

**Reconceptualising Parkinson's from illness to wellness:
Advancing physiotherapy practice through Action
Research**

RAMASWAMY, Bhanu

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Reconceptualising Parkinson's from illness to wellness:
Advancing physiotherapy practice through Action Research

Bhanu Ramaswamy

A doctoral project report submitted in partial fulfilment of the
requirements of Sheffield Hallam University
for the degree of Doctor of Professional Studies

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Summary

'*Staying well*' is a reason people attend exercise classes run by the Sheffield Branch of the charity Parkinson's UK.

'Wellness' is a social construct given meaning by the context in which it is used, and by whom. It is hard to define, yet is an aim of physiotherapy professional practice, and a main goal of health policy in the United Kingdom.

The Doctoral Research Project was undertaken to explore the role of physiotherapy for people affected by Parkinson's undertaking activities to attain wellness through the use of Participatory Action Research (PAR) methodology.

PAR is a transformative method, and the project evolved through three successive cycles of interaction with recruited co-researchers (the MontyZoomers). The scope developed from action research (a listening and responding role), through participatory action (advising, social involvement and knowledge generation), broadening into emancipation action (regaining a political stance after group and individual identity had been [re]established).

Exchanging stories of altering health experiences (even pre-diagnosis) enabled a review of how negatively communicated beliefs and information from health professionals had formed peoples' understanding of Parkinson's (epistemology). The qualitative and quantitative projects chosen and analysed by the MontyZoomers allowed them to develop a new way of seeing their journey (ontology), one they wanted communicated to the wider health and social care professionals.

The MontyZoomers utilised their new knowledge to construct a socially-driven consensus model. The message of interdependence and hope that enables people affected by Parkinson's to remain well is what the thesis contributes to physiotherapy practice and knowledge.

In the current political climate pushing self-management and empowerment agenda for people with long-term conditions, physiotherapy education and practice can facilitate the process of self-determination for people with Parkinson's to achieve control over their own health, decided by their own actions to support one another, and be supported by all involved others through interdependent relationships within the broader community.

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 this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed:

A handwritten signature in black ink, appearing to read "Chau Ranswamy". The signature is written in a cursive style with a long horizontal stroke at the end.

Dated: 1st September 2016

Reconceptualising Parkinson's from illness to wellness: Advancing Physiotherapy practice through Action Research

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Abbreviations:

ACPIN	The Association of Chartered Physiotherapists in Neurology; a CSP professional network
AGILE	An association of physiotherapists working with older people; a CSP professional network
AHP	Allied Health Professions
APPG	All Party Parliamentary Group (for Parkinson's Disease)
APTA	American Physical Therapy Association
AR	Action Research
BGS	British Geriatric Society
CSP	Chartered Society of Physiotherapy
DH	Department of Health
EBM	Evidence based medicine
EBP	Evidence based practice
EPDA	European Parkinson's Disease Association
EQ5D	EuroQol 5 Domain measure of health status
ESRC	Economic and Social Research Council
GP	General Practice
HCPC	Health and Care Professional Council
HRQoL	Health Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
MUPS	Medically Unexplained Symptoms
NHS	National Health Service
NICE	National Institute of Health and Care Excellence (previously National Institute of Clinical Excellence)
NIHR	National Institute for Health Research
NP	A co-researcher who does not have Parkinson's. The NP categories are further split into 'S' for a spouse, 'F' for a friend, or 'P' for professional
ONS	Office of National Statistics
PAR	Participatory Action Research
PDS	Parkinson's Disease Society
PEST	Political, Economic, Socio-cultural and Technological framework
PHOF	Public Health Outcomes Framework

PPI	Patient and Public Involvement
PWB	Psychological wellbeing
pwP/P WP	People or person with Parkinson's
QALY	Quality-adjusted life year
QoL	Quality of life
RCGP	Royal College of General Practitioners
RIPE	Realistic Improvement in Parkinson's through Exercise
RCN	Royal College of Nursing
SHU	Sheffield Hallam University
SUCAG	Service User and Carer Advisory Group
SWB	Subjective wellbeing
UK	United Kingdom
WCPT	World Confederation for Physical Therapy
WHO	World Health Organization

Glossary:

Action Research	Collective self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out (Kemmis and McTaggart 1990, p5).
Ayurvedic and Eastern Medicine	The principles of Ayurvedic and Eastern (usually intimates Traditional Chinese Medicine) health philosophy stems from holistic science, treating disorders through the consideration of a person's complete way of life. This is inclusive of the body, mind and spirit, unlike in Western Medicine where management is through discrete treatment of disease processes (Ovallath and Deepa 2013, Garodia <i>et al.</i> 2007, Zheng 2009)
Co-researcher	Co-researchers are individuals who work together to achieve mutually determined and beneficial goals, reflecting a shared belief in both the means and the ends of the research (Given 2008)
Department of Health Policy (since devolution)	Since 1999, the way the United Kingdom is run has been transformed by devolution - a process designed to decentralise government and give more powers to the three nations, which, together with England, make up the UK. The United Kingdom is made up of England, Wales, Scotland and Northern Ireland. As the Doctoral Research project has been conducted in Sheffield, a northern city of England, much of the information considered pertains to the Public Health England, or Department of Health England policy.
Exercise	Planned, structured, and repetitive movement to improve or maintain one or more components of physical fitness (aerobic exercise training, resistance exercise training, flexibility exercise and balance training (American College of Sports Medicine 2009)
Full Monty Exercise Club	Exercise arm of the Sheffield Branch of Parkinson's UK (self-named, based on the location of initial classes being a room where a scene in the film ' <i>The Full Monty</i> ' was shot)
Health Promotion	Health promotion is the process of enabling people to increase control over, and to improve, their health (World Health Organization 1986)
Illness	A socially constructed term combining a biological construct (medical label of disease based on causation and origin) and social meaning (Eisenberg 1981) with an emphasis on lived experience, influenced by cultural and social systems (Conrad and Barker 2010)
Levels on interaction within a healthcare system for people with chronic conditions	Micro level (patient and family) - importance of empowered behaviour and the value of quality interactions with others in influencing the outcomes of health care Meso level (healthcare organisation and community) - creates an environment to promote quality interactions and partnerships to contextualise delivery for all, including connection with

	<p>community resources</p> <p>Macro level (policy) - develops shared values and principles for strategy and policy by connecting the patient, community and larger organisation (WHO 2002).</p>
Long-term condition	A Long Term Condition is defined as a condition that cannot, at present be cured; but can be controlled by medication and other therapies (Department of Health 2012a)
MontyZoomers	The Stakeholder Group, co-researchers for this Doctoral Research project (self-named). As they are named in the thesis, they are tagged as 'pwP' if they are a person with Parkinson's, or 'NP' if they do not have Parkinson's. The tag allows the interdependent relationship to be considered in actions or statements of the MontyZoomers. The NP categories are further split into 'S' for a spouse, 'F' for a friend, 'Partner' for partner, and 'P' for professional.
Parkinson's UK / Parkinson's Disease Society	Main charity in the UK supporting people with Parkinson's. Parkinson's Disease Society was renamed Parkinson's UK in 2011 following a campaign to develop a consistent approach to increasing awareness and understanding of the work of the voluntary organisation
Participatory Action Research	A paradigm for bridging science and clinical practice that is community-based for the creation of knowledge, combining social investigation, education, and action in an inter-related approach (Koshy <i>et al.</i> 2011, p1, Hall 2005, White <i>et al.</i> 2004).
Physical activity	Refers to body movement that is produced by the contraction of skeletal muscles and that increases energy expenditure (American College of Sports Medicine 2009).
Policy	Policy covers the vision and broad direction of a plan (World Health Organization 2010)
Sedentary living or behaviour	An issue becoming increasingly proven to be related to increasing mortality, is defined as a way of living or lifestyle that requires minimal physical activity and that encourages inactivity through limited choices, disincentives, and/or structural or financial barriers (Wojtek <i>et al.</i> 2009).
Strategy	Strategy covers the plan for implementation, and operational plan and budget (World Health Organization 2010)
Wellbeing	<p>Description agreed by Sheffield Branch of Parkinson's UK exercise participants (no one definition) taken from Scottish Executive Social Research (2006) document about mental wellbeing, and includes the elements of life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, and a sense of belonging and support.</p> <p>Some of these elements are in common with those of participants in a '<i>Shaping our Age</i>' project looking at wellbeing in older people, who would add 'feeling healthy, free from pain and able to lead a positive life' to the definition (Hoban <i>et al.</i> 2011).</p>
Wellness	Definition agreed by Sheffield Branch of Parkinson's UK exercise participants that: ' <i>Wellness is an active process of becoming aware of and making choices toward a healthy and fulfilling life</i> '

	(from University of California Davis 2015).
Western medicine	This describes the science or practice of medicine in the West, as distinguished from surgery, psychiatry, by examination to assess a person's state of physical health or fitness, by separating the physical body into discrete physiological areas or disease processes.

I dedicate this thesis to:

Karen Cotterhill 04.01.1966 – 28.08.2016, my '*fab and fifty*' kindred spirit, and one tuff mudder, I love you and miss you.

Mik Heys – my '*ripped*' husband, one mean cook, and *of course* I love you too!

Acknowledgements:

There are so many people to thank and acknowledge for their time, support and patience over this 6-year journey, without which this written work would have remained an idea, or unfinished document.

First to my academic colleagues, starting with my Doctoral supervisors who kept my synapses fired during the extended, tortuous route to submission; Dr. Jill Aylott, Director of Studies, whose light and agápē guided me to the end of the long tunnel, and Dr. Alex McClimens, who provided breakfast and space to talk based on a theory that cognition is enhanced in the well nourished (Taras 2005)!

My thanks are extended to Peter Allmark, Maria Burton, Kate Grafton and Hilary Piercy whose preparedness to explore different methodologies and ethical approaches led to the final approach chosen for this project; to Dr Hazel Horobin and Ange Wright for lending me the 'Ba(a)' hat, and to Mel Lindley for our runs that I know she kept purposely slow enough to let me talk theory or just talk!

Second, to my family (the Ramaswamy and Heys Clans) who endured this process as they tolerate most of my eccentricities and absences.

Third, to the countless friends who kept me buoyed and scolded according to need. The list of names is longer than the document word count, so I can only name a few (in alphabetical order of course): The Banditos (Bob, Pete Boot, Charlotte Forsyth, Mik and Susan Taylor) who kept my heart, head and belly filled; Cinemates (Sal Foulkes and Lynn Whyke) who taxied me to alternative worlds; the Cragmoor Crew (Bob and Jo) with sage tea and wisdom; Raymond Danger (Peter Newlands) and his 'alrightie' attitude; the Eaton Drive duo (Christine Ludlam and Richard Dexter) for feminism and film theory; Helen and Peter Fisher for Freirian philosophy and friendship; 'Happy Friday' Amy Hartley and her rhubarb crumble; the 'always-manned Jones phone' operated by Anna and CCM Alan; to Jill McClintock & Pam Couchman for being great roomies, and the Scrivens – Rita for proof reading and Dil for keeping my spirits up (with sublime whisky supplies)! Finally, to those who enriched my understanding of 'wellness' through their lived experiences of Parkinson's, Multiple Sclerosis and stroke.

PROLOGUE

I want particularly to express my gratitude to all the Parkinson's Community who have shared their experiences of living with the condition, opening their hearts and homes to teach me much of what I now understand of the condition 'Parkinson's'.

'*Staying well*' has been an often-expressed reason people have attended exercise classes run by the Sheffield Branch of the parent (national) charity Parkinson's UK. It is a concept associated with sustainability of the Branch's physical activity section, The Full Monty Exercise Club, and wider Branch activities, which forms the basis of this study.

Terms such as 'wellness', 'wellbeing' and 'illness' are social constructs, given meaning by the context they are used for, in health provision for example (Conrad and Barker 2010) or in political initiatives to promote or measure population health (Dodge *et al.* 2012, Hill 2012), as a means of monitoring resources used to fight ill health. The varied dictionary definitions inform us of the origins and historical usage, but cannot convey conceptual clarity for these terms, which embody value judgments based on personal experience (Boyd 2000).

Being 'well' is a personal experience, with differences in understanding between the idea of what it means to be 'well', to experience 'wellness' or 'wellbeing'. What follows are a few thoughts from some co-researchers¹ of this Research Project about the meaning of wellness and wellbeing to them.

The issue of confidentiality, and the naming of research participants require noting at this point. Whilst it is customary that participant confidentiality and anonymity is maintained as an ethical requirement of research, specific guidance can be obtained about institutional requirements from the Institute's Research Ethics Committees where information does not fit the ethical tradition of the research conducted (Economic and Social Research Council [ESRC] Research Ethics Framework 2015).

For this Research Project, the role of the co-researchers was of involvement in a participatory endeavour. This style of 'cooperative inquiry' i.e. inquiry where the

¹ Co-researchers are individuals who work together to achieve mutually determined and beneficial goals, reflecting a shared belief in both the means and the ends of the research (Given 2008).

research is undertaken *with*, rather than *on* people engages participants in an exploratory process to understand their own experiences. There is an assertion of their (political) rights for involvement in decisions made affecting their lives, and any knowledge generated from the process that is about them (Reason and Bradbury 2008, p9). This alters guidance around the ethics of anonymity for individuals cited or quoted in qualitative research who are part of the whole process, including any research outcomes. As per suggestions in the literature looking into the ethics of naming people seeking to advance the word of the service user by narrating their experiences (Allen and Wiles 2016, Kaiser 2009, Giordano *et al.* 2007, Grinyer 2002), people involved in the Doctoral Research project were given the choice of being named in full, or of anonymity (picking a pseudonym of their choice). All individuals named in this thesis have given their consent to be addressed by their given name.

Pamela Goff, the current Chair of the Sheffield Branch, and person diagnosed with Parkinson's, made clear the stance of those involved stating:

'I would encourage as much of this named/ personal information as possible. It's a refreshing change to read an academic paper that identifies the individuals involved as real people. I know the Data Protection Act means that patients shouldn't be identified in reports and papers, but this leads to the attitude that people with Parkinson's, or similar, are an amorphous group of people who don't have every day problems and create embarrassment if they dare to live an independent, integrated life.'

(Goff 20.08.2013. Personal communication).

This Research Project therefore departs from more traditional service-user based work in recognising a specific model of interdependence that has evolved before and during the life of this project. This is seen in the relationships between people diagnosed with Parkinson's, their carers or close family, friends and others, such as the health and social care professionals.

Having known the group members for over 15 years as a physiotherapist working both independently and in a voluntary capacity, this defines my role as an 'insider-researcher'. To explain this role and my interdependence, I have sought to become reflexive throughout this study, to provide an accountable and acceptable

narrative to the closeness of my personal and professional role with the group members. This thesis will explore and theorise the nature of this model of 'interdependence' as a concept and its role and contribution to understanding the concept of wellness with people with Parkinson's.

The next few pages serve the following purposes:

- 1) They introduce some of the 15 research stakeholders (people with Parkinson's and interdependent others), including myself as insider-researcher – we considered our group to be a collective of co-researchers self-named 'MontyZoomers'
- 2) The introductions will be made through a series of quotes about wellness and wellbeing from some of the MontyZoomers, with photographs² chosen by the narrator himself or herself enabling each of us to voice our thoughts

From this point forward, the MontyZoomers are to be understood as an interdependent group of people with Parkinson's, their carers or close family, such as spouses, friends and myself as a professional/volunteer.

The journey is a joint one but departs from traditional political theory of working with a named oppressed group through a participatory action research (PAR) methodology. The narrative documented in the thesis is of interdependence, through PAR, where all interdependent people in the relationship affect oppressive practice with people diagnosed with Parkinson's. This stance includes my own professional subjugation through the body of knowledge generated by professionals and not by people affected by Parkinson's.

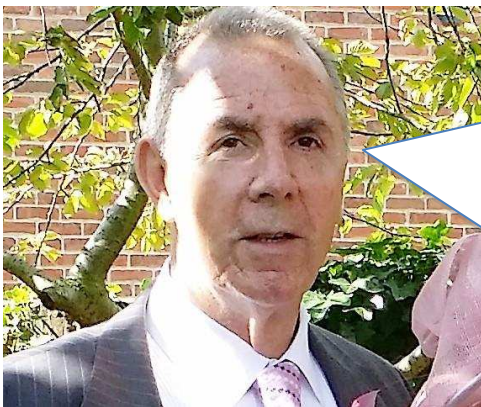
² In visual research, the utilisation of photographs has transcended their use simply as a two-dimensional representation of an image into a recognised methodology that also analyses identity and social status (Emmison and Smith 2000, 4 – 5, 190- 192).

Ann Goodall (has had Parkinson's 6 years)

I think I would not use either word – wellness or wellbeing – to me they sound sharp and uninviting. The word 'well' however, sounds soft and gentler – it means body, mind and soul in harmony



Bob Raeburn (has had Parkinson's 13 years)

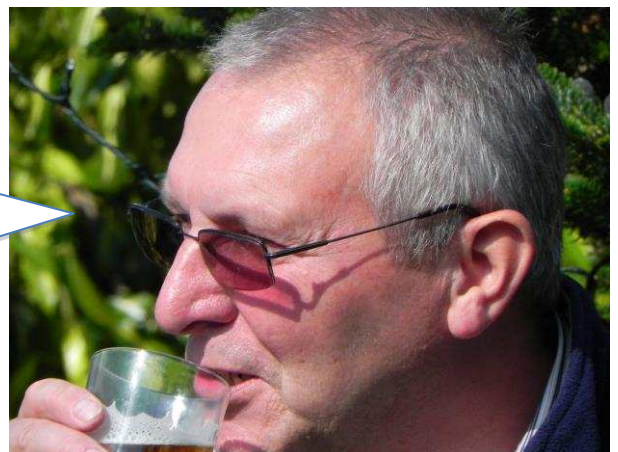


The biggest difference to my mind between Wellness and Wellbeing is that: Wellness is the specific goal we MontyZoomers [Doctoral Project co-researchers] set ourselves to achieve and maintain as good a standard of health and fitness that we were physically capable of and includes the special friendship that we enjoy as MontyZoomers - which is "special" because of what we share - those PwP [people with Parkinson's] and those who support us are a great group, whereas Wellbeing is a general term to describe your general sense of keeping well

David (Dave) Rose (Harry and Sheila Wall's

friend who does not have Parkinson's, and now a volunteer with the Branch)

'Wellness' to me means how I am feeling in purely health and physical terms, whereas 'well being' includes my non physical state on mind, in terms of 'am I happy, content, feeling good about myself'



Denise Webster (has had Parkinson's 21 years)

Wellbeing is of the brain/mind e.g. positive mental attitude. It cannot be physically measured.

Wellness is of the body and general health. It can be physically measured and monitored e.g. blood pressure

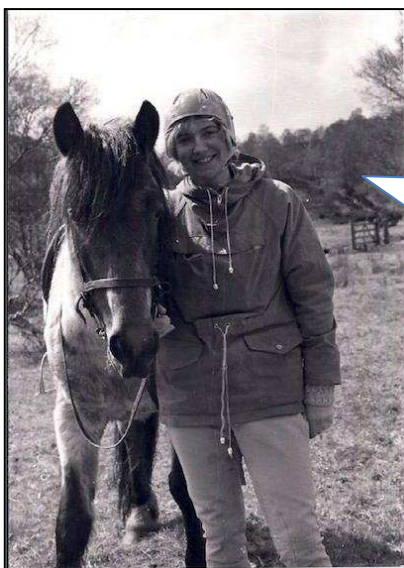


Harry Wall (has had Parkinson's 20 years) and his wife Sheila (does not have Parkinson's)



We think wellbeing means looking after someone making sure they are managing, coping in general

Wellness is how they are feeling with the illness good or bad day etc.



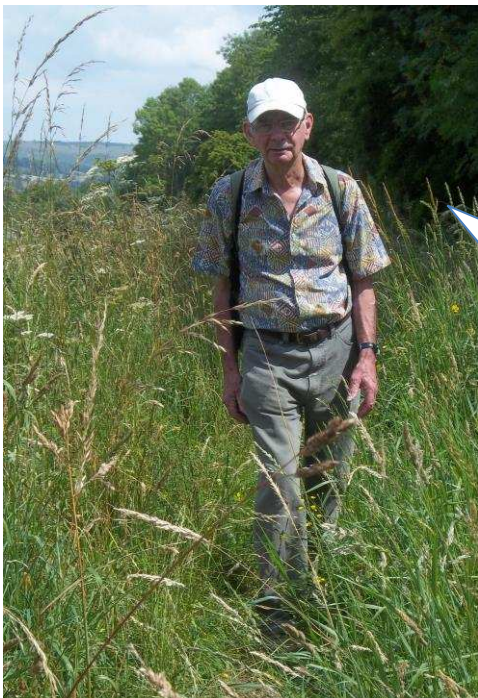
Janice Forder (has had Parkinson's 7 years)

I see 'wellbeing' as a more general term than 'wellness'. The latter is the opposite of illness. In short 'wellness' implies physical healthiness whereas 'wellbeing' suggests feeling good.

Michael (Mike) Masterson (left) and George Hart (right; both have had Parkinson's 10 years)

I think they can mean different things to different people. They experience different things at different times of what we call development. Wellbeing is a set of conditions of our bodies and our minds and those of our families, friends and neighbours. I think we use the terms wellbeing and wellness loosely. Wellness is feeling a sense of controlling ones activities.
'Well' is what matters – it feels like a good round sort of word: Father Christmassy!

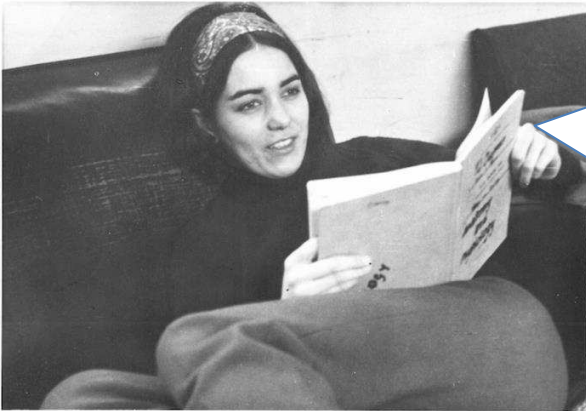
*This is how I see it:
My wellness is my physical state at any time whereas my wellbeing is my mental state at any given time.
(E.g. I can walk a couple of miles, do exercises etc. I would be happy with my wellness but if I sit back in comfort and think of my mental shortcomings and happiness that would be my wellbeing)*



Noel Parkin (has had Parkinson's 5 years)

I don't perceive a difference between the two terms 'wellness' or 'wellbeing'. Wellness comes from my interaction with others in both, or for both social and health reasons.

Pamela Goff (has had Parkinson's 7 years)



*I use the word "wellness" specifically as a contrast with the word "illness".
I believe use of "well being" is a passive state of one or more people and I wanted to emphasise the activity associated with both illness (as in treatments or 'care') and wellness (as in activities that enhance the physical, social, behavioural, cognitive and spiritual aspects of an individual).*

Sylvia Masterson (in red coat, surrounded by family, does not have Parkinson's)

To me wellness or wellbeing is both a physical and mental state. A feeling that all is well in my world, my health and happiness, and that of those whom I care about.



Bhanu Ramaswamy, thesis author and lead for this Research Project.

Wellness-wellbeing (interchangeable) is a state of health influenced by life-affirming factors e.g. positive health and life quality. Working with people affected by Parkinson's made me consider contextual influences and the changeable nature of each factor. I.e. how the social 'collective' supports a person to a greater extent than any individual health professional. We are ALL a necessary part of the mix that enables people affected by the condition to live life well, and in wellness to their best ability



An advantage of spending time with a group to whom wellness was openly expressed as an important issue allowed discussion and consensus of the definition that made most sense to them i.e. one that embraced qualities of '*flourishing*' and '*making positive health choices*' (National Wellness Organization 2003, Seligman and Csikszentmihalyi 2000).

The definition of wellness by the World Health Organization (WHO) (1967):

'Wellness is not just the absence of illness but a state of complete physical, mental, and social well-being',

was discounted by the group as being too medicalised. Class members consulted felt it implied they could never attain wellness as the nature of Parkinson's affected all three dimensions mentioned in the definition. Most reported they currently felt 'well' by their personal understanding of the term, and not ill.

An Illness-Wellness paradigm created by medical doctor, John Travis (Travis and Ryan, 2004) was also looked at. Travis's vision was to enable medical students to stop defining wellness from within a 'disease' framework, utilising a new relationship of treatment for illness and wellness along different ends of a continuum. However, it was only seen by the Parkinson's group as positive for its illustration in rainbow colours, whilst the actual message was considered too linear and directional and not reflective of the ups, the downs and what Pamela (pwP) likes to call '*the meandering path*' of the Parkinson's experience.

Denise (pwP) noted herself to be disabled, stating: '*I now have a Blue Badge to prove this*', with awareness that her diagnosis would not improve. According to the Travis continuum however, her next step was to a premature death. As she attended classes to maintain how well she felt from better movement, the diagram sat her experiences at opposing ends of the spectrum and made little sense.

The group chose a definition of wellness that allowed for the changeable nature (sometimes within one day) of a feeling of wellness and illness, and the description of wellbeing that related it to life-satisfaction (See Glossary), both which had an impact on health (Scottish Executive Social Research 2006, University of California Davis 2015).

These discussions (within and out with the Doctoral Research Project) have

created the impetus from which some of the exercise participants have redefined theirs, and my ontological belief about Parkinson's, basing it around the need to stay well. Although they agreed to use 'wellness' as the term of preference for this Research Project, the terminology of wellbeing/ wellness isn't of consequence to many within the group, as either are considered better than 'disease' or 'illness'.

Not all people had the same understanding of the two terms (wellbeing and wellness), yet it was generally accepted that *wellbeing* comprised more individualistic traits or goals of positive (mental and physical) health, whilst *wellness* was used in a more collective sense. People gained energy from activities conducted together, as integrated and interdependent groups of people, and their individual wellbeing was strengthened from the collective identity.

The MontyZoomers are:

Janice Forder (pwP)

Pamela Goff (pwP)

Ann Goodall (pwP)

George Hart (pwP)

Michael (pwP) and Sylvia (spouse) Masterson

Noel Parkin (pwP)

Bhanu Ramaswamy (physiotherapist)

Bob Raeburn (pwP) (31.07.1944 – 10.01.2017. Happy hunting Bob!)

Duncan (pwP) and Hazel (spouse) Raynor

Dave Rose (friend and volunteer)

Harry (pwP) and Sheila (spouse) Wall

Denise Webster (pwP)

Project Co-optee:

Jo Darley (partner of pwP)

External stakeholders during the Doctoral Research Project:

Dr Anna Jones, Reader, University of Northumbria at Newcastle

Iain Young (pwP), Chair Aberdeen Branch of Parkinson's UK

In consultation with:

Committee members of the Sheffield Branch of Parkinson's UK

CHAPTER 1: INTRODUCTION

1.1 An overview of the Doctoral Research Project

The primary focus of the Doctoral Research Project (referred to henceforth as 'Research Project') was to enable the development of the concept of wellness³ in a group of people in Sheffield affected by Parkinson's⁴. The process was fostered through their engagement as co-researchers of the Research Project, gradually watching them regain confidence to become involved socially and politically with Parkinson's-related events (for local needs and to the wider community), as would be expected of any empowered citizen.

This was achieved in spite of the negative implications medical labelling ascribes Parkinson's, a neurological condition with 'disease', 'incurable' and 'illness' implicit in its progressive, degenerative nature and name. This branding is perpetuated by influential health professions and organisations that control (international) health policy and strategy⁵ (National Institute of Health and Clinical Excellence [NICE] 2006, WHO 2006). It strips people of social identity, interrupts life-course and experience of wellbeing (Soundy *et al.* 2014).

The written work that follows considers wellness through a process of discovering who holds the power and control that normally determines the (expected) behaviour of people diagnosed with Parkinson's living in the community, involved in support group activities. Participation in the Research Project altered the co-researchers' understanding of their condition enabling them to construct a social framework that offered a chance to self-determine personal requirements through the course of Parkinson's.

Through a model of interdependency, all affected by Parkinson's demonstrated facets of 'wellness' (through Participatory Research Action [PAR] methodology),

³ The term 'wellness' was the preferred word used by the co-researchers with Parkinson's as clarified in the *Glossary*.

⁴ The term 'affected by' is inclusive of people with the diagnosis of Parkinson's, their friends, family and carers, plus professionals who deliver services to improve the life quality of people with the condition. Parkinson's UK also consider it good practice to use the word *Parkinson's* in preference to the term *Parkinson's disease* when undertaking to describe the condition, or to refer to individuals with the condition as 'people with Parkinson's'.

⁵ As WHO definitions are utilised in much UK health documentation, their definition of policy and strategy has been utilised. 'Policy' covers the vision and broad direction of a plan, whilst 'strategy' covers the plan for implementation, and operational plan and budget (WHO 2010).

and have provided the physiotherapy profession (my background) an understanding of a way to support people affected by Parkinson's.

1.2: Structure of this document

Chapter One outlines the background to the Research Project setting out the research question and aims undertaken with co-researchers affected by Parkinson's, providing some underpinning context of the work.

Chapter Two comprises the literature reviewed that explores perspectives of wellness, wellbeing and illness, the values upon which this Research Project is based. The viewpoints are appraised from an ontological stance of key players who impact the lives of community dwelling people affected by Parkinson's. Policy drivers in the United Kingdom (UK) are reviewed, providing an epistemological positioning of how physiotherapy practice knowledge has evolved into its contemporary form.

Chapter Three investigates the use of PAR, the chosen methodology for this Research Project undertaken by the key players of people affected by Parkinson's. This style of research is community-led, involves co-researchers from marginalised groups commonly seeking to improve conditions and practices, supporting one another to understand their situation and change it through collective inquiry and reflection.

The information gathered through methods chosen by the co-researchers have been interpreted and analysed to inform **Chapters Four, Five and Six**. These data chapters respectively describe the process of emergence from diagnosis to wellness of the co-researchers, exploring survey data characteristics of wellness, focus group discussions, and personal stories and for this group of people through iterations of three PAR cycles. The motivation of the stakeholder group (self-named the MontyZoomers) to sustain wellness redefined their ontological beliefs through this research process about living with a diagnosis of Parkinson's. Their newfound joint knowledge was used to co-construct a social (positive health) framework, based on their interdependent relationships to run beside the linear (negative health) medical models describing condition progression and degeneration.

Chapters Seven and Eight respectively discuss the significance of the research and the reconceptualisation of Parkinson's. The implications for the physiotherapy profession are considered in terms of how the use of PAR has accentuated the manner in which physiotherapists isolate people within their 'illness', instead of embracing our wider health roles and relationship to social organisational structures. It is these wider associations that enable people to attain wellness and my contribution to new knowledge is identified in Chapter Eight, with recommendations for research, policy and practice from the Research Project findings in terms of possible Parkinson's-developed quality indicators.

Chapter Nine provides a conclusion to the thesis, followed by the Epilogue.

There are two issues for the reader to be aware of in terms of the whole document:

First, although I was the Research Project instigator, and for clarity of University documentation the Principal Investigator and author of this written work, the decisions taken over group undertakings, analysis of information gathered during the 18-month Research Project period, and agreements of outcome was shared amongst the MontyZoomers. This is consistent with the core values of (and my emergence as) an action researcher.

Second, before I undertook the Research Project, my involvement with the Sheffield Branch of Parkinson's UK committee member and co-ordinator of physical activities extended over a 16-year period. As is appropriate in this style of Action Research, the narration fluctuates between third and first person accounts reporting objective or reflexive stances with interpersonal dialogue that occurred with the co-participants in the project (Reason and Bradbury 2008, p6).

1.3: Background to the Doctoral Research Project

The rise of ill health (physical and mental) and increasing diagnoses of long-term, chronic conditions (see Glossary) affecting the nation means attainment of health and wellbeing is given primacy in health policy and strategy in the UK (Government Office for Science 2016, Department of Health [DH⁶] 2012b, DH 2011a, DH 2011b, DH 2010a, DH 2010b, DH 2007, DH, 2005a, DH 2004, DH

⁶ See Glossary under 'Department of Health and devolution', regarding the use of policy literature pertaining to England

2001a, DH 1997). The positive impact of feeling well creates a healthier society, enabling those already diagnosed with a long-term condition⁷ resilience to withstand health set backs (DH 2012b, DH 2010a and b), whilst reducing the financial burden on the Treasury from increased health costs (Health and Social Care Information Centre 2010).

Historically, events have positioned the medical profession as ultimate experts in health practice (Gawande 2015, p69, Illich *et al.* 1977, p20–26, Parsons 1951, p430-35), making decisions on behalf of others and influencing strategy in ways that do not always fit the ethos of inclusive policy. ‘Choice’ is based on the conclusions of robust (statistically-proven) scientific research (Coulter and Collins 2011, DH 2010a), with wisdom possessed by the general population ‘*disqualified*’ as inadequate compared to the erudite knowledge of the health professionals maintaining control of decisions (Foucault 1977, p82-83).

These conventions are being challenged. International networks such as the Evidence Based Research Network, create opportunities for shared and innovative research shaping health practice of the future. The broader paradigm of mixed research methodology merging the experiences of clinicians and people with medical conditions is enhancing the collective of health knowledge (Flemming 2007, Rycroft-Malone *et al.* 2004).

Physiotherapy practice has undergone significant change to match these developments (Chartered Society of Physiotherapy [CSP] 2015, American Physical Therapy Association [APTA] 2011, World Confederation for Physical Therapy [WCPT] 2011), but expansion into novel working environments with advanced therapeutic roles requires a transformation in physiotherapy education and practice too (CSP 2012 a and b, APTA 2011, WCPT 2011). Wellbeing is now an integral and global treatment outcome:

‘Physical therapists provide services that help people maximise their quality of life, looking at physical, psychological, emotional and social wellbeing’ (WCPT 2011).

The UK regulating body, the Health and Care Professions Council [HCPC], has adopted international policy in their description of professional expectation:

⁷ A long-term condition is one that is presently incurable, but has controllable symptoms (DH 2012a)

'Physiotherapists deal with human function and movement and help people to achieve their full physical potential. They use physical approaches to promote, maintain and restore wellbeing' (HCPC 2014).

It still intimates provision of physiotherapy to a (passive) recipient population as per the underpinning culture of the profession, but a more critical future for physiotherapy practice and research is emerging (Kell and Owen 2008, Parry 1997).

Service provision is not always accessible to all, and therapies do not always address patient-specific needs (All Party Parliamentary Group for Parkinson's Disease [APPG for Parkinson's Disease] 2009, Parkinson's Disease Society [PDS] 2008, Enderby *et al.* 2000), but increasing transition towards partnership models of the new research paradigms means individuals with long-term conditions can determine their own care and support needs (Coulter *et al.* 2013, Rycroft-Malone *et al.* 2004). People with conditions such as Parkinson's increasingly turn to non-health sources of information and support to improve their wellbeing, promote optimal health and personal potential, regardless of any medical diagnosis (PDS 2008, Bergman 1983).

Health research investigating whether people with long-term conditions can be educated to improve their condition management and wellbeing outcomes is positive (Gatley *et al.* 2007, Wilson *et al.* 2007, Barlow *et al.* 2002, Alderson *et al.* 1999). The initiative to lessen health and social care costs may have driven the self-management and empowerment models (Ham *et al.* 2012, Gatley *et al.* 2007, Barlow *et al.* 2002), but have also created opportunities for laypersons to be part of the health debate (Coulter *et al.* 2008).

Sharing of experiences is evident in clinical encounters, but the use of personal expertise to construct new knowledge involves a different way of thinking from researchers (Laws 2009, Gesler 1992).

Whilst working with well, community-dwelling people over the years who self-referred to an exercise club for people with Parkinson's, I observed how social-engagement developed an active socio-political community, engendering support and concern for one another's wellbeing. This was different to hospital-based observations, where treatments were dictated based on professional knowledge

and expertise to a more passive patient caseload in a clinical environment (Conrad and Barker 2010, Laws 2009, Gesler 1992).

I had heard Pamela's⁸ (pwP) perspective at teaching events and meetings saying:

*'The NHS [National Health Service] looks after our illness; **we** look after our wellness'.*

Her statement highlighted how people sought varied (non-health) methods to manage their Parkinson's as part of a personal responsibility to keep well.

Understanding better what other people with Parkinson's might make of this statement fashioned my thoughts about the role exercise classes played in maintaining participant wellness, sparking the subject of the Research Project.

1.4. Research purpose and questions, plus and overall objectives of the Research Project

1.4.1: The primary Doctoral Research Project purpose and research question

The Research Project was set up to explore how support might be sustained to maintain wellness in members of the Sheffield Branch of the national charity, Parkinson's UK, who took part in Branch-funded exercise classes for its members.

It was conducted using a participatory and emergent methodology, developing through a series of reflective research cycles, each prompting subsequent action (Reason 2006). The activities and expectations of the co-researchers soon extended beyond just our exercise group and Branch to encompass projects impacting on people with Parkinson's across Sheffield.

My position as a student of a Doctorate in Professional Studies influenced this study towards examination of my professional role, campaigning to develop physiotherapy champions who support wellness in those with the neurodegenerative condition, Parkinson's.

This contradicts the mainstay of physiotherapy practice for a person with Parkinson's viewed from the medical model lens, perpetuated by clinical practice

⁸ Pamela Goff is an exercise class participant diagnosed with Parkinson's and a co-researcher in this Research Project

guideline defining individuals by their physiology and function (Keus *et al.* 2014, NICE 2006, Keus *et al.* 2004).

In order to develop insight and awareness of the strength and support people affected by Parkinson's could offer to others in their 'community' the research question evolved to ask:

How can people affected by Parkinson's be supported to have a voice to define and enable their 'wellness', and restore or sustain their individual political and social contribution to this Parkinson's group?

1.4.2: The Research Project objectives

The MontyZoomers (Research Project co-researchers) agreed the importance of understanding why the Parkinson's UK Sheffield Branch Committee took decisions to support activities, and how directives from the national headquarters (London) affected these decisions.

Thus were decided the first two objectives:

1. To chronicle the evolution of the (physical) activities programme of the Branch, and its development to represent the membership needs and vision of the national charity.
2. To investigate exercise class members' opinions of why they attended, and what would enable classes to become self-sustaining

Two further objectives were identified, one that supported the academic expectations of the Doctorate, and one a more personal objective

3. To explore the role of physiotherapy for people with Parkinson's undertaking activities to attain wellness, yet labelled with a medical diagnosis that implies deterioration and illness
4. To gain personal experience and involvement in PAR as a process of enhancing the quality of health for people with Parkinson's.

Elements of the Research Project altered over time as participants became more engaged within the project and increasingly vocal in decisions agreed upon (Reason 2006). As the Research Project progressed, plans were revised and broadened to give greater significance to activities *in addition to* existing exercise

classes the Branch Committee might support (Greenwood *et al.* 1993).

1.4.3: Reflexivity in the research project write-up

A colleague and I established this exercise group in 1999, so I have known participants for a long time, some for 15 plus years. Therefore the information could neither be neutral, nor free from a subjective stance as expected in positivist research (Pillow 2003, Lather 1986). The choice of a critical research approach through participatory methodology placed the control of outcome with the co-researchers more so than if it had been obtained through a more objective, scientific approach (Lather 2004).

To limit acknowledged personal bias, to establish trustworthiness of the research process and credibility of the information generated, gathered and investigated, a self-critical stance in the application of the information presented was required through a process of reflexivity (Cumming-Potvin 2013, Lather 2004, Pillow 2003, Lather 1986).

Reflexivity involves the practise of self-awareness to enable transparency in the process of knowledge construction in qualitative methodologies (Pillow 2003). It differs from 'reflection' as is influenced by the actual research process (Lather 2004, Pillow 2003). Consciousness to represent the notions of those involved in the study is not excessively self-analytical (Cumming-Potvin 2013), but balances the 'self' as writer whilst recording the social and political ideology of all involved (Cumming-Potvin 2013, Pillow 2003). Critical methodology is preserved by capturing varied and multiple voices of the 'others' who participate in the research and contribute to the information gathered (Cumming-Potvin 2013, Pillow 2003). No one interpretation can be presented as a final truth (Cumming-Potvin 2013), or treated as a 'neutral technique' (Mauthner and Doucet 2003).

This makes reflexivity uncomfortable and difficult as the author positions themselves to explore their own role in the research, disclosing aspects about their relationship that differ in terms of ideology and experience from that of the co-researchers (Pillow 2003), more so if he or she is an 'outsider' to those being researched (Cummings-Potvin 2013). The process challenges identified, socially embedded norms and habits underpinning forms of power, and power relationships in the research process (Pettit 2010, Reason and Bradbury 2008, p100, Pillow 2003).

1.5: Setting the scene

1.5.1: The Full Monty Exercise Club

The Full Monty Exercise Club provides community-based exercise to people affected by Parkinson's, informed by physiotherapy practice guidelines and evidence (Plant and Jones 2001, Ramaswamy and Webber 2003). It was initially funded using local partnership monies for work undertaken between health and voluntary sector services (Addicott 2013, DH 2011a and b, 2010a, 2007), heralding the formation of the exercise division of the Sheffield Branch of Parkinson's UK.

Classes are accessible to those who self-refer, or those discharged from NHS rehabilitation services, and provided into the long-term, in addition to NHS time-limited courses in Sheffield for people recently diagnosed with Parkinson's (Parker 2014, Francis *et al.* 2014).

Group activities providing both health and social benefits are critical in engaging participation of people over a prolonged period (Bayly and Bull 2001), so our agreement with the Branch Committee was for The Full Monty Exercise Club to:

1. Promote regular physical activity for people with Parkinson's
2. Provide a 'safe' social atmosphere to participate in with peers, under the guidance of physiotherapists advocating on-going, self-management, knowledge and experience sharing opportunities (Laverack 2005, p62–64).

From the outset, participants demonstrated responsibility to improve their health, many indicating enjoyment at the prospect of exerting ownership, developing social bonds and their wellness (Bidonde *et al.* 2009, Bayly and Bull 2001).

