



English National Ballet, Dance for Parkinson's:

An Investigative Study 2

A report on a three-year mixed methods research study

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English National Ballet

English National Ballet brings world-class classical ballet to the widest possible audience - delighting them with the traditional and inspiring them with the new. We aspire to be the United Kingdom's most exciting and creative ballet company. Under the leadership of Artistic Director, prima ballerina Tamara Rojo, the Company stands for artistic excellence and creativity. We honour the tradition of great classical ballet while embracing change, evolving the art form for future generations and encouraging audiences to deepen their appreciation of it.

English National Ballet, *Dance for Parkinson's*

English National Ballet's (ENB) *Dance for Parkinson's* programme was inspired by the work of Mark Morris Dance Group's *Dance for PD*® in Brooklyn, New York. Since initiating the programme in 2010, ENB's model and approach has been artistically driven, encompassing the practice and repertory of ENB. The ENB *Dance for Parkinson's* programme has also included a structured training programme for practitioners wishing to engage in developing dance for Parkinson's classes, providing a model for practice, professional development and cultural engagement across the country. Since 2012, and with the support of the Paul Hamlyn Foundation, the model has been rolled out nationally through four strategic hub partnerships: Oxford City Council, MDI, DanceEast and National Dance Company Wales.

ENB commissioned a ground-breaking piece of research: English National Ballet, *Dance for Parkinson's: An Investigative Study 1*, to provide evidence of impact on the benefits of dance for people living with Parkinson's led by Dr. Sara Houston and Ashley McGill (MSc), from the University of Roehampton. Dr. Sara Houston was awarded the Bupa Foundation's prestigious Vitality of Life Prize for her ground-breaking research which demonstrated how dance can positively affect well-being, physical movement and social integration for those living with this debilitating condition.





Executive Summary

English National Ballet commissioned University of Roehampton to conduct a second phase of research into the effects of dancing for people with Parkinson's, as seen within its three-year programme, funded by Paul Hamlyn Foundation. Dance sessions were hosted at Markova House, London from 2011 and the programme also included four national hub pilot projects in Oxford (2013), Liverpool (2014), Ipswich (2015) and Cardiff (2015). The research examined the London and national programmes.

The research collected qualitative and quantitative data to understand more about physical, psychological, social, and emotional changes as a result of participation in the programme. The resulting report analyses and documents the findings.

The research study concluded that dancing, as seen within the English National Ballet programme:

- may have a beneficial effect on non-motor symptoms and psychological health
- as a group activity can help encourage feelings of inclusion and positive social interaction, possibly more so than some other activities
- as a group activity can help to promote a sense of community that is meaningful and motivating for individuals with Parkinson's, possibly more so than some other activities
- may have a positive impact on postural stability, possibly more so than some other activities
- aids fluency of movement
- could promote a general sense of body awareness
- could lead to decreased amounts of freezing temporarily
- may help to improve aspects of quality of life that participants felt were important
- may help participants feel that their condition interferes less with aspects of daily life
- may help to provide ways of doing things that participants can use outside of the studio to aid daily life
- helps people with Parkinson's express their personality and communicate
- helps promote a sense of achievement
- may help people feel positive about the future
- could encourage confidence to initiate and take part in activities in their communities
- may promote feelings of freedom from some physical and social constraints of being an individual with Parkinson's
- can energise and motivate participants

1. INTRODUCTION

The report documents research examining English National Ballet's *Dance for Parkinson's* programme, September 2011 – July 2014, with evaluation of the Ipswich and Cardiff hubs in 2015. The research aimed to:

- examine how dancing affects participants physically, socially and mentally
- measure the physiological impact of dancing on participants over long and short periods of time, specifically the effect on dynamic stability, gait patterns, pelvic and thoracic range of motion, posture
- measure the progression of Parkinson's
- evaluate dance as an aid to daily living
- assess the motivation to keep on dancing
- measure balance confidence
- evaluate dance as a contributor to participant quality of life
- assess feelings of self-perception, self-efficacy and certainty for the future
- assess social and cultural participation
- evaluate the success of the hubs
- evaluate how Engagement has realigned to Artistic within English National Ballet

The research develops the ideas from the previous pilot investigation (Houston & McGill, 2011). The study was supported by the Bupa Foundation Vitality for Life Prize, English National Ballet and University of Roehampton.

