Patient Representation and the Research Agenda in Neurodegenerative Disease

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Abstract

Patient organisations are often characterised in sociological literature as patient representatives, speaking for people affected by an illness in medical, political and scientific spheres. Using Motor Neurone Disease and Parkinson's organisations as case studies, I investigate the challenges faced by patient organisations attempting to fulfil this role, focusing in particular on the need to balance responsibilities associated with care and campaign functions and increasing engagement in research. The principal focus of this PhD is to examine different conceptualisations of *representativeness* that have been discussed overtly and implicitly by participants. I have examined the extent to which patient organisations represent their members' needs and cultivate a sense of collective identity, the way in which the patient organisations represent their members during the setting of research agendas, and finally I have considered the extent to which representation coincides with the concept of patient involvement.

22 in-depth interviews were conducted with volunteers, staff and members of MND and Parkinson's organisations as well as researchers affiliated with them. 5 research-based meetings and conferences were observed and website homepages and social network interactions were analysed to enable comparison between statements made at interview with the way in which patient organisations present themselves in public. This empirical data was used to support a normative, ethical analysis of patient organisations as patient representatives.

Despite being commonly described as an expected attribute of patient organisations, my research suggests that representativeness is a far more ambiguous concept. Furthermore, representation is made more complex to define by the attempt to combine research engagement with more traditional patient organisation roles such as campaign and care-related activities. As such, I suggest representativeness cannot in this case always be combined with a significant commitment to engagement in research.

CONTENTS

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to these or any other university for degree, and does not incorporate any material already submitted for a degree.

Signed

Dated **01/06/15**

CHAPTER 1

Introduction

Against the background of a well-established literature on patient organisations (POs) and social movements, this thesis aims to provide a rich case study of organisations working with and for people with Motor Neurone Disease (MND) and Parkinson's Disease (Parkinson's). Conducted between October 2010 and March 2014, this research uses a mixed qualitative methods approach combining interview, observation and web analysis data to provide an in-depth account of four POs representing people with Parkinson's or MND in the UK: PUK, The Cure Parkinson's Trust, the MND Association and MND Scotland.

The role of POs could be said today to be in question. It is increasingly common for POs to engage in research, providing funding, aiding recruitment and disseminating results. However, it can be the case that 'traditional' self-help group activities providing community support are gradually supplanted by the aim to carve a role for the PO in setting the research agenda. The assumption often appears to be made that research and support activities are incompatible, and that POs can find it difficult to combine advocacy with research leadership. Nevertheless, many contemporary POs try to continue to combine these roles, resolving any tensions between them in different ways. This thesis therefore aims to explore the way in which POs working in the field of neurodegenerative disorders attempt to perform different, potentially conflicting, roles in patient and research communities.

The thesis aims to contribute to the literature on POs and social movements by examining the question: what does representation mean to the POs working in the field of MND and Parkinson's? I approach this central question by exploring the different relationships involved in PO work and the different representations that take place in the many roles POs perform, representing themselves and their work to patients and the public, and patients in interactions with both the public and research communities. The thesis therefore examines four questions relating to patient representation:

1. How and to what extent do POs create and represent a sense of collective identity amongst their members?

2. How and to what extent do POs present themselves as patient representatives to their members and the public?
3. How and to what extent do POs represent and support patient involvement in the research agenda?
4. How and to what extent do POs influence the research agenda?

The research examines how POs can create and enforce a sense of responsibility to, and within, the patient community. I analyse both how employees understand their responsibility to advocate for patients and how people living with the conditions perceive their responsibility to the PO and the community as a whole. The research contributes to structural accounts of POs in the literature by examining how representation is expressed in the different roles that POs perform and the tensions and negotiations involved.

Epistemological Approach

The initial focus of this research was the creation of public ethical discourse around experimental neuroscience; and the extent to which POs are part of social movements in health and research. Exploring this area, I began my research with an ethical landscaping exercise, examining the two conditions, their position in mainstream media, and the medical and social support available to those diagnosed and their families. I also explored the principal ethical policy debates in which the POs engage or which tend to involve MND or Parkinson's to some degree. I then conducted a review of the literature on POs and social movements and began data collection, seeking to understand the different activities of POs working with and for people with Parkinson's and MND in the UK.

Because this project started with a social movements perspective, I entered into it expecting to explore the impact that POs have on traditional research power structures. This literature tends to draw attention to the work behind creating a collective identity and shared agenda, and then consider how that agenda was promoted by an established movement. In particular, it tends to be assumed that collectivisation and subsequent collective representation is a common characteristic of POs and social movements. To a certain extent, I made similar assumptions to those made in the literature −that charities could be expected to be representative of and acting upon the patient view. It was after exploring the academic field, and talking to some participants that I considered the issue of representation more carefully.

In response to the structural analyses of POs found in the literature, I became increasingly interested in the impact of changing activities and campaigns on the POs' relationship with members, the public and scientific researchers. Analysing early interview data highlighted a range of different claims about the representativeness of the organisation and how 'representation' was performed in practice. This theme, together with the fact that representation as a concept was largely absent in the PO and social movements literature I reviewed, led me to the conclusion that I could make a contribution by exploring what representation means in this context.

Much of the analysis within this thesis is thus based on the 'claims' to representation made by the people I have interviewed as well as the organisations online, in the media and at the events I have observed. Information gathered from interview as well as online data about the work that the POs do is used to build an understanding of how representation occurs in practice. Throughout the thesis, I use the data to present both a descriptive and normative account of representation from the perspective of the POs I explored and the people I interviewed, occasionally drawing attention to any differences between the claims that people make and the actions I observed. However, I also draw on political philosophy theories of representation to suggest an external framework for evaluating POs and their role in the patient and research communities.

The remainder of this chapter will outline the academic and biosocial context of this research. Beginning with an overview of the literature exploring PO engagement in research, the chapter will go on to provide an introduction to MND and Parkinson's. I will describe the symptoms and available treatment options, as well as the principal public debates with which they are associated. I will then outline the Parkinson's and MND POs that work in the UK, detailing their history, size and primary objectives. Finally I will provide an outline of the thesis as a whole, and the contribution it makes to the study of PO engagement in research.

POs as Social Movements

Perhaps due to their focus on activism, empowerment and increased influence in health and research, a significant link is often made in the literature between POs and social movements. Indeed, the language used in much of the literature on POs suggests that the terms 'PO' and 'social movement' are almost interchangeable. This is particularly apparent in the language used to describe both POs and social movements and the motivation behind

their formation. Both social movements and POs have been defined to all intents and purposes as networks of collaboration, providing an outlet for shared discourse(Baggott et al., 2005, Allsop et al., 2004, Brown et al., 2004, Panofsky, 2011). Furthermore, POs are often observed to be created to effect change in policy, care or research schedules, in response to a negative experience, either from the disease itself or as a patient receiving care(Baggott et al., 2005). Here, the connection to social movements seems quite clear as the purpose of a social movement is to bring about socio-political change, by attempting to emancipate a social group from association with medical authorities, for example, or to gain a greater role in medical decision-making. Moreover, it has been suggested that health issues lend themselves particularly well to social movement mobilisation as problems relating to health and the body are easily relayed to the public(Epstein, 1998).

What is surprising about the link between social movement theory and the PO literature, however, is that there seems to be a common assumption that all POs have, or should have, the principal aim of acting as, or part of, a social movement. This is illustrated in assertions that merely fundraising for research is not radical enough and is not likely to allow POs to influence the research agenda effectively(Baggott et al., 2005, Panofsky, 2011). Although it might seem likely that a PO would want to influence scientific research and policy, given that many tend to act in this way, it does not necessarily follow that all POs are created with the view to becoming part of a social movement. Moreover, it has not been clearly defined whether each PO constitutes a social movement in itself or whether the creation of such organisations is indicative of a wider social movement in health.

PO Structure

As well as frequently aligning POs with social movement theory, many studies have focused on structural analysis, aimed at categorising POs by focus, activities and membership. For example, Baggot, Allsop and Jones(2005), analysing why different 'types' of group vary in their health policy engagement, and consequently their level of influence, split POs into three categories: condition-based groups, population-based groups, and formal alliance groups. Though useful for analysing the focus of PO policy campaigns, it could be said that separating these categories excludes the possibility of analysing those that cross the boundaries. For instance separate national groups might occasionally join together to campaign as an alliance, whilst at the same time continuing to represent their own individual patient populations.

Other analyses have explored PO structure by focusing on the relationship between POs and health and research professionals(Panofsky, 2011, Rabeharisoa, 2003, Allsop et al., 2004). These accounts are perhaps best summarised by the three models used by Rabeharisoa(2003) to describe PO engagement strategies: the auxiliary, the emancipatory and the partnership models. Groups working under the auxiliary model are described as "mutual self-help organisations" with a role somewhat outside the scientific and medical worlds they seek to influence. Such POs will acquire scientific knowledge to enhance a notion of lay-expertise, but will tend to defer decision-making to scientific experts(Rabeharisoa, 2003). Importantly, as POs will rarely disagree with 'the experts', they often become "grant-making" organisations with no tangible influence on the research conducted. They fund research but only involve patients in decision-making processes after expert peer review identifies key research areas(Panofsky, 2011).

According to Rabeharisoa(2003) this imbalance in power and influence led other groups to follow the emancipatory model for action. Moving away from the paternal model of medicine, emancipatory organisations act as advocacy groups –representing the needs of those marginalised by a system that affords 'the expert' greater influence. In terms of research, this model calls for a more participatory approach, giving the patient more influence and a greater stake in the research process(Allsop et al., 2004, Rabeharisoa, 2003).

In the partnership model, scientific knowledge and the experiential knowledge of the patient are seen as equally important, rather than being in conflict. Experiential knowledge becomes operational in research, rather than being an adjunct to scientific knowledge as in the auxiliary model or a replacement as in the emancipatory model. Therefore, groups will tend to focus on leading their own research agenda rather than seeking either merely to fund projects or focus on participatory research. Scientific expertise is sought in an advisory capacity but decision-making is undertaken by the PO itself not 'the expert'. This suggests that the partnership model aims to empower POs to move beyond being a stakeholder, grant-maker or protest group, to influence more effectively the research conducted on the disease in question(Rabeharisoa, 2003).

Attracting Research Collaboration

Much of the literature further suggests that in order to influence research or healthcare strategies POs must actively seek a relationship with professionals in these fields, making

collaboration attractive to them(Baggott et al., 2005). Consequently, despite centring on such concepts as patient empowerment and emancipation, the literature often focuses on what POs can offer to other organisations and researchers and not the opposite.

POs have been shown to encourage professionals to collaborate with them in two very different ways. Either, POs will professionalise their approach and patient knowledge to enable interaction with researchers on a professional level(Van De Bovenkamp et al., 2009, O'Donovan, 2007). Or, they will socialise their interactions, using social and personal experience of illness to ground researchers in the purpose of their work(Panofsky, 2011). In both cases POs are thought to be responsible for engaging researchers, and encouraging collaboration. Consequently, the assumption remains that collaboration must be made to appear attractive.

"Professionalisation"

Addressing the move to create a PO-professional partnership, Van de Bovenkamp et al.(2009) have described a process of "professionalisation", whereby POs professionalise their interactions with medical and scientific professionals in order to be involved in decision-making processes. Others suggest that the influence that POs and social movements can have depends on the resources available to them(Corrigan and Tutton, 2006, McCarthy and Zald, 1977, Nahuis and Boon, 2011, Carroll, 2006, Jenkins, 1983). This implies that those with access to more resources will be more able to interact with researchers in a professional capacity. In contrast to the partnership model then, this would suggest that in order to influence the course of research in their field, POs must adopt the resources and language of the professionals with whom they interact.

Social movements theory has also defined "professional social movements". Under full-time Management direction, members support professional social movements in name but generally do not actively participate in the movement's campaign. As such, the leaders of these movements often do not address the community for which they speak, focusing instead on policy and industry circles(Della Porta and Diani, 2006). This suggests that a particular risk of professionalising patient or social movement organisations is that a move to legitimise interactions in policy and industry circles corresponds to a lack of interaction with the membership or community.

Sociability

In contrast, others have suggested that the significant power that POs can utilise when engaging with researchers relies on their access to patient experience rather than scientific professionalism. That is to say that, POs can better influence research by promoting their unique access to patients' personal accounts and experiential knowledge of the illness(Panofsky, 2011, Baggott et al., 2005, Baggott and Forster, 2008, Epstein, 1995, Naiditch, 2007). This knowledge, it is suggested, is looked upon by scientific professionals as a means of improving the quality of research and ensuring ethical practice, allowing the inclusion of the views of potential participants in research planning(Dresser, 2001, Corrigan and Tutton, 2006, Goodare and Lockwood, 1999).

Panofsky(2011) has termed this type of interaction "sociability", describing the process by which POs can build a working relationship with researchers by using more emotive forms of information than pure scientific fact. In fact, Panofsky states

> the factors suggested by the literature –resources, mobilization, timing, expertise, and organization– are insufficient for understanding how PAOs influence research if they do not take account of sociability(Panofsky, 2011)

Therefore, the professional or scientific resources often emphasised in the literature are seen as incapable of explaining alone the amount of power that a PO can wield in research. For Panofsky(2011), it is the less formalised forms of interaction that aid PO influence rather than scientific resources and expertise.

This implies that the question of whether or not POs are able to match the expertise of their research associates may not be as important in determining patient power as other studies have suggested. This is partly because the grants that a PO will provide are likely to be too small to encourage a sustained business-like relationship with collaborators. By emphasising the emotional and social importance of a research project, POs can better secure continued researcher interest researchers when the grant ends(Panofsky, 2011). This process has been described as a way of humanising a project for researchers(Terry and Boyd, 2001, Terry and Terry, 2011, Terry et al., 2007). POs are seen to be sources of social capital, allowing researchers to redefine their work as benefitting patients, activists and society as a whole(Baggott et al., 2005).

That being said, Panofsky himself also alludes to the problems involved in a sociability approach. Panofsky both implies that POs ordinarily require scientific expertise to be translated to their needs and that socialised relationships could replace scientific interaction with researchers(Panofsky, 2011). Given that others(Weiner, 2008, Van De Bovenkamp et al., 2009) have clearly shown the reluctance of researchers to devolve power and knowledge to "lay experts", relying too much on social interaction could mean that POs appear even less professional than researchers might already assume them to be. By suggesting that the notion of "cognitive barriers" becomes irrelevant, Panofsky's(2011) sociability might in fact prevent POs from interacting with researchers on the level that the researchers would expect. This illustrates one of the problems that POs might encounter in engaging in research, since too great a focus on patient-based knowledge can distance organisations from the scientific discussions that researchers are likely to expect.

Risks of Research Engagement

Another significant feature of the PO and social movements literature is the risk posed to the PO by a relationship with researchers. One criticism raised against sociability-like approaches in particular is that, rather than significantly influencing research, using patient experience to attract researchers can result in POs being used merely to bolster the reputation of research and researchers(Callon and Rabeharisoa, 2003, Panofsky, 2011, Dresser, 2001, Langstrup, 2010, Mintzes, 2007, Radin, 2006). Crucially it has been suggested that the resultant "professionalisation" of patient experience can have a detrimental effect on the representative legitimacy of the PO itself(O'Donovan, 2007, Van De Bovenkamp et al., 2009). The main risk attached to collaboration with researchers (the pharmaceutical industry in particular) is that POs can occasionally be perceived to have sacrificed some of their supportive, representative, function(Baggott et al., 2005, Mintzes, 2007, Epstein, 1995, Allsop et al., 2004). This seems to imply a certain intrinsic lack of ethical conduct amongst research professionals that can be transferred to the POs with whom they interact.

Indeed, because of the generally bad reputation that these companies have, many POs will choose not to collaborate with them(Mintzes, 2007, Rabeharisoa, 2003). This illustrates the problems that POs can face when attempting to gain influence over scientific research; they must choose between having a stake in research agendas and avoiding the stigma attached to such partnerships(Callon and Rabeharisoa, 2003). This presents an interesting

dichotomy since POs, in engaging with research, can be seen as both promoting the involvement of their members and risking becoming less representative.

This therefore illustrates the difficulty in defining and categorising POs or social movements, since legitimacy to some might be seen as undue professionalisation to others. It may be presumptuous to assume that social movements can only truly advocate for the needs of their members if those members have an active part in the campaign. However, it seems that if externally-led goals are followed to such an extent as to decrease the organisation's capacity to influence the governing systems it seeks to change, then the organisation's legitimacy as an advocate for a particular cause might be called into question. This highlights the usefulness of representation as a conceptual tool, since the success or failure of POs to attract collaboration is often evaluated in terms of the effect research engagement could have on the PO's reputation of providing support.

Introduction to MND and Parkinson's

This research began at a time of great change for the MND and Parkinson's POs. In this section I will provide an account of the conditions, their media profile and the POs at the centre of this research. I will give a brief history of each PO and discuss how their size, services and funding activities have changed in the course of this project.

Motor Neurone Disease

First described in 1874 by Jean-Martin Charcot, Motor Neurone Disease (MND) is a neurodegenerative disease, that affects 7 in 100,000 people a year and is characterised by progressive weakening of muscles causing difficulty of movement, breathing and eventually swallowing(MND Association, 2012a).

There are four different types of MND, which differ in symptom progression and life expectancy. *Fig.1* shows the information that the MND Association provides on the different forms that MND can take

Fig.1 Four types of MND(MND Association, 2014a)

Life expectancy from symptom onset can vary from 6 months to 5 years, although those with PLS can live for several decades. It is thought that 90% of cases are sporadic, showing no familial link, although there are four known genetic causes. Not much is known about the causes of this condition and there is no known cure(The MND Association, 2011b). Furthermore, MND has a comparatively low media presence, with articles about MND and research appearing very rarely both in the news and in academic journals. Searches for academic studies returned results comprising mainly of scientific research papers, looking at the genetic aspects of MND. Academic databases hold little to no recently published sociological literature on the social and ethical aspects of this disease. At the start of this research, an extensive literature review revealed only one academic article looking at the use of support groups by those with MND(Locock and Brown, 2010).

However, MND is often referenced in public ethics and policy debates relating to end of life care. In particular, MND is often linked to debates around the provision of palliative care, since legislation stipulating that palliation is strictly intended for the last stages of illness means that people with MND can receive insufficient care(Clarkson, 2008, The MND Association, 2011a, Public Accounts Committee, 2009, Gérvas et al., 2009, Heath, 2010). Furthermore, MND is mentioned remarkably frequently in studies, reports and documentaries looking at the legality of assisted death. In part because of the palliative

nature of MND care, this is perhaps also due to the fact that a disproportionate number of those who apply for services such as those provided by the *Dignitas* clinic in Switzerland are diagnosed with MND(Russell, 2011, Newsnight, 2011, European Court of Human Rights, 2010).

MND Treatments

The only licensed drug used to treat MND is Riluzole (Rilutek), although others are undergoing clinical trials(BNF, 2010). All other treatments are based on palliative and social care, treating symptoms as they occur in order to improve the comfort of people with MND. The most common forms of treatment act to alleviate problems with eating and breathing as throat and respiratory muscles weaken. Feeding tubes (PEGs and RIGs) are fitted abdominally or endoscopically to allow non-oral feeding if necessary. These procedures are often no-longer possible once respiratory difficulties begin, which means that people with MND may have to decide whether or not to have feeding tubes fitted early on in their disease trajectory.

The main procedures used to treat breathing difficulties are ventilators and non-invasive ventilation (NIV). NIVs are more commonly used, as these are seen as less invasive by both patients and health professionals as they allow speech to continue and their use can be stopped and started again with fewer problems. In contrast, ventilation is generally used after complete respiratory failure, raising significant ethical issues with respect to ending treatment, since withdrawal becomes an end-of-life decision(HealthTalkOnline, 2008, Kent, 1996).

Parkinson's Disease

First defined as "the shaking palsy" by James Parkinson in 1817(Parkinson's UK, 2014c) Parkinson's Disease is a neurodegenerative condition that affects 1 in 500 people (127,000 people in the UK). Characterised by a loss of dopamine-producing brain cells, Parkinson's affects muscle function, swallowing and saliva control, with the most common motor symptom presenting as resting tremors and rigidity. The life expectancy on diagnosis can be several decades, so that unlike MND, people with Parkinson's can often live a 'normal' life-span. As *Fig.2* shows, Parkinson's is also often associated with cognitive symptoms including memory loss, dementia and occasionally hallucinations where people with Parkinson's "experience a feeling that an animal or object is present, just next to them, but they do not actually see it"(Parkinson's UK, 2011b).

Fig.2 Symptoms of Parkinson's(Parkinson's UK, 2014f)

Parkinson's disease, or idiopathic Parkinson's, is classified as the most common condition in the group of diseases termed Parkinsonism that share some common symptoms. There is also thought to be an inherited form of Parkinson's, although this is very rare and there is no conclusive evidence for heredity. Diagnosis is based on a trial and error process, monitoring response to Parkinson's medication. If there is a positive response to the medication Levodopa, the individual is diagnosed as suffering from idiopathic Parkinson's.(Parkinson's UK, 2011a, Parkinson's UK, 2011b).

Importantly, many of those I met as part of this research who were living with Parkinson's expressed considerable disagreement with the word "disease", suggesting that the term "Parkinson's Disease" was an inappropriate description of such a varying condition. To reflect this disagreement, in contrast to medical convention, in this thesis I will continue to use "Parkinson's" alone as a term and will use the word "condition" rather than disease where necessary.
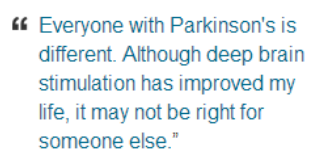
Parkinson's has a significantly higher public presence than MND both in academic and media circles. Projects by the Michael J. Fox Institute frequently featured in the media at the start of this research(Mail Online, 2011, Herz, 2009, Parkinson's UK, 2010a). Furthermore, using Zetoc alerts as an –albeit limited– indicator of publishing activity, Parkinson's has featured more prominently in published academic studies, both scientific and sociological. As such, Parkinson's tends to be the focus of more academic study than MND. Despite its slower progression, Parkinson's is also commonly raised in debates around assisted death. Most remarkably, in recent years Parkinson's has been the subject of legislative debates about assisted death due to two Bills tabled by MSP Margo MacDonald,

who herself had Parkinson's(BBC News Online, 2010a, BBC News Online, 2010b, Black, 2013).

Parkinson's Treatment

Similarly to MND, Parkinson's treatment consists predominantly of symptom management and control. The main drug used to control motor symptoms is Levodopa, although much research is currently being conducted into alternatives with fewer side-effects(Shoulson, 2010, Parkinson's UK, 2011b, Parkinson's Disease Society, 2008). A major problem caused by Levodopa is the 'wearing-off' effect, where efficacy systematically decreases at every dose, so that increasingly higher doses are needed(Zappia and Nicoletti, 2010). This makes physiotherapy and other non-medical movement therapies all the more important in Parkinson's treatment, since levodopa cannot control motor symptoms long-term. In particular, many people use occupational therapy to improve their gait(Snijders and al., 2011, Nieuwboer, 2008, Nock, 2007).

There are also some surgical treatments available for the motor symptoms of Parkinson's, including lesioning where a destructive lesion is made in the brain using electric currents, in order to damage specific brain cells(Parkinson's UK, 2014d). Another relatively recent development in Parkinson's care is the use of Deep Brain Stimulation (DBS), where small electrodes and leads are implanted into the brain at one of three target sites, and connected to a "neurostimulator" placed in the chest. DBS sends high-frequency signals to the brain which can improve the movement disorders associated with Parkinson's. However, this procedure is risky and is not effective in everyone(Parkinson's UK, 2014a). As quoted on the PUK website:

Fig.3 Patient account of DBS(Parkinson's UK, 2014a)

Therefore, the characteristic symptom variability of Parkinson's can have a significant effect on the treatments available.

It can also be difficult to treat the non-motor symptoms such as depression. Some anti-depressants can react with Parkinson's medications, so that the treatments available for motor symptoms can disrupt the treatment of non-motor symptoms or the psychological effects of living with Parkinson's(Parkinson's UK, 2014b).

MND Association

The MND Association (MNDA) is the largest charity working for people with MND in the UK. It combines support and awareness campaigns, with a focused aim to provide more funding and resources for research into MND. MNDA was founded in 1979 by scientist Jim Tew after he was diagnosed with MND. A photograph of the first meeting suggests that MNDA initially had just 11 members. At the time, according to MNDA, there was very little information available for people with MND and neurologists alike, and no funding available for research on MND(MND Association, 2011c). Filling a gap in knowledge on MND was, therefore, one of the principal motivations behind forming MNDA. Performing the dual role of support for those diagnosed with MND and pushing for more research and information was the central objective of the association in 1979.

> 30th anniversary > Then > The Formal Constitution

THE FORMAL CONSTITUTION

The Motor Neurone Disease Association officially became a charity with its constitution adopted on 6 October 1979.

The objectives:

1. The relief of persons suffering from MND and its associated conditions by providing financial support for such persons and their families in cases of needs, and by providing or paying for items, services or facilities which are calculated to relieve the suffering of such persons and which are not readily available to them from other sources.

2. To promote research and the dissemination of the useful results of such research for the public benefit into the cause and possible prevention of the said disease.

Our vision then was as clear and direct as it is today.

Fig.4 MNDA constitution 1979(MND Association, 2011a)

In 1980, within a year of its registration as a charity, MNDA had successfully established its first research project at the Charing Cross Hospital(MND Association, 2011c). Therefore, campaigning for more research has been a core MNDA objective since its foundation, although *Fig.4* suggests that the primary goal was always to support people with MND(MND Association, 2011c).

At the start of this research MNDA consisted of 68 volunteer-run branches, 24 groups and 3 affiliate groups(MND Association, 2010a). In the latest report this has changed to 61 branches, 25 groups and 3 affiliates(MND Association, 2012b). The management of MNDA is overseen by the Chief Executive and the Board of Trustees(MND Association, 2010a, MND Association, 2012b). The Board of Trustees is advised by the Biomedical Research Advisory Panel (BRAP), and Healthcare Research Advisory Panel (HRAP) on the funding decisions made by MNDA regarding biological and scientific research, and health and social care research respectively. Both Panels consist of experts in biomedical and neuroscientific research, neurological medicine and palliative care, and two lay members. However, it is the Board, not the Panels, who determine the budget for each project(MND Association, 2011b).

Support & Campaign Agenda

As in 1979, MNDA continues to provide support and information for people with MND through its quarterly magazine *Thumbprint,* educational events and conferences, local support groups and the support hotline *MND Connect*. At the start of this research, the 2009 Impact report(MND Association, 2010b), reported a membership of 7,284, a staff of 134, and an annual income of £11,690,093. Comparing this to the most recent impact report available, for the year 2012-2013, membership has risen to 8,000 and staff numbers to 140, which suggests that MNDA is in a stable position

Fig.5 MNDA Impact 2012-2013(MND Association, 2013)

The wider impact of MNDA and its campaigns can also be seen in its social networking and website hit figures. In 2009, the MNDA website had 330,545 hits and its Facebook group had 917 "likes"(MND Association, 2010b). In the 2012-2013 report, the online impact is listed in Facebook and campaigning activities rather than the number of website hits, making comparison more difficult. However, it is apparent that social networking has become more important to the MNDA campaign strategy with Twitter followers increasing

from between 200-400 in 2011 to, 2,983 for @mndresearch and 2,715 for @mndcampaigns in 2014(MND Association, 2014c, MND Association, 2014b).

MNDA also campaigns for the improvement of MND care. As well as running educational events for healthcare professionals and members of parliament, MNDA provides services and equipment such as communication aids, wheelchairs and suction units, when the NHS or other care providers fail to provide them. MNDA also funds 18 specialist MND care centres(MND Association, 2010b, MND Association, 2013). A particularly important part of MNDA's care strategy is the Association Visitors, of whom there were 373 in 2009 and 330 in 2013(MND Association, 2010b, MND Association, 2013). The Visitors volunteer to care for and support people with MND in a similar way to a social worker or key worker, maintaining regular contact with a number of people with MND and their families. This illustrates that the support provided by MNDA is often more tangible than information alone, expanding to provision of care supplementary to that provided formally by the NHS or informally by family carers.

Research

In the last thirty years, MNDA has significantly increased its research contributions, investing £468,000 in new research in 2009, and £7.5 million overall into 39 different projects(MND Association, 2010a, MND Association, 2010b). By 2012-2013, 62 projects overall were supported in a £7.6m portfolio(MND Association, 2013). MNDA funds research into a range of scientific, clinical and sociological aspects of MND. The majority of projects funded by MNDA are genetics-based, looking to improve diagnostic tests by finding biomarkers, or investigating new DNA targets for therapy. However, it is also involved in projects investigating the quality of life of people with MND, in an effort to improve healthcare research and provision. For example one project investigated the impact of Non-invasive ventilation on quality of life, and another the issue of end-of-life decision making.

MND Scotland

The MND Association only represents people in England, Wales and Northern Ireland. Therefore there is a separate, though affiliated organisation in Scotland. Formerly the Scottish MND Association, MND Scotland (MNDS) was founded in 1981 by John MacLeod, who had MND. MNDS is smaller than MNDA, with 15 members of staff and an annual income of £1.7m in 2012(MND Scotland, 2013). It is, however, very similar in

terms of the support it provides for people with MND. It aims to provide information and support to all those with MND in Scotland, liaising with health and social care teams to ensure that people with MND get the right kind of support. It also leads educational events and campaigns for better awareness.

The nature of MNDS affiliation with MNDA is unclear. The *History* page on its website describes the formation of MND Scotland as independent – not mentioning MNDA at all. Founded only two years after MNDA, MNDS appears to have been set up specifically to cater for people in Scotland, so that there has always been a clear geographical separation between the organisations. However, MNDS was founded as the Scottish MND Association and they share a patron in HRH Princess Anne. This suggests that, although they split their responsibilities in terms of the areas they represent, MNDS and MNDA are connected or affiliated in some way. This makes MNDS an important organisation to explore in this project, despite the fact that it appears to be scaling back its commitment to research funding.

Research

In contrast to MNDA, MNDS only added research to its formal agenda in 2006-7. Until recently, research was funded sporadically, depending on the availability of finances. Now, funding is regularly provided for PhD studentships in basic and clinical science and sociological research, with £247,000 being invested in 2010. However, by the year 2012-2013 funding for research significantly decreased, as shown in *Fig.6* taken from the MNDS website:

Expenditure	£
Care Service	520,039
Information Service	264,283
Research	190,438
Fundraising	204,612
Cost of Generating Voluntary Income	96,158
Governance	21,890
Total	1,297,420

Cost of the Care Service includes funding our Care Team, Equipment Loan Service, Counselling Service, Befriending Service, and Small Grants Scheme.

Fig.6 MNDS Expenditure 2012-2013(MND Scotland, 2014)

Furthermore, the MNDS website does not provide information as to how the research department is organised and the name of an R&D director is not given. This suggests that the research funding activity of MNDS remains more informal than that of MNDA. Indeed

as *Fig.6* shows, MNDS invests significantly more in care than it does in research. Its particular focus on care services is also reflected in the 2012-2013 report.
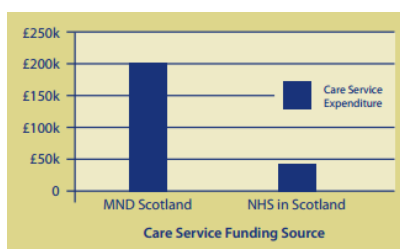
Fig.7 MNDS 2012-2013 Annual Report(MND Scotland, 2013)

Therefore, MNDS tends to focus more on care provision, due to a perceived lack of NHS care expenditure on MND in Scotland.

Parkinson's UK

Parkinson's UK (PUK) was founded as the Parkinson's Disease Society (PDS) in 1969 by Mali Jenkins whose sister was living with Parkinson's. PDS was founded with three core aims: to support patients and their families, to collect and disseminate information, and to encourage and fund research. The main reason for starting the group was that Jenkins and her sister had been unable to find a source of information written in layman's terms. This suggests that, at first, the central aim for PDS was to provide information to people with Parkinson's. PDS was renamed PUK in 2010, as part of an anniversary re-branding and, arguably, now has more of a research focus, with the funding of research listed as the primary aim in the 2010 impact report:

Fig.8 PUK mission statement(Parkinson's UK, 2010b)

This prioritisation of research can also be seen in the new tagline used by PUK: "Change Attitudes. Find a Cure. Join Us".

The overall governance and annual financial reporting of PUK is managed by the Board of Trustees. Four of the twelve current Trustees are living with Parkinson's, four have had a family member who was diagnosed with Parkinson's while the remaining four have expertise in health or social care, and the charity sector. Likewise, the Research Advisory Panel, which advises the Board on PUK grant-making activities, and Recruitment Interview Panel frequently involve people with Parkinson's.

Support & Campaign Agenda

Comparing the 2010 Impact Report and the latest available one for 2012, membership has increased from 34,000 to 38,600. Local groups have likewise increased from, 350 to 372(Parkinson's UK, 2010b, Parkinson's UK, 2012a). Furthermore, with an annual income of £23.9m (an increase from £17.1 million in 2009) and 305 full time staff, PUK is much bigger than the other POs at the centre of this study(Parkinson's UK, 2012b, Parkinson's UK, 2009). Another indication of the comparatively larger size of PUK, is its online impact. The 2010 Impact Report(Parkinson's UK, 2010b) states that PUK had 72,500 website hits per month and 1,600 Twitter followers. In 2012 Twitter followers have increased to 24,400.(Parkinson's UK, 2014e, Parkinson's UK, 2010b, Parkinson's UK, 2012a) and the website hits have also risen to an average of 130,000 a month.

Fig.9 PUK Impact Report 2012(Parkinson's UK, 2012a)

In terms of the services provided, however, PUK and MNDA are rather similar(Parkinson's UK, 2010b, Parkinson's UK, 2009, MND Association, 2013, Parkinson's UK, 2012a). PUK provides information and support to people with Parkinson's and their families through local groups and networks, and online forum and educational events. It also provides one-to-one support through support workers who conduct home, hospital and nursing home visits to help people with Parkinson's access the care and benefits to which they are

entitled. Additionally, PUK funds 310 specialist Parkinson's nurses in hospitals, hospices and other clinical settings to ensure people can access specialised care(Parkinson's UK, 2010b). It also actively provides training for health and social care professionals including GPs, care workers, and other care providers such as hospice centres, to help advance care provision for people with Parkinson's(Parkinson's UK, 2010b, Parkinson's UK, 2012a). Therefore, like MNDA PUK is significantly involved in providing supplementary care services, and advocating on behalf of patients to improve their care.

Research

In terms of research investment, PUK is by far the biggest charity of those at the centre of this project. PUK is currently funding 90 research projects and invested £5.7million in 2012 alone(Parkinson's UK, 2012b). The projects funded by PUK cover a range of different subjects, focusing on therapy, new models and symptom control. Many of the projects investigating what causes Parkinson's are looking at genetic factors. Likewise, several of the treatment-based projects are looking at potential genetic targets for new therapies.

PUK has also invested in qualitative research looking at the effect of Parkinson's on day-to-day life(Parkinson's UK, 2010b). Part of this involves looking for better symptom management, and one study commissioned at the start of this research investigated the use of Nintendo Wii games as a way to improve motor symptoms. As a result, a PUK member featured in a TV advert for Wii(Parkinson's UK, 2010a, Herz, 2009, Parkinson's UK, 2010b).

The Cure Parkinson's Trust

The Cure Parkinson's Trust (CPT) is a research charity founded in 2005 by four people with Parkinson's in order to fill a perceived gap in research specifically looking to cure Parkinson's rather than treating its symptoms. This suggests that it might have been founded in direct competition with PUK, as until 2005, PUK was the only major PO funder of Parkinson's research. There are no membership figures available for CPT, as supporters instead become "friends" who donate regularly to the charity and receive updates on its progress. However, like PUK and MNDA, CPT is very active on Twitter and Facebook though it has a significantly smaller following with 3,495 followers on Twitter and 869 likes on Facebook(The Cure Parkinson's Trust, 2014).

CPT is, structurally, the smallest organisation with only six members of staff. The President and the Trust Co-ordinator oversee the activities and management of CPT. The final four members of staff are the Research and Development Director, the Fundraising Manager, Event Coordinator and the Financial Secretary. The investments and grants that CPT makes are decided upon by the Board of Trustees, the R&D Director and President. There are currently eight people on the board, including two members with Parkinson's and the co-founders of CPT. Five have no previous relationship with Parkinson's or research, coming from managerial, CEO or directorial backgrounds in business, banking and law.

In contrast to PUK, MNDA and MDNS, CPT does not provide support or care activities, focusing instead on research. Although CPT does organise local meetings for people with Parkinson's, these are geared towards linking patients with researchers, rather than providing support. At each meeting scientists present current trends and possibilities in research and people with Parkinson's present their experience of the condition and the aspects of it that they would most like to see being researched. CPT also frequently surveys patient opinion in order to document individual people's illness experience and collect data on Parkinson's. As a result CPT has created a Parkinson's Self-Assessment Tool (PSAT) to enable people with Parkinson's to monitor their symptoms and keep track of the aspects that bother them most. This, CPT suggests, will help people to make the most of medical appointments allowing them to think about the question they want to ask in advance.

Another notable aspect of CPT, is that in all its activities there is a very distinct sense of activism and social change. For example, the following was found in the 2010 Annual report:

> There has never been a time in the evolution of science and healthcare when patients have had more opportunities to influence both the quality of their healthcare and the speed with which science moves from lab to clinic(The Cure Parkinson's Trust, 2011a)

Furthermore, at the biannual World Congress on Parkinson's, CPT's Patient Advocates take part in workshops with representatives of different research departments and the R&D directors from pharmaceutical companies in order to draw up plans for more patient-centred research. The engagement of people with Parkinson's is thus at the core of the CPT research strategy.

Research

Reflecting its singular purpose, CPT invested £717,198 of its total income of £980,103 in research in 2010(The Cure Parkinson's Trust, 2010). CPT's 2013 review states that "the Trustees committed over £1 million to new research projects" in 2012, but does not detail how much was spent(The Cure Parkinson's Trust, 2013). The central aim of CPT is to find a cure for Parkinson's; as such it only funds research which has the same goal. There is a particular focus on neuroprotection and regeneration so that few of the research projects that CPT funds look at symptom management, and none at biomarkers or diagnostics.

CPT also had, at the start of this research, a promotional partnership with the controversial online company 23andMe, which conducts genetic testing to provide people with information about their ancestry, and until recently disease carrier status. In 2013, the FDA (Food and Drug Administration) restricted the ability of 23andMe to compile and interpret genetic data related to health and illness, so that it can no longer provide members with health-related updates(23andMe, 2013). At the start of this research, however, the *Patients* page on the CPT website, had a section entitled *Genetic Testing,* which described a 23andMe project aiming to compile genetic data on Parkinson's "to enhance understanding of the disease and accelerate new discoveries and therapeutic breakthroughs"(The Cure Parkinson's Trust, 2011b). This study was not free for participants, however CPT described a promotion where the first 10,000 to sign up would be given a discount by 23andMe from $499 to $25.

Therefore, CPT provides a contrast to MNDA, MNDS and PUK by focusing only on innovative cure-based research and not providing any support activities. It is also the most outspoken in the aim to find a cure, tending to discuss it more optimistically than the other POs.

PatientsLikeMe

Although it does not form a significant part of my analysis, PatientsLikeMe is an important organisation to mention here, due to the considerable excitement surrounding it at the start of this research and the fact that it was often mentioned during interviews with PO staff. PatientsLikeMe.com is an online forum based in the USA, and since 2010 its membership has increased from 114,327(PatientsLikeMe, 2005) to "More than 220,000 members,"(patientsLikeMe, 2014). Searching the database shows that of these, 8,432 members have Parkinson's and 6,495 MND.

PatientsLikeMe is a for-profit organisation, created in 2004 by Jamie Heywood as a result of his brother Stephen Heywood's diagnosis with MND five years earlier. The forum was created in response to the lack of treatments available for MND and the deficit in clinical research. PatientsLikeMe aims to link patients, allowing them to discuss the different aspects of their disease experience with others(PatientsLikeMe, 2005). However, as well as discussing problems, patients share data on their symptoms, the treatments they take and the trials in which they have participated. This means that people can match their data against others and the average of the group, creating graphs and diagrams to see how they compare and gain a deeper understanding of their disease progression.

PatientsLikeMe also conducts research, using member data to analyse the effect of treatments, social programmes and symptoms on disease progression and quality of life. Significantly, the data has been used to conduct a study that approximates a clinical trial. By analysing data on people with MND taking Lithium, which was being trialled by a research group at the time, PatientsLikeMe discovered that the drug had no overall effect (good or bad) on MND symptoms. This was discovered a year before trial results were published in the Lancet giving the same conclusion. One drawback to the PatientsLikeMe study design is that it is purely based on data analysis, and depends on the number of members that happen to be eligible. This means that their research is often dismissed as not statistically powerful enough for conclusions to be drawn. Nevertheless, the potential impact that this huge collection of data could have on both Parkinson's and MND research seems important, not least because it is becoming a new way to provide data to research groups(Heywood, 2009). PatientsLikeMe further illustrates the increasing shift towards promoting the patient-led research and patient involvement advocated by POs and other organisations such as INVOLVE. However, PatientsLikeMe presents a particularly unique method for instituting patient-led agendas.

Thesis Outline

This research takes place in a context of social and organisational change. The two incurable neurodegenerative conditions are increasingly drawn into controversial public, legislative debate around ethical issues in death and dying. The POs working with and for people with MND or Parkinson's in the UK are also undergoing changes, in size, branding and research focus. As well as aiming to ensure that research into new treatments receives funding, the POs are increasingly called upon to provide a number of different support services, including the provision of supplementary healthcare. Therefore, PUK MNDA and

MNDS are continuing to attempt to combine a significant role in research with a commitment to patient support. Furthermore, the way in which research funding is described by the POs, in particular CPT, suggests that the concept of patient involvement forms a significant part of the PO role in research.

Beginning with a review of the literature around POs and social movements, Chapter 2 examines the political literature on the models of representation and the growing literature around the concept of patient involvement, in order to provide the theoretical and empirical background for this research. Chapter 3 gives a description of the research methods used in this project as well as the study limitations. I also discuss the ethical considerations involved in recruitment, data collection and analysis.

Taking into account the number of care, support and research services that the POs provide, and the symptomatic heterogeneity of the conditions themselves, Chapter 4 then explores how a sense of collective identity is created in such potentially divergent patient populations. The literature describing POs as collaborative networks and alliances implies that POs can be characterised by a sense of collective purpose, both within and between organisations(Baggott et al., 2005, Allsop et al., 2004, Brown et al., 2004, 2006, 2008). However, Hardnack(2011) has also suggested that PO or social movement members can experience and express various divergent identities, which can alter their commitment to the movement with which they engage. Therefore, I explore what it means to be a member of a collective or community, given that individual members are likely to have different experiences of PO membership and the illness itself. Using interviews with PO employees, volunteers and patient members, I explore the question: how and to what extent do POs create and represent a sense of collective identity amongst their members? This chapter explores how PO employees understand their membership-base as individuals as well as a collective entity.

The analysis of collective identities suggests that it can be difficult for a PO to connect the identification of individuals as members of the patient community as a whole, with a similar commitment to membership of the PO. It is therefore important to consider the way in which the organisation attempts to maintain a sense of collectivisation through its activities. Chapter 5 explores the way in which PO employees and members understand and describe the "day job" of their organisation. Illustrating that POs are increasingly met with a dual responsibility to support and research agendas, this chapter examines the

question: how and to what extent do POs present themselves as patient representatives to their members and the public? This is to explore how POs maintain a sense of collective responsibility to, and ownership by, the community in the context of existing intra-organisational tensions regarding PO management. Furthermore, I explore what the patient-centred approach can tell us about the way that patient representation can be defined in this context.

The literature around POs and social movements suggests that POs, are not always able to focus on engaging with research funding and management, as well as providing advocacy and support(Baggott et al., 2005, Rabeharisoa, 2003, Rabeharisoa and Callon, 2002, Callon and Rabeharisoa, 2003, Novas, 2006). Interviewing and observing MND and Parkinson's PO members and employees, and analysing the increasing use of social media, also suggests the potential for a conflict of interest between the need to maintain support for research amongst the membership, and to appear scientifically knowledgeable and professional amongst research associates. Furthermore, the inconsistency in the way in which the wider role of the PO is described by employees and members means that the patient-centred agenda promoted by POs can be difficult to identify in PO support activities. This raises the question as to how POs continue to promote their commitment to a patient-centred agenda in research. Building on the growing body of literature on patient and public involvement in health and research, Chapter 6 examines the question: how and to what extent do POs represent and support patient involvement in the research agenda? This chapter also begins to analyse the PO-researcher relationship by exploring tensions that promoting patient involvement can create.

Exploring the extent to which POs can enact their theoretical commitment to patient involvement and a patient-centred agenda (in support services as well as research) suggests that POs can be less than successful in overturning the assumptions that research associates make about the capabilities of people with MND or Parkinson's to understand and engage with scientific discourse. To analyse this further, Chapter 7 looks in more detail at the role of the PO itself in the research process. This chapter examines the amount of influence POs are able to exert over the researchers they fund and the research agenda they promote. Given the difficulty in enacting patient involvement in research, I explore the differences between the way in which research and the PO-researcher relationship is promoted by the PO amongst its membership and the way it is structured and funded in reality. This

analysis therefore addresses the question: How and to what extent do POs influence the research agenda?

The concluding chapter then draws together the main conclusions of this thesis, and summarises the potential for generalising the findings to other POs or patient populations. Using political theories of representation to provide a conceptual background, this chapter discusses the way in which the main findings of this research can be summarised under a central problem: that POs must balance the responsibility to represent their members with the responsibility to represent researchers. This chapter reviews the challenges that POs face when combining these responsibilities in the various roles they perform in the patient community as well as in research. Focussing on the issues around collective identification, patient-centred support agendas and patient involvement research, I summarise the challenges I have observed in the way in which Parkinson's and MND POs attempt to combine a commitment to community representation with a greater, more respected role in research. I then discuss how this idea of a dual responsibility to members and researchers, and resultant tensions, can help to explain some of the challenges that POs encounter when attempting to combine roles in support and research.

Exploring the extent to which POs increasingly conform to researcher opinion, I discuss the way in which the responsibility to represent research associates creates the conflict between research and support agendas. I suggest that this case study contributes to the study of POs and patient involvement by illustrating the complexity of the analysis and definition of patient representation. Public claims for representativeness, and even representation of the patient experience in research as well as to the public, are not enough to define representation in the context of POs. The concept involves, not only the added responsibility to represent researchers and the conflicts that creates, but also requires an understanding of the intended audience of campaigns that promote the PO as patient representative. This is because, the patient experience that POs choose to present, can be based on its intended effect as much as it focuses on the lives of people with MND and Parkinson's.

CHAPTER 2
Literature Review: Representation

Introduction

As discussed in the introduction to this thesis, much of the literature exploring POs and social movements comprises structural analyses of how the organisations work. This body of literature centres on the idea that organisations have a responsibility to engage with and influence research, health and policy decisions, and to mobilise their patient community towards that cause. Indeed, it has been suggested that one of the principal roles of POs in general is the pooling of patient and professional knowledge and experience in order to facilitate an environment of "mutual learning" where patients and professionals collaborate as partners(Barbot, 2006). This suggests that in engaging in research, POs gain a responsibility not only to ensure the production of knowledge about their illness of interest, but also to create an effective partnership with scientific and medical professionals as well as patients(Van De Bovenkamp et al., 2009, Diamond et al., 2003, Entwistle and Watt, 2006, Hickey, 1998).

However, although representation has been discussed broadly in the literature on disability rights(Finkelstein, 2004, Hughes, 2009, Shakespeare, 1993, Shakespeare, 1996, Thomas, 2004) and Silverman's(2008) study on "self-advocates" within Autism groups, there seems otherwise to be very little explicit discussion about representation and what it means in the context of POs or social movements. Despite the fact that much of the literature focuses on such issues as rights, and the position of POs in policy settings, representation seems to be taken for granted as a concept applicable to POs. As such, the representativeness of POs is not often addressed as a problem or question to be answered. Explicit mention of representation in the PO literature tends to discuss demographics and the proportion of a patient population represented by a PO(Grinton et al., 2013). Implicitly, the idea of representation appears throughout the literature through discussions about collective, alliance and network formation. For example, research activity has been described as increasing the need for patient representation. As patients become more involved in research, they become more invested and interested in the research process(Callon and Rabeharisoa, 2003). As a result it is assumed that future PO research activity indirectly becomes representative of member interests and POs can redefine research as a representative activity(Callon and Rabeharisoa, 2003, Baggott et al., 2005). Another aspect

of the debate around patient representation, therefore, is the extent to which research engagement informs and affects the definition of POs as representatives.

Some of these studies also acknowledge that research engagement can have a potentially negative effect on patient representation. As suggested previously, it seems to be common for POs that become more involved with industry researchers in particular, to be described as potentially less able to represent the needs of their patient community(Callon and Rabeharisoa, 2003, Panofsky, 2011, Dresser, 2001, Langstrup, 2010, Mintzes, 2007, Radin, 2006). Indeed, Baggott et al(2005) make a clear differentiation between POs and "research charities", the latter described as less representative due to their perceived distance from patient priorities. Therefore, it is thought that, as POs increasingly collaborate with researchers, they can begin to lose sight of their priorities as patient representatives accommodating instead the needs of researchers(Rabeharisoa and Callon, 2002, Pinching et al., 2000, Wood, 2000, Epstein, 1998). It does not necessarily follow that because peers view a PO as less representative, that it is unable to represent the needs of its members. Nevertheless, this illustrates the connection between PO engagement in research and a wider issue of patient representation.

In contrast to the PO literature, the definition of representation has been debated in political science literature for centuries. Political scientists have long been examining the different ways in which representation can be defined and enacted. In particular, the debate around the meaning of political representation has centred on how much it signifies a transfer of power, and whether it can be analysed in terms of symbolism – how ideas, interests and people are "re-presented" by a person, picture or description(Runciman and Vieira, 2013, Fairlie, 1940).

To a certain extent exploring power structures, Edmund Burke defined two models for representation: the 'trustee model' and the 'delegate model'. Trustees are seen as making decisions and judgements for the public, who are assumed not to have the information necessary or the inclination to make a rational decision. Delegates on the other hand are seen as relying more closely on the opinions of constituents, and their decisions are more dependent on instruction by the public(Ferber et al., 2007, Eulau et al., 1959, Fairlie, 1940, Runciman and Vieira, 2013, Urbinati and Warren, 2008). Similarly, in Pitkin's Principal-Agent typology the Principal (constituent) sends their Agent (representative) to present their views and represent their interests with varying degrees of independence. Pitkin

suggests that Principal-Agent representation can be described as a matter of either "acting for" or "standing for". Echoing Burke, then, Pitkin defines representation as a unidirectional relationship, where the representative can either be closely directed by the constituent, and thus stand for their interests, or be more independent, acting for them. Defined elsewhere as a difference between instruction and interpretation, this view of representation, despite allowing the constituent or principal a role in the relationship nevertheless places much of the power and responsibility with the representative(Runciman and Vieira, 2013, Urbinati and Warren, 2008, Stewart, 1996, Pitkin, 1967). As Stewart(1996) points out, although Pitkin stipulates that both the representative and the represented must act and think independently, she argues that because this has the potential to create conflicts and disagreements, the representative is responsible for ensuring that no conflicts take place.