The original class participants in 2000 actually chose the club's name on the basis that classes were established at a venue where part of the film *The Full Monty* was shot. The name has been a source of amusement to participants on many occasions, illustrating humour emergent from socialised groups (Scott *et al.* 2014, Solomon 1996). It was an important aspect of positive group dynamic encouraged to create adherence to activity for people with Parkinson's, a condition

where motivation and self-efficacy to continue exercise becomes a challenge (Ellis *et al.* 2013 and 2011, Ene *et al.* 2011).

The Doctorate in Professional Studies Research Project provided an opportunity to explore the capabilities of the people who were members of the Full Monty Exercise Club, its relationship to the Sheffield Branch of Parkinson's UK, and the roles undertaken by key members, including myself.

1.6: Coming up next

The concepts of wellness, wellbeing and illness are explored in the next chapter as the central tenets of this Research Project. They are considered from the perspective of the profession of medicine (influential over health care provision), of physiotherapy, and the perspective of people affected by Parkinson's.

A brief introduction to Parkinson's as a condition is provided, allowing exploration of how physiotherapy practice has developed (from historical origins established under the guidance, agreement and continued influence of the medical profession).

The concerns about the predominantly impersonal focus of current physiotherapy research and practice set the scene for the chosen methodology for the Doctoral Research Project and subsequent chapters.

CHAPTER 2: LITERATURE REVIEW ON THE PERSPECTIVES OF WELLNESS, WELLBEING AND ILLNESS

2.1: Introduction with rationale for the literature search strategy

The CSP, the professional body for physiotherapists practicing in the UK, describe physiotherapy as:

‘...a healthcare profession that works with people to identify and maximise their ability to move and function. Functional movement is a key part of what it means to be healthy. This means that physiotherapy plays a key role in enabling people to improve their health, wellbeing and quality of life (CSP 2011).

The theme of wellness and health (decided by the people affected by Parkinson’s) and wellbeing (from a healthcare professional perspective) informed the Doctoral Research question.

A research process should involve a review of related literature around a subject to be investigated, not only to understand the perspective of available proof, but to identify gaps in that information (Abeyasinghe and Parkhurst 2013). An approach favoured by health professionals supported by the National Institute of Health and Care Excellence (NICE) is the ‘PICO’ method, which constructs a detailed search by identifying the Population or Perspective, Intervention, Comparison and Outcomes of a study (Lennon and Stokes 2007, p 7 – 9, Booth 2004, pg 61 - 70).

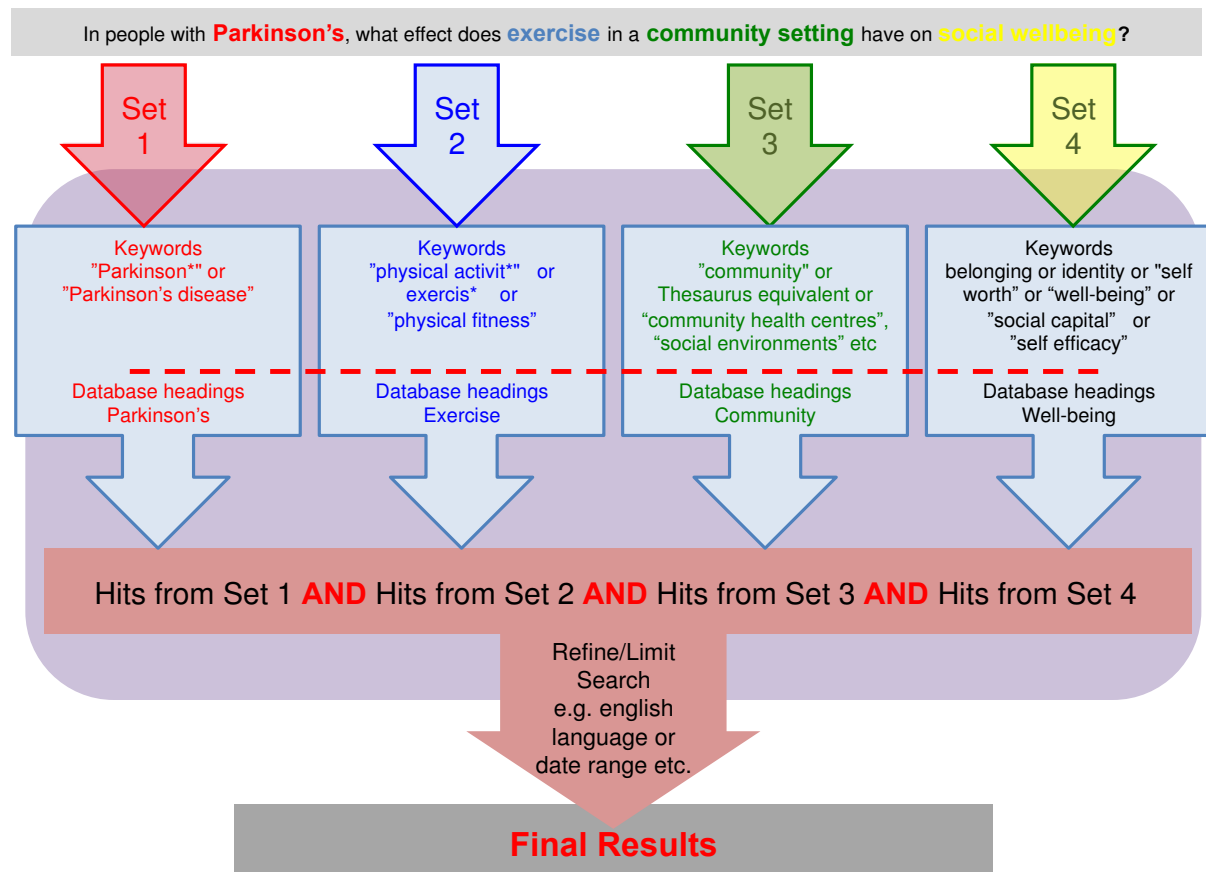
An initial literature search was undertaken after a discussion with an Information Specialist at Sheffield Hallam University (SHU) to determine the best databases to explore given the breadth of the question. The main electronic databases used initially (January 2013) were CINAHL, Medline, SPORTDiscus, PsycINFO, ScopusLit and AMED.

At this point when first searching literature, the idea was to consider wellness from a perspective of those participating in exercise classes, so for example, *population* or *perspective*, used search terms such as ‘community-dwelling’, ‘people with a long-term condition’ or ‘Parkinson’s’. For *intervention*, used terms that promoted wellness and health such as ‘exercise’, ‘physical activity’, ‘fitness’; for *comparison*, terms used included ‘individual’ and ‘physiotherapy’ in a ‘community’ or ‘social’ setting, and for

outcome, sought effects such as 'wellbeing', 'exercise benefit', 'motivation', 'behaviour' and 'social capital' (Figure 2.1).

A filtering strategy was utilised to combine terms and refine the search based on the four aspects of what impact exercise/ physical activity in a community setting had in supporting the wellbeing of people with Parkinson's (Figure 2.1).

Figure 2.1. Initial literature search strategy



To maintain focus on the areas of relevance to this study, and keep the number of publications viewed within reason, titles and abstracts of articles sourced were screened for applicability, excluding those not written in English, or alluding to very different circumstances (clinical settings and younger age groups).

The PICO strategy draws from the customs of evidence-based medicine (Sackett *et al.* 2000), as do the traditional databases used to search for literature, with a resultant group of articles found that followed a positivist, scientific paradigm attempting to prove cause and effect from short term interventional studies. During the period I was undertaking the literature review guided by the PICO strategy, I was

still working with people affected by Parkinson's, listening to their stories. The narratives of their experiences felt disconnected from the literature being obtained through the search with little found that supported the social quality of wellness that people involved in this Research Project were describing. The research evidence found using the initial strategy was concerned more with outcomes of investigation utilising varied tools that measured aspects of wellbeing of people in the community or hospital settings following a particular intervention (usually physical or medical), and not around dialogue and stories that dealt with maintenance of support.

Wellness and wellbeing⁹ were linked to 'health' (Mackey 2000) and 'quality of life' (QoL) (Barnes *et al.* 2013), each considered as having similar traits of personal experience and perception depending on context (Barnes *et al.* 2013).

The perspectives of 'health' that were investigated, integrated internal features such as genetics, diseases, cognition, and emotions, and external characteristics, such as relationships and experiences (Wells 2015). One paper distinguished health as a '*state of being*', as opposed to wellness, considered a '*process of being*' (Jonas 2000, p2).

QoL also had many definitions according to notion and need. Health professionals working with people post-stroke perceived QoL to mean happiness, physical ability and social wellbeing (McKevitt *et al.* 2003). In health policy, QoL was defined as the '*average EQ5D¹⁰ score reported by people with long term conditions*' (DH 2010c, Rabin and de Charro 2001). These exclude the positive relationships exemplified by older people asked what QoL included, who stated feeling safe in the neighbourhood, access to services, having money and the mental and physical ability to engage in personal hobbies and leisure, plus having control (autonomy) and a role in society (Hoban *et al.*, 2011. Gabriel and Bowling 2004, Higgs *et al.* 2003).

Although informative, the returns from the search strategy did not fit with what people affected by Parkinson's were saying about their perception of wellness, which strongly engendered socio-political engagement. The literature obtained using this

⁹ In health practice and research, the terms 'wellness' and 'wellbeing' are used interchangeably, with 'wellbeing' used more widely in health research and policy. In this thesis, the terms will be used according to the specific source from which they came.

¹⁰ The EQ5D (EuroQol) is a self-completion, standardised measure of self-reported health outcome with 5 domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

method omitted the user voice, with no co-research evident in community projects. A different research paradigm was required.

In a later search to update the review (March 2014), more effort was made to specifically identify participatory research articles and qualitative narratives.

My approach thus transitioned to incremental searching, starting first by reading policy documents from websites plus books (hitherto set aside for the bibliography) that described aspects of wellness or wellbeing (Edwards and Talbot 1999, pp 20-21). This approach more satisfactorily led to further sources of relevant literature (many in report form) that verified stories and accounts of wellness from people with long-term conditions. This alternative style of searching provided a user-focused strategy, more valid and commensurate with the thoughts of the people as noted in the Prologue.

The individuality of experience of health, wellness and QoL, the multiple, and context-dependent descriptions (differing cultural understanding and societal use) make a definitive definition unattainable (Corbin and Pangrazi 2001). All are pivotal concepts to human flourishing (Dodge *et al.* 2012, Seligman and Csikszentmihalyi, 2000). The literature of (Public) Health addresses and measures individual needs yet expects to influence a collective population. The opposite is found in professional (e.g. medical and physiotherapy) literature, where the information is gained from a wider population yet utilised to rationalise individual management.

An issue that pushes healthcare into the political arena is that at one and the same time, there is an attempt to deal with individual needs at a societal wellbeing level, whilst serving the populous from the economic standpoint (Bambra *et al.* 2005, Diener and Seligman 2004). Although currently an unachievable financial conundrum, the social determinants that are the foundations of good health are responsive to political interventions and action (Bambra *et al.* 2005, DH 2014a, Addicott 2013).

To establish the theoretical framework for the thesis and justify the research question, the literature pertaining to wellness, wellbeing and of illness has been reviewed from four viewpoints: Public Health (the driver of social policy towards population wellness), medicine (the origins of my profession), physiotherapy, and the perspective of people affected by Parkinson's.

2.2: A Public Health perspective of wellness, wellbeing and illness

The concept of wellness is given prominence because holistic approaches to influence environment, housing, health, and nutritional factors are linked to worldwide disease prevention and health promotion (DH 2014b, WHO 2006, 2001). Alongside gross domestic product, social and environmental measures, it provides a representation of how society is faring (Office of National Statistics [ONS] 2012).

Wellness in the Public Health arena is discussed as a concept about more than just the individual. It is described in the literature as an active process of becoming aware, making choices towards a '*more successful existence*' (National Wellness Organization 2003), and '*a healthy and fulfilling life*' (University of California Davis 2015), with two focal concerns potentiating: '*...an individual physically, psychologically, socially, spiritually and economically,*' and the realisation and fulfilling of: '*...one's role expectations in the family, community, place of worship, workplace and other settings*' (Smith *et al.* 2006, Greenberg 1985).

Similarities to those of wellness are evident in (multiple) definitions of 'wellbeing', that include aspects of the individual '*...positive physical, social and mental state*', are about '*...absence of pain, discomfort and incapacity*', whilst giving individuals a sense of purpose and ability to achieve personal goals and participate in society, a feeling of safety and connection with people, communities and the environment (Barnes *et al.* 2013, Hoban *et al.* 2011, Department for Environment, Food and Rural Affairs 2010, NHS Confederation 2009, Blanchflower and Oswald 2008, Scottish Executive Social Research 2006). People describe life satisfaction, associated with involvement with social networks, optimism, self-esteem, mastery and feeling in control as important (Xu and Roberts 2010, Fowler and Christakis 2008, Scottish Executive Social Research 2006).

All descriptions acknowledge the highly personal and individualistic understanding of being well yet recognise a relational context in which the person undertakes their choice of activity with others. The current healthcare system and practice segregates people, whether by socio-economic status or race (Bambra *et al.* 2005), by health condition (Ustün *et al.* 2003, Ustün 1999), disability (Kitchin 1998), geography (Eng *et al.* 1997) gender (Bauer *et al.* 2009), and so on. This

level of isolation can be detrimental to the health of people with a long-term condition (Freedman *et al.* 2012, Lucas 2007, Scottish Executive Social Research 2006, Jensen and Allen 1994).

There are many constructed frameworks, and in health research literature, the two most commonly used are Subjective wellbeing (SWB) and Psychological wellbeing (PWB) (Huppert and So 2013).

SWB covers personal feelings of happiness, life satisfaction, positive emotions and meaningfulness, known to have an advantageous impact on illness (DH 2014b, nef 2012), particularly where involvement in social and community activity is high (nef 2012). The concept of PWB considers more the theories embracing aspects of happiness and life-satisfaction that account for personal wellbeing, including aspects of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth (Ryff 1989).

Whilst both concepts are necessary, they have been considered divergent, with PWB approaching wellbeing from a 'eudaimonic' perspective i.e. relating to sense of meaning, values, dignity, virtue, or purpose far more in relationship with others, as opposed to the SWB approach given the more individual 'hedonic' traits e.g. feeling good, pleasure, or satisfaction (Ryff 2014, Henderson and Knight 2012).

It is vital to allow for variations in wellbeing status as people's lives change. For example, the dynamic equilibrium theory of wellbeing (Headey and Wearing 1989), the effect of life challenges on homeostasis (Cummins 2010) and the lifespan model of development (Hendry and Kloep 2002) have been combined with the idea of human flourishing (Seligman 2011), to provide a definition of wellbeing as a concept illustrated by a see-saw visualising wellbeing as:

'.....the balance point between an individual's resource pool and the challenges faced' (Dodge *et al.* 2012).

The concept depends on a person recognising and being supported to utilise existing psychological, social or physical resources to keep in balance as they experience differing psychological, social or physical challenges (Foot *et al.* 2012). It differs from the lifestyle behaviour view of the WHO wellness definition, which suggests one can attain a single optimal moment of wellness (Smith *et al.* 2006).

The more dynamic view (Dodge *et al.* 2012) is relevant where health states fluctuate. The 'wellness–illness' relationship is portrayed as dialectical in that health, wellness, and illness are part of the same discussion and define each other. Without illness there would be no concept of wellness, each changing proportionate representation (Jensen and Allen 1994), allowing one or the other to be more in the foreground, as suggested in the *Shifting Perspectives Model* conceptualised about how people with chronic illness manage their condition (Paterson 2001).

The global Public Health message is pushing a more positive focus of wellness and health inclusive of the needs of carers, and has shown the positive impact on societal health of people who are more socially connected with others (Fowler and Christakis 2008). Research still classically focuses on more negative aspects and impact on health on the individual with the diagnosed health issue (Glendenning *et al.* 2015). For example, people who exhibit more negative emotions e.g. stress (a proxy for wellbeing), have poorer healing, decreased immunity, increased risk of illness and slower recovery from illness compared to those with a more positive outlook (Lamers *et al.* 2012, nef 2012, Gouin and Keicolt-Glaser 2011, Barak 2006). In such cases, life expectancy provides a measure of health status (WHO 2016), with wellbeing quantified by SWB or objective wellbeing to consider basic human needs (DH 2014b).

2.2.1: Measuring wellness or wellbeing in the Public Health domain

Wellness and wellbeing have moved from the peripheries of treatment expectation to being a central theme of Public Health policy (Dolan *et al.* 2011, DH 2009), with an expectation the concept can be measured (Barnes *et al.* 2013, nef 2012).

A single wellness score cannot measure the divergent characteristics with health related quality of life (HRQoL) capturing physical, emotional and social wellness of individuals (Hechtner *et al.* 2014, Jones *et al.* 2014, Bowling *et al.* 2007), but often omitting wider contributions people make to their community and relationships with others (Dodge *et al.* 2012, Shah and Marks 2004).

The UK ONS who provide country-status statistics that inform policy, measure 10 domains of wellbeing (ONS 2013a and b), using easily calculated measures for

example, of income, population happiness, or health profiles and mortality (Barnes *et al.* 2013, Dolan *et al.* 2011, Pickett and Wilkinson 2010, Sassi 2006). In terms of wellness, SWB (hedonic) measures of people's perspective on life are easier to measure these than the eudaimonic ones (Diener and Seligman 2004).

Measures of societal determinants of better housing, transport, education, and social support that affect wellbeing status are comparatively neglected due to the infrastructural costs and resources needed, hence provide little proof of improved population health (nef 2012, Marmot Review 2010, Marmot 2005, Dahlgren and Whitehead 1993), or spiritual health, itself hard to define due to its personal nature (Greenberg 1985).

We know that the happier and healthier people are, the longer they live (Deiner and Chan 2011, Xu and Roberts 2010), coming full circle to the basis of Public Health policy driving quality and vitality for longevity (Buck and Gregory 2013, Shircore 2009). However, a major shortfall of Public Health policy is in not promoting measurements of relationship quality, and of interdependence.

2.3: A medical perspective of wellness, wellbeing and illness

In addition to wellness, illness also has a biological construct (the label of disease) and social meaning (Eisenberg 1981), as does disability (Kiernan 1999). People can live well with most long-term conditions, but the language of illness pervades allowing 'sickness' to become the focus of life, and not the reason for death (Stacy 1988, p143).

Medical practice became politicised in the 18th Century as provision of services for payment divided society into those who could afford to be healthy and those who could not (Lynch 2014, Bambra *et al.* 2005). The political processes of the 1940s placed 'modern medicine' within the developing social systems, setting expectations doctors would apply their professional knowledge and skill to cope with illness and disease (Bury 2001, Parsons 1951, p432-435). The social system envisioned health as a prerequisite for individuals to function in society, with illness, and the 'sick role' a disturbance of this ability, requiring treatment (Parsons 1951, p430–431).

The medical model developed by categorising conditions according to etiology (causation and origination), leaving little room for variation in presentation (Gage 1997). This contrasted the social constructionists' emphasis of the role and experience of sickness influenced by culture, society and the Welfare State (Freedman *et al.* 2012, Conrad and Barker 2010, Boyd 2000, Kiernan 1999).

2.3.1: Medical labelling of Parkinson's

In the western world, Parkinson's (disease) is a medically diagnosed neuro-degenerative condition, with no known cure (Parkinson's UK, 2014).

Symptoms and treatments were recorded in ancient Sanskrit Ayurveda (Ovallath and Deepa 2013) and Traditional Chinese Medicine centuries ago (Zheng 2009), but the condition was named after James Parkinson, whose published work (1817) detailed six cases of patients with a shaking palsy (Parkinson 1817)¹¹.

Medicine views Parkinson's pathologically as a decline in motor (movement-related) and non-motor function over the course of the condition affecting QoL (Hechter *et al.* 2014, Schrag *et al.* 2000a). The understanding is reductionist (Beresford 2010). The social consequences are of an illness label, with a detrimental effect on wellness (Conrad and Barker 2010, Jenkinson *et al.* 1995), undermining a person and their family's method of coping (Conrad and Barker 2010, Ellis *et al.* 2011a and b, Chenoweth *et al.* 2008, Fleming *et al.* 2004,). Many people on receiving this life-changing diagnosis are not left clear of the future implications (APPG for Parkinson's Disease 2009 PDS, 2008, Pinder 1992), hence continue to seek professional support (Chenoweth *et al.* 2008, Whitney 2004).

In the UK, of the one in 500 people diagnosed with Parkinson's, most are over 50 years, but five percent of under 40 year-olds are diagnosed, still of working age with family to raise (Gumber *et al.* 2016, Parkinson's UK 2015, Pringsheim *et al.* 2014).

Diagnosis occurs through observation, physical testing and investigation to detect physical (motor) manifestations of slowness (bradykinesia), with stiffness (rigidity) and tremor (NICE 2006).

¹¹ An upbringing strongly influenced by both traditional Indian (Ayurvedic) and modern Western medicine (see Glossary for distinction) has permitted me to embrace a dual approach with people with medical conditions.

Life expectancy is within a few years of the general population, but physical and cognitive decline occur sooner. Symptomatic medication intervention treats the deficit of the chemical neurotransmitter, dopamine, but is only effective for a few years (NICE 2006). The promotion and maintenance of QoL, wellness (and hope) for as long as possible becomes essential, but only considered more widely than through the doctor/health professional-patient relationship (Gross *et al.* 2014, Keus *et al.* 2014, Eccles *et al.* 2011).

Numerous non-motor symptoms are associated with Parkinson's, many discernible prior to the motor signs (Braak *et al.* 2004). Issues such as mild cognitive impairment (changes to memory, planning or thinking), or urinary and bowel dysfunction have more catastrophic implications on socialisation and QoL than the motor symptoms (Chaudhuri *et al.* 2006, Schrag *et al.* 2000 a and b).

2.3.2: Measuring wellness or wellbeing in the medical domain

Medical parlance measures health behaviour in terms of individuals.

Taking medication as prescribed is measured through 'compliance' (Sacket *et al.* 1975), 'adherence' (ability and willingness) (Inkster *et al.* 2006), or 'concordance' (decision with patient) (Vermiere *et al.* 2001).

Condition progress is monitored through linear scales (Venuto *et al.* 2016) for individual 'disease' progression from diagnosis (stage 1) to advancement (bed-bound, requiring full cares) (stage 5) (Hoehn and Yahr 1967) (noted as part of Appendix 8); through Clinical Staging of fluctuation and recovery from temporary illness (MacMahon and Thomas 1998) (noted as part of Appendix 8), or through self-reported recording of specific impairment and function using the condition-specific Unified Parkinson's Disease Rating Scale (Goetz *et al.* 2008). No measure considers wellness or wellbeing.

Research is mainly conducted at mid- and later stages of Parkinson's, when the impact of decreasing physical and mental QoL increases health resources utilisation (Hechtner *et al.* 2014, Whitney 2004, Schrag *et al.* 2000b, Jenkinson *et al.* 1995).

Despite this being a time of increasing support needs, there is no review of group interaction on QoL and wellness.

Generic measurement tools, the SF-36 or SF-12 (Short Form with 36 or 12 questions) measure QoL and aspects of daily life in individuals with Parkinson's (Martinez-Martin *et al.* 2011, Kuopio *et al.* 2000), or compare self-reported health status between neurological conditions, such as Parkinson's with Multiple Sclerosis (Ware *et al.* 2007, Raizi *et al.* 2003, Ware *et al.* 2002). Although the SF-36 has highlighted significant impact of Parkinson's on the wellbeing of caregivers (Peters *et al.* 2011), the scales limit our understanding of condition-specific QoL and wellbeing facets (Hagell *et al.* 2008).

The validated self-completion Parkinson's Disease Questionnaires (PDQ-39 and PDQ-8) measure specific QoL (mobility, activities of daily living, emotions, stigma, social support, cognitions, communication and bodily discomfort) (Jenkinson *et al.* 2008, Peto *et al.* 1995). The PDQ-39 results have decided formal health and social care needs of a community living person (Clarke *et al.* 1995), informed commissioners of perceived superiority of specialist clinic to GP clinic care (Rochow *et al.* 2005), investigated relationships between medication-associated movement problems and different domains of HRQoL as Parkinson's progresses (Hechtner *et al.* 2014), and indicated when specific assessments needed instigating as anxiety or depressive traits increased, pathology known to affect emotional and social wellbeing in people with Parkinson's (Jones *et al.* 2014, Schrag *et al.* 2000a).

Medical research generally compares negative wellness attributes to treatment outcome, e.g. deep brain stimulation surgery for motor complications of Parkinson's and result on apathy, depression, impulsivity, executive dysfunction and anxiety (Castrito *et al.* 2014, Bronstein *et al.* 2011), or asking people to self-rate non-motor symptoms, including anxiety and apathy (Chaudhuri *et al.* 2006).

WHO developed the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001) to describe and classify (code) functioning and disability in relation to health conditions, building a common global language for professionals to compare data globally.

The framework fits the holistic aspiration of contemporary health practice by considering the wider influence of environmental and personal factors affecting health and wellbeing (Royal College of General Practitioners [RCGP] 2013), yet

uses the bio-psycho-social model to dissect the body into function and structure. This view perpetuates the language of disability and impersonal coding in relationship to limitations in activities, and restrictions in participation to be managed through healthcare interventions (Beresford 2010, de Kleijn-de Vrankrijker 2003, Üstün *et al.* 2003, Wade and de Jong 2000).

2.4: A physiotherapy perspective of wellness, wellbeing and illness

Physiotherapy evolved over a century ago from its origins of providing massage and exercise prescribed by doctors (White 2002, Barclay 1994, p4-8). Despite the profession achieving a status of autonomy (CSP 2008, DH 1977), much of physiotherapy mirrors the medical model of thinking, research and practice.

The benefits of earlier intervention physiotherapy for people with Parkinson's are poorly interpreted (Clarke *et al.* 2016). Physiotherapy-led exercise interventions in early stage Parkinson's demonstrate both the maintenance of function and wellness traits through social interaction with others affected by Parkinson's, as well as health professionals (Combs *et al.* 2014 and 2011, Keus *et al.* 2014, McConaghy 2014). However, people continue to be referred for physiotherapy only in the mid-to later stages for individualised healthcare provision when the risk of falling and injury increases (particularly if hospitalised secondary to the incident) (Keus *et al.* 2014, Snijders *et al.* 2010, Pickering *et al.* 2007, NICE 2006), or where impairment to cognition deteriorates to affect mobility and daily living tasks management (Keus *et al.* 2014).

The consequence of such late referral means research concentrates on studying the effect of individual interventions for physically manifested mobility problems and not achievement of (group acquired) wellness (Keus *et al.* 2014, NICE 2006). Practice guidelines omit qualitative research information limiting practitioner's insight into people's wellness values, belief and behaviour physiotherapy might be one part of (Keus *et al.* 2014, Keegan 2006, Mays and Pope. 2000), with current reporting methods rarely recording to what level person-centred holistic approaches are being integrated into practice.

As with other forms of healthcare delivery, the provision of physiotherapy services for people with Parkinson's is discriminatory (APPG for Parkinson's Disease 2009,

PDS 2008), with the health inequalities requiring political intervention to remediate the disparities (Bambra *et al.* 2005).

2.4.1: Measuring wellness or wellbeing in physiotherapy

The profession's descriptors of physiotherapy practice intimate a holistic approach, enabling an individual to achieve a state of health or wellbeing as a consequence of the wider social duty of physiotherapy practice (HCPC 2014, CSP 2012a, 2012b, 2011). Measures still focus primarily on physical outcomes, again ignoring gains from interaction and interdependence within supportive groups, of which physiotherapy plays one part.

The WCPT and CSP advocate the use of the ICF by physiotherapists (Grill *et al.* 2011, Stucki *et al.* 2007, de Kleijn-de Vrankrijker 2003, Üstün *et al.* 2003), with use recommended for intervention with individuals with Parkinson's to find solutions that stem or minimise the rate of decline (Keus *et al.* 2014). In its current form, this model does little to remind the therapist to step back and see the person within their wider context (Grill *et al.* 2011, Snyder *et al.* 2008).

2.5: A perspective of health and wellness of people affected by Parkinson's

Society imposes value judgments and social responses to manifestations of certain conditions, 'oppressing' those with disability (Conrad and Barker 2010, Boyd 2000, Kiernan 1999). This may be through perceptions of stigmatisation people with Parkinson's experience as their disability increases, becoming observable as slowness, excessive movement (Schrag *et al.* 2000a), or physical environment limitations of access and freedom (Kiernan 1999).

Individuals can become immersed in the routine management of their condition (Clark *et al.* 1991), but not all are prepared to be passive, positioning themselves to manage through education and support (Conrad and Barker 2010, Wilson *et al.* 2007). Some people respond to stressful situations by succumbing, whilst others demonstrate resilience, although this can change with condition-manifested alterations over time (Barnes *et al.* 2013, Boyd 2000, Clark *et al.* 1991, Rutter 1987).

A diagnosis of Parkinson's creates tension where a person wants to believe the

expertise of the diagnostician, yet experiences uncertainty as individual differences to those of other people with Parkinson's is obvious (Eccles *et al.* 2011, Platt 2004).

Much of what is known of Parkinson's wellness-related perceptions comes from questionnaire data from small numbers of participants, usually associated with progression of the condition. The standardised questions provide only a 'snapshot' of life for people with this progressive, variable condition (Kelley *et al.* 2003), and the meaningfulness of categorising information into numerical scales is questionable (Allen and Seaman 2007).

Changes include adjustments in identity (Platt 2004) and body image (a mental representation of the body) (Gamarra *et al.* 2009), which can also alter in the 50 – 85% of people with Parkinson's who experience chronic pain (Fil *et al.* 2013, Ford 2010). Alterations in self-concept (mental representations of personal characteristics that defines the self and adjusts behaviour), reporting less self-confidence and lower social receptivity as a result of Parkinson's, both signs correlated with depressive symptoms (Gamarra *et al.* 2009). Community dwelling adults reported fear of impending physical, emotional, mental disability, and decreasing social connectedness (Soleimani *et al.* 2016, Jenkinson *et al.* 1997). Where sexual identity and QoL was reviewed by looking at gender¹² stereotypes (a significant aspect of the 'self' that influences behaviour), coping mechanisms were better in women with Parkinson's who exhibited strong feminine qualities (Moore *et al.* 2005).

In the UK, people in mild to moderate stages of Parkinson's report satisfaction with their lives (Rosengren *et al.* 2016), but QoL declines as the condition progresses (Gumber *et al.* 2016, Schrag *et al.* 2000a and b), especially with worsening physical factors including difficulty turning tasks and recurrent falls (Visser *et al.* 2008, Schrag *et al.* 2000a).

People experiencing changes in speech report a deficit in perception of loudness worsening ability to communicate (intelligibility and word finding problem) (Kwan

¹² Gender is defined as the learned social characteristics that distinguish males and females in society. By reflecting normative power relations it can sustain social inequalities between women and men. Other normative power relations that create social inequalities include those relating to social class, race, age, sexual orientation, etc.

and Whitehill 2011), particularly after deep brain stimulation, affecting a person's wish to, or ability to socialise (Miller *et al.* 2011). The perceived stigma causes people to avoid situations in public places where they might be embarrassed or feel they cause others embarrassment (Jenkinson *et al.* 1997).

The longer the duration a person has had Parkinson's, and the worse their experienced symptoms, a decline is seen in the mental wellbeing and physical health of carers and other family members (Gumber *et al.* 2016, Schrag *et al.* 2006, O'Reilly *et al.* 1966).

2.5.1: Interdependence models as a way to maintain wellness

A focus of wellness noted in the literature relates to the capacity of people to cope with Parkinson's through their relationships with others, with models of interdependence considered from several stances. They do not however record any quality of these interdependent interactions.

Despite reports of increasing stress and disability in all parties affected by the condition (those with a diagnosis, and those caregiving) as Parkinson's progresses (Gumber *et al.* 2016), all literature found was supportive of emergent or preserved wellness facets from the association with others. Only two examples were found reporting a relationship breakup as a consequence of Parkinson's (Gumber *et al.* 2016, Fleming *et al.* 2004), but it is not uncommon in practice to find spouses who are barely coping, particularly with cognitive and hence identity change of the spouse with Parkinson's (Williamson *et al.* 2008, Gallant *et al.* 2007).

The models described include the interdependent dyadic connection between spouses (Mavandadi *et al.* 2014, Lyons *et al.* 2009, Williamson *et al.* 2008, Gallant *et al.* 2007, Lewis *et al.* 2006, Birgersson and Edberg 2004), often called 'Actor-partner interdependence models' or close family, such as children and parents (Silverman and Brahce 1979); between friends and people with a health condition (Gallant *et al.* 2007, Fleming *et al.* 2004, Karen 2001); between health professionals and people with a health condition (Gross *et al.* 2014, Gray 2010, Giroux *et al.* 2008); and also between groups of people with health problems such as those found in social networks and support groups (van der Löwe and Parkinson 2014, p126–128, Vassilev *et al.* 2014).

The facets of wellness gained relate to improved personal growth and marital quality (Mavandadi *et al.* 2014, Birgersson and Edberg 2004), learning new strategies to help with coping such as using social comparison (Williamson *et al.* 2008), shared decision making about the 'illness' (Gallant *et al.* 2007), and using social or communal networks (Gallant *et al.* 2007, Lewis *et al.* 2006).

None of the literature interviewed people together in the context of these interdependent relationships, instead splitting them into groups with Parkinson's, or those without Parkinson's. Where all parties were included, responses gained were through survey/ questionnaire data, again, separating the responses of spouses/ carers from those of people with Parkinson's.

2.5.2: Measuring wellness or wellbeing by people affected by Parkinson's

No literature was found in research databases of people with Parkinson's choosing to self-report measurement charting their own wellness.

The concept of gauging health and wellness however is described through narratives of their lived experience, compelling a redefinition of the meaning to people affected by Parkinson's.

The stories provide a powerful narrative of their journeys with the condition, with biographies (Vallance 2016, Isaacs 2008, Fox 2002, Harshaw 2001), articles published both by people with Parkinson's (Baker and Graham 2004, Platt 2004), or by the people affected by Parkinson's (Lawton 2015), and online fora for people to put on 'Real life stories', so others can understand the positives and negatives of a lived experience with the condition (Parkinson's UK 2016a and b).

In summary, research is primarily individualistic, but people affected by Parkinson's, note a decreasing social connectedness. Policy attempts to improve this through individual intervention, yet stories by people with the diagnosis show that they achieve wellness through interdependence with others. Health professionals understand Parkinson's through a blinkered perspective; this has to change.

2.6: The changing face of health and social care policy and strategy in the UK

UK health policy aims to enhance life quality for people diagnosed with a long-term condition (DH 2012a). To effect this, health strategy has increasingly pushed to provide a person-centred approach by giving individuals greater involvement in setting health care agendas and responsibility in managing their health and care needs through shared-decision making and Public Health programmes (DH 2014a and c, Solomon *et al.* 2013, DH 2012b). In direct conflict with this strategy is the increase in professional accountability that has escalated use of written guidance and clinical practice standards based on experimental evidence that objectifies health, and inhibits the application of an individual's choice (Solomon *et al.* 2013).

A publication review was conducted of the models influencing policy and subsequent strategy, as these inform the epistemological basis of service delivery. The models have been considered from the perspective of Public Health, medicine and physiotherapy, with an understanding of the consequence on the lives of service users i.e. people with a long-term condition such as Parkinson's.

Policies reviewed will alter in time to support incoming strategy, but political debate states that austerity measures will continue to be a central issue (Dykes 2016).

This increases the urgency to find means by which people with chronic conditions self manage, and self-determine their wellness needs. The empowerment agenda of larger national charities that collaborate with, but work independently of the Department of Health, is a way forward to address the issue.

2.6.1: Policy influencing Public Health delivery

UK Public Health was NHS-led from the 1970s until the decentralising process of devolution in 1999 returned responsibility back to local government (DH 2011a).

To achieve the engagement of the wider population, collaborations and partnerships are forming across the health (including with the independent sector), social and voluntary sectors (The Labour Party 2014, Addicott 2013, DH 2011b and c).

Strategy makes three assumptions. Firstly, that people with long-term conditions know their needs, and secondly, they wish to take responsibility for their health.

These assumptions are discussed later. The third assumption is that services to support holistic needs are available (Buck and Gregory 2013, DH 2010a).

Planning and implementation required for countrywide change is barely achievable (Bardsley *et al.* 2013, Buck and Gregory 2013, Dixon and Ham 2010), especially when research creates opposing messages about health and lifestyle choice for individuals across the wide spectrum of population (Piggin 2012). Physical and mental health problems are on the rise, particularly in those with long-term conditions (Banks *et al.* 2010, Lutz *et al.* 2008, Malina and Little 2008, DH 2007), as are health inequalities, shaped by the apportioning of power and of resources (Marmot Review 2010, Dahlgren and Whitehead 2006, Marmot 2005).

Policy reforms attempting to address these issues are heavily criticised.

Consultations are unrepresentative of key stakeholders (including carers) who the changes will affect (Bardsley *et al.* 2013, DH 2014c, 2012b); services are open to private investment and provision (Buck and Gregory 2013, Royal College of Nursing [RCN] 2012), and policy cannot be realised until the designation of power and leadership is distributed to people that policy affects, to engage communities in the change process (Ham *et al.* 2011, Holmström and Röing 2010).

A style of distributed leadership could directly affect how people with Parkinson's manage their condition through interdependent relationships with wider community support, empowering their self-management skills, and improving their life quality (European Parkinson's Disease Association [EPDA] 2003).

2.6.2: Policy influencing frontline medical and physiotherapy perspectives

Following a period of exposure of the failings of NHS systems, the 1990s saw the Clinical Governance initiative drive forward quality improvement and patient safety, requiring scrutiny of professional impact on service delivery and of competence in practice (Scully and Donaldson 1998, DH 1998, DH 1997).

The Evidence-based Medicine (EBM) movement established to help doctors standardise clinical decision processes was adopted to enable 'best practice' (Sackett *et al.* 2000, Evidence Based Medicine Working Group 1992), with large institutes created to provide research and guidance for health professionals (Greenhalgh *et al.* 2014, Halligan and Donaldson 2001).

The EBM approach was developed to integrate research evidence, clinical expertise and patient values (Sackett *et al.* 1996), but evolved into a hierarchical structure using positivist methodology as the 'Gold Standard' dictating clinical interventions (Robertson 1996, Roberts 1994) and educational syllabus (Curtis 2002, p37–39, Barclay 1994, p241-243). In its current form, it denies individuals their stories and the significance of their experiences in research, and they remain passive recipients of doctor-led practice (Mykhalovskiy and Weir 2004).

Newer models of health provision and research evidence a change towards the humanistic stance (Greenhalgh *et al.* 2014), however, the medical profession's dominance has been so great that physiotherapy research remains predominantly quantitative, searching for one optimal technique to work with all patients (Kell and Owen 2008, Higgs *et al.* 2001). This has detached practitioners from a holistic focus of outcome of physiotherapy practice where all determinants of health might be explored, to one of single element intervention (Abeyasinghe and Parkhurst 2013). Different research styles should be utilised to answer different questions, but the current bias of research-obtained evidence that informs clinical practice is not discussed through critical and reflective dialogue, especially with the students who will become the profession's future workforce (Laitinen- Väänänen *et al.*, 2008). This perpetuates practice of decision-making between just an individual and the professional (RCGP 2014, Barr and Threlkeld 2000 Jensen *et al.* 2000), so the health professional is seen to support patients 'ill' and 'suffering' with Parkinson's 'disease' (Keus *et al.* 2014, Union Européenne des Médecins Spécialistes 2006).

Most guidelines overlook the influence of personal values and knowledge about the experience of living with Parkinson's the individuals should bring to the dialogue and decision-making. There is also little recognition of the capability of the person with Parkinson's to choose the management of their own condition utilising a support network of family, friends, employers, as well as the formal health and care services.

2.6.3: Self-management policy influencing the perspective of service users with Parkinson's, a long-term condition

The UK working definition of a long-term condition is one that cannot be cured, but can be controlled by medication and other therapies (DH 2012a). The widely used

description neglects to see the person and complexities of the condition holistically, including their mechanisms of coping involving interdependent relationships (House of Commons Health Committee 2014).

Self-management as a healthcare concept gained popularity in the 1990s as more people were diagnosed with long-term medical conditions, with implications of enduring use of costly resources, making it a priority for service providers (Jonsdottir 2013, DH 2001b). The concept is informed by Social Cognitive Theory (Bandura 1991, 1982, 1977) using personal beliefs and environmental factors (both physical and social) to influence behaviour (Clark *et al.* 1991). Lorig and Holman (2003) describe the process as a way people participate effectively in managing their own health care needs on an on-going basis.

Self-management uses adult education (Alderson *et al.* 1999) to maximise functioning (Nakagawa-Kogan *et al.* 1988), and teach control of symptoms utilising a set programme that focuses on understanding the healthcare perspective of the condition on physical and mental faculties (Jonsdottir 2013, Wilson *et al.* 2007, Simons *et al.* 2006, Barlow *et al.* 2002, Clark *et al.* 1991). They are usually carried out in a group situation, segregating the sessions to people with the medical diagnosis (Simons *et al.* 2006, Barlow *et al.* 2002, Clarke *et al.* 1991). The setting limits the tailoring of knowledge, and opportunity to increase behavioural change (Behm *et al.* 2013, Chou and Wister 2005, Barlow *et al.* 2002).

Few programmes explore social and societal implications, discuss beliefs based on lay knowledge or information from sources such as the Internet (Henwood *et al.* 2003) or share experiential knowledge of the person with the diagnosis living with the condition (Barlow *et al.* 2002).

Programmes often exclude carers, and rarely actively recruit people with cognitive impairment (Tickle-Degnen *et al.* 2010, Barlow *et al.* 2002, Montgomery *et al.* 1994), so we neither understand the impact of managing complex variability of a condition into the long-term, nor how interdependent relationships with others support needs (Expert Patient Programme Community Interest Company 2007, Gatley *et al.* 2007).

