University of Edinburgh attach high priority to the ethical conduct of research. We therefore ask you to consider the following points before signing this form.

*Please tick the appropriate boxes*

*Yes No*

### Taking Part

- |   |   |
|---|---|
| I have read and understood the attached information sheet dated 18 <sup>th</sup> July 2013.   | <input type="checkbox"/> <input type="checkbox"/> |
| I have been given the opportunity to ask questions about the project.   | <input type="checkbox"/> <input type="checkbox"/> |
| I agree to take part in the project. Taking part in the project will include being interviewed and recorded by an audio recorder and/or notes being taken             | <input type="checkbox"/> <input type="checkbox"/> |
| I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part. | <input type="checkbox"/> <input type="checkbox"/> |

### Use of the information I provide for this project only

- |   |   |
|---|---|
| I understand my personal details such as phone number and address will not be revealed to people outside the project. | <input type="checkbox"/> <input type="checkbox"/> |
| I understand that my words may be quoted in publications, reports, web pages, and other research outputs.             | <input type="checkbox"/> <input type="checkbox"/> |

*Please read carefully and choose **one** of the following two options:*

**I would NOT like my real name to be used** in the above research outputs and would like to be given an alternative name instead. If I have a preference for the alternative name to be used I will inform the researcher.

**I would like my real name to be used** in the above research outputs and have been briefed on the subsequent implications of this concerning identification of myself and any of the data I have given to this project.

### Use of the information I provide beyond this project

*(Please read the accompanying information sheet **Data Archiving Procedures before completing this section**)*

- |   |   |
|---|---|
| I agree for the data I provide to be archived at the UK Data Archive. This data will consist of written transcriptions of an audio transcript (if taken) and/or researcher interview notes and field notes. | <input type="checkbox"/> <input type="checkbox"/> |
|---|---|



18<sup>th</sup> July 2013 Page 4 of 5*Please tick the appropriate boxes**Yes No***Use of the information I provide beyond this project (continued)**

I understand that other researchers will have access to this archived data only if they agree to preserve the confidentiality of the information as requested in this form.

I understand that other researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

**So the information you provide can be used legally**

I agree to assign the copyright I hold in any materials related to this project to Tirion Seymour and the University of Edinburgh.

\_\_\_\_\_  
Name of participant [printed] Signature Date

\_\_\_\_\_  
Researcher [printed] Signature Date

**Researcher contact details:**

Any further questions are welcomed at the contact details below:

Project researcher: Tirion Seymour

Email contact:-----

Telephone contact:-----

Postal address: -----

18<sup>th</sup> July 2013 Page 5 of 5**Participant contact details**

(Optional, but it is necessary to provide at least one working contact if you wish to be informed about any quotes being used, receive research updates and/or wish to obtain a copy of your transcript.)

Email address \_\_\_\_\_

Telephone number (work) \_\_\_\_\_

Telephone number (personal) \_\_\_\_\_

Contact address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Do you wish to be kept up-to-date with briefings and reports related to the research?  
(please select option(s) below. Individuals may opt out of receiving updates at any time):

No \_\_\_\_

Yes, by email address provided above \_\_\_\_

Yes, by postal address provided above \_\_\_\_

Yes, by a different email or postal address (please enter below)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Appendix E: Data Archiving Information Sheet

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## **Data Archiving Procedures**

*This information sheet has been developed to provide information on what a data archive is and how your data will be used if stored in the UK Data Archive as part of the ESRC-funded project 'Community-building around genetic conditions in Scotland.' More information can be found at the UK Data Archive website at <http://www.data-archive.ac.uk/> and at the research project contact details at the end of this sheet.*

### **What is an archive?**

An archive is a secure place where different types of materials are stored and looked after indefinitely. Most traditional archives deal with paper records, such as a local history archive. In the digital age many archives now hold electronic records. These demand different methods and skills to curate the materials to ensure that they can be used well into the future. The UK Data Archive houses several thousand datasets of interest to researchers, teachers and students who work in the social sciences or humanities.

### **Why put information in an archive?**

For many participants of a research study, taking part is a way of getting their voices heard and of being listened to. Sharing their lives and stories in an in-depth interview is a way for them to have a say about topics that are important to them. Some people are happy to have their own names attributed to material they provide, while others prefer not to. Either way, providing 'voice' is an essential job for an archive.