In fact, many have struggled to define a satisfactory model for representation in part because it is such an ambiguous concept. In prescribing both the need for a coherently identified "represented" group, and the fact that this group needs a representative to act for it, representation as an idea implies both presence and absence, public engagement and lack of interest(Runciman and Vieira, 2013). Some have interpreted this ambiguity to mean that any attempt to describe representation models will be detrimental to gaining an understanding of what the role actually entails and what representatives do(Saward, 2006). Shapiro(2009) has extended this view to suggest that representation is so vague as to make it useless in analyses of democracy and the political process. However, it could be said that, dismissing representation theory entirely is also misguided, since for modern democracy to work there needs to be some concept of a representable group or "people", to allow the Governmental democratic process to work.

Others suggest that ambiguity illustrates that representation is rarely as simple as the Principal-Agent or Trustee-Delegate typologies might imply. Representatives are unlikely commit completely to one model or the other(Brown, 2006, Fairlie, 1940, Mansbridge, 2003, Eulau et al., 1959, Ferber et al., 2007, Parkinson, 2003). Instead Burke's dichotomy is thought to provide two end-points of a continuum, where representatives can act as both trustees and delegates to different degrees in different contexts(Eulau et al., 1959, Ferber et al., 2007, Stewart, 1996).

> One can think of representation as a continuum, with the Trustee and Delegate orientations as poles, and a midpoint where the orientations tend to overlap…Within this middle range the roles may be taken simultaneously, possibly making for conflict, or they may be taken serially, one after another as conditions call for (Eulau et al., 1959)

Eulau et al.(1959) suggest that a representative might occasionally act as both a trustee and a delegate. This is because a representative (in the political context) will be responsible to both the state and a "district". Consequently, it will be necessary to combine the interests of both – representing the state as a trustee and the district as a delegate. This is defined as the "politico" role(Eulau et al., 1959). Perhaps due to this need for flexible interpretation, political theory tends to approach analysis of representation by placing conditions on its definition; for example the right to object, public interest and authorisation.

Drawing on this political debate, this thesis will build on the literature exploring PO involvement in research, by analysing how representation and the represented can be understood in this context. This literature review will introduce key concepts and themes within political science discussions around representation which might help to understand the representational responsibilities that are typically ascribed to POs. Although this thesis is not based on political science methods, as most discussions about representation and its definition have taken place in this discipline, it was important to include this literature.

As they are the most commonly discussed historically defined models for representation, I will focus on the trustee-delegate, principle-agent and social contract models. The question of what representation means is very broad and exploring in greater detail the literature around the history of political representation is beyond the scope of this thesis. However, to broaden my own understanding of this complex debate I have included both the principal historical accounts of representation as well as some more contemporary analyses of how to interpret and apply previous theories to the modern political context. Furthermore, to assist the development of my research questions and methods I included both descriptive accounts of how representation takes place and normative analyses of how representatives should act. This is to provide a contextual example of how political science has been applied elsewhere. As outlined in the introduction to this thesis, my research comprises a combination of normative and descriptive analysis. Therefore, the literature review will serve to highlight the different concepts and theories that might be used to analyse both how POs do and should act as patient representatives.

Incorporating the literature that has begun to comment on non-governmental representation, this review will explore the ambiguities often highlighted in the literature discussing political representation. I will examine the debates around the right to object to representatives and their actions and the way in which "interests" are defined. I will also discuss the different conditions placed by the literature on the definition of representation or representatives. Exploring the way in which collectivisation and identity politics are discussed, I will illustrate the way in which such concepts as community "interests", authorisation and accountability are implicit in the PO and social movements literature. I will then explore patient involvement as an area of the sociological literature on POs where the links to representation are more explicit. Drawing on the political debate around participation and expertise, I will review the way in which patient involvement has been discussed in policy, healthcare and research contexts. Finally, I will re-visit the principal ideas raised in this review, highlighting those that might be most helpful in the current study. This is to summarise the conceptual background to the thesis as a whole.

The Right to Object

A prominent debate in analyses of political representation is the extent to which the represented have the right to consent or object to the actions of their representative. On the one hand, discussing the social contract created in representational relationships, Hobbes stipulated that in becoming a "people" represented by one individual, the public must assume responsibility for the actions of the representative. A prevalent criticism of this perspective is that, by effectively discounting public objection, it could pave the way for representatives assuming extreme power. By ascribing the representative creative power but sharing responsibility for the consequences between the representative and the "people", Hobbes effectively excludes the "people" from the democratic process and allows too great a transfer of power and control to the representative(Fairlie, 1940, Runciman and Vieira, 2013, Kymlicka, 2002).

In contrast, most contemporary theories of democracy and representation focus on consent rather than responsibility. Thus, for representation to be effective the representative must obtain the consent of constituents both to act as their representative and for the decisions they make. As a result it is also crucial that the represented, or the constituent, has the right to object to the representative's actions and decisions(Pitkin, 1967, Runciman and Vieira, 2013). Consequently, the right to object has been described as in direct opposition to trustee-based models of representation, since they stipulate that constituents cannot object

because they are not in a position to make rational, considered choices about policy decision(Runciman and Vieira, 2013).

At first glance, then, the right to object appears to be related to notions of political power and public freedom, stipulating that representation requires some level of public participation. Indeed, some commentators have interpreted this to mean that the representativeness of governing bodies should be measured not by the power they hold but by the control to which constituents have access(Stewart, 1996). However, others have taken this condition to mean that some groups of people are excluded from participation in a representation relationship. Most notably, Pitkin(1967) suggested that children cannot be represented in any circumstances by parents or teachers or others in a pastoral care position since they cannot object to the decisions that people make. Furthermore, since parents will speak for their children without specifically being asked to do so, it could also be said that children rarely give their consent to people who might be observed to be representing their interests(Runciman and Vieira, 2013). Although it might be true that children do not have an opportunity to consent or object to the decisions their parents and teachers make, this interpretation of the right to object has potentially wide-reaching consequences for the way in which representation is analysed. If objection is so important as to be an excluding factor, this raises the question as to how marginalised or disadvantaged groups could ever be represented in policy and other contexts. If Pitkin's ideas are to be extrapolated, if a group or section of society is unable to raise objections to the policy decisions that affect their lives, they cannot be described as participating in a representation relationship. Therefore, this interpretation of the right to object ignores the possibility of two types of representation. An elected representative might make decisions that do not directly represent marginalised groups within their constituency. However, since the group is technically made up of constituents, she is nevertheless physically present as *a* representative.

The issue of defining representation through the right to object has been addressed in studies exploring Non-Governmental Organisations (NGOs). Acting as they do in overtly political debates, campaigning or advising on policy issues, NGOs are often described as representative organisations, speaking on behalf of particular marginalised communities. However, they are rarely elected or selected by the community in question, acting instead as self-authorised representatives(Runciman and Vieira, 2013, Urbinati and Warren, 2008). Consequently, NGOs tend to act in the interests of a group, but cannot necessarily be

described as directly acting for it. This means that members of that group arguably will not have the opportunity to engage with or object to the perspective the NGO presents(Runciman and Vieira, 2013).

In fact, Stewart(1996) has suggested that, although the opportunity to object is the measure of governmental representativeness, opportunity is the operative word. Actual responsiveness on the part of the constituent is not necessary, merely the fact that they could interject if they wished. This, the author states, will allow representation to be defined while still allowing the representative to lead the decision-making process(Stewart, 1996). However, this seems to allow empty or false promises. If actual objection is not necessary, then it is possible that a representative might promise the right to object for her constituents, but will not facilitate a physical interaction where the objection takes place. This again raises the question as to how objection and representation might be defined here. Although stipulating that constituents must have a right to object might seem like a straight-forward move to preserving equality and public influence in the political process, it does raise several difficulties with respect to how representation is defined. A condition that appears to be placed on representatives to prevent undue power and a lack of public interaction, can so easily be interpreted as enforcing a trustee-like distance between the representative and the views of the represented.

Defining "interests"

A similarly difficult condition to define is that of public "interests". The idea of a representable, knowable set of "interests" is key to most definitions of representation(Saward, 2006, Runciman and Vieira, 2013). Indeed it has been suggested that a representation relationship is only possible in matters of interest. This is because representation has been described as impossible in matters of taste and unnecessary in matters of fact(Stewart, 1996). Looked at simplistically, keeping the interests of the represented at the heart of political discussion seems an understandable condition to place on the representative. However, it is unlikely that the interests of all the represented will be constant and the same. Furthermore, there is some debate within the literature as to whose interests the representative should represent. For example, Burke's ideal representative, is primarily accountable to the state, focusing on national rather than local interests(Runciman and Vieira, 2013, Urbinati and Warren, 2008, Ferber et al., 2007).

Likewise, Pitkin views political representation as primarily concerned with interests rather than individual people. However, the focus on interests is interpreted to mean that it is not necessary for each person to have elected the representative, only that that their interests are then represented(Conniff, 1977). This illustrates the effect that the definition of "interests" can have on the way in which we understand representation itself. Pitkin defines representation in such a way that again ignores the possibility that within the political system a representative might fail to accurately represent the interests of their constituents, while remaining in the physical role of representative. In such circumstances, the elected individual could be described as both unrepresentative and *a* representative(Runciman and Vieira, 2013). As such, whereas the Trustee-Delegate model purposefully discounts individual interests, Principal-Agent theory arguably focuses on interests to such a degree as to bypass the role of the represented and the physical presence of the representative.

Rubenstein(2014), on the other hand, has suggested that, since their decisions are unlikely to always benefit everyone, representatives should seek instead to make decisions that do not significantly undermine the interests of any party with whom they interact(Rubenstein, 2014). Although this standard to a certain extent lessens the burden on representation theory, by no-longer stipulating that "interests" are unilaterally kept central to the political process, it nevertheless assumes that the interests of any group of people can be defined enough for a representative to understand and act upon them. This assumption can limit the scope of analyses of representation to explore the possibility that the represented comprises several different, perhaps competing, sets of interests(Saward, 2006). It is perhaps for this reason that Runciman and Vieira(2013) suggest that a particular weakness of many representation theories, is that they are very difficult to apply to situations where one or more representatives act on behalf of a larger group. This is precisely because it will be difficult to represent the wider interests of the group as whole without acting against the wishes of some members of it. This, the authors contend, risks the formation of a "permanent minority" in the group, who are given the opportunity to object to decisions and to present their interests but are ignored in favour of the interests of the majority(Runciman and Vieira, 2013). Furthermore, it can be the case that a representative will be called to represent interests of which the represented are unaware(Brown, 2006). This further raises the question as to whether "interests" must be expressed by the represented in order for the representative to act on them and whether consent is always necessary for representation to be effective.

Additionally, no representation occurs in isolation, but will be informed by the cultural and political context(Saward, 2006). The way in which the representative interprets and acts on the interests of their constituents will be informed by the way in which they understand and delineate the constituents as a represented group. Rather than comprising a single, unidirectional relationship, as in the Principal-Agent and arguably Trustee-Delegate models, representation is likely to involve different parties who interact in different ways. As well as involving the Principal-Agent relationship, representation will include third party actors from different political parties, organisations and groups who will also be interpreting the way in which representatives present the represented and their interests. Therefore, analysis of representation must also consider the construction of Principal-Third Party and Agent-Third Party interactions(Runciman and Vieira, 2013, Urbinati and Warren, 2008). This is again where non-electoral representation provides a useful example of representation theory in practice. As interest groups, NGOs, and most other forms of non-electoral representative will rarely present more than the interests of a finite group, can they ever be evaluated in terms of a representation theory that places so much emphasis on public interest? This question has clear implications for the present study, since organisations similar to POs tend not to be evaluated as representative.

A potential answer might be found in Urbinati's(2000) work on advocacy. The author suggests that rather than placing advocacy in opposition to representation, advocacy can be evaluated as representation and vice versa. Although they will never be described as representative of the wider public, interest groups are indisputably involved in representation activities by providing one, albeit selective, public perspective. It seems to me that although interest groups and other unelected organisations have been excluded from representation theory, this analysis relies on a very inflexible interpretation of the word representation, and the models that are typically discussed. Their dismissal tends to result from discussions about the extent to which they represent the public, and a particular set of interests. As such there seems to be a gap in the literature exploring how non-governmental organisations could be described as representative, instead of focusing on why they are not.

One way in which "interests" has appeared implicitly in the PO literature, is in the discussion around collective and community formation. For example, Gamson(1996) describes the potential tension that can arise between organisational and community priorities. As a "community organisation", the group must maintain their social and

political position as an organisation whilst at the same time not weakening ties to the community itself. This mirrors the discussion around representing community interests without significantly impeding the interests of any individual member of that community(Rubenstein, 2014). Many studies looking at POs and social movements in health, frequently refer to 'networks', 'alliances' and 'collectives' implying an assumption that patients and POs collaborate and work together(Baggott et al., 2005, Allsop et al., 2004, Brown et al., 2004). For example, in writing about PO networks, Baggott et al(2005) suggest that PO involvement in health policy constitutes a collaborative movement in health. Others describe the power of POs as 'bringing people together' into a cohesive mobilised collective(Gibbon and Novas, 2008, Rabeharisoa and Callon, 2006). Consequently, a significant purpose of POs and social movements alike is thought to be to foster community ties that can originate from as well as inspire collectivisation. Although representation is rarely explicitly mentioned, discussion of collectivisation in this way does imply that the PO is on some level seen as a patient representative. That is to say that POs are described as a collectivising, unifying factor that will empower patients in policy debates

More overtly, the study of biosociality tends to describe PO communities in terms of their engagement in and use of biopower(Gibbon and Novas, 2008, Rabinow and Rose, 2006, Shostak, 2004, Epstein, 1998). Rabinow and Rose(2006) suggest that the engagement of "biosocial communities" such as POs in biomedicine and science could lead to a new definition of biopower as a "[strategy] for intervention upon collective existence in the name of life and health". That is to say that the involvement of a PO (community) in research requires individuals to act in others' interests as well as their own. Therefore, viewing POs as "biosocial communities" provides an interesting way to understand the way in which they might be viewed as representatives – collectivising interests and sharing the responsibility to represent them.

Authorisation

Representation is also often assessed through the degree to which the representative is authorised by those they represent. Historically, authority has been described as a matter of transfer of power. For example, Hobbes suggested that people can only become "a people" by being represented by one "sovereign" person(Fairlie, 1940, Runciman and Vieira, 2013, Kymlicka, 2002). Others, most notably Locke, described the social contract theory of representation as a process by which agencies are gradually given authority to govern.

Rather than being one instance in which the people give their consent, the contract in this case comprises a series of incremental "consensual exercises" which overall serve as a social contract giving that representative authority(Waldron, 1989).

More recently, within deliberative democracy theory, however, the idea of authorisation is related to notions of self-determination and equality rather than power per se. Echoing the consent/objection condition, it is seen as crucial to the democratic process, and the representation relationship, that the constituent has the power and opportunity to authorise those acting as representative(Pitkin, 1967, Urbinati and Warren, 2008). In democratic political systems this condition appears straightforward, as there are election protocols in place that allow representatives to gain a collective authorisation from their constituents. However, in other contexts the process by which authorisation is gained becomes more difficult to define. Within deliberative democratic discussions, it is often the case that secondary representatives such as citizen panels will be chosen to deliberate on behalf of smaller sections of the community, or for a particular cause. These, though potentially elected in the same way as political representatives, will often be chosen or selected either as a random selection of the community or for a particular purpose(Brown, 2006). This makes the concept of public authorisation more complex to identify because it raises the possibility that representatives can be selected by means other than direct election by the public. Brown(2006) suggests that in these cases representatives gain authorisation either through the fact that they have been selected by elected officials or an officially sanctioned, randomised process. Alternatively, depending on the discussion at hand, the representative can be authorised to act by virtue of some form of expertise on the subject(Brown, 2006). This suggests that as well as being hard to define outside of the formalised election process, authorisation has been described in some contexts as obtainable indirectly, not requiring the input of the public or the represented.

This is a very important part of the debate surrounding the definition of representation, since, as Eulau et al.(1959) point out

> The term "representation" directs attention, first of all, to the attitudes, expectations and behaviours of the represented - to their acceptance of representatives' decisions as legitimate and authoritative for themselves… the reasons they have for doing so, their rationalizations of the legitimacy and authority of the decisions made by their representatives(Eulau et al., 1959)

When analysing representation it is important to consider, not only the extent to which "the represented" accept the decisions made by representatives, but also the reasons why decisions are deemed acceptable. This is because the word "representative" can mean merely that the method for electing representatives has been approved by the public, not that the individual is seen as legitimate. As a result, support for policy decisions can illustrate no more than an assumption that they are correct because the process by which decision-makers were chosen has been accepted(Eulau et al., 1959). Therefore, it is also important to consider what "representative" means in different contexts – in particular whether it is used as a technical term denoting procedural authorisation.

This is precisely the objection that Rubenstein has raised regarding the analysis of NGOs as representatives. Discussing what Urbinati and Warren(2008) describe as surrogate representation, Rubenstein(2014) suggests that NGOs can only ever be described as "second best" representatives. Curiously, the author contends that because of this, and because the NGO would not describe itself as directly representative, representation theory cannot be used to analyse the work of the NGO. Furthermore, she suggests that representation theory would ignore all "other activities" in which the NGO engages and that studies should instead focus on the way in which the organisation responds to or misuses its power(Rubenstein, 2014). This idea seems to stem from the fact that the community for which the NGO claims to speak has not directly selected the organisation. Although this might be true, this analysis of NGOs does ignore the possibility raised by others(Runciman and Vieira, 2013, Brown, 2006) that representatives can argue for interests of which the represented are unaware. Furthermore, Rubenstein constantly refers to contexts in which NGOs nationally and internationally represent their particular cause or community. As such, despite arguing for the inappropriateness of representational analysis of NGOs, the study itself appears to be an evaluation of the extent to which NGOs can be described as representative. Although NGOs are perhaps less connected to the groups they represent, it seems misguided to interpret this lack of direct involvement as proving the uselessness of representation as a concept in a context where the author herself admits that representation is one of the activities in which NGOs participate. Furthermore, as Parkinson(2003) points out, contexts where people have an interest in a discussion but no desire or inclination to participate in the deliberation is precisely where representation plays an important role.

At the heart of these debates, is the issue of accountability. The idea that effective representation requires the representative and her decisions to be held accountable to the represented has been a feature of most representation theories to date. However, the manner in which accountability is enforced has been open to debate. For example, in Burkean analyses representatives are held accountable for their decisions by having to present their actions to the public(Conniff, 1977). Likewise, some deliberative democracy studies describe accountability as the process of "giving an account"(Brown, 2006). Therefore, although it seems to stipulate some form of public control over the representative, many theories interpret accountability to mean that the representative must merely present the decisions, right or wrong, in a public forum. Interestingly, one reason that is often given for this interpretation is that 'true' accountability, demanded by the represented, is not possible because of the "informational deficit of most citizens"(Brown, 2006). That is to say, demanding that representatives justify their actions requires knowledge and expertise to which most people will not have access(Brown, 2006, Dunn, 1999). Therefore, beyond viewing accountability as difficult to define, some have described it as impossible to ensure due to the lack of public expertise. This has interesting implications for the way in which representation is analysed, since the representative, once elected need never justify decisions and actions to the represented. This would beg the question as to where the representative's lasting authority comes from, if one of the principal conditions placed on the democratic representation relationship is seen as impossible to uphold.

Some have explored the notion of authorisation through the concept of descriptive representation, which assumes a direct link between social identity and social perspectives or interests, so that an individual selected from a particular social group can be expected to present the same perspective and decision as others from a similar background(Brown, 2006, Runciman and Vieira, 2013). This concept is best summarised by the criticism waged against interest group involvement in political deliberation. In speaking for a particular group, interest groups have been described as too representative of a narrow section of society. Because they speak for particular groups or issues, interest groups are often evaluated as unrepresentative of the wider public and consequently inappropriate participants in public deliberations. Consequently, interest groups are often viewed by policy makers as descriptively unrepresentative, including too small a range of public perspectives(Parkinson, 2004).

How, then, do interest groups continue to play a role in public deliberation, campaigning on policy issues on their members' behalf? Parkinson(2004) suggests that rather than widening the scope of their discourse, interest groups will often make their cause more specific, and gain public support for it via petitions. By making the cause publically relatable, the interest group gains the ability to claim to be more publically representative – creating a public interest in their cause that they can then claim to represent(Parkinson, 2004). However, it must be said that this representativeness relies on technicality – the interest group has not become more widely representative but rather creates the impression that it has done so.

Community Identification

An aspect of the PO literature that implicitly involves the idea of descriptive representation is that exploring community identity. Indeed, the working environment of the PO is thought to hinge upon the definition, mobilisation and maintenance of community identity. Unified identities, including common diagnosis and illness experience are seen as so important by many PO theorists, that the "fragmented" character of cancer movements, is curiously looked upon as less successful(Baggott et al., 2005). This is despite the self-evident success of the great many cancer campaign and research organisations working in the UK.

A significant aspect of social movement and PO literature that relates to representation is therefore analysis of their engagement in identity politics. In particular, social movements and POs are thought to aim to change the social identity of their constituents, often by taking ownership of that identity and any stigma attached to it. This goal can also be observed in the creation of lay experts as described in most studies of PO engagement in research, and indeed the literature describing professionalisation(Van De Bovenkamp et al., 2009, Corrigan and Tutton, 2006, Epstein, 1987, Epstein, 1998, Epstein, 1995, Novas, 2006, Terry and Boyd, 2001, Terry et al., 2007). In many such studies, POs are characterised as involved in identity formation. Focusing particularly on the formation of illness identities upon diagnosis, and the creation of scientific expert identities through engagement in research(Silverman, 2008). Indeed, it has been suggested that, participation in, or membership of, a PO can not only create, but also permanently cement in an individual an identity specific to that cause. For example, in the case of Muscular Dystrophy organisations in France, Rabeharisoa and Callon(2006) describe participation as "endow[ing] the patients or their direct representatives with a long-lasting identity as both

the objects and the subjects of research". This echoes political science debates around the way in which the representative and the represented are co-created and authorised. In this case the existence of the PO both validates and is validated by the patient or membership identity.

Collective Identities

In fact, Bernstein(1997) has suggested that the creation of a collective identity is necessarily the ultimate goal of a social movement. Others since have noted that collective or community identities rarely precede the creation of the communities or organisations themselves, but are forged in collective action(Gamson, 1996, Gibbon and Novas, 2008). Once created however, collective identities can become a reason for people to join the community or organisation in question, and may ensure lasting membership through the cultivation of a sense of "we-ness"(Gamson, 1996, Hardnack, 2011, Bernstein, 1997). That being said, it has also been suggested that as one community will be comprised of several individual identities, individual patients can also experience various divergent identities depending on the context in which the act. As Barbot(2006) notes, patients inhabit different worlds, both social and medical, each giving them a different view of illness and disease. That being the case, it is to be expected that patients have varying conceptions of their illness experience, which they express in different ways, depending on the perspective that they use. However, since social categories and therefore social identities are not static, individual identities can also vary in their prominence depending on their social context. That is to say that an individual can have numerous identities attached to the different roles they play in different situations (patient, mother, daughter for example), that will become more or less important depending on the social situation(Hardnack, 2011, Lock, 2008, Stryker and Burke, 2000). Indeed as Stryker and Burke(2000) describe

> [people possess] as many selves as groups of persons with which they interact

Therefore the identities expressed by the individual are strongly informed by the groups in which they participate. Thus, it could be said that by bringing otherwise unconnected individuals together, POs have a potentially significant part to play in the way in which their members identify individually, with each other and as a collective.

However, it has been suggested that community identities can be weaker than personal activist identities(Stürmer and Simon, 2004). Crucially, although defining individuals by diagnosis can mean they lose their subjectivity, the focus on genetics highlights differences between individuals that could prevent lasting identification with the illness group(Brekke and Sirnes, 2011, Lock, 2008). Furthermore, it is thought that the unpredictability of genetic diseases will mean that the individual's "personal identity" will rarely change, further weakening ties with the group(Lock, 2008). Consequently, it could be expected that individual members sometimes prioritise their needs over those of the community.

Therefore a particular difficulty of fostering community identity, and then representation of the collective, is that it necessarily involves the individual's own identification as someone living with an illness. A member of a PO is likely to express at different times both their identity as someone living with a disease or disability and the identity attached to a diagnosis or symptoms shared with a wider community. In order to combat the potential impact of symptomatic differences on community identification, it has been suggested that most POs will revert to a collectivisation around social or experiential identities(Wehling, 2011). This would imply that in order to successfully promote and represent a collective identity, POs must distance themselves from the very biological reason behind their formation. However, in much of the literature, POs are not generally observed to move away from discussion of illness and patient identity, instead engaging with the differences between members and indeed the individual's personal experience of living with the condition of interest(Rabeharisoa, 2006, Rabeharisoa, 2003, Barbot, 2006, Olzak and Ryo, 2007). As such, it seems more likely that POs will combine a focus on biological and experiential identities when forming and maintaining their communities. This underlines the importance of observations in the political literature, that in analysing representation, the motivations behind the way that representatives understand and construct the represented must be considered(Runciman and Vieira, 2013, Urbinati and Warren, 2008).

Patient Knowledge

Relating directly to political science debates around constituent independence, influence and accountability, much of the literature examining the creation of POs and collective identity involves some discussion of patient self-ownership. It is suggested that the responsibility felt by patients over their own biological identity leads them to desire more control over their own health. As Allsop et. al(2004) describe, by viewing their illness in terms of their biological identity, POs and their members can view any insufficiencies in

care or research as targets for action to allow them to gain ownership over their bodies and consequently their health outcomes.

Jasanoff(2005) has related this sense of ownership to the information the individuals hold. Here the "knowledgeable citizen" will demand control over technologies that impact upon her own life. As she gains understanding of her condition, the individual will demand more influence over its treatment. This illustrates the need to combine biological and experiential identities, since the patient view is legitimised both by their biological knowledge and their experience of patienthood. A second effect, therefore, of the focus on biological identity is that it may encourage POs to seek to reconstruct a more positive and powerful patient identity. Often, as suggested above, this leads to a greater focus on the patient experience, further legitimising the individual's experiential knowledge of the illness(Allsop et al., 2004). That is to say that, faced with the potentially negative social identity of someone personally responsible for their illness, patients and POs can seek to create a positive identity as lay experts able to challenge the establishment(Brown et al., 2004).

In contrast, studies of biosociality have described the way in which new identities form around new knowledge(Gibbon, 2008, Gibbon and Novas, 2008, Brekke and Sirnes, 2011, Hughes, 2009, Novas and Rose, 2000, Wehling, 2011). Similarly, Rabeharisoa and Callon(2006) and Jasanoff(2006b, 2006c) have described a process of identity formation and collective action through the creation of collaborative lay-professional partnerships. Through a process of "co-production", the "layperson" becomes a "knowledge-bearer", with an active role in research(Jasanoff, 2006a). This 'active' role can vary from fundraising to research participation, development, and dissemination; however all aspects of involvement confer upon the former layperson the status of "scientific practitioner"(Novas, 2008). As Lynch(2006) notes, words such as "expert" and "science" tend to denote agency, credibility and authority. Consequently, it could be expected that the increasing focus on patient expertise might increase the credibility given to experiential knowledge. This is, in many ways, at the heart of PO activities, given that they tend to aim to enhance the importance of patient needs in professional circles. Importantly, rather than POs focusing on patient experience *instead of* biological identity, these studies suggest that biological identity and knowledge can be woven into patient experience in order to legitimise the expertise and importance of the layperson or patient. Mirroring the literature on citizen panels(Brown, 2006), the PO and social movements literature describes the

importance of authorising the traditional "lay patient" as an expert capable of engaging in professional discussion. This not only authorises patient participation in the discussion but also strengthens the PO's case as a patient representative, by placing the organisation at the heart of the authorisation process.

Echoing descriptive representation theories, as politicising and enacting a collective identity becomes crucial to health related movements, POs can increasingly assume the decisions they make are those of the collective(Hughes, 2009). Furthermore, POs can gain credibility by emphasising the experiential knowledge to which they have access and the lay or patient identities of their membership(Wehling, 2011, Martin, 2008). Therefore, the identities possessed by patients, can allow POs to gain authority as representatives amongst both medical and scientific authorities. Indeed, the fact that POs are created and led by patients themselves is often seen as evidence of their representative legitimacy. As a result, laity is often conflated with representativeness(Martin, 2008, Baggott et al., 2005). Indeed, some authors seem to assume that any action by POs can automatically be described as the action of patients. For example, in Novas'(2006) *Political Economy of Hope,* PO funding becomes 'funded by patients'. This points to a particular aspect of the PO role that is implicitly related to the representation debate: patient and public involvement.

Participation: Patient & Public Involvement

Related to the idea of descriptive representation, and the debate around lasting representational authority, is citizen or lay participation. In health, the increasing importance of Patient and Public Involvement (PPI) is thought to have originated from changes in health policy requiring participatory medicine. Since the 1980s, there has been a particular focus on patient participation in health policy in order to enable responsiveness to public demand and improve the quality of care provision(Baggott et al., 2005, Callon and Rabeharisoa, 2003, Hayden, 2007). At the root of this policy change is an increased emphasis on lay expertise as an important source of knowledge. Particularly, it has been suggested that appealing to the lay expertise of patients improves the legitimacy of health policy decisions. This has also been the case in research sectors, where the move towards participatory research has seen the 'research subject' become the 'research participant'. Here too, PPI is believed to improve the quality of research design as well as increasing public support, by more accurately meeting the needs of patients(Dresser, 2001, Corrigan and Tutton, 2006). In this section, beginning with an overview of the literature on

participatory politics, I will review the way in which PPI has been defined in health policy, healthcare consumerism and research.

Participatory Politics

Public Involvement has formed an important part of political science theories of representation. Although participatory politics is somewhat the norm in modern government, earlier theorists strongly argued against public participation. Burke, for example, did not accept the idea of public consultation, suggesting instead that the act of representation was a matter of presenting unattached interests, separate from local opinion. Burke's Trustee model thus assumes a lack of engagement by the largely uninterested public, and suggests that where representatives do seek to follow constituent opinion they must take care not to be too distracted by their individual interests(Conniff, 1977, Stewart, 1996). This was because Burke believed, due to the complexity of the public state identity, the essence of public interests would always be lost in the process of political representation. That is, the representative can only ever give an approximate, second-hand view of a policy's effect on "the people" and therefore cannot describe objectively the interests of the public. However, rather than advocating for greater public involvement to achieve a closer presentation of public interest, Burke interpreted this representational dilemma to mean that a desire for more transparency or public influence would be mis-guided(Runciman and Vieira, 2013, Brown, 2006).

In contrast, recent analyses have tended to focus on deliberative democracy, producing "talk-centric" rather than "vote-centric" views of representation(Kymlicka, 2002). Deliberative democracy theory explores the process of opinion-forming that takes place before votes or decisions are made. As such, it relies heavily on the idea that politics involves "authentic deliberation by all those subject to the decision in question"(Parkinson, 2003). Deliberative discussion with everyone affected by a particular policy or decision is quite unrealistic, nevertheless democratic theorists have suggested that representation should require more than merely "making present" the constituents and their interests, giving constituents a more active role(Runciman and Vieira, 2013, Brown, 2006).

However, despite being seen as increasingly important, public participation is viewed by some as fundamentally incompatible with any concept of representation which would necessarily require a process of substitution(Brown, 2006, Fishkin, 1997, Bowler et al., 2007). It has been suggested that increased interest in opportunities for public participation

are often linked to a dissatisfaction with trustee-like democratic processes rather than a genuine interest in participation. Therefore, enthusiasm for direct democracy, through referenda for example, comes from a sense of obligation to monitor political representatives rather than a desire to participate(Bowler et al., 2007). Thus, even when participation in politics is discussed, the general public is nevertheless assumed to be uninterested in being involved, engaging instead out of a sense of obligation. Furthermore, according to Fishkin(1997) the deliberative polls often used to encourage participation can too often become substitutes for genuine deliberation. The poll or referendum presents the decision that people would reach were they to deliberate, rather than genuine public opinion.

Mansbridge(2003) has addressed this issue of public engagement and influence by looking specifically at the role of deliberation and discussion in different models of representation. Using Habermas'(1990) discourse ethics and argumentation theories, Mansbridge(2003) argues that the assumption of equal respect between participants in a discussion allows representatives to retain some control over the direction that conversations with constituents take. For her, all forms of representation involve some level of public participation in political discourse, which neither precludes nor enforces genuine public influence over the outcome of deliberations and discussion. Crucially, she points out that delegate models and others emphasising the need for equal influence, must also acknowledge that the delegate can exert power in decision-making processes without being unrepresentative. It is to a certain extent to be expected that the delegate would set the agenda of a discussion, for example(Mansbridge, 2003).

Exploring the effects of the internet on public engagement, others suggest that the advent of online discussion boards has led to a "cyberdemocracy" where citizens can more easily contact representatives and as a result are more able to influence the political agenda(Ferber et al., 2007). However, it must be said that the public has long been able to communicate with political representatives, by other means than email or online discussions, so that cyberdemocracy is unlikely to break new ground in the representation debate. Indeed, Ferber et al.(2007) observe that in most cases, the public use resources such as Governmental websites as sources of information rather than opportunities to exert any influence over policy decisions. Therefore, even interactive forums, allowing political debate, are thought to result in little constituent power or influence. Cyberdemocracy has perhaps succeeded in improving access to debate and information, but has not allowed the

public to gain more tangible power over the decisions that representatives make(Ferber et al., 2007). It seems that rather than being related to existing media power structures, the failure of cyberdemocracy to develop could be connected to the ideas raised above about the obligation or otherwise of representatives to listen to constituents. If any model of representation allows the representative to decide at different times when to follow constituent wishes and when not to listen, then improved ease of communication will not increase public influence. If a representative is not obliged to act upon a letter sent to them by a constituent, they will be under no more obligation to read an email or discussion board. Therefore, in cyberdemocracy, as in other contexts, the influence of the public depends very much on the way in which the representative defines their own position on the trustee-delegate continuum.

PPI in Health Policy

Mirroring the trend for participatory politics, as a result of the growing policy requirement for participatory medicine, PPI is increasingly seen as a means for improving public health policy as well as healthcare itself(Parkinson, 2004, Renedo and Marston, 2011). Part of the reason for this, could be that PPI is often defined as an ethical requirement to ensure the effective engagement of patients in their own care(Crawford et al., 2002, Entwistle and Watt, 2006). For example Entwistle & Watt(2006) define PPI as a matter of fairness, ethical practice and ensuring "good quality healthcare". Indeed, PPI has also been linked to better quality of life(Grosset and Grosset, 2005). Directly reflecting the debate around political participation, several studies have extended this ethical definition of PPI as "fair" to suggest that it is a matter of democracy. It has been suggested that participatory medicine is important because involving patients in decision-making processes is more democratic than top-down models of healthcare, where clinicians make all the decisions about a patient's care(Van De Bovenkamp et al., 2009). Similarly, Diamond et al.(2003), have described PPI using Hickey's(1998) conceptualisation of it as a continuum ranging from information provision to consultation, partnership and finally user control. Crucially, the information–consultation end of the continuum is described as an approach based on consumerism, whereas the partnership–user control end is defined as "'a process of democratisation'"(Hickey, 1998, Diamond et al., 2003). Therefore, perhaps answering the political science debate, the authors make a distinction between consultation and partnership, to suggest that genuine democratic involvement of patients in healthcare decisions, requires more than the top-down process of providing information. Patients must have a partnership-based role in decisions rather than merely being consulted. Therefore,

discussions around PPI go further than those focussing on direct democracy, to suggest that participation is not enough to secure PPI.

Discussing the difference between participation and involvement, Thompson(2007) suggests that, although it requires a transfer of power, the form the partnership takes depends on the level of involvement the patient wants. Importantly, the author suggests that involvement can entail varying degrees of patient influence, depending on how involved a patient wants to be. Participation in decision-making, however requires some level of power transfer from the professional, to enable a degree of partnership in the process of making healthcare decisions(Thompson, 2007).

Despite being framed as a democratic process, built on the requirement to involve members of the public to represent the overall public view, it has also been suggested that PPI initiatives will be more successful for those patients who already have a tendency to seek control or more information. This has been discussed since the beginnings of the participatory health policy described above. For example Brody et al(1989) suggested that patients who approach meetings with a clinician intending to request more information or input tend to perceive themselves as generally having more control over their healthcare than those who do not.

Relating this to the literature as a whole, this could imply that PPI as a method for empowering patients in healthcare is dependent on the individual patient already seeking more power and control. This suggests that rather than generally empowering patients to take control of their care, PPI instead increases opportunities for influence for those who already take an active role in their relationship with care professionals. This would seem at odds with the description of PPI as a democratic, ethical process, since it improves the position of the few rather than patients in general. In fact, a significant part of the literature around PPI suggests that it is not intended to radically empower the patient population at all. For example, Crawford et al(2002) in their review of the literature examining user involvement implied that in some cases PPI in health policy was "not intended to devolve power to patients but to legitimise the decisions of policy makers"(Crawford et al., 2002, Harrison and Mort, 1998).

Relating this to the representation debate, studies exploring PPI as a representational activity have pointed out that, as is the case in any political deliberation, PPI initiatives

cannot involve everyone. As a result the issue of who has the authority to sufficiently provide the patient perspective is open to debate(Parkinson, 2004). Furthermore, the presence of a representative can make PPI even more difficult to define. Parkinson(2004) suggests that this is because representa*tion* is often confused with representative*ness*. That is to say that, because representation models often rely on a descriptive definition (where representativeness comes from similarity), representatives can either be given too much influence or be dismissed. It is for this reason that interest groups (or perhaps POs) might be deemed unrepresentative, because as an organisation they do not count as "ordinary people". In that case, a lack of descriptive representativeness is taken to mean that the group is unrepresentative. Alternatively, a group or individual's status as representative, can be interpreted as authorising them as a substitute for the involvement of the patient community. In the health policy context in particular, this representativeness often comes in the form of a "people's champion". Although it might be true that the champion is able to give a patient perspective, their authority originates in the idea that the "people" in question cannot speak for themselves. Consequently it could be said that representation in fact limits the scope of PPI by perpetuating the idea that the representative's role is to be involved on the patient's behalf(Parkinson, 2004).

The effect of representation on PPI initiatives has particular significance in the context of POs. This is because POs and the charity sector in general are often framed as a crucial participant in policy making, and participatory politics. However, in engaging in policy in this way, the PO can risk what has been termed "corporatisation", where they effectively become an official, professional partner of the policy process. They can consequently be obliged to follow the conventional norms of the policy process and the healthcare sector. This in turn limits the organisation's ability to champion the patient's cause and thus limits the input that patients themselves might have(Martin, 2011). This not only affects the way in which the PO role in health policy is reconciled with notions of representation and PPI but also has potential implications for the extent to which PPI initiatives in general can be described as representative of the patient view. By including representatives, participatory politics risks marginalising the role that patients the public have in health policy discussions. Indeed as Shapiro states:

> Why should we attach any legitimacy at all to a deliberative process
> that involved very few of those whose healthcare priorities were
> actually being discussed? (Shapiro, 2009)

In fact, this tendency to limit the influence that PPI initiatives give patients can be seen in the way in which it is described in the literature. Several authors seem also to suggest that, far from "devolve[ing] power"(Brody et al., 1989) PPI must be guided by medical professionals in order for it to be effective. For example, echoing the view criticised by Hickey(1998), Brody et al(1989) defined PPI as a process of knowledge transfer. This suggests that, as was the case in the cyberdemocracy discussion, the role of the patient is merely to receive information and as such to remain a less influential member of the partnership. Likewise, Davis et al.(2007) more recently suggested that, although patients could be ascribed a role in improving patient safety in the care setting, the role could only be that of a "safety buffer" so that the real responsibility remained with the professional. The patient role in healthcare systems appears to be somewhat limited by the continued need for a hierarchy where professionals act as guides and knowledge-holders who enable the patients' involvement. There remains a tendency, therefore, to impose a restriction on the amount of influence that patients can have even in a literature that generally advocates for a democratic partnership. Consequently, PPI in health is often described as a process for improving patient choice, as opposed to patient control.

PPI in Healthcare: Healthcare Consumerism

An example of how this is put into practice is health consumerism. As suggested above, part of the reason for a continued imbalance of power in the patient-clinician partnership, is that professionals are more likely to see PPI in terms of consumer culture rather than stake-holder control(Martin, 2008). Consequently, PPI in practice often remains a top-down transfer of tacit power, improving choice rather than involving patients in service planning. Here, the informed patient is given more responsibility to choose the path their healthcare will take and is thus more involved in the decisions made at an individual level(Baggott et al., 2005, Langstrup, 2010). This has to a certain extent become a part of the institutional landscape of healthcare provision in the UK. For example, today patients are given the choice of hospital, doctor and specialist when referred by their GP(NHS Choices, 2014). As a result, the process of accessing specialised care is now based on the choice the patient makes rather than the decision of the GP. Similarly, in private healthcare BUPA's recent campaign has the tagline "helping you find healthy"(Bupa, 2014). Here, patient choice takes a conceptual form, perhaps linked to the debate around the "somatic individual" raised above(Novas and Rose, 2000). The choice to access private healthcare, and the institution involved is to a certain extent based on the responsibility of patients to monitor and improve their own health. Therefore, consumerist PPI models involve

increased responsibility as well as increased choice. With this increased responsibility, patients inevitably have a greater stake in the treatments they are given and therefore the services that are paid for. The move towards patient choice has thus been described in terms of capitalist models, where consumers define demand and consequently the supply of services available(Jasanoff, 2005, Novas, 2006).

Although health consumerism has been described as leading to less patient power, by re-enforcing established systems of top-down information transfer(Hickey, 1998, Diamond et al., 2003), others have tended to ascribe more powerful meaning to the health consumer. It has been suggested that this process creates a new generation of patient who, as a 'health consumer', is no-longer obliged to accept externally determined healthcare(Allsop et al., 2004, Rabeharisoa, 2003, Dresser, 2001). In fact, Hughes(2009) has gone so far as to describe this transition as the "death of the patient". In this sense, consumer choice models of PPI are described as a means for overturning the power structures that keep the patient a passive participant in the healthcare setting.

Indeed, this rising influence of capitalism on healthcare is thought to have led to an increase in the mobilisation of "health consumer groups"(Allsop et al., 2004). These are groups representing the needs and demands of health consumers, typically affected by a particular condition. Therefore, it could be said that an institutionalisation of consumer demand-focused healthcare, as well as the importance placed on lay expertise and PPI, has legitimised or perhaps triggered collective action through POs. That is to say, firstly, that consumer-led medicine means that patients have a renewed entitlement to demand certain treatments, which might lead them to campaign for, or engage in activism around, the licensing and provision of new treatments. This is illustrated by the fact that pharmaceutical companies have been known to support initiatives to better inform patients about all of the options available to them(Langstrup, 2010). Secondly, the increased focus on PPI and lay expertise gives POs cause to promote their own involvement in decisions, as they can provide access to it. This illustrates the importance of the literature around PPI to the current research exploring the PO role in the community.

PPI in Research
As well as being a central concept to healthcare policy and the development of healthcare services, PPI is increasingly discussed as crucial to the research process. In particular, increased PPI has been linked to significant changes in the way in which scientific

information is created and distributed. For example, Anderson et al.(2012) describe the increasing importance of PPI in genetic research, due to the many online tools now available for patients to engage and participate in the creation of genetic databases, and even to conduct certain types of research. Mirroring studies describing PPI in the healthcare setting, the authors suggest that new ways of planning and conducting research signifies a "shift to more participant control"(Anderson et al., 2012). In fact, PPI is generally conceptualised in a similar way in relation to research, as it was in healthcare. It is often linked to patient empowerment and patient-professional partnerships, where patient influence is deemed to require a transfer of power from professionals so that patients can have a role in decision-making processes.

The move to involve patients in research decision-making has been a particular focus of the study of disability rights. Here the focus is not just on increased control over research results and benefits, but also greater service-user input into the decision-making and design stages of research. Beresford(2002) in particular has described three ways in which activists have argued for more user input: emancipatory research, user-controlled research and user involvement in research. Similarly to the descriptions of PPI in health policy, user involvement in research is described as ranging from consultation-based input to partnership-based influence(Hickey, 1998, Diamond et al., 2003). Interestingly, however, Beresford(2002) suggests that emancipatory research, whilst principally geared towards the empowerment of service users, does not necessarily have user *involvement* as its focus.

> User involvement has generally been treated by disabled researchers much more as a means to undertaking helpful research rather than as an end in itself. There are concerns (similar to those expressed in policy and practice development) that the nature and focus of participatory research encourages the abstraction of participation from its political and ideological relations. This is why the emphasis has been on emancipatory rather than participatory research. (Beresford, 2002)

Therefore, emancipatory research is seen as distinct from participatory research. The reason for this seems to be that participation as a goal is perceived by proponents of the emancipatory model to detract from the broader social issues of disability, focusing instead on the specific issue of user involvement(Beresford, 2002). By making participation a goal in itself, participatory research enforces the positioning of service users as auxiliary to professional opinion rather than separate from it. In contrast, user-controlled research is focussed principally on placing service users at the heart of the processes by which research ideas originate. Contrary to PPI in healthcare, user involvement is seen here as a

continuum ranging from little to no involvement to complete control over research, rather than revolving around a distinction between input and choice.

Crucially, user involvement in research is described as distinct from user research(Beresford, 2002). The latter is defined as research conducted and controlled by service users and disability rights groups, whereas user involvement entails gaining a role for service users in externally organised research. Reflecting Thompson's(2007) distinction between involvement and participation, then, 'involvement' is thought to mean a potential lack of influence, not requiring a transfer of power from the professional to the patient. Consequently, the purpose of PPI in research is often described as ensuring that patients are involved strategically in research planning. Indeed, many studies have also explored the efforts of some POs in enhancing the role of patients and patient knowledge in the research process. Here it is suggested that PPI in research should be based on equal partnership rather than a hierarchical structure(Diamond et al., 2003, Hickey, 1998, Tritter and McCallum, 2006). The purpose of such a partnership is to encourage medical and research professionals to understand the patient experience better and to utilise service user-based knowledge in the research design process(Diamond et al., 2003). Many health movements have thus argued for patients to be afforded more control over both the products of research and the knowledge-base behind it(Novas, 2006, Wehling, 2011).

Strikingly, Tritter et al.(2006) have directly placed PPI in research at odds with PPI in healthcare decisions. The authors argue that PPI in care is not innovative enough and that it is instead PPI in research agenda-setting that could have a real impact on the patient-professional relationship. That being said, the issue of power-transfer is a significant part of the study of PPI in health as well as research. This suggests that there is some disagreement as to what that power should entail. In health, patient power arguably involves improved choice and influence at the individual level. As such, it is possible that Tritter et al.(2006) understand power more globally, perhaps in a similar way to Rabeharisoa(2003) denoting patient influence over knowledge production itself, so that involvement in how information is used is not radical enough to allow patient influence. Nevertheless, many question whether in those cases where PPI is sought, the "transfer of power"(Thompson, 2007) actually takes place.

In fact, looking at the literature exploring how PPI can be enacted in research, suggests that often power is assumed to remain with the professional. Despite being theoretically

defined in terms of partnership and emancipation, PPI has also been described as generally ascribing fairly low levels of control to patients. For example Nilsen et al.(2009) describe PPI as being most effective in the creation of information sheets, to make them more understandable to prospective participants. Although this does indicate some level of involvement, the patient's role seems to be restricted to encouraging the participation of others. This is because an information sheet backed by patient opinion is seen as more likely to be accepted by other patients. Consequently, PPI can become merely an information seeking exercise, where the patient is not afforded much power. Therefore, echoing the literature on healthcare decisions, the patient is instead given an auxiliary role in research and their involvement is used to legitimise the aims of the project(Croft and Beresford, 1989, Crawford et al., 2002).

Indeed, Beresford(2002) has suggested that PPI can often be at risk of "tokenism" where the minimum requirement is met to appease regulators. As such, scientific professionals often retain control as "the only really empowered social element"(Brekke and Sirnes, 2011). Diamond et al(2003) describe this as a fundamental discord between the equality necessitated by the creation of partnerships between patients and researchers and the prevalent tendency of researchers to assume control, due to the belief that patients will "mess up" if they do not. Therefore, although PPI might be seen as important, to improve research strategy, as was the case in healthcare, it is deemed to require the guidance of a professional. Indeed Martin(2008) has observed this in a cancer genetics project, where professionals often constrained the involvement of service users or patients in accordance with a very specific and narrow definition of the capabilities of 'lay people'. Causing a project to "[miss] out on the range of skilled contributions that users make"(Martin, 2008).

A key feature of many analyses of PPI thus seems to be the suggestion that rather than truly engaging with patient views and experiences, PPI initiatives will become a mere formality. Despite being described as a democratic process, improving healthcare services, and research efficiency, PPI often seems to be given a relatively minor role, even in the literature advocating for its importance (in reviewing safety or consent procedures for example(Nilsen et al., 2009, Davis et al., 2007)). This relates to the debate around citizen panels and the extent to which they can substitute for actual public deliberation(Brown, 2006). In becoming a formality, PPI initiatives might detract from genuine public engagement in the discussion at hand. The reason for this trivialisation seems to be that PPI is thought to require the guidance of professionals, suggesting that patients are potentially

deemed incapable of making decisions alone. This can be summarised as a conflict between PPI (in the emancipatory sense described by Beresford(2002)) and professional expertise.

Expertise: Representational Legitimacy

In both political and sociological discussion, a particular theme throughout the PPI and participation literature is expert legitimacy. Much of the discussion around PPI as an ethical, democratic process concerns the legitimacy of the involved patient, or member of the public. Likewise, notions of expertise pervade discussions of how representation is authorised, the extent to which the represented can demand accountability from representatives and participate themselves in the deliberative process. However, what "expertise" means in the context of representation, and who can legitimately perform the role of "expert" is not very clear.

The term "expertise" generally implies in politics a reliance on external sources of information. However, as Brown(2006) points out, political decisions will rarely be made without "expert" input or backing. This suggests that the expert role is more than providing information that the representative or represented do not have. As well has having the power to advise others on the decision that could be made, expert participants in political deliberation are to a certain extent a validating factor, legitimising the outcome of the discussion. Taking into account the public participation-reliant definition of representation, this raises the question as to what the role of the represented is in such deliberations.