In programmes led by people with a condition (e.g. arthritis and Parkinson's), educators reported greater freedom to share information, modify needs to

individual participants (Simons *et al.* 2006, Macht *et al.* 2007, Lorig *et al.* 1986), compare and self-evaluate their situation as described in Social Comparison Theory (Festinger 1954). The programmes are about the individual, and assume active participation, a wish and ability to take responsibility managing their treatment (British Geriatric Society [BGS] 2014, Jonsdottir 2013, Hammel *et al.* 2008, Lorig and Holman 2003, Lorig *et al.* 1986). A person with fluctuating health from a progressive condition may not wish to dwell on their future health, especially when they are periods of wellness and independence; the forward planning is often a role that falls to the carer (Behm *et al.* 2013).

The Parkinson's UK Self-management programme, run since 2013, facilitated by people affected by Parkinson's, using participant feedback from the 500 plus people who have been through the programme to inform successive courses (Parkinson's UK 2016b). They include close family as well as people with Parkinson's to either facilitate or participate, opening the support environment more widely to other relational support than with just a health professional or programme facilitator (Jonsdottir 2013).

2.6.4: Supporting empowerment in people with health conditions

Empowerment refers to a wide range of practices whereby a person is enabled to undergo an attitudinal change (usually an increase in confidence and autonomy) providing opportunity for greater involvement and ability to exercise initiatives to the benefit of an organisation (Wilkinson 1998).

Empowerment is represented in contemporary healthcare policy as patient- or person-centred care (Holmström and Röing 2010, DH 2008), but has more political connotations, evolving as a reaction to widespread oppression and inequality within society (Freire 1996). The concepts are not opposed (Holmström and Röing, 2010), but are used indiscriminately, with minimal criticality between the broader socio-political context and use in community-based work with individuals (Skelton 1994).

Generally, people are disempowered from seeking their own health solutions, diminishing policy intention of true person-centredness (Coulter 1999), with health professionals communicating through classic disabling professional behaviour

(Keus *et al.* 2014, College of Physiotherapists of Ontario 2013, Illich 1977, p16-19).

Treatments available cannot delay the degenerative process of Parkinson's into the long term (Aujoulat *et al.* 2008, Salmon and Hall 2003), dictating a need for people to utilise their own support networks to remain well (Vassilev *et al.* 2014).

Empowered individuals are considered the healthiest in society through combined interaction with health systems and formal education programmes (Holmström and Röing, 2010), driving policy to reduce service utility through empowerment models (Chaudhuri *et al.* 2006, DH 2005a and b, EPDA 2003).

Increasing examples of narrative medicine are emerging (an integrative exemplar of discourse between patients and healthcare) (Gross *et al.* 2014, Aujoulat *et al.* 2008). This means of delivering clinical practice, whilst costly in time and resources, enables people to believe in their ability to control and change their lives through education and dialogue (Gross *et al.* 2014, Wallerstein and Bernstein 1988).

Research programmes mirroring this collaborative approach facilitate co-production and co-design of health practice for people (Horne *et al.* 2013), placing them central to decisions, creating meaningful partnerships between health staff and patients, health policymakers and local communities (Coulter *et al.* 2013, ACEVO 2011).

Engagement of empowered people makes a case for transformational change to create a health system fit for the future (Horne *et al.* 2013, Salmon and Hall 2003, Coulter 1999). This could be enhanced with investigation into wider support systems and relationships with others people who the diagnosed individuals are also dependent on to remain well.

2.6.5: Engaging the voice of the public in healthcare

Since the 1970's policy has promoted involvement of patients and public¹³ in decisions about healthcare at both an individual and a strategic level (Houses of Commons Health Committee 2007, DH 1999, 1998, 1997). Although strategy pursuing economic growth through 'marketplace' health and social care provision

¹³ The INVOLVE (a National Institute for Health Research body that supports public involvement in NHS, public health and social care research) definition of the term 'public' includes patients, potential patients, carers and people who use health and social care services. It is also inclusive of such as myself, from organisations that represent people who use services.

restricted people's chance to influence the wider agenda (Horne *et al.* 2013, Morris 2011), it is a statutory requirement in England for involvement of patients and carers in decisions that relate to their care or treatment.

Large voluntary organisations like Parkinson's UK have utilised participation and collaboration to understand the motivations and goals of varied parties e.g. researchers, health practitioners, and lay members of the public, to create a vision of a healthier population meeting the needs of the community and individuals (DH 2012b, Michener *et al.* 2012, Coulter and Ellins 2007, Rowe and Shepherd 2002).

Parkinson's UK have used the tactic to inform their business policies (Parkinson's UK 2015) around the needs of their membership in response to health commissioning requirement (MacMillan 2010). An organisational rebranding was implemented following extensive consultation with members, staff and external associates in 2010. This resulted in changing the name from the *Parkinson's Disease Society* to *Parkinson's UK* permitting the charity to clarify its new values and communicating positivity by removing '*disease*', disliked by many for the negative connotations and stigma ascribed with the word (Heisters *et al.* 2014 personal communication, Borkfelt 2011). The momentum to utilise opinions of its members was sustained in the development of the latest business strategy (2015 – 2019), based on member consultation and research undertaken by Parkinson's UK.

The DH published documents advocate the use of service users, whether to consider involvement in the more holistic policy issue of sustainability of the NHS (NHS Estates, 2001), support in self-management of own health (DH 2005a and b, DH 2004), or involvement in research (National Institute for Health Research [NIHR], 2013, DH 2006). One part of the Parkinson's UK Strategy includes the development of a UK-wide Excellence Network for professionals to ultimately improve service quality. A sub-group is the Service User Involvement Thematic Working Group, an empowered voice informing other sub-groups, thus improving services for those affected by Parkinson's, and for education of those delivering the services. Service-users are encouraged to engage in general politics, and utilise experiential knowledge to inform healthcare practice and research (Parkinson's UK 2015). Their involvement is introducing members of the network to the concept that they use a wider circle of support than health professionals.

2.7: Summary

The literature around health perspectives shows that the current bio-psychosocial perspective dominating physiotherapy practice and research does not go far enough to fulfil the holistic model of wellness suggested in physiotherapy descriptions (AGILE Standards Working Group 2013, CSP 2011). An ethnocentric belief in measured 'truth' is perpetuated by organisational (NHS) and professional, solution-seeking culture (O'Shaughnessy and Tilki 2007), a model that disables clinical construction of health behaviour (O'Shaughnessy and Tilki 2007, Wilson *et al.* 2007).

Health strategy upkeeps principles of self-management and empowerment for people to voice ideas and share experiences to enhance services impacting on their wellness (DH 2010c and d, 2005 b). Inclusive models of research enable people from marginalised groups to explore this capacity to learn and improve their situation by engaging in inquiry connected to their situation in life (Reason 2006, Boote *et al.* 2002), but most are done by separating people into specific groups e.g. those with health conditions, or carers, to find personal, and not shared perception despite relationship connections.

Critical research examples of people with mental health problems, and older people as active partners in research have shown that through involvement in the design, activity and dissemination, there were multiple benefits that empowered and aided self-management. The noted benefits included increased participant's knowledge, awareness, confidence, and engagement with their community from their role co-designing the research undertaken (Hoban *et al.* 2011, Fudge *et al.* 2007, Hounsell and Owens 2005).

The use of methodology such as participation and co-design is investigated in the following chapter, broadening our understanding of how wellness was explored with people affected by Parkinson's, supported by a physiotherapist.

CHAPTER 3: METHODOLOGY AND METHODS

3.1: Introduction to Action Research and Participatory Action Research

Action Research (AR) is an umbrella term encompassing a ‘*family of* [methodological] *practices*’ (Reason and Bradbury 2008, p1). Although not the first to use the method, Kurt Lewin (1946) was the first to record the method’s theoretical stance for organisational development (Herr and Anderson 2005, p11). This was developed further and utilised in diverse circumstances (Bergold and Thomas 2012, Brydon-Miller *et al.* 2003) including education (Cohen *et al.* 2011, Stringer 2004, Carr and Kemmis 1986), healthcare (Koshy *et al.* 2011, Cresswell and Clark 2010, Cresswell 2007, Hart and Bond 1995) and community development (Reason and Bradbury 2008, Greenwood and Levin 2007).

A commonly accepted definition of AR is:

‘...a form of collective self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out’

(Kemmis and McTaggart 1990, p5).

The broad definition, insufficient clarity that AR is conducted with a critical understanding of participatory practice (Hayward *et al.* 2004, Waterman *et al.* 2001), indiscriminately utilising AR without understanding the process (Pettit 2010, Eden and Huxham 1996), and poor transparency for reproducibility of the research (White *et al.* 2004) leaves it open to criticism (McKay and Marshall 2001). Condemnation is also leveled against AR by academics looking to directly compare social research methods with medical research models, as localised outcomes cannot be extrapolated to a general population (Eden and Huxham 1996).

The expectation of collective participation of those involved in the research (Reason and Bradbury 2008, p8) results in the terms ‘action research’ and ‘participatory action research’ (PAR) often being used synonymously and interchangeably in the literature. But PAR’s distinct and diverse use is also conceptualised by researchers through other titles. It has been called ‘Co-

operative inquiry', 'Participatory rural appraisal', 'Participatory Development', 'Participatory learning and action', 'Participatory Evaluation' and 'Participatory learning research' (Bergold and Thomas 2012, Hayward *et al.* 2004, Heron and Reason 1997, Greenwood *et al.* 1993). Whilst I (as the researcher) am in transition from a professional career sustained by scientific, positivist research methodology, the varied iterations of AR and PAR have been confusing during the evolution of my learning to encompass social constructionist ontology, and the lack of detail into the practical specific of the methodology make the texts read as an 'anyone can for (P)AR', and a 'one size fits all' manual.

PAR was not the first methodological choice for my Research Project.

A lack of understanding of the nuances of qualitative study meant that my choices of methodology for this Doctoral Research Project underwent changes from considering the research to be ethnography due to my position within the group, then case study design of a Sheffield-specific case, to finally selecting PAR as the most suitable way of answering the research question.

I always understood my position as insider-researcher who identified strongly with 'belonging' to the Parkinson's collective, however, I clearly did not have a lived experience of Parkinson's, and hence could never truthfully interpret their experience. I could not study the support of wellness in Full Monty Club participants through observation as I felt far more involved than that, so on this basis I rejected ethnography and case study design (Ritchie and Lewis 2003, p100-103).

I was looking for an emergent inquiry methodology that allowed me to enable me to study what it was about this Sheffield-based group that sustained wellness, and my role in supporting that outcome (Dwyer and Buckle 2009). I wanted to work alongside Full Monty Exercise Club members to understand issues that contributed or damaged their perspective of wellness, and to consider new ideas and alternatives they might choose to support this (Pettit 2010, Keegan 2006, Maunthner and Doucet 2003). I chose the methodology of PAR based on intellectual and pragmatic needs, realising my study time would be constrained by work and life commitments (Pettit 2010, Maunthner and Doucet 2003).

We had already gained momentum from other projects and activities and needed a methodology that continued to allow us to move forward as a co-dependent group. Grounded Theory (Glaser and Strauss 1967) and phenomenology, whilst ideal qualitative methodologies to explore the meaning of wellness for people, would have deconstructed our cohesive group to an individual level and removed me from within that group. PAR offered the ability to continue moving forward together through our interdependent relationships.

AR examples in health practice often exclude people from marginalised or under-represented groups, as those who participate are from articulate and able elements of society, available to attend research meetings (Brydon-Miller *et al.* 2003, Waterman *et al.* 2001). PAR, a more politicised evolution of AR looking to alter oppressive political and social tradition through educational practice with populations normally excluded from such practice counters this issue (Hall 2005, Freire 1996). In PAR, 'generative themes' (Freire 1996, p82-85) i.e. concerns of utmost significance agreed by a community are investigated combining the expert knowledge of a researcher or academic with the expertise of the local co-researchers with ideas about their own problems and solutions, collaborating to influence attainment of a valuable outcome for the study participants (Greenwood *et al.* 1993). This style of research, when conducted under the auspices of the social model of disability is categorised as 'Emancipatory' AR (French and Swain 1997).

There is no consensus on the definition of PAR, but like AR, a common aspiration of this approach is to use varied perceptions of everyday practice to alter social reality through a collaborative process (Bergold and Thomas 2012, Cook 2012).

PAR is:

'.....a paradigm for bridging science and clinical practice' (White *et al.* 2004),
'...a community-based approach to the creation of knowledge' (Hall 2005),
and one *'that combines social investigation, education, and action in an inter-related approach'* (Koshy *et al.*, 2011, p1, Hall 2005).

It is utilised for:

'... collaboration between consumers and researchers' (White *et al.* 2004)
conducted *'with and for people, rather than on people'*, with an attitude of

being ‘....*already a participant, part-of rather than apart-from*’ (Reason and Bradbury 2008, p8).

The methodology fits the expectation of public and patient involvement (PPI) in health and social care research policy in the UK.

Conventional research utilises objective data to inform knowledge and justify clinical practice decisions (Pettit 2010, National Health Service [NHS] Executive 1999, Scally and Donaldson 1998, DH 1997, Stineman *et al.* 1995). Most physiotherapy practice informing the epistemological basis of the profession is investigated this way (CSP 2012 b). (P)AR however views knowledge differently, approaching research by looking at where knowledge comes from and the way it can influence through an inquiry process that reflects not just on information gathered, but also on the reflections and experiences of participants (Pettit 2010, Bergold and Thomas 2012, Cook 2012).

PAR is distinct from AR by promoting full control of the research by those affected by it, thus upholding principles of social validity (Seekins and White 2013). The process recognises that it is not feasible for all participants to engage fully all of the time, as the practice of identifying problems requires differing skills and knowledge of participants to deal with these (Hayward *et al.* 2004, White *et al.* 2004). This approach is suitable for people with a chronic illness, like Parkinson’s, who may not be able to sustain or be consistent with their contributions according to the state of their health (Paterson 2001).

Another distinction between PAR and AR is the change of emphasis from ‘action’ toward ‘collaborative research action’, reinforcing the ideology of PAR as more than just a research method, but also a process and a goal of the research (Greenwood *et al.* 1993).

3.2: The use PAR for public and patient involvement in research

PPI in research is a requirement of many funding bodies hopeful of creating relevant and reliable analysis with stakeholders (Cook 2012, Ives *et al.* 2012, DH 2006). It makes sense that people with altered health states research the effects of personal to protective (promoting the health of others) health behaviour (Simons-Morton 2013), but implementation of this vision has not been managed on a wide scale.

Strategies for engagement in participatory research lack consensus of what a 'user' or 'consumer' is, how to engage people and for what purpose, resulting in inconsistent user involvement in research (Salsberg *et al.* 2015, Michener *et al.* 2012, Cook 2012, Hounsell and Owen 2005, Chambers *et al.* 2004, Trivedi and Wykes 2002, Buckland and Gorin 2001).

The challenge of working together, designing approaches and agreeing methods to answer problematic questions is a recognised difficulty in participative research, as individuals are invited under the guise of 'participation' and 'co-design', when the research is often about fixing current systems and not using an individual's experience to create fresh ways to review service provision (Dale 2016).

The lack of understanding of roles and research expectations counters appreciation of the impact of proposed research leaving several questions unanswered (Cook 2012). Do laypersons with an interest in a researched condition have the same perspective and knowledge as people with a lived experience of a condition (Cook 2012)? Do people engaging in research projects truly represent the wider public with a potential to a biased view (Boote *et al.* 2002, Buckland and Gorin 2001)? Might repeat engagers develop 'consumer fatigue' with repeated involvement in different projects (Buckland and Gorin 2001)?

Practical barriers such as meeting venues and timescale affect user involvement (Salsberg *et al.* 2015, Bergman 1983), as do the difficulties implementing change imposed by the organisational processes and staff attitudes unsupported to deal with yet more change (Salsberg *et al.* 2015, Ives *et al.* 2012, Michener *et al.* 2012, Coulter 1999, Forbat *et al.* 2009). Yet service users and the public are vital co-researchers from designing relevant research through to dissemination (Cook 2012, Morgan *et al.* 2005).

Insufficient expertise in using critical inquiry methods by health professionals or academics limits methodological development into true participatory inquiry (Pettit 2010, Gatley *et al.* 2007, Barlow *et al.* 2002). To achieve this requires the ability to move beyond professional domination, sharing the ability to influence the process, enabling empowerment and self-determination of all research partners.

3.3: Choosing this methodology for the Research Project

The research question for this project, in seeking how people with Parkinson's could be supported to enable their own wellness, required a method of inquiry that investigated the support currently utilised from varied and interdependent perspectives (people with Parkinson's, family, carers, friends, volunteers and health professionals). It necessitated an understanding of the education and knowledge people affected by Parkinson's considered of worth to sustain members' continued involvement, whether as recipients of support, or individual contributors to the political and social activities of this Parkinson's group.

Whilst not 'oppressed' in the sense of the populations studied by people such as Freire and Fals Borda in the mid-20th Century, the status of power and leadership assumed by holders and providers of health knowledge, usually medical control, can obstruct the ability of people with a lived experience of Parkinson's to overcome 'medical oppression' and become a self-managing and 'whole' person, despite the rhetoric of health policy makers (Ramaswamy 2010, Mykhalovskiy and Weir 2004). Given that it is of medical authority we speak, it is ironic to read Freire's words that state:

'The behaviour of the oppressed is a prescribed [author's emphasis] behaviour.....' (Freire 1996; 29)

'The oppressed are regarded as the pathology of healthy [author's emphasis] society. (Freire 1996; 55)

As a method, PAR has been utilised successfully in projects with marginalised populations previously excluded from research - usually older people (Ellins and Glasby 2016, Tanner 2012). For example, Tanner (2012) reflected on the process of engaging older people with dementia as co-researchers for a wider national study looking at experiences of transitions between care services. The co-researchers who were diagnosed with dementia collaborated in the process of agreeing a topic guide to interviews with other people with dementia and their carers. They were motivated to partake from a desire to help others, in addition to taking the opportunity for participating in meetings that provided social and peer support. Their presence as interviewees not only provided a sense of hope and reassurance to interviewees who were amazed that the co-researchers also had

dementia yet were functioning in this co-researcher role, but demonstrated that people with dementia still had a role to play in determining their own needs.

Likewise, Ellins and Glasby (2016) recruited co-researchers from ethnic communities to help inform how services might be enhanced for the ethnic minorities when admitted to hospital, especially for the older people with language barriers negatively affecting their understanding and experience. The co-researchers helped design and develop all phases of the study, including some interviewing, data analysis and dissemination of the results, and were invited to consider their role and personal experiences as research collaborators in a socially and politically informative project.

Using PAR methodology in these studies provided a participatory, socially engaged approach to research and evaluation congruent with the values of empowerment and democratic practice as observed from the engagement of participants (Ellins and Glasby 2016, Tanner 2012, Brydon-Miller *et al.* 2003).

The processes were seen as 'political' as the participants were actively involved in revising their situation (in this case, services) (Hammel *et al.* 2008), although the 'marginalised' collaborators were only one segment of their population. This leaves us with little understanding of the role and support from interdependent relationships with others e.g. association with people *without* dementia in Tanner's work, or *with* non-ethnics in Ellins and Glasby's study.

PAR was the chosen method of inquiry of this Doctoral Research project as it has a foundation based on co-operation and shared control of co-researchers, implying the process of participation and development to be empowering (Hayward *et al.* 2004). It seemed ideally placed to engage people affected by Parkinson's in collaborative research processes to investigate and change their communal situation (Brydon-Miller *et al.* 2003, McTaggart 1994). The context-specific and democratic process of this methodology could facilitate participants to utilise their life experience and view of the world around them to develop group understanding and knowledge about the important issue of sustaining social and physical Branch activity, attempting to generate solutions through their action and reflection (Pettit 2010, Bradbury and Reason 2008, p1). It is this sort of action that brands PAR as

'political', as it seeks to entwine personal and political encounters within the research process to empower the interactions of participants (Cook 2012).

An effective process and outcome of social action requires awareness of aspects of power at play related to research thus increasing empowerment and influence by participants (Pettit 2006, Kuokkanen and Leino-Kilpi 2000).

3.4: The impact of power and identity on participation

Power is a multi-dimensional concept that in healthcare is acknowledged as exhibiting three variations: '*power-from-within*', '*power-over*' and '*power-with*' (Laverack 2005). Where the connection of health professional to patient has been reviewed, each has been respectively matched to concepts of '*self-esteem*', '*domination*' and '*shared power*' in the relationship (Bradbury-Jones *et al.* 2008, Kuokkanen and Leino-Kilpi 2000).

Concepts are separated to enable a better understanding, but in the lived world the manifestations of power permeate throughout mechanisms by which we understand 'truth', and the character of power changes intensity and constancy when explored through discourse and action (Habermas 1984, Foucault 1977, p91–94).

UK healthcare promotes empowerment models to enable people to manage their health needs, yet not all health professionals are empowered themselves (Bradbury-Jones *et al.* 2008, Skelton 1994). Hence, individuals are educated according to their expertise with provided professional '*fixes*', disempowering the individual from seeking their own solutions or ways to self-manage their situation (Eisenberg 2012, Nicholls and Gibson 2010, Skelton 1994). This 'banking' style of education is a form of oppression, feeding knowledge to individuals, providing little opportunity for reflection on its meaning, especially when multiple medical diagnoses or social situations influence health status (Freire 1996, p53-56).

Personal empowerment is encountered when the stance from which we understand the fluidity of power relationships is recognised. This makes it rare that one group of people can be truly disempowered by another, as individuals will seek the truth of their situation (Foucault 1977, p98–99), through a process of

'humanisation', the capacity of humans to be aware of, reflect on, and transform their condition (Freire 1996, p1-3).

Even within a small group, each person brings a sense of their own identity, different to others because of gender, class, ethnicity, and in the case of Parkinson's, a level of (dis)ability (George 2007, Hogg *et al.* 1995).

By reflecting first on personal experiences of significant moments of power and powerlessness, applying the examination to real life situations, one starts the discourse of truth (Pettit 2006).

In terms of my experiences, life-choices have culminated with my achievement of a position in a global arena in the clinical field of my profession, permitting me to meter out knowledge to others from my perspective.

Gender is a power relationship that determines the place and experience of women in the workforce (George 2007). During my working life, as a successful woman, of Asian ethnicity in a predominantly white, female profession, in a health organisation, or academic institute headed by predominantly white males (Brydon-Miller *et al.* 2003, Waterman *et al.* 2001), I chose (had the power) to ignore encounters or discrimination on the basis of my gender or colour (Schwanke 2013, George 2007). My personal drive to break through the '*glass ceiling*' and negotiate the '*labyrinth*' women experience in male-dominated organisational culture was a need to prove myself to my family and social group (males and females) with deep-rooted cultural prejudices of the fact I was not a boy, and worse still, not a doctor (George 2007).

Any experiences of true powerlessness came from institutional authority erecting barriers to the pace and change promised through strategy, with continued allowance of the medical profession to dominate health legislation and research strategy. This realisation led to my resignation from the NHS.

Only noticeable once you step outside of the NHS institution is the nature of power palpably different, with a revelation of tensions between 'old' and 'new' power (Heimans and Timms 2014). 'New power' is less about control, advocating for participatory development models away from old-style authoritarian thinking (Heimans and Timms 2014). The ethos has helped me start the journey of changing the ways my practice embodied power, towards a more '*shared-power*'

relationship (Bradbury-Jones *et al.* 2008, Laverack 2005).

As a consequence, I came to this research project viewing people with Parkinson's through a different lens, but still from a '*power-from-within*' (an intact identity), and '*power-over*' (as principal investigator) stance (Laverack 2005). The people who forwarded themselves to the Research Project put themselves forward by right of their social identity as people affected by Parkinson's (a label of illness) (Galinski *et al.* 2003, Tajfel and Turner 1986). A reflection of their experiences, and significant moments of power and powerlessness will be considered in Chapter 6).

People can be empowered to be their own advocates for change. Participation through collaborative and cooperative processes to mobilise for change, encompass the political ideals of participatory democracy through active citizenship (Dingle and Heath 2001). These models of working encourage the creation of ideas, bringing expertise, and resources to social movement (Heimans and Timms 2014).

In healthcare, this requires that professionals relinquish power to enable individuals to make their own health choices (Bradbury-Jones *et al.* 2008). Given most health research is positivist, the value placed on experiential evidence contributable by service users challenges the epistemological stance from which the professional gains knowledge (McClellan and Shaw 2005, Boote *et al.* 2002, Ong 1996). 'Subjects' and 'patients' are used for 'consultation', and (tokenistic) presence on research panels or strategic boards, but otherwise considered passive suppliers of data, not direct contributors to realistic and individual information (Cook 2012, Buckland and Gorin 2001).

There are a few examples where the collaborative and participative approach has been successful for informing UK-based healthcare needs however, including its use in research. For example, cancer services have utilised social research and investigative approaches to improve hospital, community, primary care and voluntary services advocating methods that enhanced public perspective through consultation, co-design and action research projects (Tsianakas *et al.* 2012, Boyd *et al.* 2012, Edwards and Elwyn 2009). The implementation and sustainability of the approaches suggested from the process is ongoing and looking to turn the

vision of collaboration, empowerment and engagement of all involved parties into actuality.

An example where engagement with the public led by an academic institution has happened successfully is at Staffordshire University, where a research training programme was developed to enable members of the general public to identify and carry out a study as co-researchers (Morgan *et al.* 2005). Two lay members on the programme chose to consult members of the general public about their awareness and knowledge of stroke and stroke risk (Morgan *et al.* 2005) in the wake of their city being named as the highest mortality rate from stroke in the UK (DH 2001b). The process was written up as an exemplar by Morgan *et al.* (2005) demonstrating how consumers involved in healthcare research could take the opportunity to learn about, and understand local health provision and education issues.

Research utilising public participation such as the above examples are not without their challenges, as where research is instigated by health organisations or academic institutions with professionals leading or chairing the process (usually a medical professional in the NHS), true partnership engagement is often negated (Rowe and Shepherd 2002).

Yet meaningful engagement can occur if existing power disparities between lead researcher and the others on the team are eliminated. This does not mean all members will have equal knowledge, as people are invited to participate in research due to the differing skills and expertise offered, but each must feel equally valued to contribute freely and fully (Ben-Ari and Enosh 2011, Morgan *et al.* 2005). It helps to work to the same agenda requiring a clear definition or vision of the research, thereby attracting people with the necessary skills and experience (Buckland and Gorin 2001), and furthering a common understanding by all participants (Simons-Morton 2013).

3.5: Ethics

The PAR methodology is not predictable, and involvement to participate occurs as the study unfolds. This gives 'informed consent' a different meaning to other research approaches, with participants only consenting to the principle of what is

provided in the information brief (Williamson and Prosser 2002). It makes it more important that the ethical principles of non-coercion are upheld, allowing people to withdraw involvement at any stage (Williamson and Prosser 2002).

Research ethics and governance permission from the Sheffield Hallam University Research Ethics and Governance Committee to develop this project was gained on 18.12.2012.

The Participant Information Sheet sent out to recruit stakeholders provided basic information about this Research Project (Appendix 1). Those recruited at this initial stage were the main stakeholders¹⁴ involved in the Research Project process.

The variable process enabled the co-researchers to establish their own levels and expectations of commitment to the research to sustain the project to its conclusion. This included consideration of the welfare of participants in activities undertaken by the MontyZoomer stakeholders.

The ethical issues related to confidentiality of the MontyZoomer stakeholders to this Research Project have been discussed in the 'Acknowledgement' section. All MontyZoomer Stakeholders agreed to have their names provided in full, testifying awareness that this did not uphold the usual principles of anonymity.

The Sheffield Branch Committee of Parkinson's UK agreed that the need for individual permission to participate in an activity was task-specific, dependent on perceived benefit and harm to members, and could be decided by the MontyZoomers (McIntyre 2008, p11, Williamson and Prosser 2002). They were satisfied that the two members who were both MontyZoomers and Branch Committee members would feedback any issues that arose.

Ethical considerations were discussed for each action suggested, agreeing those that required more substantial disclosure of the purpose of the activity, what aspects of information gathered were to be treated confidentially, and how to ensure that participation remained voluntary (DePoy and Gitlin 2016, p27). It was agreed that all MontyZoomer projects involving 'others' would treat the person anonymously. The only exception was in the use of the photographs included, as

¹⁴ As the Research Project stakeholder group included myself, the self-named MontyZoomers are often described as 'we' – they represent the collective co-researchers, some with a diagnosis of Parkinson's and some without, supporting one another through interdependent relationships.

they were forwarded to me to place on an open access photograph repository established by our group.

In experimental research, the process of ethical consenting has limited recruitment of people with Parkinson's to research based on subjects' ages (FitzSimmons *et al.* 2012), cognitive state (Ashburn *et al.* 2007), or alternatively because some people have been unable to understand the language used to describe the research (DePoy and Gitlin 2016, p39). We did not wish to create such barriers or exclusion in our investigations, so the MontyZoomers decided how best to communicate and gain consent for activities pursued with general Branch members.

Not all types of research require a signed consent (DePoy and Gitlin 2016, p34). When postal surveys were sent asking questions about personal profile data and Branch activities, a letter of information was established as sufficient (Appendices 2 & 3), whilst for participation in the Focus Group discussions, it was decided that people should sign a group consent form for each of the interviews they participated in to indicate an understanding of what agreement to participation would mean (Appendix 4). All consent forms were based on templates available from SHU, but reworded by the MontyZoomers to make the wording easier for potential participants to understand (DePoy and Gitlin 2016, p34).

3.6: Rigour

In relativist ontology, the co-researchers construct multiple realities, so their context governs the research outcome (Dieronitou 2014). The issue of 'validity' expected of positivist research paradigms is illogical, but instead, the process seeks to ensure rigour is applied (referred to as 'face validity' in older literature) (Lather 1986).

Rigour was achieved through varied forms to minimise my bias as author of the collaborative process:

1. The MontyZoomers collectively agreed, and to varied extents designed and developed all proposed projects. This included the survey content, Focus group topic guide and analysis, thus ensuring credibility of the information gathered.

2. 'Member checking' was used to verify the value of information to the people it affects (Lather 1986).
 - As part of an internal verification process, the initial themes of wellness collected from a project to survey members in summer 2013 and mapped to a 'Wellbeing framework' (nef 2008) were taken for discussion at the November and December 2013 Branch Committee and Branch meetings, and also sent to the two external Stakeholders for comments and additions.
 - In my professional role as a residential Therapy Lead at an annual Blackpool Holistic week organised for 100 – 150 people affected by Parkinson's during the October 'Illuminations', I was able to network more widely with people affected by Parkinson's, sharing the results with people from at least 6 other Parkinson's UK Branches (Barnsley, Blackpool, Oldham, Rochdale, Trafford, and the Wirral Branches), permitting a review of the themes for added iterations and ideas, also providing a way of member-checking accuracy.

There was overwhelming confirmation that the themes were appropriate and also the same issues experienced elsewhere other than Sheffield.

3. During the write-up stage of the Research Project, I presented the results I would be including in my Doctoral report to the MontyZoomers as a means of sharing my understanding and gaining their input. Introducing people to the theory of PAR does not guarantee they will realise the methodology and its full emancipatory, knowledge-creation intent (Boog 2003). The three cycles discussed were only visualised by Pamela and myself. No one else reported that they could see beyond the cycles as distinct 'project-specific' entities, as determinants of a successive cycle (Herr and Anderson 2005).

As per SHU research regulation PS7.4, I have also made an attempt to indicate clearly my individual contribution and the extent of the collaboration (SHU 2014).

3.7: Study limitations

The two main limitations to this study were both issues relating to me as a novice researcher.

First was my inadequate grasp of what PAR truly encompassed, basing my method of conduction on a process I had used in the past (Hayward *et al.* 2004). Although the projects undertaken became more collaborative, decided and designed by co-researchers, the original research idea for the study stemmed from a previous research project I interpreted as being useful to take a step further.

Second are my years of clinical practice as a physiotherapist, taught to listen, observe and record (solvable) therapeutic problems with individuals. These are different skills to those expected of a research facilitator, observing social interaction and group dynamic. At the start of the project, most issues have been documented through Stakeholder meeting notes, an objective confirmation of what happened written through paraphrasing and interpretation rather than recording verbatim contributions.

3.8: Summary of PAR methodology

Health policy, at the time this Doctoral Project was undertaken, advocated an approach to utilise individual's capacity to self-manage their conditions, and members of the general public to improve their health by taking steps (and responsibility) to make positive lifestyle choices (Nesta 2013, Ham *et al.* 2012, DH 2010b, 2001d). Such expectation required patients, the public and appropriate spokespersons (health and social care professionals and Council officials) to collaborate in more localised, democratic working styles that enabled this tactic (National Voices 2015, Barratt 2014, Baggott 2005).

Health research has attempted to investigate how the participatory models might generate ideas for healthier population lifestyles (Michener *et al.* 2012, Rowe and Shepherd 2002), by using the results to improve services for the users (Morgan *et al.* 2005, Hanley *et al.* 2003). The models are viewed as cyclical in nature, each cycle progressing to the next following a period of reflection on action (Costello 2007, p6, Kemmis and McTaggart 2000, p595, McTaggart 1994).

PAR offered an opportunity to collaborate with a group of people affected by Parkinson's, in all its complexities, and through people's varied interdependent relationships to seek an understanding of their support needs to remain well.

3.9: An introduction to the PAR process

Our PAR process enabled co-researchers to agree the nature and outcome of their participation through the sharing of activity, some theory and their lived experience, with a role in enhancing constructive attributes from their contribution to the wider Parkinson's community (Hayward *et al.* 2004).

During the Research Project period, three AR cycles emerged, the final one progressing beyond the 18-month timeframe allocated to the process. Over this time, the roles, relationships and responsibilities undertaken by the MontyZoomers changed (White *et al.* 2004), as did the conceptual space (Bevan 2013) and the reasons for undertaking action (Hart and Bond 1995, p44–48).

In terms of the development of physiotherapy, the process highlighted ways in which the profession could move from its position where intervention is imposed, to one where it is included into people's support systems, and utilised as and when required. This requires therapists to understand the concept of interdependent relationships as understood by the populations affected by Parkinson's (Williamson *et al.* 2008, Gallant *et al.* 2007, Lewis *et al.* 2006, Birgersson and Edberg 2004, Fleming *et al.* 2004).

Introducing collaboration and co-design as the main research method to stakeholders who interacted in exercise classes for people with Parkinson's, but otherwise had little experience sharing learning, resulted in many differing perspectives about participation (Wulff and Nyquist 1986). The MontyZoomers explored how we support and sustain wellness through both fixed and emergent mixed method design, with the developmental research process creating ideas that each required different approaches to the gathering of information and analysis (Creswell and Plano Clark 2010, p54–56).

Part of my role in leading the Research Project was to manage expectations of the multitude of ideas put forward, some which were rejected by the others in the group as personal stances as to 'what and how' it was investigated differed (Punch 2009, p23–28), occasionally resulting in disagreement (Stringer 2014, p24-26).

Only certain projects have been singled for discussion in this thesis from the many activities and undertakings of the group during the Research Project period (Appendices 5 and 6). These were the ones that generated subsequent action with

outcomes, serving the social or political purpose of regaining identity and achieved wellness, a necessary part of being whole (Aujoulat *et al.* 2008, Charlton and Barrow 2002), and those in which the participants analysed information they gathered, enhancing existent literature within which people with Parkinson's historically lack voice or their input is overlooked (Nind 2011).

As expected, PAR developed through a cyclical process of '*planning, action, observing and reflecting*' from one cycle to inform and guide the next (Reason and Bradbury 2008, p390, Cook 2009, Hart and Bond 1998, p15, 37–45, Lewin 1946).

The AR spiral is a symbolic prompt of a process emphasising dynamism and continuity, as opposed to normal empirical-analytical research (Hart and Bond 1995, p54-55, McTaggart 1994). Too literal a take on the spiral ideology has created confusion about AR, as collective reflection by participants can only occur through discourse that requires an appreciation of the issue researched in the context of understanding organisational and power relationships (McTaggart 1994).

Our cycles differed greatly according to the methods used and projects accomplished. For example, where only one outcome was seen, e.g. the continued sale of Noel's cards, Hazel and Duncan pursuing a pot of money from a benevolent organisation, the undertaking to organise and run a car boot sale, the process was seen as complete after one cycle (Figure 3.1).

This was different to the way projects, such as Dave's fundraising efforts were viewed, where the initial effort was great, and the accomplishment of this resulted in a succession of similar activities (applications for grants and sponsorship). Over time however, the activity dropped as Dave drained his list of potential funders, yet there was a ripple effect a year or two later. For example, one organisation that had originally been approached chose the Sheffield Branch as their 'Charity of the Year' the following year, and undertook to raise money for the cause, plus we now receive an unsolicited donation from two companies annually (Figure 3.2).

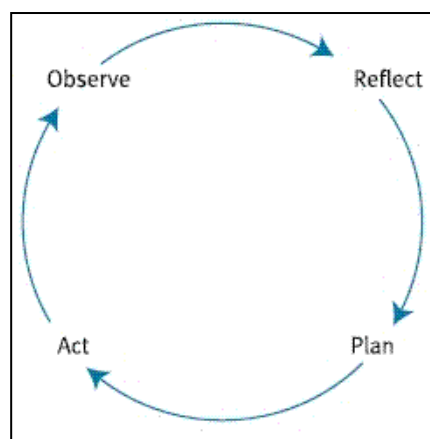


Figure 3.1: Single AR cycle with discrete project

Figure 3.2: AR spirals with ripple effect at later stage

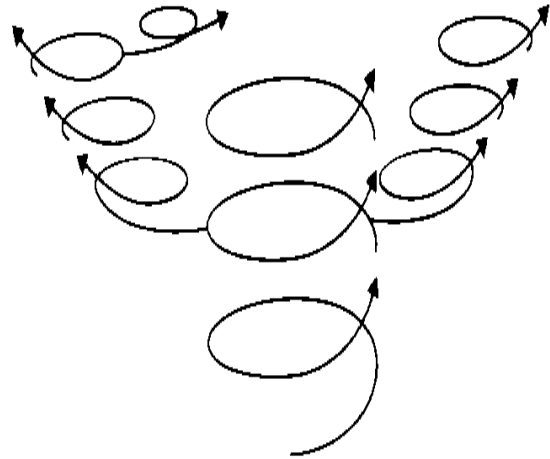
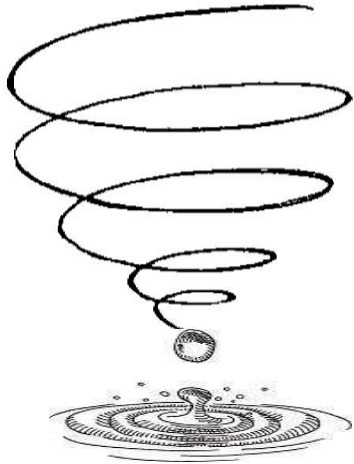


Figure 3.3: A generative transformational evolutionary process - copied without permission from McNiff (2013).

The reality of 'neat' cycles as originally visualised and theorised is a diverse, often unpredictable set of cycles generated during the process of '*mess*' created in PAR as spirals create other action cycles, forming a necessary part of the developmental process of PAR (McNiff 2013, p66-67, Cook 2009) (Figure 3.3).

The following three chapters review the research process through the pre-cycle and three cycles of action that took the MontyZoomers from a position of engagement in general action research, through to increasing participatory and emancipatory behaviour. Some developed further demonstrating personal empowerment to follow individual projects of social or political value.

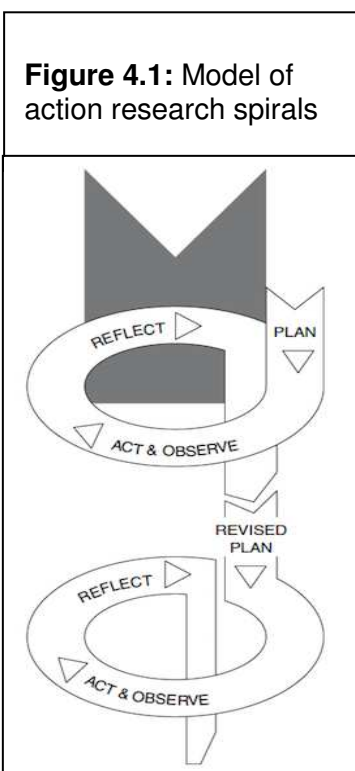
CHAPTER 4: THE RESEARCH PROCESS

AND CYCLE ONE - ACTION RESEARCH

4.1: The research process

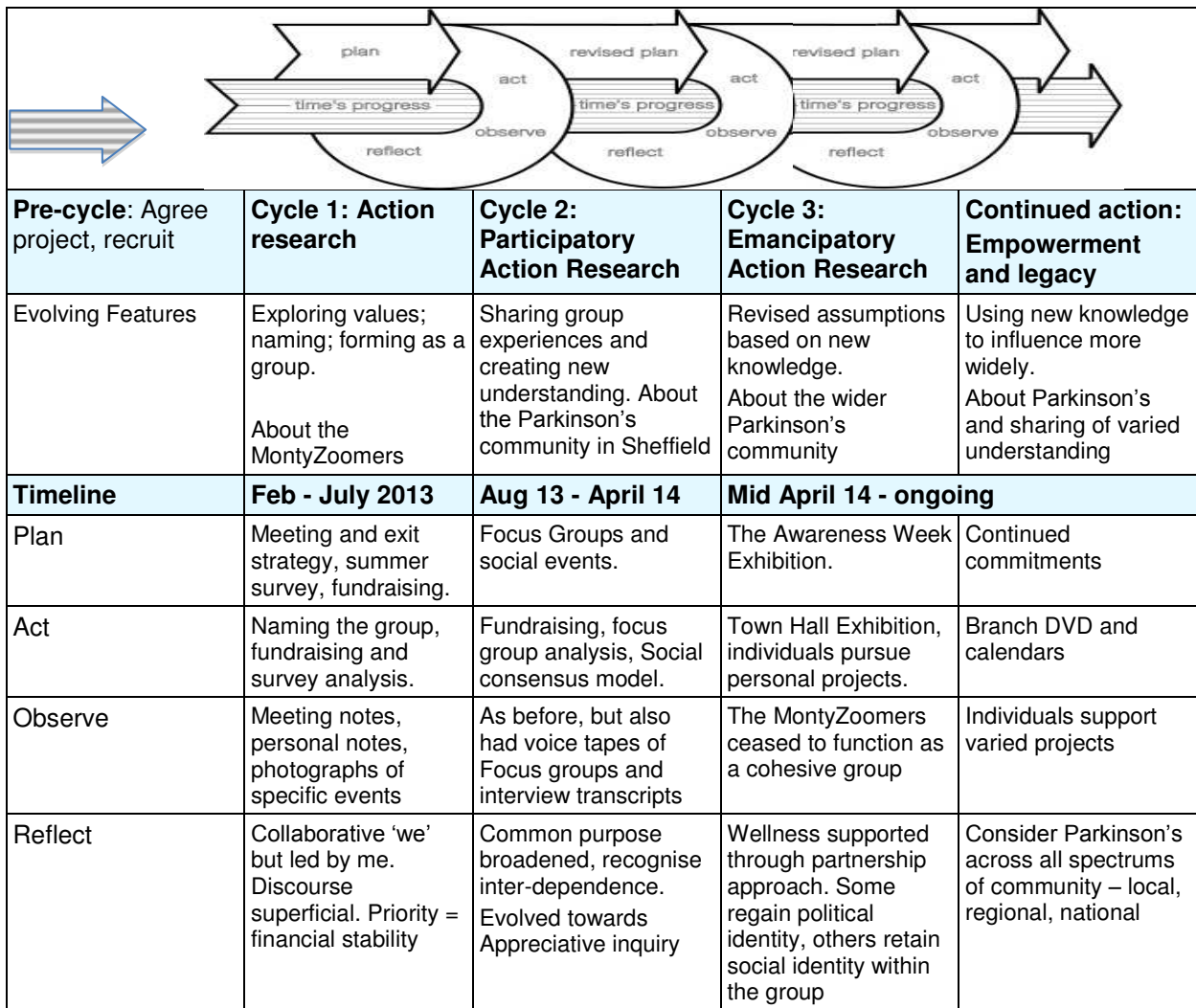
Lewin's action research concept was based on work with large organisations and an assumption that 'communities' within functioned through mutual consent (1946). This is different to a Freirian ideal, with a focus on emancipation of people with inequitable rights (Lather 1986, Freire 1996). Examples of 'action', 'participation', 'emancipation', and 'empowerment' can be found in this Research Project, described in the following three chapters.