A second reason to put materials in an archive is that it is impossible for researchers to learn everything they want to from data they collect at the time of their project. Because so many things can be learned from the data, preserving them means they can be shared with other researchers who will find the data useful now and for many years to come.

Another important reason to archive data is that some of the data have been provided by very hard-to-reach groups, politicians, the sick, the very elderly, the socially excluded or those who otherwise are not usually included in research projects. It is often very difficult and expensive to recruit such participants for research and, once they have contributed, it is important to make full use of the information they have given.

Lastly, archives are very good places to keep data safe and secure. Archivists are experts in backing up data, protecting them from viruses and more. They also specialise in looking after data to make sure they can still be used many years in the future when technology will be very different from today.

### **How do I know my data will be used ethically?**

Putting data into an archive is not the same as making them available on the web. Archivists value the materials deposited with them and take their duty very seriously to make sure the materials are used only in appropriate ways. Their primary concern is to protect research participants. To that end, there are three strategies for protecting data. The first is to gain informed consent from participants to share data; the second is to anonymise the data; and the third is to control access to the data, via licensing.

'Community-building around genetic conditions in Scotland'  
Tirion Julia Seymour, PhD researcher in Sociology, University of Edinburgh

In almost every archive, some data will be available to the public, some will be covered by a standard licence, some need special permission, and some data are made unavailable for a lengthy period.

#### **What does anonymising mean?**

This means removing anything that could identify a participant or anyone talked about in the data. Good examples are names of people and places. In archives, personal contact details are never made available. Examples would be address and telephone number or email. Here is an example of anonymising some real names:

<b>Original</b>	<b>Example of possible change</b>
Schools e.g. St John's Primary School	Local secondary school or chosen made up name
Businesses e.g. MacDonald's	Fast food outlet/restaurant or chosen made up name
Family and friends' names e.g. Auntie Betty	Changed to Aunt or chosen made up name

#### **How might data be used?**

Data can be used in many ways. For example, one well-known collection known as *The Edwardians*, which interviewed 450 older people born before 1918, has been used to study topics as different as men's roles in family meal preparation, and how young civilian soldiers survived trench warfare on the Western Front by drawing on the emotional and practical support of their families.

Archived data may also be used by researchers, to compare with their own materials; by teachers, for use in their courses; and by journalists and policymakers. Others may be interested in how the research was done, e.g. how questions were asked. Of course, it is almost impossible to predict all the ways that data might be used. Past examples have shown that users are very creative in looking at data in very new and innovative ways.

#### **Who owns the data and what is copyright?**

If you are asked to sign a copyright statement this means that the person asking will have the legal right to use your contributions on agreed terms. For example, they can publish an article on the research which may quote some of your words. A researcher can further sign a licence with an archive that allows the archive to legally distribute the material to bona fide researchers, under the conditions agreed by the researcher.

**How do archives store my data safely?**

In many archives, data are stored in conditions that meet national and international standards - temperature, security and so on. They will have licences and access controls to ensure that only authorised and registered users can get hold of data.

**The current project and the storing of data in the UK Data Archive**

The research project in which you have been invited to participate, 'Community-building around genetic conditions in Scotland', is a doctoral research project that is sponsored by the taxpayer-funded organisation, the Economic and Social Research Council. Data generated within this project will be stored within the UK Data Archive to provide public benefits such as those mentioned above in this information sheet.

Within the current research, stringent confidentiality measures like those outlined above and in the project consent form will be employed. When filling out the consent form in the research interview, all participants of the project will have the option to select whether data related to their own participation in the project will be stored in the UK Data Archive or not, which will occur pending the completion of the research in 2014. The types of qualitative data that will be archived will include written transcripts of audio-recorded interviews (where this was the case), written notes from within interviews and additional materials such as researcher fieldnotes. As explained in the sheet above, all archive material within the archive is anonymised.

It should be noted that whether participants choose to allow their data to be archived or not has no bearing on their other standard participation rights to confidentiality, right to withdraw their data and so on for the purposes of the current research project.

**Contact details**

Any further questions about data archiving procedures in relation to the current research project are welcomed at the contact details below.

Project researcher: Tirion Julia Seymour

Email contact: -----

Telephone contact: -----

Postal address: -----