In answering that question, the first point to consider is the way in which the citizen, or the "lay" person, is defined in this context. In participating in deliberative democracies, "lay" citizens are at once expected to present a useful but different perspective. As such, they must be engaged in the discussion but there is also a firm expectation of a lack of expertise. Thus, for the most part, in representation theories, the "lay" role of the represented is to read or listen to the expert materials and extract the key ideas or interests that allow them to assess the credibility or acceptability of that information. The principle reason for this is that expert advice is though not to be necessary in matters of fact. Since "lay" citizens can be expected to read expert materials and come to a "correct" decision, they are thus expected to follow the overall judgement of the experts(Brown, 2006). The way expertise and laity are defined, therefore has potential consequences for the way in which deliberative democratic theory can describe representation, relying as heavily as it does on

public participation and influence. In particular it becomes difficult to reconcile the fact that while participation is important for representation to be democratic, expert input effectively allows public judgement to be outsourced.

A potential solution is to formalise the involvement of the public by creating designated citizen panels designed to gain the "public perspective" and thereby meet all the conditions for deliberative democracy .This is because, the resulting discussion is between formal and informal deliberation. Informal in the sense that the members of the panel are not elected and therefore are not present in an official capacity, but representing a formalised version of the discussion that the wider public might have(Brown, 2006, Kymlicka, 2002). Therefore, citizen panels contribute to the expertise element of deliberative democracy by clearly describing public priorities and providing advice and feedback on the processes by which knowledge and expertise are created. However, this suggests that the capacity for citizen panels to act as expert advisers is limited to supporting the development of 'real' expert ideas. Indeed, taking into account the expectation of laity placed on public participation, it can be the case that citizen panels are expected to be involved in political deliberation purely to present a specifically defined lay/public perspective(Brown, 2006). This again restricts the involvement of the panel to a clearly defined role and perspective.

Nevertheless, in both healthcare and policy, PPI often hinges on the assumption that the public is in some way "intrinsically" legitimate as a participant in the decision-making process(Contandriopoulos, 2004). Both Contandriopoulos(2004) and Martin(2008) suggest that the legitimacy of PPI initiatives often relies on the continued acceptance of the public or patient view as innately representative of the wider population. Indeed, Croft and Beresford(1989) summarised PPI under the central question "are services deficient because we have no say in them?". The principal purpose of PPI thus seems to be improvement of services by involving patients in their development. As a result the success of PPI as a concept requires the assumption that services will only be effective if they reflect the 'patient view', and that is only achievable through the involvement of patients themselves. Likewise studies of political participation suggest that participatory political deliberations, and the systems such as citizen panels that are in place to achieve it, rely on the assumption that all "citizens" have the potential to take part in political deliberations(Brown, 2006).

However, most deliberations will involve more than one participant and will often include more than one group or party that claims legitimacy as a representative of the public, or as

an expert on the policy or issue under discussion. Thus, the issue of public participation harks back to the discussion around fixed, knowable interests. Selecting a panel of representative members of the public relies on the concept of descriptive representation described previously. However, all those from a particular socio-political background are unlikely to deliberate in exactly the same way. Therefore, defining representative lay experts demographically presents the same complexities as describing elected political representatives and the question remains as to who can legitimately present the public view or the interests of a section of society.

Indeed, as Parkinson(2004) points out, different models or types of representative will present a different "voice" and will have a different form of legitimacy. Thus, whereas a principle-agent type representative will have the procedural legitimacy of having been "sent" by the public to present their voice, a descriptive representative will be 'more legitimate' in their ability to speak for those from a similar background. Nevertheless neither model has "perfect legitimacy", since they will only ever present one version of the public voice. Moreover, opposing voices will highlight the faults in each other's legitimacy in a bid to gain the most influence over a debate(Parkinson, 2004). In fact, Martin(2008) has also discussed the idea of competing legitimacy claims in the context of POs and PPI in research decisions. He suggests that where patients begin to gain too much influence, professionals will seek to defend their own position of power by questioning the legitimacy of the patient representative. Therefore, whereas PPI can be employed in some circles to legitimise the decision-making process, the legitimacy of individuals or groups of other patients will be challenged if PPI becomes too influential(Martin, 2008).

Because there is no shared definition of legitimacy or PPI, different groups are able to construct their own definition and redefine it when necessary. Therefore, in situations where there is a dispute between professionals and other actors over legitimacy and power, different parties will "deploy" different definitions of legitimacy in an attempt to fit to their own idea of PPI. Patients themselves will view it as a stakeholder process, where they as service users should have a stake in the decision made. Contrastingly, professionals are more likely to view PPI in more consumerist terms, ensuring patient choice rather than influence(Martin, 2008). Furthermore, in describing themselves as representative, representatives "deploy" their own selective interpretation of what representation means and who the "represented" are(Saward, 2006) . This suggests that representatives will legitimise their position in terms of the way they themselves define and understand the

voice of those they represent. In this sense, it seems that the innate legitimacy of the public can be used to improve the legitimacy of policy decisions, or the role of representatives in the policy sphere, rather than to allow patients a legitimate position of influence. Indeed, Parkinson(2003) has said that representation theory as a whole tries "to find rules that legitimately exclude, rather than making legitimacy depend, impossibly, on full inclusion". Therefore, as was the case in studies suggesting that the complexities of representation as a theory made it weak as a descriptive tool(Runciman and Vieira, 2013, Rubenstein, 2014), the temptation remains to respond to the difficulty of reconciling representation with notions of patient/public legitimacy by lessening the burden on representatives and policy makers alike to seek to fully involve those affected in the deliberation process.

Applying Representation Theory in this Thesis

As described in the introduction, much of the literature that looks at PO engagement in research tends to assume that POs will seek and are often able to gain an influential position within the scientific, medical and research worlds. This further tends to be described in terms of empowering the patient or representing their interests. As such a clear connection seems to be made between patient representation and research influence. However, there are also a number of barriers, both internal (relating to the PO itself and its structure) and external (imposed by other organisations or actors) that can make it difficult, if not impossible, for POs to become influential. If a PO is identified mainly as a grant-giving organisation it can risk being looked upon merely as a fundraiser or mediator rather than a leading actor in the field(Panofsky, 2011, Naiditch, 2007). On the other hand, the scientist-PO relationship can be damaged if POs attempt to exert too much control over the projects they are involved in(Panofsky, 2011). This suggests that POs can lose influence both by failing to exert enough control over their resources and by seeking too much control over the progress of research. Furthermore, the very fact that POs are concerned with research on only one condition can mean that policy makers view them as too one-directional and self-interested(Wood, 2000). If applied to research, this could further discourage research groups from collaborating with POs since they may view their targets as too limited.

The external barriers exerted by actors outside of the PO can be unified under one key observation: the presence of a collaboration or partnership between a PO and a scientist or research group does not necessarily mean that the PO has an influential role in the relationship(Allsop et al., 2004). There are many reasons why health and science

professionals may enter into a collaborative partnership with POs, not least the benefits to their own reputation. Therefore, it could be that such partnerships are established in order to benefit the researcher and thus, the PO will not have the controlling stake(Corrigan and Tutton, 2006, Allsop et al., 2004). Similarly to the debate above about PPI, the literature suggests that PO involvement in science may merely be something that is allowed rather than accepted by professionals(Van De Bovenkamp et al., 2009). This somewhat limits the scope for POs to gain real influence over research, since the extent of their involvement is fundamentally controlled by professionals in the field, and limited to "input"(Martin, 2008). This suggests that the success of POs might depend on the willingness of political, scientific and medical authorities to engage in PPI initiatives.

As discussed above, PPI is one area of study where representation has been discussed directly. However, despite the fact that they are frequently linked to PPI representation, POs are rarely analysed as representatives, unless to suggest that they cannot be or are not conventionally evaluated in such terms. Although, it must be said, that this gap in the discussion is largely due to the design and focus of the studies. For example, Martin(2008) focuses on the individual legitimacy of patients participating in a cancer research project. As such he cannot be expected to explore the position of POs or other organisations as representatives. Furthermore, Panofsky(2011), though focusing on patient communities, explores the way in which POs can or should engage with researchers. Therefore, the wider issue of representation has not tended to feature in the way in which STS and other sociological scholars have designed research into PO and patient engagement in research. To address this gap in the literature the final section of this review will examine the way in which the representation theories discussed thus far could be useful in examining patient representation in the context of MND and Parkinson's POs.

Representation Model: Trustee-Delegate

Relating the models of representation to the context of POs, we can see that the various roles that POs perform mean that, as Ferber et al(2007), Eulau et al.(1959) and Mansbridge(2003) suggest, it can be difficult to analyse representation within the strict definition of a particular model. A representative, or in this case an organisation, is unlikely to solely resemble one model more than another. Looking at the Trustee-Delegate model, a case can be made for seeing POs as both. Given that POs are often structured as a national governing office that oversees the work of local groups, it is possible that the state-district conflict might help to elucidate the tensions that others have

described(Epstein, 1995). If we re-interpret the "state" in organisational terms, the PO employee could be described as simultaneously working for the national office (*the state*) and representing the PO's local groups (*the district*); so it is likely that POs will to a certain extent have to combine a trustee and delegate role, listening to the wishes of members but also maintaining organisational structure. The distinction made between delegates and trustees in political sciences is therefore played out rather differently here - not least because the Trustee role takes a different definition to that described in political theory. Although it might be true that PO Trustees tend to act without expressly asking the membership for an opinion every time a decision must be made, they are bound by the PO governance structure to include member opinion in their agenda.

However, we have also seen that collectivisation, through network formation is often described as a key characteristic of PO purpose(Baggott et al., 2005, Allsop et al., 2004, Brown et al., 2004, Panofsky, 2011). Furthermore, studies analysing identity, suggest that the PO purpose is to facilitate the creation of community identities and enact them towards a common purpose(Silverman, 2008, Bernstein, 1997, Rabeharisoa, 2006) This implies that in general, POs might be assumed to fit the delegate model of representation, due to their close links with the patient population they represent and the fact that their actions are based on a common, community supported, goal involving ongoing discussions between the patient population and its representatives. This suggests that analysis of PO activities might use the delegate model to view POs as basing their priorities and actions on the outcome of discussions with members. This is further illustrated in the conflicts between lay-lay activists and lay experts, where a failure to conform to the expectations of the patient community can result in a PO being branded unrepresentative(Epstein, 1995). The assumption therefore appears to be made that a PO will act as a delegate-like representative, as it seems to be the distance that research can create between POs and their members that leaves them open to criticism for being unrepresentative.

Representation Continuum

Reviewing the principal political theories of representation thus illustrates how difficult it can be to ascribe a representational model to this context. POs must engage with divergent identities, opinions and values that are unlikely to always align. As a result, any given decision or activity is likely to appear representative to some but unrepresentative to others, so that the PO is simultaneously a delegate and trustee, depending on the way in which individuals perceive the legitimacy of the decision that has been made. This

suggests that the politico model might be useful, suggesting as it does that representatives can move between models and even combine them(Eulau et al., 1959). However, the politico model is arguably less a concrete definition, and more the absence of an appropriate model to describe the way in which representatives act. Its very definition depends on viewing the politico as able to be flexible, *not* conforming to a particular view or procedure. Furthermore, as Mansbridge(2003) suggests it can be more appropriate to examine the representation models as normative ideals to be interpreted and explored, rather than concrete standards to be met. This is to a certain extent illustrated in Martin's(2008) investigation of PPI in cancer research. Here, the legitimacy of professional and patient representatives was observed to be flexible, with both continually redefining their own and the other's representative legitimacy depending on the context, discussion and decision in question.

Collective Interests

As discussed above, it has been established that members of a PO or social movement are likely to experience and express more than one identity, which may or may not conflict with the idea of community membership(Olzak and Ryo, 2007, Hardnack, 2011, Stryker and Burke, 2000, Barbot, 2006). Furthermore, as Bernstein(1997) points out, the "strategic deployment" or organisational use of a collective identity may be very different to an individual's personal understanding or experience of it; so in presenting a collectively held identity in order to represent that community, POs may risk becoming unrepresentative of some members. Those who do not recognise the way in which the identity is used may no longer be able to identify with the organisation.

This raises the question as to how representativeness can be measured in a context where the "represented" constitutes a broad, diverse community. The fact that research is thought to create a distance between representatives and the patient community suggests that the theories around deliberation and fairness might be useful here(Kymlicka, 2002, Parkinson, 2003). As Habermas(1990) suggests, the outcome of discussions are only valid if they are accepted as fair by all those involved.

However, the interpretation of some decisions as unrepresentative because they do not reflect the opinion of the community, gathered through ongoing or periodic communication, suggests that POs can only be representative if they act as a delegate. As Mansbridge(2003) suggests, discussions need not be completely equal for outcomes to be

legitimate. In particular the agenda can be determined by the representative, without the discussion being perceived to be unfair. Moreover, a further potential issue here is that it is unlikely that all people with a certain disease want to become involved with a PO, notably in the case of severe, degenerative diseases, where many do not want to meet others with the same condition. This is often because they do not want to see what could happen to them in the future(Baggott et al., 2005, Small and Rhodes, 2000). Therefore, POs will rarely be able to survey the opinion of all members of the wider patient community, and it is possible to suggest that they do not have to always follow the opinion of PO members either. This suggests that there are certain circumstances where the trustee model might be more applicable, particularly if we accept that the divergence of a patient community means PO decisions will always disappoint some members(Bernstein, 1997). Therefore, the way in which collective discursive equality is perceived in the decisions POs make, might help to understand how those decisions are, or are not, defined as representative.

Authorisation and the Representative Claim

Related to the discussion around authorisation, a further method for describing representation that could be useful here is that of the representative claim. Much of the literature has tended to view representation as a definable entity, exploring how or to what extent a representative is authorised or legitimised by constituents, the deliberative process or the way in which representation and represented are defined by either party. In contrast Saward(2006) suggests "representation is not a mere fact that 'just is'", as such it could be more helpful to examine the claims that are made for representativeness. Exploring the claims behind the representative's actions allows analysis of representation as more than an information-giving or fact-adducing exercise. Echoing Mansbridge's(2003) caution against seeing representation models as standards to be reached, it is suggested that analyses should explore the intentions behind the claims that representatives make with respect to their actions as well as the interests of the represented. This is because, the claims that representatives make can directly affect the way in which the represented understand their own position, and the interests under discussion. That is to say that

> If I allege that you, a potential constituent of mine, possess key characteristic X, and if I can get you to accept this, I can then present myself as possessing capacity or attribute Y that enables me to represent you(Saward, 2006)

Therefore, the claims that would-be representatives make about themselves and their constituents can play a pivotal role in the way the act of representation progresses. This seems particularly pertinent to the study of POs since they often work in public, media circles where they are required to provide visual and symbolic claims for representation. Furthermore, the fact that POs engage in many different activities suggests that they will have a wide variety of interests, perspectives and priorities to represent. It could be useful to explore these activities through the intentions behind the way in which they are presented by the PO.

Throughout this thesis I will return to the idea of representation in an empirical way firstly. Rather than investigating whether POs fit one model or another, whether that's of social movements, PPI or political representation; I will explore how representation is understood and enacted in different situations, discussions and PO activities. Exploring further the idea that POs can resemble different models at once, the thesis will use the concept "representation" to understand how PO employees and members accept (or not) the legitimacy of the decisions that POs make on their behalf. Following the political science literature that suggests that different interpretations of the term "representative" can greatly affect the way relationships, identities and motivations are understood, the thesis will explore how members and employees, perceive their organisation as following (or not) their idea of what the PO is supposed to be. As such, the term "representative" will take on different meanings throughout the thesis, referring to both the act of being representative and a representative of people with MND and Parkinson's.

Summary

In summary, the political science debate on representation illustrates the complexity and ambiguity of the concept; implying as it does the presence of a definable group with shared interests while simultaneously suggesting that those interests can only be presented by a representative(Runciman and Vieira, 2013). Likewise, the conditions placed on successful representation – described in different disciplines as authorisation, accountability, participation and expertise or interests and objection – are very much open to debate(Brown, 2006, Parkinson, 2004, Pitkin, 1967, Runciman and Vieira, 2013, Urbinati and Warren, 2008). Therefore, there does not seem to be a clear, agreed upon definition of representation or any of its conditions. Depending on the context, a representative can fit different models or characterisations of representation. In particular, when looking at participatory politics an underlying sense of responsibility to represent the community or

the state over the individual can make public engagement and influence difficult to maintain. As such the view of the representative as *a* representative can often be in conflict with their presumed responsibility to represent community interests and sufficiently include public perspectives in the deliberation process.

Furthermore, as the discussions around expertise and legitimacy showed, the way in which the representative validates her own role through an interpretation of the public/constituent perspective has potential consequences for the way in which representation is defined and analysed. The perception of the term plays a significant role in the way that representatives act on their relationship with "the represented". Consequently it is particularly important to consider the way in which representative claims are made and the intentions behind the representations that constructed of public interests(Saward, 2006).

Applying this to POs, it is interesting to note that much of the PO and social movements literature seems to take representation for granted, seemingly analysing POs as automatically legitimate as patient advocates. Given that POs tend to perform various roles within and on behalf of their membership communities, it would be expected that their priorities will fluctuate and as result the nature of the PO-member relationship will change.

A principal purpose of the PO has been described as community formation; mobilising a collective population or network based on the definition of biosocial community(Gibbon and Novas, 2008, Rabeharisoa and Callon, 2006, Baggott et al., 2005, Allsop et al., 2004, Brown et al., 2004, Rabinow and Rose, 2006). However, others have shown that resulting collectives can also include several divergent definitions of community, identity and even PO purpose(Bernstein, 1997, Olzak and Ryo, 2007, Hardnack, 2011). As a result, the PO role in unifying members as a community can be difficult to sustain(Finkelstein, 2004, Hughes, 2009, Shakespeare, 1993, Shakespeare, 1996, Thomas, 2008, Barbot, 2006, Epstein, 1998, Epstein, 1995, Thomas, 2004).

Furthermore, POs increasingly operate in an environment where PPI is viewed as an essential ethical standard for improving healthcare and research decisions. However, although POs might attempt to further the PPI agenda by promoting or speaking for the collectives they create, they can face significant difficulties in doing so effectively. This is largely due to competing claims for expertise and legitimacy between POs, patients and professionals(Martin, 2008, Parkinson, 2003). As a result the role that patients are given in

research, healthcare and health policy still often depends on the willingness of professionals to allow their involvement(Beresford, 2002, Brody et al., 1989, Diamond et al., 2003, Martin, 2008). Furthermore, if attempting to act as patient representatives, POs may open themselves to criticism if that reduces the scope for individual patients to be present or heard(Parkinson, 2004).

In the remainder of this thesis I will continue to explore the way in which representation can be understood in the context of MND and Parkinson's POs in the UK. The thesis will explore the claims that POs make to represent people living with MND or Parkinson's, and how PO staff, volunteers and research associates appear to understand representation as part of their role. This will inform an understanding of the different ways in which representation can be conceptualised in this field, and how it is shaping the research agenda in particular.

CHAPTER 3
Research Methods

Following the methods used by many who have studied POs and social movements, this research project employs a case study approach. Using interviews, observation and web analysis data this PhD provides a rich case study of MND and Parkinson's organisations and how they work. However, in combining social science methods with ethical theory, the output from this project is both descriptive and normative. The majority of my analysis was built on my interpretation of what people said to me and the events I have observed. The empirical data was used to make suggestions about participants' attitudes towards their PO and each other, and to explore the underlying repertoires informing participant opinions.

In this chapter, I will describe the methods I used to create this case study and my approach to analysis. I will then discuss some of the study limitations and outline the scope of this research.

Case Study Approach

Moreira states that:

> At its most minimal, a case-study is defined as a detailed exploration of a
> single event, process or setting.(Moreira, 2011)

Looked at in more detail, however, case studies can be particularly useful for identifying new relationships in particular contexts and find new ways of understanding those relationships(Moreira, 2011, Ragin, 2004). In qualitative research, case studies allow the researcher to situate the case in its larger social context(Creswell, 2007). Furthermore, Hardnack(2011) has suggested that the case study approach is particularly suitable for exploring social movement organisations. One of the main reasons for this is that in constructing a case study, several methods can be used to collect a large and varied data set to analyse different aspects of the organisation(Hardnack, 2011, Lofland, 1996). Therefore, this approach seemed very appropriate for this research, since it allowed me to gain an in-depth insight into the relationships that form and affect POs.

However, it has also been suggested that, although case studies might identify relationships, it can be difficult to understand, as Moreira says "the contribution of the

relationships to the overall phenomena"(Moreira, 2011). That is to say, Case studies might be more descriptive than analytical, in terms of the social contexts they explore. Indeed, a common criticism of the approach is the lack of generalisability of results. This is in part because to generalise, the researcher must assume that all similar organisations, groups, or contexts will behave in the same way(Moreira, 2011, Ragin, 2004). Or that the fact that organisations do behave in the same way always carries the same significance or meaning. It must be said, however, that much of this critique tends to come from a quantitative research perspective, which criticises the normative and interpretative character of many social scientific case studies(Ragin, 2004).

The claim that the descriptiveness of case studies makes them less able to facilitate an analysis of the deeper meanings behind the relationships that are identified seems misguided. The rich description of a group or social context that a case study provides can, as is the case in this research, act as an illustrative base for interpretative analysis. If we accept that case study research will be largely interpretative in character, then it allows us to use the empirical data to reach normative conclusions about the group in question. Furthermore, with respect to generalisibility, it seems possible that to make suggestions about organisations or groups beyond the case itself the researcher can postulate that others might, rather than will, behave in a similar way or face similar issues. Consequently, although this research is admittedly focused on specific conditions and organisations, the conclusions made about PO culture, and the wider research and social context could be applicable to other organisations working in similar contexts or under similar conditions.

Choice of Cases

This PhD was conducted as a standalone project, however it was also part of the Wellcome Trust Strategic Grant *The ethics of translational research: from 'unnatural entities' to experimental treatments*, awarded to the London & Brighton Translational Ethics Centre (LABTEC). The focus of LABTEC is neurodegenerative disease and translational research, including projects examining other aspects of Parkinson's, MND and Dystonias. The particular set of charities I explore, and indeed the conditions themselves, are very under-researched in social science and ethical literature. Therefore, they present interesting case studies to enable further exploration of the very well researched subject of POs and social movements.

Ethics Approval

This project and the methods used received approval from the BSMS Research Governance and Ethics Committee (RGEC) on 14th March 2011. I also submitted an enquiry to the NHS ethics approval board, asking whether or not I should apply. It was decided that although I might interview people about health-related issues, as I was not planning to recruit on NHS premises and was not researching the NHS directly, that I did not have to apply for NRES approval.

I also underwent a Criminal Records Bureau (CRB) check in preparation for interview recruitment.

Recruitment

In order to explore MND and Parkinson's POs and their responsibilities, I began this project wanting to interview as many individuals as possible, performing various voluntary and formal roles in their organisation. Considering my interest in the role POs have in research, it was also important to interview researchers receiving funding from or collaborating with a PO. My approach to recruitment was to establish initial contacts within each organisation to initiate snowballing recruitment.

This proved to be more challenging than anticipated with people appearing reluctant to meet with me. In particular, mid-level administrative staff were most reluctant to take part. The most common reason given for not wanting to participate, or to recommend others, was that once I have interviewed one person, others will have nothing new to say as they all have the same experience and are likely to say the same thing. This meant that recruitment and interviews took longer than expected to complete, and data collection and recruitment were conducted simultaneously over a 9 month period.

Because recruitment was very slow and challenging, I interviewed fewer people than I expected, but I was able to interview sufficient people to provide a rich data set for analysis. The struggle to recruit also helped me to understand how the POs work, particularly since some staff appeared to feel they had an organisational line to follow which excluded the possibility of sharing their personal views. I subsequently discovered that some of these organisations have had 'bad experiences' with researchers before, which might explain why people were occasionally wary of participating in a project focussing directly on them and their work.

Data Collection

Hardnack(2011) suggests that the potential for bias in social movement interviews requires the researcher to be "more assertive" in analysing the data by clarifying responses through further questioning and comparing interview discussions with external evidence of events or life histories(Hardnack, 2011, Blee and Taylor, 2002). This advice illustrates the importance to this kind of study of triangulation: combining data sources to better understand participant motivation and provide a deeper insight into the case study(Jick, 1978). Triangulation is defined by some as combining qualitative and quantitative research methods, however it can also be seen as a means of seeking convergence between different data sources looking at the same subject(Creswell and Clark, 2010). As such, I used three main methods of data collection, around which to base my interpretation of the case study.

Interviews

To understand the POs as organisations and the nature of representation it was important to talk to people from different levels of the organisation. Therefore, interviews formed a crucial part of the data I collected, allowing me to explore how organisations create an identity, a shared language and organisational purpose.

The potential difficulties of compiling and analysing interview data have long been the subject of discussion. It has been suggested that as they are artificial interactions, interviews can be limited in presenting an accurate picture of the social context they are intended to explore. Interviews are necessarily one-sided in that they feature a researcher asking questions, as such they will not represent a natural conversation. Moreover, interviewing people from too similar a background or social/organisational position can present the risk of biased information from a narrow perspective(Denzin, 2001, Myers and Newman, 2007). Furthermore, the interview environment can have unintended effects on the reaction of participants to the questions they are asked, not least because different people might interpret the meaning of questions very differently(Myers and Newman, 2007). There is also a risk of emotional distress when asking people to talk at length about personal stories and difficult subjects(Corbin and Morse, 2003).

To counter the risk of interviewer influence over the ideas and stories that interviewees express, Myers and Newman(2007) suggest that researchers acknowledge their own part as an actor in the conversation and the influence of their own views. This helps the researcher to be reflexive. However, it is also important to ensure that the researcher presence does

not direct the answers that people give. To guard against the possibility that interviews simply confirm the researcher's view, it is important to take a critical approach to analysis, understanding the root of what is said rather than accepting statements as truth.

I conducted 22 interviews, including 1 pilot interview, with a wide range of people within four MND and Parkinson's organisations in the UK. Participants were all staff, volunteers, members, or research associates of a Parkinson's or MND PO. This was to allow me to compare the opinions and experiences of people in different roles and different organisations. Particularly, it has been interesting to compare the experiences of employees and volunteers, and staff and associate researchers. *Table 1* (below) shows the code name for each person quoted in this thesis, their role, PO affiliation and the level of anonymity requested at interview (discussed under limitations).

	Role	Affiliation	Anonymity Level
V1	Volunteer	Parkinson's UK	Identifiable
V2	Volunteer	MND Association	Identifiable
V3	Volunteer	Parkinson's UK	Identifiable
V4	Volunteer	MND PO	Full Anonymity
V5	Member	Parkinson's UK	Identifiable
V7	Member	Parkinson's UK	Identifiable
V9	Volunteer	Parkinson's UK	Identifiable
V11	Member	Parkinson's UK/ CPT	Identifiable
E1	Employee	Parkinson's PO	Full Anonymity
E2	Employee	MND Scotland	Identifiable
E3	Employee	Cure Parkinson's Trust	Identifiable
E4	Employee	MND PO	Partial Anonymity
E5	Employee	Parkinson's PO	Full Anonymity
E6	Employee	MND Association	Identifiable
E7	Employee	Parkinson's UK	Identifiable
E8	Employee	MND PO	Partial Anonymity
E9	Employee	Cure Parkinson's Trust	Identifiable
P1	Researcher	PO Funded	Full Anonymity
P2	Researcher	PO Funded	Full Anonymity
P3	Former Associate	Parkinson's Care	Identifiable
P4	Researcher	PO Funded	Partial Anonymity

Table 1. Interview Participants

To avoid influence over participants as much as possible, interviews were semi-structured so that questions were carefully worded but remained open to allow people to interpret them as they wished. Indeed, as one of the points of interest in this research was the way in which shared language and ideas arose across the organisations, different interpretations of interview questions in fact presented an interesting source of data. As such, the ambiguity of participant interpretations presented less of a problem than Myers and Newman(2007) have suggested. Those occasions where participants interpreted a question very differently to staff or members from the same organisation helped to highlight the interaction between organisational and individual reaction to certain subjects or issues.

Reflecting my initial focus on Social Movements, the interview schedule focused on PO structure, the roles that interviewees played and key relationships with patients, researchers and the research industry. To allow some direct comparison between interviews, some questions were asked in almost exactly the same wording each time (Appendix 1). This allowed me to directly compare the answers that people gave to questions on certain key issues such as their perceptions of the role and purpose of the organisation, and their experience of the PO's relationship with other organisations. Otherwise, interviews were kept as conversational as possible, letting participants talk uninterrupted as much as possible and allowing the interview to follow tangents that they raised. Consequently most interviews were approximately 90 minutes long with up to 15 minute answers to single questions, giving me a very rich data set. I have chosen to use some of the longer quotes in full as part of my analysis, in order to illustrate the detail that interviewees went in to as well as the way in which ideas developed through allowing respondents to provide open answers. Although the semi-structured approach with set questions risks interviews being too similar in the themes that arise, in reality, in contrast to Hardnack's(2011) observation, (once recruited) participants were surprisingly candid and willing to talk openly, particularly about tensions and frustrations within their organisation.

As I focused on UK-wide organisations, interviews required me to travel across the UK, including to Scotland and Cornwall. However, as *Table 1* shows, I was unable to interview as many people from MND as from Parkinson's organisations. This is partly because of the difficulties I had in recruiting through the contacts I had established. More significantly, however, others in LABTEC have experienced similar difficulties in recruiting people living with MND to their projects. In some cases this has meant that the subject of MND was removed from their projects entirely. This is because of the rapid and serious effects of

the condition, which amongst other things can make it difficult to talk for extended periods of time. Furthermore, MNDA was commissioning a qualitative research project looking at end of life decisions at the same time, so that many potential respondents were already participating in an interview-based project. Indeed one of the researchers I interviewed emphasised the dangers of exhausting the few people with MND who are physically able to participate.

I was able to interview similar numbers of staff members from each PO, but have interviewed significantly more Parkinson's organisation volunteers and members. This has meant that some aspects of my analysis are more focussed on Parkinson's than MND

The issues with recruitment also meant that I occasionally had to change interview protocol, by interviewing people in pairs or in open office settings rather than in private. A particular concern was that interviewing people in pairs might limit openness in terms of people's opinions of their organisations, and that interviews would start following a set organisational line. However, these interviews were particularly interesting in showing the dynamic between colleagues. Both pairs that I interviewed were a mix of one person with Parkinson's and one person who did not have Parkinson's, so they gave very different answers to some questions and contradicted each other quite strongly.

Observations

An additional method of data collection that I used was observation of five research events organised by three of the charities. I also attended the European Parkinson's Disease Summer School in 2011, which was not funded by any of the UK Parkinson's organisations, but did help me to establish contacts in CPT.

Event	Organisation	Audience
Research Conference	Parkinson's UK	PO-Funded Researchers
Members Day	Parkinson's UK	Research Network Members
Learning Day	MND Association	Carers & Professionals
Learning Day	MND Scotland	Healthcare Professionals
Research Meeting	MND Scotland	Members

Table 2. Events Observed

The events in *Table 2* allowed me to observe the way in which PO representatives discuss their work with different audiences, as well as the relative import or significance placed on different areas of research. One particularly helpful opportunity arose when I was able to hear the same MND PO employee speak to two very different audiences.

The decision to undertake these observations to a certain extent arose organically out of the interview and recruitment process. I was invited to attend and observe three of these events by contacts I made during interviews and recruitment. As a result, it must be acknowledged that I mostly observed events that were highlighted to me by people within the organisations. The intention behind this data collection was not to compare the way in which similar events are run by the different organisations. Rather, observations of PO research conferences, meetings, and learning days provided contextual detail for my analysis. Observations allowed me to understand how the POs relate to their membership, the public and researchers but also provided context for specific themes raised in interviews. I was able to compare interview discussions about research conferences and meetings with my own observations of the events I had attended. I also had the opportunity to experience some of the organisational tensions that were raised by PO volunteers.

As the aim was to gain contextual detail, my approach to observation was to attend the events as a participant or delegate (with the exception of the MND Scotland members meeting, where I was unable to participate as I was not a member but was introduced by the person leading the meeting as a visiting researcher). I attended all of the talks and presentations, making notes about content and speakers as well as the audience. I wrote down any questions asked by the audience, noting where possible the position of the person asking the question (i.e. researcher, clinician, patient, carer). Additionally, I made notes about any campaign or advertising stands displayed at the events and took copies of any promotional materials being handed out to participants.

However, as all the events were relatively large, I could not be certain that I would have consent from all those present to publish details of conversations I overheard or had with other delegates. I decided that it would not be appropriate to quote conversations or statements that were not made publically – in contrast to those made during presentations or question and answer sessions. As such, I ensured that everyone I spoke to in person knew who I was and that I was conducting research into MND and Parkinson's POs and made notes about the things that were said to me directly. These conversations then

informed my own contextual understanding of the PO and the volunteer/member – staff relationship rather than becoming quoted data sources.

Web Analysis

As part of this project I have also monitored PO's websites as well as their social networking activities on Twitter, Facebook and Youtube. This was helpful in examining how POs present themselves to the public as well as how they develop new ways of connecting with their membership. I took regular screenshots of the homepages of PO websites to see how their key messages and public image have changed over time, which served as an indicator of their key priorities and as a way of comparing different organisations. However, it must be acknowledged that much of my website analysis centred on PUK, MNDA and CPT. MNDS became a significant part of my project after interviews with volunteers and employees of the other organisations highlighted local isolation as a potential research avenue. As a result, I was unable to compare the changes to the MNDS website over the same time period. Therefore, my more recent analysis of the MNDS website was used to supplement the longitudinal comparisons I make between MNDA, CPT and PUK. This has enabled me to compare the way in which all four POs structure and design their websites and the kind of information that is provided on their homepages. Looking at the way the websites are constructed has allowed a comparison of the overall character of each organisation, with some having much more technical and elaborate websites than others. This analysis also enabled me to compare what was said in interviews about PO actions with what they actually do and what they present online. Also, the purpose and value of PO websites and social networking was raised in a number of interviews so it has been useful to compare those discussions with the websites themselves.

I also regularly checked the main PO Twitter feeds: @mndresearch, @mndcampaigns, @ParkinsonsUK, @CureParkinsonsT and @MNDSFundraising. "Following" these accounts meant that I received an email whenever a new tweet was posted. This allowed me to monitor the POs' response to the increasing popularity of Twitter as a means of communication. In the case of PUK in particular, I was also able to observe the way in which the research conference I attended was promoted and discussed via Twitter. As a result, screenshots of the "mentions" PUK received also formed an important part of my observation of that event.

Following the Facebook pages and blogs for some of the PO campaigns, such as the *Incurable Optimist* pages*,* also alerted me to tweets and videos that were not posted on the main PO Twitter feeds. As a result, I was able to compare the way in which POs promote their campaigns with the way in which the 'faces' of those campaigns described their experiences. The *Parkinson's Movement* Facebook page also helped me to monitor the Youtube video campaigns that were posted in association with CPT.

Another potential source of data could have been the online discussion boards that these POs run or with which they are associated. In conducting background research into MND, Parkinson's and the POs I discovered a number of online forums specifically intended to discuss the issues surrounding diagnosis and life with the conditions. These could have provided considerable data on the way in which people living with MND or Parkinson's experience research, support networks and PO membership. However, at the time of writing there was no clear guidance available for ethical use of online forum discussions. As others have discussed, although being online makes forums technically publically available information, the tone of discussions makes clear that they tend to be used as "safe spaces" for people to talk about private matters with others in the same circumstances. Consequently, publishing analysis of these discussions can be viewed by participants as unsolicited and intrusive(Bassett and O'Riordan, 2002, Battles, 2010, Berry, 2004, Eysenbach and Till, 2001, Grinyer, 2007).

A potential solution to problems around privacy in internet research is to gather consent from participants to a researcher being involved or present on the board. However, others have noted that methods for gaining consent are not without their problems and present the potential for harming participants. First, if a researcher's presence is announced to a forum, prior to observation, it is possible that they will no longer be as candid and open as they would have been, thus limiting the use of the data. Moreover, announcing observation can risk people leaving the group, which signifies a considerable intrusion into the way they access support. The other option is to gain consent retrospectively, after having observed a discussion and analysing the data. However, this involves telling people that conversations that they assumed to be private were being observed by an uninvited researcher, which could be upsetting to the individual but also damage peoples' trust in the group and forum as a whole(Eysenbach and Till, 2001, Battles, 2010).

As a result, because the discussion boards I could have researched specifically described themselves as directed at people with or affected by MND or Parkinson's, I decided that it would be inappropriate to include such data in my analysis. In the absence of clear guidelines, I could not be satisfactorily sure that I would be able gain the necessary consent for such research, whilst avoiding harm to the individuals involved and retaining the natural atmosphere of the discussion group.

Data Sharing

As this PhD was conducted as part of the LABTEC grant, another PhD researcher in my department was conducting a parallel project to mine, looking at Parkinson's patient experience. Therefore, as well as discussing my data with my supervisors, I shared some of my data and findings with a fellow PhD researcher, in order to compare what we had observed in the same patient community. This was particularly useful in providing another perspective on some of the Parkinson's PO campaigns that I had observed.

Discourse Analysis

As discussed above, although empirical methods were used to build a case study of Parkinson's and MND organisations, the core analysis of this project is very interpretative. A particular aim of the analysis was to understand what the data might illustrate in terms of the beliefs of and relationships between participants. As such, my approach to analysis in many respects followed a discourse analysis framework.

Although it can be seen as a linguistics-based syntactical approach, it is generally the case that in social science research discourse analysis can revolve around the potential meaning behind the use of language(Brown and Yule, 1983, Chouliaraki and Fairclough, 1999, Potter, 1996, Hodges et al., 2008). For example, Hodges et al.(2008) make the distinction between "linguistic discourse analysis", "empirical discourse analysis" and "critical discourse analysis", stating that the latter two forms focus on the social use and implications of language rather than its structure. The authors suggest

> Discourse analysis at this level involves not only the examination of text
> and the social uses of language but also the study of the ways in which
> the very existence of specific institutions and of roles for individuals to
> play are made possible by ways of thinking and speaking(Hodges et al.,
> 2008)

As such, discourse analysis can be very useful in analysing the beliefs and values that underpin the language used by participants, and the relationship between the individual and the social institutions from which they speak(Chouliaraki and Fairclough, 1999, Potter, 1996, Hodges et al., 2008).

This approach has also been used to explore the way in which language, rhetoric and dialogue might be interpreted by others(Chouliaraki and Fairclough, 1999, Brown and Yule, 1983, Franklin and Roberts, 2006). This is particularly important when taking into account the caution raised by Hardnack(2011) in discussing his approach to social movements research. It is suggested that, in the case of social movement organisations in particular, the researcher needs to be aware of the purpose behind the answers given at interview. Devoted activists or members will often tailor answers to fit their idea of what is relevant and helpful to their cause. As such, it is important to consider the impact the participant intends to elicit through their answers(Hardnack, 2011). Perhaps answering this concern, Hodges et al.(2008) have suggested that critical discourse analyses necessitate data showing the use of language and detailed information about the individuals or institutions involved, to contextualise the written or oral samples of language and discourse. Therefore, critical discourse analysis, as defined by Hodges et al.(2008), was useful in analysing my data set.

Critical Discourse Analysis

As is the case in discourse analysis as a whole, critical discourse analysis has been described as complex, encompassing many disciplines and approaches(Edley, 2001, Fairclough et al., 2011). Where critical discourse analysis differs, however, is that it tends to be firmly focused on issues around power, justice and cultural change(Fairclough et al., 2011, van Dijk, 1993). Consequently it is often viewed as an analytical approach that cannot be neutral and must focus on imbalance of power, and in particular must support changes to the benefit of those oppressed by it. This has been interpreted to mean that critical discourse analysis should not concern itself with interests of those in power, focusing only on those who are not(van Dijk, 1993). Applying this to the current study, critical discourse analysis could seem an inappropriate approach for studying PO if it does require the researcher to have an existing view of the power structure, as it might preclude analysis of the views of those in top-level organisational positions. However, as Fairclough et al.(2011) note, rather than viewing power structures in as strict a way as Van Dijk, discourse can be analysed

in terms of the creative mixing of discourses and genres in texts, which over time leads to the restructuring of relationships between different discursive practices within and across institutions(Fairclough et al., 2011)

This more moderate view of the approach, suggests that critical discourse analysis can analyse persuasion and justification that over time creates a certain social structure, particularly in political movement contexts(Fairclough et al., 2011). This definition might lend itself better to the analysis of POs, and the way in which relationships and language have become institutionalised.

That being said, the authors(*ibid*) in their own analysis of a specific policy exchange, rely very heavily on a pre-existing understanding of discursive devices and their intended meanings. As such, as was the case in Van Dijk's definition, Fairclough et al.'s critical discourse analysis appears to require the researcher to have already identified the power structure and the language that enforces it. It is the use of that language that is then analysed. Wetherell(1998) suggests that this could preclude analysis or identification of unknown or unexpected discursive devices. As such the approach could prevent exploration of a context with which the researcher is unfamiliar. A potential solution to this problem could be found in the work looking at interpretative repertoires, which allows the identification of repertoires followed by an analysis of their origins.

Interpretative Repertoires

Analysing the difficulties of critical discourse analysis Wetherell(1998) suggests that analyses should combine a focus on social space and agency (discourse analysis), the conversation phenomenon (conversation analysis) and, ideology and what has been described as interpretative repertoire. Rather than focusing on the construction of institutions of language, interpretative repertoire approaches explore the historical ideas and ideological frameworks that inform current conversations or discourses. Interpretative repertoires represent the "common sense" of a community, the ideas and terms behind the way in which people express themselves(Edley, 2001). This suggests that focusing on repertoires could be particularly useful in this study, allowing analysis of shared language and the way in which people's opinions are informed by a historical or institutional frame of reference. Furthermore, Edley(2001) points out that understanding repertoires allows the analysis of the opposing point of view that is created with it. As such, ideological dilemmas can be explored – that is, the conflict people can experience when expressing views opposed to their interpretative repertoire. This in particular echoes the representation

and PO literature, which has focussed in great detail on the tensions that can arise due to conflicting responsibilities and dialogues.

In this thesis, my analysis in some respects combines the interpretative repertoires approach with aspects of discourse analysis and critical discourse analysis. In particular, reflecting Edley's(2001) definition of discourse analysis, I explore how repertoires are structured in the PO context and how cultural/institutional concepts might inform how people think or talk about particular subjects. In order to better understand the context of the discussions I had with interviewees, I aimed to interpret from interview data, what participant statements might suggest about the PO as a whole and their relationship with it. As such, following the recommendations made by Hodges(2008), my analysis brings together statements made by different people, the PO on websites and in the media, and observations I have made about individuals and the organisations. The empirical data was used as a springboard to normative analysis, to gain a deeper understanding of the relationships involved in PO activities (between staff and members, and PO and researchers) and the tensions and difficulties that POs can face.

Following Edley's(2001) suggestion that the best way to identify and analyse repertoires is through familiarity with the data, I approached this analysis by immersion in the data by re-reading and listening to interviews, and gaining a familiarity with the PO environment through observations and web analysis. This familiarity allowed me to identify the concepts and repertoires that seemed to arise most often in interviews. I was then able to approach observations and web analysis with these concepts in mind. I also continually referred back to the interview data, to reanalyse it in light of the events I had observed. This enabled me to ground the concepts in the observational data, which helped me to eliminate participant bias and identify those concepts and repertoires that were more significant and required further investigation through additional interviews or observation.

This process of analysing and reanalysing my data, meant that it became clear that my original aim to explore social movement theory was not as relevant as anticipated. Although interviews were intended to explore the social movement as a concept, the data and the reflexive approach to analysis highlighted representation as a more significant concept. Within this concept, informed by a review of the literature, I identified such repertoires as trusteeship, delegateship and expertise as implicit in the statements I heard and observed.

Limitations

Reflexivity

Preparing for data collection, an important consideration was my own part in the events that I attended, and in the interview process. I was registered as an attendant at all of the events, so that I was in effect a participant. In fact, at one of the research events that I attended, I presented a poster on an aspect of my research. This required me to be very careful in understanding my own role in the event as I observed the proceedings. I also had to make sure that people that I spoke to knew who I was, however this tended to mean that they talked to me in more detail about their organisation rather than less. To avoid difficulties, I contacted each organisation in advance to alert them to my presence as a researcher with an interest in their organisation and asking them for permission to go to the event. My participation in the poster exhibition, and attendance at other meetings was on two separate occasions suggested by the person running the event in question. Therefore, my presence and participation was known to those running and overseeing the events.

Echoing Myers and Newman's(2007) observation of the need to be reflexive as a researcher when conducting interviews, I also found that I often had to be very mindful of the impression that people I interviewed had of me. Several interviewees began our meetings by asking about my academic background, often referencing my age. On occasion participants appeared to be checking my qualifications, and double checking that I was in fact studying at PhD level. For the most part, this was a fleeting moment in the interview and did not cause a significant problem. However, as many did seem to react to my age, carefully preparing the way I would present myself became an important part of preparations for each interview.

Anonymity

A more significant issue throughout the project was the need to protect the identity of my participants in a relatively small community. There are only four main MND and Parkinson's POs working in the UK. As a result, it would be impossible to keep the names of the organisations confidential. Therefore, it was decided that it would be appropriate to name the organisations in the study. However, preserving the anonymity of individual participants was a considerably more difficult task. Although it was made clear in the participant information sheet, and before each interview, that confidentiality would be carefully maintained, several interviewees actively tried to guess who else I had spoken to.

Occasionally, some attempted to interpret everything I said to find out if I had spoken to a particular individual. Others openly said that even if I didn't say anything, they would see the person in question soon and would ask them directly.

Confidentiality also became an issue when using snowballing recruitment in some contexts. As these organisations are based on small local groups, when I asked after interviews if participants could recommend someone else, they would often suggest people I had already met. As I could neither confirm nor deny that I had interviewed them, this led to some problematic conversations where two interviewees in particular assumed I had not met someone I had already interviewed and actually expressed some disappointment in that person. I decided at the time that it was more important not to break confidentiality, so I had to merely state again that I could not talk about any of my participants, including any who had declined to take part. In fact, this might perhaps shed some light on the difficulties I experienced in recruiting for this study. It is possible that because this set of POs is a small community, potential participants may have been aware that their colleagues or associates may find out that they had taken part, and consequently been able to guess what they had said.

Others have described that whilst ethically necessary in the majority of both medical and research contexts, the protection of anonymity and confidentiality can in practice be very difficult particularly when attempting to present a rich case study(Draper and Rogers, 2005, Tyrer, 2005, Corbin and Morse, 2003). Indeed it has been suggested that complete anonymity can be so difficult to ensure in some contexts that it becomes an unrealistic expectation of research ethics. This is because, to remove confidential data can often mean that the value and interest of a case study is significantly reduced(Draper and Rogers, 2005). Furthermore, it is possible that strict adherence to the principle of anonymity, requiring full consent for use of any information, could lead to a significant selection bias where only those who are most willing to waive rights to anonymity are discussed and researched(Tyrer, 2005). As such, trying to protect the anonymity of participants can have methodological consequences. For example, Adshead(2005) has suggested that since research participation involves concepts of altruism and truth, consent cannot be forced by misinformation. As a result, most projects will include the possibility for patients to withdraw consent at any point(Adshead, 2005). This does not, however, factor in the equally common clause in participant information sheets stating that even if participants withdraw, their data up to that point will be kept at the discretion of the researcher. In such

cases, it could be said that anonymity becomes a rather fluid concept. Similarly, discussing the cause of harm in confidentiality disputes, Draper & Rogers(2005) suggest that it is a sense of violation of trust and confidentiality that can cause harm to participants or patients. So that, only if individuals read a project using their data and perceive it to be identifiable, does confidentiality cause feelings of violation. Moreover, attempts to anonymise details can make cases all the more identifiable since it could become obvious which facts have been changed. As such, it could again be argued that anonymity is quite flexible as a concept, since the consent that a participant gives may not account for the feeling of violation they might feel on publication.

Taking all of these points in to account it was decided that, at the point of seeking participant consent, information sheets would stipulate the right to withdraw, as well as my right to keep the data. Then, in order to allow for flexible attitudes towards anonymity, the consent form would give a number of options including, complete anonymity, quoting by name, and quoting by organisation. As shown in *Table 1*, most interviewees were willing, even eager, to be quoted openly, by name if necessary. Some, however, wished to be completely anonymous, while others did not select anonymity or the option of being connected to their PO. Consequently, as suggested above, the need for anonymity did present methodological as well as ethical difficulties, in terms of the way in which interviews were quoted. In writing this thesis, I have had to adapt the way in which I have quoted certain individuals because of their differing anonymity requirements. This presented some problems, particularly in deciding whether to connect anonymised data to a particular condition. As all interviewees were aware that I was specifically examining MND and Parkinson's POs, I decided that, where it did not reveal specific detail about the individual, it would be appropriate to connect quotes with the condition but not the organisation. However, in some instances this has not been possible, so that I have had to either remove quotes completely or generalise them to apply to the issue under discussion. Therefore, in some cases, although the quotes are used to accurately represent participant views, certain details have been obscured in order to protect the anonymity of the individuals in question.

Scope of the study

In refining the project, I chose to examine POs working in the UK in order to make the study more focussed on the particular difficulties that POs can face in engaging with research, rather than having to also consider the national and geographical differences

between the UK and the USA for example. In the case of Parkinson's in particular, it would have been interesting to compare the position of charities in research in America, however this was not in the scope of this study. Furthermore, as shown in the literature review, this project involves and references a wide variety of theories and literatures that would have been interesting to explore further. In particular, the relationship between POs and the pharmaceutical industry is a subject that has an extensive literature, however in this case I chose not to focus on the role that the industry plays in MND and Parkinson's research. Likewise, I would have liked to investigate further the idea that POs can be described by social movement theory however given the particular focus on representation, this was not in the scope of this research. Furthermore, as it has been a significant feature of much of the PO literature, I decided not to analyse the success of POs in terms of financial gain or scientific achievement in great detail. I focus instead on success through the more theoretical lense of representativeness. Finally it must be acknowledged that the fact that I was unable to interview as many people from MND organisations as from Parkinson's organisations could limit the ability to generalise my analysis across the POs. However, as discussed above the case study approach and my more interpretative analysis nevertheless allows me to make general observations about this study.