The participatory research method is known to be chaotic due to its emergent process (Cook 2009, Brydon-Miller *et al.* 2003, Greenwood *et al.* 1993). In health research, it can be mapped along a spectrum of 'expert-led research', that given time, can evolve into a fully collaborative process of participants engaged in achieving a purpose common to their needs (Brydon-Miller *et al.* 2003). As lead researcher my role was expected to change from '*privileged possessor of expert knowledge*' to that of a motivator enabling the co-researchers to discuss, understand and find solutions to their considered problems (Lather 1986).



The participatory features emerged from the MontyZoomer stakeholders several months into the 18-month Research Project period, developing to a point where evidence of co-research elements, and then emancipatory qualities of some of the MontyZoomer members become apparent (Reason 2006, McTaggart 1997). Full details of the timeline, actions and information gathered can be found in Appendix 5. Each single AR cyclical process, and the shared findings amongst participants occurred as an ongoing requirement for subsequent discussion informing successive stages and activities (Cook 2009, Reason 2006, Hart and Bond 1998, p15, 37–38, Lewin 1946) (Figure 4.1 and 4.2).

Figure 4.2: Emergence of participatory ethos over three action research cycles



2012	2013												2014						
Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul
Ethics																			
Recruiting MontyZoomers																			
First meeting and naming group																			
Summer survey + analysis---Winter survey + analysis																			
Committee then Focus Groups																			
Story telling; social consensus model conceptualised																			
Ongoing group projects																			
Individual projects:																			
Bob starts R.I.P.E																			
Bob creates Flickr with Tony (not Parkinson's)																			
Janice - SHU revalidation																			
Pamela increasing involvement in stakeholder meetings; presentation to management; project with nurses and Regional Excellence network																			

4.2: Pre-step to entering action research cycles

The cyclical process of active problem solving through *planning, action, observation* and *evaluation/ reflection* is the hallmark of action-style research (Kemmis and McTaggart 2000, p595). Before the iterative process can begin, a 'pre-step' is required to articulate and explore ideas, generate objectives for investigation, and create an opportunity to gather information about the current state behind a proposed project (Lewin 1946).

The 'communicative space' (environmental space plus forum for people to openly voice their thoughts) to engage in collaborative discourse (Bevan 2013) was instigated by discussions with the Branch Committee, as the 'authority' supporting suggestions agreed by co-researchers (Williamson and Prosser 2002).

When a PAR project is first undertaken, the initial agenda may reflect an issue of more importance to the proposer (Herr and Anderson 2005, p100–102). Having run the Full Monty Exercise Club for ten years prior to the study, the consideration of how attendance supported people, and could be sustained into the long-term was more my (reductionist) question, and not that of class participants. The Branch Committee agreed sustainability of the Full Monty Exercise Club was worthwhile exploring and supporting, assuring me there had been no unreasonable imposition on my part (Reason 2006), and proposed to consider the relevancy of the work to the wider membership (Koshy *et al.* 2011, p86–88).

They helped recruit to the Research Project.

4.2.1: Recruiting stakeholders and meeting venues

The proposed brief was primarily advertised to recruit local stakeholders through the Sheffield Branch Newsletter, meetings and events, plus word of mouth at exercise classes (Tiffany 2006, White *et al.* 2004).

The 15 people present at the first official meeting in February 2013 were a self-selected combination of 10 individuals with Parkinson's, two of whom were active members of the Sheffield Branch Committee, ensuring activities would be communicated and discussed at Branch Committee meetings (Williamson and Prosser 2002). Three were spouses, two of whom often helped out at classes, one person was a friend (chauffeur) to a regular class attendee, and myself.

Whilst not a prerequisite to be part of the stakeholder group (henceforth referred to by the title 'MontyZoomers'), it was unsurprising that all offers to become involved were received from members who participated or assisted in the various exercise classes, all of who knew one another at least by sight. The selection reflected a respondent-driven sampling style of recruitment, with enlistment to the stakeholder group occurring as a direct consequence of contact between myself as the recruiter, due to a prior existing relationship with the people recruited (Tiffany 2006, Heckathorn 1997).

In other forms of research, this heavily-influenced recruitment style might not be acceptable. For this Research Project, peers were considered as desirable to encourage participation from others in their social circles for varied projects that might otherwise be '*hidden*' to recruitment from an unfamiliar researcher (Heckathorn 1997). This fitted the Theory of Communicative Action, which supposes that people's interactions are based on a common framework of understanding, affiliating to social groups whose actions represent common values (Habermas 1984, p85). The value brought by the recruited stakeholders was of direct experience of a diagnosis, or knowledge of someone with Parkinson's (Smith and O'Flynn 2000), reflecting the basis of AR with people engaging to shape, change and construct new knowledge, for themselves and the wider community (Jones and Gelling 2013).

Choosing a physical communicative space at SHU city campus facilitated the process (Bevan 2013). Partly based on travel access, the neutrality to participants, so as not to be '*in someone else's territory*', plus the symbolism of meeting at a university enhanced the perception of being part of a group facilitating education and learning (Bevan 2013, Jones and Gelling 2013)

In addition to the 15 MontyZoomers recruited locally, I approached two people as stakeholders from a wider Parkinson's-related network on the basis of their longstanding work with their local Branches. One was a person diagnosed with Parkinson's who had recent involvement as a Scottish Trustee on the Parkinson's UK Board, and the other, a physiotherapist and a Reader at Northumbria University with a background involved with Parkinson's and qualitative research methodology. Having external stakeholders with a broader outlook authenticated

the research credibility and project's social validity (White *et al.* 2004), ensuring it remained positioned in the context of Parkinson's UK developing national strategy (2015).

By the end of the Research Project period in April 2014, all 15 Sheffield members, plus the two external consultants remained active MontyZoomers (see 'Acknowledgements' for names of the MontyZoomer stakeholders), offering different skills, commitment and levels of participation.

Members of the main charity, Parkinson's UK are mostly white, middle class and with higher levels of education (Deane *et al.* 2014). This was certainly the case with most membership of the MontyZoomers (as of Indian origin, I was the exclusion), who comprised of academics, business or health service managers, and civil service professionals in high positions.

This impacts on the relevancy of the findings to the Sheffield Parkinson's population, and on the priorities and projects undertaken by the MontyZoomers over the course of the Research project. The choices of the co-researchers contributed to actions that enhanced the political and social stance of the Parkinson's Branch community, whilst opening some of the MontyZoomers' eyes to how they were responsible for shaping their understanding of Parkinson's, and their motivation to sustain their wellness (Beresford 2013, Nijhof 1995). This created a different ontology for the Parkinson's community in Sheffield than if the participants recruited had had greater levels of mental or physical disability, or were from a different socio-economic background (Beresford *et al.* 2010).

4.2.2: Naming the stakeholder group (The MontyZoomers)

A challenge in embracing a PAR approach, even when stakeholders know one another, is to effect engagement and ownership ensuring project outcomes are accomplished (Jones and Gelling 2013), and to provide a conceptual space where interpretation and experience-sharing can be facilitated (Bevan 2013).

The stakeholder group identity was based on their affiliation with the 'Parkinson's' label¹⁵. They were a mixed bag of interdependent persons some with the

¹⁵ The MontyZoomer stakeholders henceforth named in the thesis will be tagged by a label of pwP – for a person with Parkinson's, or NP, for a person who does not have Parkinson's, so the

diagnosis, those close to them who did not have the diagnosis, and myself as a health professional and researcher (Tuckman and Jensen 1977). My relationship had developed into friendships with those who came forward, formed over several years of meeting at classes and Branch events (Thornquist 1994).

People can belong to several groups that do not require exclusivity from one another (Jones and Gelling 2013). The stakeholders who involved themselves in the Research Project also chose to name the group, separating this from their identity both as members of the Sheffield Branch and the Full Monty Exercise Club (Bevan 2013).

Naming a group demonstrates control of actions believed could make a difference, and is a creative aspect of PAR offering opportunities to contribute to collective wellbeing (Borkfelt 2011, McIntyre 2008, p40). At the first stakeholder (henceforth referred to as 'MontyZoomer') meeting, people agreed to submit potential names for the group, many of which were mischievous, reflecting the humorous nature of the membership of many Full Monty Exercise Club members.

The runner up was 'Bhanu's Rascals' (which of course was my favourite):

'Working on the premise that we could adopt an acronym' (Dave [NPF] -
MontyZoomer Stakeholder Meeting 2: 15.03.2013)

Ramaswamy's

Academic

Study

Consultation or **Coordination**

And

Learning

Support

Dave's choice of words aptly identified the important participatory and emancipatory elements we would achieve as co-researchers through this group, as well as combining it with the Doctorate of Professional Studies foundations (Koshy *et al.* 2003, p1-3), however, the '*MontyZoomers*' was the name chosen for the group.

interdependent relationship can be considered in their actions or statements. The NP categories are further split into 'S' for a spouse, 'F' for a friend, or 'P' for professional

Janice (pwP) and Sylvia (spouse of someone with Parkinson's) put the suggestion forward as the name combined the exercise club and Research Project membership:

'.....elements of belonging to the Full Monty Exercise Club we are all members of, and indicates swift action on our part' (MontyZoomer stakeholder meeting 2: 15.03.2013)

Looking round the group (ageing and affected by Parkinson's or other pathologies requiring a mobility aid), Janice's cheeky adjunct was to note that:

'Zoomers' might also be a misspelled pun on the word 'Zimmers!'
(MontyZoomer stakeholder meeting 2: 15.03.2013)

The act of naming communicates representation of an object in both language and impression, and the 'MontyZoomer' title was better than choosing the acronymic name intimating participation in a project initiated and led by me, rather than one of a joint venture (Borkfelt 2011, McIntyre 2008, p40).

It is not unusual for people to participate in social action to support the cause of a person who previously supported them (Kilgore 1999). Some individuals were open about the fact they joined this Research Project to support me through my studies (stated in the introductions made at the first meeting). The selection of a generic name was therefore an important decision, especially as two members of the group with Parkinson's suggested it, producing the first action of ownership (Borkfelt 2011).

The MontyZoomers, an interdependent and collective group of people affected by Parkinson's were ready to start.

4.3: Cycle one - Action Research

This cycle ran over the first six-month period between January and July 2013.

The sources of information used to illustrate the cycle as it progressed through the stages of *planning, action, observation and evaluation/ reflection* initially came from MontyZoomer stakeholder notes and comments from individuals during the meetings. Later in the chapter, information gathered during a project undertaken by the MontyZoomers is used to explore meanings of wellness.

In terms of planning, the MontyZoomers met monthly to agree activities, and to establish an end point for the Doctoral Research Project period (May 2014), with an exit strategy that supported mechanisms suggested to sustain the anticipated, ongoing work of the MontyZoomers (Hart and Bond 1995, p197).

I name this first cycle one of AR, as the activities undertaken were pursued as tick-box tasks, undertaken through a principal researcher-led process (Reason 2006, Costello 2007, p5–6). People arrived at the first meeting ready to go with ideas.

'If you can send me a letter about the Full Monty Club, I know where to get access to a one-off pot of money – the deal is as good as done!' (Hazel [NPS] - MontyZoomer Stakeholder meeting 1: 15.02.2013)

'...I can paint cards that we can sell at meetings; I have done this at church events, and can bring a selection as well as a card-display stand' (Noel [pWP] - MontyZoomer Stakeholder meeting 1: 15.02.2013)

'I was really surprised when Harry was first diagnosed, and there was no information at our GP surgery about Parkinson's. We can draft a leaflet that might be displayed at GP practices and pharmacies to advertise the exercise group' (Sheila [NPS] - MontyZoomer Stakeholder meeting 1: 15.02.2013)

The process followed that seen in most AR literature, paying attention to the identification of a problem (for us, it was financial sustainability of classes), gathering information, acting (our fundraising projects), later disseminating the findings, with comparative inattention of the process of data analysis, key to the next stage of reflection to complete the AR cycle (Nind 2011).


Each stage still required discussion and agreement amongst participants, were time-consuming and rewarding, but had not reached a level of criticality to engender the construction of new knowledge or increase (political) wakefulness through a level of criticality (Reason 1999, Hart and Bond 1995, p196).

I documented the process with meeting notes of agreement, actions and timescales, by jotting down personal observations of the way people behaved and occasional comments that struck me as significant, and by taking photographs to record specific events (Koshy *et al.* 2003, p86–88).

Looking back on the quality of material gathered to inform the data chapters

highlighted the lack of my understanding of the true participatory nature of PAR. The detached stance to note recording and photograph taking was an obvious outcome of my professional career steeped in objective statements and recording (Parry 1997, 1991).

For example, I tabulated the success of Noel's (pwP) card sales dryly accounting for the income and illustrated Noel posing by his cards – nothing dynamic or participatory by asking Noel for his thoughts on the sales, or how he would like to be photographed 'selling' his cards (McIntyre 2008, p5).

<p>2</p>	<p>Projects underway:</p> <p>Noel's cards – currently raised £60.50 on sale at exercise classes and branch meetings.</p> <p>ACTION: Following a suggestion of two members at the Branch meeting, Noel has agreed to paint some with balloons / cakes – more in keeping with children's cards.</p>	
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Source: MontyZoomer Stakeholder Meeting notes 3: 11.04.2013.

The period was important to enable the sharing of ideas using existing (some rediscovered) skills mostly in relation to fund-raising events, as the stakeholders believed financial stability a group priority to sustain current exercise class provision by the Sheffield Branch.

The varied discussions during the first months demonstrated a visible attempt to establish an understanding of the PAR concept and the social (and political) restrictions that the Full Monty Exercise Club was subject (Koshy *et al.* 2003, p17), whilst asserting their identity and role within the MontyZoomers (Koshy *et al.* 2003, p19).

'Ann [pwP] fed back with some gentle persuasion. It was clear she felt a little uncomfortable at first, but she knew us all and the others were attentive and encouraging. By the end of her say it was hard to stop Ann talking!

Fewer numbers meant the quieter ones were more vocal in their contribution – especially to the draft letter. Denise [pwP] is particularly good at this sort of stuff. There was a wish for inclusion of questions wider than just about exercise, as the group felt it would be useful to find out what other activities the exercisers partake in offered by the Branch.

BOY! have I a lot to learn re: record (account) keeping. Pam [pwP] doing an amazing job sorting these.'

(Personal notes reflecting on MontyZoomer Stakeholder meeting 4: 10.05.2013)

The quality of group reflection and discourse was not at any great depth during this cycle as the process of facilitation of genuine PAR was novel to me. This is not an uncommon issue identified in physiotherapy and general health research practice, with true empowerment of participants restricted by an overriding quantitative stance to physiotherapy education-related and work processes (Reason 2006).

Despite my awareness of the expected PAR process, the MontyZoomers initially responded to the original research agenda, led by a process largely concerned with the completion of a task to evaluate the existing exercise classes (French and Swain 1997).

4.3.1: MontyZoomer project to identify and illustrate characteristics of exercise participants' wellness

This project documents the findings by the MontyZoomers of responses from a question asked in survey of exercise participants about their reasons for participation in Branch-run activities in June 2013.

The request agreed at MontyZoomer Stakeholder Meeting 5: 13.06.2013 was for respondents to:

'Use two to four words to describe why you continue to attend classes and other events'.

The wording was agreed by the MontyZoomers to gain an understanding of what positive traits drove people to sustain their participation.

The words were initially illustrated using a Word cloud (Figure 4.3) suggested by Mike (pwP) who had seen one used recently.

'We can use pictures, Wordle, or Clustered word clouds' (Personal notes reflecting on MontyZoomer Stakeholder Meeting 5: 13.06.2013)

A Word Cloud randomly organises large volumes of collective keywords by sizing them proportionately to the number of times they are mentioned into a pictorial

The first piece of analysis agreed by the MontyZoomers was the exploration of the meaning of the words and phrases gathered from the survey, mapping them to a 'Wellbeing' framework (nef 2008), a model I had used for a past facilitatory event.

4.3.2: Analysis of survey by MontyZoomers

Denise and Ann (both pwP) offered their help, adding a second layer of personal (critical) understanding to the first table of mapped words (Appendix 7), comparing this to the wellbeing framework (Table 4.1).

'When I did my teacher training, we were taught to think like this, and also my experience as a yoga teacher makes me always think about things to keep you well' (Ann, personal correspondence 10.05.2013)

The results were primarily discussed at MontyZoomer Stakeholder meeting 7: 13.09.2013, then taken to two subsequent Branch meetings to share the work more widely amongst non-exercisers, again to gain further insight of the membership.

The *'Five ways to Wellbeing'* document headings are 'connect', 'be active', 'take notice', 'keep learning' and 'give' (nef 2008). They represent functional means by which to motivate and facilitate action on wellbeing within groups and communities.

The process Denise, Ann and I undertook was to first order the survey response words, then map these to the five facets of wellbeing. Finally, Ann and Denise added a layer of their understanding founded on the how they viewed the context based on which people responded to the survey.

For example, the messaging 'connect' relates to connections made with people around and about, with an expectation that investing time to develop this aspect of wellbeing will create a network to support everyday life (nef 2008).

Survey responses mapped to this facet included association to socialising e.g. *'Like meeting other members'*, *'Enjoy social occasions'* and *'Fun'*, the first two statements in keeping with the understanding that activities social engagement has a positive effect on wellbeing (Everard 1999). Responses suggesting the tackling of isolation, an issue for people with Parkinson's (Benharoch and

Wiseman 2004), often related to deterioration in mobility (Bloem *et al.* 2004) included: ‘*Social gathering*’; ‘*Company*’; ‘*Social contact*’; ‘*Socialise*’; ‘*Social interaction*’, or the specifics of the exercise class still permitting them to ‘*Exercise with others*’ and ‘*Exercise in a group*’.

The importance of connecting with others experiencing similar problems was seen by: ‘*Mix with other Parkinson’s*’, ‘*Contact with Parkinson’s*’, ‘*Meeting others with Parkinson’s*’, and ‘*Comforting to be with people who understand*’ something of value for people with Parkinson’s exercising in a same-condition group (Mazanderani *et al.* 2012, Locock and Brown 2010, Roger and Medved 2010, O’Brien *et al.* 2008).

Ann and Denise identified a further category related to many of the ‘connect’ facets, of ‘psycho-social benefits’ of participation, as well as sources of ‘support’, recognising the subjective and more hedonic aspects of wellbeing (Henderson and Knight 2012, Heiberger *et al.* 2011). They mapped survey-collated words and phrases to the other facets of wellbeing, categorising them in a similar fashion onto a comparative summary table (Table 4.1).

Table 4.1: MontyZoomer agreed analysis of survey characteristics of wellness

5 ways to wellbeing concepts mapped against terms	MontyZoomer collaborative analysis of wellness terms
Connect	Health & Wellbeing benefits and Psychosocial benefits
Being active	Social benefits of being active and Physical outcomes from being active
Take notice	Motivators
Keep learning	Education
Give	Support

The principles are similar, but not the same. In chronic-illness management, social support in engagement and role reshaping has been shown to be of great value (Vassilev *et al.* 2014), and we see in two instances that the social versus the physical health issues are identified as significant enough to separate.

Words from the survey like: *'understanding'*, *'(self) confidence'*, *'common morale of the group'*, *'optimism'* and *'purpose'* were equated to psychological dimensions of happiness and wellbeing (Ryff 2014), and as the knowledge-related words were understood by Ann, Denise and myself to be about information learned about Parkinson's, these were placed under the category of 'education'.

'The words are in the present tense – they must have Parkinson's..... these mention getting information at meetings [points at two different statements], so I think they are learning about Parkinson's they are being educated about new things'. (Denise [pwP] at a subgroup meeting 06.09.2013)

The responses to the survey were specifically about the Full Monty Exercise Club and Branch activities, and collected early on in the Research Project timeline before increased social activity had begun, so few words described the wider aspects of 'Give' and 'Take notice'. This second layer acknowledged a point at which Ann and Denise were becoming critical, creating MontyZoomer collaboratively driven data, different to the professionally driven words proposed for the wellbeing framework.

4.4: Moving forward to the next cycle

The mapping of the exercise participants words and phrases to a wellbeing model (nef 2008) allowed us as MontyZoomers an experience of exploring the thoughts of Branch members as a group. This was our first attempt at a joint educational project within the Research Project working together as partners, and not a 'physiotherapist' working with 'patients' and 'carers' (Roger and Medved 2010).

Health research pushes for active engagement between consumers and researchers to achieve a more relevant outcome (Boote *et al.* 2002), but allows little time for the development of relationships within the co-researchers (Bonebright 2010). This was our time for *'Forming'* (Tuckman and Jensen 1977), a period for growth in small group dynamic exploring agreed tasks and group behaviour to evaluate the results. Our evolving shared vision from this collective social action positioned the theme of 'wellness' as a central tenet of future MontyZoomer projects (Kilgore 1999).

The survey project provided a space for collaborative learning (Bevan 2013), with an increase in group identity and consciousness through collective, organised working towards a goal of social action (Kilgore 1999).

My reflection on this period is an experience of 'wellness' working as a collaborative, watching people dipping in and out with their specific skills and ability to support the Research Project and one another. It was as I had expected from a group gradually rebuilding an identity of the 'self' from within a group identified by 'Parkinson's' (Abes *et al.* 2007, Ashforth and Mael 1989).

The attempt at analysis set an agenda for further projects to control and change the situation of a wider membership in and around the city (Alexander 2010, Brydon-Miller *et al.* 2003, Greenwood *et al.* 1993). We saw opportunities to learn and construct theory from our own historical perspective and experiences (McIntyre 2008, p67-68, Greenwood *et al.* 1993), and commit ourselves to this Research Project by reason of personal investment (White *et al.* 2004).

This process of creating space for collaborative effort evolves over the course of a group's working life. It was coming into being by the end of this cycle, emerging more fully during the succeeding cycle (Bevan 2013, Reason 2006, Hart and Bond 1995, p196).

CHAPTER 5: CYCLE TWO - BECOMING CRITICAL - AN EMERGENCE OF THE SOCIAL AND POLITICAL

5.1: Introduction

It is naïve to assume PAR projects commence with the participants engaging fully from day one as participation must be generated and allowed to gain momentum over the course of the research process (Bate and Roberts 2006, Greenwood *et al.* 1993).

The identification of strengths and abilities of the MontyZoomers continued to emerge and the level of criticality developed during this second AR cycle. Not everyone understood the concept of PAR methodology, and not all of those who understood it did so at the same pace (Reason 2006).

This cycle ran over a nine-month period between August 2013 and mid-April 2014.

5.2: Sustaining more than just fundraising

The sources of information used to illustrate the stages of the cycle (*planning, action, observation and evaluation/ reflection*) again came from MontyZoomer stakeholder notes and personal comments noted. The attention of this chapter is on the Focus Groups and interviews conducted with members of the exercising members of the Branch and with the Sheffield Branch Committee respectively. The transcripts from these provide the main data sources used for analysis.

The cycle highlights two issues. First that the term ‘sustaining’ evolved into a concept that was more than the fundraising tasks people had begun the project offering, although these continued. Noel’s cards were available at meetings, and Dave was unrelenting in his application for grants and sponsorship:

‘[Named wife] is at choir every Tuesday evening, so I am sending a letter or application each week – don’t worry, the stationery and stamps are my contribution!’ (Dave [NPF] – MontyZoomer Stakeholder Meeting 7: 13.09.2013)

Second, we see a change in the language and perceptions of people during some of the analysis from the collective ‘us’ prominent during the first AR cycle, with separation evident between the interdependent groups of people with Parkinson’s,

close family (in this case spouses), friends and the professionals.

Two catalysts were responsible for the change from AR of the first cycle to PAR and the level of participation of the MontyZoomers during this cycle.

The first catalyst was a large social fundraising event planned for the coming August.

‘Jo [NPPartner] and I are planning a Strawberry Fayre at our home in [named village]..... The proceeds will be split between Voice Class and the Full Monty Club. We are working with Pamela to have a flyer and tickets ready for the May Branch meeting’ (Bob [pwP] at MontyZoomer Stakeholder Meeting 3: 11.04.2013).

The event had the same goals as the Coffee Morning at Harry and Sheila’s in the July of the same year, i.e. a fundraising social event conducted in a family-friendly and fun atmosphere, but it was to be on a larger scale, as recorded in the MontyZoomer Stakeholder Meeting notes (with another posed photo!)

<p>Item 2.</p>	<p>Strawberry Fayre planned for Saturday 10th August 2013: Bob and Jo provided a run down of the organisation of this fundraiser to be hosted at their home. Leaflets are already in general circulation, and Jo gave a full break down of activities, the fundraising and people she has already got involved in the event. We all agreed there has been a phenomenal amount of thought and work gone into the planning and gaining ‘co-operation’ from others. At the meeting, Jo received offers of help.....</p> <p>ACTION: Several issues to be checked by MontyZoomers:</p> <ul style="list-style-type: none"> ○ Jo to print tickets for us to sell at the Branch tea in July. ○ Bhanu to check Gift Aid forms and if spare Parkinson’s UK T-shirts for the ‘staff’ ○ Bhanu to check if [names person] can man the Lawn Croquet during the day. 	
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MontyZoomer Stakeholder Meeting 5: 13.06.2013

<p>Item 1.</p>	<p>Strawberry Fayre. Jo has provided printed tickets, which we have now started to sell; Dave consulted a friend in the Police force to ascertain the legalities of having a ‘bar’. The information about obtaining a license has been forwarded to Bob to organise; (Branch Treasurer) has provided Gift Aid forms; (Branch Secretary) has provided a collection bucket and 2 pots + the 2 remaining Parkinson’s UK T-shirts she had for the ‘staff’ to wear (previous ones given to the Voice Group).</p> <p>ACTIONS: 1. Bhanu and Janice to organise lifts; people have offered to transport from the Lodgemoor area. 2. There is an ‘Organiser’s meeting’ at 11.00 am, 30th July.</p>
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MontyZoomer Stakeholder Meeting 6: 12.07.2013

Bob and Jo's venture swept the MontyZoomer's into the next level of transformation, running the occasion almost as a commercial 'event', directly involving a wider, non-Parkinson's community to support the Sheffield Branch.

The second catalyst was an invitation for my Research Supervisor to present at a meeting to critically inform and engage the MontyZoomer members. I had requested her attendance to help my process of transition into a participatory researcher, and needed help to facilitate the group's thinking about the social and political constrictions that they might have been subject to. The outcome of the meeting is detailed and analysed in Chapter 6.

5.3: The Focus Groups and Branch Committee interview

The MontyZoomers utilised our new experience of collective learning to design and develop projects investigating and evaluating a sustainable provision of exercise classes and Branch activities (Ellins and Glasby 2016, Tanner 2012, Brydon-Miller *et al.* 2003, McTaggart 1994). One specific project was the focus groups and Branch Committee interviews, analysed here to demonstrate the development of networking and the continued building of capability as MontyZoomers.

Focus groups and group interviews provide an acceptable way to explore opinion, values and motivation (Byrne *et al.* 2015, Gill *et al.* 2008, Wilkinson 1998, Frey and Fontana 1991), allowing the researcher to probe, through the language of those in the group their experiences and concerns, whilst permitting an opportunity to witness a process of collective sense-making in action (Wilkinson 1998).

The analysis of wellbeing characteristics from the survey responses prompted the MontyZoomers to investigate participants' reasons for engaging and continued participation in classes in more detail (Byrne *et al.* 2015, Morgan 2010, Gill *et al.* 2008). It was agreed that a series of focus groups would enable this goal to gain collective information about the specific issues of sustainability of the classes into the longer term, and of support available/ expected from the Branch (Casstevens and Cohen 2011, Wilkinson 1998).

We agreed that given the limitation in time to plan, conduct and analyse the

findings (restrictions imposed by the Research project time frame), that group interviews¹⁶ would be the best way to do this.

We followed a six-step process that had proved successful in co-design for healthcare improvement with cancer services, part of which had included interviews with cancer survivors (Boyd *et al.* 2012). Like the ‘*Five ways of wellbeing*’ framework, it was a process I had utilised before in a hospital-led AR project.

The procedure facilitated the MontyZoomers (already a proactive group for the *engage* phase) to establish a topic guide, allocating roles based on recognition of each other’s, and their own strengths (*plan*). They implemented the focus groups (*explore*) and co-opted someone with skills to analyse the data (*develop*). After agreement over the themes identified in the analysis, they chose things they could influence by disseminating the results (*decide*), and recruited other Branch members where necessary to take action on some of these issues (*change*).

Each stage in the process demonstrated ownership of the process (Nelson *et al.* 1998) as expected with PAR methodology (Bergold and Thomas 2012, Cook 2012, Reason and Bradbury 2008 p8, Greenwood *et al.* 1993).

The activity belied the ‘passive patient’ experience of prominent health models, strengthening the social ideology of empowerment and improvement through co-design (Boyd *et al.* 2012, Bate and Roberts 2006).

5.3.1: Planning for the focus groups

The discussion about the focus groups had begun at MontyZoomer Stakeholder Meeting 7 (13.09.2013), when the group were introduced by my Doctorate Supervisor to the work of Paulo Freire and his ideas of community education and oppression (Freire 1996). They were questioned on what they were contributing and learning as a MontyZoomers.

She asked those present about their experience of gaining knowledge:

‘Has this group sown the seeds for sustainability?’

‘How might you capture people’s knowledge and experience in art, pictures,

¹⁶ The words ‘interview’ and ‘focus group’ were used interchangeably during our conversations due to peoples’ experiences using or hearing about one or the other. See Glossary for definition of each.

music and other forms?' (Stakeholder meeting 7 - 13.09.2013).

Discussing whether they considered themselves passive or active participants created a more academic tone, thus increasing the educational intent of the process (Turner 1982). The MontyZoomers split into two groups to reflect more deeply with discourse directed to the topic guide questions for the focus groups (Table 5.1).

Table 5.1: Transcript of Flip Chart ideas from the two MontyZoomers agreeing the following ideas to ask at interview, and themes for the topic guide

Group 1:

- *Possibility of further engagement and motivation from a scale of 1 – 10*
- *Ask are you learning about your condition; is any learning happening at exercise class? What have you learned?*
- *Does it help?*
- *What about learning outside the exercise class?*
- *Does class encourage you to seek further information regarding the condition?*
- *Attitude impact of exercise class? Physical? Mental?*
- *Give examples of what extra you can do after exercise*
- *The interviewers have to consider what questions will elicit personal a response? e.g. What words would sum up your feelings after exercise classes?*
- *Reciprocity between leader and class.*
- *What kind of relationship exists between leader and group? e.g. instructional? Autocratic? Directive? Supportive? Enabling? Trust?*

Group 2: PROCESS

- *Use of open questions to ascertain why / why not people take other classes*
- *Personal experience of why they are there in the first place*
- *Why do they come back?*

THEMES

- *Sustainability – e.g. looking wider than Branch activities, why do people sustain attendance in non-Parkinson's UK Sheffield Branch classes e.g. class style preference/ class leader; what about hobbies – what reason to pursue this?*
- *Engagement – alone to others, to this group*
- *Awareness – How will we promote this through Parkinson's Awareness Week?*
- *Influence – is there anything to change?*

QUESTIONS: *Do we use a mix of individual interviews as well as group interviews?*

One group considering what we wanted from the interviews e.g. engagement from other Branch members, an understanding of what people learned at class and

outside of the class environment, and to think about the words and qualities people would use to describe the class, and the leader.

The second considered the process the interviews might take, agreeing themes for the topic guide to be 'sustainability', 'engagement', 'awareness', and 'influence'.

When returning the attention to the impending focus groups, members of the group chose roles they wished to take based on recognition of each other's, and their own strengths, even though none of those who offered themselves forward as focus group facilitators had any experience.

Denise: *'I've previously offered support for any reviewing of the write-up – that still stands'*. (Stakeholder Meeting 5 – 13.06.2013)

Mike: *'Bhanu cannot be part of the interview process for the class members due to the bias of her profession, and the fact the interviews will seek to ask specific thoughts about the classes being run by (neurologically specialised) physiotherapists..... She can transcribe the tapes afterwards..... She can also conduct the Branch Committee interviews as that is more exploratory of their decisions to sustain funding for the classes and their thoughts on the evolution of the Full Monty Club'*. (Stakeholder Meeting 5 – 13.06.2013)

Mike: *'I can provide insight from my experience of interviewing in the past if you'd like.....'* (Stakeholder Meeting 6 – 12.07.2013).

5.3.2: Conducting the focus groups and Branch Committee interview

PAR should be led from a perspective of those directly concerned by the matters under investigation, rather than through the opinion of a researcher's preconceptions and preference (Doyle and Timonen 2010).

People with 'disability' are rarely included in participatory research as co-researchers however, sometimes due to economic disadvantage (WHO 2011), but that was not the case with the MontyZoomers. It is more likely that their role is considered to be that of 'interviewee' and not 'interviewer' (Smith-Chandler and Swart 2014, Doyle and Timonen 2010), or that PAR leads do not understand the true nature of the methodology (Pettit 2010, Waterman *et al.* 2001, Eden and Huxham 1996).

The process of PAR should identify responsibilities of the co-researchers that are

both congruent with the research goals but that would also enable them to discover their own learning and support needs (White *et al.* 2004).

In addition to an interview (voice-recorded) with the Branch Committee conducted by myself in August 2013 to pursue the first objective of this Research Project, four focus groups were organised for the October and November 2013 to investigate exercise class participants' motives for engaging and continued participation in classes.

They MontyZoomers who put themselves forward to act as facilitators were Janice and Ann (pwP), and Sheila and Sylvia (NPS), spouses of MontyZoomers with Parkinson's, who also volunteered for varied Branch activities, so knew many participants Table 5.2).

Table 5.2: Details of the Branch interview and focus groups conducted by MontyZoomers

Which MontyZoomers facilitated	Whether facilitator has Parkinson's or not	When/ where	Mix of the group members
Bhanu (voice recorded transcript)	Physiotherapist; does not have Parkinson's	27.08.2013 - Committee interview	People with Parkinson's, those without, and a health professional (nurse)
Janice and Ann (voice recorded transcript)	Both have Parkinson's	21.10.2013 – aquarobic group	People with Parkinson's, and spouses without
Sheila and Sylvia (voice recorded transcript)	Neither have Parkinson's; their spouses do	23.10.2013 – circuits group	People with Parkinson's, spouses and friend without
Janice and Ann (no voice record; personal reflection provided)	Both have Parkinson's; their spouses do	29.10.2013 - Posture group	People with Parkinson's only
Sylvia (voice recorded transcript)	Not have Parkinson's, supported by husband Mike as Sheila unable to attend	04.11.2013 – Posture class	People with Parkinson's, and spouses without

This activity evidences a growth in the MontyZoomers becoming more political, as they chose to take on a project to investigate the thoughts and needs of other people with Parkinson's in the hope of altering their situation to the better (Hammel *et al.* 2008).

None of the four facilitators had ever conducted interviews in this context before, but Janice and Sylvia had done so during their working life. Each was asked to feedback to the MontyZoomers at the meeting after the focus groups had finished. It is not uncommon for novices to interviewing to feel uncomfortable the first time they interview due to lack of practice (Byrne *et al.* 2015). Whether or not the facilitators had Parkinson's, all had initially felt out of their comfort zone with the task, but reflected that they enjoyed the overall experience, as explained by Sheila (NPS):

'How I felt? I was nervous at the beginning, but then my mouth cut in and soon got into the swing of things. Sylvia was lovely to work with, very calm. People were happy to take part but speech and hearing made it more difficult for some, but by giving some non verbal cues e.g. smiling, nod of head, I felt most people had a say without embarrassment. I found the experience enjoyable' (Personal correspondence after 23.10.2013 Focus Group)

The main difference between a focus group and group interview is the observation of group interaction, i.e. the interactive dynamic of both what is said, and how the participants are saying what they do (Morgan 2010, Wilkinson 1998, Frey and Fontana 1991). Ann added, looking to Janice for agreement (her partner for both the focus groups they had facilitated):

'I don't do much talking, I watch and listen more.....I noticed a difference in the attitude between our two groups. The Tuesday class didn't really know anyone else, they don't go to anything else [referring to a class at a venue permitting access by the less physically mobile members of the Branch].....they were not as easy to ask questions of, and some just wanted to talk about their problems.....I think they would have done so if we had of let them' (Ann's personal notes handed to me after both 21.10.2013 and 29.10.2013 Focus Groups).

Echoing a point that it is easier to commence the actual business of interviewing where there is prior relationship between the researcher and participant (Byrne *et al.* 2015), Janice, speaking about the difference between the two focus groups she and Ann facilitated, added:

'It was certainly easier to talk with the hydrotherapy group [an exercise that both Ann and Janice attended] than the Posture group. It was a shorted interview - I think we only knew one person there' (Janice's personal notes handed to me after the 29.10.2013 Focus Group).

The last sentence possibly intimated a problem in building a relationship with the group, creating less data (Frey and Fontana 1991).

5.4: Analysis of the focus groups and Branch Committee interview

The findings from the transcripts are explored from two positions, both using thematic analysis, a method used in qualitative research to identify, analyse and record patterns noted within data (Braun and Clarke 2006).

The first position is that of the MontyZoomers insight of emergent themes from the focus groups, and the second, a thematic analysis of characteristics of wellness that emerged from my reading of the transcripts.

The interdependent relationships of the key group participants become more evident in the second analysis, but has four identifiable associations:

1. Spousal relationships between husband (all in the group had Parkinson's) and wives (none had Parkinson's, but one had a disability limiting her mobility)
2. Between the people with Parkinson's and a friend of one, who has since continued in a role as volunteer to the group
3. Between people with Parkinson's and other people with Parkinson's (from recently diagnosed and new to the group, to people who had been coming since the classes started in 2000)
4. Between people with Parkinson's and the health professionals

Interdependence viewed through a relational context can be either harmonious or strained (Kitayama *et al.* 2010), and the commitment of the people between whom the relationship exists creates a state of dependency or satisfaction (Rusbult and Buunk 1993).

5.4.1: Collective analysis by the MontyZoomers

The Focus Group transcripts were coded and thematically analysed by a co-optee to the group. At a meeting to discuss the Strawberry Fayre, Jo, the partner of Bob (pwP), present when the approaching interviews were discussed, offered her skills in this field when it was clear no one in the group felt confident to code for analysis:

'I have had experience analysing interview data at the Language School I ran as my business. I'd be happy to look at the transcripts with Bob'

(MontyZoomer Stakeholder Meeting 5: 13.06.2016).

The themes were reviewed through a three-stage process. Jo categorised the transcript data, with Bob and I adding pertinent comments; we were the 'Analysis subgroup' for this project. To reach a consensus, we sent out the themes to the other MontyZoomers for discussions at Stakeholder Meeting 10 (12.12.2013), to be able to discuss meanings of the findings. The third stage was sharing the themes with the external stakeholders and both my research supervisors for additional comments.

Jo's originally forwarded themes remained unchanged. They were:

Communication: *was a hit and miss issue, and sometimes needs to be better/consistent. There were ideas forwarded on how to improve this*

Education: *saw elements of both people learning and teaching one another - whether the people in the Branch or from professionals without Parkinson's*

Personalities: *the humour / optimism/ inspiration from the group members, the atmosphere of support, from class leaders and their character(istics) came out as important – the elements of positivity*

Other support: *social elements, shared experience and Committee back up in the background were seen as essential. There was a point raised that there were currently too few leaders.*

Both external stakeholders and supervisors felt the themes had captured the data, with Iain (Chair of the Aberdeen Branch) emailing confirmation the value of the work, emphasising the issues to be valid outside for people affected by Parkinson's outside of the Sheffield group:

'The output from your project ...is thorough and comprehensive. My initial reaction on reading the documents several times was the effectiveness of both the questions and the interviewer(s). The meetings all covered the scope comprehensively and the common threads running through them were readily recognised and in reality would have been similar to other parts of the country with similar population density.....' (Iain Young: email correspondence 18.11.2013)

I end this section with Pamela's (pwP) response. As one of the dual MontyZoomer-Branch Committee members she took the initiative to contact and invite the Branch Secretary to attend MontyZoomer Stakeholder meeting 10 to be part of the 'focus group theme' discussion.