1.1 PARKINSON'S

Parkinson's is a neurodegenerative disease resulting from the depletion of the chemical dopamine in the basal ganglia of the brain. The lack of dopamine interferes with the ability to initiate movement, to keep movement going, or, contrariwise, to stop moving voluntarily. Parkinson's, therefore, can curtail the implementation of everyday tasks and actions. Symptoms can vary greatly from one person to another. Some of the more common symptoms include:

- tremor
- rigidity or stiffness in muscles
- slowness of movement (bradykinesia)
- a hurried, shuffling walk (festination)
- lack of co-ordination, where an arm or arms stop swinging whilst walking
- 'freezing', where people suddenly cannot move despite wanting to
- change in posture from a more upright, vertical stance to a more stooped and curved line in the thoracic spine
- the voice may become quieter
- facial expression may lessen
- depression is common

Many people with Parkinson's lose balance easily and are at risk of falling regularly. Multi-tasking is often difficult. Neuromuscular tension and pain is common. There are a range of medicines prescribed to ease symptoms or to help other drugs metabolise. Many of these usually need to be taken several times a day and with continued use can become unreliable; many people also experience uncontrollable movement (dyskinesia).

Parkinson's is a progressive, degenerative condition for which there is no cure. The disease does not progress in a linear fashion. Some people may experience periods where they feel more affected by Parkinson's than at other times. Even in a single day people may have 'off' and 'on' periods; 'off' periods being moments where symptoms are much worse than 'on' periods.

1.2 DANCE FOR PARKINSON'S

English National Ballet has become a major provider of dance classes for people living with Parkinson's and professional development for dance artists in the UK wanting to learn more about dance for Parkinson's. In general, dance classes for Parkinson's have grown in number over the last four years, not only in the UK, but also worldwide. Many classes follow the *Dance for PD*[®] model – the inspiration for English National Ballet's programme – and these may be found in 14 countries around the world: Australia, Belgium, Canada, Germany, India, Ireland, Israel, Italy, Mexico, the Netherlands, Portugal, UAE, UK and USA.

English National Ballet was the first large-scale dance company in the UK to offer a specific dance programme for people living with Parkinson's. The Company is an active member of the *Dance for Parkinson's* Network UK, helping to provide a national source of professional development for community dance artists in the UK. The Network is a relatively fast growing confederation of independent dance artists and companies offering dance for Parkinson's classes and training and is housed as a special interest network by People Dancing (formerly the Foundation for Community Dance), the national strategic support organisation for community and participatory dance in the UK.



1.3 THE DANCE FOR PARKINSON'S PROGRAMME

English National Ballet's flagship London class caters for 50 people and taster classes also have been provided frequently and before the start of each hub pilot. It has successfully set up four hub classes in Oxford (2013), Liverpool (2014), Ipswich (2015) and Cardiff (2015) in partnership with local dance organisations, dance artists and musicians. Hub partners are Oxford City Council, MDI (formerly Merseyside Dance Initiative), DanceEast and National Dance Company Wales. The programme includes visits to see the Company perform and behind-the-scenes talks and demonstrations. Alongside the classes and theatre programme, professional development workshops have been provided regionally for dance artists, musicians and allied health professionals. These have taken place in Oxford (2013), Liverpool (2013), Ipswich (2014) and Cardiff (2015).

The programme uses the current Company repertory as a basis for the content each term. Since 2011 the choice of repertory has been diverse encompassing the classics, such as *Swan Lake*, *Sleeping Beauty*, *Raymonda Act 3*, *Le Corsaire*, *Coppélia*, 20th century work, such as *Petite Mort*, *Petrushka*, *Song of a Wayfarer*, *L'Après-Midi d'un Faune*, *Le Jeune Homme et la Mort*, *Études* and new work, such as *Dust*, *No Man's Land*, and *Second Breath* from the Lest We Forget programme.

In addition, there have been other cultural activities that English National Ballet has provided. London participants were invited to private views of two Tate Britain exhibitions with a talk by one of the curators. They also received discounted tickets to watch Mark Morris Dance Group perform at Sadler's Wells. Participants in Cardiff have been invited to performances by National Dance Company Wales and their associate youth programme and Ipswich participants have attended a theatre show directed by their own *Dance for Parkinson's* Associate Musician at Jerwood DanceHouse, DanceEast.

The programme has been strategically directed by English National Ballet's Engagement Director, Fleur Derbyshire-Fox, and facilitated by specialist dance artists and musicians. Administration has been organised centrally from Markova House, London, with support from hub partners.

ENB Associate Dance Artists in London, Danielle Jones and Rebecca Trevitt, have had substantial experience in leading ENB's *Dance for Parkinson's* classes and have received training from *Dance for PD*® in New York as part of the professional development strand of ENB's *Dance for Parkinson's* programme. ENB Associate Musicians Jonathan Petter and Nathan Tinker have contributed as equal artistic and teaching partners to Jones and Trevitt. Jones, Trevitt, Petter and Tinker have all contributed to mentoring hub dance artists and musicians and facilitating the professional development course, as well as supplementary and one-off workshops in higher education settings. Dance Artist Katherine Hartley and musician Nia Williams from the Oxford hub have contributed to facilitating professional development workshops and mentoring. Hartley has received training from *Dance for PD*®, as part of the professional development strand of ENB's *Dance for Parkinson's* programme.