CHAPTER 4
Carving Community Identities

As Martin(2001) notes, in order to survive, a collective or community organisation cannot rely merely on the process of "self-identification" as a collective and the identification of its members, but must also gain recognition from others outside that group. The identities that a PO chooses to present online, in campaign literature and advertising, will generally be the first impression that the patient population, their families and the public will get of that organisation. As such, charitable or collective organisations will target the information and narratives they present to bolster a particular image. For example, narratives illustrating that the organisation is working towards a particular goal, can strengthen its coherence as a productive force(Polletta, 1998). Furthermore, organisations can attract support using descriptions of their own uniqueness and the individuality of their collective and members' identities. Such narratives can help to elicit sympathy for the cause of the organisation, encouraging better public recognition(Polletta, 1998). Therefore, it is important to consider the collective identity that POs convey, when examining the way in which the organisation is perceived by its members. Furthermore, as the literature suggests, the focus of representation debates is often "the represented", and what they expect from a representative. As well as the way in which representatives define their constituents(Eulau et al., 1959, Saward, 2006). As such, it is important to consider how representatives understand and perceive their constituents or publics, when examining how the role of the representative is understood and enacted.

Therefore, this chapter will focus on "the represented" in MND and Parkinson's POs. I will examine the way in which PO members were described by PO staff as well as members themselves. I will explore the way in which identity, collective or otherwise, was discussed both implicitly and explicitly in interviews with PO staff, volunteers and research associates. Building on the literature which describes the way in which individuals experience and enact different identities in different contexts, this chapter aims to illustrate the challenge faced by POs in representing the divergent identities expressed by their members.

Throughout interviews with PO staff, members and associates, there was a significant focus on the subject of community, and in particular community ties and responsibilities. These findings reflect those in the wider literature review. Such analyses have explored the

role of POs in identity formation, focussing in particular on expert identities as a contrast to illness identity(Hardnack, 2011, Silverman, 2008). What is particularly pertinent to this study, is the suggestion that individuals can experience, express and enact a number of different identities depending on their social environment(Rabeharisoa and Callon, 2006, Olzak and Ryo, 2007, Barbot, 2006, Hardnack, 2011, Lock, 2008, Stryker and Burke, 2000). In particular, Hardnack's(2011) work on social movement organisations provides a useful example of the way in which activist identities can conflict with personal, family identities and the priorities associated with them. This was a particularly significant aspect of interviews with people from Parkinson's POs. Admittedly more of the Parkinson's-related interviews focused on personal experience of the condition, whereas most MND-related interviewees had a professional, PO or research, connection to the illness.

Illness Identity: "it can either defeat you or define you"

Reflecting the literature, the first identity that was often discussed at interview was the illness identity. Previous studies have disagreed over the effects and manifestations of illness identities. Some(Silverman, 2008, Novas and Rose, 2000) suggest it will increase a natural interest in biology and genetics. Others contend that focusing on illness alienates individuals from the illness community either by reducing subjectivity(Brekke and Sirnes, 2011) or increasing focus on individuality(Lock, 2008). As such, it seems important to explore further what illness identity means to those involved in PO activities.

Individuality is an important aspect of Parkinson's and MND because the symptoms associated with both are variable and consequently no two peoples' experience will be exactly the same. The effect of this on joining POs was explicitly discussed in interviews with Parkinson's organisation members. However, many gave differing ideas as to the effect that heterogeneity could have, directly reflecting the literature describing the positive and negative effects that heterogeneity has on PO membership(Lock, 2008, Shostak, 2004, Zimmerman, 1999).

Several interviewees suggested that one barrier to joining POs was the fear of seeing someone in a more advanced stage of progression. For example, one interviewee described initially feeling that joining the PO seemed like "admitting defeat". This suggests that symptom variability might prevent people from becoming PO members, because it can be difficult to identify with others who have different, more advanced, symptoms. However, others suggested that heterogeneity within Parkinson's can in fact assist identification with

PO members. For *E5,* the ability to divide the Parkinson's community into "freezers or shakers" could be unifying, precisely because it enables the group to be split into categories

> *E5:* There's a [cohort] who are quivering in one corner and there's another group who are sat immobile in chairs unable to move and a range of symptoms in between but I actually think bizarrely that actually draws the community together. You can… go up to people at meetings and say "I see you're a fellow shaker" and it does in a strange sort of way bind the community together

The unification thus relies on an individual seeking out those in the same category, suggesting that they are less likely to approach those in the other. This would seem like a barrier to binding the wider community together, as it hinges on separation and sub-communities. However, in the broader sense, sub-communities enable people with Parkinson's to find something to identify with within the group. Therefore, identifying as someone with Parkinson's is not necessarily impeded by the heterogeneity that makes Parkinson's hard to define in terms of symptoms and progression.

A more common discussion about illness and diagnosis, concerned the idea that people have a responsibility to embrace their diagnosis. For example, discussing a person with Parkinson's who was initially reluctant to engage with the local group, *V3* said

> *V3:* He was so busy denying Parkinson's as his identity it was almost like lopping off his arm. Now he's taken Parkinson's and he's found out who he is with Parkinson's. Rather than he's not Parkinson's or he's not the person he was, he's more of a whole now.

Hesitation to join is compared to "denying Parkinson's as his identity it was almost like lopping off his arm". Furthermore, discovering his new identity with Parkinson's is described as allowing this person to become more whole, allowing him to stop focusing on what he has lost and who he used to be. *V3*, then, sees the relationship between the illness identity and PO membership as signifying self-acceptance. This suggests that willingness to engage with a PO allows people with Parkinson's to stop "denying" their illness.

The idea of embracing illness was also linked to patient empowerment in patient-clinician relationships

> *E3:* If you can encourage people to start to embrace their own condition and learn about their own condition and take on board their own self-assessment that change will start to happen because suddenly you've got an informed patient group, very informed patient group who are going to be asking questions and I think that that changes the way that people are treated. They're asking sensible, sane questions because they're coming from an informed base, I think that's incredibly important

Here, 'embracing' the condition is linked to "asking sensible, sane questions" and gaining more influence in the treatment process. *E3* suggests that individuals, by actively embracing their illness identity, can become more engaged in their own care. *E3* also implied that embracing Parkinson's and the treatment process is a responsibility for people with the condition

> *E3:* I mean, I told you about what was happening in Teesside about the lady who was having a terrible time when she was off and she hadn't told her neurologist about it. And that's almost irresponsible in a sense because it comes down to the neurologist to treat as best he can and it's putting him in an unfair position if he doesn't have all the information to deal with.

In this example, a woman is described as avoiding the issues she had with her treatment[1]. Notably *E3* describes the woman experiencing an "off" as irresponsible, and unfair for not explaining her situation to the neurologist. This idea of a responsibility to be empowered through illness was echoed by several interviewees from Parkinson's POs.

> *E9:* I don't think there is enough involvement, engagement by patients. And it comes from both sides, it's partly the patient's fault for not, for not engaging sufficiently

Similarly to *E3*, *E9* raises the concept of an individual "not engaging sufficiently", suggesting that there is a proper level of engagement that people with Parkinson's should achieve. Although *E9* discusses fault, some in fact related this sense of responsibility to positivity or a positive mind-set

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[1] "Off" refers to the varying effects that the drug Levodopa has on Parkinson's, colloquially described as being "on" or "off". Prolonged use of Levodopa results in a lessening in effectiveness of the drug over time. As a result, people with Parkinson's taking Levodopa will frequently experience periods of time where their symptoms are worse ("off") or much less pronounced ("on").

> *V5:* It's like shaking, yeah it's great I just put toothpaste on my brush and away I go you know, don't even need an electric brush it's fantastic whereas older people maybe will hide away and not be as outspoken, not be so honest about it, they'll try and hide it. I sit on my hands to stop them shaking.

V5 suggests that placing a positive spin on Parkinson's symptoms, in this case on tremors by joking about electric toothbrushes, is more honest than the less outspoken attitude of others. Hiding from Parkinson's symptoms is seen as dishonest and unhelpful. *V7* built on this idea to describe the attitude of those diagnosed with Parkinson's

> *V7:* So it's that still trickling down with someone saying I have Parkinson's, what shall I do, how do I act as a person with Parkinson's, what exercises do I do, what food do it eat with a person who has Parkinson's. So it's almost I've got the Parkinson's, how do I act as a opposed to you know I'm me what do I do.

Here, reframing one's life as "a person who has Parkinson's" and adjusting activities accordingly, is seen as approaching the illness in a negative way. It is suggested that people should not allow the illness to change their sense of self –"I'm *me* what do I do" rather than "I've got the Parkinson's, how do I act". This illustrates the conflict that individuals can experience between their personal identity and their illness identity, as a result of the inability to live as before diagnosis. *V7* suggests that the pre-ill self should be identified with more strongly.

Interestingly, this is something with which *E5* appears to have disagreed

> *E5:* It's a condition that as I often say to people it can either defeat you or define you and you have that choice, it's largely down to you as a patient

Contrary to the above, *E5* seems to suggest that being defined by Parkinson's is a positive alternative to being defeated by it. This shows the different way in which empowerment and engagement can be interpreted by different people. *E5* might argue that empowerment is achieved by accepting Parkinson's as an identity-defining condition. In contrast, *V7* seems to argue against allowing Parkinson's to define the individual, although both advocate for greater power and patient control. It should be said that *V7* was much less engaged with PO membership, describing later that she used PUK principally as an information-source rather than being particularly enthusiastically involved. *E5,* however,

has worked more closely with POs, which might require a more positive attitude towards Parkinson's as a defining label, since it allows for the patient-led approach of the charity. That being said, a CPT employee was surprisingly negative about the idea of disease ownership

> *E9:* I think that it's very easy for people with a chronic illness [to] become self-indulgent, to become selfish and to think in terms of why me, think in terms of you know this is my disease, why did I have to get it, everything is against me… there's a responsibility on people with conditions such as this to, to strive not to be needy but to feel needed. So I think it's about erm, retaining your dignity, your self-worth, your sense of fulfilment by doing what you can, to concentrating on what you can do, rather than what you can't

Here, "my disease" is described as indicative of a self-indulgent, selfish attitude causing the individual to become "needy" and lacking in dignity. Therefore, a sense of responsibility is imposed upon people with Parkinson's to be self-aware without being self-pitying. The responsibility is to be empowered in terms of not being "needy", which, contrary to *E5*'s statement, is achieved by refusing to be defined by the illness. Furthermore, the final sentence echoes the opinions of *V7* and *V5*, that it is better to focus on what can be done post-diagnosis rather than how much is no-longer possible. This suggests that positive attitude is similarly important to *E9.*

This was discussed much less in interviews with people involved in MND POs. However *E4,* for example, talked about people with MND having "a period of denial" that could prevent them from being "as involved as possible". "Get involved" is a fairly positive statement, suggesting that involvement and perhaps embracing diagnosis is more positive than the alternative. This to a certain extent mirrors some of the views expressed by Parkinson's PO staff and members. However, considering that ownership of disease has been described both negatively and positively, it could be said that diagnosis and engagement with POs can result in a pressure to express the "right" kind of identification.

Activist Identity: "There is a sort of head in the sand cohort"
Related to this notion of a responsibility to embrace diagnosis is the idea of the activist identity. As Barbot(2006) notes, in the age of health consumerism, activism around an illness has in many ways become an intrinsic part of the patient experience. Indeed, Nahman(2008) suggests that the very act of forming a collective or community around a diagnosis or disease constitutes activism, further illustrating that illness and activism are to

some degree beginning to merge. One reason for this could be related to the theory of the "somatic individual"(Novas and Rose, 2000) as it confers a certain amount of responsibility on the individual not to be passive, encouraging engagement in scientific progress. This does not mean that all patient activism revolves around engagement in science, as evidenced by the disability rights movement(Hughes, 2009, Finkelstein, 2001b, Finkelstein, 2001a, Finkelstein, 2004, Shakespeare, 1993, Shakespeare, 1996, Thomas, 2004, Thomas, 2008). Indeed Watson(2002), has illustrated that many reject notions of disability or illness when constructing a sense of self. In the case of Parkinson's and MND, activism has centred around both research and the provision of proper healthcare. However, rather than debating the purpose of activism here, I will instead focus on what it means to be a Parkinson's or MND activist, and the expectations that are often attached to that identity.

Mirroring the discussions about illness identity, and indeed Lindemann Nelson's(2001) work on narrative creation of identity, many interviewees raised ideas about responsibility when discussing activism. Some also introduced the concept of commitment, suggesting that a lack of awareness amongst the membership of how people with Parkinson's or MND can help promote the PO agenda signifies a lack of commitment to the cause.

> *E9:* elderly people with Parkinson's tend not to engage in their own condition because inevitably you have less energy, you've had most of your life and you, you feel less passionate I guess, less inclined to do something about your condition… So, what we try and do is engage with people who are either young or young at heart, who do have the energy, who do want to commit to making a difference

Here the issue of commitment is explicitly linked not only to engagement with the illness but also to a passion for change. In mentioning that older people are less inclined to commit to bringing about change, *E9* also suggests that younger people are more likely to engage with the CPT cause so that the organisation focuses on them more often. There are significantly more "elderly" people with Parkinson's, therefore in focusing on those with more energy, CPT is excluding a vast sector of the Parkinson's community and shaping the organisational identity in a way that contrasts with PUK. Although this might be sensible if it is accepted that younger people will be more open to active involvement, it does illustrate the importance that CPT places on committed activism. This approach is perhaps supported by a statement by *E5,* relating to people with Parkinson's in general

> *E5:* there is a proportion of patients who don't want to be involved…who would rather go into the neurologists office and be told that you're going to have this, that or whatever as a treatment and you'll feel much better and thank you I'll see you in six months. There is a sort of head in the sand cohort as well but on the whole we feel that if you can, engage patients in their own treatment, and if you can't engage them in their own treatment what can you engage them in? But if you can engage them then it has benefits across the board really.

As well as describing the less engaged as the "head in the sand cohort" *E5* appears to suggest that attempting to engage the less passionate individuals in the Parkinson's community is rather pointless. Furthermore, in linking committed activism to engagement in "their own treatment", *E5* seems to imply that involvement in PO activities is to a certain extent a part of being diagnosed and then living with Parkinson's. This was echoed by others, in particular linking acceptance of Parkinson's diagnosis with wanting to work for a charity. This suggests that the acceptance discussed in relation to the illness identity is occasionally linked to commitment to activism and the PO.

Commitment was also raised in interviews with MND PO staff as an issue over which the organisation had little control

> *E4:* in the same way that you know we can't force people to join… but we do want to be in touch with people so that they can take advantage of the services that we provide. The same with research we can you know make people aware of what's going on where but ultimately the decision is theirs if and when they want to get involved

Much like *E5*, *E4* suggests that some will not want to join the PO and its activities and the organisation cannot make people engage. It was also suggested that people with MND have a certain amount of responsibility to be proactive in pursuing active involvement.

> *V4:* the best way I think is to sign up to the research team's blog and then you get this email in telling you. But it does mean that you, you do have to switch on the computer, you do actually have to actively join in to do it and I think, I do think that is the best way of knowing what's happening. But of course not everybody wants to do that, not everybody has got access to a computer

Somewhat supporting *E4's* view that the organisation cannot force people to engage, *V4* suggests that people with MND must take responsibility to find out what the PO can offer and what it is doing. *V4* later described involvement as "sheer drive and determination"

which again suggests that activism requires personal proactivity on the part of the patient. In this interview, involvement in a PO was also described as part of the diagnostic process, not just for the individual but also for their family and friends.

As Gibbon(2008) describes, part of continued PO support is the legacy-based activism of family members of those who have died from a particular illness. As the above might suggest, this continued activism has to a certain extent come to be expected of people who have known a person with MND or Parkinson's.

> *V9:* There's a few carers I know where they've either split up from their families or heaven forbid their partner's died and they are still involved, they haven't got anything to do with Parkinson's anymore because the person that they are caring for is no longer with them but they're still involved because there's still friends there. It's like 'Cheers', the place you go to meet people!

This contrasts with Hardnack's(2011) suggestion that in cases where individuals have more than one identity (family, social and activist) and the ties to the PO is lost, the activist identity will lose its salience compared to others. If this were true, it would be expected that when people are no-longer carers of someone with Parkinson's or MND they would lose interest in the PO's activities and causes. Several interviewees suggested, this is often not the case, with the death of a family member or friend tending to cement ties to the PO rather than negating them. As such, an important part of the activist identity in the case of MND and Parkinson's POs is the carer activist, who continues to engage despite or even because of the death of a family member or friend.

Lay Identity: "They're not scientific experts"

Building on discussions around increased scientific and genetic description of the patient experience, the literature highlights a significant tendency to analyse the way in which new identities form around new knowledge(Gibbon, 2008, Gibbon and Novas, 2008, Brekke and Sirnes, 2011, Hughes, 2009, Novas and Rose, 2000, Wehling, 2011). In particular, the focus seems to be the formation of identities through lay-professional partnership affording the layperson a more active role in knowledge production(Jasanoff, 2006b, Jasanoff, 2006c, Rabeharisoa and Callon, 2006, Jasanoff, 2006a). Furthermore, it has been suggested that involvement in research can increase the credibility of the patient or layperson as experts in their own right and consequently legitimise experiential knowledge(Novas, 2008, Lynch, 2006). However, some interviewees suggested that this is not necessarily the

case, indicating that patients still tend to have a reputation as not being knowledgeable enough.

In fact, in line with what Williams et al.(2011) have described as the continuing deference to scientific professionals, despite increasing focus on the rights of knowledgeable consumers to make informed decisions, many interviewees implied that people with MND or Parkinson's were possibly less credible than the "professionals".

> *V5:* But I'm obviously not medically qualified to pass judgement or suggest anything but it would be quotes and sources that of information from reputable sites, that kind of...
>
> *AG:* What would you call a reputable site?
>
> *V5:* Qualified people should I say, other sources, Parkinson's UK. Perhaps reputable was the wrong word, trusted source.

This suggests that *V5* doesn't see himself as reputable or trusted source of information. He does count PUK as a trusted source, however, which points to sense of separation between the level of expertise afforded to patient members and POs. This suggests that the "reputable" expertise that the PO has, may not be based on its access to the lay-knowledge of its members. The primary interest for POs is often said to be to promote the knowledge and expertise of members and laypeople as valid in professional circles(Rabeharisoa, 2003, Brown et al., 2004, Allsop et al., 2004). This seems to be at odds with the fact that lay-knowledge is described here as less trustworthy than that disseminated by POs. This was somewhat supported by a PUK staff member

> *E7:* obviously the staff are professionals so it's, you know, there is a good relationship between the staff who have particular expertise but also informed by people with the condition

Here, staff are described as professionals with "particular expertise" and the information received from people with Parkinson's is seen as an addendum to that expertise. In fact, *E7* also alluded to having quite a low expectation of what people with Parkinson's understand with respect to the scientific world, describing conversations where people don't seem to know that researchers "talk to each other" to find out who is conducting which project and make sure they are not duplicating their research.

This attitude towards the level of understanding that members and volunteers have was reflected in the 2012 PUK research conference. This conference was split into two events, one day for lay-members and two days for researchers. The content of talks at the two events was very different, with the members' day focussing more on real-terms impact of research, described in less technical language. In contrast the researchers' conference was very technical, with all speakers making the presumably safe assumption that all those present had sufficient background knowledge to be able to understand without introduction. Although this is not particularly surprising, given that research conferences on such a specific subject are likely to attract those who have extensive understanding of the research conducted in that area, it does highlight the fact that anyone without a background understanding was in effect precluded from participating in the discussions. Despite my past experience studying genetics at university, I was unable to understand many of the papers presented because I was not familiar with the specific field of research.

More pertinent to the present discussion, is the way in which the researcher event was mentioned at the members' day. Most of those speakers who were also speaking at the researcher event, made reference to the fact that they were going to go into more detail at the "main conference". Throughout the day, it was made clear that most of their results and research interests would be discussed at the event that they saw as the 'real' conference. This is perhaps not surprising since the main focus for the researcher is likely to be a presentation to peers at the research conference rather than a less formal meeting held for PO members. However, the fact that some who spoke to me at the time were given the impression that members were not allowed to attend the "main event" illustrates the attitude described above, that lay members and people with Parkinson's are not expected to understand science and research. So much so, that they are not given the opportunity to try. It is of course to be expected that researchers will use different language to describe research to different audiences. It is nevertheless surprising that such a distinction was made to PUK members between the conference and what was viewed by some as a less important event. Moreover, this seems to mirror the expectation of laity and lack of knowledge discussed in the literature review(Brown, 2006, Dunn, 1999)

This view of the "layperson" as less able to understand technical details was not restricted to PUK and the researchers at the 2012 conference. Several interviewees talked about the way in which research information is edited in order to make it understandable to members and people with Parkinson's and MND.

> *P1:* If I tried to describe some of the structures and things of the brain to the layperson they'd switch off within 20 nanoseconds where as some fantastic art work which is generated from it, you've captured their interest then and you can take it forward from there and then explain.

P1 indicated that he generally had a fairly low expectation of what the "layperson" could understand. Similarly, *E2* described the way he changes the language used in talks to different audiences

> *E2:* If I'm talking to an audience which is composed of let's say doctors and nurses, which I often do in hospices, I'll then use words like sialorrhea which means saliva, excess saliva, or dyspnea or apnea which are different breathing problems. Another one orthopnea which is a position, when you lay someone down. So the language has to be appropriate for the audience, otherwise you effectively disenfranchise yourself from them because if I talk to a whole lot of laypeople and I'm all about sialorrhea and positional orthopnea that's just going above their heads, right. So one is to know the, how to pitch it, the content tends to be geared for what they need to know at that time

Although it is to be expected that the content of talks will differ according to the context, the sentence "if I talk to a whole lot of laypeople and I'm all about sialorrhea and positional orthopnea that's just going above their heads, right" illustrates the expectation that *E2* has of lay audiences capabilities to understand their own condition. In fact, during a meeting that I observed, *E2* described to me the lengths to which he attempts to make research information palatable to the level of knowledge he perceived the audience to have. Comparing the presentations given at an event for healthcare professionals to a meeting for organisation members, *E2* suggested that in order to facilitate understanding, he would not only simplify the language used but would also dress as informally as possible. It was suggested that suits or more smart attire would make lay-members less likely to listen to and trust the information he gave. This again gives the impression of a rather low expectation of the ability of "lay"-people to not only understand science but also to pay attention to it, despite the fact that the presentation audiences are likely to be self-selecting. *E2* made clear that attendance was relatively low on that occasion, and that members are given advance notice that a talk about research is scheduled on a given date. This suggests that those who had no interest simply didn't go to the meeting, implying that those who did attend particularly wanted to hear about research. As such, it would seem strange to assume a lack of interest or understanding on the part of those present.

Part of the discussion about lay and indeed patient identity concerned the way in which people with Parkinson's and MND use their experience and knowledge. For example, *V1* discussed the research grant reviewing process conducted by the Research Network[2] at PUK

> *V1:* I'm always going to be more interested either in ones which I have been affected by most seriously… So I'm still interested in the causes of that which can lead into molecular biology and all the other sorts of things. But at the same time I, I have to, I'm trying to be a good person for the laypeople as a literate person that can read grants, that can affect anyone with Parkinson's.

This quote suggests an interesting dilemma: *V1* will always be more interested in grants exploring something that has affected him personally. However, in his role as a "literate person", he feels he has to be a "good person for the laypeople" and try to understand and evaluate grants that address issues that are important to others. This suggests that putting lay and patient experience to use in a PO to a certain extent involves the individual suppressing their own patient identity, since they must respond to grants by taking into account the needs of all patients rather than their own personal, occasionally scientific, interests. Furthermore, describing himself as a "literate person" and others as "the laypeople" suggest some level of hierarchy in lay identity. Although, PO leaflets on the grant review process make clear that members and people with Parkinson's are involved specifically as lay panel-members in order to provide the patient perspective, *V1* sets himself apart from the "lay" category. It is possible that this is due to his background in scientific research, so that he has a deeper understanding than a presumed typical "lay" person might have. However, this does illustrate the separation, in terms of relative expertise, between scientific knowledge and the more experiential knowledge that patients are often asked to contribute in grant review processes and PO-led research in general.

'Expert' patients

Nevertheless, much of the discussion about lay identity involves the concept of an "expert patient". For some, including patients themselves as well as professionals and PO employees, this expertise did indeed come from experiential knowledge gained as a patient. Some, however, mentioned personal expertise as coming from previous training

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[2] The Research Network is a group of people affected by Parkinson's who, as well as engaging in other PO activities, volunteer to review research grant proposals from the lay, patient perspective

> *AG: What do you mean by informed patients?*
>
> *E8:* Well for some, patients have expertise in areas of research in the medical side of things. We know from MND that it affects everyone so there will be for want of a better word the expert patient out there and I think if we have those types of people then you should utilise the skills and knowledge that they have and they can feed into the process. But equally anyone who's experienced in the condition will have an opinion and that opinion is valid.

Although expertise does here occasionally depend on previous skill-sets, it is suggested that in being diagnosed the individual is automatically considered to have a "valid" opinion. Furthermore, when asked to elaborate on whether expertise can be acquired through diagnosis, *E8* suggested that many become experts by independently reading about the condition.

In fact, a commonly expressed idea was that an "expert patient" is someone who is able to combine both previous research expertise with their patient experience.

> *E2:* just occasionally you get the odd expert patient who might give us a bit of insight, you never know.
>
> *AG: What do you mean by expert patient?*
>
> *E2:* Well sadly there was a chap who died, he was American, earlier this year, who was a medical doctor who specialised in Motor Neurone Disease. One of life's ironies. He spent his life studying it and he died of it. Now I don't know if he did give any special insight but it's that kind of thing you know that somebody just suddenly as they experience it there might be something, even if it's only you know I can't do this but if I design that bit of equipment it might help me to do it.

Despite not knowing what this individual's input was in research discussions, *E2* in linking him to the general description of expert patients, seems to expect that his contribution may have given the PO a "special insight". Crucially, it is the combination of a diagnosis and a previous career in MND research that, for *E2,* supports this assumption. In contrast, despite having a scientific background *V1* still separates himself from "experts"

> *V1:* there's a whole area about strategy of research, which I don't necessarily feel that I'm competent to do. Er I'd just say yes let's have a cure, that would be great. But it then comes down to the nuts and bolts, where do you put your money and, you really need, you really do need some experts about the science

Given that others suggested that a previous career in research in combination with patient status confers expertise, this separation between himself and "experts" seems significant. This raises the question whether *V1* sees this division because of the distinction made above between his personal scientific interest and being a "good layperson"? Perhaps it is because *V1* sees his role as representing laypeople with Parkinson's that he also perceives himself as not an expert. This is reflected in a statement made by *E4*

> *E4:* And the Trustees' role, because they're not scientific experts, although the ones we have of course do have an understanding of the scientific process, they, they sit on that panel, they sit round that table with consultant neurologists and university professors for two reasons, one is to ask the "so what" question as I call it, "so what does this apparently anodyne bit of biochemistry mean for people with the disease?"

Echoing *V1, E4* separates knowledgeable Trustees and experts, despite describing Trustees as having an "understanding of the scientific process" and being capable of asking probing questions of the "experts" on the panel. This suggests that the layperson here is again viewed as only being able to contribute in that role, almost ignoring the "anodyne" science to ground the real experts in the focus on the patient experience. Furthermore, it seems to be expected that this is what the Trustees will do, and that they will not approach the research grant in scientific terms. *E4* therefore supports *V1's* perception that a lay expert sitting on a research review panel must only give opinions from that point of view, rather than drawing on expertise that they may have in science or research. This suggests that in both cases the Trustee, and the lay representative are seen more as delegates, charged with understanding and following lay member wishes.

In fact, the separation between scientific and personal understanding of Parkinson's or MND was discussed by several interviewees. One person for example, described the difference between finding Parkinson's "fascinating" as a scientist and his reaction to symptoms as a patient. This suggests that a certain amount of conflict can exist between an individual's patient identity, their previous working identity, and indeed their "expert patient" identity.

Others who had the opportunity to use both their lay and scientific knowledge also described this conflict within the context of their identity as PO members

> *V1:* So I now approach the layman's reviewing with a double hat on as far as I'm concerned, because I'm interested in making sure the science is good, I don't understand it all but I know when I read a good application. But the significance is what's in it for me in terms of the Parkinson's. Can I see a response?

This idea of having a "double hat" reiterates the separation between scientific and patient experience-based expertise, whilst at the same time implying that both can be employed when reviewing grants for the PO. However, when examining this idea within the context of PO membership, *V1* described a particular consequence of the potential conflict between scientific and patient identities when discussing the guidelines given to lay reviewers

> *V1:* if you're a lay reviewer, you've got to think of it as a layperson, a person with Parkinson's or a carer or someone closely affected by Parkinson's. And so there are some really excellent sections in the grant application which are, er, like a layman's review. A layman's abstract, a description of the project in layman's terms, and that's only about five or six pages when you get that lot together.

It seems that it was made clear that members involved in the grant review process were to read applications only from the "lay" perspective, to the extent that they were advised only to read the layman's abstract. Although *V1* said that he does briefly read the rest of the grant, he later emphasised that the decision on what to score the grant and how to vote "always comes from what's in it for me as Parkinson's". This was something that *V4* had also experienced when meeting researchers. However, she illustrated the difference in the conflicts between expert and lay identities, depending on the context in which research is discussed.

> *V4:* I would always say that I bring my medical hat in. I always think that I've got an understanding of both sides of the fence. I can see where the researcher's coming from and I can also see the issues that are very pertinent to the patient. And I feel that that gives me a, a reasonable strength to be able to look at things in a fairly balanced manner.

Here, similarly to *V1*, *V4* thinks about research from both a scientific and lay perspective. *V4* also later mentioned a sense of responsibility to focus more on her lay opinion. In contrast to *V1,* however, *V4* discussed these identity conflicts as occurring differently in different contexts. In particular, *V4* suggested that in certain contexts, it would be easier to detach emotionally from the research subject

> *V4:* I'm not going to say that things don't affect you, you don't sometimes feel personally but I have to say it's quite rare, the majority of times I can feel detached, I don't look at it as related to me… I find the science and the cell biology particularly very fascinating.

Here, the scientific identity seems to be stronger than the personal associations with a condition, so that *V4* is able to focus on research as primarily scientifically interesting. Therefore, in some circumstances, *V4* finds it easier to think neutrally about subjects that could be expected to be upsetting to someone with personal experience of the condition. In fact, *V4* suggested that researchers often assumed that she might find discussions about research difficult, even in situations where she was not struggling to understand the science. This implies that scientific "experts" will tend to principally perceive those with whom they interact through their patient or lay identity.

In assuming that some subjects will be upsetting, the "experts" do not appear to realise that knowledge and understanding of the scientific aspects of any given research project in fact allows *V4* to view the issue more neutrally. Furthermore, they appear to act upon this assumption by expressing their empathy with her, asking about the discomfort they expect her to feel, thereby to a certain extent seeking to validate or confirm their assumption. That being said, it becomes almost surprising that *V4* feels her scientific identity more strongly in these situations, since interactions with others often serve to enforce the dominance of her lay identity.

This reflects the situation described by Hardnack(2011), where identification with an organisation will be affected by the way in which an individual's commitment to the cause is perceived by others. It is implied that the individual may express the identity tied to their organisational role more strongly if required by interactions with others. As such, it could be expected that *V4* might express her lay identity more strongly, to conform to the expectations of those she meets, which makes the fact that she does the opposite all the more curious. This points to another significant identity discussed in interviews: collective or community identities. Many described very different effects of the community as a whole on their experience of PO membership.

Collective Community Identity: "Commonality of purpose, commonality of message"

As suggested in the literature review, collective identity formation is often seen as the primary goal, and outcome, of POs and other social movements(Bernstein, 1997, Gamson,

1996, Gibbon, 2008). Furthermore, collective identification, or "sense of we-ness"(Hardnack, 2011), once established can become a driving force behind recruitment and continued PO membership(Hardnack, 2011, Gamson, 1996, Bernstein, 1997). Particularly, it has been suggested that although collectivisation might be aided by a concept of shared biology, most POs will tend to focus instead on social experience in order to counter the potential individualism of disease genetics(Novas and Rose, 2000, Wehling, 2011, Lock, 2008). This is pertinent to the Parkinson's and MND organisations, since they involve groups of individuals with very different symptoms, unified as people with Parkinson's or MND. This would seem to contradict the idea raised by Lock(2008), that symptomatic and biological differences will result in a tendency for group members to work towards their own benefit over that of the organisation.

One way in which community identification arose most explicitly in interviews was through discussions about POs as presenting a 'common voice'.

> *E9:* I think people with Parkinson's can engage with all members of the Parkinson's community and they have, and with a, with a common voice I think they can make a big difference and accelerate the process

Talking about the research process, *E9* not only mentions the "Parkinson's community", but also the importance of a common voice. Expecting the Parkinson's community to speak with one voice suggests that *E9* has a fairly strong sense of a community identity, particularly when considering the general theme of that interview. *E9* used terms like "team work" very frequently, often alluding to the benefits of collectivisation. Therefore, it is also significant that "Parkinson's community" is described as bigger than just people with Parkinson's. Furthermore, a responsibility is placed on people with Parkinson's to engage with other members. As quoted at the beginning of this chapter, *E9* explicitly suggested that the Parkinson's community needs a "common language". Some interviewees did in fact imply that this language already exists. It seems Parkinson's in particular comes with its own colloquialisms, so that interviews with people from different POs and different parts of the country start to talk about Parkinson's in the same way. A good example of this is the "on and off" concept, that people often mention offhand without explaining it. In fact, this is also true of medical professionals, suggesting that it is embedded in the way that Parkinson's tends to be described. Similarly, many people with Parkinson's describe the tremors or dyskinesias they experience in colloquial terms. As

illustrated in the discussion about illness identity, it is common for people to be described as "movers", "freezers" and "shakers". Here again medical terms have been translated into a colloquial language that has been widely adopted by the Parkinson's community. Furthermore, several interviewees from both MND and Parkinson's POs used the word "frustration" when discussing illness and living with the conditions. Given that they tend to be described in more overtly negative terms, the fact that MND and Parkinson's are so frequently described as "frustrating" could suggests again a certain commonality in the way in which illness is described, this time across the two conditions.

Interviews also suggested the two patient communities share a preoccupation with broader philosophical concepts that go beyond a shared language. Most interviewees highlighted "hope" as a concept on which both POs and patients themselves must focus. Many expressed in particular the idea that to live or work with MND and Parkinson's necessitates living in hope. Although it is not an example of common *language* per se, this firm focus on hope, suggests that the apparent commonality between the conditions and POs transcends language to collectivise certain ways of thinking about MND and Parkinson's. This further suggests that the goals emphasised by POs, and the conditions themselves, seem to carry with them an inherent sense of commonality.

Community Status

Curiously, reflecting conversations about activism and illness, some interviewees alluded to the presence of hierarchy in community membership, linking level of engagement in community activities with an individual's importance. For example, CPT staff gave me a diagram they use to show the progression from diagnosis to acceptance (Appendix 2). Crucially, this triangle shows the engagement of people with Parkinson's as a process leading from isolation to effective community involvement. Interviewees suggested that reaching the top of the pyramid signifies not only a realisation that there is a community of people with which the individual can interact, but also that this realisation brings with it more power to influence that community and it's activity. Furthermore, those at the bottom are perceived to have distanced themselves from those at the top by struggling to complete the pyramid. Somewhat reflecting discussions about the responsibility to engage associated with illness identity, this implies that people with Parkinson's are expected to gain an awareness of the wider community and that those who do not do so are failing to fulfil the responsibility to engage with others. Despite the bottom of the pyramid being the largest group of people, interviewees suggested that it would be impossible to reach those who

had not yet begun to engage. When asked if CPT is involved in the "diagnosis" stage *E3* said

> *E3*: No, not at all. For us, I think we come in here at communication, erm, because at diagnosis everybody deals with that in a different way. We have information, people can communicate to us, we can provide information, we can be a source of information and we can enable people to consolidate and then from there, if we can get them to work with us and share their voice from there on in we can help them move up that triangle.

This suggests that CPT only approaches those already at the community seeking phase of the pyramid, and consequently those who have already begun to connect with others, rather than people who might need some encouragement. This might suggest two things about the CPT approach. Firstly, that they generally do not market CPT to people at the point of diagnosis, instead relying on people to approach the organisation themselves. Consequently, it would seem that CPT expects individuals not to want to engage early on in their diagnosis and therefore does not perceive it to be useful to approach them. Secondly, disregarding those who are not ready to engage sufficiently, suggests that CPT is only interested in the involvement of a certain type of person, deemed willing to engage in the right way. That being said, *E5's* description of diagnosis might suggest a reason for CPT's approach

> *E5:* You remember the date, you're not even thinking of treatments at that stage, you're just focusing on those two words. So for someone to say "well don't worry about it we have a number of pamphlets which you can read and which you help you through this" it's just not going to register. [So] the point in which you catch them is later on, really, and hopefully at that point, as you say, you can engage them

E5 explains that, on receiving the diagnosis, people with Parkinson's will not be ready to hear about activism. As such "the point in which you catch them" is when they are more able to listen. Applying this to CPT, it could be said that only approaching those who are already beginning to engage with POs, rather than cultivating an interest amongst those who are not, may in fact be quite an effective tactic for engaging people with Parkinson's. Knowing that people may not want to be bombarded with information, when they are still coping with a new diagnosis, it seems sensible only to approach people when they are more able to listen. This is to a certain extent practical for a relatively small charity with a very strict definition of its goals. CPT does not claim to be a support charity for all people with Parkinson's, therefore focussing only on those more likely to engage in activism and

campaigning is not too surprising. It is however somewhat in contrast with earlier statements about engaging with all members of the Parkinson's community. By effectively ignoring what was acknowledged to be the vast majority of people with Parkinson's, CPT appears itself to be failing to engage with the community for which it advocates.

This idea of targeting information to people at different stages of acceptance was also alluded to by *V2*

> *V2:* Well I think sometimes they're a bit mystified about what, you know who we are and what we do. We can tell them what we offer them and I've got a leaflet here to give you about, which is not what we give to patients necessarily because it does talk a lot about MND but it's publicity about how we work as a local branch. But the, when we go in, you're sort of there to assess where they're at.

In describing how the local branch approaches new people and prospective members, *V2* described the necessity to "assess where they're at" in terms of their diagnosis and emotional reaction to receiving it. This bears a certain similarity to the CPT triangle, since again much of the publicity information is restricted to those perceived ready to receive it. However, those who are not ready are still approached and offered more simple information and the opportunity to talk to a volunteer or employee from the organisation. Therefore, although there is again an allusion to a hierarchy in terms of readiness to be involved in the organisation, those "at the bottom" are not ignored in this case.

As was the case with illness and activist identity, responsibility to the wider Parkinson's or MND community was often raised in interviews. Particularly, many discussed the responsibility to join the community and a responsibility to act in its interests. Perhaps unsurprisingly, given the expectation that some expressed, that people with Parkinson's in particular would seek out the wider community. Mirroring discussions about illness and activism, some interviewees associated peoples' engagement with the community with a process of "accepting their condition". This implies that, as was the case in discussions about illness, not contacting the community is a sign of denial

More frequent, were discussions about the responsibility to the community once the individual joins. As Hardnack(2011) describes, individuals prioritising other identities that they might possess, over the community identity, can be seen by other community members as less dedicated to the cause. This could be because community identities are

often linked to specific roles and expectations(Stryker and Burke, 2000). That is to say that failure to commit to an expected role within a community is interpreted as a lack of commitment to the community itself and consequently a failure to meet the responsibility of owning the collective identity. This situation arose in one interview in a discussion about people raising money to engage in stem cell tourism – the practice of travelling abroad to access stem cell treatments that are not yet licenced in the UK.

> *V4:* well it impinges, it means that not only are you defrauding an individual you're defrauding a community And, and in a sense that's the individual's responsibility, I think, to look in. And if they can afford it and they want to spend the money on whatever that is entirely their choice but I think they should be responsible about how they spend other people's money.

This seems to a certain extent to reflect the literature suggesting that personal identities will be prioritised over community identity, allowing community members to sometimes prioritise their own needs(Stürmer and Simon, 2004, Lock, 2008). However, in this situation, the desire to pursue, an albeit questionable, therapy was described, as well as being unfortunate to the individual, as doubly bad because the money raised for the trip could have gone to a collective cause. *V4* believes that any funds raised by people with MND should be used to benefit of all people with the condition, otherwise the individual is "defrauding a community". Many acknowledge that people with MND are often particularly vulnerable to persuasion by dubious therapeutic opportunities, frequently suggesting that it is understandable for people to want to do anything they can to access a cure. Therefore, this quote provides a stark contrast by blaming those who opt for this treatment. Furthermore, it suggests that while on a personal level, Stürmer and Simon's(2004) assertion may be correct, the expectation amongst the community is that the needs enforced by community identities will counter those of the individual.

The Necessity of Community

Perhaps unsurprisingly, given the emphasis placed on an expectation that people with MND or Parkinson's will seek out the wider community, the concept of community feeling, was often described at interview as bringing people together and enabling positive action. Indeed many suggested that a sense of community was essential for PO activities to work.

> *E3:* it brings it back to the sense of the value of Parkinson's Movement because it brings everybody together in an incredibly positive way. It's about focussing on the issues that are really important and trying to make a difference but doing it from the grassroots level rather than doing it from the Daily Mail health pages which can always distort the facts and you're not in control of the messages whereas with Parkinson's Movement people with Parkinson's are absolutely in charge of those messages and that's what matters

E3 suggests that it is by bringing people together that the campaign group Parkinson's Movement is able to effectively disseminate and control the information presented to a wider audience. Additionally, it would appear that *E3* is alluding to a perceived difference with another organisation's actions, by making clear that their "grassroots" approach is more positive than using a relationship with the mainstream media. CPT employees were often very vocal in describing their deliberate shunning of a media relationship, whereas PUK spokespersons frequently appear in newspaper articles about or related to Parkinson's disease. Therefore, the above could perhaps be interpreted as a criticism of the PUK approach, since working with the media is said to result in the distortion of facts.

Indeed, others suggested that collectivisation could positively impact the Parkinson's cause

> *V9:* Without PUK we'd be lost completely or the CPT or the EPDA or the Victoria one. I'd love to see a world Parkinson's society to be honest, under one banner so all the money is going in one direction or being used properly.
>
> *AG*: *What would properly be do you think?*
>
> *V9:* By people who know what they're doing. I've not got the knowledge. We've all got different knowledge on different aspects of life but the more it's pooled the better it should be

When asked what "properly" means, *V9* says that money should be used by those who "know what they're doing", but also that this is more likely to happen if everything is collectivised. This suggests that collectivisation of resources amongst different organisations would almost by default ensure that they are used by the right people. Furthermore, this implies that *V9* thinks this is not happening at the moment, that money is being used by people who do not "know what they're doing", and that there is an absence of community identification between different organisations. However, *V9* also said global progress in Parkinson's research would not be possible without PUK. Therefore, although

the world Parkinson's community is described as a dream, *V9* nevertheless believes that existing worldwide collectives would not be possible without PUK.

Looking at more implicit notions of community, interviews with people in different roles in POs often featured words such as "us" and "we". For example

> *E2:* And we campaigned, this was long before I joined, we campaigned to make it available to all and that campaign was successful.

As would perhaps be expected, those engaged with or working for a PO often described their organisation in these terms, highlighting a sense of community identity. However, in this case *E2* attaches a sense of "we-ness"(Hardnack, 2011) to a campaign that precedes his involvement in the organisation. This suggests that the strength of community identification can transcend actual involvement with that community. Similarly, others applied the word "we" to all people with Parkinson's and all campaigns and activities that relate to them, typically in statements saying what "we" are perceived to be like by the public. However, the use of this language was not always positive, *V1* for example laughed at his own use of "we" when saying "if we didn't have Michael J Fox", suggesting that that level of community identity seems strange to him.

In contrast, relating to research showing that the internet may preclude active membership in a PO(Lock, 2008), discussions about community identity often referenced the presence of anonymity in Parkinson's and MND communities. Particularly, this seemed to be enabled by remote communication. For example, when discussing a charity event

> *V11:* no success of anyone biting to say "I'll help you" because the Parkinson's community of people is quite a closed community, you have to get into it first and I was actually criticised for not introducing myself and telling everyone who I was, and this is all in writing there, it's on the forums, it was "how dare you" almost "come along and say you want to do a ball without telling us whether you've got Parkinson's or not, how old you are". And I didn't really want to give all my details out to people I didn't know, I just wanted to do a charity ball!

Here, the community enabled by remote internet interactions causes *V11* to use the word "community" in a rather negative way, describing the Parkinson's community as "quite a closed community". Furthermore, the hostility *V11* experienced seems to have been

sparked by a lack of previous connection to that community so that she was approaching others as an outsider, despite being willing to help and in a broader sense being part of *the* Parkinson's community. This illustrates the effect that technology can have on community ties, since it is the remoteness that makes people suspicious of unannounced guests. Moreover, it highlights that community activities, in using the internet and other remote communication, now in many ways necessitates anonymity, since many might never meet the person with whom they interact. This was also described by *V2* but in a very different context.

> *V2:* But it's quite difficult because I want to be sure that someone is going to do something the next day and I never hear from him again you see… So we're anonymous in that sense and we always have to say that, well you know you listen and if they're anxious you try and listen to what their anxieties are and if you know that there are systems in the MNDA that can help them then you say those sorts of things and that someone will definitely get back to them the next day

Here, in the role of giving people telephone counselling and advice, anonymity again plays a negative role. Although, in the course of one conversation *V2* might build a certain bond with an individual they too will generally never meet or even speak again. Furthermore, it suggests that much of the advice service that MNDA provides is based on anonymity. As such, anonymity is a significant part of the MND community ties cultivated by the MNDA, since the advice line is one of its main community support activities. This means that community identities might be formed without any physical contact at all, suggesting a very different basis for collectivisation. Far from involving face-to-face contact and traditional campaign meetings and rallies, POs can now foster a community identity for people with Parkinson's or MND by providing internet, telephone and other anonymous, remote interactions.

Membership Identity: "yeah but I'm not a member"

Although it may seem on the surface to be the same as community identity, interview data shows that the identity associated with membership of an organisation can in fact be very divergent from an individual's identification as a community member. Stürmer and Simon(2004) describe the fact that people, even if they identify as part of a disadvantaged group, will often not actively participate in the social movement linked to that group. This is because it is important to identify within an organisation or movement in order to identify fully as a member. This suggests that there can be a difference between identifying as, for example, part of the Parkinson's or MND community as a person living with the

condition, and identifying as a member of the PO. This separation of illness and even activist identity, from a membership identity arose in some interviews, where a rather detached membership to the organisation was described. This could provide another perspective on the representation debate. Others have suggested that the extent to which the public identifies representatives as legitimate and fair has a significant effect on their willingness to accept the decisions representatives make(Eulau et al., 1959, Carman, 2010). Applying this to the issue of membership, it seems that the suspicions that individuals hold about the priorities of PO staff, can affect their willingness to accept the membership, or the "represented", identity.

This is best illustrated in the following extract, which, though long, shows how the idea of membership develops. This was part of a discussion about the extent of *V5* and *V7*'s interaction with the PO.

V7: Haven't even thought about if I'd like more I guess because I've not felt there's been a need because, because we get the specialist nurses and because of the Young Onset Group and the information and support officer that has covered everything I've needed so far. It might change in the future but so far that's covered it.

V5: I guess if there was a locally, I say locally, a south west rep or south west champion for Parkinson's UK it might have some benefit. Somebody you know resident in the area who is maybe a champion for Parkinson's UK or yet to take on the role of representing Parkinson's UK locally that could speak for them locally.

V7: Well at the group we get the Chair or something down don't we?

V5: No that's our Chair

V7: But they're Parkinson's UK.

V5: No she's Chair of the, the, yeah but she's not

V7: They're still Parkinson's UK, like *[Jenny]* is Parkinson's UK

V5: Yeah but she's not active, actively involved.

In this exchange, *V5* and *V7* describe a tacit membership to PUK, where they access the benefits of membership such as meetings with a Parkinson's Nurse and access to information but do not consider themselves 'real' members. Furthermore, although they know that their group's chair is from PUK, they still describe her as "not active, actively involved". This insistence that their chair is not really a PUK member could suggest that "active" membership is viewed with suspicion, since it seemed important to reiterate that fact. For example, *V7* also discussed the difference between the group approach of PUK

and how things might work for an individual and both debated whether as an organisation, PUK can actually be more personal and integrate all dislikes and likes. Similarly, in a discussion about management *V1* mentioned "people on the ground" and "*ordinary members*", suggesting differences between staff and other members and a generally negative attitude towards PUK organisational representatives. As such, it seems that although interviewees like *V1* appeared earlier to suggest that PO Trustees should act as delegates, presenting the patient or lay view; in this case people who are perceived to represent the organisational agenda are assumed to be more detached from "ordinary members", which is arguably more closely related to the trustee end of the continuum.

Alternatively, this separation between membership and "active" membership may point to the way in which "active" membership, and what it entails, is understood.

> *V5:* Yeah but I'm not a member of their research committee or their steering group or anything like that. By saying I'm a member I pay to be a member and have a magazine sent to me once a month

So, despite paying membership fees, *V5* does not view himself as a member because he is not part of certain committees and as such does not participate in certain activities deemed necessary for "active" membership. This was echoed by *V11*

> *V11:* I don't feel like I'm part of Parkinson's UK other than the fact that I am and I get a membership card and I get a magazine - 4 quid to be a member, is 4 quid too little?… you give them £4 and you get a magazine back that you have no input into – does that feel like a good way of spending £4? Getting a magazine that's pretty boring. Yeah it's just a bit dry and people with Parkinson's we want to have a laugh, we want to enjoy our lives, we want to feel like we haven't got to slit our wrists because things aren't as bad that magazine will make out. Because you have to remain positive at the end of the day, it does help!

V11 also seems to feel that her membership of PUK is no more than paying a fee and receiving a regular magazine, but is rather more scathing than *V5*. In emphasising the importance of "belonging to something" *V11* is very critical of PUK's success in cultivating that attitude, saying both that the membership fee is too low and that the magazine, the sole communication she seems to receive, is boring and irrelevant and therefore uninvolving. *V11* in fact sounds rather distant and disillusioned with PUK, doubting that the organisation is even capable of representing the needs of people with Parkinson's in a magazine. This illustrates the difference between community and

membership identities, since *V11* has a clear idea of the benefits of being part of a community, to the extent that she will pay for something she appears to dislike, but does not identify at all with the organisation of which she is a member. This example, therefore seems very much in line with Stürmer and Simon's(2004) theories.

Both *V5* and *V11* seem to exhibit the sense of obligation to engage with representatives, described in the literature(Bowler et al., 2007). Both continue to pay membership fees despite not particularly wanting to engage with the organisation, and its committees. *V11* in particular, reflects the assumptions made in the literature about the tendency for the represented to mistrust representatives. However, neither volunteer seems to actively try to monitor the representative, to make them 'more fair' as Bowler(2007) has suggested. Although both receive the magazine that they seem not to like, their engagement is arguably limited to continuing to dislike the monthly magazine rather than trying to make it more relevant to their needs. Instead of being involved to make the PO more trustworthy, *V5* and *V11* choose to maintain tacit engagement (although it must be said that *V11* mentioned attempting to be more involved organisationally). This therefore adds another dimension to the characterisation of representation through engagement or direct democracy. Although both volunteers exhibit the mistrust coupled with a sense of obligation to be involved, that in the literature is linked to direct democracy, neither pursues an active role in the PO, and indeed *V5* earlier directly disassociated himself with "active" membership. Therefore, a very tacit and unengaged form of membership can also be linked to dissatisfaction with representatives and a sense of obligation to continue to be member, despite feeling very removed from the idea of PO membership.