Pamela's reaction had been very interesting in itself, captivated by the transcript information where something was suggested as not done well, and focus group members proposals what might be done to address the issues. Her words and actions are of empowerment, optimistic of a future seeking to solve problems both by herself and with others affected by Parkinson's for their betterment. They are not as expected of a 'victim' of a 'disease', suffering, stripped of identity, incapable (cognitively) of making decisions because of a stigmatizing disease label (Boyd *et al.* 2012, Moe 2012, Eccles *et al.* 2011, Galinsky *et al.* 2003).

Her headspace was back into her role as Manager in an NHS Trust!

'I think the analysis of the transcripts is fantastic, and I am sensitive to what I can do to improve the four areas. So - as usual - my mind has started to leap ahead with further analysis.

Have you ever studied Risk Analysis - for instance the 5 Whys? E.g. Why did everyone miss the call for volunteers in the Newsletter? (Re Meadowhall)

I have taken the liberty of not putting my answers after each Why. The answer should lead to the next Why - I'm sure you get the drift.

We are obviously missing a trick at Branch meetings in not promoting the classes/ Full Monty either verbally or as a poster. I have commented that the content of the Branch meetings is never on the routine Committee Agenda - and [names Branch Secretary] has now given me a slot'.

(Pamela [pwP], personal email correspondence, 18.11.2013)

5.5: Thematic analysis looking for interdependent relationships

Claiming authorship of a thesis where others have been integral to the research process is difficult. Developing an argument of my own, beyond the collective consensus required a different (original) interpretation of the gathered information, and a distinctive level of theorising (Teixeira da Silva 2011).

Jo coded basic themes according to the read content of the interviews, making no distinction as to who had said what. The coding used to analyse and develop the themes illustrated the practical aspects of communication, but probed no deeper to explore the meaning of the themes, nor any relational attributes (Attride-Stirling 2001).

I found the behaviour relating to how things were communicated also of interest as it revealed facets of group culture that supported the emergent 'wellness based on interdependent relationships' ideology of the thesis (Vassilev *et al.* 2014, Ryff 1989). My analysis of basic themes is therefore more abstract, founded on characteristics of behaviour of, and within the group (Attride-Stirling 2001).

A criticism leveled against the Social Identity Theory is the loss of the individual identity to the collective of the group (Brown 2000, Hogg *et al.* 1995). However, individualism is a facet of wellbeing that underpins people's ability to be self-determining and independent, maintaining own personal standards and needs (Ryff 2014). People can maintain both individual and group identity (Brown 2000), but individual interaction affects the outcome of group social evolution (Balliet *et al.* 2016).

5.5.1: Capturing the voice of people affected by Parkinson's

The voice of both the facilitators and the focus group participants has been explored and described below. Where appropriate, these have been described in terms of interdependent relationships between the key participants. The coding at the end of a quote clearly states if a respondent does not have Parkinson's, and their relationship to the group e.g. spouse, friend.

MontyZoomers are named only when in the role of facilitator. If partaking in a focus group with other participants, their anonymity is maintained as agreed by signed consent.

- **The language of partnership (interdependence on spouse and close family)**

Chronic illness in one spouse changes the relationship role and identity of married couples (Martin 2016, Politynska 2013, p16). The literature on spousal roles in Parkinson's deals with adjustments as the person with Parkinson's loses physical and mental capability (especially to identity and personality) (Williamson *et al.* 2008, O'Reilly *et al.* 1996). It is narrative about the 'carer' and the 'cared for', however, sometimes the interaction is that expected of a normal dyadic relationship couple (Balliet *et al.* 2016, Rusbult and Buunk 1993).

For example, on becoming aware that Sheila (NPS and facilitator) was prevented from partnering his wife Sylvia (NPS) as planned to facilitate a focus group, Mike (pwP) attended as a participant. He assumed a normal spousal role of supporting a wife to boost her confidence (a competence issue) as she was taking on a new experience.

Support group activities offer an increased likelihood of inclusion of spouses and friends than do health service provision (Vassilev *et al.* 2014). The presence of someone who understands or is part of the person with Parkinson's life is as much a part of the '*collective efficacy*' when sharing experiences as the other people with the condition (Vassilev *et al.* 2014, Gallant *et al.* 2007). For spouses, especially those growing old together with Parkinson's, the network of family and friends is part of the normal dyadic relationship, keeping people (and partnerships) whole (Politynska 2013, p13–16, Gallant *et al.* 2007, Gregory 2005, Birgersson and Edberg 2004), known to be both positive in the sense of support, but negative in the reduction of wellbeing over time (Gumber *et al.* 2016, Tod *et al.* 2016), creating tensions that arise from disagreements in health behaviour (Kitayama *et al.* 2010, Gallant *et al.* 2007, Rusbult and Buunk 1993).

The discussions between spouses below highlight the cognitive support offered one another, and the transition they have gone through demonstrated as united relationships (Gallant *et al.* 2007, Gregory 2005, Birgersson and Edberg 2004).

In a conversation about differing activities available to people with Parkinson's in Sheffield the spouse without Parkinson's clarified issues, acting as memory aids (Gallant *et al.* 2007) in a two-way (affirming) conversation found in dyadic

relationships between caregivers and care-receivers with Parkinson's (Politynska 2013, p16, Rusbult and Buunk 1993)

'Something along the lines of what you might be after has been provided in the past by something called 'Keep Active and Positive.....'

[Spouse interrupts to add explanation to rest of the group]:

'They've done Tai Chi and things like that'....

[First person continues]: *'They've done a variety like this.'* (Husband [pwP], wife [NPS], then husband again – FG1; 21.10.2013: 319 – 323¹⁷)

In qualitative studies where relationships of couples affected by Parkinson's are investigated (Martin 2016, Williamson *et al.* 2008, Birgersson and Edberg 2004, Fleming *et al.* 2004), spouses acting as caregivers experienced relational strain as a consequence of the cognitive deterioration of their spouse affecting the way they communicated, or relational harmony (Kitayama *et al.* 2010). The latter response was seen in the way couples communicated in the focus groups, where a wife (NPS) sought confirmation from her husband (pwP) that she had given the group the correct information:

'They're [monthly Branch meetings] at 2.00 o'clock aren't they [husband's name]?'

'That's right.....' (Wife [NPS], then husband [pwP] – FG4; 04.11.2013: 155 – 156).

and where they filled in details for one another:

'.....one of the nurses..... [after a brief pause, you hear the spouse reminding him the name of the nurse, then he continues].... said 'exercise is good for you.....'(Husband [pwP], with wife [NPS] as reminder of how they found out about classes – FG1; 21.10.2013: 60 - 61)

The spouses also saw themselves involved as part of group activity by right of supporting their wife or husband with Parkinson's (Vassilev *et al.* 2014, Birgersson and Edberg 2004):

¹⁷ Coding = facilitator's name or respondent gender; Focus group (FG) number, date and transcript lines

' I think spouses – I mean speaking for myself, spouses get involved quite a bit as well don't they? Do you feel that your support is necessary?'

'I've got no option but to do it' [group laughter].

' You can't say no, coz she's sat there!' [Laughter again] (NPS 1, then NPS 2, and NPS 1 again – FG2; 23.10.2013: 269 – 272)

Although it was sometimes other family who instigated membership to groups (Gallant *et al.* 2007):

'I've only been here a couple of months, I've moved up from Kent where we had all the experience of these groups so we knew in advance about what was available or should be available.....' (becomes unintelligible by paragraph end, so spouse completes the point)

'We did it through Parkinson's UK because we were moving. I got in touch with them and said.....' (Husband [pwP], then wife [NPS] – FG1; 21.10.2013: 26 – 30)

This was more important where people were not in the right frame of mind to initiate contact:

' I think there's an element as well of people who want to exercise, who want to do it, or make enquiries themselves.....'

'Not necessarily. I think you're too shocked at the time to do anything yourself, I mean it was my daughter.....'

'I don't mean straight away.....'

'Yes, perhaps if everyone's automatically informed shortly after diagnosis that these classes are available, and some assistance with doing that.... might be helpful'. (Conversation between two pwP – FG1; 21.10.2013: 113 - 119).

▪ **The language of liberation (joint control model of interdependence)**

The term liberation often has political, emancipatory meaning, and has been used to describe the process of retaliation through the education of oppressed people (Freire 1996), of black slaves (Blanchard 2002), and of feminism (Maher 1987, Elshtain 1982). I term the language used in the focus groups as 'liberated', as it contradicts traditional expectations of a passive response to disability of people

with Parkinson's (Moe 2012, Eccles *et al.* 2011). It supports positive interaction with others when in a situation sharing knowledge (Vassilev *et al.* 2014) with a condition known to erode self-confidence (Phillips 2006), worsened by oppressive public and professional responses (Gross *et al.* 2014).

For example in a conversation about her medication and anticipated clinic appointment with the neurologist, Janice (pwP) stated:

'I would never instigate the discussion with Dr [named consultant]' (Janice, private conversation, 12.05.2014)

This relationship with the Consultant is one of dependence, and as such is unsatisfactory (Rusbult and Buunk 1993). Yet this is not what we see in a situation with others with Parkinson's where the relationship of interdependence is a joint one (Balliet *et al.* 2016). When getting the focus group underway, Janice made clear what she and Ann were expecting, utilising her prior expertise in interviewing. Her opening statement to the group she knew from exercising with was without preamble and confident:

'OK – shall we make a start? The first question is about your awareness of Parkinson's and generally what's available in the Sheffield Branch in the way of activities. We'd like to start by finding out how you discovered information about the classes you go to, and also which classes you go to'.
(Janice [pwP] – FG1; 21.10.2013: 6 – 9)

Keeping up with this direct and probing manner:

So you found out from the information that comes from the Branch Newsletter [Respondent making noises of agreement]. How about other people? How did you find out? (Janice [pwP] – FG1; 21.10.2013: 13 – 14)

The language and approach was different to that of Sheila and Sylvia (both spouses of people with Parkinson's and retired nurses). A career communicating with patients had taught them a different tone, with preamble and a more explanatory (long-winded) manner (McLean 2004):

'What we're actually going to do today isexploring why the exercise group has been going for 12 years, what keeps people comingand anything we can think of that might improve things.Sylvia and I are obviously very

involved with Parkinson's through our husbands, but we are friends amongst friends, so feel free to say what you want and every thing that's said will be confidential and respected. Sylvia's going to start off just talking about
(Sheila – FG2; 23.10.2013: 6 – 19)

▪ **Mirroring language of others**

Socialisation increases the likelihood that people imitate those around them (Iacoboni 2002, Chartrand and Bargh 1999), especially in social groups (Vassilev *et al.* 2014). During the conversations, there were several instances where the language used mimicked the medicalised perspective of Parkinson's, or experimental research arenas from both people with Parkinson's and those without. For example, the language utilised by Sheila (NPS, nurse and facilitator) was to ask if people gained knowledge about the 'illness' side of things when they talked with one another at the class. The same language is used in a response:

'I think for me as somebody who's fairly newly diagnosed, I found it very helpful to talk to other people who are further down the line with the illness'.
(Female [pwP] - FG2; 23.10.2013: 122 - 123) [underlined to emphasise language]

Whereas occasionally the language is unprompted, e.g. when describing how they had heard about the Branch activities:

'Well, I knew [named friend with Parkinson's] before I ever suffered Parkinson's' (Female [pwP] - FG2; 23.10.2013: 44) [underlined to emphasise medical language]

This language of the medical model of disability was unnoticed and unchallenged at the time of the interview by both facilitators and participants. It was most prominent in those diagnosed in the past two years, echoing how people heard the condition described (Gross *et al.* 2014), influencing whether they sought support through these groups (Lockock and Brown 2012, Moe 2012).

Speaking with Ann (pwP) recently, she says of the use of medicalised jargon:

'The word 'disease' makes me feel dirty, but really, I don't think we often notice what is said, but how it is said and what that means to us.....I often use the work 'Parkys' to describe us – it's not P.C, but I think Mike said it years ago,

and it sounded more friendly' (personal conversation, 10.08.2016).

Some initially concealed the diagnosis (Lockock and Brown 2012, Moe 2012):

'Yes, certainly for the first two years I had it....I didn't want to see myself as a disabled person – I thought 'I'm not disabled, I'm perfectly OK and I don't want to be with all these sick people' (Female [pwP] - FG4; 04.11.2013: 115 - 118)

'I sympathise with what I heard about. I didn't want to become someone who was labelled with a 'disease' and to make 'I have Parkinson's' a significant thing about me for the rest of my life'. (Male [pwP] - FG1; 21.10.2013: 245 - 247).

The reticence to engage may be in the period of initial adjustment of changes to identity (Moore *et al*, 2005, Fleming *et al*, 2004), to self worth (Mazanderani *et al*. 2012, Platt 2004), and relationship with others (Roger and Medved 2010).

Spouses also expressed reservations to joining, but for a different reason. As a partner in the diagnostic process, they coped by attempting to retain 'normality' in their lives (Politynska 2013, p10, Williamson *et al*. 2008, Gregory 2005), and spousal relationship (Rusbult and Buunk 1993):

'When [names husband] was first diagnosed, and as you said... it hits you between the eyes, and the first response is I just didn't want to know. I just wanted to keep it at arms length. And there was that feeling that you didn't just want your social life to be entirely about people who share the same problem as you, it was about just wanting to get on with life' (Female [NPS] - FG1; 21.10.2013: 175 - 180).

Both the people with Parkinson's and their spouses express their reserve in terms of denial. For the person with Parkinson's, this may have been denial during the initial period post-diagnosis, not wanting to see a possible future (Mazandarani *et al*. 2012, Philips 2006). For the spouse there is a wish also of not wanting to witness a possible future, both of other spouses and of the people with Parkinson's (Mazanderani *et al*. 2012), but also not wanting her social life defined by people with Parkinson's (Williamson *et al*. 2008, Gallant *et al*. 2007

Even when people with Parkinson's did join, some still struggled to accept the diagnosis (Philips 2006). They experienced difficulty managing the conflict

between a need to feel supported (maintaining self-respect and confidence), and what this might mean in terms of loss of independence, expressed as *'being in the shade of support'* (Birgersson and Edberg 2004).

'Personally, I've found the help and support I've received from people in this group phenomenal and also from the generalbut I find I get overwhelmed with the people that will help me, almost to the point whereby I pull back.....'

(Male [pwP] – FG1; 21.10.2013: 358 – 361)

The man did not continue to explain the meaning of the point, but changed tack to respond to the discussion positively.

Research-orientated language was heard in an example where one person spoke of attending *'....for a six-week trial period'* (Female [pwP] – FG1; 21.10.2013: 58), and another spoke about how the group might communicate in a more *'standardised'* way (Female [pwP] - FG1; 21.10.2013: 95).

The professionals who determined these outlooks provided inadequate communication in the medical encounter or Practice environment (Gross *et al.* 2014, Satchidanand *et al.* 2012) despite the expectation of support and information by all people affected by Parkinson's (Gross *et al.* 2014):

'Yes, it is sad when I look at my local surgery – they have a stand with leaflets about every conceivable condition, except Parkinson's' (Female [NPS] - FG1; 21.10.2013: 377 - 378).

Although seen by the Consultant, the usefulness of, and choice to help in their management of the condition was of insufficient significance during the consultation for people to be informed of the classes (Gross *et al.* 2014):

'She [Parkinson's nurse] gave me a pile of information when I eventually contacted her. The doctors didn't, they told me to go on the Internet' (Male [pwP] - FG2; 23.10.2013: 56 - 57)

'.....I was diagnosed at the [names hospital and Consultant], and they didn't give me any information..... at all. (Female [pwP] - FG2; 23.10.2013: 183 - 185)

It has been suggested that individuals spend the short time frame for the consultation describing physical needs and medication, so a wider perspective is not offered during the appointment (Gross *et al.* 2014).

'I find my Consultant...he's happy to give me pills but we've never discussed diet, it that must be very important – I read articles about it. I find that they just put you on a shelf and if you don't keep scream out nothing much happens. I'm surprised how little they – your ConsultantI have a catheter and Parkinson's and the catheter is something they just – it's an awkward piece of equipment that works most of the time, but every so often is a total disaster. And those kinds of things aren't discussed at all; you just manage' (Male [pwP] – FG4; 04.11.2013: 55 - 60)

Not all found this an issue, and for one, the advise from his Consultant at diagnosis, a powerful message of hope, had been an essential coping mechanism:

'The best advice I was givenfrom my Consultant, the best advice he said as I left, 'Don't become the disease', and it really works' (Male [pwP] – FG4; 04.11.2013: 120 - 121)

The comment typified people's expectation of the medical environment to be the primary source of information about their condition, still conditioned to believe the doctor as the 'great advisor and expert' (Foucault 1977, p177), especially the spouses:

'I still think the GP surgeries if they had on their notice boards that there was exercise classes for people with Parkinson's, it might generate a few more people' (Female [NPS] - FG1; 21.10.2013: 375 - 376).

'Can you ask the Consultants to – the Geriatricians mostly who deal with Parkinson's to hand out any information about these exercise classes?' (Female [NPS] - F2; 23.10.2013: 79 - 80)

▪ **The language of self-determination**

The language moved on demonstrating a rethink from the conventional frameworks of disability (Moe 2012). As the conversations continued, the language of 'illness' ceased to be heard in the interviews, and by the end there were multiple

examples of self-determined action. Initially, people described the route to joining activities and then suggested how the group might develop their own capability.

Starting with how they had been signposted to the Branch activities, many noted the role of health professionals (other than the medical staff) as a major source of information:

'I heard about it from the nurse – the Parkinson's nurse' (Female [pwP] - FG2; 23.10.2013: 29)

'I was going to [private] physiotherapy....and the physiotherapist said to me 'Oh we do a specialist class for people with Parkinson's disease, do you want to come along?' (Janice [pwP] - FG1; 21.10.2013: 21 - 23).

They determined however, to try the classes for themselves. In the literature on psychological wellbeing, self-determination and acts of independence are seen as traits of autonomy, necessary to the concept of wellness (Ryff 2014, Thorne *et al.* 2003). This is evident in the extraordinary lengths people went to, motivated to maintain control of their condition, to join networks that they believed would positively influence their health (Thorne *et al.* 2003):

Janice recounts how on being informed by the physiotherapist (contact point 1) there were classes, she:

'.... joined the Parkinson's Society (point 2), and that's how I got involved in the first place (point 3 was contacting the Branch). How about other people?' (Janice [pwP] – FG1; 21.10.2013: 23 - 25) using this to open the conversation to how others joined in.

'I found out by a completely different way. I was a member of a walking group and... the person who more or less runs the group she knew someone else with Parkinson's disease (contact point 1) and she put me in touch with him (point 2), and it went from there into touch with Mike [was the Branch Committee contact for exercise classes at the time] (point 3) and from there into the classes (point 4). So a convoluted, sort of word of mouth basically' (Female [pwP] - FG1; 21.10.2013: 15 - 20)

'We did it through Parkinson's UK because we were moving, I got in touch with them and said 'We're going to Sheffield, can you give me contact details

for the local Branch?’ (contact point 1) and they put me in contact with [names Secretary] (point 2) who sent me the paperwork and then through that, spoke to [named therapist] (point 3) who explained how it all worked and we said ‘Can we do this, this and this?’ (Female [NPS] - FG1; 21.10.2013: 30 - 33)

Activities may be accessed as a result of the influence or encouragement of another person they knew, some also with Parkinson’s (Mazenderani *et al.* 2012):

‘I found out about the class from a friend who’d seen an advert in a newspaper. It was largely due to an advert on the Parkinson’s and the gist of it, and there was a mention of this group. From that, this friend told us about the group, so we came down and joined them’ (Male [pwP] – FG2; 23.10.2013: 22 - 25)

‘.....the Parkinson’s nurse...gave me a leaflet, and a lot of other leaflets from the Parkinson’s Society, and I was also in touch with [names Branch member], who recommended coming here to class, so I joined here (Female [pwP] – FG2; 23.10.2013: 29 - 31)

‘But I had heard about it from hospital, but I think it was [names Branch member] who kicked me off into coming; which was then at Broomhill...’ (Male [pwP] – FG2; 23.10.2013: 35 - 36)

The identification of the ‘self’ within a group requires self-awareness (Stryker and Burke 2000, Ashforth and Mael 1989), and an acceptance of one’s status, roles and experiences (Stryker and Burke 2000). As people settle into the groups they have joined, they gradually assimilate into others (Cohen 1994, p11) as can be seen with some of the people who gradually tried multiple activities offered through the Branch:

‘I learned from you guys [in response to the mention of the voice classes, and already attending one exercise class] – when you said you were going singing, I thought ‘Right, I’ll go with you!’ (Male [pwP] – FG4; 04.11.2013: 35 - 36)

‘I started with the posture class, and then young [names physiotherapist] told me about the aquarobics’ (Male [pwP] – FG1; 21.10.2013: 75 - 76)

5.5.2: Wellness characteristics

Characteristics of wellness came across in a variety of ways, encompassing the social benefits of attending the classes, the humour, optimism and inspiration from the group members, and the atmosphere of support, including the characteristics of the class leader.

Such features have been described in varied theories of identity, whether considering interaction within and between groups through a Social Identity (Tajfel and Turner 1986), or assessing one's condition against others when faced with sudden and uncontrolled uncertainty through Social Comparison (Festinger 1954). As the focus group members knew one another and knew their MontyZoomer facilitators, the information is being treated as if small group relationships are already established (Tuckman 1965). Throughout the conversations in this section are traits of psychological wellbeing, plus strands both of independent action, and of interdependence, relational to varied parties e.g. those with Parkinson's, spouses, family, friends, and health professionals (Ryff 2014, Balliet *et al.* 2016, Kitayama *et al.* 2010).

▪ **Autonomy**

When a posture class had to stop due to the physiotherapist's inability to continue, Mike (pwP), an active Branch Committee member at the time, offered his help to look for another venue and therapist to lead a class [individual personality trait], as he recognised the benefits of exercise to himself as a person with Parkinson's, and to the other exercising group members.

Tuckman (1965) described this way of acting in his first concept of small group formation as a stage of '*performing*', where the group had settled to allow members to find solutions to problems that arose:

'...so I happened to get to know [names Secretary] I ended up with her looking for a place where we could get exercise groups started' (Mike [pwP] – FG1; 21.10.2013: 80 - 84).

Once this service was available he determined people needed a point of contact to find out about the new class:

'We had a class in existence, so we needed a telephone number so that people could get in touch and [names Secretary] number and my number were given to the nurses for Parkinson's – and that has become a standard feature of the network for telling people where the classes are' (Mike [pwP] – FG1; 21.10.2013: 90 - 92).

There were instances where people put forward ideas, using the focus groups to suggest activities they found of benefit [individual trait], testing the ground to see if others were interested [an appropriate activity for the exercise group]. For example, a suggestion to extend the monthly walks throughout the year rather than just the spring and summer months:

'Yeah, we do the walks – they've finished now till spring'.

'I don't mind walking over the winter, I'm perfectly happy to walk over winter; I don't know about other people, and perhaps different lengths of walks to a greater extent – I'd value that positively.....we all get together and then choose' (Conversation between two pwP – FG1; 21.10.2013: 289 - 294).

Spouses' conversations highlighted traits of individuality and of collective as people created their own level of commitment to the group, demonstrating responsibility to others, whilst benefitting personally (Turner 1982, p16–20):

'I do notice that there's a big difference. An even if he's [talks about her husband with Parkinson's] not feeling very much like going, but feels a) he mustn't let [names class leader] down so that he goes, and he's lucky he gets lifts from [names two other group members], so there's no excuse really, but when he comes back, you know he's really buoyed up and had a lovely time (Female [NPS] 1 – FG1; 21.10.2013: 229 - 232).

'It's a little bit like all those joined slimming classes really. There's that sort of discipline of.... would you at home settle down and do a solid hour's exercise, and then you'd try to do it everyday, but life gets in the way. But when you have a class, you don't want to let other people down, and you know that it's kind of guided and it just seems more..... and it's that - that's today's little block of exercise and I feel better and.....' (Female [NPS] 2 – FG1; 21.10.2013: 233 – 237).

For people with and without Parkinson's, wellbeing came from the fact they took advantage of opportunities offered suitable to personal needs and values (Ryff 2014), and in particular, the exercises, known to be good for maintaining physical self-care and for promoting health through mind/ body interactions (Teichberg 2000). The spouses of people with Parkinson's noted:

'...he doesn't respond to the drugs, but exercise is absolutely paramount - makes a real difference' (Female [NPS] – FG1; 21.10.2013: 40 - 41).

'As an observer, I notice that when [names husband] goes to his classes, he is much happier, better, I can't say more 'with it' – that's not right, but you know, it does something for him, and - I think it's both the exercise and the company, and [names class leader]...is very, very important in these things...' (Female [NPS] – FG1; 21.10.2013: 224 - 227).

'It's what we experience really – I mean for us, because we'd had a difficult patch for a whole variety of reasons – [names husband] physical health had declined quite a bit before we moved to Sheffield and one of our hopes was that the group would be able to help put that right. And the improvement in him is out of all recognition – his posture's better, his immunity's better, he's walking better, his stamina's improved, and an enormous amount of that is down to the amount of energy from the physiotherapy, and the class on Friday morning. ...'(Female [NPS] – FG1; 21.10.2013: 446 - 451).

The people with Parkinson's stated:

'It's because I feel better. And even though I'm going through a bit of a 'patch' at the moment, I still feel better every time I finish the class, and I always hope that's appreciated by the people doing the running of the class' (Female [pwP] – FG1; 21.10.2013: 186 - 189).

Janice: *When you say 'better'....*

'I feel physically, spiritually, mentally better[silent pause and murmurs audible as people take this in and agree] (Female [pwP] – FG1; 21.10.2013: 191 - 192).

'Actually, you feel better - the exercise makes you feel better....' (Female [pwP] – FG2; 23.10.2013: 116).

▪ Staying well through socialisation

People with Parkinson's and spouses have expressed that preferred social activities and interaction reduce as the condition progresses (Williamson *et al.* 2008, Birgesson and Edberg 2004, Fleming *et al.* 2004). Membership of support groups reintroduced people to the prospect of socialisation (Vassilev *et al.* 2014, Gallant *et al.* 2007), the social experiences permitting expansion of knowledge and self-identity with which to manage the expectations of the condition (Cohen 1994, p56–57), and friendships to help cope (Vassilev *et al.* 2014).

Several social theories explore relationships people form with one another. Whether people speak of 'I' or 'we', respective aspects of Identity Theory (an individual's role-related behaviour) and Social Identity Theory (group processes and intergroup relations), the differing perspectives still allowed insight into a socially constructed self and values gained from group membership (Hogg *et al.* 1995). Through the 'shared manifold' hypothesis we understand how people with (mental) health conditions form empathy with others from the sense of identity binding them together (Gallese 2003). The group responses also provide insight into aspects of homophily, a tendency for people to choose relationships with people who have similar attributes (Fowler and Christakis 2008).

'Meeting other people in the same boat, and varying degrees of disabilities and abilities. Sharing things that make life easier – yeah, you're not on your own [general murmurs / words expressing agreement and how important that is]' (Female [pwP] – FG1; 21.10.2013: 241 - 243).

'It's just meeting other people with the same disease, so you can talk it through with people....'

'So it's sort of the support that you can get from the group, meeting people who are in the same circumstances [respondent agrees]' (Conversation between two females [pwP] – FG2; 23.10.2013: 111 - 114)

'But the fact that it tended to be about certain people of generally about the same age and quite often, like-minded souls, it's produced friendships and companionships that were perhaps a little unexpected and very welcome. So I think it was a bonus rather than an aim if you like from our point of view' (Female [NPS] - FG1; 21.10.2013: 180 - 183).

There were conversations throughout the focus groups about varied topics, with people allowing others to speak. The trait of 'turn-taking' is an important feature of conversation between group members who legitimise the contribution of others (Chartrand and Bargh 1999). We see this in a conversation with participants in focus group 1, after Janice (pwP and facilitator) had posed a question about the importance on socialising, and in the responses as people expressed the level of importance they placed on being with others.

'I mean, it's useful to get the information and do the exercises, but it's also nice just to chat with people at the end. It's not necessary that you've got to have Parkinson's – it's something that's common (Female [pwP] – FG1; 21.10.2013: 193 - 195)

'I think it's very important' (Female [pwP] – FG1; 21.10.2013: 200)

'The social life?..... Very much so.....a major part of it' (Male [pwP] – FG1; 21.10.2013: 202)

'I felt the social aspect's brilliantI like the fact it's relaxed but specific.....' (Female [pwP] – FG1; 21.10.2013: 204 - 206).

Positive relations with others are an important aspect of staying well, showing concern for one another, seen at times where the facilitators ensure all are given a chance to participate (Ryff 2014). Although this is part of the role of an adept facilitator (Wilkinson 1998), none of the facilitators had led focus groups before. They did however understand traits of Parkinson's, choosing a good time to draw a contribution from the quieter ones.

'How about you [names pwP], how did you discover what was available?'
(Janice [pwP and facilitator] – FG1; 21.10.2013: 64).

Then later:

'[Names person], I haven't heard from you' (Janice [pwP and facilitator] – FG1; 21.10.2013: 203).

In addition to the obvious benefits of keeping people healthy and fit in terms of maintaining wellness, the changes in level of engagement and communication between Branch members were noted during the discussion (interview) with the Branch Committee members. They were witness to the positive change in the chattiness and familiarity between members socially networking via Branch events

(Vassilev *et al.* 2014) e.g. the monthly meetings, cream teas, and the increase in numbers of members attending events, described by Whitney (2004) as ‘*engaging in meaningful experiences*’.

Committee member 1: *Yes, I think in [monthly Branch] meetings, people know one another now, and they chat more.*

Committee member 2: *Yes, that’s true* IC.13.V & D [195-196]

Committee member 1: *I think I have noticed there are more sort of friendship groups going on* IC.13.V [197]

Committee member 3: *I think new members seem to be getting more involved.....* IC.13.P [198-199]

In addition to the sense of ‘belonging’ that emerged from the focus group discussions, for some there was no one clear reason explaining they attended, but self-acceptance of participating for several reasons, or things that could not easily be voiced, but of value to the person (Ryff 2014).

‘I think part of the class is that it’s always cheerful and I think that’s very much a positive point. It certainly helps me maintain some flexibility, and to me that makes an enormous difference. So to me, it’s the cheerfulness, the flexibility and the social aspect’. (Female [pwP] – FG1; 21.10.2013: 252 - 254).

‘It just fills – filled a void that I needed. I mean, I’ve been diagnosed – what – 18 years now, and I really wish that some of these things that are coming out now had been available then.’ (Female – FG1; 21.10.2013: 272 - 274)

Optimism and positivity were strong reasons for adherence (Ryff 2014).

‘I tell you what you’ve just done for me, looking at it from the outside, and having been in two separate groups [a couple who recently moved to Sheffield and were new to the Branch], it strikes me that as a group, and this is not meant to sound patronising, just how incredibly optimistic everybody is. You’ll hear people saying – ‘you know I’m having a bit of a hard patch’ but d’you know, I don’t think I’ve ever heard anybody whinge and moan. It’s all, ‘It’s a good day/ it’s not such a good day’ – there’s very much a ‘can do’ attitude, and I don’t know whether that’s the group, or what it.... I don’t know. But there’s this positivity and this optimism’ (Female [NPS] – FG1; 21.10.2013: 275 - 280).

Participants spoke in terms of 'we', relating these to friendships formed, noted in the inclusive nature of the communication. This has been described in Social Identity Theory as identifying with the 'in-group', with Branch Committee and members of the Branch who did not exercise referred to as a collective 'they', a term used for the 'out-group' (Tajfel and Turner 1986). This was very noticeable when discussing the change about to occur in venues at which classes are held.

'Why couldn't they decide by looking at where everyone lives and where everyone needs to be, and then work out where the best place is to go, rather than trying to superimpose it all?' (Male [pwP] – FG4; 04.11.2013: 228 - 230).

'I think from the Branch meetings, they could let you know about a bit more than they do.' (Male [pwP] – FG2; 23.10.2013: 98 – 101)

The 'out-group' label usually has negative connotations as people are seeking to raise the self-image of their group. For those in several groups, this obviously does not sit comfortably. The identification of the 'self' within a group requires self-awareness (Ashforth and Mael 1989), stemming from a synthesis of one's various statuses, roles and experiences, and allowing an individual to experience several personal 'selves' associated with differing circles (Cohen 1994, p11, Tajfel and Turner 1986). Mike (pwP), in the dual MontyZoomer-Branch Committee member role, defended the position of the Committee, who he perceived being criticised without people understanding their input fully.

'The Branch's Committee has been responding to [names a poorly attended activity] by encouraging it, which is in itself important..... I think, something I wanted to say was, some of the benefits we've got from the exercise groups and similar we have got by the aid of the actual Parkinson's Branch. The Parkinson's Branch itself is important to us, so it shouldn't as it were receive all the credit for the successes, because there is useful work going on by the Branch [committee]..... the existence of the Branch [committee] and the way it works has helped in this endeavour and we need to stimulate that always, because it's going to be useful always.'

'What more can the Branch do to bring other people in and keep them coming?'

'I don't know what we could do, because they do put a lot - a small number of people put a lot of effort into that sort of thing – not always with an identifiable clear result' (Mike in conversation with participant [both pwP] – FG1; 21.10.2013: 325 – 337)

- **Humour, laughter and having fun**

'Enjoyment' and *'Fun'* are characteristics of wellness described in the summer survey (Appendix 7).

Humour is a social construct, considered an essential part of human nature (Goldberg 1999), and associated *'with bonding, agreement, affection and emotional regulation'* (Scott *et al.* 2014). There are degrees of laughableness how people perceive humour, which may be generated through various means, such as exaggeration, ridicule, embarrassment, or satire (Veatch 1998).

Several examples of humour and laughter were notable in the discussions with Branch members. Humour used in the context of cheeky familiarity and banter demonstrates a social relationship between people who feel familiar enough to approach the boundaries of what might, in another context, with a stranger be considered overfamiliar or rude (Scott *et al.* 2014).

Comment on being an early adopter of the classes:

'I'm the original dinosaur', raised laughter and comments in jest such as *'can't get rid of her'* and *'how many years she had been coming?'* (Several pwP - FG1; 21.10.2013: 57 - 58).

Humour was heard generating levity in the form of one-liners, each resonating social and physical importance (Scott *et al.* 2014, Veatch 1998).

For example, during one of the Focus group discussions, when asked by the facilitators to indicate reasons they returned to classes, the one-liners that generated laughter from two respondents were:

'Chocolate biscuits!' (Male [pwP] – FG1; 21.10.2013: 109) – a humorous allusion to the important end of class tea and biscuit period, and

"Legs?....it's legs that keeps me coming!" (Male [pwP] – FG1; 21.10.2013: 131).

Humour and the response of laughter changes with personal experience, and whilst some people may or may not have been affected or offended by jokes about 'disability' in the past, the diagnosis and experience of Parkinson's may have changed their perspective (Veatch 1998). The comment:

'I forget where I think that point was going, so I think I'll just shut up and let someone else speak.....' (Male – FG1; 21.10.2013: 249 - 250)

was delivered by the speaker with a humorous inflection, but received a quieter quality of laughter (murmurs) and encouraging comments. The speaker is a well-respected member the group knew had been attending Memory Clinic for cognitive decline causing him distress.

'My wife hates – suffers greatly by the fact I tend to 'moo-moo' - to mutter and very quite in what I say. Sometimes, I speak too loudly, but I never seem to get my own personal viewpoint.....'(Male – FG1; 21.10.2013: 135 - 138).

This, from a man whose ability to communicate is deteriorating, delivering the sentence with a tone expectant of raising an empathetic laugh.

Both the statements and responses demonstrated collective humour seen in situations of loss and adjustment to uncontrollable adverse circumstances, a positive quality of wellness supported by those 'in the know' (Solomon 1996).

5.5.3: Learning

The focus group conversations demonstrated several methods by which learning occurred. The person with Parkinson's or spouse sometimes took it on themselves to seek information, class participants learned things from their conversations over coffee break at the end of classes, and sometimes they attended formal educational activities put on by the Branch. The learning was mainly about Parkinson's as a condition and its management, responding to the self-management ethos (Lorig and Holman 2003).

Some was sought through formal means.

'....Parkinson's Society local Branch monthly meetings at the Friend's Meeting House [various conversations about when]. And there's usually a topic, which

is of interest to us. Tomorrow it's diet for example, which should be good.

(Female [pwP] – FG4: 04.11.2013 – 152 - 154)

Then group-shared information through collective learning and teaching about the activities of the Branch, first checking what was known:

'Yes, I know some people here, I only know go to aquarobics, I haven't seen you at other activities, although you may take part in them. Do people know what's available beyond aquarobics and Posture and balance classes?

(Janice and Ann [pwP and facilitators] – FG1; 21.10.2013: 120 - 124)

'You do the walks don't you – I don't think you've mentioned that yet' (Female [pwP] – FG1; 21.10.2013: 288)

Telling others about the voice group:

'It is very good. Those of us who go to Voice Group find it very helpful. You don't have to ...we sing and we do lots of exercises, which are all helpful, but it's for fun – you don't have to be able to sing. If you have a quiet voice, then it can help to be able to project your voice. (Janice [pwP and facilitator] – FG1; 21.10.2013: 139 - 142).

Association with others also provides role models and the ability to discuss problems with people who understand them (Behm *et al.* 2013, Festinger 1954). For the Parkinson's group, seeing people attend, or who have had Parkinson's for a long time engendered hope. The Social Comparison Theory suggests that people with similar problems, especially those with a condition of a variable nature, such as Parkinson's, who join self-help groups, compare their circumstances and can assess their situation against others (Festinger 1954).

'I know we've got some founder members here who....

'I'm the original dinosaur. I answered an advert in the paper – in 1999 in the Star – they wanted volunteers for a 6-week trial period, and I carried on coming ever since (Janice introducing female [both pwP] – FG1; 21.10.2013: 54 – 56).

'Well I must say, I personally..... I always say to [names pwP] 'You're my inspiration' because [names pwP] has had Parkinson's for 23 years, and I think you're marvellous [named person audible saying 'Thank you!'] - and I

hope that when I've had it for 23 years I'm as good as [names pwP], and I find it very encouraging to meet a lot of people who've had Parkinson's – like [names another pwP] – for a long time, and are still as you say, positive, and doing well' (Female [pwP] – FG1; 21.10.2013: 281 - 285).

Learning of helpful snippets occurred at break times after classes with those who were experiencing problems.

'And actually, it's the bit of information, because talking to the other patients, you seem to pick up bits of information that they've gleaned and then to compare them with yourself, and it makes you feel perhaps better than you otherwise would do, as you know that you're not the only one with those symptoms' [general murmurs of agreement] (Female [pwP] – FG1; 21.10.2013: 255 - 258).

'I'd agree with that – particularly I'd picked up – actually, it was from a question you asked [names a pwP], about how to take the drugs, and I'd been told by the Parkinson's nurse to take drugs over 12 hours and you asked [names physiotherapist leading class] and she said take them over 24 – and that was a revelation – that was much better – a much superior method of taking them. I think you pick up lots of good information, helpful information from others [interrupted] (Female – FG1; 21.10.2013: 259 - 263).

When she continues, she highlights an issue that recognises the expertise from within the group, a form of power(-from-within) (Laverack 2005, French and Raven 1959, p263)

'[continues] I've heard people talking about, you know, what's the best sort of bed for them, people who come forward with 'Well there's this and that – but there's this advantage and this disadvantage'. And you know you're getting the advise from people who have the condition, not just an occupational therapist who has read up about it or has been told about it' (Female – FG1; 21.10.2013: 265 - 268).

'.....So you learn to take some of the advice, but a lot of the advise is to get up and do it yourself, it might take an hour to put in place but you can do it' [Comments of agreement and laughter with personal examples of the time it

takes to do things when you have Parkinson's]. (Male – FG4; 04.11.10.2013: 123 - 125).

5.5.4: Voicing concerns and posing solutions

The focus group discussions helped people see that they gained from the discourse and learning environment created.

'I think it's an ideal situation to perhaps have a little of this sort of thing included in the Branch meetings, so that you get peoples' views rather than just the odd one' (Male [pwP] – FG2; 23.10.2013: 98 – 101)

'We never had this opportunity to have this feedback' (Male [pwP] – FG1; 21.10.2013: 164)

Discussions in both the focus group and Branch Committee interview highlighted people voicing concerns and solutions to some of the issues. The drive forward has been viewed as seeking to improve communication, build capacity and make connections, a model of social capital (Bailey *et al.* 2012).

▪ **Improving communication**

Discussions in the three voice-recorded focus groups highlighted the multiple sources of information about the Branch activities, and about the condition and management. The *'Parkinson's Nurses'*, *'Physiotherapist'*, *'Newsletter'*, *'newspaper'*, *'email'*, and *'word of mouth of people with and without Parkinson's'* were several of the ways people found out. For some this proved an information overload.

'She gave me a pile of information....' (Male [pwP] – FG2; 23.10.2013: 56 - 57)

'We get a lot of emails....' (Male [pwP] – FG2; 23.10.2013: 89)

And was seen as an inconsistent way of ensuring people received important information.

'It does seem though, listening to what you have said so far that there are blind moments of relying on chance as to whether you're picked up or not in the scheme' (Male [pwP] – FG1; 21.10.2013: 75 - 76)

'I think you make a very good point in that despite that, it does seem a bit hit and miss as to how people discover what's going on and what's available'

(Female [pwP] – FG1; 21.10.2013: 93 - 94)

But people learned to filter what they needed, with consensus that the Newsletter was a valuable resource:

'I can't remember who gave me the papers [Newsletter]... but it was information about what was available and it was to contact Mike for the Posture classes, where I heard about the Aqua classes' (Female [pwP] – FG1; 21.10.2013: 65 - 66)

'For the ones who've been coming more, well my experience is that you got the information from the monthly write-up from the Branch, and I find that very useful' (Male [pwP] – FG2; 23.10.2013: 65 - 66)

Sylvia [NPS and facilitator] asking what and how people get to know about events:

'If it's in the newsletter, yes. If it's not in the Newsletter, no'. (Male [pwP] – FG4; 04.11.2013: 22)

'It's very good the Newsletter; very informative' (Female [pwP] – FG4; 04.11.2013: 23)

People were also able to communicate the qualities they valued in the class lead. From the three voice-recorded focus groups, and Branch Committee interviews, these included the expected issues of expertise and personality e.g. *'She's a dynamo'*, *'laugh is infectious'*, but support provided that recognised the class participant's worth and struggles were also seen as essential.

'I think it little things like getting us biscuits and always having cards for people to sign – if somebody's died or there's a big birthday coming up, [names physiotherapist]'s always there with a card. I think that's very good' (Female [pwP] - FG1; 21.10.2013: 437 – 439)

'And it's organised, so when you turn up, the session's there, you know that sort of thing. If there's a change in arrangements, she lets people know about it. Groups often flounder on those sorts of things. If you go along and it's not there and not been told about it, you're less inclined to go out the next time if

the weather's bad, so it makes a difference.... (Male [NPS] - FG1;
21.10.2013: 435 – 443)

- **Building financial capacity**

Sustaining the Branch activities required financial capital. The Branch Committee interview highlighted there was a gain in money (legacies), but a need to find ways to spend it to prevent the central Parkinson's UK headquarters from claiming some general for use. They were concerned the Sheffield members would lose out, so made a Committee decision that the newly proposed exercise classes could be a way to spend their money.

Branch Treasurer: *'....and we started getting all those legacies. We've had three so far over the past three to four years, and it was something to fill out the Spending Plan, for want of a better.....'*

Branch Secretary: *'It was when Head Office took the... threatened to... promised to take away anything beyond three years worth of funding that we were holding. If we could spend it, we were allowed to spend it, so we thought of'* (Committee interview - 27.08.2013: 62 - 66)

- **Making connections**

People put forward ideas on how to promote the needs of the people with Parkinson's by lobbying for resources (Fox 2002, p234). Whilst people were clear that information should initially be sourced through health professionals, there were differing opinions about who should be responsible for promoting and raising awareness about Parkinson's and the classes (Moe 2012):

'I know I'm going back to how to publicise the organisation, and get more people involved. I know a few years I went to an 'Over 50's' fair.....in the Town Hall if its an annual event, that might be useful with posters and information leaflets for people who are interested. Because they certainly had a lot of interesting information from the point of view of my son-in-law's aunt, which I picked up at the time – but I wasn't thinking in terms of Parkinson's Disease or anything else at the time..... it could be useful for us to have a stand. It did deal with illnesses and various problems people of an older age

group have, and obviously this is one of them'. (Female [pwP] – FG1; 21.10.2013: 412 - 419).

Not all the changes to the proposed class expansion of classes were seen as positive, as some members felt established in their exercise groups, and the change to a social norm, plus transport was seen negatively. But in acknowledging an understanding, they sought solutions.

'Well, I've had my driving licence taken from me you see, so I couldn't drive any more' [sympathetic comments] (Female [pwP] – FG4; 04.11.2013: 176 - 177).

'Couldn't we organise transport area, if everyone knew who had a driving licence and where they lived, can't we meet people on the way through? So, a sort of centralised database for the local pockets of people?' (Male [pwP] – FG4; 04.11.2013: 178 - 180).

'Yes, I feel a bit sad that the new venues are not additional to what we already have. I understand perfectly the space here is limiting and the new venues have got more space and they can attract people from other areas of the city, but it's a shame to do away with what we already have' (Female [pwP] – FG4; 04.11.2013: 181 - 184).

'[named person] and I chat.....but then you see we won't be able to when everything changes. That's one of the things that I'm a bit, sort of disappointed atI could be the only woman stuck up at [names venue]' (Female [pwP] – FG2; 23.10.2013: 181 - 184).

One issue discussed related to sustainability of the way classes were currently run, condition-specific and by a physiotherapist, or whether classes could be mixed-pathology and run by an exercise professional. There were mixed feelings, but people understood the need to sustain the classes, so were prepared to alter the current situation.

Response to Ann (pwP and facilitator's) question:

'Do you prefer to go to a Parkinson's-specific class or Parkinson's Disease?'

'I think you need to keep the main thrust as Parkinson's, but you need to keep it broad, otherwise it becomes too specific and strict. If you have a varied

background, then that enables you to investigate what is happening a little further'. (Male [pwP] – FG1; 21.10.2013: 161 - 163).

With regards to the physiotherapy-led class, people were mostly in favour of this, and whilst they had obviously built bonds with the person who ran their class, they were open to change, if it was necessary to keep the classes going.

'I think having a physio there, or somebody who's got a knowledge of Parkinson's helps, because [husband's name]'s only been diagnosed for three years – if you ask the wider world, they all know about the shake, but very few people seem to know about the initiation problem and the fact things take you longer. And you can find people getting impatient, where in fact you are...the brain sent the message, and I'm getting there. So, I think the fact that they're aware that everything takes that little bit longer is quite good thing'. (Female [NPS] – FG1; 21.10.2013: 161 - 163).

Continuity of provision was seen as important, succession planning and the training of a new generation of therapists with specialist knowledge in Parkinson's.

'She's also, I think, is inclined I think to train younger physios in her pattern, like [names newly qualified physiotherapist], who does the hydro has slowly changed – not so slowly changed into reflecting some aspects of the way she goes about things'.

Although not something considered necessary by all, several of the Branch Committee members articulated a security in knowing that for new members classes were run by health professionals with knowledge of Parkinson's, adapting classes to their needs, and providing an environment of learning and support; it seemed a welcome prospect.

Committee member: *'From my point of view, being able to tell people there's something specifically for people with Parkinson's run by physios, you know, I think it gives people faith to think, 'that's something really designed for me.'whereas if I just said to people 'it's an exercise class'(Branch Committee Interview – 27.08.2013: 102 – 104)*

Branch Secretary: *'When I talk to new referrals on the phone and I say that they are specifically for the Branch, they perk up, and they say 'Oh really, you know I*

must do that; that sounds really interesting', and it is because it is specific to Parkinson's'(Branch Committee Interview – 27.08.2013: 108 – 110)

Committee member: *'How would you guarantee the quality of the leadership from somebody that's not a physio? That may not have the understanding of a) a physio and b) of Parkinson's? How would you monitor that?'* (Branch Committee Interview – 27.08.2013: 111 – 113).

5.6: Becoming critical - an emergence of the social and political

In clarifying her stance to my Research Supervisor on the evolution of the MontyZoomers, Pamela (pwP) stated:

'K.A.P¹⁸ emerged from negative reasons against the Branch, but the MontyZoomers have emerged for positive reasons'

(MontyZoomer Stakeholder meeting 7 - 13.09.2013).

Just summarising the projects undertaken as MontyZoomers to the Branch Secretary invited to MontyZoomer Meeting 10 (12.12.2013) enabled us to witness how people affected by Parkinson's were (re)establishing a social identity, negotiating life to regain a 'normal' place in society and connection to their world (Stanley-Hermanns and Engebretson 2010, Hogg *et al.* 1995). Throughout all the group's interactions, we were witness to increasing connectedness to others.

I have been witness over the years to 'people with Parkinson's' joining in the Branch classes, and for a short time allowing their individual identity to be subsumed into the collective of the group (Tajfel and Turner 1986). Although joining a 'labeled' group signifies one step towards accepting the diagnosis that disrupts their sense of self (Bury 1982), such is the support through their experience (narrated and observed) from the existent group members that the new, de-personalised individual soon found ways to continue their adjustment to the physical and psychological manifestation of Parkinson's, and allow their own identity traits to emerge again (Bury 2001).

In addition to the focus group analysis offering general members the opportunity

¹⁸ K.A.P. are the 'Keep Active and Positive' group of younger Branch members with Parkinson's, who felt the Committee was only providing activities suitable to older members. They retained membership of the main Parkinson's UK charity, but split affiliation to the Sheffield Branch.

for dialogue, the activities took on an increasingly political characteristic as well as continuing to fundraise, seeing the potential to bring about change through collective voice and action (Hammel *et al.* 2008).

The organisation carried out behind the scenes, did a lot to cement growing friendships, increasing the appreciation of each other's varied skills, enabling the planning of ever-increasing awareness raising as part of their projects.

Parkinson's is known to negatively impact confidence, and increase anxiety in social contexts (Stanley-Hermanns and Egerbretson 2010, Schrag *et al.* 2000a). To gain strength from connectedness with others, or finding new '*family of friends*' (personal conversation with Mike [pwP] during a 19.12.2015 monthly walk) is important.

The focus group work enabled an appreciation of the interdependent relationships Branch members had with one another, whether they came to the group diagnosed with Parkinson's, as spouses, friends or myself as a health professional (Sfard and Prusak 2005, Bury 2001).

Activities to support the needs of the Full Monty Exercise Club members swiftly gave way to including all members of the Sheffield Branch in their considerations, and then wider still to include thoughts of raising awareness of the condition with the general public as something they were capable of (Bate and Roberts 2006).

The evolution was towards emancipatory action, freeing themselves from societal limitations of their 'disease' label, and seizing opportunities to fight for social rights of the membership (Smith-Chandler and Swart 2014, Boog 2003).

This practice in itself creates challenges, when a few in number attempt to achieve mass impact on behalf of others (Gustavsen *et al.* 2008, p63-64). The MontyZoomers had approached projects as a collective group, affected by Parkinson's in different ways. This collaborative action allowed them to gain appreciation of their capacity to utilise individual knowledge and experience to contribute to society (Brydon-Miller *et al.* 2003). The joint relational interdependence fostered their confidence and willingness to action change now they had knowledge of it being relevant to the Sheffield community (McIntyre 2008, p67-68, Bate and Roberts 2006, Brydon-Miller *et al.* 2003). They had entered the stage of 'political' (Hammel *et al.* 2008).

CHAPTER 6: CYCLE THREE - STORIES FOR CHANGE

6.1 Introduction

The PAR methodology has direct consequences on the lives of co-researchers with a disability, so the experience of self agency (control) is considered a step towards emancipation (Pettit 2010, Hayward *et al.* 2004, Kiernan 1999).

Emancipation in relationship to AR methodology intimates freedom from the restriction or power of someone else (Boog 2003). The latter is not necessarily the case, nor realised if co-researchers are prevented from contributing fully to the PAR process or not facilitated to achieve personal growth (Kiernan 1999).

During the pre-step phase of the Research Project, I had asked people who attended exercise classes what '*having Parkinson's*' meant, and services they would seek to keep them well. Their responses were based on ideal health provision e.g.

'I would like to actually see my Consultant and not a new junior member each time' (Full Monty Exercise class participant with Parkinson's)

'I need information about progression and medication when I need it ...you know – timely' (Full Monty Exercise class participant with Parkinson's)

'I would like to know where to access information about the best exercise and diet for my Parkinson's' (Full Monty Exercise class participant with Parkinson's)

This should have been expected given their ontological perspective of Parkinson's is based on expectation of health professionals' knowledge and support (Parkinson's Disease Society 2008, NICE 2006).

The increased Research Project social activities, the focus group analyses and discussion established a point where the MontyZoomers started to voice their reservations about the linear expectation of deterioration the 'illness' and 'disease' model proposed.

'.....there's an irony that most 'health' professionals are not advocates of the positivity and hope we [talking of pwP] need to feel well' (Mike [pwP] personal conversation during 11.08.2013 monthly walk)

The MontyZoomers agreed to dedicate a Stakeholder meeting for exploration of their experiences with Parkinson's. We chose MontyZoomer Meeting 7 (13.09.2013) for which one of the Doctoral supervisors (JA), supporting my progress to facilitate the PAR process, was available.

Knowledge construction is the essence of this methodological approach, utilising reflexivity to investigate and share experiences from which to construct new theory (Reason 2006, Lather 1986). Using Freirian theory (1996) to initiate discussion, the MontyZoomers were asked to consider three questions:

'Have you been passive recipients of knowledge or have you been engaged in a problem posing approach in your group?

'How have you linked your knowledge gained from a variety of sources from this group to action?'

and:

'Have you considered the nature of your health need and how it is understood by others?'

The sharing of different experiences of Parkinson's at this, and a follow up session (on 21.02.2014) stated to broaden their knowledge, impacting on their epistemological and ontological understanding of the condition (Mauthner and Doucet 2003). Once those present began exchanging stories of their experience, little was discussed related to the first two questions posed. The two sessions mainly concentrated on the third question.

6.2: Experiences of Parkinson's

During the first story telling event, I set a flip chart page ready to start jotting down experiences the MontyZoomers with Parkinson's had along their 'Parkinson's journey'.

'It didn't start there (pointing to my heading of 'Diagnosis'), you have missed a major period – the 'before' (Pamela, pwP)¹⁹

¹⁹ Stories were gathered during the official meetings from the whole group, Pamela and Denise sent me a chart of their own experiences with Parkinson's, the non-Parkinson's group provided a chart they developed at the 12.02.2014 meeting, and Dave emailed his personal chart as 'friend'.

She spoke first in terms of the time before her symptoms were even noticeable (Figure 6.1), seeing herself with well-defined roles in life, and a clear path ahead (Lloyd 2001).

'My roles were defined between work and home. As a wife, mother, and daughter I had supporting roles'
(Pamela, pwP)

This led her into a discussion of the period just before diagnosis, with MontyZoomers adding their experiences:

'It went very grey; didn't know what on earth was going on' (MontyZoomer with Parkinson's)

'Know there is something wrong'
(MontyZoomer with Parkinson's)

'Couldn't do the things I used to' (MontyZoomer with Parkinson's)

Probing the time period pre-diagnosis whilst awaiting investigation and results can be stressful for people. The beliefs varying greatly about what the actual diagnosis might be, with raised anxiety dependent on the presentation of symptoms and past experience (usually of family members or a past personal health issue) (Bury 2001).

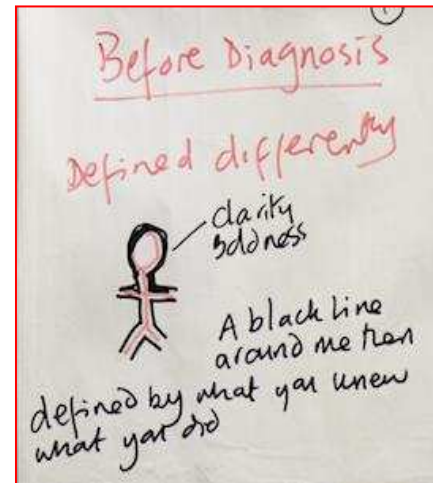
'Lung cancer!?' (MontyZoomer with Parkinson's experiencing physiological symptoms)

'Depression – I self referred to a mental hospital because no one believed me that something wrong' (MontyZoomer with Parkinson's mental health symptoms of increasing anxiety and paranoia)

'Attributing problems to arthritis' (MontyZoomer with Parkinson's physical symptoms of slowness and stiffness).

An important part of narrative and story telling for people with degenerative conditions is an audience to listen and understand the distress of the storyteller

Figure 6.1: Pamela's experience pre-symptoms. Intact identity



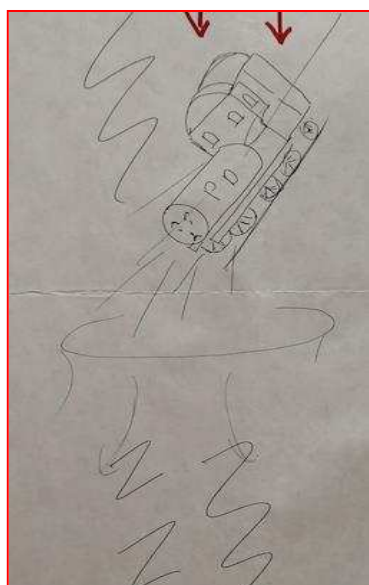
(Brown and Addlington-Hall 2008). Accounts were of painful memories e.g. when she was '*low and tearful*' (Denise, pwP), and similar from others. The empathy and encouragement from one another as they contributed enabled them to continue (Bramley and Eatough 2005, Baker and Graham 2004).

The language about receiving the diagnosis of Parkinson's emphasised the continuing difficulties people experienced during that period; many feelings related to non-acceptance and shock at the diagnosis (Stanley-Hermanns and Engerbretson 2010, Bramley and Eatough 2005).

'It felt like the ground had been kicked out from under me' (Ann, pwP).

Visual representation enabled a way to communicate critical reflection for the people occasionally stuck for the right words to express their feelings, or to add emphasis to their words (Lapum *et al.* 2012, Craig 2009).

Figure 6.2: Pamela's vision of diagnosis



The imagery was in different forms. Bob (pwP) for example, represented his experiences in terms of colour, recalled diagnosis being '*the black of despair*'.

Pamela (pwP) drew a train (Figure 6.2):

'Like falling off a cliff – surviving the fall'. Later, she expanded the statement: *'It has been a grieving process. You always had an idea what ageing is about and when Parkinson's comes around, it is like a train derailling'* (Pamela, pwP). She described her life as feeling: '*Bleak*', and her role changed to that of now needing the support she normally provided her family (Bramley and Eatough 2005, Lloyd 2001).

The group members described the disruption of their identity upon diagnosis, undergoing change in their sense of self-agency, as they perceived a disappearance of control of their situation (Bramley and Eatough 2005).

'The first couple of years was when I could have done with information from the hospital, but apart from tablets, I was offered no other help as there were no services for people until you were older' (MontyZoomer with Parkinson's).

It was at the point of diagnosis where people included their thoughts about immediate family. Denise (pwP) speaks of 'we' of her close family as she describes the period of mourning that follows diagnosis (Figure 6.3).

There was frustration about the lack of support or information at that period, as a lack of understanding of Parkinson's from the professional services prevented them realising the impact of the condition on their expectations of life (Nijhof 1995):

'No idea of what it is. Thinking of the children – I hope I can make it to the end' (MontyZoomer with Parkinson's)

'Going into free flow when first diagnosed, no knowledge, no understanding' (MontyZoomer with Parkinson's)

'Everything being defined by the diagnosis - 39 pages of disability living allowance application - but they don't know what you have lost' (MontyZoomer with Parkinson's)

'There's no support if you have low mood; it's all about how things are going to get worse when I want to know how to make me better' (Bob, pwP)

'I was confused and lost confidence – I needed support' (Pamela, pwP).

The journeys progressed at different paces, but all in this group eventually adjusted, although most still sought ways to maintain some normalcy in life (Soundy *et al.* 2014, Stanley-Hermans and Engebretson 2010, Brown and Addington-Hall 2005). Their personalities and support structure permitted appraisal of their reality and adaptation to maintain a sense of identity (Bury 2001, 1982). Each became involved in Branch activities, with the supportive ethos contributing to personal strength and positivity (Soundy *et al.* 2014, Stanley-Hermans and Engebretson 2010).

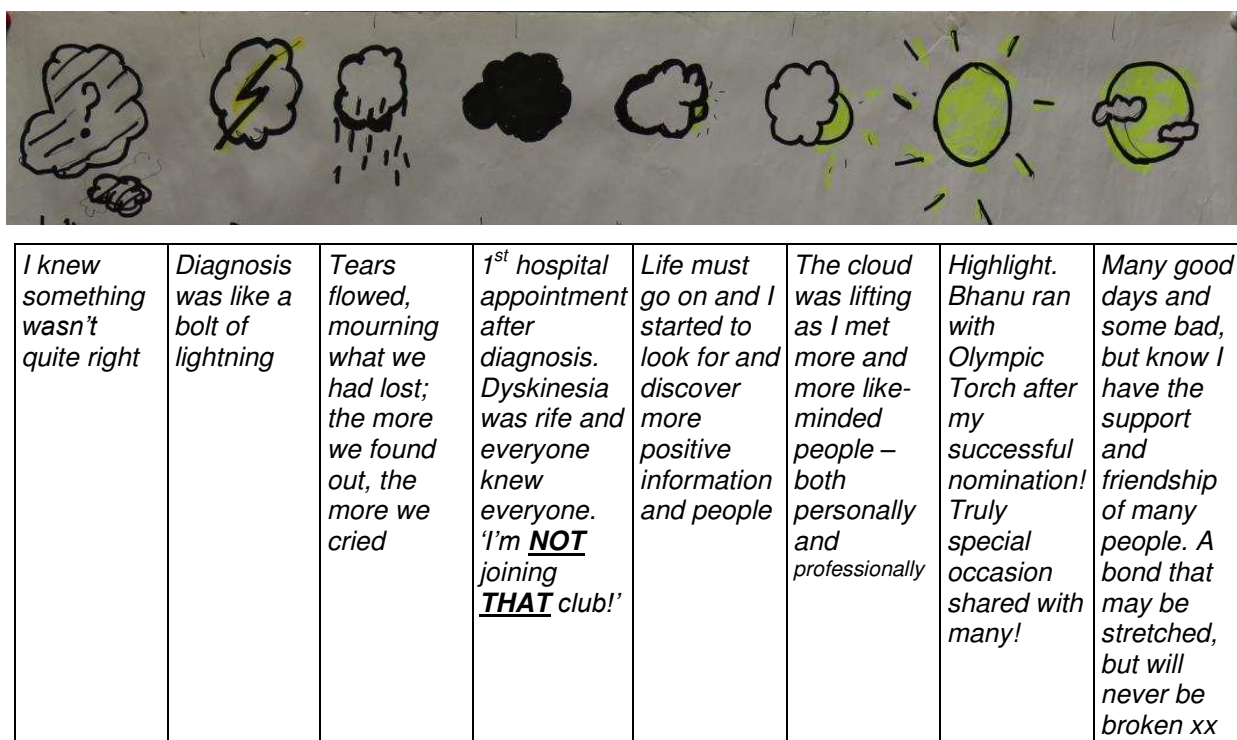
'The group put me back on track... never felt isolated or offended, feel so much better after the group, more energy' (Ann, pwP)

'Attached me firmly to an optimistic point of view until I have a bad day and I realise that Parkinson's is really the bastard I always knew it was' (Mike, pwP) - other colleagues immediately responding with: *'Come on, we have to stop that!'*

'I reviewed my values, and concentrated on what I CAN do – I can shape PD in Sheffield' (Pamela, pwP).

Denise summarised the whole journey in her personal chart from the period pre-diagnosis, and still looking to a bright (hopeful) future (Figure 6.3).

Figure 6.3: Denise's pictorial representation of her journey with Parkinson's



At the second meeting (21.02.2014), a split was agreed between those diagnosed with Parkinson's, and those without. The former group wished to use the time to continue recounting their stories to one another, and the non-Parkinson's group (spouses, friend and myself) decided to chart our collective journeys.

'Harry didn't get a chance to tell his story, and I think it is because he doesn't like Sheila [spouse] to hear his despair' (Dave, NPF)

The starting point of the non-Parkinson's group was at diagnosis with memories of the traumatic messaging from health professionals, but the relief for them of knowing there was a reason the spouse had exhibited the symptoms:

'Dead within 10 years! – Panic'

(Sheila, NPS, and Harry's wife), angrily recounting the doctors words at diagnosis

when Harry was only 55 years, working and with a young family. At our meeting, Harry was going strong at 18 years since diagnosis.

Relief was voiced to see spouses with Parkinson's find support (joined classes):

'Pleased he met like-minded people – nice' (Sylvia, NPS, Mike's wife)

'Relief at sourcing practical help' (Sheila, NPS, and Harry's wife)

'The services are all so different in Sheffield – the ones who attend [names old day hospital] with the geriatrician gets a full MOT, but the ones who see a neurologist are only offered tablets.....the nurses are great though'

Little is recorded in literature specific to the role of friends in support networks apart from acknowledging their importance (Vassilev *et al.* 2014, Fleming *et al.* 2004), and a connection, however distant from an immediate network of friends (Scott 1988). Dave's (NPF) friendship with Harry (pwP) is through his wife who worked with Harry's wife, Sheila (NPS), so Dave joined:

'To provide support for Sheila' (Dave, NPF)

But, as happens with people who experience the personal benefits of volunteering into the long term, Dave has since evolved roles from 'Harry's chauffeur to exercise class', into joining classes as a participant, and now volunteers help setting up or taking class in my absence, as well as volunteering to be a MontyZoomer (Piliavin and Siegl 2007), feeling now he had some:

'Awareness and responsibility' (Dave, NPF).

Jo (NPPartner of Bob, pwP), was at this meeting having driven Bob there. She met Bob after his diagnosis when he lived in the South of England, so had chosen a relationship with a person diagnosed with Parkinson's, something spouses voice as having no choice about (Gallant *et al.* 2007, Williamson *et al.* 1998). Jo recalls being '*ignorant*' about Parkinson's, describing her first Branch event as a '*Baptism of fire*', but like the rest of the non-Parkinson's group recognised two issues.

The first related to the isolation people with Parkinson's create from their normal social networks from perceived social stigma, not liking to be seen in the new light of a disabled person, and communication problems (Moe 2012, Eccles *et al.* 2011, Galinsky *et al.* 2003). Spouses noted that being part of the group meant people

with Parkinson's:

'Felt worthwhile – that they are the lucky ones [to have a group such as this to belong to]' (Jo, NPPartner).

The second is the improvements of socialisation and communication with members of the 'new' support network (Stanley-Hermanns and Engebretson 2010), the:

'.....camaraderie, and being accessible to others who need the support' (MontyZoomers without Parkinson's group collective sentiment).

This is not always welcomed by spouses, heard before in comments from the focus group interviews, and noted in the stories as those without Parkinson's were increasingly drawn into Parkinson's-related activities.

'Don't want to let Parkinson's dominate life and social activity' (unnamed MontyZoomer without Parkinson's)

'No ambition re: lobbying. People with P may do this if they like' (unnamed MontyZoomers without Parkinson's)

As per literature, they also noted there was a:

'Need for support just for carers – to let off steam – to keep positive (what's the alternative)' (MontyZoomer group without Parkinson's) (Gallant *et al.* 2007, Williamson *et al.* 1998).

All in all however, they felt that:

'All the above drive the desire for the Branch and group to succeed and continue' (MontyZoomers without Parkinson's collective statement, 21.02.2014).

6.3: Collective experiences

Although people had different reasons for why they, their spouse or partner participated in the exercise groups, one thing everyone agreed on was that *'fun at the group'* helped to motivate people to stay well. This is linked to adherence for people with Parkinson's with apathy, showing regular exercise improves SWB and QoL (Combs *et al.* 2014, Goodwin *et al.* 2008, Baatile *et al.* 2000).

I took two medical scale models of Parkinson's – the Hoehn and Yahr scale

(1967), and the MacMahon and Thomas model (1998) to the meeting of 21.02.2014 (noted in Appendix 8).

The stories from the 13.09.2013 shared group experience, were initially not described in the same categorised fashion i.e. about stages of illness with Parkinson's. The group only recognised the period before diagnosis, and the period around diagnosis as clear phases (Brown and Addlington-Hall 2008). Sometimes however, people will sequence a narrative to suit their audience (Phoenix *et al.* 2010). For the purposes of matching their journeys alongside those of the medical scales therefore, the MontyZoomers members with Parkinson's named their experiences according to four stages (Table 6.1):

'Pre-diagnosis period

At diagnosis, and immediately after

Elapsing years ('meandering, and not a straight incline downward' [Pamela, pwP])

The future (holding onto hope)'

These were placed alongside the medical models, and developed into a socially-constructed consensus framework. The MontyZoomers visualised their needs from social and political perspectives as well as health care needs.

The 'elapsing years' points included general thoughts about their activities and relationships with people in the Branch, as well as the upcoming Exhibition for Parkinson's Awareness Week.

As the MontyZoomers discussed and reflected on the benefits of the support group and its activities, their realisation grew of the inadequacy of the medical or health professionals' input, and the need to be more in control of their own life outcomes.

With regards their future, the group were well aware:

'We are time limited by the nature of our condition' (MontyZoomers with Parkinson's),

Unlike the medical models that state:

Stage 4: Severe disability; still able to walk or stand unassisted

Stage 5: Wheelchair bound or bedridden unless aided (Hoehn and Yahr disease staging, 1967)

or

Palliative stage:

- *Inability to tolerate adequate dopaminergic therapy*
- *Unsuitable for surgery*
- *Advanced co-morbidity (life threatening or disabling)* (MacMahon and

Thomas, 1998)

Table 6.1: MontyZoomer’s socially constructed concept of lived experience of people affected by Parkinson’s (a model of interdependence)

Pre-diagnostic phase	Diagnostic and immediate post-diagnostic experience	Elapsing years	The future: Holding onto hope
<p>Period leading towards diagnosis difficult, with a (long) wait for confirmation.</p> <p>Some not believed; may look on Internet for information.</p> <p>Disconnect between available health service provision and need from people affected by Parkinson’s to support them into next phase.</p>	<p>Paradox in messaging: social support gives hope; clinical message stresses decline</p> <p>This is the time most support needed to counsel family through difficult experience pre-diagnosis, and adjustment up to 2 years post-diagnosis as roles and identity change.</p> <p>Very different for each person. Often better experience with geriatricians compared with neurologists, the latter only offer medication.</p> <p>Better experience still if supported by nurses and Parkinson’s UK groups.</p> <p>Little support for mental health; most caters for physical needs.</p>	<p>Noting that life with Parkinson’s has ups and down with periods of betterment and sometimes some recovery of lost skills following lapses, especially if due to other medical conditions (whether a spouse or person with Parkinson’s).</p> <p>Not always the straight path to decline stated by the medical models.</p> <p>Need relevant support as time elapses, NOT the current system of people with Parkinson’s fitting their needs to available services.</p> <p>There is little care of the carers</p>	<p>Research promises a cure, plus taking part in activity (attitude, behaviour) slows decline, and coping is better.</p> <p>Reduced inclination for most people with Parkinson’s to think in terms of future needs. Carers often consider needs more, pre-empting decline. Person with P might consider needs more if they had annual support and built rapport with staff and services.</p>

The MontyZoomers had an understanding of the reality of the condition but recognised a need beyond self to wanting better services developed, and better understanding of Parkinson’s. This would make them well:

‘Our mission is to spread the word about Parkinson’s to the rest of the world’
(MontyZoomers with Parkinson’s)

‘Feel yellow and blue for the rest of my life’ (Bob, pwP) alluding to his image of a sunny day with clear blue skies.

There were amendments decided with the ‘non-Parkinson’s’ group, as they felt that sometimes:

‘It is left to me to think of practical future needs, as Bob is busy looking for the

cure' (Jo, NPPartner to Bob, pwP).

The agreed socially constructed model of interdependence for people with Parkinson's (Appendix 8) has been used for in-depth interviews to identify intangible (psycho-social) costs in a research project investigating the costs of Parkinson's to society (Gumber *et al.* 2016). The trial provided knowledge and rigour to the research process, and also relevance into researching life with Parkinson's (Lather 1986).

6.4: A socially constructed model of interdependence for people with Parkinson's

The socially constructed interdependence framework provides a novel and adaptable perspective of a journey people with Parkinson's might experience, inclusive of the period prior to diagnosis (a stage ignored by clinicians) towards what they considered as their future years. It counters the negative language and linear focus of the medical models currently utilised by health professions to describe and understand Parkinson's by considering the positive strategies of management utilised by people affected by Parkinson's over its time-course as the condition progresses. Most importantly it is a truly social model, integrating the relationships people have with one another over the course of the condition.

The message from their consensus social model is one of hope and wellness, and not of decline and illness, understanding of the importance of, and interdependence on both the medical and social aspects of support (Maunthner and Doucet 2003).

6.5: Closing thoughts

The practice of storytelling was a means of gaining insight into different perspectives and experiences of Parkinson's that shaped the MontyZoomers' collective understanding of the condition (Bate and Roberts 2006, Nijhof 1995).

The two meetings provided the space for the MontyZoomer to review their ideas about fundraising, and champion further supportive activities. Their ability to focus on the importance of their lived experiences and expertise in understanding Parkinson's describes the process of 'conscientization', as they (re)discovered

their reality, and in knowing this, found the hope in transforming it (Freire 1996, p68-96).

The storytelling and other qualitative methodology literature investigating experiences of people with Parkinson's generally start with accounts of 'illness' and coping after diagnosis (Thurman 2013, Stanley-Hermanns and Engebretson 2010, Platt 2004). Two articles mention the notion people with Parkinson's know there is some thing wrong, hence seek medical advice (Soundy *et al.* 2014), and Bury (2001) outlines the narrative of people's pre-diagnostic experiences, but of other illnesses, not Parkinson's. This is the first description I have found in the literature of narrative about the period before diagnosis being of such impact in setting a background for disruption or fracturing the biography of a person with Parkinson's.

The specific time set aside for story telling were undertaken through an Appreciative Inquiry approach, another evolution of AR that considers the affirmative aspects of social groups and associations rather than the problem-laden view, permitting an approach that '*embraces the miracle and mystery of social organization*' (Cooperrider and Srivastva 1987).

The end result was a forward-thinking and positive socially constructed framework the group agreed on – a model of interdependence based on *their* knowledge of experience (Nijhof 1995), very different from the descriptive knowledge of health professionals (Pinder 1992). What kept the MontyZoomers and other members of the Sheffield Branch of Parkinson's UK well (outcome from varied projects) were dependence on the actions and relationships of the individuals within the Parkinson's community, people outside the immediate circle and ancillary services (Balliet *et al.* 2016, Johnson and Johnson 2009). Exploration of how they had learned what they *knew* about Parkinson's as a collective influenced their past and present ontological stance (Koshy *et al.* 2011, p14).

Their overview of needs can be identified through original Interdependence Theory conceptualised by interactions between those in close relationships (Thibault and Kelley 1959), broadened to consider co-operative relationships with allies (functional interdependence) (Balliet *et al.* 2016), acknowledgement that even though acting as a group, some aspects had to be undertaken individually

(Wagennan 1995).

A review of the three AR cycles reveal that interactions and behaviour of the MontyZoomers were shaped in part with an expectation of benefit to the parties involved (Rusbult and Buunk 1993, Thibault and Kelley 1959). There was also concern for another's goals, even though at times there was tension within the group, and some relationships developed into ones of obligation instead of the mutual bond they had initialised from (Balliet *et al.* 2016, Rusbult and Buunk 1993). The process of PAR had the effect of emancipating the group, utilising discourse and action based on one another's ideas of what constituted 'Parkinson's identity' to determine our social and political needs (Smith-Chandler and Swart 2014, Sfar and Prusak 2005).

Each successive cycle of the Research Project exemplified a broadening of the MontyZoomer's scope from a 'listening and responding' role we had assumed in the first cycle, to advising, involvement and starting to generate knowledge by the end of the Research Project timescale (Brydon-Miller *et al.* 2003).

CHAPTER 7: PROFESSIONAL IMPLICATIONS 1

STORIES OF EMPOWERMENT

7.1: Changing perspectives from disempowered to empowered

The status of belonging to a 'profession' confers the qualified member a degree of autonomy (Kell and Owen 2008, Higgs *et al.* 1999, Barclay 1994, p70-78). The practitioner has governance over their own working circumstances by fulfilling a professional obligation to upkeep their skills and specialised knowledge to serve the best interests of the public (CSP 2011, Kell and Owen 2008, Sandstrom 2007, Higgs *et al.* 1999).

Although physiotherapy practices have diversified and expanded over the past decades alongside health and social care reform (Petchey *et al.* 2012), modernisation and innovation of practice has advanced within the framework of evidence-based practice (EBP) through observance of the historical, medically predominant origins of the profession (Kell and Owen 2008, Hopkins *et al.* 1996). This has led to most physiotherapists taking a technical-rational stance in their clinical work, an attitude in opposition to the person-centred approach (of shared knowledge, power and decision making) advocated by the DH (DH 2010a and b, 2008, 2005, 2004, 2001a and b, 1998, 1997). It is remote from the socially constructed professional origins of functionalist philosophy (Nicholls and Cheek 2006, Higgs *et al.* 1999, Lindblom and Ruland 1997). Functionalism understands that a (scientifically deconstructed) understanding of society allows problems to be (re)constructed to the benefit of the individuals living within it (Ramp 2008, Hughes *et al.* 2003, p11). The contribution and interdependence of different parts of society towards the whole state is what is considered to create societal stability (Hughes *et al.* 2003, p11, 30, 149).

Current physiotherapy education and practice has developed over the century to engendering the notion of superior expertise, a position from which to advice and manage a person with Parkinson's segregated from family and community (Keus *et al.* 2014, CSP 2011, NICE 2006). It is difficult for healthcare professionals to conceive that our practice diminishes the generative power of creativity and energy people have within communities and organisations, the way society should work

(Raelin 2014, Freire 1996, p82-85).

Whilst health, wellbeing and quality of life are the ultimate goal of physiotherapy intervention, the profession's drive to measure outcome and compare treatment efficacy has focused intervention towards curative or palliative input of mechanically (measurable) presented problems more so than the pursuit of wellbeing and life quality through supported and shared management with the individual (CSP 2012a and b, APTA 2011).

Being given a label such as Parkinson's can undermines a person's self-efficacy to cope with the condition (Ellis *et al.* 2011a, Chenoweth *et al.* 2008), and people look to the professionals for support (Chenoweth *et al.* 2008, Whitney 2004). By complying with a medically dominant model, the NHS services perpetuate a perspective of professionally-led health delivery as the main way of managing the condition (Aujoulat *et al.* 2008, Giroux *et al.* 2008). This '*treating the primary symptom*' approach however challenges the control of the person with the condition (Politis *et al.* 2010), which could be better managed through a person-centred approach and with the use of organisations, such as third sector voluntary organisations and grass-root support groups, who can deliver acceptable elements of 'social prescribing' (Coulter *et al.* 2013, Chenoweth *et al.* 2008) and self-help support (Chenoweth *et al.* 2008, Munn-Giddings and McVicar 2006).

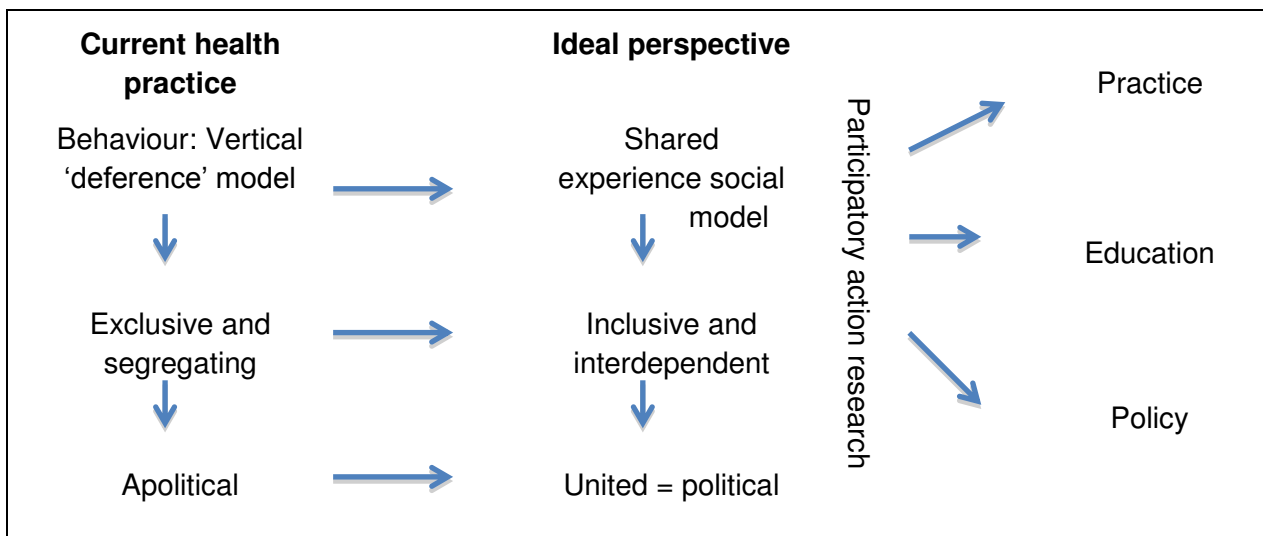
This creates a contradiction in what NHS policy is advocating between informing intervention utilising a bio-medical model, whilst asserting that practice is about the individual, verbalising the need for more social, person-centred models of enquiry; this paradox challenges the foundations of professional knowledge and ethics of practice, requiring recognition of more holistic and mixed research methodologies to inform the profession through the inclusion of a patient perspective and involvement (Kell and Owen 2008, Parry 1997, Richardson 1999).

As an exemplar, the MontyZoomers considered 'wellness' to be reflected by positive ways they might exert control of their lives (Roscoe 2009). We see growing instances whereby Parkinson's UK engages with all members (people with Parkinson's, those affected, volunteers, and health professionals) to provide condition-specific support e.g. meetings, activities, online factsheets, information and education forums, research, illustrating that an agenda for wellness can be

managed outside of the NHS alone (Cleaver 2015, Parkinson's UK 2015).

To acknowledge a different status, one where interpersonal relationships are more equal, generating greater trust, and shared practice between professionals and 'patient' requires a new lens from which to socially construct relational leadership roles (Raelin 2014, Fulop 2013, Koch *et al.* 2009, Uhl-Bien 2006). PAR provides a model by which to realise this through varied means (Koch *et al.* 2009) (Figure 7.1).

Figure 7.1: Perspective shift needed in Parkinson's management



(With thanks to Peter Fisher for sharing his visions of health, and theological philosophy to create this perspective)

7.2: How PAR involvement has shaped an understanding of Parkinson's in Sheffield

Our collective actions demonstrated a shift from depersonalisation towards shaping a cultural identity for the group (Sfard and Prusak 2005, Hogg *et al.* 1995, Tajfel and Turner 1986). The MontyZoomers, all affected by Parkinson's in different ways, took responsibility for one another by way of our interdependent relationships. We collaborated through a research process to shape a path towards wellness producing a model of interdependence (Appendix 8). This involved the understanding that a life lived with Parkinson's included people with Parkinson's, spouses and other family, friends, carers, health and social care professionals, and other members of the wider community. The relationship is akin to social networks, whose memberships are governed by relationships to a person of varying degrees of closeness at any one time (Wensing *et al.* 2011).