Summary

This chapter has focused on the idea of "the represented"(Eulau et al., 1959), exploring the relationship between POs and those they represent. By looking at how identity was discussed in interviews, I have examined how people with MND and Parkinson's describe themselves and others and how PO staff understand their members as individuals (to the extent that they do) and as a collective or community.

Reflecting the literature review, this chapter has shown that people with MND and Parkinson's can experience several divergent identities depending on their social, medical and organisational context. This can create certain challenges for the PO, when attempting to unify these identities under the collective umbrella of PO membership, and maintain a

sense of collective responsibility. For example, the membership identity cannot be characterised by the payment of fees or even attendance at events and meetings alone, since some who do all of those things nevertheless perceive themselves to be outside of the 'real' membership group. This highlights the difference between identification with a community as a whole and a more individual perception of one's own membership of that community. Consequently, potential reasons behind community identification such as a strong sense of illness identity and the commonality of purpose that that creates, or the activist identity that might drive involvement in a community, also become difficult to maintain. This in many ways reflects the work of Hardnack(2011) which describes the conflicts and interactions between the different identities that an individual might hold. However, rather than presenting a tension between personal illness identity and community identity, the potentially divergent identities that PO members possess, were often discussed in terms of the responsibilities they created towards the community as a whole.

Nevertheless, as both elements of membership or belonging rely on establishing the balance between all the different aspects of an individual member's identity and experience, it is likely to be difficult to achieve a constant success in collectivisation. Consequently, it can also be difficult to understand the nature of the representative-represented relationship over time.

Representation as a concept has appeared in many forms in this chapter, including direct discussion of PO Trustees as well as the role of lay representatives and the PO more generally. In particular, the discussion about "lay" members and the extent to which they can understand and engage with scientific language, suggests that in the context of research POs often resemble more closely descriptions of trustee-representatives. However, the fact that the role of PO Trustees and lay representatives was also often described as principally to ensure that PO and research board decisions conform to member opinion, suggests that the delegate-representative model also applies here in certain circumstances. Thus, as suggested by the literature, the "representative", or the PO, can simultaneously act as a trustee, making decisions on behalf of members, and as a delegate, making sure that members' wishes are accurately followed.

It seems to be the case that, POs promoting member-led research can nevertheless exhibit a tendency to assume that patient members will not be expert enough to make reasonable suggestions about scientific research. This has resulted in the lay perspective being

somewhat marginalised to the extent that lay members have on occasion been explicitly excluded from scientific discussion. Therefore, although the POs tend to emphasise their position as member-led organisations, closely representing a coherent collective community, this chapter suggests that it is not always possible to maintain a commitment to member involvement in PO decisions.

In the following chapter, I will continue to analyse the way in which POs maintain a sense of collective or community connection, exploring the way in which PO activities and services are promoted as patient-centred, I will examine the challenges involved in matching commitment to patient representation with the apparent lack of community cohesion observed in this chapter.

CHAPTER 5
Defining the Day Job

Chapter 4 explored the way in which collective identities are constructed and perpetuated by POs through the ways in which they conceptualise and promote the experience of their membership. This analysis illustrated that it can be difficult to unify a diverse group of individuals under a sense of common membership of, and responsibility towards a community predicated upon a shared illness experience. Nevertheless, MND and Parkinson's POs continue to emphasise the importance of collective identity, to the empowerment of the individual with Parkinson's or MND, and they certainly consider it to be crucially important to the success of the PO activism agenda. In this chapter, I will examine the way in which the organisations maintain a sense of community cohesion through their support-focused activities. I will explore the way in which interviewees described PO priorities and activities. Discussing in particular the provision of information, I will then use interview, observational and web analysis data to explore how the POs approach their role in advocacy. Finally I will examine the increasing importance of the internet and social media. This is to present an account of how the POs understand their role and impact and how day-to-day activities contribute to or detract from the POs' claims to be representative of the interests of their membership.

PO Role in the Community

The literature shows that representation is often assumed to be the primary goal of POs, and that in analysing their activities many conflate organisational actions with those directly conducted by patients or members themselves(Novas, 2006, Hughes, 2009). Furthermore, it has been suggested that in order to represent members, POs will enact or promote various identities depending on the circumstances – negative social identities might be used to increase public awareness, for example(Hughes, 2009, Wehling, 2011, Panofsky, 2011). However, as others point out, organisational use of member identities, collective or otherwise, can risk the PO becoming less representative of some members, since the collective presentation of illness experience may differ greatly from the experience of the individual(Bernstein, 1997). Moreover, as Popper and Walzer's theories of community suggest, where there is too great a focus on the benefit of the many over the few, communities can become based on power and control rather than freedom(Armbruster and Gebert, 2002, Popper, 1945, Walzer, 1990a, Walzer, 1990b). Although, the intention here is not to compare POs with tyrannical regimes of control, it nevertheless seems

important to further explore the idea of community representation in a similarly normative way. This is because the vast majority of research looking at the representativeness of POs seems to focus on geographical or demographic representation in the organisation(Grinton et al., 2013). In contrast, I will examine how employees, members and volunteers perceive representativeness in their organisation,

Patient-Centred Priorities: "we tried to be all things to all people"

As described in the Introduction, much of the PO literature focuses on organisational transition from support or self-help activities to incorporating more research engagement(Gibbon, 2008, Gibbon and Novas, 2008, Langstrup, 2010, Novas, 2006, Wehling, 2011). It has been suggested that the increasing interest amongst patient communities in research engagement is part of a wider move to shift power from scientific professionals to patients and their representatives(Williams et al., 2011, Rabeharisoa and Callon, 2006, Barbot, 2006). However, it has also been suggested that in creating a collective, all the activities in which POs and their members engage, must to some extent represent or promote the health and benefit of at least the majority of community members(Gibbon and Novas, 2008, Rabinow and Rose, 2006, Gläser, 2004). As such, PO activities become a matter of balancing responsibilities to different parties as much as they involve a balance of priorities.

Considering Gamson's(1996) theories on the effect definitions of community have on the activities that take priority; in turning their focus to research funding, MND and Parkinson's organisations might risk other functions becoming secondary or on the periphery. Relating this to the representation literature, the trustee-delegate Continuum illustrates that the attitude of representatives towards constituent or public opinion can be very changeable. The delegate end of the continuum for example requires representatives to listen more closely to the wishes of those for whom they speak. Therefore the way in which PO representatives understand their role in the patient community might shed some light on their attitude towards patient opinion.

In line with Hughes'(2009) characterisation of POs as having the needs and issues of patients at the core of their aims, many of those interviewed described Parkinson's and MND organisations as very patient-centred.

> *V2:* I think I'd describe the MND Association as a charity that really puts the person with MND and their families at the centre of all the activities, which is a very good thing.

Interestingly, *E2,* talking about his PO's patient focus, started calling people with MND "clients"

> *E2:* Our main focus is on clients, so all our services are to the clients. So we've got the complementary therapies, we've got the education service which is to the professionals dealing with the clients, so they're better prepared to deal with it, the welfare and benefits to the clients, we have a counselling service next door to the clients and the carers, we have an information service and across the road we've got the equipment service, so they're all focussed on the clients with MND.

The purpose of this quote is to describe patient-centeredness and the fact that all PO services and activities are specifically designed to benefit people with MND. However, the use of the word "client" gives it a very business-like tone, suggesting that the patient-focus here is a customer-service-like obligation. This then raises the question as to what constitutes patient-centeredness and what it means. *V2* might suggest that it is the act of keeping patients in mind in all aspects of the organisation. *E2* on the other hand might see patient-centeredness as the continued provision of effective and appropriate services.

To investigate this further, each interviewee was asked to describe their organisation, imagining that I had never heard of it before. The answers to this question were quite varied, in terms of the way people chose to describe the organisation and the function or activity they listed first.

In general, volunteers tended to describe support and care activities first in a list, if not exclusively. For example, describing PUK's purpose:

> *V9:* what's that saying "no-one has to face this disease alone" which is great… people with Parkinson's need help they just don't admit it

Here, PUK is described as making sure people with Parkinson's have support, even if they don't ask for it. *V9* then expanded on this to describe all the ways that the organisation supports people with Parkinson's, describing the organisation as essential - "as good as a

walking stick". This kind of answer, not mentioning research, was also occasionally given by PO employees who have worked more closely with the research department.

> *E7:* Gosh, ok. Well Parkinson's UK is the leading charity in the UK providing support for all people with Parkinson's... We also have local branches throughout the country where people can meet, get support, exchange ideas and talk to each other etc so we are there for all people with Parkinson's.

Therefore, a particularly important part of the patient-centred approach is to provide people with a meeting place, where the patient community can develop. Although the POs substantial support agenda is of course likely to feature in the way in which a staff member describes their organisation, it seems significant that research was not mentioned at all. It is possible that because most of that particular interview discussed research, *E7* wanted to highlight PUK's other activities. However, as even employees from research departments gave such answers, it seems possible that the commonality of the way in which many interviewees spoke about their PO illustrates a certain habit of language. The speed with which interviewees were able to give a description, pretending that I was new to the field, suggests that this is a task that they are used to performing. Indeed, considering the issues described in Chapter 3 with respect to recruitment, it seems likely that employees would have a rehearsed way of listing PO activities and an organisational line to follow.

This was also reflected in answers that combined research and support activities

> *V4:* Well I would say to start that [it] is the only national charity that supports people with Motor Neurone Disease and their families… and its mission is to fund the research to find [a cure] whilst at the same time supporting and caring all those affected by the disease and affected by the disease means those who've actually got it and their families and carers. So that's their sort of vision and mission.

This is characteristic of the answers several interviewees gave – beginning with care, mentioning research and then returning to care again. The frequency of this type of response suggests that, for the most part, employees and volunteers agree upon the priorities of their POs. This could, again, point to a habitual or practiced way of describing POs to the public. Alternatively, it might reflect Gamson's(1996) assertion that community ideals will rarely change although public goals continually shift from the periphery to the "centre stage". In the case of PUK, MNDA and MNDS, although it could be inferred from their websites and public engagement activities that a primary focus is research funding

and management, talking to members at all levels suggests that the core community ideal is in fact support and care.

That is not to say that everyone presented this view. Perhaps unsurprisingly, although some were volunteers, most who described research as the main PO priority, tended to be, employees who had more connection with research. This was particularly the case with CPT employees

> *E9:* I'd describe it to you as, a small to medium sized charity which is blazing the trail toward a cure we're, we are doing everything in our power to not only find the science but also deliver the science into the clinic and to create impact in Parkinson's.

Perhaps echoing Fishkin's(1997) debate over deliberative polls, some interviewees justified the amount of money spent on research as a response patient and member opinion polls.

> *V2:* every year we raise a lot of funds in our branch and we always ask our people, we can, we can put it into care, we can put it into equipment or research, and they, we always usually give 50 to 60% of the money we raise to research and the rest to the other more practical things.

Nevertheless, the fact that the money not donated to research is described as going towards "other more practical things" suggests a certain amount of ambiguity in this conceptualisation of patient-centred decision-making. Although this branch's members support research enough to allocate 60% of its funds to it, the research is seen as less practical than other causes, suggesting that research is seen as less useful. *V2* is describing research as both patient-sanctioned and as somewhat distant from the immediate needs of people with MND. In fact, many suggested that research was prioritised to the detriment of care and support.

> *V11:* The charities do their best to try and tell people what Parkinson's is but with the focus on research they're not really going to be focusing on telling the public and making public aware of the symptoms that people can encounter with their Parkinson's

Here the potential failure to meet people's needs and raise public awareness is seen as a consequence of an increased focus on research. This therefore illustrates the complexity of keeping PO activities patient-centred since support needs can be very divergent.

Furthermore, *V11*'s and *V2*'s comments show how difficult it can be to maintain a commitment to patient-centredness when balancing 'traditional' support activities with a growing interest in research. Some will think that investing in research corresponds to fewer resources for support and care services. Others however, will tend to think that more money should be allocated to research. Together with the variation in the way individuals described PO priorities, this suggests that there is often disagreement over what the role of a PO is and should be.

This was also apparent in the PUK 2012 research conference, where researchers were provided with leaflets titled "*what a cure would mean for me*", designed to keep them mindful of the people who might benefit from their research in the future. However as one volunteer pointed out in a tweet, patients themselves were largely absent from the discussions taking place, not only physically, but also in the tenor of presentations about research and PUK alike.
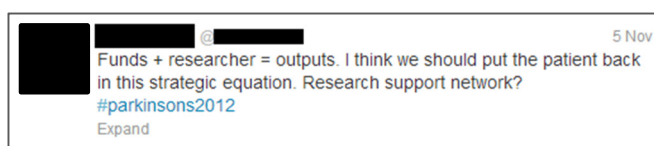
This tweet was in response to a presentation made by the Director of research who gave the equation "funds + researcher = outputs" to demonstrate the importance of partnership between the organisation and researchers. However, as the tweeter noted, the person with Parkinson's was completely absent from that talk and most others at the conference. This and the description of funding by *V2,* suggests that POs can face the challenge of balancing patient-centredness with research leadership.

In fact, this challenge was mentioned by *E4*

> *E4:* It might be a blessing and a curse but we try, I think we tried to be all things to all people. But the twin pillars on which the [PO] was founded are care, support, befriending, reducing the isolation for people given this diagnosis that they need never have heard of before and know nothing about. And on the other hand the other pillar is funding research

E4 describes the need "to be all things to all people" as "a blessing and a curse". In providing these services, the organisation is able to describe itself as representing the varied needs of its membership. However, the very separate responsibilities can make the

POs' work unwieldy and difficult to manage. It could be said that depending on the support needs of individual members, the PO will always appear to closely represent the views of some more than others. This further suggests that a significant challenge that POs face, is to maintain the patient-centred reputation in a diverse patient community that is likely to have varying needs and priorities.

Staff-Volunteer Tensions: "headquarters is a big black hole"

The issue of PO legitimacy as representatives with a close relationship to the patient community was the source of considerable tension in several interviews. As Gamson(1996) suggests, detachment from the community can shift community organisation priorities away from members towards structural and organisational concerns. This seemed to be a fairly common criticism of PUK in particular, with several volunteers mentioning an "us and them" culture between grassroots members and head office staff. In line with the communitarian and open society debates described previously(Armbruster and Gebert, 2002, Popper, 1945, Walzer, 1990a, Walzer, 1990b), this was often qualified by further criticism of the head office for being too controlling. Some interviewees implied the presence of a certain amount of unwarranted "headquarters" control, potentially caused by a lack of understanding of how local groups work and what they need.

The perceived lack of national contact was discussed frequently, as was the insufficient number of groups in some local areas. This inadequacy was often assumed to result from an established sense of distance between head office and the more remote local branches. For example, *V5* made a clear distinction between central groups and remoter areas, stipulating the difference between "the main area" and "outside areas".

> *V5:* it's the same with most organisations, well most organisations isn't it, it, there's a lot of activities on in the main area, but in the outside areas, like I suppose in the extreme west of Wales and North of Scotland there's the same problem that very little goes on

In this discussion about his region of the UK, *V5* described having access to only 2 local groups, both of which were difficult to travel to on a regular basis. *V5* suggests both that there not enough groups in certain areas and that there is a perceived difference in priority attached to different regions of the UK, with "the main area" generally referring to places with a closer proximity to London.

V7 raised further concerns about the amount of contact local groups receive from PUK headquarters. She implied a sense of isolation from the rest of the organisation caused by the desire for access to more information about the rest of the UK. This appears to contradict the claims made above about the patient-centredness of the PO local support network. Rather than helping to maintain community connections, local meetings appear in some cases to be nationally divisive.

Furthermore, although *V7* agreed with *V5* that there were too few local groups in some regions, she suggested that this was partly due to a lack of commitment by PUK to motivate volunteers to establish groups and maintain that enthusiasm. *V7* suggested that staff should be more pro-active in supporting the management of local groups

> *V7:* coming down and saying "okay who would like to set up a group?" So on the night they were "oh yeah I'll do it". And then Parkinson's UK go back up the county and maybe post the person some information. If they're not there saying how did the group go, have you booked the room, here's a venue, have you done this, have you done that, it would be the same or like I don't know it takes me a long time to get to there and I don't know if I've got the time, you'd have the same apathy again.

V7 reasserts the view that PUK is not engaged enough with local groups, but also suggests that "intensive" engagement is necessary because volunteers cannot maintain groups alone. This highlights the ambiguity of discussions about London-centrism. Although many expressed a dislike for a perceived organisational headquarters focus and the resultant disregard for regional branches, some simultaneously acknowledged that headquarters needs more influence and power in order for the organisation to flourish. Relating this back to descriptions of patient-centredness, it seems that the local groups described by employees as ensuring community support, might need extensive PO management. This suggests that the notion of community may not thrive naturally amongst members, without the PO promoting it.

For the most part however, particularly regarding PUK, volunteers tended to describe a certain dislike for the apparently London-centric attitude of staff. Indeed, *V1* suggested this attitude was linked to a significant misunderstanding of the way in which local groups and grassroots volunteers work. In particular, *V1* suggested that PUK exhibits a fundamental lack of understanding about the amount of money required both to travel to London-based events and to maintain local groups.

> *V1:* I have enough money, should I want to go, I'll go, I will pay to go to a meeting. Whereas there are many people that are on our committee don't have the money, they have to claim for everything, and again rightly so, so that the society can get an appreciation of how much it costs to run a branch or whatever. Because many of these places, are subsidised by middle class people that have enough money and don't claim, so, anyway that's another aspect.

Significantly, *V1* suggested that because certain wealthier middle class members are able to run events and travel without claiming expenses, PUK headquarters staff have an unrealistic idea of how much group activities cost. Furthermore, *V1* implied the expectation is that expenses will not be claimed too often, so that those who cannot afford to travel to meetings, for example, will feel that they are not allowed to, because expenses will not be paid. This suggests a quite substantial distance between headquarters and local groups, not just in the geographical sense but also in the way in which their support activities are organised. *V1* seems to think that PUK headquarters is so removed from the day-to-day work of the local groups that it actually hinders their progress by assuming they can be run on lower sums of money.

In fact, financial issues seem to be at the heart of *V1's* concerns with the way in which headquarters deals with regional branches

> *V1:* and there is a big thing in that headquarters is a big black hole for money and there are so many posts that never used to exist. Now it's great and you look at the number of people that [the director] has got working for him it's enormous, absolutely enormous… you know are they really all necessary?

The principal concern seemed to be that members and local branches are continually asked to raise more money but are not provided with information on what happens with the money they raise. This has been linked to a suspicion that much of the money is spent on an overly extensive staff, so that when more money is requested at meetings, local members tend to react badly. *V1* also linked this to a suspicion about PUK's claimed successes. He questioned the success that PUK claims it has had because of the apparently constant plea for money. In particular, *V1* believed that in order for the expensive rebranding to be justified, PUK would have to show that it raised more money than it cost, which evidently has not happened.

> *V1:* I went to another one of these, was it the south west meeting and the financial guy got up and said most of the money within Parkinson's UK is held within the branches, they need more money to go to headquarters. And you can hear the *[intake of breath]…* because people don't want the money to go to the black hole.

It seems understandable that a continued focus on the success of rebranding in drawing attention to the charity would be jarring to a local group that already feels angry about the money it is asked to contribute to for undisclosed headquarters activities. This is particularly evident in the phrase "people don't want the money to go to the black hole". The fact that it is "the" not "a" black hole seems significant because it suggests that headquarters in general is seen as the place where money disappears. "*A* black hole" would indicate a worry that money might be used unproductively, but "*the*" suggests that any money that is sent to headquarters tends to be absorbed into an unknown cause.

In fact, this highlights an issue raised by several interviewees: a perceived difference in priorities between headquarters and grassroots volunteers and a lack of communication between the two. This is illustrated by a comment made by *V4* discussing the role of Trustees in a MND PO. Suggesting that a lack of communication can lead to a "them and us" culture where local groups have very little understanding of what is happening in the national office, and become suspicious as a result. When asked what caused the previous discord between volunteers and staff *V4* said

> *V4:* probably the people at the local level were thinking "we're beavering away having all our coffee mornings, raising money to support people with MND in our patch but we're having to send you know half our money up to national office and what are they doing, they're just employing the staff to, I don't know, pen push or something"… And quite often it's down to often simple things like that, understanding what things are being used for and feeding back what's happening on the research so that you know that that 250 quid you made sort of with your bake sale has made a difference

V4 in many ways summarises the suspicions expressed by PUK volunteers, saying that volunteers became unhappy with the amount of money being taken away from their activities to fund unexplained ventures in headquarters. However, the fact that the volunteers are described as "beavering away having all our coffee mornings" implies quite a disparaging attitude towards those who were complaining. Volunteers are also described as not understanding how much staff do and how essential they are, which is almost

exactly the same attitude with which PUK staff were charged by *V1, V5* and *V7*. This illustrates that tension can arise because of a mutual lack of understanding of the role of volunteers and PO staff. It seems that both parties can feel that conflict is caused by the other not appreciating how much work they do, suggesting again that community identification can be very hard to maintain. PO staff can fuel the separation felt by some volunteers by failing to understand both the needs of the branches and how little volunteers know about the staff themselves and what they do. It seems that an assumption is often made that local groups should understand why they are asked for money to be sent to headquarters, so that the purpose is not fully explained. This then causes suspicions to arise amongst volunteers and members, which in turn lead to feelings of isolation and separation.

Not all interviewees described this type of argument, however. Indeed, even *V4* suggested that past discord between staff and volunteers has been remedied by a targeted focus on communication and mutual understanding. Moreover, *V9* described a very different attitude towards PUK headquarters to those quoted above. *V9* felt that it is always very clear why certain decisions are made. In almost direct opposition to *V5* and *V7, V9* suggested that it is clear that activities are not restricted simply for bureaucratic reasons and as such he has no issue with the control headquarters exerts on local branches.

> *V9:* now Parkinson's UK is doing everything that YPN used to do, which is cool because it's all under one branch then. There's no bickering, no fighting, no penny pinching, not, no nothing and it really is working quite well.

Here again, headquarters control of certain activities is described positively, as something that prevents "bickering". Interestingly, headquarters control is also associated with "no penny pinching" which again is in stark contrast to the suspicions that others raised. Indeed, *V9* tended to be much more positive about PUK staff than other volunteers. Rather than viewing headquarters as a drain on resources that has little or no connection with volunteers, *V9* sees the role of staff as bringing the organisation together and preventing arguments. This, therefore, illustrates again the curious ambiguity in discussions about headquarters control. Although some might see the absorption of a previously thriving sub-group into the wider responsibilities of PUK as over-zealous, London-centric control, *V9* shows that it can also be viewed as a positive step towards unification.

Community Relevance: "sledgehammer to crack a nut"

As well as describing a disconnect between local groups and PO headquarters and a lack of community cohesion, some interviewees also questioned the relevance of PO activities to the day-to-day needs of people with MND or Parkinson's. Reflecting the literature on political representation, it seems that identifying with the PO is significantly linked to members feeling connected to and represented by the decisions that the PO makes(Bowler et al., 2007). A significant part of this analysis of patient representation is, therefore, the extent to which members and volunteers perceive PO activities as relevant to their specific needs. This is because it can illustrate how well POs have cultivated a sense of collective belonging or identification with the organisational cause.

This idea of relevance was again most frequently discussed in interviews with PUK members. For example, *V7* linked the fact that complementary therapies are not provided by or specifically endorsed by PUK to a perceived trend in the organisation not to see "the whole person". This illustrates that PO volunteers can connect the lack of a particular service with an inability within the whole organisation to properly understand those living with the condition. Another example of this was given by *V5*

> *V5:* one of the things that really annoyed me about the Parkinson's UK site was that, the inference that if you, if you're having trouble drinking a cup of tea for instance you can get a special cup with a sealed top and a spout on it. Sorry, sorry why would I want one of those? Let's look at other ways to solve the problem, use your other hand you know take some relaxation classes, do some exercise to stop your hand shaking. Don't just treat, what's the word I want it's like treating, erm, the sledgehammer to crack a nut kind of thing, you know the worst case scenario.

Whereas others described the benefit of having utensils specifically modified for people with Parkinson's, *V5* views it as illustrative of a tendency to patronise people with Parkinson's and ignore the root of the issues they face. Throughout this interview *V5* frequently described PUK as patronising, in particular in discussions about activity and meeting organisation. Similarly to the "special cup" description, *V5* criticised PUK's focus on activities, such as exercise classes, specifically geared towards people with Parkinson's, saying that people should be able to go to 'normal' classes without having to find out if they are "for Parkinson's". Here again, *V5* felt that people with Parkinson's were being singled out or isolated as needing "special" treatment, which he saw as patronising and unproductive. It is fairly common for POs to endorse activities that are specifically

designed for their members. Therefore, the fact that *V5* perceived this practice as illustrative of a lack of understanding of people with Parkinson's on the part of PUK shows the difficulty of catering for members' needs. Although some will benefit from knowing that there are utensils and classes tailored to people with Parkinson's, others will find it offensive that the need for such services is even suggested. It is perhaps not surprising that different people will require different kinds of services and activities from their PO. However, it is significant that disapproval of services can lead to a negative perception of the organisation as a whole and how it relates to its membership. *V5* and *V7* did not merely disapprove of a specific service, but interpreted the lack of services relevant to them as indicative of PUK's inability to understand what people need.

Curiously, this description of PUK as unable to understand the lives of people with Parkinson's was hinted at by *E3* when responding to a question about what sets CPT apart from PUK.

> *E3:* We have very different histories and we were founded by people with Parkinson's and those people with Parkinson's were determined to try and move things forward towards a cure and just as fast as they possibly could

As well as mentioning its focus on a cure, *E3* appears to contrast the patient-focus of CPT with PUK. *E3* implies that the two are different because CPT was founded by people with Parkinson's. In fact other CPT staff members criticised PUK for not being led directly by people with Parkinson's. This would appear to contradict the views of PUK staff, that the organisation is very patient-centred

Indeed, *V7* extended this discussion to her local group. Having indicated that not enough information was provided at meetings, *V7* was asked to describe how she would like meetings to be structured

> *V7:* it's a good mix to have you know an hour of information, half an hour of social or whatever. So people have an actual purpose for going so they can say "ah I can go and listen to so and so, I'm interested in that"… as opposed to just going along with, having a chat and then coming home again

This suggests that *V7's* structural and informational needs are not being catered for. What is particularly significant, however, is that the social aspects of a meeting are not seen as

"an actual purpose for going" suggesting that meeting other members is not the reason that *V7* joined PUK. This would appear to be in contrast to the PUK campaigns, and indeed the statements of several interviewees, that a principal goal for the organisation is to ensure that 'no one faces Parkinson's alone'. "Just" being with others is not enough for *V7,* so that community formation and continued engagement needs more than physical contact. This comment was made in the context of a discussion about the disorganised structure of that local group, where *V7* suggested again that the lack of structure was partly caused by a low level of contact with the rest of the organisation.

V9, however, related the patient-centredness of group activities and meetings to the rise of internet community formation

> *V9:* older groups where people used to go before to Parkinson's groups to meet or mingle they use the web now… And their branch is now becoming the website. These weekends we've booked recently they're really good because they bring so many people together from different walks of life, I mean there's coppers there, lawyers, builders, boat builders loads of people from all different walks of life all sat down laughing and joking and having a boogie which is great to see. But, as I say, the older groups are dying out

Here, the increasing use of the internet is described as a concern because some groups and meetings that used to take place are now solely available online. This, as *V9* asserted, could affect the support that older people or those who are less technologically literate might receive. Furthermore, *V9* suggested that younger members are not joining the more traditional group formats to sustain them as the older generation dies, so that some groups are disappearing altogether. As well as shedding some light on the trend described in Chapter 1 for the number of local PO branches to decrease over time, this suggests that those who want the more traditional meeting have little say over what happens to their group. *V9* later related this back to the general centralisation of fundraising activities, saying that they are becoming more centralised because local groups are dying out. This then provides another perspective on the changes in PUK as a whole. As it becomes more central and London-focused, a cycle is created where local group dissatisfaction and inactivity causes a decrease in new members. Consequently, activities are lowered further and local groups eventually disband as younger generations meet more online and local meetings become less necessary. Taken together with the views of those doubting how much people with Parkinson's can influence organisational decisions, this paints rather an odd picture of patient-centredness. This is because organisations can claim to be led by

people with the condition, and that all their activities are patient-focussed, but at the same time have members who experience a complete lack of control over how their group is organised, and a sense of disillusionment from the organisation as a whole.

This again raises the question as to what patient-centeredness and representation mean. All organisations will at times have to take actions of which at least some members will disapprove. Reflecting political literature, representation in this context is not as dichotomised as Burke would suggest(Ferber et al., 2007). In this case, PO representation is not always as close to the delegate-end of the continuum as might be expected. PO statements emphasising their focus on people with MND or Parkinson's, keeping patients at the core of what they do, cannot be taken for granted as signs of patient-centredness in their activities, agendas and organisational structure. As this section has shown, some organisations that make such claims in fact experience an often serious separation from their membership, to the extent that regional branches do not trust staff members to act appropriately. Furthermore, the level of influence that people with the condition can exert on organisational decisions, structures and activities has been called into question. As such, simple assertion of the intention to listen to members and keep them informed is not enough and patient representation often remains a patriarchal trustee-like entity, where people with Parkinson's or MND are participants in a process where others speak for them.

Advocacy: Provision of Information and Knowledge Exchange
The analysis of patient-centred PO activities also illustrates how difficult it can be to unify a disparate membership-base under the idea of a collective, activist identity. Particularly in the case of *V9*'s fear that increased promotion of online groups means that those who prefer meeting in person will become marginalised and lose their support network. This suggests that at least part of the move by POs to become dynamic, modern organisations can be difficult to promote, perhaps, in particular to older members. This can also be seen in Chapter 4, where the expectation of patient activism amongst those diagnosed with MND or Parkinson's was not always reflected in the way patients act. Indeed others assert that not all those affected by a condition will want to engage with a PO(Lock, 2008, Kitschelt, 1993, Silverman, 2008). As a result, some PO activism may become a top-down process where enthusiasm amongst staff is not necessarily matched by more traditionally-minded members.

To explore this idea further, we can look at the way in which advocacy seemed to be discussed at interview. Others have noted the difficulty that POs can experience in unifying

a disparate group of people who may disagree on who is a legitimate representative and what advocacy entails(Silverman, 2008, Finkelstein, 2001b, Finkelstein, 2001a, Finkelstein, 2004, Shakespeare, 1993, Shakespeare, 1996). This debate was also present in my interview data.

Some interviewees described the advocacy role of their PO as principally concerned with the provision of care. The implication was that without the involvement of POs, people with MND would not get the standard of care that they need. Care strategies for both MND and Parkinson's tend to involve contact with a vast number of professionals from a number of different specialties, including occupational therapy, neurology, social care and palliative care. Consequently, the POs often seem to perform the role of mediator; communicating the needs of people with MND or Parkinson's to care teams and disseminating medical knowledge to their membership to enhance understanding on both sides as to what care is needed and available in the local area.

Notably, this role was often qualified by the proportion of people with which the PO is in contact. For example *E8* described knowing 99% of people with MND in the catchment area. This kind of statistic would be hard to confirm, however the fact that it was mentioned in such a way suggests a feeling of legitimacy where, reflecting the representation literature, around procedural legitimacy(Eulau et al., 1959), or descriptive representation(Brown, 2006, Runciman and Vieira, 2013) the characterisation as a membership-organisation is perceived to lend authority to the role that the PO performs.

Although, many interviewees took a traditional 'lobbyist' stance, there was a significant tendency to describe advocacy as a role of knowledge transfer from the PO to the member. In fact, Barbot's(2006) "mutual learning", was reflected in some of my interviews, describing advocacy as the provision of information to members. This information tended to be split into categories: information upon diagnosis aimed at educating people about the illness they have developed and their rights as patients, and information about research. In particular, it seems that this kind of advocacy was aimed at protecting members from the vast amount of information that is available online.

Information about Illness: "most of them have no idea"
As shown in Chapter 1, the POs have dedicated pages on their websites, giving information about MND or Parkinson's – the different types, their symptoms, and outcomes. A

particular responsibility attached to this advocacy role seems to be to ensure that people get the right information at the right time.

> *E1:* I think just the fact that they can access the right information, and quality information rather than Googling it, on the website and coming up with all this stuff which has actually no substance to it. So I just would like us to see actually getting in there, in surgeries, in consultancies and actually at first diagnosis… then it's up to them if they want to take it any further but at least they've got the right information because I worry that people just get the wrong information

This illustrates a commonly expressed view that, without the PO, newly diagnosed individuals will take to the internet and access unhelpful, and potentially harmful information. Discussing what the PO can do to counter unhelpful information, *V2* said

> *V2:* they've got what they call MND Connect on the website which is a telephone number which anyone can ring and you can get advice, even if you, your GP is not very helpful or you're worried or you're whatever it's an excellent helpline

As well as further illustrating the role of POs in countering the vast amount of unverified information that can be accessed online, this quote also raises another issue −that POs can be called upon to provide information that GPs or other Doctors have not given.

> *E2:* the diagnosis happened after consultation with a neurologist and it's not that easy to come out and say "Look could we rerun that please because I've now got other questions and my family have got questions?" So what we do is we offer family information evenings… Usually I'll do about a forty minute presentation, talking about MND, putting across some of the gentler aspects of diagnosis. I don't talk about life expectancy to that audience simply because we don't know what the life expectancy will be

This information provision role therefore involves supplementing medical consultations and allowing people to ask the questions they are afraid to ask their doctor. However, *E2* also suggests that MNDS will not give all available information about MND, specifically avoiding the issue of life-expectancy. This suggests that, along with the responsibility to provide accurate information, some PO staff feel they must protect people from the worst aspects of their diagnosis. This is particularly curious given that *E2* specifically highlighted the fact that consultations can be discouragingly incomplete.

Another significant aspect of this information-based advocacy was to ensure that people understand their rights as patients. For example,

> *E2:* most of them have no idea at all about the welfare services beyond their GP and local hospital. Most have no idea about claiming welfare rights or benefits, most have no idea about welfare entitlements. And as an organisation we exist principally to, if you like, act as a signpost to people.

As *E2* points out, on diagnosis, people will suddenly be confronted with the benefits and welfare system, in all likelihood without prior knowledge. Therefore, it is important for the PO to assist people in accessing the right information and ultimately the appropriate help. Interestingly, *E2* extended this role to all POs for all neurodegenerative diseases, suggesting that this role of "sign-posting" is not limited to one condition or one organisation, but rather is a pivotal part of the PO model. Crucially, sign-posting or information provision was described as, rather than being a paternalistic role, a process of enabling people to understand and act upon their rights. Therefore, as suggested by *E1* it is also important for POs to respect and enforce individuals' right to decide to accept and act upon the information given, or not.

Research Information: "we'll also make a big deal about the results"

This idea of allowing members to choose the information they read was also raised in discussion about the dissemination of research updates. Given that all four POs engage in research, it is unsurprising that their information-based advocacy includes the provision of research information. However, echoing Wehling(2011), there appears to be a difference between the organisations as to how much they publicise research to their membership, and the type of information they agree to provide. Yet, contrary to Wehling's distinction that "self-help groups" will be less likely to accept scientific information than others(Wehling, 2011), in the case of Parkinson's organisations, it is CPT that appears less enthusiastic about conveying research results than PUK, which is at least in part based on "self-help" activities

> *E3:* it's something we've done very little of... it is up to the researcher to publicise the results of that, it's not up to us to do it.

This is in direct contrast to PUK which publishes the progress of all the projects it funds, as well as any other relevant news. It is curious that CPT, which promotes research as its core aim, would be so reluctant to publicise results from CPT-funded projects. It is likely that

this is related to a general hesitance I found at CPT to engage in media relations, but it is nevertheless interesting that a research charity would not carry out this function.

In contrast, others from both MND and Parkinson's organisations raised the idea that a key responsibility for POs is to reassure donors and members that funding is used responsibly. This therefore illustrates the role of information in strengthening the position of POs as patient representatives. The information is used to prove that member ideas and donations are being implemented for the good of the community. This makes CPT's decision not to do so more surprising.

That is not to say that CPT never provides information about research to its supporters. It is much more likely to provide details about actively recruiting drug trials, than the results of its own research. Speaking in general about the role of Parkinson's organisations in publicising research

> *V11:* they're almost like a media channel for the researchers to be able to talk about what they're working on, for the researchers to be able to have access to people with Parkinson's. I'm trying to think of an example – the Cure Parkinson's Trust is always talking about drug trials like Cogane and Exendin and they very much use their website as a, not a forum but as a media channel by which to communicate the fact that there's a clinical trial going on

Therefore, although it tends not to publicise results, a significant role that CPT plays, is to provide supporters with details about trials in which they could take part. Indeed, all of the organisations at the heart of this research provide trial information on their websites.

Crucially, some interviewees were keen to emphasise that it is not the PO's responsibility to decide which trials or projects they would advertise. Many preferred a position of neutrality – providing all available information and allowing members to decide for themselves what they read and do

> *E8:* our role is to put the information out there, people then can decide whether they want to have and see that information. It's not up to us to dictate what folks should know or not know… And that's it, I just think the main thing from us is that we won't hold back anything, if we have information we put it out there

In contrast, some suggested that the practice of providing research information can also be more targeted – aiming to build enthusiasm amongst members for research in general

> *E4:* we'll advertise the trial, not just to try and recruit people into it but we'll also make a big deal about the results of the trial as they come out and just keep that enthusiasm, people can see that there are outcomes coming from this and benefits coming from this you know and that's, I think that's absolutely essential.

E4 makes clear that part of this role is to "make a big deal" out of the results in order to increase support for research. Not only does this benefit the PO itself, but the publication of research can also encourage and facilitate recruitment. This was also discussed by a Parkinson's PO employee. In describing the very different experience that PUK and research teams have of the enthusiasm of people with Parkinson's for trial participation, *E7* linked slow recruitment to a lack of information. He implied that recruitment is faster if PUK provides people with information. This goal to improve recruitment is understandable – support for research necessarily involves a desire to improve the number of people taking part. However, it does seem to be at odds with the role of neutrality expressed above. Presenting information with the specific aim to encourage recruitment and participation seems to be the opposite of merely posting information and allowing people to decide for themselves what to do. Relating this back to the idea of maintaining collective activism, this suggests that POs can provide targeted information to promote their own priorities and causes amongst the membership. Rather than maintaining community identification through a unifying cause, the PO attempts to create collective support for its own idea of patient priorities.

Indeed, *E7* suggested that the PO provides extensive research information because members *want* to hear about it. This was raised by several interviewees as a justification for enthusiastic research reporting in PO newsletter and online communications.

> *E2:* People with MND always say they want to know about research, always want to know about research. I, we have a quarterly magazine we put out called Aware and I always have a page in there that I've written which is on some topic of research.

This is an important point to consider because, if this is the case, the vast amount of research information in all PO-to-member communications, would support the POs' patient-centred reputation. However, several volunteers and members in fact said that they were not that interested in research and the dominance of the subject in magazines had become irritating. This was particularly the case in interviews with people from

Parkinson's organisations, although this could be because of the larger number of Parkinson's PO volunteers that participated in the research.

As discussed in Chapter 4, *V11* and *V5* when describing their detached view of PO membership, often mentioned the type of PO magazine they received. For example, *V11* when talking about the extensive research coverage in the PUK magazine, said that most people with Parkinson's are not interested in research

> *V11:* I can't blame them to be honest, because when you've heard it's "round the corner, round the corner, round the corner", you're either going to get disillusioned that it hasn't been round the corner, or you're going to get sceptical or whatever but most of the people I know are like "oh, let's just get on with our lives and do what it is we need to do because it's not round the corner" so the information that we're being fed is, I think, what they, what *'they'* want us to know rather than reality

This suggests that the focus on research and the information that Parkinson's organisations provide is not always representative of what people with Parkinson's want. Furthermore, the enthusiastic reporting of research, has made *V11* less likely to engage with it and more sceptical about the progress made. Examining this within the context of the information debate raised by the representation literature(Ferber et al., 2007); here, information about research is not enough to engage *V11* in the subject, and in fact seems to have the opposite effect. This then, in a rather convoluted way, reflects Ferber et al.(2007) assertion that providing information does not encourage public influence. Reading about research has not inspired *V11* to campaign for or on behalf of the PO research agenda. Furthermore, when taking into account the requirements of discourse ethics for equal acceptance of the outcomes of a debate(Habermas, 1990, Mansbridge, 2003), it seems significant that *V11* is convinced that the information provided is skewed towards what "they", the PO, want members to know. This seems to suggest that the discussion between POs and members over research is not equal, with the PO is firmly in control of the information that members access.

Moreover, some volunteers felt that they receive the wrong information about PUK-led research

> *V5:* they seem to publish articles that a pharmaceutical company in America has made a discovery into some new treatment and that's it that's all you hear. So what Parkinson's UK do on the research front I have no idea at all.

This was said in a discussion about a general lack of interest in research information. *V5* has no interest in receiving updates, but seems to suggest that the information he does get, does not help him to understand what PUK actually does. Newsletters and Magazines do include information about the grants awarded to projects in the UK, however *V5* nevertheless seems to see PUK communications as largely unhelpful.

This illustrates the difficulty in trying to maintain a collective cause amongst the membership. Although POs might be under the impression that their members are very interested in the information they send out, some will dislike the PO communications to such a degree as to disengage with the organisation as a whole. As was the case in the PO activities, a deficiency in the information that *V11* and *V5* want is interpreted as the inability of the PO to respond to members' needs.

POs Hit the Internet

In the course of this research, the websites of the MND and Parkinson's POs have been monitored, focusing particularly on the homepages, any high profile campaigns and social networking activities. I chose to focus on homepages as the first impression that anyone visiting the website would get of the PO, its purpose and its priorities. As Seale(2005) suggests, despite often being described as more democratic, fluid and reflexive, the information on health-related websites can in fact be as constructed and targeted as that provided by other media. In particular, the way in which information is presented can greatly influence the experience of those reading it. This is supported by the suggestions made above by PO employees that providing research information is, at least in part, motivated by the desire to improve research recruitment and enthusiasm amongst the membership. Crucially, relating this to cancer POs, Seale(2005) states that information provided on PO websites can be less independent and 'democratic' than is often assumed "because of the influence of large institutions representing medical, governmental and mainstream voluntary sector perspectives"(Seale, 2005)

Furthermore, others have noted, the internet is increasingly important for group formation, presentation and maintenance(Lock, 2008, Langstrup, 2010, Silverman, 2008). Moreover, it has been suggested that the internet, through cyberdemocracy, has a significant effect on the way in which we can understand representation, and the role of online information in democratic processes(Ferber et al., 2007). Therefore, it is as important to analyse the way in which information is presented by POs online as it is to explore its content.

Looking at PUK, the homepage itself is very simple and its overall content and design barely changed between October 2011 and January 2013, as evident in Appendix 3 showing the first and last screenshot I took during data collection. The Heading for the PUK website is the organisational tagline "Change Attitudes. Find a Cure. Join Us". The Homepage itself has very little content, providing instead links to the different page headings of the website, and its helpline. The main feature of the homepage is a large banner with between 2 and 5 alternating headlines or campaigns. For example,
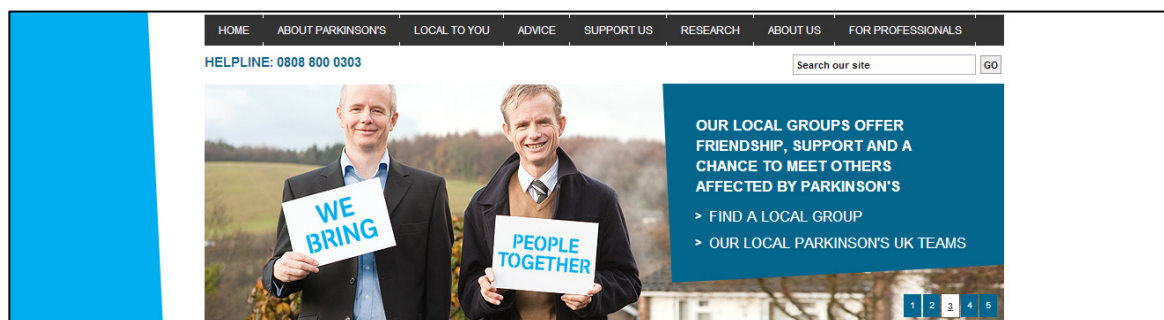
This banner is used to promote the campaigns that PUK is running, either publicising poster campaigns or a fundraising event. Alternatively, as in the picture above, it will promote the core purpose of the organisation, showing members or employees holding signs saying such things as "*we bring people together*". Others have said simply "*we can help*" or "*help us find a cure*". Therefore, the homepage appears to have been designed for promotional impact. Rather than providing detailed information, it is generally used by PUK to create a clear, succinct impression of what the organisation does.

In contrast, as shown in Appendix 3, the MNDA website homepage, although it also now has similar banner, contains a lot more information than PUK. The heading of the homepage is similarly succinct, showing the MNDA logo and links to the headings of all the different pages on the website, and the page where the organisation can be contacted. Underneath that, however, there is far more content. First, there are links titled "*What is MND?*" and "*Just been diagnosed?*" that lead to the pages where the condition is described. The rest of the homepage lists the main news about MND research, the progress of certain campaigns and the details of upcoming fundraising activities. Before the website was redesigned, certain aspects of the homepage rarely changed. For example, both the *Patrick the Optimist* and *Alistair the Optimist* campaigns were continually featured as was a campaign saying simply "*will you help us?*"

The new format now features a similar campaign-focused banner as the PUK homepage, showing alternating pictures advertising current campaigns or upcoming national meetings and conferences.

The new format also has more information about social networking and external links than the original. This suggests that promoting MNDA's presence on *Twitter* and *Facebook* is now a greater priority than it used to be. The main difference however, between the two homepage designs is that the tagline "our vision is a world free of MND" has been removed and the heading now only shows the MNDA logo. This suggests quite a significant change in the image that MNDA is presenting, as curing MND no-longer seems to be a main, defining goal. Furthermore, research news is not featured as prominently as it used to be. Rather than posting continual updates on the homepage, MNDA instead only occasionally advertises a new project or the start of a new funding programme.

In comparison to both MNDA and PUK, the CPT website is much less stylised. It is a lot simpler, in terms of style and graphic design and is not very well formatted. Under the heading with the CPT logo and page headings, sits a quote from a CPT founder saying "*It has to be about a cure*". Therefore, CPT has also designed the homepage to clearly present its core aim to find a cure. Although Appendix 3 shows that certain aspects of the design changed over time, the homepage content does not often change, with the constant presence of a statement titled "*Where there's hope there's fire*". Other campaigns or events highlighted on the homepage, tend to remain for several months. For example, the campaign video featured on the second screenshot in Appendix 3, titled "*Facing the Light*" was on the CPT homepage for five months.

A particularly important aspect of the CPT homepage to discuss is its design. The fact that the content rarely changes and that other pages of the website were also poorly formatted,

to the extent that certain links overlapped and were not easy to follow, suggests that it is not professionally managed. This could reflect the size of CPT, however the relatively less professional website does seem to be at odds with the business-like way in which CPT staff present the organisation and themselves. The simple design seems inconsistent with the corporate terms in which CPT describes itself, listing its staff and founders by their business experience. The website creates the impression of an organisation that is not very proactive in promoting its work, despite the fact that CPT has been very active in promoting discussions, campaigns and events elsewhere online such as on *Facebook*. This could be explained by the tendency at interview for employees of CPT to suggest that they purposefully withdraw from a public presence in the media, so that public promotion is not a fundamental part of the CPT agenda. That being said, it must be acknowledged that since data collection ended CPT has radically changed the design to a format more similar to that of the other organisations. This could suggest that CPT is changing its approach to engaging with the public. This is supported by the fact that CPT has recently been the subject of several BBC Radio 4 programmes and appeals.

Although as explained in Chapter 3, I was unable to compare the MNDS website over the same time-period as MNDA, PUK and CPT, Appendix 3 shows a more recent screenshot of the MNDS homepage. This to a certain extent resembles the former design of the MNDA homepage, as it contains a great deal of information. Under the MNDS logo and tagline "*Supporting People affected by Motor Neurone Disease*" the homepage lists the website's main headings and then provides details about the main campaigns, events and fundraising opportunities. Similarly to MNDA, the MNDS website features very prominently the PO's twitter feed. There is a box on the homepage listing "recent tweets" and there are links at the bottom of the homepage to Twitter and Facebook.

Curiously, the main difference between the MNDS homepage and those of the other three POs is that it makes no mention of research. With the exception of a lecture about brain regeneration mentioned in the Twitter feed, current projects, news or updates are not featured on the homepage, neither is there a direct link to information about its research grants. Clicking on the heading *News & Events* produces a drop-down menu where "research" is listed. This leads to a page providing news about research but no explicit details about the involvement of MNDS. The executive research summaries that are provided for some of these projects do include the MNDS logo on their front pages, suggesting some level of sponsorship. However, details are again not provided about the

nature of this relationship. The MNDS events I observed suggested that research was of significant interest to the PO. Furthermore, Chapter 1 shows that MNDS does invest in a small number of research projects. As such it is surprising that the website would not promote this aspect of the organisation's work. That being said, as the tagline suggests, the principal focus of MNDS is care and support. Therefore, the focus on support activities, campaigns and events fits with the core aims of the PO.

Targeting the Public: Awareness Week

Having examined the way in which POs present themselves on their homepages, I will now look at a particular instance when the POs used their websites to target the public. As part of this research I monitored the PUK, MNDA and CPT websites during the Parkinson's and MND awareness weeks in 2012. These weeks are at the centre of awareness campaigns and during interviews have been described as the most important aspect of both PUK and MNDA initiatives to engage the public. Therefore, it was important to see how much these periods were used to promote various causes, and to compare this with CPT whose employees were less active in pursuing public awareness of Parkinson's.

Looking at Appendix 4, both PUK and MNDA had links on their homepage advertising awareness week. PUK promoted the launch of "*tracking Parkinson's*" as well as all the awareness week activities that people could support or join. The media centre section of the website also had a page dedicated to Parkinson's awareness week, showing how much Parkinson's was in the news – announcing coverage on BBC radio as well as national newspapers.

Similarly, the MNDA homepage featured prominent links to awareness campaigns launched for awareness week, such as the *MND Charter* and an advertising campaign linked to the London Olympics - "*Why support a dying team*".