For the MontyZoomers able and prepared to work independently of the group, the emancipatory action (collective acts the group had achieved towards social capital) gave way to more empowerment projects (i.e. 'individual' in concept) (Boog 2003).

The individuals who developed a confidence to become involved socially and politically with local Parkinson's events and the wider community (locally and nationally) did so outside of the MontyZoomer remit, continuing after the main Research Project had stopped, undertaking the activity alone (Punch 2009, p136-137). This is recognised as deeper level participation, when group members awaken to their ability to construct and use knowledge from their own perspective, although that knowledge is still of use to their group needs (Reason and Bradbury 2008, p9).

Involvement in health research should describe an active partnership in the research process of those who use services and can also include in those who are empowered to do their own research. A desired outcome however, is for those empowered by the process to take forward their political belief into the general PPI forum, to ensure the ethos is maintained '*with or by the public rather than to, about, or for the public*' (Hanley *et al.* 2004).

Lay participation in healthcare decision-making is shown to occur across three participatory levels: consultation, collaboration (ideal for PAR and PPI), and user-led (noted in some autonomous projects undertaken by MontyZoomers empowered to take the initiative, following and leading work related to their own interests) (Hanley *et al.* 2004, Charles and DeMaio 1993).

A set of narratives was emailed to me from three MontyZoomers (each with Parkinson's) to explore empowerment in activities they pursued as part of a personal agenda. Each demonstrates the impact of awareness-raising of Parkinson's with different audiences who influence service provision or education affecting the Parkinson's community.

Excerpts from Janice's story describes the direct impact participation had on educational curricula for future health care professionals, excerpts from Pamela's story is of direct impact on healthcare policy, and excerpts from Bob's story describes the practical relevance to partnership working to deliver exercise relevant to people with Parkinson's (Personal correspondence, 24.08.2016)

(Figure 7.1). Full stories in Appendix 9.

The significance of their activity is linked to professional practice by a framework used in Sheffield to visualise where in a chronic condition management healthcare system influence might be exerted i.e. at the micro (patient and family), meso (healthcare organisation and community), and macro (policy) levels (WHO 2002, Mohan 1996).

7.2.1: Excerpts from stories suggesting influence at the micro level

These demonstrate the importance of empowered behaviour and the value of quality interactions with others in influencing the outcomes of health care

Education: *'Service User and Carer Advisory Group (SUCAG's) standing increased. Sally Fellows²⁰, another 'service user' (with Multiple Sclerosis), the SHU lecturer and I attended the CSP conference on 11th October 2014 to present some of the Group's achievements'*

(Janice, Personal correspondence, 24.08.2016).

Health policy: *'Joining the Branch, attending meetings and exercise classes, expanded my Parkinson's social circle. I naturally volunteered when Bhanu formed a study group, using my 'lost' skills to plan fundraising and a Parkinson's Awareness Week exhibition for 2014'*

(Pamela, Personal correspondence, 24.08.2016).

Research activity for health policy: *'Bhanu suggested an invitation onto a steering committee for a SHU research project about service needs. Initially I felt I had little to contribute – until questions for the draft report were circulated. They were generic, about older people only, with nothing explicit to living with Parkinson's. I suggested specific issues, which were acknowledged and included. At last I found my voice'*

(Pamela, Personal correspondence, 24.08.2016).

Practice: *'At one class I met a frail elderly lady in a wheel chair who showed willing to at least to pull a Theraband to exercise. I was so impressed with her 'can-do' attitude and, realising that exercise could benefit all PwP irrespective*

²⁰ Permission obtained from Sally Fellows to use her real name 30.08.2016

of their physical state, I became a zealot on the subject. I researched the benefits of exercise and the new knowledge gained together with my own experience led me to write a paper entitled “Realistic Improvement in Parkinson’s through Exercise (R.I.P.E.)”

(Bob, Personal correspondence, 24.08.2016).

7.2.2: Excerpts from stories suggesting influence at the meso level

Involvement at this level creates an environment to promote quality interactions and partnerships to contextualise delivery for all, including connection with community resources

‘I approached Bhanu on how best to “spread the word” about the benefits of exercise to PwP – both at the individual and community level’

(Bob, Personal correspondence, 24.08.2016).

7.2.3: Excerpts from stories suggesting influence at the macro level

Involvement at this level develops shared values and principles for strategy and policy by connecting the patient, community and larger organisation.

Education: ‘The Approval Panel Meeting for the Revalidation of the Physiotherapy degree was held in March 2014. Our most important contribution related to changes proposed by SHU to assessment criteria whereby, inter alia, students who had passed most modules (rather than all) would be allowed to progress. Such was our dismay, that the Course team was emboldened to make a case for exempting the Physiotherapy degree from the proposed compensation rules, lobbying both the Faculty VC [Vice Chair] and the professional bodies, the HCPC and the CSP. To the team's surprise, exemption was granted. Other degrees successfully followed Physiotherapy's lead’

(Janice, Personal correspondence, 24.08.2016).

Health policy: ‘Soon after my diagnosis. I had represented Parkinson’s UK, meeting with the Minister for Health and PM [Prime Minister] to discuss major changes in the NHS. Although I offered further involvement, I heard nothing; it

felt my presence had been tokenistic, and left me feeling that all my past education, experience and knowledge was for nothing'

(Pamela, Personal correspondence, 24.08.2016).

7.2.4: Excerpts from stories suggesting influence at various levels

Education: [mentions name] *invited me to join the newly formed SUCAG [at SHU], which I did in 2011'* [micro and meso levels]

(Janice, Personal correspondence, 24.08.2016).

Health policy: *'The MontyZoomer involvement altered this as I realised that having an understanding of the NHS, I could use my voice to influence service delivery. I accepted invitations e.g. Sheffield Parkinson's Stakeholder Group; a Pathway group; nurse education sessions; at our Town Hall Exhibition; a learning session at the CCG [Clinical Commissioning Group] (the first 'patient' speaker), and presented at the first Regional Excellence Network event'* [micro, meso and macro levels].

(Pamela, Personal correspondence, 24.08.2016).

Health and voluntary provision: *'I am now the Chair of the Sheffield Branch and care deeply about the service that pwp in Sheffield receive – NHS or voluntary'* [micro and macro levels]

(Pamela, Personal correspondence, 24.08.2016).

Practice: *'We discussed the paper and after editing, issued it widely across the Parkinson's community. I sent a copy to the Parkinson's Foundation, Cure Parkinson's Trust, Parkinson's UK and a number of local branches, plus through my MEP [Member of European Parliament], to the European Parkinson's Site. I have issued it, through contacts and various Parkinson's websites, all around the globe. Indeed, I was contacted, only last week by a PwP in Queensland who had heard of the paper and wanted a copy'* [micro, meso and macro levels].

(Bob, Personal correspondence, 24.08.2016)

7.2.5: Overall reflection of the benefits of involvement in the PAR process

‘On reflection, my participation in MontyZoomers validated my right as a PWP to expect a high level of service from Health Care professionals and helped give me the confidence to act if that high level were threatened. It also taught me the power of the collective voice’.

(Janice, Personal correspondence, 24.08.2016)

‘What now seems obvious to me as I live with P, appears revolutionary to clinicians in the field. My skills have returned, and I am able to converse with managers and clinicians as well as feeling comfortable discussing aspects of care with my MontyZoomer colleagues’.

(Pamela, Personal correspondence, 24.08.2016)

‘On becoming an enthusiastic participant in her MontyZoomers study, I gained confidence to think more widely’.

(Bob, Personal correspondence, 24.08.2016)

The innate values of social interdependence (cooperation, competition and individual efforts) provide psychological wellbeing. They are evident on reading the enthusiasm and pride each individual generated from their success in a change-making process (Johnson and Johnson 2000).

Generally, healthcare reviews of service effectiveness talk of patient-centred care but only investigate teams who deliver on behalf of patients (Poulton and West 1999), rarely considering collaborative resources (Kvarnström 2008). These stories demonstrate that given opportunities to support and influence involvement of individuals (in this case using a critical research approach), innovative outputs can be achieved through the collaborative approach between organisations, communities and support networks (Xyrichis and Ream 2008, WHO 2002).

7.3: A story of personal empowerment

I use reflection of my field notes to write this section for physiotherapists about to embark on projects that use PAR as a methodology with people with long-term conditions.

The constructivist element of this methodology takes time to develop as our

professional education leaves us lacking in familiarity with the qualitative research process (Pettit 2010). Our organisational setting (NHS or Higher Educational Institute) and expectations of quantitative or outcome driven research constrains our ability to create co-designed, collaborative inquiry (Punch 2009, p3, Bate and Robert 2006).

Following JA's (Doctoral Supervisor) attendance to facilitate my PAR process at MontyZoomer Meeting 7 (13.09.2013), I noted with dismay:

'I have not begun to nurture knowledge, just projects that are more and more social.....how can I learn to redefine the position of who has knowledge? – this is how we accomplish the 'Change attitudes' in the Parkinson's UK strapline'

JA seemed delighted to witness the growth in the 'social', noting what she saw was:

'.....kindness, motivation, and energy – your community of people with Parkinson's are driving ideas forward.' (Personal discussion with JA following MontyZoomer Meeting 7, 13.09.2013).

She had identified the importance of collaborative working that first had to build through a social relationship for a group normally excluded by stigma, isolated from low confidence, self esteem or disability (Gallinsky *et al.* 2003, Ellis *et al.* 2011). This had taken several month to evolve, a period of time in limited supply in much healthcare based AR (Cook 2012, Pettit 2010), where social interaction and constructions of meaning are rarely considered as part of the research process (Corlett 2012).

It was easier to discuss items of relevance to fundraising (a primary objective for the group), tick-box outcomes useful for a specific setting as might be seen in much health-driven action research (Waterman *et al.* 2011). When individuals began sharing ideas, it was to better the lives of the exercise participants. Then after eight months together, conversations expanded to personal experiences that gave insight into the people researching together (Brown and Addlington-Hall 2008, Bramley and Eatough 2005), and finally discourse included the wider population affected by Parkinson's (Risse and Wiener 1999). Having just read Paolo Freire's work (Freire 1996, p46–50), and after a meeting discussing the

focus groups with the MontyZoomers, I wrote:

'The process of reflection and action seems to be liberating for all, taking us from a stance of little knowledge or expertise of the process of participation, to one utilising unique skills, knowledge and experience to create and construct a new understanding of wellness – between us all, we know a lot'

(Field notes after MontyZoomer Meeting 9, 04.11.2013)

The MontyZoomer development during the Research Project has been akin to a process of 'unlearning', relinquishing deeply rooted traditions and assumptions, stepping out of a known (physiotherapy or passive patient) standpoint and questioning the validity and essence of what one knows (Thomas 2011, Klein 2008). 'Relearning' occurred by building an understanding around the same information infused by dialogue that constructed new knowledge; it was a shared process (Corlett 2012, Klein 2008).

Not all interaction was positive with this diverse group of people involved in social research, and opposing ideas created negative interdependence, requiring consideration of the roles people fulfilled during the process (Johnson and Johnson 2009).

When documenting details of our dynamic relationship as MontyZoomers for this thesis, I made a conscious decision to record the positives from our interactions, as our aim as a group was to promote wellness by moving forwards and away from negative influences (Cooperrider and Srivatsva 1987). The lack of in-depth reflection about conflicts that arose is purposely omitted so as not to dwell on issues that were resolved, but still had potential to kindle underlying sensitivities. This ethical consideration from my position of leadership (power) as research lead and physiotherapist acted as my moral compass. In contemporary leadership models, behaviour that acknowledges the interdependent relationships within a group, considerate to members' support needs is regarded as an essential quality of relational leadership key to social network or social group development (Uhl-Bien 2006). For this thesis, I felt more responsibility to the group than to individuals, but as part of the dissemination process following completion of the doctorate, an article will be written that details the relational ethics and power dynamics reflected on as part of the research process given my prior relationship

with individual MontyZoomer members as a health professional (Etherington 2007).

As a clinician new to undertaking PAR, I was naïve in my expectation that the MontyZoomers with Parkinson's would remain 'emancipated' following my planned exit. It was therefore an enormous disappointment to observe the lack of cohesion within the group as I withdrew my support. Two meetings were planned without me following the end of the Research Project in May 2014, however an incident that created an open conflict became unresolvable, and for a time, the MontyZoomers ceased to meet, although all the stakeholders still refer to themselves as a member to this day.

Near the end of the 18-month Research Project period I had been busy pursuing the final project, a culmination of our work together organising an Open Day/ Exhibition of MontyZoomer artwork at the Sheffield City Town Hall in collaboration with the Public Health team at SHU. As a result, I failed in several respects to take stock of the reality of the Research Project in an attempt to go out with a bang!

First, I had not truly grasped that the people who participated for my benefit helping me towards a Doctoral award might not wish to continue (Northouse 2013, p5-6). Having recapped how much we had achieved over the Research project period, the conversation about my proposed exit the following month was not well received. I wrote:

'I don't get it, why would they not wish to continue towards the same goal? All actions still support and sustain wellness in members of the Sheffield Branch of Parkinson's UK. They are well enough' (Field notes after MontyZoomer meeting 11, 21.02.2014)

I neglected to realise the position (of leadership) I held as interdependence grew, with a role of bringing the group together for the purpose of accomplishing our goals (West *et al.* 2015). I also did not take into account the significance for a person with a deteriorating condition of receiving ongoing (unfluctuating) support into the longer term from someone who does not have problems with variability in health state (Caap-Ahlgren and Dehlin 2004, Paterson 2001). Dave and I were two such 'constant' features during the research period, and whilst he was fully

supportive of the group, he was busy pursuing his agenda of fund-raising on their behalf.

I knew that the varied symptoms experienced with Parkinson's would affect levels of participation (Hammel *et al.* 2008). The degree to which people took the initiative to change their circumstances also reflected their opinions and ambitions, levels of empowerment and whether the actions permitted the realisation of their needs (Cornwall 2008, Arnstein 1969).

For those experiencing cognitive decline, the ideology of shared-learning and knowledge-construction to influence the wider political sphere was difficult to achieve and a main reason for exclusion from research involvement (Cubit 2010). PAR is an ideal process of encouraging excluded voices (Reason 1999). Literature however rarely discusses the role of people who have physical and mental health problems who may wish to participate and contribute, but be limited in this ability due to their health. A plan to reach those unable to partake as fully as others maintains effective participation (Wilcox 1994).

Noel asked to speak with me privately after a meeting a few months into the Research Project. He stated he wished to remain a MontyZoomer member, but that he could no longer keep up with conversations:

'I feel a bit lost and unable to contribute to the project during meetings, but I still want to be involved'. (Private conversation with Noel after MontyZoomer Stakeholder meeting 7, 13.09.2013)

We agreed that I would visit him at home to bring him up to date prior to a meeting, and from these discussions enabled him to process the information in his own time, to air his thoughts and continue to input to decisions, which I duly reported at the subsequent MontyZoomer meeting.

Where capacity is lacking, onus to make decisions falls on a responsible person – usually, as in this case, a spouse, who may act as a proxy on behalf of the care-recipient (Politynska 2013, p13, DH 2014c, 2012b, Cubit 2010).

Hazel (NPS) and Duncan (pwP) had attended the first MontyZoomer Stakeholder meeting (15.02.2013) with an excellent idea for fundraising and Hazel agreed to pursue this outside of the meetings. She contacted me that evening:

'Duncan (pwP and her spouse) and I won't be attending further meetings. He was in hospital recently and with his Parkinson's and dementia, it's too much effort to get him ready and get into town. Anyway, he didn't say anything at the meeting today, was tired this afternoon – it is all a bit much for us both'

(Hazel, personal telephone conversation, 15.02.2013)

It is not unusual to witness both spouses in a dyadic relationship become entwined with the consequences of a health condition, although affected in different ways (Politynska 2013, p16). It was interesting to note the difference in Hazel's opinions of Duncan whose silence she had taken as non-participation, to those of the MontyZoomers who knew Duncan from an exercise class he attended (Gallant *et al.* 2007). From his chattiness when engaged in conversation at class they felt Duncan would have had nuggets to offer in MontyZoomer conversation. However, their awareness of his dependence on Hazel's assistance to get Duncan ready and to drive him to the meetings resulted in their resignation to the situation. As Duncan was still a regular participant in a weekly class, we were kept informed of their progress (which, in time, yielded our greatest donated income), and in turn we kept both Hazel and Duncan informed of MontyZoomer activity so they could input opinions should they wish.

In this way, all the MontyZoomers who had signed up to involvement in the Research Project remained active participants to their ability and preferred method of involvement to the end of the 18-month period.

7.4: Chapter summary

PAR was an educative process used by a Sheffield-based (marginalised) group of people with Parkinson's to address specific, somewhat politically driven problems to change how they sought to support activities that kept them well (Hart and Bond 1998, p36–45).

The process utilised participants' specific skills, acknowledging how personal values influenced the methods chosen, rendering it unique to this group of people (Herr and Anderson 2005, p100–102). In research such as this, as the outcomes are determined by the context of the research group, the method is open to great scrutiny and must be conducted with rigour (Norton 2009, p56-57).

To ensure success with this methodology, the participants must be enabled to understand their role is in taking responsibility for change as well as for their involvement in the research process (Bergold and Thomas 2012). This can be difficult for some participants with limitations (physical and mental) imposed by the Parkinson's, affecting how fully they can participate and contribute to the process, and must be managed by the research lead (Cubit 2010, Paterson 2001, Wilcox 1994).

In PAR, social change is effected through shared ownership of research projects with group learning and decision making as a matter of principle, based on a community of people affected by Parkinson's choosing projects of relevance to their own lives (Cook 2012, Koshy *et al.* 2011, p2–3, Hart and Bond 1998, p20–21). As the group developed their participatory position, my role became increasingly facilitatory (Hart and Bond 1998, p20–21), and theirs more emancipatory and empowered (Smith and O'Flynn 2000).

The stories of empowerment destroyed the vision of passive patient involvement in promoting own needs through the segregating, medically led nature of health policy and provision (WHO 2002, Gage 1997). The WHO (2002) framework pushes for '*informed, motivated and prepared*' patients through self-management and empowerment at the micro level, and this is what we have seen (Epping-Jordan *et al.* 2004, DH 2001d, DH 1999).

This exploration of PAR methodology and the research process have laid the foundations for a considered description of the use of the interdependent consensus model developed during the Research Project.

CHAPTER 8: PROFESSIONAL IMPLICATIONS 2

RECONCEPTUALISING PARKINSON'S

8.1: Learning to see Parkinson's differently as a professional

Professionals need to be open to consider 'power sharing' in health behaviour that takes into account a person's value systems, health beliefs, spiritual needs and personal choice related to their cultural belief and personal experience (Leavitt 2012, Low 2004). Agreeing compromise and avoiding misunderstandings is essential with an increasingly multi-cultural population (Lehman *et al.* 2012, Low 2004, Greenberg 1985), to the use of alternative, culturally acceptable interventions in self-management.

Lived experience reflects an existing structure of understanding in social policy (Wiesel and Bigby 2014). Physiotherapists, as part of the health professionals should be educated and enabled to view inclusion as a wellness concept whose foundation originates from a perspective of the lived experience of individuals, and not through the lens of a 'disease' or 'illness' framework.

There is a need for physiotherapists to reconceptualise any long-term condition from the social, psychological, and possibly spiritual perspective in addition to the physical if people are to be supported in regaining a quality to life (Joyce *et al.* 2010, Whitney 2004, Bensley 1991, Bergman 1983).

It is only at this level of understanding that the concept of wellness can be promoted, which will result in the person (with Parkinson's) exploring what gives their life meaning (Whitney 2004) leading them to make greater contributions to social (including work, and political) roles (Joyce *et al.* 2010, Bergman 1983) whether by informing practice directly, or through research output.

The quality in how people voiced ideas at our MontyZoomer meetings and chose tasks evolved. Some transformed into projects initiated by, and carried out by individuals (Reason 2006).

Social media sites (including photo-sharing sites) have increasingly become adopted by charitable organisations as a means of showcasing and promoting activities to interested parties (Curtis *et al.* 2010, Saunders 2008). Bob (pwP) is a

member of several sites and proposed he set up a Facebook site for the Branch. This was met with negative responses from the rest of the MontyZoomers.

Undeterred, Bob recruited the help of Tony Hird, an active spouse of a regular Full Monty Club participant to set up and populate a Branch Flickr page. This photograph repository links to the main Sheffield Branch website page hosted by Parkinson's UK (Appendix 10), and has received anecdotal positive verbal feedback from Parkinson's UK headquarters, Branch members and their family directed to view the site since set up in September 2013.

I will use this to explore a change I underwent in understanding about Parkinson's.

Bob enlisted Tony to set the site up purely to share photographs of the increasing social and physically active events groups of people affected by Parkinson's were joining in with. As a health professional still in 'measurement' mode, I viewed the potential for the site differently. Although the creation of a profile in non-profit organisations has not been shown to increase public awareness or participation, use of social media has been recommended as a way to 'sell their brand' (Waters *et al.* 2009). This is the approach I took when explaining to the Branch Committee why the MontyZoomers were agreeing the project, to see if we might generate increased membership numbers (quantifiable)!

Virtual communities have been studied by academics in relation to the dynamic and multidimensional ways people interact and exchange health-related knowledge (Leibing 2009), so I took the opportunity to share the photographic content within the Flickr site (with the MontyZoomers' knowledge) as my contribution to a qualitative researcher interest group run at SHU (QRIS) during Parkinson's Awareness Week 2015.

The following statements are records of what the two reviewers set the task of examining the site made of them:

Reviewer 1: Commenting about their general impression, stating:

'The photos are people-driven.....the events look shared.....there is a lot of activity' (QRIS meeting, 23.03.2015)

Reviewer 2's comments were similar, also noting the general positivity in the feel of the site, but lack of any photographs depicting intellectual activity. They added:

'.....there are many different activities – irregular, some with family support and some withoutmany happen in nature.....' (QRISS meeting, 23.03.2015).

Both reviewers specifically looked at three albums uploaded to Flickr. The first was of the 'Sunday lunch club' album (25.01.2015), which they described as follows:

'It looks like a disease of white, hetero-normal mature couples.....because the photos are sifted and chosen – even controlled, they are similar in every way. This could be off-putting for someone looking to join the group.'

(Reviewer 1, QRISS meeting, 23.03.2015)

The photographs in the album looking at the Olympic torch carried in Sheffield by a nominated group member (26.06.2012) came across as:

'Authentic, alive, genuine, fun, achievement, pride, physical – but not just physical'

(Reviewer 1, QRISS meeting, 23.03.2015)

With Reviewer 2 adding that the whole album:

'....looked more natural with a mixed-diversity of people.'

(QRISS meeting, 23.03.2015)

The final group of photographs reviewed were in an album with the Steel City Tremorloes (voice group) performing in the Winter Gardens (13.05.2013). The reviewers described the images as a balance between appearing:

'Solidarity versus institutional [as people were in the same Parkinson's T-shirts]....the blue T-shirts make one wonder what has become of the identity of the individuals.....this event seemed more organised, with people led or herded'

(QRISS meeting, 23.03.2015)

The last comment is interesting when compared with a photograph taken at a Car Boot sale on 14.12.2013 (Figure 8.1). For me, the photograph accounted for the people involved in fundraising. I had not comprehended any deeper meaning.

For Ann (pwP) it was the point at which she crossed a personal line ready to be seen in public 'advertising' the fact she had Parkinson's, an important step forwards in accepting her diagnosis. Whilst she had supported the charity raising funds e.g. at supermarket collections, she had not previously seen photographs of herself wearing the charity's T-shirt for public events, although photographed at

the Steel City Tremorloes (voice group) Winter Gardens performance (13.05.2013).

On seeing a photograph²¹ of herself at the table with Harry (pwP) (Figure 8.1), Ann commented:

'I realise I have come a long way since being diagnosed. I could not have pictured myself 'in uniform' declaring - to myself, let alone the world - that I had this awful disease'.



Figure 8.1: Ann and Harry manning the stall at the Christmas Car Boot sale, 14.12.2013

Later, she added:

'It is odd to see me with the others.....[laughs as she says] I almost blend in....I am amongst friends....'

(Personal conversation with Ann when choosing photos for our Branch Flickr repository, 19.12.2013)

As a physiotherapist working with older people and those with Parkinson's, we are taught to take a full (relevant) social history, including professional background and leisure activities (Keus *et al.* 2014, Ramaswamy and Thomas 2010). We link the knowledge to 'posture' and determining 'fitness', yet look no deeper for understanding of identity and interaction in social environments, and how these can influence individual's experience of Parkinson's, connectedness with others,

²¹ Permission was obtained from people in the photographs for use in the Doctoral Project write-up, or are available to view on the Sheffield Branch Flickr page

and subsequent management (Sunvisson and Eckman 2001).

The next photograph is taken during a break at a monthly walk at a local park (Figure 8.2). As the health professional that organises and leads the walks, I



requested the photograph to be taken to illustrate the 'social' during the walk.

Figure 8.2: Mike reading out the history of the Hillsborough Park Hall, 28.07.2012

I was sat on the grass next to Pamela (pwP) chatting, probably about the weather, when Mike (pwP) turned up with a sheet of paper and asked everyone if we wanted to know about the Hall at the park. Following murmurs of interest, he started. As he read the information out, Pamela turned to me and said:

'It's the historian in him – did you know he was a University lecturer up in Dundee before he came to live in Sheffield?'

(Personal conversation, 28.07.2012).

In that one statement, Pamela considered both Mike's past and present identity, recognising his as both 'Mike with Parkinson's, and the academic'. Identity is a large part of feeling well, from being recognised and known for who one is (Wiesel and Bigby 2014, Platt 2004).

The final photograph I have chosen was sent to me by Tony Hird (NPS) showing Bob (pwP) and June (pwP, Tony's wife) running (Figure 8.3).

'That was such a laugh. Bob challenged June to a race as I think she poked fun at him about the Boxing class - he lost! I've not seen June so competitive since school!'

(Tony, email correspondence, 21.06.2013).

He was describing how people pushed themselves to the limit through fun and competition, a *'feeling of capability'* (Sunvisson and Eckman 2001), not the recognisable passivity of a 'patient' with Parkinson's (WHO, 2002).



Figure 8.3: Bob and June racing at Millhouses Park, 21.06.2013

'Fun' is not a specific term found in peer reviewed health literature associated with people with Parkinson's who exercise, but an important motivator found in several Blogs written by people with the condition (James 2015, Robb 2015, Twinks 2015, Flossie 2009), and noted for its positive outcomes on people who use leisure-based coping strategies to deal with life's stresses (Hutchinson *et al.* 2008).

People used humour and laughter in classes to cope with the Parkinson's (true of the people with Parkinson's as well as their spouses), to buoy or support one another as seen in the focus group conversations, and in the 'Naming' of the MontyZoomers.

The psychological and social benefits of humour are recognised in medicine as important to health (Calman 2001), yet something rarely witnessed in a hospital setting. Isaacs (2008) describes his first visit to the hospital clinic after a diagnosis of Parkinson's:

'The room was heavy with melancholy born out of resignation to a life less wonderful than it once was....it was a cheerless pilgrimage; a biannual expedition to measure the extent of my degeneration. The mood was contagious, I felt bleak.....'

Most of my encounters of people with Parkinson's were previously in a clinic setting. Without this new understanding I gained through PAR of the lived experience of an individual, I would have continued to provide inappropriate and prescribed treatments for people with Parkinson's based still on *my* professional understanding (Sunvisson and Eckman 2001).

I had not comprehended the impact of humour and fun in recreating identity, as people who are unwell are unable to generate a feeling of wellbeing when ill, although they may crack jokes about their condition (Scott *et al.* 2014).

8.2: Using the socially constructed interdependence model for Parkinson's

For people with Parkinson's, the voluntary organisation is driving forward the empowerment model by engaging individuals to provide a voice alongside those of the professionals (Parkinson's UK 2015). This is resulting in the sharing of knowledge between one group with a lived experience, and another with a scientific understanding mixing beliefs, values and perceptions (Kuokkanen and Leino-Kilpi 2000, Lather 1986).

It has been recognised that most members of Parkinson's UK (whether volunteers or people looking to meet a personal need) are white and middle-class (Deane *et al.* 2014). To have an effect on addressing the needs of people affected by Parkinson's throughout society as a whole, volunteers need to be recruited from all areas, especially from the more deprived areas, where people are more diverse, but vulnerable and marginalised (Dingle and Heath 2001).

This is different to social prescribing, a medicalised term describing referral from health professionals (usually the GP) for 'patients' to connect with non-medical support resources in the community, usually hosted by the voluntary sector, adjunctive to health treatments that improve wellbeing (Brandling and House 2009). While some people who join Parkinson's UK do so through this route, only their social engagement is enhanced via health-related activities such as exercise programmes, with no incentive to effect social capital or to become active politically (Brandling and House 2009, La Due Lake and Huckfeldt 1998).

The social networks they belong to play an important part in building social capital (Vassilev *et al.* 2014, La Due Lake and Huckfeldt 1998). Social capital is a product

of social interaction that occurs with sufficient regularity that people get to know one sufficiently to create relationships and bonds based on respect, shared-values and beliefs in context to a situation (La Due Lake and Huckfeldt 1998). It may develop in communities (Begum 2003), through educational processes (La Due Lake and Huckfeldt 1998), or as part of physical activity resource in the community (Bailey *et al.* 2012, Bayly and Bull 2001).

We might utilise the socially constructed interdependence model to influence Parkinson's social structure and networks that support communities of people affected by the condition (Scott 1988). Social networks are evidenced as being protective of health and wellbeing in older adults (Holt-Lunstad *et al.* 2010, Buchman *et al.* 2009, Pinquart and Sörensen 2000), in people with conditions such as diabetes (Vassilev *et al.* 2014), something only recently considered for research into people with Parkinson's (Tickle-Degnen *et al.* 2014, Wensing *et al.* 2011).

In considering the dynamic and hence changeable nature of wellness, one must consider it through the integration of social, mental, emotional, spiritual and physical health whether the person is feeling healthy or ill (Paterson 2001, Bensley 1991, Greenberg 1985). This is a vital issue for healthcare professionals as it is only by knowing human behaviour that we can look at how we interact and respond to agree a need for our intervention (Smith *et al.* 2013, p365-367). If we don't know the person's identities or their beliefs that dictate health behaviour, how can we interact and respond properly?

There are 'Quality indicators' developed by physiotherapists for physiotherapists to measure the quality of service they deliver to people with Parkinson's (Nijkrake *et al.* 2009), and Quality of Care' indicators developed by expert movement disorder specialist to consider the quality of care provided people with Parkinson's (Cheng *et al.* 2004). No quality indicators have yet been designed by people with Parkinson's to consider their holistic needs.

For each of the four suggested headings of the interdependence model, an example of where the voluntary sector, or social support groups may be of value to enhance wellness have been proposed in terms of a possible (measureable) quality indicator, using one point noted as helping people with Parkinson's to stay well (See Table 6.1 and Appendix 8 for details).

8.2.1: Pre-diagnostic phase: Support through the diagnostic period

The MontyZoomers noted that the wait for confirmation was sometimes long during this period and that some may look on Internet for information. One aim of Parkinson's UK is to become the first point of access for information for people who want to know more about Parkinson's, and they are currently developing an online Resources Centre with varied information

Possible quality indicator: To establish various types of information about Parkinson's that answer frequently asked questions about Parkinson's.

Possible measures: To investigate how people accessed the information, the use to them (considering language, education, culture, gender), and whether the source felt informative

8.2.2: Diagnostic and immediate post-diagnostic experience

The MontyZoomers noted the paradox in messaging: social support gives hope; clinical message stresses decline, yet this is a time when most support is needed.

Despite pre-diagnostic symptoms evident from GP notes (Schrag et al 2014) and repeated surveys to gain information of self-reported physical problems (Oxtoby 1982, Yarrow 1999, PDS 2008) that people request support for, medical staff with the power to refer do so at mid to later stages based on out-of-date research (Weiner and Singer, 1989). Parkinson's UK last year for the first time sent a self-reporting survey for members to report on their experience with health services. To maintain higher life satisfaction experiences that people with Parkinson's report in the mild to moderate stages of the conditions, support must be instigated earlier by health professionals, including referrals on to the local activities provided (Rosengren *et al*, 2016).

Possible quality indicator: For Parkinson's UK to broaden the survey so people with Parkinson's report on aspects wider than health service provision that keep them well

Possible measures: These will be based on the issues people affected by Parkinson's report are important at that time (up to a 2 year period post-diagnosis)

8.2.3: Elapsing years: Consider relevant support over time

The needs of people over time are too variable to consider one indicator and measure, but one thing the MontyZoomers mentioned was that they enjoyed discovering lost skills.

It may be of use to review the works of Parkinson's UK 'Links' project and the Parkinson's UK Excellence Network. 'Links' is socially mediated and user determined, asking each of the Branches throughout UK what activities they see as necessary to maintain people with Parkinson's health and wellness. The Excellence Network is health-policy and professionally driven, and apart from the work of the Service User Involvement Working Group, all other working groups are completing projects dictated to from the health professional perspective, or have minimal (or no) involvement of service users (Ramaswamy *et al.* 2016).

For people to be supported, such projects need to understand how each scheme develops capabilities and connections, utilising collaborative working, and in time researching the interdependencies of the groups.

8.2.4: The future: Holding onto hope

Studies of the ageing experience consider numerous diverse groups who fall within this category based on age bands, culture, belief, gender (Putnam 2002, DH 2001a). According to the Continuity Theory people make choices and adjustments that preserve structures (internal and external) of their own identity. Continuity from a past with set social behaviour and preferences alters for people with Parkinson's (Bury 2005), yet the sense of belonging and the maintenance or development of new interpersonal relationships maintain wellness into the longer term (Gumber *et al.* 2016). For people affected by Parkinson's, several aspects can be considered, but one might be based on the MontyZoomer individuals who pursued political influence.

Possible quality indicator: Influence over 'Stewardship' e.g. communication with the people who make decisions on the information used to guide health planning and care systems, and the application of research that inform policy (Alvarez-Rosete *et al.* 2013).

Possible measures: A review of individuals 'user' experience to influence a

project. A narrative such as one provided in the 'Empowerment' section

8.3: The importance of interdependence to professionals

There is a need to utilise the opportunity for people affected by Parkinson's to engage in a (powerful) collective learning experience (Pettit 2010). To maximise the likelihood that someone can self-manage their Parkinson's effectively, they should be encouraged at different periods of their condition to share responsibility of decisions with another person as necessary whether peers, carers (Jonsdottir 2013, Barlow *et al.* 2002), medical and health staff (Salmon and Hall 2003). The importance of peer (physical and social) support activities enabling people with chronic conditions to remain well, to swap stories of their lived experience and to provide lay education about a condition should be considered in addition to professionally led educational programmes (Mead and Copeland 2000).

Just as contact with services and health providers will shape a person's experience and long-term expectation, health professionals need to understand the complexity of a person's lived experience with a chronic condition, and how to enable someone to utilise services effectively (Gatley *et al.* 2007), yet empower them to take over characteristics of self-management that would traditionally be the domain of the health professionals (Wilson *et al.* 2007).

When considering information gathered by co-researched, and knowledge produced as the output, these cannot be separated from research practice, epistemology and ontology (Mauthner and Doucet 2003).

During the 18-month Research Project two emergent issues relate to relationships of interdependence.

The first relates to self-determination²² to follow their own interests to achieve wellness in the people diagnosed with Parkinson's, decided by their own actions to support one another, and be supported by all involved others (Ryan and Deci 2000).

²² Self-determination has been defined using the Ryan and Deci (2000) work, as it has implications for health care, physical activity adherence and in determining 'happiness'. See Glossary

The second issue is of power and control, determining the (expected) behaviour of people with Parkinson's, from themselves, those close to them affected by the diagnosis, and the formal health and care professionals (Raven and French 1959).

Exchanging stories of their altering health experiences (including the period prior to diagnosis) enabled the co-researchers to review how the negatively communicated beliefs and information had formed their understanding of Parkinson's (epistemology). The varied research activities chosen by the group allowed them to develop a new way of seeing their journey with Parkinson's (ontology) – one they wanted communicated to the wider health and social care professionals as they felt it should be a shared journey.

Individual's relationships change with the people who they socially network with as time elapses (Vassilev *et al.* 2014), and so too should relationships develop with professionals who help people with Parkinson's along their journey according to times of health need for illness, and wellness (Paterson 2001).

Because all people are given one diagnosis, services provide the same intervention despite knowing that experiences of motor and non-motor symptoms differ so widely. Individuals want recognition for themselves and not to be recognised by the medical label (Bramley and Eatough, 2005).

CHAPTER 9: CONCLUSIONS

I will start my conclusion by stating that all the original aims of the Doctoral Research Project have been achieved.

My role was to facilitate this transformative method (PAR) to engender and expose the positive qualities of individuals, to enhance group identity following biographical disruption in the context of the degenerative condition (Aujoulet *et al.* 2008). The outcome was of empowerment from within a group of people undertaking activities that supported their wellness (Smith-Chandler and Swart 2014).

With regards the research question, the Research Project highlighted that there is a role for physiotherapy to support people affected by Parkinson's to have a voice that defines and enables their wellness.

Kurt Lewin is quoted as saying:

'To proceed beyond the limitations of a given level of knowledge, the researcher, as a rule, has to break down methodological taboos which condemn as "unscientific" or "illogical" the very methods or concepts which later on prove to be basic for the next major progress' (Lewin 1949. p 275)

The Research Project illustrated the wider remit of the profession beyond the main expectation to promote health and wellbeing health through physical means (CSP 2011), utilising personal resources through social interaction to enable maintenance of control over health (Vassilev *et al.* 2014, Nesta 2012, WHO 1986).

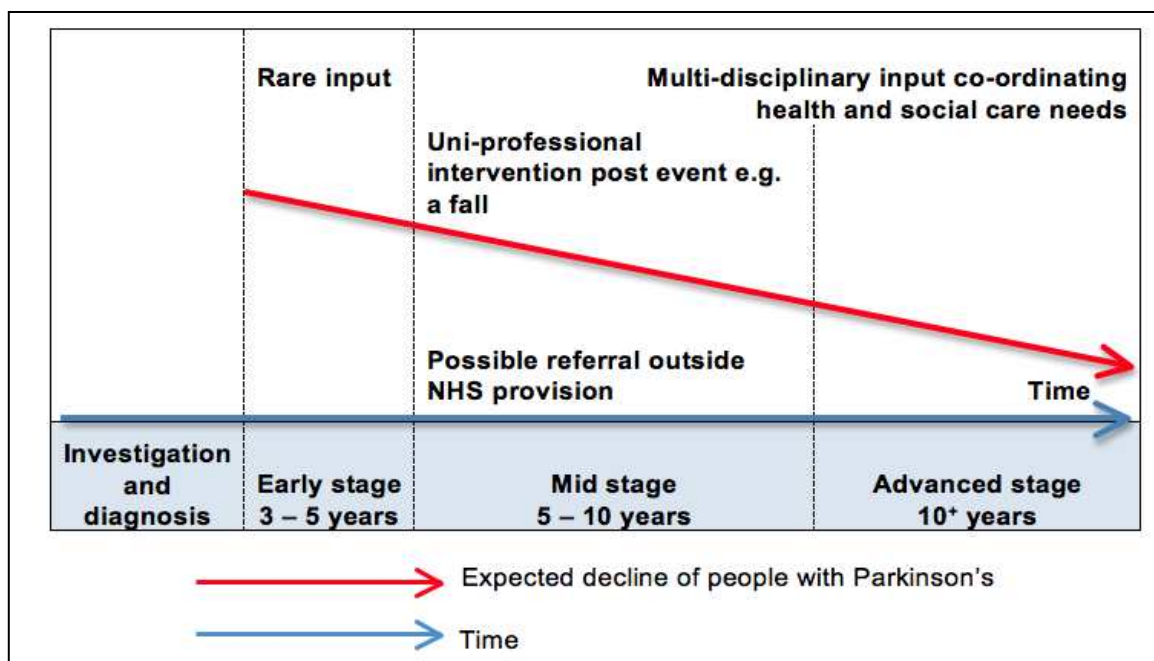
The two critical discoveries that contribute to professional knowledge are of the necessary relationship of interdependency that has become lost in much of contemporary health care provision, and also the issue of the time it takes in populations with long-term conditions to build such relationships to become part of the fabric that supports their wellness.

My first critical finding was that physiotherapists have a more holistic and long-term role evolving in an interdependent relationship with people affected by long-term conditions. They can be part of a support system along the course of the journey of the person with the disorder called on at points of need as perceived by the individual. This role in keeping a community-dwelling adult population of

people affected by Parkinson's well is neither consistently taught at an undergraduate level, nor practiced by clinicians where assistance is provided according to service availability.

Currently, most of the physiotherapy provision is sporadic, occurs later in the course of Parkinson's, as a diagnosed condition, and is initially through uni-professional involvement, fitting people into existing services based on research evidence. In spite of seeing improvement with intervention, our mindset still visualises Parkinson's as a condition with steady decline into dependence in conveniently spaced incremental periods of about 5 years (Figure 9.1).