Interestingly, MNDA extended its coverage of awareness week to include "awareness month", described as a *Month of Optimism campaign*". Likewise, the employees responsible for awareness week publicity were called *team optimism"*. This suggests that a principal means of raising awareness was through the optimist campaigns. Like PUK, MNDA had a page showing the impact of Awareness Month campaigns in the media and amongst the public, including the number of people who had signed the MND Charter aimed at increasing understanding of MND. This page also included information about the appearance of people with MND in the public, as Olympic torch bearers for example. Both PUK and MNDA therefore did use their websites extensively to promote their respective awareness weeks, although these features remained the same throughout the week, with no updates on the progress of awareness events, apart from the information on news coverage.

In contrast, CPT made no reference to Parkinson's awareness week on its homepage. Although it did advertise the fact that "Parkinson's Advocates" would be taking part in the Olympic Torch route, this was not linked explicitly to awareness week. A search for the words "awareness week" on the CPT website gave one result (Appendix 4), a page announcing the release of a non-motor symptom mapping tool, that people with Parkinson's could download as an aid to communicating and explaining their symptoms to others. This means that people would have to already know about awareness week in order to find out about CPT's involvement, as it was not clearly signposted on their website. In discussions about awareness, most people from CPT mentioned non-motor symptoms specifically, as well as the general appearance of people with Parkinson's in public, so it is not surprising that the main awareness week activity was linked to this issue. However, it is surprising that it was not emphasised more. This raises questions as to the use of the website, and CPT's profile as a Parkinson's organisation. Awareness week would seem to be an easy way to promote CPT's cause, as it is already established as a time when there is increased media interest in Parkinson's in general.

Views from the ground: "it's a bit commercial"
In fact, the appropriateness of the PO online presence has featured significantly in discussions at interview about the way in which members perceive and experience their respective organisation.

First, a common criticism amongst volunteers of the PUK website was that it did not relate very well to people with Parkinson's. For instance, *V5,* reflecting his views of PUK in general, described it as "patronising"

> *V5:* They for instance have pieces of advice on their website for dealing with people with Parkinson's and it says when you're talking to somebody with Parkinson's hold their hands, they find this comforting… give them a cup of tea and be nice to them, it's all for personal reference and it's not very personal, it doesn't actually, how can I describe it, it's a bit commercial do you know what I mean, it's put together to be a bit commercial

Here, then, the increased public accessibility of PUK online, is related to a decline in a personal and relevant presence for people with Parkinson's. This appears to be linked to a perceived corporatisation of PUK's image, with an increased focus on commercial concerns making the website harder to relate to. Interestingly, following this statement, *V5,* who is living with Parkinson's, and *V7,* who is not, had a rather illuminating disagreement. *V7* in fact has found the website quite useful when people have asked her questions about Parkinson's

> *V7:* I've signposted them to some of the leaflets there and we're able to sort of download any of the information leaflets there if we need them for, like, other family members who might not understand. So that's all there and there's all the sort of how to donate and charity stuff that they do. But I think because we're in [this area] it doesn't really relate to us whereas we go to the [local group] because it's, it's local, it's here, it relates to the person and our environment here whereas Parkinson's UK is very much what's going on up the county.

V7 who is not living with Parkinson's seems to find the PUK website much more useful than *V5,* who is. This is particularly true of the information about the condition itself. Nevertheless, *V7* does agree that the PUK website is not always as useful or relevant as it could be. The website is perceived as focusing only on certain areas of the UK, so that some local groups are not accurately represented. As a result, *V7* and *V5* prefer to rely on the information provided by their own, local group's website.

This provides another perspective on national versus local representation(Eulau et al., 1959, Urbinati and Warren, 2008, Runciman and Vieira, 2013). Without local representation, the PO cannot maintain its position as nationally representative, since it will lose the connection to local areas. However, due to the a sense of distance from the

national organisation that was also discussed above, for *V5* and *V7* the local group and its website has become a representative or delegate in its own right, expected to be more representative than the national PO.

Discussing the website itself, *V1* described how hard it is to navigate unless one takes the time to learn where everything is

> *V1:* we've met the new web designer or whatever it is and she's trying desperately to get it improved because the search engine is awful, really awful. So we did a practice on trying to find the various key bits of work on there and I gave up on some of it, some of them I knew how to do because I use the site regularly, if you use a site regularly you know where everything is.

This suggests that people who are new to PUK or visit the website for the first time may find it hard to find the information they need. Indeed, looking at the website itself, as *V1* says, it is difficult to use the search engine to find particular pages. Additionally, the different pages within the website are all very different in terms of the information they provide. For example, most of the detailed research information is in the section labelled "for researchers"

> *V1:* should you keep a professional section for professionals only? No you shouldn't everyone should be able to read it, even if you don't understand it, it should be accessible because that's the society. But then you suddenly find there's a whole stack of stuff you're interested in hidden away in professionals that's not advertised on anywhere else

Not only does this illustrate that some people might be discouraged from finding information that they could be interested in, due to exclusive sounding page titles, it also echoes the feelings of a lack of representativeness expressed by *V5* and *V7*. Research or "professional" information is described as 'hidden away' from people who might want to find it, suggesting that PUK is perceived by some to be excluding its members from certain aspects of its activities. This harks back to the discussion in Chapter 4 about the extent to which POs and researchers discuss science and research with PO members. Here, too, the assumption seems to be that only researchers will be interested in certain information, so that the PO does not attempt to make it attractive to the membership. This raises further questions as to the effectiveness of the collective identity promoted amongst PO membership. This is because even the PO website was described by some members as further dividing local groups and members from headquarters employees.

Social Media: "we're probably the most likely to tweet things"

As shown in Chapter 1, the MND and Parkinson's POs are steadily increasing their presence on social media sites such as Twitter and Facebook. In fact, when discussing at interview the use of online resources, PO employees tended to focus more on social media than on the PO websites. For example, in response to a question about the use of the website to provide research information, *E7* explained that although the website and magazines were important

> *E7:* We've actually started to get into social media now so you know, Twitter and Facebook and we can, you know, get research stories up on those quite rapidly and actually I think, of the, in fact comparing us with most of the other charities maybe with the exception of the British Heart Foundation we're probably the most likely to tweet things. Because what we look for is, you know, if there is a breaking story… there is only a limited amount of space on our website so we wouldn't be able to put all of them up

This suggests that although the more traditional forms of PO communication such as the magazine are still useful in providing broad updates on the progress of Parkinson's research, even the PO website is steadily being replaced by the faster, more responsive social media. In terms of breaking research news, it seems that PUK is increasingly relying on Twitter to publish the stories that cannot fit on the website. The use of Twitter to compensate for PUK website restrictions, perhaps serves as an answer to *V5* and *V1*'s criticism that the website does not provide enough up to date information. The emergence of Twitter and Facebook as fast-paced news outlets appears to have made the website less popular or at least less at the forefront of the way in which staff communicate with the public.

One example of this increasing use of Twitter, is a the following tweet by *E7*
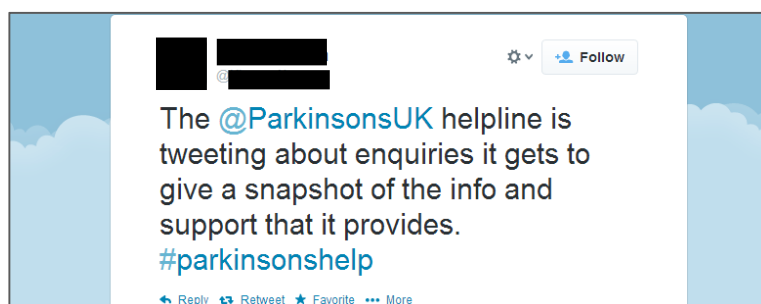
The PUK helpline promotes its role by posting the questions it gets from people with Parkinson's and their families on Twitter. This suggests that Twitter is increasingly being used as an awareness raising tool as well as a method for publishing research information. Twitter allows the PO to reach a much larger potential audience, so that it can simultaneously raise public awareness of Parkinson's and the work of PUK

Similarly, *E8* raised social media as an increasingly important avenue for providing information and engaging people in his MND PO's activities. However, he seemed less optimistic about the success of social media in public engagement than PUK staff, expressing reservations about its use and impact in anything other than fundraising. The answer *E8* gave to a question about whether they can monitor who is attracted to the PO online, might explain his reluctance to engage with social media

> *E8:* unless you're touched by Motor Neurone Disease then it's not something that I think you actually will register. And that's a dilemma for us, for us to expand our fund raising activities and our awareness raising activities is how do we reach the folk who don't have that connection? And I don't have an answer to that yet. Social media has allowed us to do that to a small extent and but if you look at people that are following us or are following on Facebook or on Twitter then the majority have some form of connection with MND.

E8 suggests that it is hard for a PO to have an impact on the general public, because people are unlikely to seek information about MND unless they have already had some experience of it. Consequently, social media is less useful than it could be, because those who "follow" MNDS are people who are already engaged with the PO either as members, supporters or people affected by MND. Therefore, *E8* might believe that the influence Twitter campaigns can have is limited, because awareness campaigns are generally unlikely to impact upon public understanding of MND.

That being said, *E8's* view was not typical of those expressed by interviewees. Most PO employees were more open to the possibility of using Twitter and Facebook as campaigning tools. Indeed CPT in particular bases most of its activities on the *Parkinson's Movement* Facebook page. However, as discussed above, members and volunteers have not always been favourable to the idea of increasingly moving PO activities online. Therefore, the question remains as to how to combine the modern methods of communication with a continued local presence amongst the membership.

To analyse this further, we can look at a particular example of the use of Twitter by PUK. Throughout the PUK research conference in November 2012, staff promoted the Twitter hashtag #Parkinsons2012 as the preferred way for those present to share their views, experiences and research results. In fact, the information sent out prior to the conference mentioned that PO staff would be using the hashtag and that attendees were encouraged to do the same. As shown in Appendix 5, most of the tweets using the hashtag came from PUK itself, however several researchers who were presenting at the conference tweeted their response to other talks during the two day event.

This hashtag was not promoted at the 2012 Research Conference Members' Day. However, during this event a Twitter stand was set up outside the main room with a demonstrator to teach people how Twitter works. The Twitter stand was no-longer there during the two-day conference not attended by members. In its place was a stand advertising "Researchfish" a research results sharing network, which was also announced as something that PUK researchers would be asked to use to improve data compilation and research impact. Here again the focus is on speed of information provision, and a research-specific form of social networking that improves upon slower methods of results sharing, such as journal publication.

It seems significant that the use of social media and other online resources was approached in a very different way across the two events. The assumption appears to have been made that, whereas researchers would already be aware of Twitter, and would be able to use it effectively, members would have to be taught. Reflecting the assumptions made in Chapter 4 about the capacity of "lay" members to understand scientific detail, PO employees seem here to assume that members will not be able to understand the technologies the organisation uses. This suggests that, in finding new ways to promote the PO cause and priorities, PO staff are to a certain extent a step ahead of the way in which PO members understand and receive information. Given that some members criticised the use of the internet in general, this raises certain questions as to the purpose of this reform in communication. Although Twitter might be useful for promoting PUK to a wider audience, the PO seems aware that this new way of publicly representing people with Parkinson's will not engage its members. Relating this back to the discussion of PO activities, here too there seems to be an issue of collective ownership. POs were occasionally described as unable to maintain patient-centred relevance and community connection in their support agenda. Likewise, it seems that the continued promotion of social media can be divisive –

separating POs from the informational needs of members, and member engagement from public impact.

Summary

Analysing the way that PO support agendas were described illustrates both the challenges that POs can face in providing the various types of support and care services that members might expect, and the difficulty in assessing the success of POs in doing so. Combining research with support, advocacy and activism necessarily results in the involvement of staff and volunteers with different priorities and causes. As illustrated by the divergent way in which interviewees described their organisation, different individuals will favour and prioritise different aspects of the PO's function. However, what is also clear is that although it may be at the core of all PO activities, community cohesion and collectivisation is by no means easy to maintain.

Although, as was evident in the previous chapter, the idea of community seems to have resulted in a great sense of responsibility to collectivise being transferred on to people with MND and Parkinson's, the significant tensions I observed here between staff and volunteers suggests a lack of true community connection across lay/professional boundaries. Despite presenting themselves as patient-centred, POs are not always able to ensure that their activities and mode of working is relevant to their members. As such, although the requirement for patient-centredness might imply that an organisation is firmly at the delegate end of the continuum defined for political representation, the lack of cohesion implies that the status of POs as patient representatives is as ambiguous as the political science literature might suggest.

In the next chapter attention will shift to another crucially important element of PO activity i.e. research. Whilst considering how the research agenda is crafted and pursued by the organisations I studied, particular attention will be paid to the role of lay and patient members. Building on descriptions of patient-centredness reported here, I will seek to establish whether research activity demonstrates an element of the PO's commitment to patient-centredness or whether in fact this area of work further calls in to question the claim that patients' views and priorities substantially underpin the POs activities.

CHAPTER 6

Embracing Patient Involvement

In the preceding chapters, I have looked at how 'representation' functions conceptually and practically in discussions about community identification and the construction of the POs' patient-support agendas. Chapter 5 illustrated both the emphasis that POs place on the need to maintain patient-centredness in their work and the challenges involved in doing so. To take this analysis further, I will now look at how the POs I studied engage the theory and practice of Patient and Public Involvement (PPI) as a means to an end and as an end in itself.

As described in the literature review, PPI has been widely adopted as a means of improving service delivery in healthcare settings and ensuring ethical research(Crawford et al., 2002, Entwistle and Watt, 2006, Grosset and Grosset, 2005, Tritter and McCallum, 2006). However, it is also clear that this extensive body of literature has not reached a consensus as to what PPI means and how it can or should be enacted. Different studies provide very different models, depending on the academic, social and political context. As Felt et al.(2008) have observed:

> the term participation is often used in a very general fashion, and is presented almost as an end in itself, without any critical discussion of the precise aims to be achieved and the methods to be used to achieve these ends…the meaning of participation is mostly defined top-down, by (social) scientists and policy makers alike.(Felt and Fochler, 2008)

The "top down" definitions of PPI have to a certain extent perpetuated the idea that participation is automatically good, without providing detailed guidelines for its implementation.

Although introducing PPI in all stages of research is increasingly stipulated as an ethical requirement, the literature suggests that the role of the patient often remains quite minor, affording little influence over the research process(Crawford et al., 2002, Entwistle and Watt, 2006, Diamond et al., 2003, Hickey, 1998, Grosset and Grosset, 2005, Contandriopoulos, 2004, Martin, 2008, Croft and Beresford, 1989). This chapter will therefore explore the way in which PPI was described at interview as ethically and procedurally essential to research, and compare participant statements with the role that

patients are given in practice. I will then analyse the extent to which PPI is promoted in the organisational structure and the public campaigns they endorse.

PPI as a Necessity: "the patient's priorities should be everyone's priorities"

Some interviewees described PPI in a similar way to the literature(Dresser, 2001, Corrigan and Tutton, 2006, 2002, 2006), as a necessary part of the research process required by regulatory boards. For example, *E7* suggested that membership of AMRC means the PO must ensure that it is "doing the right thing". This included removal of bias and involving lay reviewers.

Others described the importance of PPI in ensuring that research agendas continue to focus on the problems patients experience. For example, in response to a question about his experience of PPI, *E5* described it as central to the research activities of the PO, allowing people with Parkinson's to take a leading role in "every step of that research process". *E5* later described a specific research survey that confirmed that a large number of people experienced a particular aspect of Parkinson's

> *E5:* a phenomenal 67% came back and said "absolutely, we have that, find out more about it please!" so therefore opening up a whole therapeutic area just purely because we asked people "Do you ever experience this? What do you know about it? What is it? What is going on?" and because we asked the question it's opened up a whole new area of research which is great. It's exactly as it should be.

Here then, a new therapeutic target was identified as a result of a survey of people with Parkinson's. PPI is therefore perceived as driving research to the extent that novel research avenues can be identified by listening to patient accounts and experiences. Furthermore, in ending the quote with "It's exactly as it should be", *E5* clearly asserts not only that PPI is necessary for research to progress, but also that those managing research are obliged to ensure the engagement of people with Parkinson's. This was reflected by *P2*, discussing a research project that was redesigned in response to patient input

> *P2:* they were busy concentrating on looking at some particular area that they thought was a big problem for the, for this group of patients when actually when they talked to the patients it was something completely different that was the main problem for this group of patients and they were "mm right okay fine, we need to start looking down that area". So I think they found it beneficial.

Therefore, a significant aspect of discussions about PPI in research was the role that people with Parkinson's or MND could or should play in decision-making processes. For some, PPI was primarily a baseline process for inspiring research. For example, *P4* suggested that the involvement of people with MND is the best way to generate ideas. *P4* went further than describing PPI as ethically necessary to describe it as a "knowledge transfer or knowledge exchange". *P4* implied that without the involvement of people with MND, and without the "knowledge exchange", genuinely useful new research ideas would be harder to identify and consequently research would make less of an impact on the field. This is perhaps similar to the ideas raised in the representation literature, that the legitimacy of democratic decision-making hinges on the participation of the represented, and authorisation of the representative by their public(Pitkin, 1967, Urbinati and Warren, 2008, Schmidt, 2013).

This was echoed by *E4,* a MND PO employee, when discussing the need to make research agendas relevant to the organisation's membership-base by relating even basic research back to the real life experience of the individual living with the condition

> *E4*: Oh yeah, otherwise there's always the danger that your research is going to be anodyne and you know we don't fund research for the sake of funding research... I don't think you'd find a, certainly not a patient-led charity that would say anything different. The bigger organisations, the endowment based organised like the Wellcome Trust who don't have a membership-base, who don't have to go out and raise money from the public of course can fund more academic questions whereas you know our, I guess you'd say we're more cure focused

Organisations such as the Wellcome Trust that do not need to retain a clear patient-centred approach are deemed more able to conduct research looking at "academic questions". This suggests first that *E4* interprets the importance of conducting research relevant to people with MND as limiting the organisation's scope for exploratory research. Secondly, PO-funded basic research seems to be interpreted as targeted and cure-focused rather than exploratory and answering questions at the molecular level. It could be the organisation's ability to connect basic research with patient opinion that enables *E4* to describe basic research as "cure focused", distancing his own agenda from the perceived anodyne nature of other molecular-level research projects. This, then, illustrates another effect of PPI on PO research activities. By involving people with MND at some stage in the research-design process, even peripherally as sources of inspiration, the organisation is able to fulfil an obligation to patient-centredness and to redefine certain research approaches as patient-

centred. The presence of the "membership-base" allows *E4* to distance his own organisation's basic research from the labels "anodyne" and "academic", attaching it instead to the goal to find a cure.

Relating this to the representation literature, in contrast to arguments promoting the intrinsic legitimacy of the democratic process(Eulau et al., 1959), the patient (public) is described here as legitimate by nature rather than the process by which they are chosen. This might reflect Contandriopoulos'(2004) theory that the efficacy of PPI depends on the acceptance that 'the public' are in some way intrinsically, legitimately representative of the public view(Contandriopoulos, 2004, Martin, 2008). Echoing the debate around descriptive representation and whether social similarity allows public participants to legitimately represent the views of the public as a whole(Parkinson, 2004, Brown, 2006, Runciman and Vieira, 2013), both *P4*'s and *E4*'s conceptualisations of PPI and the patient role in research, might rest on some notion of the intrinsic ethical legitimacy of the patient point of view.

This can, likewise, be seen in two statements by *E3,* when talking about Parkinson's research

> *E3:* And patient priorities are exactly that, the patient's priorities should be everyone's priorities and that's very much the slant we take on it

And

> *E3:* if you fail to take into account the patient priorities then you're simply missing the point

Thus, "the patient's priorities" must be appropriated as "everyone's priorities" simply because they are the patient's. Furthermore, "missing the point" implies that research without the patient view is useless. This idea is perhaps to be expected of a patient-led organisation, since as *E4* implied, the organisation must satisfy certain member expectations. Likewise, the literature suggests that POs are likely to promote the patient perspective as essential to research design(Beresford, 2002). It is nevertheless interesting that PPI is interpreted in such a way as to make it both necessary and expected due to the patient's innate ability to be appropriately engaged. It could also be the case that the intrinsic need for PPI is related to the legitimacy of a person with MND or Parkinson's in speaking for and to others(2004, 2008).

POs as the 'patient': "we are the voice of Parkinson's"

Perhaps in contrast to the idea of descriptive representational legitimacy, some interviewees suggested that in certain circumstances POs could represent the patient perspective to the degree that their involvement could substitute the inclusion of patients themselves

> *E7:* if a story breaks about Parkinson's the first point of call is Parkinson's UK… they know that we are the voice of Parkinson's. And we can not only give an expert scientific perspective but we can also give a perspective of people with Parkinson's

This quote runs counter to previous statements about the fundamental importance of PPI, suggesting that PUK acts as a gate-keeper to the experience of people with Parkinson's. A PO could be expected to emphasise its ability to present the patient view. However, looking at this from the perspective of representative claims(Saward, 2006), the organisation's claim here is more than being a member representative in this quote. In describing PUK as "*the* voice" *E7* implies that the organisation and its staff are able to speak for all people with Parkinson's, suggesting more than mere representation of the views of organisation members exclusively. Relating this to the debate around procedural legitimacy, this would bypass even the need to elect a representative, since it is not just members who are the represented in this case. This therefore adds another dimension to the legitimacy debate, since this PO is legitimate even without an accepted election or democratic process. This was implied by others talking about CPT, for example

> *E3:* We want to engage people, we want to hear the voices and we want to be able to speak for the voices as well.

Nevertheless, many interviewees were very critical of the idea that PPI would become a formality, without the genuine involvement of the patient voice.

"Box Ticking Exercises"

Supporting Beresford's(2002) analysis, when discussing the role that POs play in encouraging PPI, some interviewees raised the idea that certain external organisations can have a tokenistic approach to PPI. A discussion with *E4* illustrates very well the difficult position in which POs can find themselves when engaging with regulatory bodies such as the Department of Health. As *E4* describes, in a lengthy section of his interview, there are

circumstances where the presence of a PO representative will be enough to tick the PPI box, regardless of whether or not the individual happens to be living with MND themselves.

> *E4:* There's actually a broader issue around how you define patient and public involvement because as far as the Department of Health is concerned if I turn up I'm a patient representative. Therefore they tick that box. Whereas from the way I would define it is it's somebody with the disease or somebody affected by the disease…
>
> *E4:* I think that the [PO] has, erm, has a good reputation within certain circles that and we're also, of course we estimate that we are in touch with something like 75% of people with MND [here] so that gives us a lot of expertise and a lot of clout. We are truly a patient representative organisation, you know you can have other patient charities who might only be in touch, more common disease, but they might only be in touch with 5% of the individuals. So do they truly, are they truly able to understand the needs and wants of that particular constituency? I don't know.
>
> *AG:*   *So you do kind of think it's correct to see you as a patient representative then for the Department of Health?*
>
> *E4*:   Well yeah, I think it depends on the circumstance. I wouldn't want it to be, be done as a box ticking exercise, you know I think if, if it's better for representatives of the patient association to be involved great but there is a time and a place often, particularly in healthcare research, to get that direct patient involvement. It doesn't necessarily have to be done through the [organisation]

E4's opinion on the PO's position as a representative seems to fluctuate. At the beginning of the extract, *E4* seems to strongly disagree with the use of PO staff to fulfil PPI commitments. By the end of his thought process, however, *E4* reflects on a Burkean style position where patient representatives might be better placed than patients to engage with PPI initiatives. Furthermore, reflecting the literature on direct democracy(Bowler et al., 2007, Carman, 2010), *E4* makes a clear distinction between PPI and *direct* PPI, with the involvement of representatives deemed less acceptable in the latter. This suggests that, although the PO might be able, through its continued contact with people with MND, to accurately represent the needs of the MND community, it cannot claim to act as a substitute for direct contact with people with MND themselves. As such, *E4* appears to experience the fluidity of the representation continuum raised in the literature. He appears to realise both that the PO position as representative requires patient input, and that there are circumstances where the PO (the trustee) knows best.

This idea of a "tick box" approach to PPI was also raised in a discussion with *E5* about the relative absence of people with Parkinson's in care and research debates. Similarly to *E4*, *E5* suggested that many merely pay "lip-service" to PPI, without giving people with Parkinson's any real power. *E3* however, when describing a particular positive example of patient engagement in healthcare, suggested another interpretation of PPI.

> *E3*: I think there's probably relatively few who are actually, actually genuinely involved… Bastiaan Bloem is a case in point though because he's certainly very much interested in patient empowerment in terms of their own health care, not for any soft cuddly feely reason but I think he actually believes it generally produces better health outcomes in the long-term and if he can be persuaded otherwise I'm sure he'd change his view but at the moment, as I said, that's his rationale for supporting it. I think he believes that it does have genuine healthcare implications.

E3 appears to feel it is necessary to qualify praise of Bastiaan Bloem's(2011) approach to Parkinson's care, by stating that he supports PPI "not for any soft cuddly feely reason". Bloem's extensive support for PPI in healthcare decision-making is instead described as a rational choice based on evidence that it "produces better health outcomes". Furthermore, *E3* suggests that if there was evidence to the contrary, even Bloem, a well-known proponent of PPI, would reconsider his opinion. *E3* seems to be attempting to distance the concept of PPI from potential characterisation as irrational or "soft". This suggests that *E3* believes that this is how PPI tends to be described. Consequently, PPI is reframed as evidence-based, so that it becomes not just an ethical requirement, but also a rational or practical part of healthcare processes.

Similarly, *E9* addressed the idea of "lip-service" in research contexts, suggesting that patients were now becoming increasingly meaningfully involved in the research process.

> *E9:* it was just lip service to begin with, now it's beginning to be, it's beginning to become real. I think it's a, it's a quite a long process because you've got to engage the patients first and patients have got to realise they can influence the system, and er once they realise that, and they are beginning to realise, then er, they become more knowledgeable, more educated, more engaged, more involved and that then impacts on the scientific arena… I think there's been a lot of fear in the past of patients just standing up and shouting and screaming and shouting, when actually they don't know very much

E9 alludes to the need to change the perception of PPI as "soft" or irrational. However, unlike *E3*, *E9* focuses specifically on the reputation that patients themselves have for "screaming and shouting when actually they don't know very much". Rather than reconstructing the concept as a whole as evidence-based, *E9* is to a certain extent reframing the involved patient as more knowledgeable and capable of rational argument. Crucially, this re-characterisation of the patient requires considerable proactivity on the part of patients themselves. They must not only "realise they can influence the system" but also make sure that they are educated enough to avoid being assumed to have nothing constructive to add. Furthermore, the move away from paying "lip service" to PPI is described as corresponding to an increased position of power for patients themselves. *E9*'s lip service therefore differs very much from *E4*'s "tick box exercise". *E9* implies that unsatisfactory implementation of PPI initiatives revolves around a lack of patient engagement rather than the use of inappropriate representatives.

Enacting the PPI agenda

As the above shows, many interviewees attached a great deal of importance to PPI as a concept that could both empower patients and improve research ethics and efficacy. However, examining the way in which interviewees described how PPI was enacted by the POs, highlights a disparity between intentions and actions. For example, although in an earlier quote, *E9* tended to describe PPI as a transfer of power and influence to people with Parkinson's, the actual role ascribed to patients was rather more traditional.

> *E9:* people often forget that a lot of research is funded through POs, and POs get their money predominately from people who have Parkinson's or their friends and supporters so, so, er, raising money is a big thing. Then there's media, there's er, well bringing attention to, by sort of offloading your personal story or, or by engaging the press… which is all good awareness, and awareness helps create a better profile, a bigger profile for Parkinson's.

Rather than aiming towards substantive influence over the research agenda, people with Parkinson's are given fundraising and awareness-raising as a primary role.

In contrast, *E2* limited the role of people with MND to research participation

> *E2:* involvement is essential but at the right stage. I think until now researchers have not known enough about MND to make appropriate decisions… Therefore what we do need to do at this moment in time is to learn what is going wrong there. And the only way we can do that is by having tissue samples from patients in order that they can be investigated to try to find out exactly what's going on

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Significantly, the importance ascribed to PPI is qualified by its enactment "at the right stage". Although *E2* implies that PPI is vital to improving scientific understanding of MND, it seems to consist only of participating in research and providing researchers with the resources and materials they need. This to a certain extent follows the observations made by Martin(2008) that professionals often constrained the involvement of service-users or patients to fit a very specific and narrow definition of the capabilities of lay publics. Likewise, in this study, despite the fact that POs were often described as particularly well-placed to promote PPI, interviewee ambitions were modest and people with MND and Parkinson's were limited to participating in certain, carefully subscribed activities.

PPI as Fundraising: "you've got to get enough money"

As implied by *E9,* a significant aspect of PPI appears to be fundraising. Even where members are given a more extensive role in research planning, fundraising is nevertheless highlighted as an important responsibility

> *E7:* And this lay review panel is part of a larger group of members called our 'research support network' and this is sort of a grouping of members who are involved in research in many different ways; the review of grant applications is one of them, research fundraising is another, talking to researchers, organising events. Basically it's, what we do is we have assembled this group of people, anyone can join you don't even have to be a member, and we then provide you with information about what's going on, how you can help, what sort of events you can hold

As discussed previously, the Research Network (described as the Research Support Network by *E7*) is a group of people with Parkinson's who review research grant applications as part of the funding process. The network clearly has some influence over the direction that research takes, but *E7* highlights fundraising event-organisation as a particularly important function of the group. Curiously, it is described as a group that "any one can join you don't even have to be a member", which broadens the pool of people who can potentially be involved in what is ostensibly a PPI initiative. This could reflect the tensions described by Martin(2008) between patients and professionals over legitimacy to represent the patient community in decision-making processes. It has been suggested that in cases where "service-users" begin to gain more influence, those in power might act to undermine the legitimacy of their position(Martin, 2008). This could be an extreme conclusion to draw, however it does seem significant that the aspect of a genuinely

extensive PPI initiative that this PO employee chooses to emphasise is external to the research process.

V11, when discussing continued involvement with an organisation she had left, gave another perspective on this issue

> *V11:* they still call me a patient advocate I guess because I'm a fundraiser. I don't think they have the same term, way of describing that kind of terminology because to me a patient advocate is someone that promotes the charity for them, does that make sense? But I don't promote the Cure Parkinson's Trust, I raise money for them

V11's continued position as a patient advocate is troublesome for her because the role does not correspond to her understanding of the word advocate. Rather than promoting or advocating on behalf of the charity, *V11*'s patient advocacy in this context revolves around fundraising. Mirroring the discussion around *E7*'s quote, it seems to be made clear that involvement must be limited to fundraising, although the role sounds like a PPI initiative giving patients a position of influence. Moreover, it seems that neither the charity nor *V11* interprets "patient advocate" as someone who acts on behalf of patients, as might be expected. Even in *V11*'s account, advocacy is constrained to promoting the organisation rather than issues affecting people with Parkinson's. Therefore, the notion of patient advocacy appears not to be defined in relation to patient perspectives. The role is instead described as organisational advocacy, which happens to be performed by patients and thus seems distant from the ideals of PPI as a concept.

That being said, the CPT website description of the patient advocate role stipulates that the main function is to represent people with Parkinson's in discussions with health and research professionals, particularly at events such as the World Parkinson's Congress. This could suggest that *V11* has misunderstood the role as defined by CPT. Alternatively, it might be the case that it was explained to *V11* in very different terms. It is, nonetheless, significant that *V11* interpreted what was said in such a way that makes advocacy so far removed from the traditional definition and indeed that promoted by CPT itself. Therefore, this also illustrates the difficulty discussed in Chapter 5 of defining the role that POs play in their community and the relevance of PO activities to members. Here again, advocacy appears to mean very different things to different people.

As fundraising was raised as a significant aspect of PPI in Parkinson's and MND research, another important issue to consider, is the amount of influence people with Parkinson's and MND have over the use of the money they raise. In a discussion about raising money for PUK, *V1* explained that members and branches could only specify the project to which they wished to contribute if they raised over £2000

> *V1:* Whereas what really is important is that you've got to get enough money now if you send money to research, the people, to have a say in what the research is. So that our branch gave £5,000 last year because it was over the magic £2,000 sum we actually had a say in which grant it went to

This suggests that many people who raise money for PUK research, do not "have a say" in the specific use of that money and are not likely to know which project it funded. Although this might not be surprising, given the size of the organisation and its funding portfolio, *V1*'s description of the organisational reaction to this £5000 donation, illustrates the importance of this point. Following the donation, the Director of research and the researcher leading the project visited the branch to present research plans and prospective results. The strength of this reaction, and the personal attention that the researcher and Director gave to the branch was credited with bolstering support amongst branch members for research in general and PUK staff in particular. Therefore, being able to direct the use of their money corresponds with feeling more involved in the research process and the work of the organisation, and indeed ensures more attention from "HQ".

The opposite could also be true, if a branch is never able to raise as much as £2000, they will never know where their money goes and will not be visited by the researcher who benefited from their activity. As well as illustrating the way in which fundraising might be incentivised by organisation staff, this example speaks to the wider issue of making fundraising a principal goal of PPI. If fundraising forms an important part of the PO approach to PPI, it could be expected that those raising money might have some influence over the use of it. Since most will not have this opportunity, it seems that fundraising as a PPI initiative is rather less influential than the label of "Patient Involvement" might suggest. People with Parkinson's might be very engaged in raising money for research, and as such ensuring that research can occur. However, this engagement remains auxiliary since it is furthering the ability of the charity to fund research in general rather than research on a particular issue chosen by people with Parkinson's.

This, therefore, harks back to the suspicions raised by *V1* in Chapter 5, over money vanishing into the headquarters "black hole". In fact, *V1* suggested that this dislike for sending money to disappear into headquarters finances, would lead his branch to fundraise for increasingly specific local activities, so as to put limitations on where the money can go. This suggests that there is a certain amount of uneasiness in the organisation over the lack of influence that members have over the use of their money.

PPI in Decision-making: "I don't think they should ever be in the majority"

Despite the claims made above about the intrinsic necessity of PPI to the research process, interviewees were also considerably less emphatic when describing the practical role that people with MND or Parkinson's could play in research decision-making. This was implied by *V11* when discussing a specific example of PPI in research

> *V11:* We didn't really have any say on what the clinical trial was or who was involved in doing it… certainly the groups or panels that I've sat on haven't really had a say on what the trial is going to be. It's just the communication of it, how it's communicated to people like ourselves, how it's going to be fundraised for by people like ourselves.

Therefore, rather than using the panel of people with Parkinson's to generate ideas and promote patient-led research, as implied by *E3* and other PO staff members, *V11*'s experience is that PPI is used to improve research communication and fundraising. This suggests both that the theories surrounding PPI are not always implemented, and that in situations where people with Parkinson's are ostensibly involved in research decision-making, their input can be limited to decisions about fundraising and communication to others "like ourselves". This is by no means always the case, however, reflecting the analysis of patient-centred activities, this quote illustrates that the intentions behind an organisation's theoretical commitment to PPI do not always correspond with its actions.

Furthermore, when talking about PPI in MND research, some interviewees directly discussed the role of Trustees in representing MND to external boards by promoting PO priorities. For example, *V4*, described the role of Trustees on a research panel as

> *V4:* the Trustee role is really… to scrutinise, make sure that, you know that the strategic direction of the [organisation] is being followed in terms of what they want to see from the research and also I suppose to ensure fair play and that everything is being done according to the way that the direction of the [organisation] is leading. But [they're] not currently sort of voting members

This suggests that Trustees, when involved in research decisions, are present to ensure that grants meet PO priorities and adhere to its research strategy. Trustees, who might have personal experience of MND, or are voted in by the organisation's membership to represent them, are not therefore actively participating in leading the research agenda. They are instead acting, as *V4* puts it, in a role "of scrutiny", ensuring that proper procedures are followed. Furthermore, *V4* described "the final decision" as something that scientific experts should make. This suggests that PO Trustees have rather less power than assumed in the representation literature. Since, although they might have the authority to speak for PO members, they do not have overall authority over the decision-making process. It seems that Trustees in this case are conforming to the idea raised at the beginning of this chapter, that PPI is a method for improving the ethical practice of researchers and "experts".

Additionally, the fact that lay members and Trustees are charged with making sure that decision-makers keep to the PO's strategy, seems similar to Martin's(2008) debate on intrinsic legitimacy. Rather than pointing to an inherent ability of patients to speak for others living with a condition, however, it applies a level of innate legitimacy to the PO's strategy. Merely because it is suggested by a PO, the research strategy is seen as so correct that it must be enforced by people who otherwise have no impact on the decision. Despite the stipulation that only those with particular expertise can decide which projects get funded, the emphasis is nevertheless placed on the PO research strategy as the key direction that "experts" must follow, suggesting that the organisation's perspective is more legitimate than the expert view.

Moreover, the fact that Trustees are given a fairly minor role in influencing the outcome of grant discussions, calls in to question the impact of PPI in this process. In fact, *E6*, when talking about the involvement of people with MND on her organisation's Board of Trustees and consequently in research decision-making processes, said

> *E6:* so we do get some representation from people with MND, or people that people with MND have voted in because trustees are voted in

Here, "representation from people with MND" is broadened to include those who have been voted in to their position by people living with the condition. This again extends the traditional political role of the "trustee" to make them actual substitutes for "the

represented". Furthermore, *E6* later explained that some board members may be co-opted by other Trustees and that these individuals may not necessarily have any experience of MND, much less be living with the condition themselves. This means that some of those described as representative of people with MND, occasionally taking part as representatives on PO research panels, are neither voted in by charity members nor personally connected to MND. Therefore, these co-opted members, although generally chosen for relevant skills or experience, might be considered less able to speak for the experience and priorities of people with MND. It could also be said that their position on research panels will be to represent the Trustee view. This arguably takes Burke's preference for the trustee model to the extreme. Reflecting the political science debate over citizen panel recruitment(Brown, 2006), Trustees are deemed so much better placed than the members to make decisions that they can even decide who the other Trustees should be

That being said, *E6* later gave a potential reason for the boards' and panels' inability to always ensure involvement of people with MND

> *E6:* Sometimes we do have people with MND. But Motor Neurone Disease is such a rapidly progressing disease that most people only live 2 or 3 years, with Motor Neurone Disease, so it's not that common

Because MND progresses so quickly, often rapidly reducing an individual's ability to travel and severely impeding movement and speech, the PO cannot ensure that board meetings will be organised to accommodate people in the later stages. Furthermore, because people diagnosed with MND will in most cases have a very short life-expectancy, even if individuals apply to become a Trustee, they may in fact be in too advanced a stage of progression by the time that they are elected to perform the role. Therefore, the fact that the MND organisations have a very low number of people with MND on their decision-making boards and panels is to a certain extent understandable. However, it is also the case that people with experience as carers or family members might arguably act as representatives of those affected by MND in the broader sense. If "the represented" is extended to include everyone affected by MND in some way. Additionally, the issue still remains, that some of those called to represent the membership might not be voted in at all and instead co-opted in by other Trustees. Regardless of the challenges presented by the nature of MND as a condition, it nevertheless seems strange that people with no MND experience and no direct link to member opinion might be described as patient

representatives, given that even Burke's detached representation requires an election process.

To examine why representation has taken this form, we can look at another quote from *V4*

> *V4:* I think there is a place for lay people to actually be able to give their thoughts on the way they want the research, not just to go but also to look at the applications and to give their opinion and to give it in a voting manner. I don't think they should ever be in the majority, I think you've got to have the, you've got to be led by the scientific expertise, because unless you're a specialist in the field there are lots of traps for the unwary.

PPI in research decisions is seen as appropriate, as long as patients are not "in the majority", since they will not have sufficient scientific expertise to direct the organisation's research funding. One reason that more people with MND experience are not involved in Research Panels or Trustee Boards might therefore be that experiential knowledge is not sufficient to allow active participation in the decision-making process. Indeed it might also be the case that, since a majority of "lay people" is deemed inappropriate, Panel members are co-opted rather than voted in because a majority member vote would not be based on the 'right' kind of experience. Other Trustees seem to be considered more able than members to judge whether candidates' skills or experience would be beneficial to the Board. The apparently low level of influence people with MND are given in this case seems to be due to the belief discussed in Chapter 4 that people with MND generally lack scientific knowledge and understanding.

Therefore, although PPI is seen as crucial to research, this importance tends to come with a caveat: that it can only be implemented at certain upstream stages in the decision-making process. Although it is necessary to involve people with MND, they are not deemed capable of exerting any real influence in terms of the decisions that are actually made.

"we don't tend to go to the that extreme"
In fact, this tension between theoretical enthusiasm for PPI in research decisions and the perceived limits to its implementation was tacitly or explicitly expressed in several interviews. In many ways the most interesting example of this was a discussion with *E7*

> *E7:* I think people can get involved in every area as long as everybody understands why they're there and what their role is. The worst thing you can do is have somebody on the panel, board who doesn't really know what they're really there for and nobody else really knows what they're there for, so what is seen as their area of expertise, but once that's clarified in the beginning that you're there representing somebody with Parkinson's or representing people with Parkinson's you are there to provide your expert input on what this study would mean for people with Parkinson's or Dementia whatever and once everybody understands that, it works fine.

In the first half of the quote, there is an interesting juxtaposition between the relative positivity of the description of PPI, and the rather more negative comment about "the worst thing you can do". *E7* is describing the benefits of having people on panels who can provide expertise on "what this study would mean for people with Parkinson's", suggesting a certain amount of enthusiasm for PPI in general. However, *E7* also makes clear that the rest of the panel, and the individual themselves, occasionally do not understand why the patient representative is present and the purpose of their input. Consequently, the "parameters" of PPI have to be constructed in advance. Furthermore, this quote provides another example of the tendency to conflate PPI with a trustee model of patient representation. In switching between "they're" and "you're", *E7* seems to occasionally include himself in the definition PPI. This implies again that *E7* understands the role of PUK as a gate-keeper to PPI.

Curiously, despite the criticism of the apparent "tick-box exercise" approach of some external boards, when asked about his PO's approach to PPI, *E4* suggested that, although PPI is positive, it should not go too far, and that people from the organisation can act as patient representatives in the process

> *E4:* if you're talking at the sort of top end of patient involvement in every stage of the process, a little bit like the Alzheimer's Society does, then we don't tend to go to the that extreme. We are [patient-led], our Board of Trustees are elected, the majority are elected by the membership, they are the representatives of that membership, we have trustee representation on our advisory panels. And the trustees' role, because they're not scientific experts… is to ask the "so what" question as I call it, "so what does this apparently anodyne bit of biochemistry mean for people living with the disease?" And that helps us to maintain our focus, our patient centred focus.

E4 acknowledges the role that PPI can have, but chooses to describe patient involvement in all stages of the research process as an "extreme" that the PO avoids. Significantly, the

status of the charity as "patient-led" is in this case used to justify the Trustees' role in maintaining the "patient-centred focus" in panel discussions on research funding. This not only echoes the way in which PO activities were legitimised in Chapter 5, but is also contrary to the view expressed above that it is inappropriate for PO staff to act as representatives in a PPI capacity.

This implies that *E4* separates PO procedures and those of external funding boards. As has been the case with other interviewees, it would appear from this quote that *E4* also believes that patient-led status affords a PO a sense of legitimacy as patient representative. Particularly, what is seen as criticisable in others is accepted in internal PO procedures, because representatives are "elected by the membership". Those elected may in fact not be people with MND, but because they have been voted in, they are able to assume the required legitimacy to present the patient view. This directly reflects ideas about the legitimacy of democratic processes(Eulau et al., 1959). Here, the representative is given authority by the legitimacy of the election that appointed them. Of course, this view of representation also requires *E4* to ignore the possibility that some Trustees have been co-opted, since their involvement cannot be justified by the legitimacy of election.

This raises the question: why are patients seen as so unable to participate in research design that involvement at this level can be described as "extreme"? The interview with *E8* provides an interesting potential answer

> *E8:* if it's patients saying these are the things that's important to them then that's what we should be looking at… however, just because one or two patients say a particular area, I think you make an informed decision on that.

Having said that it is imperative to research subjects relevant to patients, *E8* stipulated that research avenues cannot be followed "just because one or two patients say a particular area. I think you make an informed decision on that". This suggests that patient priorities cannot always direct research agendas. Moreover, "informed decision" seems to be placed in conflict with patient suggestions. The implication thus appears to be that the decision on whether to follow patient-inspired research avenues will be informed by a knowledge-base external to that of the patient experience. This is not necessarily surprising, or indeed negative, given that we know that POs will make research decisions based on the advice and input of a range of experts from various scientific and medical fields, as well as some

knowledge of the patient experience. However, it does point to the now seemingly common assumption raised in many of the interviews and discussed in Chapter 4 – that people with MND and Parkinson's will not be informed enough to make clear and logical decisions about what POs should fund. This might begin to explain why PPI in research decisions could be seen as "extreme", since *E8's* view implies that it would involve a lack of "informed decision"-making.

Other interviewees, also related the lack of PPI in research decision-making to the general assumption that patients will not have enough science-specific expertise to understand the research process

> *E6:* The majority of the work that we fund is biomedical research, rather than healthcare research. And, if there's, for example if it's questionnaires and things then there's an opportunity for people with MND to know they're going to be asked a load of questions how they, you know, what would make them not want to carry on, like, completing the questionnaire and what would make them want to continue and things like that, so there is useful opportunities there. But for biomedical research, it's so much more specialised, you'd have to have a pretty good grounding in the research that was being proposed to be able to really make a constructive contribution

In using the words "constructive contribution" *E6* seems to be expressing a similar view to that of *E8*, that a lack of understanding means that people with MND cannot give an informed, or in this case "constructive" input to research discussions. However, *E6* also suggests that this is partly caused by the fact that the PO mainly funds biomedical research, so that discussions about grants will involve a great deal of technical scientific knowledge. Therefore, a significant limitation to PPI in this case appears to be the organisation's own research priorities.

> *E6:* I think strategic side is perhaps a bit too high level... I think it's perhaps unrealistic to expect to get somebody with no background in biomedical research to be able to give that level of interpretation of a project. So I think that's where it becomes very difficult to contribute to which biomedical projects we fund

E6 again proposes that the biomedical subject matter significantly lessens the likelihood that people with MND will have the necessary expertise to be able to make informed decisions about research. As such, it is the PO strategy itself that limits the involvement of people with MND in the "strategic side".

E4, when explaining why it is difficult to provide people with MND with enough training to enable their involvement in discussions about biomedical research, mentioned again the challenges posed by the condition itself

> *E4:* The problem is that with Motor Neurone Disease by the time you've trained somebody they may actually be dead between one grant round and the next so it's very difficult to do. You could do it with former carers, but former carers have a very different view to patients

Therefore, the rapid progression of MND means that the organisation is unable to train enough people to understand the research process. However, it could also be said that, the amount of training required is dictated by the kind of research that the organisation chooses to fund. If the research was not predominantly basic science or biomedical research, it is likely that the training or skills required would not be so specialised. Furthermore, it is interesting that *E4* dismisses the idea that carers could be involved, since this would remove the element of time-limits for training.

This illustrates further the challenges that MND organisations face when trying to promote PPI in their research processes. A potential solution to the challenges posed by the nature of the condition is also deemed inappropriate. People who have cared for someone with MND will not present the same experience and opinion as those actually living with it. However, as we saw above, the alternative is to involve Trustees as voted representatives of people with MND. This suggests that the organisation faces a very difficult dilemma. Echoing Rubenstein's(2014) concern, the organisation must decide between two secondary sources of patient representation as a substitute for direct PPI. Neither will present the exact view of patients themselves, but both could be described as legitimately, though differently, representative.

Nevertheless, it is, I believe, significant that the type of representation that the organisation has chosen is that provided by the Trustees. Despite the fact that many have no personal experience of MND, and that some are not even elected by the membership, the democratically sanctioned representativeness of Trustees is seen as more appropriate than those who have personal experience as a carer. This might, then, point to a general suspicion of the "lay" perspective as less informed than that of the expert or Trustee with some relevant background. In this context, therefore the PO is towards the trustee end of the continuum(Eulau et al., 1959).

In fact, *V1* gave an interesting account of the potential effects of such an attitude. Referring back to Chapter 4, in the discussion about lay identity, *V1* described being told that lay reviewers must only approach research grants from a layperson's perspective rather than trying to include prior experience of research. This could suggest that the assumption that the patients will not understand the finer details of research, has led to the situation where those who do, must not draw on their experience outside of that expected of a patient. As such, people with Parkinson's participating in research decision-making are specifically limited in the scope of their input. The lay input could consequently be seen as less important, since it corresponds only to a very small part of the grant which is deliberately simplified. This would appear to be supported by *V1*'s comments on the way in which the research panel combines patient and researcher opinion

> *V1:* you would never see a scientific one which got graded 1, the bottom, funded just because someone, lay people said you know it's a number 3. But if you saw a number 3, the top grade for the science, the science might get funded but it would have to have at least some support from the lay people.

V1 is describing the process by which each reviewer grades a proposal, and how any disagreements are settled. It is made clear that strong support from patients will be overruled by any low grades awarded by scientific experts. *V1* also says that projects given high grades will require some patient or lay support in order to receive funding, suggesting that patient support is important. However, scientific expertise seems to wield more power than the lay perspective. This was supported by *E7* who said that where there is a "technical flaw" in an objectively good project, patients will know to "bow to" the opinion of scientific experts. Not only does this suggest that the experts will have more say than patients, it also supports the idea raised above that patients will be restricted in their participation. *E7* might be referring to the patients' lack of understanding of technical details, preventing them from identifying the flaw. Alternatively, "flaws" might arise in the parts of the proposal that lay reviewers do not read. A lay summary may be very brief in terms of detail tending to give an overview of the research rather than technical specifics. Therefore, lay reviewers might not be given enough information to identify problems and will vote only on the merits of the projects' general aims and goals. Furthermore, *E7* also emphasised the importance of getting "the backing of our members", somewhat echoing *V1*'s view that projects need "some support from lay people". It could be inferred, therefore, that since both an employee and a volunteer raise this idea of *support,* a significant aspect of PUK's grant review process is to gain patient backing for the

decisions it makes. As lay reviewers seem to be given less information and less influence in the process, the biggest benefit of their involvement appears to be in giving more or less support for the projects approved by the rest of the panel. This suggests that even where PPI is taken to the "extreme" mentioned by *E4*, patients retain little influence.

Indeed, *E2*, even in discussing arguably the most auxiliary aspect of research decision-making suggested that PPI would probably not be possible.

> *E2:* I think unless an individual has had a training in an academic discipline then I doubt that many of them would have the skills to actually conceive of and bring to fruition a research project that is effective because they have other things on their mind, survival being the main one

For *E2*, the lack of skills and understanding, and the physical effects of the condition, mean that people with MND might not even be able to provide ideas for research. "bring to fruition" might of course refer to conducting and managing research projects, in which case it is probably true that someone with MND would be unlikely to be able to participate in that way. However, to include that people with MND would not have the skills "to actually conceive of" a project suggests that they are even occasionally precluded from suggesting ideas.

Curiously, *E8* goes further than *E2* to suggest that PPI in setting MND research agendas will *never* happen

> *E8:* I suppose it comes down again to how informed the patients are that are making these suggestions because I don't think you'll ever get the situation where you have patients saying this is where research should be going without having somebody else looking at that and saying well that's maybe correct or maybe that's wrong because of X, Y and Z

Not only does *E8* say that patients will never be able to direct where research "should be going", he also seems to suggest that it is equally unlikely that patient suggestions for research will be evaluated in a formal process, either supporting or rejecting them for logical reasons. This is exactly what other interviewees said their organisations, or research groups, are doing – taking inspiration from patient suggestions as to what their research priorities would be and finding a way to keep research relevant to the patient experience. It seems that for *E8*, the need for informed decision-making might preclude patient

suggestions from being considered seriously, since they might not be based on the right information-base.

Therefore, as this section has shown, even in the most upstream aspects of research such as agenda-setting and grant allocation, there is a considerable amount of tension between the PPI that POs feel they should promote and what they are capable of implementing. As a result, people with MND and Parkinson's can often be restricted in their involvement to providing the patient-sanctioned support that the organisations require and want. This might seem like a strong criticism, however as the next section will show, it does seem that for many, PPI in research was described in a rather traditional way.

Trial Participation: "Patients are the only source of that material"

A number of interviewees suggested that the main way in which people with MND and Parkinson's can engage in research is research participation. Perhaps the best example of this was the conversation with *E2* where research participation, even at the level of tissue donation, was described as an example of PPI. In the previous section, we have seen that one reason that was raised for not involving people with MND and Parkinson's in strategic decisions, was that patients would have a role in research once certain upstream procedures had been completed. Here again, *E2* suggested that PPI has its place, but rather than referring to other activities such as fundraising or indeed grant reviews, he described instead research participation.

> *E2:* So at that point in the research process patient participation becomes essential because without patient participation you won't have a cure, right… Patients are the only source of that material

Whereas others, at the beginning of this chapter, suggested that PPI was essential in terms of ethical research regulation or as a moral obligation for POs, *E2* suggests that the necessity is more practical. PPI is essential because people with MND "are the only source of that material". As such, research physically isn't possible without the participation of patients. This seems to point very strongly to a sense that the part the patients play in research is still quite subsidiary: handing over biological samples for a researcher to use. In fact, this is more clearly seen in a further comment that *E2* made

> *E2:* So patients have got a role to play, I think, not necessarily as guinea pigs but more as source of information.

Similarly to other statements quoted above, *E2* emphasises the benefits of using patients as a "source of information". However, here, *E2* seems to be referring again to biological information that allows researchers to conduct research. It also seems significant that the first phrase that *E2* thought of when making this statement was "guinea pigs". He does say "not necessarily as guinea pigs", suggesting he does not want to describe people with MND in such a way. However, to mention it at all could imply that this was his instinct, or that he is aware that this is how the general attitude towards PPI might seem. After all, to describe PPI as the process of trialling experimental treatments is rather close to describing patients primarily as guinea pigs. In any case, this illustrates how minor a role *E2* gives people with MND, since the information earlier described as a source of influence, and research leadership is now described in drastically different terms. Here "information" is not provided entirely by the person with MND, rather the individual participates in a process by which the researcher gleans information from them that will inform further research. As such, the patient is given a significantly less powerful role. Furthermore, this resembles a very traditional model of PPI, framing it more as participation than engagement. Although *E2* is quick to emphasise how important this role is for the progress of MND research, it is not particularly revolutionary in terms of ensuring patient-led research. That is not to say that it is wrong to view patients as important in their role as research participants. But it is interesting to note that a PO employee chose to answer questions about PPI in such a way, given that the POs examined here all tend to highlight the importance of patient-led research.

This is supported by the interview with *E6*

> *E6:* I don't say they have particularly formal opportunities to really contribute to the strategic direction of the research. I mean, they obviously have the opportunity to take part in research and that can be anything from a drug trial to, erm, kind of, going to have scans every six months or something, brain scans, to just perhaps giving a blood sample for a project or even answering, doing this kind of qualitative research that we're doing now. So there's a whole range of different opportunities that they can have to participate in research but there isn't a huge amount of patient, what I would call patient public involvement in what happens in research

E6 also makes clear that members do not "have particularly formal opportunities to really contribute" to the research process, although "they obviously have the opportunity to take part in research". Importantly the quote ends with *E6* appearing to differentiate between this form of participation and what she calls "patient public involvement". As such,

throughout this quote *E6* seems to shift in her perception of PPI, from considering research participation as an "opportunity to take part" to suggesting that 'real' involvement would be to participate more in strategic research planning processes. This illustrates the dichotomy that often characterises patient-led research. In advertising their commitment to PPI, their status as membership organisations and the opportunities they provide for research engagement, POs must also acknowledge the continued existence of this traditional view of PPI as research participation. Consequently, *E6* simultaneously tries to emphasise the involvement of people with MND as participants, and acknowledge that research participation is not enough to fulfil a commitment to "patient public involvement".

V2 also implied a sense of tension between PO priorities and actions, but in a different context. As was the case in many interviews, *V2* raised the issue of the fast progression suffered by people with MND and how this can limit participation both in terms of research timescales and selection criteria.

> *V2:* But at the moment the research I think is mainly in the laboratory using things that, they were saying the other day, using, what was it, some little bug thing they're able to use… I forget now what the latest thing is, I was amazed, something like either an ant or a, something like that. So it isn't always easy for people with MND to take part in research, although it's always the thing they would want to do

This illustrates again the challenge faced by MND organisations. Although POs believe that people with MND want to engage with and participate in research; a great deal of basic research must be conducted before clinical trials can take place, which can limit the participation of organisation members. However, whereas others discussed the fact that people with MND are unable to participate in the strategic side of basic research, due to the need for specialised, technical knowledge, *V2* believes that laboratory research precludes all patient participation. This suggests that for *V2* PPI means participation in the way it takes place in clinical trials, rather than including tissue donation. It could be that *V2* has misunderstood the basic research process, or does not count projects where people with MND donate tissue or blood samples as basic research. In any case, it indicates a disparity in understanding between employees and volunteers over the research that MNDA funds, as well as the research goals of the organisation. This is because *V2* is either not aware that some of the projects involve tissue donations, or does not understand what is done with the collected material. This highlights a certain organisational tension regarding research

priorities. Although *V2* emphasises that MNDA improves patient participation in research, it nevertheless remains the case that the focus currently has to be on basic research so that the traditional view of patient participation is impossible.

As the rest of this chapter shows, PPI was discussed as involving to various degrees every part of the research process. Therefore it cannot be said that PPI is only seen in an auxiliary, traditional sense. However, it is nonetheless significant that trial participation was raised by a majority of interviewees as one indicator that PPI in research was increasing. Although it cannot entirely be described in these terms, the attitude towards PPI still involves the characterisation of the patient as a "research subject". This was frequently linked to the perception that people with Parkinson's and MND are crucial as research participants, since without them research could not progress. However, this importance does not seem to equate to patient empowerment or influence. This seems to reflect the difficulty raised in the literature review in defining PPI, since a distinction can often be made between *participation* and *involvement,* and *involvement* and *emancipation*(Thompson, 2007, Beresford, 2002). Indeed, as the confusion expressed by *E6* shows, the fact that the main way for people with MND to engage in research is through tissue donation rather than strategic influence is an acknowledged source of tension for the PO, not least because of the tendency to advertise the status of POs as member-led. In fact, this contrast between the PO responsibility to consider member opinion and the numerous limits placed on actual member influence on organisational strategy can also be observed in the final type of PPI that I would like to examine. The role of people with MND and Parkinson's in their own PO.

Organisational PPI: "I do feel a bit let down"

So far my exploration of PPI has focused on the role of people with MND and Parkinson's in research. However, the fact that the above highlights a sense of organisational anxiety over a perceived responsibility to improve patient influence, suggests that it is also important to consider the role that members and volunteers are given in the PO itself. As Chapter 5 showed, some of the POs seem to be experiencing a degree of conflict between the staff or "headquarters" and the grassroots volunteers. Part of the reason for this seems to be a disconnect between what headquarters needs to do and what the volunteers believe the PO priorities should be. As a result, there also seems to be a feeling amongst some that members do not have a role in the day-to-day running of the organisation.

> *V1:* it's this big lump in London and they had an open house for anyone that wanted to turn in off the street, I think 20 people turned up. So in terms of you know freedom of access to headquarters almost nothing is my opinion. But in terms of when you actually look at it in the biggest, widest terms we have a south west regional group, they produce newsletters to us, or whatever it is

V1 suggests that due to a widespread feeling that PUK is just "this big lump in London", members and people with Parkinson's feel unable to engage with or participate in what the headquarters staff are doing. To illustrate this, *V1* describes a situation where the offices were opened to visitors and the opportunity to visit was apparently largely ignored by the membership. For *V1* this seems to indicate a lack of freedom for members and volunteers to access and understand the PUK headquarters. In contrast, *V1* seems much more enthusiastic about the role that the PO volunteers have at the local level. This suggests that, as was the case in research, the role that people with Parkinson's have in the organisation is as volunteers, helping to run and manage regional groups, not necessarily participating in upper-level strategic management. As such, it seems that the organisation is more patient-enacted than patient-led: people with Parkinson's feed into organisational management without having much power to direct it.

In fact, *V2,* having said that the MNDA is very patient-led, putting people with MND "at the centre of all the activities", said:

> *V2:* because it is a small charity, they have to really work hard with volunteers because the voluntary groups, all over the country are where they raise a lot of their funds and those people are closely connected with the people normally who've got Motor Neurone Disease.

Here again the volunteer is given an important position in the management of regional groups. The reason for that role is, firstly that the organisation is very small, requiring a good working relationship with the volunteer-base. This seems to give quite a lot of power to the volunteer, since the implication is that if the charity does not "really work hard with volunteers" they will no longer effectively perform the functions that are important to the organisation. Secondly, *V2* says that the organisation must maintain its relationship with volunteers and members, because they have the closest connection with people with MND. This suggests both that, volunteers have a great deal of influence as intermediaries between the organisation and the membership; but also that without volunteers the organisation would be disconnected from people with MND. It could be inferred that, since it is the

volunteers who have that close connection, the MNDA headquarters is also at times seen as inaccessible to people with MND. This is based on inference, however this assumption is somewhat supported by the discussion above about MNDA governance and Trustees. We have seen that, albeit due to the nature of the condition, people with MND are generally not involved in the strategic governance of either MND organisation. As such it is perhaps not surprising that *V2* would imply that it is the grassroots volunteer-base that connects the organisation to people with MND, rather than the staff themselves.

Perhaps the starkest example of the disconnect that can occur between PO headquarters and people with Parkinson's or MND, arose in the interview with *V11*. As we saw in Chapters 4 and 5, *V11* has a strong sense of disillusionment with the Parkinson's organisations. This was, in part, caused by the fact that she was denied formal employment by both PUK and CPT. Despite feeling very qualified for the jobs, and also indicating that she was already doing the work voluntarily, *V11* was not employed by either organisation. The following extract shows the significant part of the conversation.

> *AG: Why do you think they turned you down?*
>
> *V11*: I think it's 'cause I've got Parkinson's.
>
> *AG: Really?*
>
> *V11*: Liability. People with Parkinson's don't very often, are not always capable of holding down a 9 to 5. I was struggling with the last job that I had… it involved travelling around the country and I'd get very tired so I was made redundant in May because of that kind of liability of not knowing whether I'd be there or not. So I think Parkinson's UK and Cure Parkinson's Trust probably saw that as a threat, not a threat, a weakness. Whereas with them it'd be easier to work from home than for the company that I worked with before. So, I honestly don't know why they turned me down and they never really expanded on it but I'm past worrying about it now.

Quite strikingly, *V11* asserts that she was not employed because both PUK and CPT saw the challenges posed by employing someone with Parkinson's as a threat or weakness. It is important to note here that CPT does in fact employ others with Parkinson's, so that it is not necessarily true that they will never do so. However, *V11*'s motives for feeling this way must also be considered as, although *V11* says "I'm past worrying about it now" she did exhibit throughout the interview a certain amount of anger towards both organisations because of this experience in particular. It is remarkable that someone who has been very engaged with both PUK and CPT would be so suspicious of their attitudes towards people with Parkinson's. To say that they would discriminate against those they claim to support

is quite startling, particularly when looking at a further comment that *V11* made about PUK

> *V11*:although there's a couple of trustees with Parkinson's, if you don't have that day to day contact with somebody with Parkinson's at the charity where you're working and it's all about working on behalf of people with Parkinson's how can you really understand your jobs, you know what I mean?

For *V11*, the lack of employees with Parkinson's results in such a distance from people living with the condition that the organisation becomes largely irrelevant. Somewhat reflecting the representation literature, suggesting that representation requires more than "making present" the views of the represented role (Runciman and Vieira, 2013, Brown, 2006). As *V11* points out, how can an organisation understand its purpose if it has no regular contact with the people it represents? This, it seems to me, relates back to *V1*'s idea that the PUK headquarters consists of an isolated office, managing the organisation but not always relating to members of the wider community. The headquarters might have some contact with Parkinson's through Trustees, volunteers and communications but in general it is still viewed as a separate entity, with different priorities to the rest of the organisation. In fact, *V11* suggested that the refusal to employ her was particularly troubling because the activities she had arranged and managed had become fairly successful and she became aware that she had very little control over what happened to the money raised as a result. This again suggests that although people with Parkinson's might be viewed as useful volunteers to be "integrat[ed]" into the organisation, they might still be afforded very little influence over organisational decisions. Not only does this support the earlier discussion on conflicts within the organisation, but also further suggests that organisational PPI remains as non-influential as that exhibited in research.

This quite effectively summarises the dilemma raised in the literature review, over the extent to which a representative is obliged to listen to constituents. The trustee model requires no contact, however most have accepted that to encourage engagement, representatives must to some degree act upon public opinion(Mansbridge, 2003, Carman, 2010, Ferber et al., 2007). Given that PUK staff frequently talked about the importance of surveying member opinion, it is interesting that V11 perceives contact to be minimal. This then also relates to the issue of perceived fairness. As suggested in the literature, successful engagement requires the perception of fair representation. In this case this appears to have failed.

PO Campaigns: "I just did that for the MNDA"

Another area where organisational PPI plays a part is in PO campaigns, both for research and awareness. Some interviewees suggested that, apart from endorsing research projects that would be relevant to them, the involvement of people with Parkinson's and MND could also be useful to the PO in promoting research to the wider public. For example, when asked about media interest in people with Parkinson's, *E7* described the different effect that someone with experience of the condition can have on public discussions by talking about participating in a research campaign with a former carer

> *E7:* she explained what it meant to her and what it meant to him, which is much more powerful than I could ever do. I could talk about the technical aspects but she could talk about the personal aspect and quite, we have a panel of people who are willing and who we train to act as media spokespeople on various aspects

Involving personal experiences of people with Parkinson's or their relatives is described as useful to recruitment and publicity drives. Thus, PPI can be seen as a campaigning tool for some POs, since the personal stories of PO members can be more effective than technical information given by staff or researchers. Importantly, *E7* states that individuals taking part in such campaigns must first be trained by the organisation. It is also made clear that those involved in this process are present as media spokespeople belonging to the organisation. Consequently, the individual taking part in an apparent PPI activity is not acting solely on behalf of other people affected by the condition. It could be said that *E7* was referring to the organisation's position as an intermediary between people with Parkinson's and the media, however this does imply that PPI here requires the PO as a gate-keeper.

This reflects some of the issues around representation and the ability for PO representatives to speak for people with Parkinson's or MND, raising again the issue of how much influence people with Parkinson's or MND have in the roles they are given. The use of words such as "powerful" might imply that the person concerned is able to exert a considerable amount of influence. However, *E7* describes the power of the patient experience in conjunction with an alternative, professional perspective, bolstering a campaign chosen by the organisation in question. The PPI being described thus appears less influential than the language of power might suggest. Rather than wielding genuine power, it seems that the people involved tend to be included to increase support for campaigns led by experts. The "powerful" patient view is not added because a particular individual feels strongly about a subject and wants to participate, but is picked by the PO.

Therefore, although research campaigns might be an important part of PPI, it seems to be another aspect where the patient role is qualified by the presence and in many cases control of either PO staff or research professionals. The literature suggests that representation, even in cases where public engagement is emphasised, need not entail complete public control. It is possible to conduct representative activities or equal discussions whilst affording some more control than others(Mansbridge, 2003, Bowler et al., 2007, Habermas, 1990). However, it could be said that in the case of POs, so much importance is placed on PPI and patient empowerment, that a lack of influence is more troublesome than it is in political debate. POs as community organisations are arguably expected to be more inclusive than policy debates. Moreover, if the PO member is presenting the organisational perspective alongside their own, and their involvement is monitored by the organisation, the question could be asked: who is the patient and what is the patient perspective that is being represented?

To analyse this question, we can examine a campaign run by PUK. Research by Jane Peek(In Print) showed that regional PUK groups were sent forms in which people with Parkinson's were asked to write a short paragraph on what "a cure would mean to me". This was as part of a promotional campaign to explain why PUK research is so important. At the conference I attended, one of the accounts was included on a promotional leaflet handed out both to members and researchers.

WHAT A CURE MEANS TO PEOPLE LIKE KAREN

Karen was diagnosed with Parkinson's at the age of 39:

"A cure for Parkinson's would mean I wouldn't wake up every morning with upsetting thoughts of what I may not be able to do in the future.

"Then I take my medication, my legs begin to work and I can get out of bed.

"I tell myself 'live for today, yesterday has gone and tomorrow hasn't arrived' and I keep positive.

"I get on with life, make the most of every moment and enjoy all the wonderful things I do have – my husband, children, family, friends, home and holidays.

"Then I think to myself how perfect all this would all be if only they could find a cure for this frustrating condition that is gradually ruling my life.

"A cure for Parkinson's would be my wish come true."

Karen

Although Karen begins by saying that a cure would mean that she would not have to wake-up knowing that she has a degenerative condition, she also seems to imply that she generally remains positive by not thinking about the future. Furthermore, it seems that thinking about the cure might in fact have a detrimental impact on her ability to "live for today" because it makes her consider "how perfect all this would be if only they could find a cure". By focusing on cures Karen is forced to confront a future that she tends to ignore as a coping mechanism. This seems to signify a certain lack of sensitivity on the part of PUK as they are asking people who will never be cured to write about how much a cure would be a "wish come true". The positivity of wishes and future hopes might be good as a campaign tool, emphasising the importance and urgency of the research funded by PUK, but it also creates a situation where members are encouraged to express distant hopes for the purposes of campaigns. People with Parkinson's appear to be encouraged to feel a certain way about research in order to better promote the research department. It is of course understandable that a PO must include its members in its bid for more research support, and the best way to illustrate the cause to prospective researchers is in the words of people with Parkinson's. However, to do so in a way that requires people, perhaps in the later stages of the condition, to express their desperate desire to be cured seems quite exploitative. This illustrates another challenge that POs face, since a well-meaning initiative to involve the voice of patients can so easily be interpreted in a very negative way.

Turning to MND, the MNDA has a high-profile campaign series called the incurable optimist campaign where a series of people with MND promote something they are trying to achieve before they die. In the course of this study this has involved two incurable optimists: Patrick, an artist and Alistair, a musician. The purpose of this campaign is primarily to raise awareness of MND. Importantly the campaigns are promoted as patient-led, built upon the ambitions of people with MND. However, a tweet by Patrick the optimist provides a different perspective on his campaign

The significant part of this is that Patrick was never a portrait painter and that he assumed this identity for the benefit of the campaign. Once his campaign stopped he returned to his own style of work. The campaign implied that Patrick's goal was to paint 100 portraits before he died. He was not able to paint all 100 and is now doing other things, and it seems that it was a MNDA influenced goal rather than the personal aim that the campaign suggested. The fact that the campaign seems to be more manufactured than implied does make it appear sensationalised, particularly when considering the fact that it received awards for creative marketing at the Marketing Excellence awards in London(MND Association, 2011d). It is perhaps to be expected that major campaigns are more constructed than they appear, as there is likely to be a lengthy process of perfecting them as marketing tools before they reach the public domain. However, this example does illustrate the importance of cause to POs, since the impact of the Patrick the Optimist campaign was arguably more important than the accuracy of the goal. Patrick seems to be suggesting that his own experience was secondary to what the campaign needed, and the act of painting portraits had more to do with raising awareness than presenting a real life account of the impact of MND on someone's life.

This section illustrates the importance of PO campaigning to the analysis of the concept of representation, since even patient experience campaigns can occasionally be rather removed from the individual's actual life. This raises questions about the position of POs on the trustee-delegate continuum. It could be said that POs follow the trustee model in some contexts to the extent that campaigns ostensibly based on patient experience are not directly informed by patients themselves. Consequently, seemingly patient-centred PPI

initiatives can be more PO-centred than they appear to be. Some campaigns aimed at representing the patient view, in fact represent the PO goal.

Summary

This chapter has examined the way in which PPI is conceptualised and enacted in MND and Parkinson's research. Interviewees regularly emphasised the importance of patient input into research decisions, and acknowledged the particular benefits of including the patient perspective, particularly in relation to establishing new research directions and inspiring particular projects. However, many also seemed to suggest that the majority of people with MND and Parkinson's would be unable to fully participate in the PO's research agenda. This 'inability' was attributed to either a perceived lack of understanding of and/or expertise in scientific and research procedures, or to the physical and cognitive effects of the conditions themselves.

Several interviewees articulated a tension between the ethical requirement to embrace PPI and the strategic needs of the organisation. This conflict was usually resolved by limiting the influence of the patient body and making it subject to the scrutiny of other stakeholders. So for example, when invited to review grant proposals lay members were left in little doubt that their conclusions might be trumped by those of the scientific experts. Some interviewees were even more limiting of the scope of PPI essentially arguing that the most important thing was to gain the support (rather than active input) of patients and members for a PO-determined research agenda. This constraining approach was usually accompanied by claims that the views of the lay members were 'scientifically unsound' and therefore unreliable.

As suggested in the literature, the 'patient-centredness' that the POs were so anxious to own when describing how they 'do the day job' (see Chapter 5) does not always translate into a substantive commitment to incorporating the 'patient view' in relation to research. Furthermore, we have seen here that some PO campaigns have perhaps inevitably become more related to image than to genuine patient experience. Therefore, this chapter further illustrates the difficulty in defining representation in the context of the PO-member relationship. This is because even in ostensibly delegate-like activities such as promoting the patient voice or experience, the PO can appear to be more a trustee – choosing the experience and story that is promoted in order to meet a wider purpose. Likewise, several interviewees indicated a conflict of interest, when attempting to balance the commitment to

PPI and the need to remain scientifically respected. It would appear that the POs sometimes felt forced to contain the role and influence of patients in the research process.

Instead of being seen as central to the process of designing, conducting and disseminating research the patient members were more readily given the tasks of fundraising for research, participating in trials, completing surveys and allowing their stories to be told in order to draw attention to patient need or to advertise research progress. Their support was gratefully received, but there was an innate scepticism about the extent to which support could or should expand into involvement without compromising the quality and progress of research.

Given that this is the case, the POs are left in the difficult position of presenting their research activity as being in tune with their patient-centred aspirations whilst ensuring their commitment to the concept of PPI does not jeopardise their relationship with researchers who are generally much more sceptical about the PPI agenda. How this unfolds in practice is explored in the following chapter, where I will examine more closely the PO-researcher relationship and the way in which it shapes and is shaped by the organisation's ethos and identity.

CHAPTER 7
The research agenda

As the literature review and my own data suggest, research is increasingly accepted as an important function of the modern PO. As detailed in the Introduction, each of the organisations at the centre of this study, to varying degrees, are involved in research from small scale funding to broader project management. As others have noted, in seeking a significant role in research, POs can face a number of challenges and potential difficulties. One of these being a loss of independence as they become more, and potentially too dependent on the support and priorities of other research organisations(Cardy, 1993, Panofsky, 2011). Indeed, Panofsky(2011) suggests that failing to maintain independent research aims can limit the influence that POs can have over researchers and the research process. Furthermore, the previous chapter illustrates that there can be a difference between the research goals that POs promote and what they are able to achieve. This chapter will thus explore the way in which PO staff and members conceptualise their organisation's position in research interactions, and how the issue of maintaining independence and thereby their ability to represent their memberships' interests was discussed. Beginning with a discussion about the way in which PO staff and members described the PO role as research managers, facilitators and ethical governors, the chapter will then describe the POs' approach to research funding. Finally, the chapter will explore the way in which professionals described the POs with whom they have collaborated. This is to investigate how POs represent patients by influencing the research agenda.

Managing Research: "we're pretty fundamental to research"

Echoing strands within the literature(Panofsky, 2011, Rabeharisoa, 2003, Allsop et al., 2004), a common concept raised within interviews was that the PO role is essentially managerial. Several participants described their organisation as 'crucial' in managing and overseeing research:

> *E9*: [CPT is a] small to medium-sized charity which is blazing the trail toward a cure we're, we are doing everything in our power to not only find the science but also deliver the science into the clinic and to create impact in Parkinson's

E9 emphatically describes CPT's aim to find a cure as leading the organisation to not only inspire and conduct research but also to bring "the science" to fruition in terms of results and clinical application. He sees the organisation as taking a strategic management role,

overseeing all aspects of research. Furthermore, the term "blazing the trail" could suggest that this kind of PO-managed research would not take place without CPT and would certainly not go in the direction they have determined.

Likewise, in MND research, the role of POs is seen as crucial to research taking place and succeeding at a global not just local level

> *E4:* I think we're pretty fundamental to research both nationally and internationally… We do a lot of influencing and partnership work to try and get others to invest

E4 sees the role of the MND PO as managing the research process to the degree that it is also responsible for the involvement of other parties. In fact, *E4* later extended his account of the PO's managerial responsibility to include legislative impact. *E4* described the role of his PO as ranging from the identification of a gap in knowledge about MND, the funding of research to fill that gap and then lobbying and campaigning to bring about legislative change as a result. Thus the role of the PO is extended beyond one of campaigning and/or funding of research on a particular area to include overseeing the research itself and then directing the application of resulting knowledge.

That being said, later in the interview *E4* withdrew from this position and suggested that research management should be seen as more of a supervisory role

> *E4:* so we don't get involved operationally but we just keep an eye on how [it] is going, is it fulfilling its objectives, most importantly you know is it collecting brains, is the tissue being used and is the, are [other groups] able to access that tissue, is it being advertised well enough and how can the patient associations help in promoting the [project] to all communities, you know to the public… So we don't directly get involved

E4 stipulates that the role of the organisation in this project is not 'operational' but does suggest that it is pivotal in overseeing its progress. He describes the role as ensuring that people with MND and the public know about the project, that it fulfils its potential and that plans are followed. In fact, interviewees frequently suggested that the PO has a role in ensuring that researchers complete the work that they have pledged to do. As such, the research management role has also become one of governance and several interviewees appeared to share *E9's* view that research would not be conducted properly without the presence of the PO as manager.

However, *E4* seems to dismiss what appears to be extensive engagement in a research project as 'not direct'. This seemed to be because the organisation does not provide direct funding for it. This illustrates the difficulty that some PO employees had in defining the nature of the PO role in research. Despite the tendency to emphasise the important impact that PO's can have, some employees nevertheless acknowledged that they were not as involved as might be assumed. Some seem to characterise PO influence primarily in terms of funding. As a result, the managerial role, which arguably affords the PO considerable power, is not seen as influential. Thus, 'operational' and 'direct' involvement is thought to entail provision of extensive funding for the research.

PO as a vital facilitator: "somebody has got to do it"

Some interviewees preferred to describe their organisation as responsible for 'facilitating' research. POs were described as vital in bringing professionals together with people with MND or Parkinson's, as well as coordinating meetings and collaborations between different researchers. This was partly because POs were seen as uniquely able to understand the needs of all interested parties and/or stakeholders:

> *E3:* Very much as a facilitator as well as a funder. Our head of research has done a phenomenal job on mapping the state of Parkinson's research and looking at the most promising areas and helping to bring those to prominence so we do that in a number of ways by hosting international research meetings… and I think for the first time the world experts in this area will come together and I think that's hugely important

E3 not only viewed the facilitation role as integral to the organisation's function in research but also as important in instigating "the first time" that Parkinson's "world experts" coordinated their research ideas and efforts. Although this does reflect the tendency described previously of CPT staff to over-emphasise their own influence, it could also explain why POs might perceive research as their responsibility. PO involvement is seen as the *only* means by which researchers can collaborate.

V4 echoed this view when discussing MND research, saying that although researchers will communicate with each other, the PO must act as a broker to ensure barriers to true collaboration can be overcome

> *V4:* you've got to facilitate bringing people together… academia and research is quite competitive, so you have got that bit of you know one lab is, really would rather like to get to, you know find out the answers before somebody else. So it's sort of breaking down those barriers to say actually you can all get something out of this and we're going to achieve more if we do it together. So it's brokering really I suppose.

Similarly, *E6,* when discussing working with different MND research centres, spoke of this facilitating role as a process of harmonising data. This view of the PO as a facilitator was also expressed by researchers

> *P1:* I think that's where the charities could actually play a bigger role as well, is actually bringing people together more

Despite generally describing his experience of PO involvement in research as occasionally frustratingly focussed on collaboration and constant contact, *P1* nevertheless highlights "bringing people together" as a role that they could focus on more.

Echoing the discussion of research management, some suggested that if POs did not facilitate research, nobody would.

> *V5:* Yes somebody has got to do it and somebody has got to lead it and be in charge of it and know what's going on… if Parkinson's UK weren't doing it, it just, it's almost passing the buck to someone else, to someone else. So you could say oh government should be doing it or this hospital should be doing it but Parkinson's UK need to be there to push for that money going into Parkinson's

V5 directly links PO research facilitation to a sense of responsibility by describing the hypothetical situation where PUK does not engage with research as "passing the buck". This suggests that, for *V5*, PUK has a particular duty to lead research and that not to do so would be irresponsible.

Professionals tended to link PO responsibility to the idea that POs might be the only source of research funding. For example, *P4* explained why POs are "absolutely crucial"

> *P4:* I think, there is a strong bias clearly in commercial research but also with a lot of kind of strategic research decisions made by the research boards is to go with the very very big diseases. In neurology it would be stroke, epilepsy, Alzheimer, Parkinson's. The smaller diseases are very likely to be left outside, and that's where I think that, particularly in this respect, the role of such funding bodies is absolutely enormous. It's not only funding, it's also raising awareness

Remarkably, *P4* believed that Parkinson's attracts more attention than MND. Whilst that may be true, it must be acknowledged that the responsibility of POs to not "pass the buck" was felt just as keenly in interviews with people from Parkinson's POs. In any case, this quote illustrates the view that because research into conditions like Parkinson's and MND are unlikely to be lucrative enough to attract the pharmaceutical industry, the responsibility to continue research into novel treatments falls to POs. This implies that POs are expected to follow their duty to engage in research to the extent that they overlook financial risk. Although industry interest is lessened by the lack of financial income that MND and Parkinson's research is likely to bring, POs are expected almost by default to fund or lead research irrespective of commercial success. This therefore suggests that responsibility in this case is often related to a sense of obligation. This further implies that PO engagement in research will be more informed by ethical principle than is the case in industry research circles.

Ethical Governance: "We had the kind of moral impetus"

The previous sections of this chapter illustrate the tendency of PO staff to present their involvement as 'essential' to ensuring research progress. The literature exploring partnership-building between patients and "professionals" shows that POs, in their role as patient advocates, assume a responsibility to ensure that such relationships are created and enacted with an aim to empowering patients(Pinching et al., 2000, Panofsky, 2011, Cardy, 1993, Rabeharisoa and Callon, 2002, Epstein, 1995). However, these relationships once created also need to be governed and again the POs see a role for themselves here.

The literature suggests that research professionals often see the benefit of involving the patient view in research as ensuring ethical practice(Dresser, 2001, Corrigan and Tutton, 2006, Goodare and Lockwood, 1999). In fact, several interviewees spoke of the POs' responsibility to engage in research in order to protect their members. This is perhaps not surprising given the suspicions raised above that researchers will focus on competition, and industry leaders on financial success. However, the idea that POs must protect people with

MND and Parkinson's from disreputable researchers was also occasionally raised by research professionals themselves

> *P3:* they're also there to protect patients against charlatans that might want to put stem cells into them or try radical things.

P3 suggests that POs have a responsibility to prevent their members from being harmed by researchers engaging in more radical experimental trials. This type of protection was expressed in terms of protecting members from both physical and emotional harm. Many mentioned the harm associated with the potential consequences of research and the disappointment of failure.

Managing perceptions and expectations of research was also a common concern. When asked if Parkinson's POs should promote or discuss research on their websites, *V11* said that this was an important part of the organisations' role because it helped to make research participation seem less daunting. Saying PO information "takes away the scariness of it all", *V11* suggest that POs have a particular responsibility to protect members from fears cultivated by horror stories reported by the media.

The duty of protection was also described in terms of carefully respecting the wishes of those who had decided to participate

> *E6:* I've realised how important it is… ensuring that you're meeting the wishes of the people who gave the samples in the first place

Here, the POs' duty to engage in research was related to ensuring that the tissue samples that members have donated are used appropriately and reflect the wishes and motivations that inspired the donation. Therefore, the idea that POs must be involved in research in order to protect people with MND and Parkinson's seems to take two rather different forms. First, the duty to protect has been described as a very traditional paternalistic responsibility. POs are expected to protect members from both physical and emotional harm that could be caused by both irresponsible researchers and inaccurate scientific information. Second, protection seems also to be seen as a form of advocacy. POs have a duty to guard the wishes and needs of members, by ensuring that researchers use their tissue samples correctly. Therefore, as was the case in discussions about the responsibility to facilitate collaborative research, the responsibility to protect people with MND and

Parkinson's was often described in very ethical terms. Reflecting the literature(Dresser, 2001, Corrigan and Tutton, 2006, Goodare and Lockwood, 1999), and the discussion on PPI, many suggested that POs were best placed to conduct and oversee research in an ethical way.

> *E6:* The DNA bank was chosen [by MNDA] because it was felt that if the Association did it, then we had the kind of moral impetus to actually encourage the researchers to work together to establish the bank, so it would be Joe Bloggs' at King's particular project, or Sally Smith's Somewhere-Else-Association is custodian, so we could arbitrate any discussions about who should get the samples

E6 implies that one of the biggest projects with which the MNDA is involved was chosen out of a perceived moral responsibility to ensure that it fosters good research. Moreover, it is suggested that the Association is more able to act ethically than researchers. This, therefore, illustrates the fairly commonly expressed view that POs have a responsibility to ensure that researchers act in an ethical way.

This innate "moral impetus" was in fact occasionally raised as something that could and should be used to lend research an air of credibility

> *E9:* everything about Parkinson's treatments is about credibility and I think if there's two words that I would like to see CPT get involved in its prioritising, prioritising the right, the best treatments, and creating credibility for the treatments that haven't quite got the funding

E9 suggested that CPT uses its position as a PO to give unfunded treatments and trials the credibility they need. *E9* implies that part of the PO's ethical responsibility in research is to use their reputation to bolster support for under-funded projects. This is interesting as the use of PO ethical credibility in this way has been widely criticised in the literature(Callon and Rabeharisoa, 2003, Panofsky, 2011, Dresser, 2001, Langstrup, 2010, Mintzes, 2007, Radin, 2006). Specifically, it has been suggested that POs that engage in research partnerships with traditionally less 'moral' organisations, in the pharmaceutical industry for example, can earn a reputation amongst peers for having an unethical approach to research. This is precisely because PO members and other charities will assume that the PO in question is merely being used to boost the ethical profile of the researcher rather than genuinely influencing their research practices. Crucially, the literature suggests that because of this, POs will often shy away from involvement with less ethically credible organisations or projects(Lofgren, 2004, Baggott et al., 2005). *E9* appears to directly

contradict this assumption, claiming instead that boosting support for research is part of the PO's responsibility.

That being said, the literature also specifies that the danger of a perceived imbalanced relationship with the industry is that it can damage a PO's relationship with members. This is because of the common assumption that industry partnerships can lead POs to sacrifice their supportive, patient representational role(Allsop et al., 2004, Epstein, 1995). CPT staff clearly identify their organisation as not membership-led, using words such as "supporter" rather than "member". Furthermore, it does not promote itself as a support organisation. The sole purpose of CPT is to engage in research and to gain support from people with Parkinson's and the public for its research agenda. As such, CPT may be less affected by the potential negative connotations of a relationship with certain researchers, because it does not have a support agenda to sacrifice or membership-base to disappoint. Therefore, CPT might be more able to use the ethical credibility attached to POs in a way that is traditionally discouraged or criticised.

Nevertheless, this illustrates the complexity of the relationship between POs and their research associates. Although some might describe the relationship as centring on the PO responsibility to ensure ethical practice on the part of the researcher, others might view it as a means to allow researchers to benefit from the moral reputation of the charity sector.

Approaches to Research Funding: "Investing in people"

As Panofsky(2011) suggests, POs can rarely fund complete large-scale projects, to the extent that other research organisations can. This means that POs must make potentially difficult decisions as to what can realistically be achieved with their relatively limited funds.

Looking at the way in which they approach research funding decisions provides an interesting comparison between the POs. Several interviewees suggested that funding is the principal part of the research process in which POs can engage. However, it was often described as a domain in which the PO would never fully achieve its ambitions. For example, talking about CPT, *E3* said:

> *E3:* We don't raise enough money to take something all the way through a phase three trial, it's too big, it's too much, we wouldn't want to, but if we can prove the concept of something and prove that it is a valid area of research then that opens it up for everybody else and that's very much our job as a facilitator to, to turn the stones over get the debate happening and move things forward in that way

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This seems to contradict *E9's* suggestion (quoted above) that CPT was responsible for managing the entire research process through to clinical application. In fact, *E9* himself also implied that CPT would never be able to fund an entire project. This illustrates again the tendency I often observed for CPT employees to overstate the organisation's capabilities. CPT employees describe the financial limitations to the organisation's research funding involvement whilst simultaneously emphasising the importance of CPT in ensuring that the right research areas receive funding and attention. One possibility is that CPT tends to view its role both in funding and management as inspiring others to take up the projects it promotes. However, this raises some questions as to the issue of representativeness. CPT media communications frequently claim a ground-breaking role in furthering the search for a cure for Parkinson's, yet as *E3* suggests they are unable to engage in the clinical trial phases of the research process. That being the case, there seems to be a significant gap between the ambitions promoted by the organisation to its supporters and the actual research it funds and promotes.

For example, *E9* suggested that the expense of a full clinical trial can be avoided by funding pilot studies in to several compounds at once. In claiming to be "trail blazers" in Parkinson's research, CPT is actually engaged in funding several projects that at best rely on the continued funding of another organisation and at worst fail to prompt further research to expand upon pilot results. In both cases, the role of CPT is rather minor, since it relies heavily on the interests and priorities of other organisations.

When CPT's research agenda is ruthlessly unpacked, it would appear that they must either conduct pilot studies specifically targeted to an area of research that others might continue to fund in the future, or they must attempt to persuade others to carry on research that they cannot afford to do. As such, the role CPT promotes to supporters appears to be rather different to what the organisation achieves in reality. The CPT role in the process relies very heavily on the choices of others, suggesting an imbalance in power in research decisions.

Therefore, limitations placed on research involvement by considerations of cost has sometimes led the POs, and CPT in particular, to look for different models of research engagement. It is perhaps not surprising that a smaller charity would not be able to fund a full clinical trial. However, the CPT approach to circumventing financial barriers is quite different to other organisations of equivalent size. For example, *E4* from an MND

organisation suggests his PO overcomes the issue of a lack of resources by funding trials of new applications of already licensed drugs

> *E4:* if it's a drug that has, isn't licensed for anything else then it's going to be expensive and it's likely usually going to be beyond the funding scope of the [organisation]. That said you know we have run a, we are running a clinical drug trial at the moment but it's of a drug that's already licensed for another condition and has been licensed for forty years so we know what the potential side effects of the drug are.

Because they have limited resources, POs are forced to conduct a cost-benefit analysis when defining the areas of research they want to pursue. In contrast to CPT, rather than putting their money into partly funding a very large and expensive study, where their individual influence will be limited, POs might choose smaller, very specific areas of study where they can have a bigger influence.

> *E8:* in the past what we have done is, we have provided some funding for research fellows, so where there's been a specific area, we would provide funding for that and try and develop the research in that area.

Thus, POs to a certain extent have to choose between the influence that their organisation can have, in leading the research agenda or supporting and contributing to already established projects or research areas.

Comparing this statement with that of *E3*, suggests a difference in the approaches of CPT and the MND POs. Whilst MND POs tend to view their role as cultivating research areas and furthering research through funding specific individuals or established projects, CPT seems more ideas-based in its approach. That is to say that, CPT, rather than providing funding for established research areas tends to fund the initial stages where ideas are developed in the hope that another organisation will then fund the development of that idea.

This attraction to a 'pump priming' style model is perhaps explained by the fact that, by their very nature, CPT employees are much more focused on cures and treatments and as such might be less motivated to fund speculative basic science or broad research fellowships. It might also point to a greater drive amongst CPT staff for a high profile organisational influence over research. Being able to advertise involvement in clinical trials (however limited) would seem to give a more substantial impression of a dynamic organisation involved in finding a cure. Although all the organisations arguably fulfil the

same role in terms of idea production, the fact that CPT is able to align itself with the clinical trial process, means that it is more able to adopt the "trail-blazer" label.

In contrast, both MND POs appear to take a more quietly influential role, participating in very upstream knowledge production processes, hoping to influence long-term research interests rather than produce immediate results. This is particularly interesting given the even more urgent need to work towards providing effective treatments for their membership.

> *E2:* we have put aside £600,000 for several PHD studentships over the last couple of years so we've funded I think in total 5 or 6 PhDs… it's a kind of a theoretical concept in as much as there are a number of departments within Edinburgh University where people were carrying out research that was relevant to MND in a vague way, it wasn't MND research per se.

The rationale given for this approach is the hope that in funding early career researchers, POs will cultivate a group of researchers with a particular interest in MND. Indeed, both MNDA and MNDS seem to view research funding in many ways in terms of the wider future impact that researchers will make in their field. As such they are attempting to shape research culture and build capacity. By creating the interest in MND early on, they hope to embed researchers in the MND cause so that all of their future work might benefit people with MND, whether it is funded by the PO or not.

> *E8:* And the idea behind that was, although we have a relatively small pot… what we wanted to do was to try and encourage new researchers, erm, to have an interest in the area so that in the future, we'd have a core group of people who have experience of doing research in this particular area, who have an awareness of what the condition is and can take things forward

This approach initially appears more modest than that of CPT, however by engaging in base-level knowledge-production in order to generate long-term research commitment their impact might be greater over time. *E4* described the strategy in the following terms

> *E4:* Another part of the strategy is investing in people because I'm a great believer that the research is only as good as the people doing it so how do we get the brightest and the best working on our disease?.. Hopefully in five years' time, ten years' time we're going to see a conveyor belt of interesting compounds coming out of the lab to be tested in the clinic. We need to have the centres that are able to perform world class clinical research so that we can really hit the ground running when we've got these compounds to test.

In this sense, MNDA and MNDS are creating an 'ideal researcher' for other organisations to adopt, rather than an ideal drug or compound.

This idea of back-grounding work was also taken in a slightly different direction by *E4,* asserting that it is not the PO's job to create the idea, but rather to cultivate ideas that "experts" have proposed and that fit the framework and funding capabilities of the organisation:

> *E4:* So you know we're saying we're not the experts here, you guys are, here's the framework, our research strategy, the big questions that we want to address… you send us the ideas and we'll review them, separate the wheat from the chaff and fund the best.

The PO role here is therefore to recognise "the best" ideas and bring them to fruition. This then links back to the idea that the PO role is to manage and/or facilitate research as well as researchers.

That being said, *E4* also seems to suggest that the organisation is simultaneously not expert enough to conduct research independently, but is able to determine which projects are better than others. Furthermore, both the CPT and MND PO approaches rely on the input and acceptance of researchers. CPT needs researchers to accept their ideas, whereas the MND POs need researchers to maintain interest. Therefore, the question remains as to what kind of relationship these POs have with their research associates. Although they might be described as pivotal to the funding and facilitation of research, the PO approach to project funding is significantly dependent on the type of researchers with whom they choose to collaborate.

PO-Researcher Relationships

As the above shows, discussions about PO involvement in science often focussed on the responsibilities attached to the PO-researcher relationship. Furthermore, it seems that POs are given a particular responsibility to foster collaborative work between research professionals. In this section, I will explore in more detail the relationship between POs and the researchers they fund. This is to examine how the influence that POs claim over the research process is reflected in their relationship with research associates.

When discussing the research agenda, communication between POs and scientists can be presented as a dialogue between experts (the scientists) and lay people (the PO staff and

members). As others have noted, tensions can often arise in meetings and interactions between "experts" and "laypeople"(Rabeharisoa, 2003, Panofsky, 2011, Terry and Boyd, 2001, Smits and Boon, 2008). In this context, this could be because such interactions are perceived to involve PO appropriation of power from scientific experts(Panofsky, 2011, Erde, 2008). In particular, the literature tends to characterise interactions between POs or lay groups and scientific professionals as affording very little influence and power to the PO. This is because PO influence in research is thought to depend upon both existing power structures and the willingness of "experts" to devolve more power to lay populations(Panofsky, 2011, Rabeharisoa and Callon, 2002, Weiner, 2008, Martin, 2008). As a result, some POs have been observed to "professionalise" their activities or adopt scientific norms and realities(Terry and Boyd, 2001, Van De Bovenkamp et al., 2009).

Indeed, Chapter 6 showed that in the case of PPI, POs can feel obliged to follow scientific rather than member opinion so as not to appear unprofessional to their associates. As a result, they can find themselves attempting to represent the interests of both members and researchers when attempting to influence the research agenda. Therefore, it is important to consider the way in which the PO-researcher relationship was described by participants in the present study.

PO views on Researchers: "Don't bother coming, just give me the money"

As was suggested by Panofsky's(2011) concept of sociability, a principal role ascribed to POs in collaborating with researchers, is to ground them and their work in the reality of people living with the condition. Some interviewees suggested that POs need to acknowledge that scientists are unaware of the challenges faced by people living with the condition and consequently lack understanding of the wider purpose of research and what it means for people with MND and Parkinson's

> *E7:* they get a much better idea of what the research actually means in other words that they realise that it maybe 10, 20, 50 years' time down the line at least "I know it may help somebody with Parkinson's and I've met somebody with Parkinson's" and it's the same for other conditions as well. If you understand the context of your research it helps you to put a slightly different perspective on it.

E7 makes the assumption that the researcher will never have met someone with Parkinson's before and will not make the connection between the research project and the

impact it could have on the lives of people affected by it. This view was shared by *V4* when talking about MND research:

> *V4:* there were all these neuroscientists beavering away in the lab who'd never met anybody with MND and… so it was bringing the real face of the disease to the people who are were in the lab and who never see it.

V4 specifically suggested that the PO role is to ground researchers in the reality of MND as a condition. Without the PO-organised meetings between neuroscientists and people with MND, *V4* believed there would be a complete separation between the research and "the real face" of MND. She therefore mirrors assumptions made in the literature about the inability, or unwillingness, of scientists to engage with patient perspectives(Martin, 2008, Van De Bovenkamp et al., 2009, Weiner, 2008, Diamond et al., 2003, Beresford, 2002). Similarly, *E9* discussed the fact that scientists will not necessarily understand the patient experience and that they need this understanding in order to conduct their research properly

> *E9:* scientists you know, tend to be looking at test tubes and, and they are not necessarily all that focused on actually what their job is. So that when they're looking at the cure for Parkinson's they're not thinking about the people so it's important to engage scientists in real life in what living with Parkinson's is like

E9 extends the idea of a separation between scientific research and the reality faced by people with Parkinson's to suggest that researchers do not understand the purpose of their work. Furthermore, *E9* seems to believe that researchers will generally not consider the real impact a cure would have, or the symptoms it aims to resolve, as they would be too preoccupied with the science itself. As such, the assumption is again made that POs are the only means by which researchers can "engage…in real life". In fact, others suggested that an innate ignorance of the Parkinson's experience could prevent researchers from working effectively

> *V11:* Yeah, yeah, definitely more collaboration needed between the professional community as well as the public community because they need, the professionals need to learn about symptoms and about how it is to live with Parkinson's before they can deal with it.

V11 suggests that without learning about the patient experience from direct contact with people with Parkinson's, "professionals" will be unable to conduct the necessary research. This is in some ways similar to the PO role raised above in ensuring ethical conduct and good research. However, here the role is extended to mean that POs must engage researchers with the Parkinson's or MND perspective, because researchers do not have the understanding or moral credibility to otherwise carry out research to the required standard. This not only reinforces the idea that POs have a responsibility in the ethical governance of research, but also echoes the debate around PPI. Here again we see the idea that patient engagement with researchers is essential to ensure that research is conducted properly and in a patient-centred way.

As well as describing them as broadly ignorant of the Parkinson's and MND experience, several PO employees suggested that researchers will tend not to want POs to have much input or influence in research, beyond initial funding.

> *E7:* Sometimes researchers can be a bit sort of, you know, erm stand offish and "I'll work in my lab doing my thing and don't bother coming, just give me the money"

E7 suggests that in a partnership, POs may not be able to exert the influence that they wish to, because researchers will not allow it. The way in which this idea is raised also implies that this imbalance of influence is related to the impulse amongst researchers to just 'do their thing', rather than grounding their work in the reality faced by people with the condition. As such, some PO employees also seem to see researchers as generally anti-collaborative. After saying that "Academic research is built on competition, not collaboration", *E4* said

> *E4:* it's the same with collaborating for funding but you know funders can push that to a certain extent because we can you know say we'll only fund joined up collaborative projects. So it's a, I'd say over the past decade or so it's been a process of evolution rather than revolution… So it certainly is improving within the research community. But I think the automatic reaction often is just to try and plough your own furrow

E4 suggests that researchers will tend to shy away from collaboration, and that "funders" will only be able to counter this impulse to a certain extent. He therefore seems to believe, like *E7*, that POs, as funders, will not always have enough influence over their research

associates to change scientific procedure. Furthermore, *E4* points to the view that researchers will not understand the need for a collaborative common cause to help people living with the condition. *E4* further illustrated this point by describing instances where calls for collaborative projects were met with very few appropriate grant applications

> *E4:* we were looking for some large-scale joined-up thinking, unfortunately it actually caused just a bit of a free for all and everybody bunged in their project grants, added a zero, called it a programme grant and we didn't fund nearly as much as we'd have hoped simply because you know everybody just kind of did a knee jerk "right I'll try and get this money myself."

E4 suggests that the call for collaborative research will lead to researchers pooling ideas to access the funding, without properly considering the aim of the research itself. As such, POs view their role as almost having to force researchers to be genuinely collaborative. Moreover, researchers are painted in a rather negative light, aiming to access funding rather than genuinely furthering research.