Figure 9.1: Current model for UK physiotherapy practice: NHS service provision based



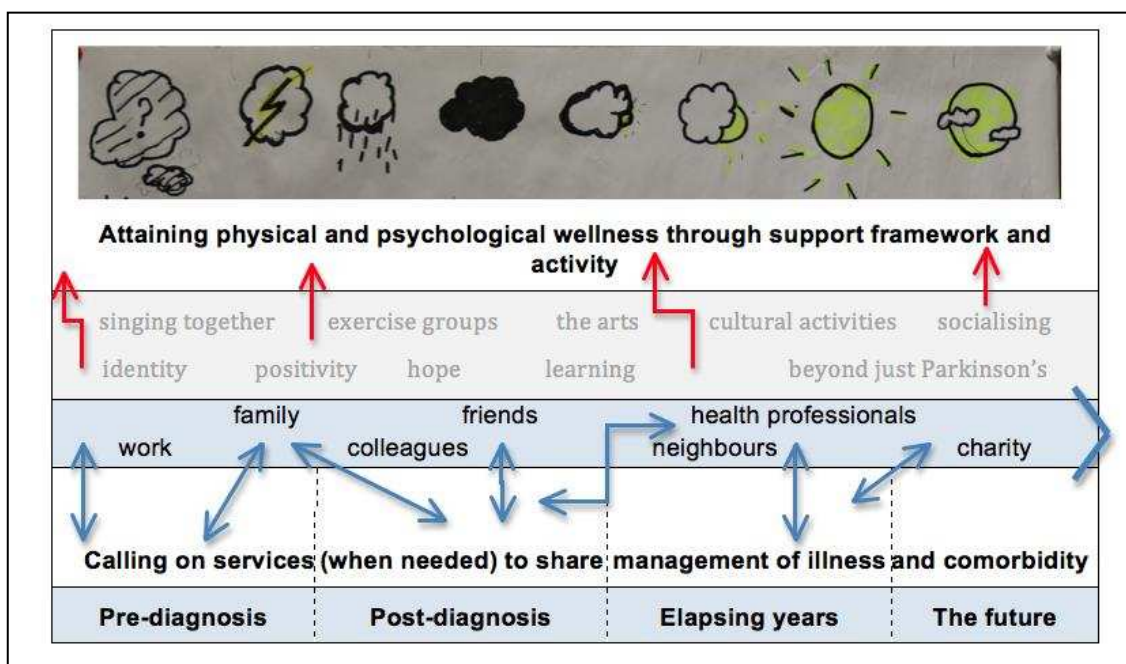
In keeping with the changing health profile of the user group, people need to better understand our role and capabilities as physiotherapists, and we to better understand their identity and experiences as individuals within a unit of support (broader than just health provision) of which we are one part. In our Research Project, this factor improved utilisation of one another's skills and knowledge at a time when each party deemed it most needed.

Individuals constructed a new identity and understanding through their interdependent relationships with others affected by Parkinson's usually 'treated' by professionals for illnesses and injuries. They endeavored to undertake activities that kept them 'well', and the social involvement gave them a voice to make decisions

ultimately affecting their lives, informing strategy and research (McDonald 2014, O’Grady and Jadad 2010). The MontyZoomers chose to look forward to a future of hope using interdependent relationships to journey alongside people they could call upon when they perceived the need arose in times of either illness or wellness (Balliet *et al.* 2014, Paterson 2001). This is paramount in a political climate where the patient experience of continuity in healthcare is reduced (Freeman and Hughes 2010). They understood the progressive nature of the condition, and the possibility of developing co-morbidities with age that would also require periods of treatment, but placed no time frames on the emergent changes expected, instead opting to keep wellness as a goal to keep striving towards (Figure 9.2).

People with life altering conditions like Parkinson’s require assistance through periods of adjustment, so they can explore and understand the disruption to theirs and their family’s lives (Berg and Upchurch 2007, Williams 2000, Bury 1982). The change it conveys to how one perceives one’s self over the life course needs to be supported if people are to manage the repercussions of a currently devastating diagnosis, emerging to live a predominantly well life (Lawton 2003, Tanner 2001, Charmaz 1993) (Figure 9.2).

Figure 9.2: New model of interdependent relationships: Needs-based as experienced by people affected by Parkinson’s



Cloud drawing reproduced with kind permission of Denise Webster; Figures 9.1 and 9.2 conceptualised by Bhanu Ramaswamy, Pamela Goff, and Janice Forder (December 2016).

The second critical issue was time.

It took time to get to know the people with whom I interacted, and time to let them get to know me, gradually developing into traits of interdependence (Sunvisson and Eckman 2001). This is a difficult ethical decision for many clinicians as our professional values embody an unstated message of distancing oneself of personal involvement and befriending patients (CSP 2012). For those of us working with individuals and their families affected by chronic conditions, a position of both friendship and professionalism fosters a trusting relationship that demonstrates moral and ethical awareness (Pollard 2015). We are privy to the complexity of peoples' abilities and needs upon which we negotiate decisions that better provide involvement, enabling an individual to make choices toward a healthy, successful and fulfilling life over a long term period (Pollard 2015, Wilson *et al.* 2007, National Wellness Organization 2003, WHO 1948).

These two issues must be taken forward into health strategy and education, where they could also have a broader impact on other conditions with an underlying philosophy of shared-care needs into the longer term e.g. cancer, dementia, other neuro-degenerative and rheumatological conditions.

The positive implication of the socially constructed model of interdependency needs to be disseminated through physiotherapy research, education and practice.

The work of the MontyZoomers accentuated that practitioner-patient communication used language not conducive to that of a professional giving 'health' care or advice. The request was for dialogue that engendered wellness that gave hope and not one that painted only linear decline and preparation for 'illness' and a 'disabled and dependent future'. They wanted to remind the health professionals that they were 'well' for proportionately longer periods than they were unwell (Putsch and Joyce 1990), and that as all people, they too need of humour from social encounters, and not just the expectation to deal with Parkinson's through individualistic and isolating experiences of clinical consultations.

EPILOGUE

My final words are of the legacy of the MontyZoomer Projects – still driving for ‘wellness’.

The MontyZoomers continue now to act as an action group led by myself alongside the Sheffield Branch Committee, no longer researchers. New members join or are recruited as and when needed based on their skills, and with increasing consultation with the Branch membership. Dave is still Chief Fundraiser!

I have listed our continued achievements since the Research Project ended in May 2014, in no particular order, but because I am proud the ethos is holding so dearly onto the theme of keeping positive and helping one another stay well:

1. We have produced a DVD about Branch activities for the health professionals to give newly diagnosed people with Parkinson’s across the city. It is called: *‘Support for living well in Sheffield’*. MontyZoomer fundraising has paid for these to be produced
2. We have a calendar for sale for 2017. The theme for photos for each month was about ‘wellness in Sheffield’, chosen by Branch members
3. The general awareness about Parkinson’s has been raised and the availability of people willing to educate others about the condition across the city has resulted in the Branch Committee receiving increasing invitations to be visible in local events e.g. holding a stall at an awareness event, requests for member involvement in varied research projects or talks.
4. There are now 5 members of the Sheffield Branch on the Parkinson’s Sheffield Stakeholders group, where before there was one token member from the Branch Committee. This group primarily consists of professionals who decide on the service needs of people with Parkinson’s in Sheffield. Pamela (pwP) continues to fly the political flag, and at the last meeting, insisted on a point being noted asking members to:

‘Stop using the word ‘disease’ in general conversation. The charity, Parkinson’s UK have been attempting to change people’s attitude since 2011. The hope is to reduce the illness-perpetuating, negative language and stigma created by words

such as 'disease', 'sufferers', 'victims', and simply refer to the condition as 'Parkinson's', and people as 'affected by' or 'with Parkinson's' (Sheffield Stakeholder meeting, 30.06.2016)

5. We also have a regular Carer's group set up with the support of the committee, but run by a carer.

Together, I think we are all doing rather well!

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APPENDIX 1: Participant information form for recruitment to Research Project



Participant information sheet

Study title:	Participatory Action Research to evaluate indicators of sustainability of a Parkinson's group.
Chief investigator	Bhanu Ramaswamy
Telephone number	0114 2552522

Study Sponsor: Sheffield Hallam University

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

The study is being conducted as part of a Doctoral project being undertaken by Bhanu Ramaswamy, and essentially will look at aspects of the Full Monty Club.

This Club is unique in that it started in 1999 to provide a *Posture and Balance* exercise class for people in the community with Parkinson's and also to offer a social element for the participants. It has been running for 12 years now, and benefits from peer support from the members as well as improving, or trying to maintain fitness levels.

The classes have developed over time and the Club now offers different styles of exercise, including hydrotherapy, circuit classes and we even have a Wii-Fit system to borrow. The members continue to support each other by taking part in, or organising social events.

Participant name:

You will be given a copy of this information sheet to keep

1. What is the purpose of this

The purpose of this study is to explore the Full Monty Club - the exercise arm of the Sheffield Branch of Parkinson's UK. In particular, we wish to explore what has kept the Full Monty Club going to show others the benefits of being part of this group, and what we might do to sustain the Club into the future.

It is being studied as part of a Doctoral project undertaken by Bhanu Ramaswamy

2. Why have I been invited?

You have been invited to contribute to the study because you are, or have been a participating member in the Full Monty Club exercise classes, or you have expressed an interest in being involved in the study.

3. Do I have to take part?

Your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. Your refusal to participate or wish to withdraw would not influence in any way your current or potential future participation in the classes.

4. What will happen to me if I take part?

If you participate in the study, you will be sent an invitation to become a member of a group of interested people (a Stakeholder Group) willing to help guide the study process by considering ways we can look into the history and future of the exercise Club. It would be your choice if you wished to take on any projects that are suggested in the meetings, or if you just want to attend and contribute at the Stakeholder meetings.

5. Expenses and payments

You will not be paid for taking part in this study; however, we hope you will be enriched by the experience of working, and learning alongside like-minded people endeavoring to sustain the classes into the future.

6. What will I have to do?

If you agree to take part in the study we will ask you to attend several meetings over the course of the next year (it doesn't matter if you cannot attend them all), and to contribute your thoughts, ideas, and maybe your skills to the process.

7. What are the possible disadvantages and risks of taking

Some people may find it difficult speaking in a group, particularly if the discussion touches on topics that they feel sensitive about. If this is the case, you would be able to arrange a separate meeting with Bhanu so your thoughts and opinions could also be considered.

8. What are the possible benefits of taking part?

We hope to gain insight into what has contributed to the success of the Club and build on this so we can continue to thrive. Also, the process may provide information of use to other Parkinson's UK branches hoping to emulate our Club's longevity.

9. What if there is a problem or I want to complain?

If you have any queries or questions please contact Principal Investigator: Bhanu Ramaswamy
b.ramaswamy@shu.ac.uk
0114 2552522

Alternatively, you can contact my supervisor: Dr Jill Aylott via Sheffield Hallam University on 0114 225 5555

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee)
p.allmark@shu.ac.uk; 0114 225 5727

10. Will my taking part in this study be kept confidential?

In this style of participatory research, the Stakeholder group and individuals will make decisions regarding how they would like to be referred to, thus deciding on levels of confidentiality.

If there is any interview information for example, this will be recorded and then written up word for word. The researcher will check that the recording and the written transcript are the same, and then will erase the recording. The transcript will be kept on a password-protected computer. Identifying details will be taken out of any final report and any publication so people reading these will not be able to identify you, unless you wish this to be the case. The written transcripts will have all links to you removed at the end of the study and will then be kept for as long as they might be useful in future research.

It might be that in the interviews something of concern arises relating to patient care. If that happens, the researcher will consult with her supervisor to discuss what to do. She will act in accordance with her professional Code of Conduct.

The documents relating to the administration of this research, such as the consent form you sign to take part will be kept in a folder called a site file or project file. This is locked away securely. The folder might be

checked by people in authority who want to make sure that researchers are following the correct procedures. These people will not pass on your details to anyone else. The documents will be destroyed after the end of the study, unless you give permission for them to be kept as guidance form the Stakeholder group.

11. What will happen to the results of the research study?

The study will form part of the report towards a Doctorate in Professional Studies. The aim is to publish the results in a professional journal, and present information at meetings and conferences. If interested, you can also be provided with a summary of the findings at the end of the study.

12. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University.

13. Who has reviewed this study?

All research based at Sheffield Hallam University is looked at by a group of people called a Research Ethics Committee. This Committee is run by Sheffield Hallam University but its members are not connected to the research they examine. The Research Ethics Committee has reviewed this study and given a favourable opinion.

14. Further information and contact details for the Principal

Bhanu Ramaswamy
b.ramaswamy@shu.ac.uk

0114 2552522

Participant consent form

Study title:	Participatory Action Research to evaluate indicators of sustainability of a Parkinson's group.
Chief investigator	Bhanu Ramaswamy
Telephone number	0114 2552522

Participant name	<input style="width: 100%;" type="text"/>
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	Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them	Please initial each box
1	I confirm that I have read and understood the information sheet dated 20.12.2012 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input style="width: 100%; height: 40px;" type="text"/>
2	I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without give any reason and without my medical care or legal rights being affected.	<input style="width: 100%; height: 40px;" type="text"/>
3	I understand that relevant data collected during the study may be looked at by responsible individuals from the Sponsor and the Research Ethics Committee where it is relevant to this research. I give permission for these individuals to have access to my records.	<input style="width: 100%; height: 40px;" type="text"/>
4	I agree to take part in this study	<input style="width: 100%; height: 40px;" type="text"/>

To be filled in by the participant

I agree to take part in the above study

Your name

Date

Signature

To be filled in by the person obtaining consent

I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.

Name of investigator

Date

Signature

APPENDIX 2: Summer survey information letter agreed by MontyZoomers

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Full Monty Exercise class participant exercise and health measures

Over the past decade, activities offered to Parkinson's UK Sheffield Branch members and their families have both increased in number and types of exercise and activity available.

With regards the Full Monty Club that specifically concentrates on providing exercise classes and physical activity events for the Sheffield Branch, participants' costs have been heavily subsidised through Grants and donations received, through the work of volunteers and also Branch funds, making the classes and activities affordable for everyone.

Given the national financial climate, the City Council Grant and other funds have been unavailable to us this year, so the Sheffield Branch has agreed to fund all classes. We are therefore looking into ways of raising money to sustain the Full Monty Exercise classes into the future; you may be aware of the fundraising events being held throughout the year.

In addition to this, we wish to ask the newly formed Health and Wellbeing Boards to commission some of our classes on a permanent basis. For this however, they require some basic information about the health and fitness of class participants, hence I am asking you to fill in these four sheets of paper. I know it looks like a lot of information, but we do need it to record information that will help us apply for these sorts of grants. I have been advised that the ideal is to repeat the measures twice yearly - once over the summer (hence this set of paperwork) and again over winter to provide a more meaningful record of changes in peoples' patterns of exercise at different times of the year. The paperwork is doable when sat quietly sipping a cup of tea and includes a sheet with:

- Questions about you, about Parkinson's if you have it, and about your exercise pattern and other Sheffield Branch activities undertaken. I would still like spouses who don't have Parkinson's to fill the questionnaires if they attend any classes.
- An Exercise Efficacy Score (*Self Efficacy for Exercise [SEE] scale*) to look at your confidence that you can exercise safely
- A record of your motivation (*Behavioural Regulation in Exercise Questionnaire BREQ-2*)
- Finally, the EQ-5D – a Department of Health suggested measure to record population health status.

I can provide a stamped, addressed envelope for you to return your filled sheets if you are unable to pass them back to me within a couple of weeks. Please remember that any information used to send out reports will be anonymised so you cannot be recognised in any way, plus the sheets will be kept stored in a locked area, so only accessed by myself.

If you have any questions about this, ring me on 0114 2552522 and leave a message; I will get back to you as soon as I can.

Thank you

Bhanu

Ms Bhanu Ramaswamy MCSP

Exercise Co-ordinator, Sheffield Branch of Parkinson's UK

Name:.....

Date of birth:

Please remember that any information on this sheet will be treated anonymously when used to describe the group in any reports.

1. Do you have a diagnosis of Parkinson's? Yes / No (delete wrong one)
2. If 'no', please explain why you attend a class e.g. spouse.....
3. If 'yes', how many years have you had the diagnosis of Parkinson's?

4. Please **circle** which of the Branch activities you have tried:
 Posture class Circuits class Hydrotherapy Aquarobic class
 Wii-Fit Walks Monthly meetings Cream tea Christmas meal
 Voice/singing group

5. Please circle which of the Branch activities you participate in regularly:
6. Posture class Circuits class Hydrotherapy Aquarobic class
 Wii-Fit Walks Monthly meetings Cream tea Christmas meal
 Voice/singing group

7. If you can remember, it would be useful for us to know how long you think you have been attending the different activities (it doesn't have to be an accurate date, just an idea of the month and / or year), plus add any comments about these activities. If there is an activity you do not participate in, strike it through please.

- Posture class.....
- Circuits class.....
- Hydrotherapy.....
- Aquarobic class.....
- Walks.....
- Wii-Fit.....
- Monthly meetings.....
- July Cream tea.....
- Christmas meal.....
- Voice group
- Other (state).....

8. Use two to four words to describe why you continue to attend classes and other events.
 1.....2.....
 3.....4.....

If you have any other comments about the Branch activities - especially the physical activities that you feel would help our application to the Health and Well-being Board Commissioners, please add these below.....

Thank you for your taking time to fill these forms in.

APPENDIX 3: Winter survey information letter agreed by MontyZoomers

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Full Monty Exercise class participant questions and health measures

Hello again, and thank you for considering finishing what we started this year with these questions and measures. They are being undertaken as part of Bhanu's Doctoral research project that is exploring the activities offered to Parkinson's UK Sheffield Branch members and their families. You are being asked to complete this second round as you either completed the first (in August), or you have newly joined the classes and Branch activities.

In addition to filling in the first round of questions over the summer, some of you were able to take part in focus group discussions this past few weeks which threw up many suggestions of how to help people in Sheffield with Parkinson's gain support, as well as concerns about the changes about to take place with classes. The questions we are asking aim to tackle both these issues.

Just to set the scene, addition to the monthly meetings in town, the annual cream tea and Christmas dinner, the Sheffield Branch of Parkinson's UK currently organises:

1. Exercise classes several times a week and physical activities (called the Full Monty Club, as they were established in the Hillsborough school at Burton Street where one of the scenes from the film 'The Full Monty' was shot)
2. Voice classes to strengthen and preserve your voice quality, and yes, some fun singing in a group
3. A newly established course of Speech Therapy.

So, this time round, we are asking ways you think you may be able to support people in the Branch, OR what you might need to support you, or new members better. The other three sheets are the measures you were asked to fill last time. Again, I know it looks like a lot of information, but we do need it to record information that will help us apply for future funding. The paperwork is doable when sat quietly sipping a cup of tea and includes a sheet with:

- Questions about you, about Parkinson's if you have it, and about your exercise pattern and other Sheffield Branch activities undertaken. I would still like spouses who don't have Parkinson's to fill the questionnaires if they attend any classes.
- An Exercise Efficacy Score (*Self Efficacy for Exercise [SEE] scale*) to look at your confidence that you can exercise safely
- A record of your motivation (*Behavioural Regulation in Exercise Questionnaire BREQ-2*)
- Finally, the EQ-5D – a Department of Health suggested measure to record population health status.

Please remember that any information used for reports will be anonymised so you cannot be recognised in any way, and the sheets will be kept stored in a locked area, so only accessed by myself.

If you have any questions about this, ring me on 0114 2552522 and leave a message; I will get back to you as soon as I can.

Thank you

Bhanu

Ms Bhanu Ramaswamy MCSP
Exercise Co-ordinator, Sheffield Branch of Parkinson's UK

Name:..... Date of birth:

Please remember that any information on this sheet will be treated anonymously when used to describe the group in any reports.

1. Do you have a diagnosis of Parkinson's? Yes / No (delete wrong one)
2. If 'no', please explain why you attend a class e.g. spouse.....
3. If 'yes', **and new to classes**, how many years have you had Parkinson's?
4. Since summer, have you tried any different Branch activities? (circle if tried new)

Posture class	Circuits class	Hydro/Aquarobic class	Wii-Fit	Walk
Monthly meetings	Cream tea	Christmas meal	Voice/singing	Speech therapy
5. The Department of Health recommended the following to maintain optimal health and well being: Activity that adds up to at least 150 minutes (2 ½ hours) of moderate intensity activity a week (if already regularly active at moderate intensity, manage 75 minutes of vigorous intensity activity spread across the week, or a combination of moderate and vigorous) PLUS muscle strengthening exercise on at least two days a week PLUS balance and co-ordination exercises on at least two days a week.

Do you achieve this amount of exercise? Yes No Sometimes
6. Sedentary behaviour is now known to be as harmful to your health as is being inactive. Do you ever sit for more than 2 or 3 hours at a time most days e.g. to read a book, to watch TV?

Yes No Sometimes
7. Some Full Monty members have done amazing things to raise funds to subsidise next year's classes, as well as searched for new venues to host classes. We needed to do this as the numbers of people wanting classes has risen. At the moment, we can't expand at some venues, and several people can't get to the more central locations. This is the reason the Monday class has moved to Foxhill. Venues at Leisure Centres have also been chosen as they are willing to train staff next year about Parkinson's, which will allow the classes to diversify and expand further led by other exercise professionals.
 - Please will you write down your postcode so we can gain a better idea of where our members live in and around Sheffield to help us plan future events?
 - Have the changes in class venues affected you? Yes No
 - Will you still attend the same classes you did? Yes No Maybe
 - If 'no', can you tell us why not?
 - Is there anything we can do to help you attend?
 - Is there anything you can do to help others attend? e.g. offer a lift

If you have any other comments about the work of the Branch - especially things that you feel would help you understand about the Branch, or Parkinson's, or that you would like to help us with, please add these below.....

Thank you for your taking time to fill these forms in.

APPENDIX 4: Consent form for participation in the Focus Group discussions

Sheffield Hallam University

Information sheet about class interviews

Study title:	Participatory Action Research to evaluate indicators of sustainability of a Parkinson's group.
Chief investigator	Bhanu Ramaswamy
Telephone number	0114 2552522

Study Sponsor: Sheffield Hallam University

We would like to invite you to continue your involvement in our research study about the exercise classes run for the Sheffield Branch of Parkinson's UK. The next step will be a series of interviews, but before you decide to take part, we would like you to understand what will be asked of you; please ask Bhanu if there is anything that is not clear before 20th October. She can be contacted on 0114 2552522.

BACKGROUND TO THE WHOLE STUDY: The research study you filled questionnaires for over the Summer is on-going, and being conducted as part of Bhanu Ramaswamy's Doctoral project essentially to look at aspects of the Full Monty Club, which provides exercise for the Sheffield Branch of Parkinson's UK.

This Club is unique in that it started in 1999 to provide a *Posture and Balance* class for people in the community with Parkinson's and also to offer a social element for the participants. It has been running for 12 years now, and benefits from peer support from the members as well as improving, or trying to maintain fitness levels. It is also different to classes run by other Branches as we have a specified person co-ordinating the physical activities offered to the Branch.

The activities and classes have developed over time and the Club now offers different styles of exercise, including hydrotherapy, circuit classes, a walking group and we even have a Wii-Fit system to borrow. The members continue to support each other by participating in, or organising social events.

1. What is the purpose of this study and why have I been invited?

This part of the study is to hear your thoughts about the classes. In particular, we wish to explore what you think has kept the Full Monty Club going for so long to show others the benefits of being part of this group, and what we might do to sustain the Club into the future. You have been invited to contribute to this event because you are a participating member in the Full Monty Club exercise classes. We hope you will share your own ideas, for example, how you found out about classes; if you think that a physiotherapist should lead (or be present in) classes; why you have chosen the one(s) you attend; why you keep coming back; what we can do to keep the Full Monty Club going, as well as what we can add to the Branch activities that will make it enjoyable and fun.

2. Do I have to take part?

No. Your decision to take part in this study is entirely voluntary. If you decide not to take part, this will not affect your attendance at class.

3. What can I expect to happen if I choose to take part?

If you participate in this part of the study, you will be part of a group interview with other class attendees to contribute your thoughts and ideas to the group. The interviews will take part instead of a class, or at the start / end of a planned class as timetabled separately, so you don't have to make additional travel arrangements. The group interviews will be overseen by Branch members who participate in or help take classes and will be voice-recorded (but you will not be identified as an individual). The interview will last between 30 – 45 minutes, and the information used to understand the viewpoint of class-goers.

4. What are the possible disadvantages and risks of taking part?

Not everyone likes to be interviewed as part of a group; some people may find it difficult speaking in a group, particularly if the discussion touches on topics that they feel sensitive about. If this were the case, you would be able to arrange a separate meeting so your thoughts and opinions could also be considered through an individual chat, or you can write your thoughts down and pass them to Bhanu.

5. What are the possible benefits of taking part?

We are hoping to gain insight into what has contributed to the success of the Club and build on this so we can continue to thrive. Also, the process may provide information of use to other Parkinson's UK branches hoping to emulate our Club's longevity.

6. Will my taking part in this study be kept confidential?

In this style of participatory research, you will make decisions regarding how you would like to be referred to, thus deciding on levels of confidentiality. When the interviews are typed up, identifying details will be taken out of any final report and any publication so people reading these will not be able to identify you, unless you wish this to be the case.

It might be that in the interviews something of concern arises relating to patient care. If that happens, the interviewer will consult with Bhanu to discuss what to do. She will act in accordance with her professional Code of Conduct.

The documents relating to the administration of this research, such as the consent form you sign to take part will be kept in a folder called a site file or project file. This is locked away securely. People in authority who want to make sure that researchers are following the correct procedures might check the folder. These people will not pass on your details to anyone else. The documents will be destroyed after the end of the study, unless you give permission for them to be kept as guidance from the Stakeholder group.

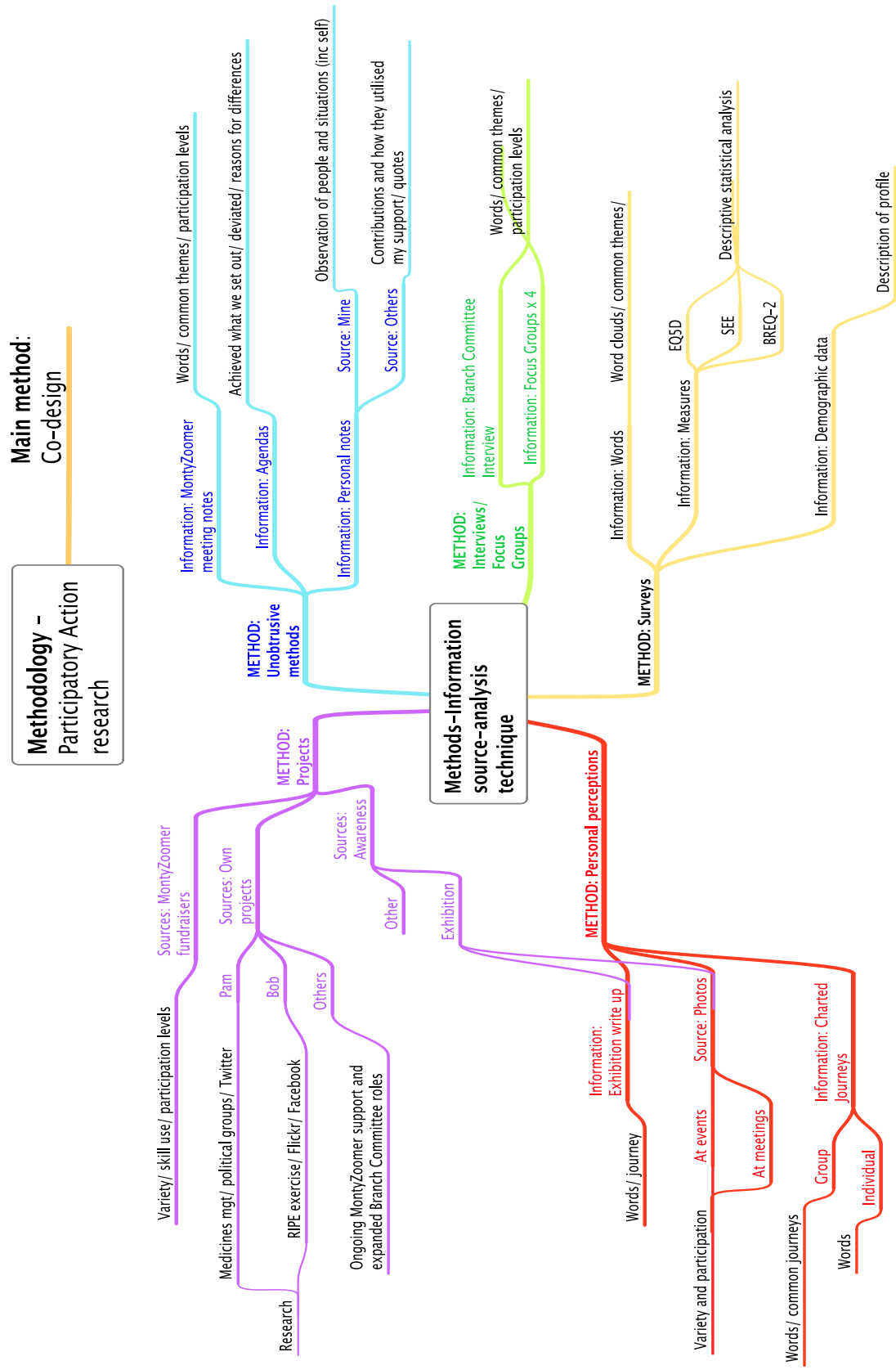
7. What will happen to the results of the research study?

The study will form part of the report towards a Doctorate in Professional Studies. The aim is to publish the results in a professional journal, and present information at meetings and conferences. If interested, you can also be provided with a summary of the findings at the end of the study.

APPENDIX 5: Timeline and list of the projects to collect and gather information conducted during the course of the project

2012	2013												2014			
Dec 2012	Jan 2013	Feb 2013	Mar 2013	Apr 2013	May 2013	Jun 2013	Jul 2013	Aug 2013	Sep 2013	Oct 2013	Nov 2013	Dec 2013	Jan 2014	Feb 2014	Mar 2014	Apr 2014
Invite to take part	Form Stakeholder group	First meeting	2 nd meeting	3 rd meeting	4 th meeting	5 th meeting	6 th meeting		7 th meeting	8 th meeting	9 th meeting	10 th meeting		11 th meeting	12 th meeting	13 th meeting
SHU	Analysis of progress through meeting notes charting changes in contributions; balance between me controlling versus chairing and others suggesting agenda items; field notes															
						Survey + questionnaires on motivation, self-efficacy and health state						Survey + questionnaires as before				
Analysis: Demographic information used for descriptive statistics to profile participants e.g. ages, years diagnosed, postcodes, activities chosen. Questionnaires analysed using SPSS and EQ5D-5L has own calculations chart																
								Committee interview by Bhanu		4 x Focus group discussions conducted and analysed by MontyZoomers and wider Branch members						
Analysis done by MontyZoomers. Committee received a copy of transcripts; all group participants were offered the same, but none accepted. Initial themes found were then taken back for discussion at Committee meeting and at Branch meeting plus sent to external Stakeholders to review for added iterations/ ideas and a way of member-checking accuracy (Oct & Nov meetings)																
			Card sales started for the year	Give it up for Parkinson's for Awareness Week		Start of applications for Grants & Sheff'd Company donations	Coffee morning + member sponsor'd walk	Strawberry Fayre + member charity cricket club event			Car boot sale	Christmas Fair Stall at local school fair				Awareness Exhibition
Analysis: Comments in field notes detailing willingness to get involved, plus promotion to others of activities																
									Start of people's thoughts on their journeys since diagnosis of Parkinson's				Journeys work continue + request MontyZoomers write their personal accounts of learning			
Analysis: Visual imagery and word meaning interpretation																

APPENDIX 6: Methods used for projects as part of the Participatory action research



APPENDIX 7: Analysis of summer survey descriptors by MontyZoomers

Responses to the request to 'use two to four words to describe why you continue to attend classes and other events'

	Main themes	Differing versions
Benefits: Health & Wellbeing	Wellbeing (be active)	Feeling of wellbeing; Feel better afterwards; Feel rounded; Physical wellbeing; I feel good; It's good
	Health (be active)	Healthy; Beneficial health wise; Maintaining health; General health; Good for health; Maintain health; Sleep well
	Beneficial (be active)	Beneficial x 4
	Relaxing (be active)	Relaxing x 3
Benefit: Being active	Fitness (be active)	Fitness
	Exercise (be active)	Extra exercise; Exercise x 4; Benefits from exercise; Exercise with others; Exercise in a group
	Push limits (take notice)	To push my limits
	Active (be active)	To be active
	Living (be active)	Living
Benefits: Psychosocial	Independence (be active)	Remaining independent
	Socialising (connect)	Like meeting other members; Enjoy social occasions; To socialise; Social gathering; Company; Social contact; Socialising; Social activity; Socialise; Social x 3; Social interaction; Exercise with others; Exercise in a group
	To keep in touch (connect)	To keep in touch
	Friendship (connect)	Friendship x 5
	People (connect)	Lovely people; Friendly people
	Companionship (connect)	Companionship; Company
	Understanding (keep learning)	Understanding
	Fun (connect)	Fun x 2
	Confidence (keep learning)	Increases confidence; Self confidence; Confidence; More confident; Self confidence
	Optimism (keep learning)	Optimism
	Enjoyment (keep learning)	Enjoy; Enjoyment x 2; I enjoy them; I enjoy the classes; Enjoy participation
	Purpose (keep learning)	Purpose; Helpful
Morale (keep learning)	Common morale of the group	

Motivators	Taken	My wife takes me
	Taking	Chauffeur my husband; Keep my spouse company
	Desperate	Desperate
	Essential	Essential
	Change of scene (take notice)	Change of scene
Physical outcomes	Parkinson's symptoms (be active)	Help my Parkinson's symptoms; To counter Parkinson's effects; Prevent acceleration
	Strength (be active)	Keep muscles working; Develop muscle strength; Strengthen muscles
	Mobility (be active)	Exercise keeps me mobile; Improve mobility; Maintain maximum mobility; Helping mobility; Helpful for my mobility; To keep mobile x 2; To improve movement; Movement
	Balance (be active)	Balance; Helping balance; Improve balance; Balance x 2
	Flexibility (be active)	Increases flexibility; Suppleness x 2; Stretch muscles
	Co-ordination (be active)	Improve co-ordination
	Dexterity (be active)	Improve dexterity
	Voice (be active)	Voice loudness
Education	Knowledge (keep learning)	To learn; Meetings are informative; Information from monthly meetings; Very helpful x 2; Useful information; Knowledge regarding Parkinson's; Information; Informative; Awareness; Informative
	Skills (keep learning)	Retain existing skills; Maintain skills; Improve skills; Competence
Support	With other people with Parkinson's (connect)	Mix with other Parkinson's; Contact with Parkinson's; Meeting others with Parkinson's; Comforting to be with people who understand
	Support (connect)	Enjoy ability to support
	Supervision	Excellent supervised; Bhanu; Skills of lead physios
	Encouragement (connect)	Encouragement

<p>Social framework – conceptual model of lived experience of people affected by Parkinson's (MontyZoomers*, 2014)</p> <p>Non-linear (meandering) new model understood by people affected by Parkinson's.</p>	<p>Pre-diagnostic phase</p> <p>Period leading towards diagnosis difficult, with a (long) wait for confirmation.</p> <p>Some not believed; may look on Internet for information.</p> <p>Disconnect between available health service provision and need from people affected by Parkinson's to support them into next phase.</p>	<p>Diagnostic and immediate post-diagnostic experience</p> <p>Paradox in messaging: social support gives hope; clinical message stresses decline</p> <p>This is the time most support needed to counsel family through difficult experience pre-diagnosis, and adjustment up to 2 years post-diagnosis as roles and identity change.</p> <p>Very different for each person. Often better experience with geriatricians compared with neurologists, the latter only offer medication.</p> <p>Better experience still if supported by nurses and Parkinson's UK groups.</p> <p>Little support for mental health; most caters for physical needs.</p>	<p>Elapsing years</p> <p>Noting that life with Parkinson's has ups and down with periods of betterment and sometimes some recovery of lost skills following lapses, especially if due to other medical conditions (whether a spouse or person with Parkinson's).</p> <p>Not always the straight path to decline stated by the medical models.</p> <p>Need relevant support as time elapses, NOT the current system of people with Parkinson's fitting their needs to available services.</p> <p>There is little care of the carers</p>	<p>The future: Holding onto hope</p> <p>Research promises a cure, plus taking part in activity (attitude, behaviour) slows decline, and coping is better.</p> <p>Reduced inclination for most people with Parkinson's to think in terms of future needs. Carers often consider needs more, pre-empting decline. Person with P might consider needs more if they had annual support and built rapport with staff and services.</p>
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*MontyZoomers are a Sheffield-based group of people affected by Parkinson's looking at support needs for members of the Sheffield Branch of Parkinson's UK.

<p>Medical Model – disease staging Hoehn & Yahr (1967)</p>	0: No signs of disease	1: Unilateral disease	2: Bilateral disease without impairment of balance	3: Mild to moderate bilateral disease; some postural instability; capacity for living independent lives	4: Severe disability; still able to walk or stand unassisted	5: Wheelchair bound or bedridden unless aided
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Linear, progressive older model understood by healthcare professionals as still useful for research (hence the numbers) and clinical/ hospital records

<p>Medical model – Clinical staging model – permits more flexibility in experience of health Thomas & MacMahon (1998)</p> <p>More allowance to fluctuate between phases. Expect acceptance of Parkinson's in 'Maintenance' phase. Used more by allied healthcare professionals</p>	<p>Diagnosis / early</p> <p>From first recognition of symptoms/ sign/ problem</p> <p>Diagnosis not established or accepted</p>	<p>Maintenance</p> <p>Established diagnosis of Parkinson's</p> <p>Reconciled to diagnosis</p> <p>No drugs or single drugs, four or less doses/ day</p> <p>1 - 2 drugs but stable medication for >3/12</p> <p>Absence of postural instability</p>	<p>Complex</p> <p>Drugs. > 5 doses or > 2 drugs or parenteral medication</p> <p>Inability to accept diagnosis despite adequate information and education</p> <p>Dyskinesia</p> <p>Neurosurgery considered</p> <p>Psychiatric manifestations – mild symptoms of depression/ anxiety/ hallucinations/ psychosis</p> <p>Autonomic problems</p> <p>Unstable co-morbidities</p> <p>Frequent changes to medication (< 3/12)</p> <p>Significant dysphagia or aspiration</p>	<p>Palliative</p> <p>Inability to tolerate adequate dopaminergic therapy</p> <p>Unsuitable for surgery</p> <p>Advanced co-morbidity (life threatening or disabling)</p>
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APPENDIX 9: Stories of empowerment

Janice Forder's story

A physiotherapy lecturer at SHU who works at the private clinic I have attended since being diagnosed with Parkinson's in 2009, invited me to join the newly formed Service User and Carer Advisory Group (SUCAG), which I did in 2011 [micro and meso levels].

The Approval Panel Meeting for the Revalidation of the Physiotherapy degree was held in March 2014. SUCAG had been involved in Admissions, including shaping assessment criteria to reflect User needs and in work concerning Placements but, perhaps, our most important contribution related to changes proposed by SHU to assessment criteria whereby, inter alia, students who had passed most modules (rather than all) would be allowed to progress. Such was our dismay, that the Course team was emboldened to make a case for exempting the Physiotherapy degree from the proposed compensation rules, lobbying both the Faculty VC and the professional bodies, the HCPC and the CSP. To the team's surprise, exemption was granted. Other degrees successfully followed Physiotherapy's lead [macro level].

SUCAG'S standing increased. Another 'service user' (with Multiple Sclerosis), the SHU lecturer and I attended the CSP conference on 11th October 2014 to present some of the Group's achievements [micro level].

On reflection, my participation in MontyZoomer's validated my right as a PWP to expect a high level of service from Health Care professionals and helped give me the confidence to act if that high level were threatened. It also taught me the power of the *collective voice*.

(Personal correspondence, 24.08.2016)

Pamela Goff's story

Devastated to be diagnosed with Parkinson's, so soon after retiring from a senior NHS management position, I concentrated on my health needs, learning how to manage life with Parkinson's whilst performing roles as wife, mother and main caregiver to my own mother.

Joining the Branch, attending meetings and exercise classes, expanded my *Parkinson's* social circle. I naturally volunteered when Bhanu formed a study group, *using my 'lost' skills to plan fundraising and a Parkinson's Awareness Week exhibition for 2014 [micro level].*

Soon after my diagnosis. I had represented Parkinson's UK, meeting with the Minister for Health and PM to discuss major changes in the NHS [macro level]. Although I offered further involvement, I heard nothing; it felt my presence had been tokenistic, and left me feeling that all my past education, experience and knowledge was for nothing.

The MontyZoomer involvement altered this as I realised that having an understanding of the NHS, I could use my voice to influence service delivery. I accepted invitations *e.g. Sheffield Parkinson's Stakeholder Group; a Pathway group; nurse education sessions; at our Town Hall Exhibition; a learning session at the CCG (the first 'patient' speaker), and presented at the first Regional Excellence Network event [micro, meso and macro levels].*

Of note, Bhanu suggested an invitation onto a steering committee for a SHU research project about service needs. Initially I felt I had little to contribute – until questions for

the draft report were circulated. They were generic, about older people only, with *nothing explicit to living with Parkinson's*. I suggested specific issues, which were acknowledged and included. At last I found my voice [micro].

What now seems obvious to me as I live with P, appears revolutionary to clinicians in the field. My skills have returned, and I am able to converse with managers and clinicians as well as feeling comfortable discussing aspects of care with my MontyZoomer colleagues.

I am now the Chair of the Sheffield Branch and care deeply about the service that pwp in Sheffield receive – NHS or voluntary [micro and macro levels].

(Personal correspondence, 24.08.2016)

Bob Raeburn's story

I was already a keen gym member because of my own experience of exercise benefits for PwP, plus attended classes organised by Bhanu. On becoming an enthusiastic participant in her MontyZoomers study, I gained confidence to think more widely.

At one class I met a frail elderly lady in a wheel chair who showed willing to at least to *pull a Theraband to exercise*. I was so impressed with her 'can-do' attitude and, realising that exercise could benefit all PwP irrespective of their physical state, I became a zealot on the subject. I researched the benefits of exercise and the new knowledge gained together with my own experience led me to write a paper entitled "*Realistic Improvement in Parkinson's through Exercise (R.I.P.E.)*" [micro level]

I approached Bhanu on how best to "spread the word" about the benefits of exercise to PwP – both at the individual and community level [meso level]

We discussed the paper and after editing, issued it widely *across the Parkinson's community*. I sent a copy to the *Parkinson's Foundation, Cure Parkinson's Trust, Parkinson's UK and a number of local branches, plus through my MEP, to the European Parkinson's Site*. I have issued it, through contacts and various Parkinson's websites, all around the globe. Indeed, I was contacted, only last week by a PwP in Queensland who had heard of the paper and wanted a copy [micro, meso and macro levels].

(Personal correspondence, 24.08.2016)

APPENDIX 10: Screenshot of main Sheffield Branch Flickr album