One method for enforcing collaborative research is making results sharing and open access publishing a condition of PO funding.

> *E6:* the open access publishing, it's a, we haven't really tested it yet, it's so new that we haven't like fully implemented it yet. With the sharing of the samples, in principal they're all happy to do it but when it comes to the crunch, they're a little precious about their samples and data…Perhaps being a little unfair, an element that might be there is the fact that they want the competitive advantage

Again, the researcher is characterised as somewhat unprincipled and "precious" when it comes to conducting research. Despite perhaps understanding in principle, the researcher is expected not to cooperate in research to further a cause that has a wider purpose than their own career. The PO thus develops ways to force researchers to go against their competitive instincts. Therefore, on the part of the PO, there seems to be a considerable mistrust of the integrity and motivation of researchers in accessing PO funding. Despite emphasising their influential role as research managers, some PO employees seem to suggest that not only will researchers try to circumvent collaborative procedures but that they may also reject PO influence.

Researcher views on PO: "[They] like to stamp their own way on doing things"

In fact, researcher opinions on the organisations and their staff also suggested a certain degree of mistrust or at least a lack of mutual respect. Whilst PO staff often viewed researchers as inexperienced in terms of understanding the impact of MND and Parkinson's on the individual; researchers tended to suggest that POs were inexperienced, owing to a general lack of understanding of scientific procedure

To look at this kind of opinion more closely, I will use quotes from the interview with *P1*. This is because *P1* more than any other interviewee paid a great deal of attention to the extent to which PO engagement in research was appropriate.

This first quote concerns the promotional materials used by one of the Parkinson's POs.

> *P1:* Well, you know, looking at that leaflet and the chap on the front was an ethnic minority and, you know, it was our opinion and indeed it was their agreement in the end that they were picturing this person on the front rather than an actual member [of my team] just because they want to increase their awareness that people from an ethnic background actually do research… Rather than having a leaflet which truly represents somebody from [here]

Here, the PO is characterised as driven by appearances rather than true representation of the scientific project in question. This raises a further issue in defining representation in this context, since the researcher views the role of POs as representing the research. This is in contrast to the general assumption that the PO is involved in research in order to represent the patient in interactions with researchers.

Furthermore, in describing the apparent on-going issue with the way in which the PO manages publicity for this research project, *P1* seems to suggest that the PO has an unprofessional and unresponsive approach to dealing with researcher complaints. It seems the response to complaints about that particular leaflet was "'we're the best at marketing, we know everything'".

In fact, this implicit lack of professionalism underlies many views that *P1* expressed about the organisations with which he has worked.

> *P1:* I had contact with them in the early stages and certainly the first money that I had from them there was no real proper application process that you would normally associate with a funding charity, it had no terms and conditions for its grants that it gave out which held everything up for quite a period of time because they had to basically write terms and conditions. And also their ambitions have not matched the amount of money that they have so they were coming round and talking to people and getting them to submit projects, yes you've got wonderfully rated in the reviews but the charity had to turn around and say "well we haven't got enough money at the moment."

This suggests that *P1* in general views POs as rather unprofessional and perhaps even incapable of engaging in research properly. Here, the issue of funding constraints is discussed, as a sign of how unrealistic POs can be in constructing their research aims. This view of POs as too unprofessional to engage in research was also raised by *P3* who suggested that POs shouldn't be involved in research at all, and should focus entirely on advocacy and support.

As well as conforming to the characterisation in the literature of researcher attitudes(Allsop et al., 2004), assuming that POs will not be professional enough in scientific interactions, *P1* suggested that researchers will be reluctant to relinquish power.

> *P1:* I think they've employed you, they've given you the money because you're the experts and rather than, you know, letting you run the [project] because you're the expert in the field, I think some of the people in the society basically like to stamp their own way on doing things which aren't necessarily correct in a scientific environment.

Here again, the reason why *P1* believes POs should not be too involved is that they are deemed to have less scientific experience and understanding, and consequently are unable to exert appropriate influence. Somewhat confirming *E7*'s view, that researchers will prefer POs to limit their involvement to the funding stages of research, *P1* suggests that as "the expert" he should be able to manage the research alone.

P1 again raised this view of PO engagement when comparing the more hands on approach of some POs with the more withdrawn approach of others

> *P1:* you've done all the hard work, you've got the reputation, what you want to do is devote 100% of your time to actually making sure what you've put in the grant application you actually do, but if you've got somebody who is coming and checking on you every now and again, they want to bring people in to see how you're doing, you know, on a regular basis they want more reports, more reports all the time you're not actually devoting, you know, 100% of your time to doing what you said you were going to be doing

P1 views the more involved approach of some POs as more cumbersome precisely because of the wish to bring researchers into contact with people with the condition. Therefore, whereas POs might believe that they have a duty to ground researchers in the moral reality of their cause, some researchers view this kind of contact or visit as a burdensome distraction from the scientific goal. As such, the way in which POs view their role in this partnership is in direct opposition to the way in which this researcher at least expects them to act. Moreover, this illustrates the reluctance of some researchers to accept PPI, since the input of patients is described as an unnecessary distraction.

One reason for this disconnect between PO and researcher attitudes might be the different way in which people with Parkinson's themselves are characterised.

> *P1:* Quite strangely people with Parkinson's are actually quite proactive and they're tremendously knowledgeable. They search the internet, and erm, you know, they are quite keen to support research whereas you can go into some disease sectors, you know I've got a research nurse at the moment… and she was saying in the Alzheimer's field that she was previously in she had a real job of actually convincing people to go into clinical trials.

Echoing the discussion of lay and expert identity in Chapter 4, *P1* appears to be very surprised that people with Parkinson's are even interested in research let alone "knowledgeable" about it. This could explain why he seems so reluctant to entertain PO-led meetings with members, since the expectation is that people with Parkinson's 'will not understand'. As such, the characterisation of the organisation as unable to engage appropriately with the researcher has been extended to apply to the members as well. This highlights the attitude that some researchers can retain, concerning the (lack of) professionalism and expertise of people with Parkinson's, despite working closely with a PO.

The views of *P1* illustrate the difficulty for POs to gain genuine influence in research. Although the organisation might provide extensive funding, it is still possible for the researcher to view patient-led research in rather derisive terms, even ridiculing certain aspects of PO procedure. Furthermore, the fact that a major factor in *P1*'s objections to PO influence was the continued enforced contact with people living with the condition raises certain questions as to the representativeness of PO research activities. Staff and volunteers tended to view the maintenance of contact with patients as a significant aspect of the PO's role in research, principally because it serves to ground research in the reality of the condition and thus counter the tendency in research to ignore the patient perspective. The fact that this was described so negatively by *P1* suggests that POs can be less than successful at promoting the importance of the patient perspective to the researchers they fund.

That being said, some researchers were quite open to PO influence and control. In contrast to the anti-PO assumptions made both in the literature and by some PO staff at interview, *P4* said

> *P4:* that makes work much much easier because as I say, if there is something that is good, they will give me a feedback and, say, "Oh, you know, I heard that it was good", if there is something that they are not very happy, they will tell me as well so, you know, we can adjust it… that's a necessary way, if you want to improve something

Beyond being open to PO influence, *P4* sees it as necessary for good research. It seems that *P4* is very willing to accept feedback from POs and even to adjust research procedures accordingly. Therefore, in contrast to *P1, P4* suggests that the particular benefit of working with a PO is the fact that a personal relationship can be developed. As such, *P4* seems to reflect the ideas raised by Panofsky(2011) where the collaboration is built on sociability, and maintained through continued connection with the personal perspective of people with MND and their families. This therefore illustrates that, contrary to what is widely suggested in the literature, some researchers can respond very positively to the way in which POs will approach research by building connections between scientists and patients,

Although *P4* was so enthusiastic about the involvement of MND organisations in research, there was also one particular instance of PO control that several employees described in very negative terms. As described previously, PatientsLikeMe famously conducted a research project using its self-reporting system and published results that Lithium was

ineffective as a treatment for MND(Mansell, 2011). Despite being promoted by the organisation as signifying a ground-breaking change in clinical trial management, this research was heavily criticised by three of my participants as not robust enough as it was based solely on questionnaire data. All three doubted the ability of the web-based group to conduct meaningful research, despite its usefulness as a support group and its potential to aid patient-led medicine.

Throughout the discussion about PatientsLikeMe, *E6* expressed her discomfort with the idea that an online forum could conduct a parallel project to a clinical trial. *E6* specifically linked the sense of discomfort with PatientsLikeMe research to the opinion of more mainstream scientific researchers

> *E6:* the research that PatientsLikeMe has come up with has not a very good reputation within the academic community. It's just riddled with holes, in terms of scientific design, data analysis, every part of the assessment of a piece of research that you choose, I think there are design flaws in it

This suggests that *E6* disagrees with the approach in part because PatientsLikeMe is viewed as disreputable and unreliable by "the academic community". Therefore, in certain circumstances, key PO personnel agree with researcher characterisations of patient-led research as lacking in rigour and professionalism. Likewise, *E4* said of the same project

> *E4:* Yeah well it's easy to come up with the result the drug doesn't work. I think PatientsLikeMe is, has uses… In research terms I think it's incredibly variable and it certainly can't replace a properly conducted clinical trial. Now they should, if they want to prove how robust and sensitive that system is, that patient self-reporting system, they should do it on a slam dunk intervention like non-invasive ventilation and if they can't demonstrate the benefits of non-invasive ventilation then the system doesn't work. You know saying lithium doesn't work, well that doesn't help

E4 also suggests that the PatientsLikeMe approach is not rigorous enough, and cannot supplement a "properly conducted clinical trial". Both *E4* and *E6* therefore appear to be mirroring popular scientific opinion of self-reported research. This could be interpreted to suggest that there is a tendency to automatically discount research typically characterised as "not robust enough". However, looking at *E2*'s thoughts on the subject illustrates another possible interpretation of PatientsLikeMe

> *E2:* Some of the papers that Paul and his team have produced have been excellent and some I've been very dubious about and the reason for that is that they're relying on patients to report on feelings, do you feel better, do you feel worse, have you got more energy. This is all down to opinion and MND is a condition whereby we know it can have cognitive effects in up to 50% of patients, we know that 50% of patients will suffer dementia, we don't know about the other 50% whether they remain entirely normal and entirely objective despite having this condition… So if you're producing papers that purport to be scientific that are based on people's self-assessment of their own symptoms then you're on, in my opinion you're on dangerous grounds.

E2 suggested that a particular problem in self-assessment research in MND is the frequent mood changes that people living with the condition experience. As such, it is not the approach itself that is problematic, but rather the context in which it is employed and the ability of people with MND to assess their condition.

This illustrates an interesting dilemma that POs can face. MND PO employees seem to be torn between conforming to the need for scientifically defined rigour and wanting to bring about change to research procedures. This example shows that PO engagement in research can be simultaneously interpreted as both radically influential and disruptive. Whilst tending to describe their own PO as capable of having a great deal of influence over the research agenda, these MND PO employees are rather scathing of the ability of others to do so. Therefore, as was the case in the discussion about PPI, a significant barrier to PO influence over research is the need to simultaneously promote the impact of PO involvement and represent patient-led research, and engage with the unwillingness of research associates to accept radical change to the research process. Given the suggestion made by *P1* that, on the part of the researcher, it is the perceived lack of understanding of scientific procedure that makes it difficult to collaborate with POs beyond accepting funding; it seems likely that the commitment to scientific rigour over radical patient-led research might reflect the POs desire to prove its scientific legitimacy. This chapter therefore, to a certain extent reflects the literature on "professionalization"(Van De Bovenkamp et al., 2009, Corrigan and Tutton, 2006, Weiner, 2008, O'Donovan, 2007) since the POs seem to be adopting scientific language, institutions and power structures.

Summary

This chapter illustrates that MND and Parkinson's organisations reflect the findings reported in the literature that POs tend to retain little influence in their relationship with

researchers, principally because researchers will be reluctant to relinquish power and influence. The POs tend to describe their own position as very influential, and even crucial in research. However my data suggests that, the influence claimed by POs is not always reflected in the research they fund, with POs rarely being able to fund a project fully from inception to clinical trial phases

In interviews with PO staff, there was a significant tendency to assume that POs must engage in research in order to ensure research is conducted properly. Furthermore, some suggested that without PO input researchers could not be trusted to conduct research in a way that understands and respects the needs of people with MND and Parkinson's. Again this is consistent with the ideas raised in literature, and discussed more fully in Chapter 6, such that the perceived lack of consideration for the patient perspective amongst scientists plays a significant part in the PO decision to engage with research(Rabeharisoa, 2003).

My data also highlights a considerable amount of tension between POs and the researchers with whom they collaborate. One researcher was shown to be receptive to the demands and suggestions of POs, however most participants alluded to a tendency for researchers to withdraw from PO control. Whereas PO staff described their role as grounding researchers in the moral reality of their research, researchers often dismissed POs and their members as not sufficiently expert in scientific procedure and therefore not entitled to direct their activities. Furthermore, MND PO employee descriptions of PatientsLikeMe illustrate that some personnel within the POs share the researchers discomfort over radical PO involvement in research. Therefore, as was the case in Chapter 6, the difficulty in defining the influence of patient-led research in this case often lies in the difference between the claims POs make and the influence they are able to have.

Crucially, a particular challenge that POs face when cultivating a relationship with researchers is the need to simultaneously emphasise their position as leading, overseeing and controlling research, and retain a reputation for professionalism amongst research associates. When setting their research goals, and deciding how to invest their funds, POs must set realistic goals without undermining their public claims for driving and controlling research. As such, it seems that part of the PO research engagement process is to manage the expectations of both members and researchers.

CONCLUSIONS

This thesis set out to present a rich account of how POs working with and for people living with MND and Parkinson's construct their identities and conduct their activities, particularly in relation to setting and pursuing a research agenda consistent with their overall aims. As a result, this research contributes to the well-established literature looking at PO and social movement engagement in research, and the growing literature around patient and public involvement, by exploring the meaning of representation in this context.

The research took place at a time of great change for the MND and Parkinson's POs. Despite a fluctuation in structure and the number of local member groups, both PUK and MNDA were experiencing a steady increase in membership as well as an increase in public attention via social networking sites Twitter and Facebook. Likewise, the research contribution of the four POs was changing, with all except MNDS increasing the amount of funding they provided for research between 2010 and 2012. Furthermore, due to high-profile campaigns around issues of palliative care and assisted death, public awareness of the conditions themselves was also increasing as people with MND and Parkinson's were increasingly drawn into public and often controversial debates.

Because it took place in a comparatively small community, this research proved more methodologically and ethically challenging than expected. Snowballing recruitment, in relatively small organisations (in terms of the numbers of staff) was more difficult than anticipated with some unwilling to participate and others to recommend colleagues. Furthermore, many interviewees, and prospective participants were known to each other, within and across the different POs. As a result, maintaining anonymity proved challenging both during data collection and the analysis. Despite these methodological difficulties, combining interview data with observations of PO research meetings and conferences, and an analysis of PO websites and social networking activities enabled me to construct a rich case study of the challenges faced by the modern PO in combining patient representation and a commitment to influencing the research agenda.

A review of the literature providing structural analyses of the increasing engagement of POs in research highlighted a need to explore in more detail the notion of patient representation. Representation is to a certain extent implicit throughout the literature as an innate purpose and goal of the PO. Likewise a commitment to patient involvement in the

research process, ensuring more patient-centred research is discussed as an accepted part of the PO role. Therefore, my thesis contributes to this literature by exploring in greater detail what it means to be a patient representative, comparing the public claims that POs make for representation and patient-centred approaches with the way in which PO employees, members and research associates understand the roles and responsibilities of people with MND or Parkinson's and their POs.

The thesis suggests that a particular challenge for the modern PO is to combine the 'traditional' role of self-help support with the desire to lead the research agenda in a context where research tends otherwise to be underfunded, and research communication is developing to increasingly rely on online technologies. Analysing the MND and Parkinson's POs suggests that combining these roles creates a tension between a theoretical commitment to patient-centredness and the practical role that patients can be given in the various PO activities. Furthermore, using the debate around political models of representation to analyse these challenges highlights the difficulty of defining how POs represent their membership. In particular, Saward's(2006) representative claim theory, highlights the differences between public assertions of patient representation, and the way in which the PO relates to its membership through campaigns, services and research leadership. Burke's trustee-delegate model(Conniff, 1977, Eulau et al., 1959), which conceptualises representatives as either speaking for the represented (trustee) or acting on direct instruction from the represented (delegate) has been useful in analysing this disparity and the changing relationship between POs and members. Depending on the context, the way in which POs approach the task of patient representation can simultaneously resemble the trustee model (allowing greater distance between the PO and member opinion) and the delegate model (implying direct involvement of members in all activities and decisions), and often a combination of the two. In particular, the effort to combine support and research can in many ways be summarised as a conflict between the responsibility to represent the patient community and an increasing responsibility to represent the views of research associates. This conclusion will discuss this conflict and other findings of this research, focusing on these themes:

1. The creation and representation of a collective PO member identity
2. PO claims for representativeness and "patient-centred" activities
3. PO campaigns for PPI in research
4. PO influence over the research agenda

I will make suggestions as to how the conclusions I make might apply to other POs and the wider issue of patient representation. I will therefore discuss the contribution the research could make to the charity sector and research policy as well as the literatures surrounding POs, social movements and PPI.

Representing collective identity

As suggested by the literature on community identity formation(Rabeharisoa and Callon, 2006, Olzak and Ryo, 2007, Barbot, 2006, Hardnack, 2011, Lock, 2008, Stryker and Burke, 2000, Silverman, 2008, Martin, 2001) this thesis illustrates that being part of a PO creates several divergent identities. The identities discussed in this thesis were analysed as illness, activist, 'lay', community and membership identities. Although these identities were occasionally in conflict as Hardnack(2011) has described, this research suggests that PO members and employees alike understand each identity in a more connected way, in terms of the responsibilities they create with respect to the wider patient community. Even the individual illness experience was discussed in terms of the responsibility to gain self-ownership of the condition to allow the individual to become an active, responsible member of the patient community. As such, despite creating the potential for tension, the separate identities tended to be discussed in terms of a collective community identity, and were connected by a sense of responsibility attached to that community.

Relating this to the idea of "the represented", part of the PO role as a patient representative is to emphasise a clear sense of collective identity. Not only does this give the impression of a coherent membership community, but also allows the PO to emphasise its own position as representative of that community. PO employees in particular attach great significance to the proportion of people living with the condition who are either members of or in contact with the PO. The sense of collective identity is used to boost the POs reputation as patient representative. Analysing this as part of the representation debate, the POs appear to promote themselves in such a way that resembles the delegate model of representation: close to and strongly informed by those they represent. However, existing doubts amongst some members as to the success of the PO in maintaining a patient-centred approach, and the distinction made by some between membership of a patient community and membership of the PO, suggests that POs can face a significant challenge in maintaining a sense of collective purpose in a potentially disparate patient community.

Presenting POs as Representatives

One way in which these particular POs promote their position as patient representatives is to re-label their activities as what people with Parkinson's or MND 'want'. Conceptually, this allows the POs to describe their activities as directly informed by the patient and therefore representative of the patient view in the Burkean delegate sense of the word. However, some members perceive the increase in funding allocated to research in particular as detrimental to the 'more important' support agenda, whilst others describe themselves as so uninterested in the research agenda that they disengage with the PO entirely and all its newsletter, online and meeting communications.

It is of course unrealistic to expect a PO to represent all the needs and opinions of all individual members. However, looking at the way in which research is communicated to members potentially provides a new way to examine PO attempts to maintain genuine patient-centred approaches, and a sense of collective purpose and ownership. These particular POs increasingly rely on social networking to provide immediate updates on the progress of research. However, staff were aware that their PO's own members are unlikely to use social media as a preferred method of reading that information. Moreover, some members complained that detailed research information was made to sound exclusive and unavailable, by being kept in web pages marked "for researchers". This suggests that in pursuing a role in research, the PO creates a technological barrier between the organisation and its staff, and the membership-base. By committing to online reporting, though admitting that a proportion of the membership will not see it, the PO risks leaving members behind.

The fact that the provision of information was often described as part of the PO's role as patient advocate, makes this analysis all the more important. This is because, by curiously shifting the focus of advocacy to the provision of information, often online, the PO has to a certain extent made advocacy a top-down process where the PO decides what information the members need, and how they should access it.

Furthermore, some members expressed concern that the increasing reliance on the internet meant that local group meetings were gradually replaced by online forums and communities. The resultant perceived lack of connection between the PO and members can result in serious tensions between the two. Some of those interviewed here have become very suspicious of their PO's motives, priorities and sensitivity to the needs of individuals

and local groups alike. This research therefore suggests that, with the rise of social media, in order to maintain their reputation amongst members as patient representatives, POs may need to pay closer attention to the physical meeting spaces that its members require. A lack of physical, local contact with the PO has resulted in serious disconnection of some members, who though technically part of the PO find it difficult to identify with the organisation, the services it provides and the priorities it promotes. Furthermore, although this tension was most prevalent in discussions about PUK, some raised similar suspicions about CPT, and implied the potential for the same tension between staff and members in MND organisations. This suggests that it is a factor that could apply to other POs. In particular those, such as Multiple Sclerosis POs, with similar attributes with respect to the activities they provide and the conditions they represent.

Relating this to patient representation, the point of contention here is again the form that representation takes. 'Patient-centred' would imply that POs adopt a delegate model, closely following member opinion. However, by excluding members from the process by which research and support information is provided, POs appear to resemble more closely the Burkean trustee model, generally making decisions and engaging in discussions without the input of the membership. Therefore, the PO, depending on the context, can be described within either representation model, or both simultaneously. In particular, the conflict here is between a theoretical claim to act as a delegate and the practical need to be more like a trustee to the patient community when planning the way in which PO activities are conducted.

Patient involvement in the research agenda

This conflict between delegate and trustee descriptions of patient representation is most clearly seen in the way in which PPI is discussed by PO employees and volunteers. Analysis of PPI in MND and Parkinson's research supports the assertions made in the literature that clinical or research professionals will often remain unwilling to divulge genuine power and influence to the patient ('lay') population(Martin, 2008, Thompson, 2007, Beresford, 2002, Brekke and Sirnes, 2011, Diamond et al., 2003). It is also the case here that patients are thought to be unable to be involved in research decision-making, so that their role is restricted to more downstream forms of participation, in the trial stages for example(Beresford, 2002, Thompson, 2007, Nilsen et al., 2009). As a result, although PO employees theoretically understand PPI as vital to improving the research process and its

outcomes, they nevertheless tend to describe it as giving patients a role either in fundraising or as research participants.

The literature further suggests that POs principally engage in research to promote patient-centred research agendas and to overturn the overt professional control of the research process(Allsop et al., 2004, Baggott et al., 2005, Baggott and Forster, 2008, Rabeharisoa, 2003, Rabeharisoa and Callon, 2002, Novas, 2006). It is also often implied that PO involvement in research is indicative of patient backing(Novas, 2006). In contrast, my data suggests that defining PO activities as part of representing and promoting patient experience and knowledge is rather more complex. To interpret PO research commitments as based on patient priorities, it is not enough that the POs are observed to label research 'patient-centred' or based on 'what people want', or even that patients and members fundraise for the research. This is because, many of those who provide this funding nevertheless appear dissatisfied with the fact that the money is absorbed into PO-prioritised activities. As a result, even in framing research as patient-centred and gaining some member support, POs can risk alienating some members by failing to represent their needs in the way they expect.

This was also the case in the patient experience-based campaigns, where the manner in which patient stories were chosen highlighted a similar distance between the PO and member opinion. The campaigns reviewed here appeared to be more constructed than is claimed in the adverts and materials. Although the campaigns do physically involve a patient, the content and purpose of the campaign is arguably not driven by the patient or their particular experience, but rather the PO's need to present the best possible story. As was the case in research, the promotion of patient-centred campaigning is not necessarily linked to a position of genuine influence for the patients themselves. It is to be expected that PO campaigns will be carefully considered for their purpose and impact. However, this research suggests that in order to understand patient representation in the context of POs, it is not enough to analyse patient experience campaigns, or for that matter claims for a patient-centred organisational approach. The intended audience appears to have a significant effect on the content of campaigns. Therefore, the motivation of the PO to present a particular message can play at least as big a part in decisions about the way in which people are represented as the patient experience itself.

Analysing PPI as a matter of representation also suggests that POs increasingly combine the responsibility of patient representation, with a responsibility to represent researchers in conversations with patients and volunteers. Viewing POs as researcher representatives, can shed light on the challenges documented elsewhere posed by a prevailing imbalance of power between POs and researchers(Martin, 2008, Hickey, 1998, Brody et al., 1989, Beresford, 2002, Diamond et al., 2003). This is because, through deeper involvement in research, the PO gains a responsibility to maintain a good reputation in the research community. As a result the PO cannot damage a relationship with researchers by overstating the role and influence that patients can have. Consequently, the PO to a certain extent begins to represent the researcher perspective, emphasising the need to follow scientific trends and expert advice. Viewing POs as researcher representatives, allows them to be re-conceptualised as following the wishes of a different set of community members, when not fully committing to PPI in research decisions. However, if the PO nevertheless suggests that its principal aim is to represent the patient experience in research it risks appearing disingenuous in its approach. This might limit the extent to which POs can be described as representing patient involvement.

Therefore, my suggestion would be that where PPI is difficult, the PO research agenda could be re-labelled as "patient-supported" rather than patient-centred. From the PPI literature standpoint, this could raise the problems associated with the distinction made in the literature between involvement and participation(Thompson, 2007), and participatory and emancipatory research(Beresford, 2002), since it would preclude active influence by patients over the research process. However, if we consider this using political theory on representation, "patient-supported research" would nevertheless allow the POs to describe research activities as representing patient experience, to the degree that they are sanctioned by members - thus, resembling the trustee definition of representation. Gaining patient support is arguably no better than failing to adhere to patient-led approaches, in terms of improving the position of PPI in research. The intention here is not to suggest that patient-supported research is preferable. However, accurately describing the PO's position could eliminate tensions caused by false expectations amongst the membership as to the influence patients will have. If PPI cannot be made more direct, or emancipatory, then an alternative would be to clearly define it in the terms of indirect trustee representation.

The research agenda

The attempt to combine patient representation with a role in research also affects the extent to which POs are able to influence the research in which they collaborate. The challenges associated with PPI suggest that POs are occasionally required to conform to scientific opinion, with respect to the appropriateness of integrating patient experience and knowledge in research decisions. Nevertheless, all four POs, as do most, tend to promote their position as influential managers, facilitators and governors of research. However, as others suggest, this is not always reflected in the amount of influence they have over the researchers they fund(Allsop et al., 2004, Corrigan and Tutton, 2006). Indeed one researcher described PO involvement as undue 'interference', and the constant contact with POs and members alike was described as unnecessary and a hindrance to his work. Moreover, some PO staff suggested that they expected researchers to view their involvement in this way. However, the particular contribution that this research can make to this debate over researcher-PO power balance can be found in the example of PatientsLikeMe. Researchers were broadly positive about the influence that MND POs and their members could and should have over the research agenda, to the extent that one advocated for changing research priorities, protocols and procedure based on the recommendation of patients and POs. Nevertheless, discussion with some MND PO employees, suggests that they can be rather less receptive to the notion of PO control over research. Discussing the potentially radical influence of PatientsLikeMe in clinical trials, several PO employees expressed great concern about the lack of rigour in the PatientsLikeMe approach.

This suggests that the PO engaging in research is presented with a conflict between seeing its own contribution as vitally important for overturning established research structures and not being so radical as to damage scientific commitment to rigorous, widely applicable research methods. In this case, the dual responsibility to promote patient-centred research and represent researcher priorities, creates a tension between the desire for radical change to the power structure and the need to interact with researchers in scientific terms. Consequently, some PO staff have distanced themselves from the novel approach of PatientsLikeMe so as not to damage their own reputation as professional, appropriate research managers.

Limitations

Because my focus on representation arose out of the data, in particular from interviews where volunteer-staff tensions were discussed, the case studies presented here are effective in showing the way in which representation, PPI and conflict were discussed. Also, comparing different sources of data allowed comparison of theoretical and ideological commitment to representation, and public statements and actions. Therefore, by combining observation, interview and web analysis data I have been able to gain an understanding of these cases but also to explore wide-reaching concepts related to representative claims, PPI and the PO-patient, PO-researcher relationship.

However, it must be acknowledged that the way in which I recruited for this study and the way that methods were chosen did limit my case studies to particular themes. Observations allowed me to compare specific statements for different organisations, for example the PUK conference served as an additional source of data on the concerns raised by volunteers about their (lack of) inclusion. However, had observations been more comparable between organisations, my case study could have included more comparison between the ways in which different POs include members in the same kind of event. I was not able to legitimately compare the Parkinson's and MND conferences I went to because they had very different purposes. The observations were very useful in providing data with which to compare interview statements from the same PO. However, the strength of the data could have been improved by planning from the outset to observe the same event at each organisation.

Additionally, I was able to interview significantly more people with Parkinson's than MND. This is in part due to the nature of the conditions themselves, however it does limit the comparisons I am able to make between the groups and the POs. Conducting similar research in the future, I would perhaps approach recruitment differently. Building a stronger relationship with admin staff from the outset may have made them less wary of my presence and improved my access to local group members. However, the risk then would be for a research bias –I might not have met people who disagreed with the organisation if my research was sanctioned by the PO. As my research highlights certain suspicions about "HQ", if I was perceived to be one of "them" I might not have encouraged such a degree of openness amongst those who were most scathing about PO staff.

Wider Implications

PO Practice

Although my research focussed on two specific condition areas and four particular POs, they share several characteristics with many POs both in the UK and internationally. The combination of research, support and advocacy is common across the health charity-sector, as is the increased use of the internet and social media. As such, it is possible to suggest that the conclusions I have made as to the relationship between POs and their members, and the way in which patient representation is understood could have implications for the wider PO sector. In particular, as noted throughout this thesis, PPI as a concept is increasingly expected of researchers by many funding organisations other than POs. Therefore, the issues identified here around the way in which PPI is defined and then put into practice could be generalised beyond the specific context of this research. Despite the creation of such organisations as INVOLVE, which creates and publishes a great deal of research, guidance and advice on PPI, there nevertheless remains a lack of clear, universal guidelines for the implementation of PPI in research and healthcare policy decision-making. Illustrating as it does the consequences of a theory-practice mismatch regarding the relationship between POs and their members, this thesis could make a number of suggestions for PPI practice in POs and the wider research agenda.

First, this research shows that genuine physical participation in discussions is not always possible in cases where patients have significant movement or speech difficulties, or indeed where rapid progression and cognitive symptoms are a factor. Therefore, although the obvious suggestion would be to commit to more genuine patient involvement in research agenda-setting, this research shows the importance of accurate and specific definition of what PPI is expected to be and what the role of participants will be. It seems that some of the tension between research network volunteers and the PO "HQ" was caused by the difference between the expectation of PPI and the role that volunteers are actually given. Therefore, where PPI is not necessarily possible, good practice could include careful management of patient expectations.

Second, this thesis shows that increased research focus can be interpreted badly by PO members, if they perceive funding as being removed from other important PO functions to further an agenda over which they have little say or control. Although most agreed that research was important, many nevertheless suggested that asking for more money made the

PO look like it was out of touch with what the membership needs. Particularly in the case of local group activities. This suggests that, part of the process of increasing research funding should be to make sure that members and volunteers are as involved as possible in the way in which the PO's research agenda is set. As well as including research network volunteers in the grant review process, POs could adopt the methods advocated by organisations such as the James Lind Alliance for surveying the opinion of large groups of people. This process involves surveying members to gain a broad list of research priorities, narrowing them down to those mentioned most often and then surveying again to pick a shortlist of those most supported by the membership. This approach, if achievable, would not only help to ensure that members understand how research priorities are chosen but could also improve the PO's position as a research funder. This is because, as this research and the PO literature shows, POs are often collaborated with mainly due to their position as representative of a clearly defined patient population. Strengthening the ties between member opinion and research targets could therefore strengthen this reputation. That being said, as some researchers expressed reservations about the implementation of "too much" patient-led research, it could also be the case that less of a direct link to the membership would be desirable to some. However, it also seemed to be the case that a cause of these reservations was an apparent haphazardness in the way in which POs organise their research activities. Clearly defined research aims informed by patient surveys could provide a structure to the PO-researcher relationship by providing a clearer outline of the research in which the PO can and cannot invest. That is, narrowing the subject down from research 'focusing on MND/Parkinson's'.

Policy

As mentioned above, although it is increasingly important, PPI is yet to be clearly defined in terms of a standardised procedure or policy. By analysing it in terms of representation, this thesis could inform the debate around PPI policy. Rather than viewing it in terms of procedure, where the patient is either involved or not, this research shows that definitions of PPI necessarily involve classification of the PO role, the form that PPI takes and what different parties expect PPI to be. First, this thesis shows that in some contexts, PO staff are viewed as an appropriate substitute for the patient in PPI initiatives. If viewed in terms of representation, this substitution could be acceptable if the PO is clearly defined as the patients' trustee. However, it does call in to question the definition of PPI, since the person involved is not an actual patient. To avoid the "tick box exercise" charge, organisations

including PPI in their discussions must be clear as to whether they involve a patient or are looking to specifically talk to their representatives.

Second, this research shows the vital importance of clarifying what PPI means in terms of the role that patients are given. Although it might seem to be a concept that firmly advocates patient-led research, many of those interviewed characterised PPI as involvement in fundraising activities or as research participation. Both of these are technically involvement. However, they cannot be described as contributing to patient-led research. Therefore, when participating in PPI initiatives, POs, patients, external organisations and researchers must all have a clear understanding of what PPI means in their context. Therefore, a further contribution that this research makes is to suggest that although clarity is important, PPI necessarily involves flexibility. Different patient groups and different contexts will require or limit PPI in different ways. Consequently, it seems possible that in attempting to define a standardised PPI policy, we should, instead of creating a set of guidelines, highlight the importance of clarity and agreement between different parties. Rather than expecting PPI to be the same in all situations, I would suggest that any context in which PPI will play a part begins with a consultation between participants (PO, patient, researcher, funding organisation) to create clear guidelines for that particular context. This could limit the tensions described by some, where researchers do not understand why the PO representative or the patient is present on a discussion board or panel and patients are perceived to be "screaming and shouting" (*E9*).

As this discussion of PPI policy involves viewing PPI as a matter of representation, it could be said that a clear typology for patient representation is required. However, the third policy contribution this research makes is to suggest that creating a representation typology is not necessarily possible. This is because different PO activities and goals have been shown to require a different representation model or relationship. Furthermore, my data illustrates that the way in which POs represent patients in some contexts, in research in particular, is likely to occasionally differ from what would be expected theoretically and what the patients themselves might expect. Rather than advocating for one model over another, this thesis suggests that POs, as they become more involved in research, now represent more than one group of constituents: patients and researchers. This means that attempts to define a model of representation, must take in to account the needs, voice and importance of the different groups. For example, when representing researcher needs, it could be said that POs are not necessarily working well as patient representatives. That

means they are at once representative and un-representative. This is to a certain extent supported by the trustee-delegate continuum but also highlights the importance of analysing representative claims. The PO only appears unrepresentative of the patient if it engages in activities that are framed as patient-centred but instead focus on research needs or interests. Therefore, rather than aiming to define representation, it is important in this context to instead compare the representative claims that POs make with their behaviours, goals and priorities.

Future Research

The outcomes of this research suggest that the researcher-/patient-representation duality could be explored further. The POs analysed here are not the only POs to combine research with support or to claim to enhance the importance of PPI. Therefore, the approach used here, to analyse PPI and other PO activities through the lense of representation could be applied to other POs or patient populations, perhaps beginning with those with a similar focus such as the MS society, which also works within the field of neurodegenerative disease. As I have made certain suggestions regarding PPI policy and practice, as well as definitions of patient representation, a participatory, ethnographic approach to PO research could help to test these theories. The researcher could join and work with a PO to implement changes to PPI strategy. In particular clearer definitions of the patient role and the amount of influence members have could be put into practice to analyse their effect on the PO-member relationship. Additionally, as PPI becomes more of a public focus, in light of recent policy debates around making untested medications available to people with untreatable conditions, further research could focus more on the researcher. I was unable to interview a large number of researchers, however those I did talk to illustrated the polarised view that researchers have on PPI and the influence that POs should have. As it seems patient experimentation is becoming more popular as an idea or research method, it may become more important to explore this polarisation. What will the effect of greater patient control over the drugs that are tested and the manner in which trials take place be on the way in which PPI is discussed by researchers?

The methodological contribution I make to case study and representation research is the use of web analysis. Comparing interviews and observations with websites, facebook and twitter gave greater analytical depth to the issue of representation. Some of the more interesting conflicts between campaigns, PO roles and patient perspectives were highlighted by web analysis. This will only become more important, as we become more

internet-centric. Therefore, it is likely that future research into POs, PPI and patient representation will need to pay considerable attention to the way in which research, illness and activism are discussed, defined and put into practice online.

Conclusion

This research has illustrated the potential use of representation theory to re-examine the established academic study of POs and PPI. Exploring MND and Parkinson's POs in the UK has highlighted the tensions created by a continued aim to act as patient representative in a context where research progress, the increasing use of the internet and the symptoms of the conditions themselves often preclude the PO from doing so. As is common in the PO sector, the data highlights a strong sense of community responsibility. This is illustrated by the way in which patient identities were discussed through the lense of a wider obligation to be a responsible member of the community. Likewise, the POs place considerable importance on the maintenance of patient-centredness both in support activities and in research through PPI initiatives. However, the significant tensions between some staff and volunteers suggest that POs are not always able to maintain a sense of the collective amongst their members. Furthermore, the dissatisfaction of some members regarding the role they and other patients and volunteers are given in research as well as the organisation itself is not compatible with the public claim of the PO to promote a patient-centred research agenda. Moreover, despite the aim to improve PPI, the view that patients, and on occasion other POs, would be unable to sufficiently conduct, discuss or understand research was remarkably common.

Using the theories of representation put forward by political theorists to analyse PO activities, this thesis provides a new perspective on these issues. Analysing different PO contexts in terms of the representative claim and the trustee-delegate continuum illustrates that POs in many ways take a flexible approach to patient representation. The claim to delegate-like representation that is made in campaign, promotional and online material is not necessarily matched in practice. Instead, in particular in research, POs have been observed to resemble more closely the trustee representative. Consequently, this thesis has not aimed to present or create a defined model or typology for patient representation in this context. Instead, it is suggested that POs can be examined as increasingly representing two communities: the patient and the researcher. As a result the decisions that are made regarding research, funding and support priorities can be viewed in terms of representing, more or less, either patients or researchers. Furthermore, given the changeability of the

model that fits PO representation, this thesis suggests that rather than attempting to define the PO's position, the focus should instead be on clarity and understanding.

Likewise, rather than focusing on creating standard guidelines for PPI across the sector, those participating in discussions where patients are involved should instead aim to create their own strategy. Each research context, patient group and PO will require and limit PPI in different ways. Therefore, the suggestion made here is to highlight the importance of clarity for all those involved regarding the role that patients can and will play. The wider contribution of this research to policy and PO practice is that analysing PPI and PO activities as a matter of representation, allows us to understand the tensions created by the difference between a theoretical claim to patient-centredness and the relatively low level of influence afforded to patients in reality. It is perhaps the initial representative claim made by POs, to strongly support patient influence that causes those who experience less power to become distanced from the PO and in some cases very suspicious of it. Therefore, the implication of this research is that in a sector where PPI is increasingly important, as is the drive to combine research with support and advocacy, balancing representative claims with a realistic account of what is achievable will be paramount to the PO-patient relationship. The need to occasionally substitute delegate-like PPI with a more trustee-like substitution of the patient with a PO representative or scientific "expert" is not in itself surprising or troubling. It is to be expected that there will be contexts when the PO staff member must speak on behalf of the organisation and its members. However, it is the continued claim in such contexts, for direct patient control that is likely to create in other POs the tensions observed here.

In conclusion, given the growing importance of the charity sector in providing care and supporting the research agenda, and the rising impact of PPI, the findings of this research could contribute to the wider study of PPI and PO engagement in research. In particular, the approach to studying POs through representation theory provides a novel way of understanding the widely documented problem of promoting PPI within a PO-researcher relationship. This thesis could therefore have implications for the way in which research policy includes POs in the discussion.

This interview schedule formed the basis for interviews conducted as part of the project. The order and wording varied, depending on whether the participant was a PO staff member, a volunteer or a research associate. Other subjects relevant to a particular individual or organisations were also discussed.

*Questions marked * were asked in the same wording to allow comparison.*

Introduction
Tell me a bit about yourself, how did you start working at/with *[PO]*?

*Imagine I have never heard of [PO], how would you describe it to me?

Organisational Relationships
Do you see [PO] as different to other organisations?

*I have read that organisations working within the same disease population can feel pressured to compete, what has your experience been of this?

Research
*In your experience, what kind of role does [PO] have in research?

Research progress is often described as "from bench to bedside" – from the lab to the clinic. Where do you see [PO] sitting in this timeline?

Where do you think the future lies in MND/Parkinson's research?

*What role, in your experience, does user involvement play in research?

*Some charities have developed a close relationship with drug companies or other research organisations where others have not. What do you understand the relationship between [PO] and drug companies is like or what do you think it should be?

What has been your experience of research regulation?

What do you find are the most common reasons why your members participate in research?

Campaigns
What is your experience of campaigns led by [PO]?

How much is media reporting needed in promoting research? What kinds of subjects tend to get the most attention?

Online Traffic
How does the PO monitor what members are looking for or interested in?

People with MND/Parkinson's
What do you find are the most common subjects that people with MND/Parkinson's want to discuss?

Vulnerable People is a common term used to describe people with long term illnesses like MND. Do you think that is a good way to describe members of [PO]?

Appendix 2: CPT Triangle
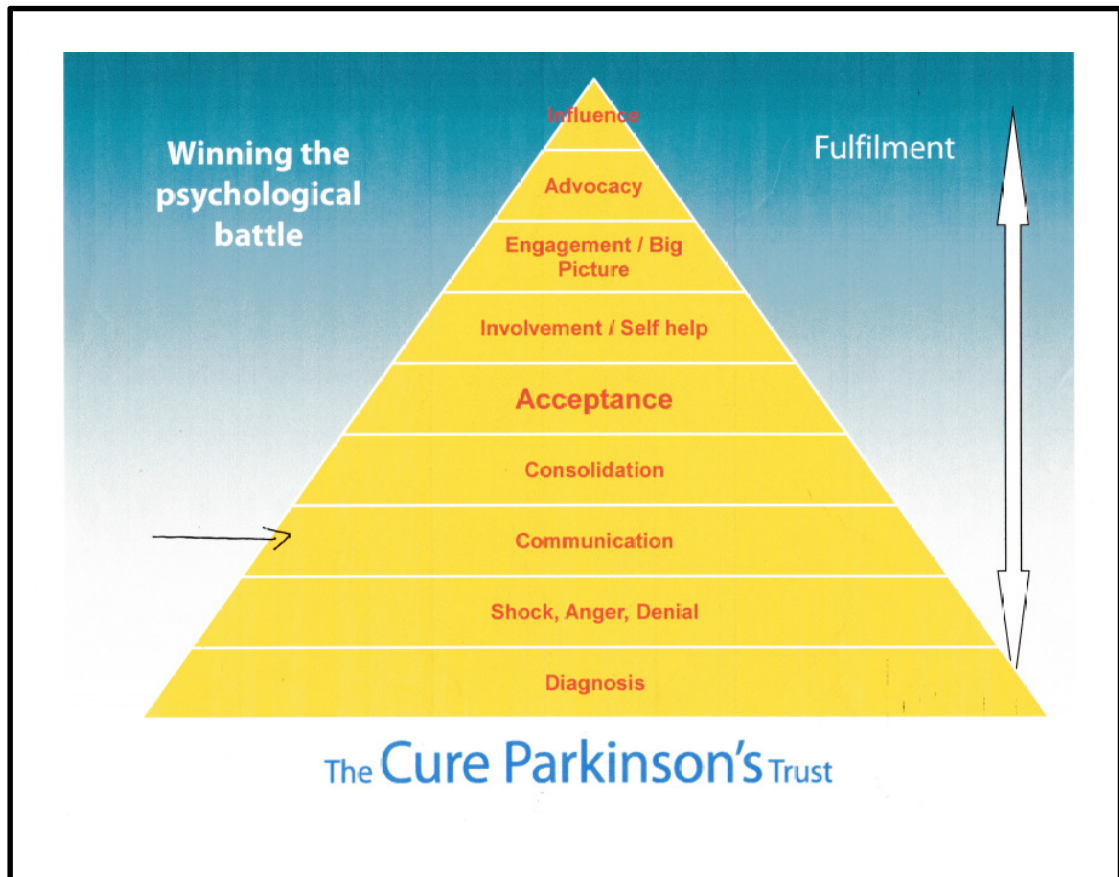
Notes: CPT diagram showing the progress of people with Parkinson's from diagnosis to "influence". The arrow on the left was drawn in to illustrate the point at which CPT staff felt they could approach prospective members/activists

Appendix 3: PO Websites

PARKINSON'S UK

11/10/2011

10/01/2013

MND ASSOCIATION

11/10/2011

CURE PARKINSON'S TRUST

11/10/2011

10/01/2013

MND SCOTLAND

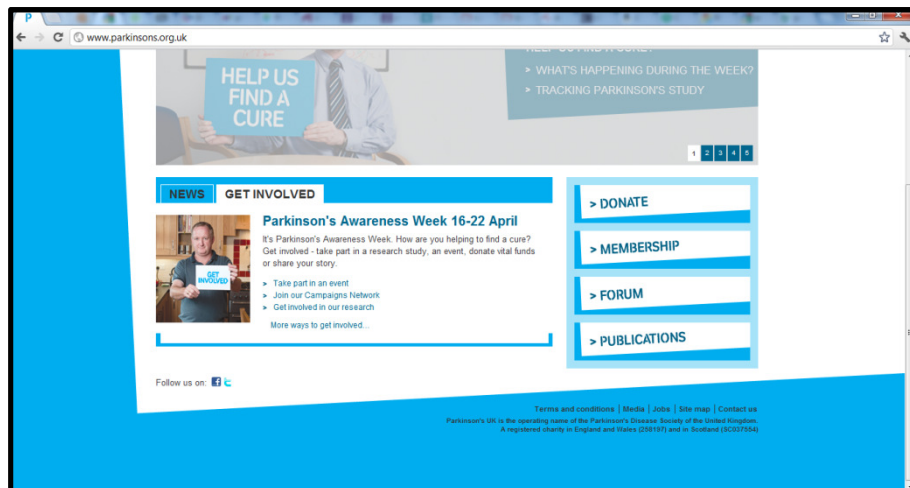# Appendix 4: Awareness Weeks

MND ASSOCIATION
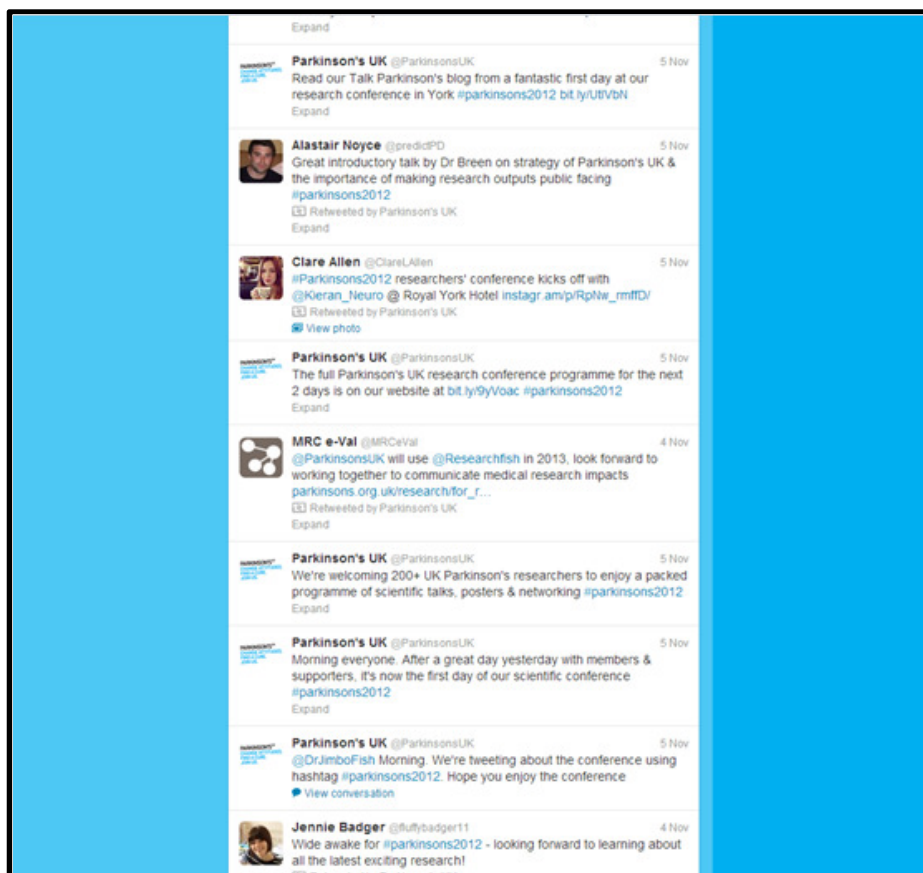
PARKINSON'S UK

Alternate End

CURE PARKINSON'S TRUST

Search: "Awareness Week"

Appendix 5: #Parkinsons2012

A sample of tweets using #Parkinsons2012 during the Parkinson UK Research Conference

	Role	Affiliation	Anonymity Level
V1	Volunteer	Parkinson's UK	Identifiable
V2	Volunteer	MND Association	Identifiable
V3	Volunteer	Parkinson's UK	Identifiable
V4	Volunteer	MND PO	Full Anonymity
V5	Member	Parkinson's UK	Identifiable
V7	Member	Parkinson's UK	Identifiable
V9	Volunteer	Parkinson's UK	Identifiable
V11	Member	Parkinson's UK/ CPT	Identifiable
E1	Employee	Parkinson's PO	Full Anonymity
E2	Employee	MND Scotland	Identifiable
E3	Employee	Cure Parkinson's Trust	Identifiable
E4	Employee	MND PO	Partial Anonymity
E5	Employee	Parkinson's PO	Full Anonymity
E6	Employee	MND Association	Identifiable
E7	Employee	Parkinson's UK	Identifiable
E8	Employee	MND PO	Partial Anonymity
E9	Employee	Cure Parkinson's Trust	Identifiable
P1	Researcher	PO Funded	Full Anonymity
P2	Researcher	PO Funded	Full Anonymity
P3	Former Associate	Parkinson's Care	Identifiable
P4	Researcher	PO Funded	Partial Anonymity

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