The London and Oxford *Dance for Parkinson's* artistic team were joined in 2014 by Helen Gould and Stephen Mannings from the Liverpool hub, Sarah Lewis and Amy Mallett from Ipswich in 2015 and Yvette Halfhide, Stacey Blythe and Helen Woods from Cardiff in 2015.

The teams hold weekly planning meetings, where they discuss class content, as well as being briefed on individual participants, who, for example, may have been ill. The teams meet up as one group in order to share ideas and to keep the English National Ballet input strong. The teams remain close-knit, reflective groups of practitioners who espouse a strong sense of community arts values and support each other in developing their practice.

All classes have been supported by a team of volunteer helpers. In London, the University of Roehampton has encouraged undergraduate dance students to volunteer each year. The students have been accompanied by other long-term volunteers, including an ex-professional dancer and a dance for Parkinson's teacher. The London class is attended by a Parkinson's UK Information and Support Worker. The hubs have relied on help from local university students and interested people with a dance or allied health background.

In London members of the Company are encouraged to participate, either within the class, or by demonstrating repertory and talking about their roles. In Cardiff, dancers from National Dance Company Wales have become involved by joining in the classes where possible.

The London class has not had to advertise to attract participants. It has attracted more than it can cater for through several features in broadcast, paper and online media. Notable broadcast features include Inside Out BBC1 (16 January 2012), Random Acts Channel 4, (February 2013), *Diversity Live* ITV (4 January 2015).

As new ventures, the hubs have had to advertise widely to attract participants. Several tasters were given, not only at each hub, but also at Parkinson's UK branches and support groups. Information was sent to local neurologists and specialist Parkinson's nurses and advertised more widely by the hub partner and on English National Ballet website and social media.

People with Parkinson's at any stage of disease progression are welcomed, as well as family members and carers.

1.4 THE SESSIONS

The once-weekly sessions in general have followed the same structure. They all last between one and a quarter and one and a half hours during term time. Refreshments are offered afterwards. The first half of the class begins seated, progresses to standing, often at the barre or behind chairs and then to moving across the floor. There is often improvisation at various points and a group dance. During the session, often near the beginning, the musician will lead one or two exercises with the focus either on voice or rhythm.

Although all termly classes are based on the current repertory, there is scope for the artistic team to interpret this in any way they feel would work. This includes encouraging participants to play a greater role in creating ideas, movement and music. Examples of how the teams have interpreted the repertory include:

- Le Corsaire*** The virtuosic circular jump sequence by the slave, made famous by the late choreographer and dancer, Rudolf Nureyev, was adapted as a seated rhythmic clapping sequence.
- Swan Lake*** The Neapolitan Dance was recreated as action in a pizza parlour through rhythm, gesture and clapping sequence with some vocalisation.
- Lest We Forget*** Participants noted what the First World War meant to them and together they created a poem and movements based on these ideas. The poem was put to music to dance to and sing.
- Petite Mort*** The fencing foils used in the work were referred to in exercises using bamboo sticks to extend body movement.
- Sleeping Beauty*** Participants learnt Carabosse's mime.
- Swan Lake*** A group dance in unison based around the swans corps de ballet section and around the arm movements seen in the ballet.

2. THE NATIONAL PROGRAMME

2.1 Adherence

In London there were 55 people on the register by the summer of 2014. Although actual figures of attendance fluctuated over the course of the three years and over the course of each term, the amount of people attending remained stable. Attendance over the course of a term ranged from 25 to 48 people at any one class.

The Oxford pilot figures show an average weekly attendance of 23.2 people.

There was an average weekly attendance of 14.5 people for the 12-week pilot in Liverpool.

The Ipswich pilot figures show an average weekly attendance of 18.5 people.

Cardiff 12-week pilot had an average weekly attendance of 19 people.

Illness is the predominant factor in why people missed classes, followed by holiday and transport problems. As Parkinson's progresses in regular participants, it should be expected that more illness will affect more people. The size of studio is also a factor in how many people can attend.

There was very little evidence of people dropping out of the sessions. For those that did, it was more to do with having difficulty facing others with the condition just after being newly diagnosed, or developing serious illness. Other reasons for not continuing were living too far away to cope with the journey, or moving house. Three people in London and one in Oxford passed away.

Adherence was extremely high across the London and national programmes.

2.2 Theatre Visits

Attendance at theatre visits:

London (2011 – 2014):

<i>Sleeping Beauty</i>	128 people
<i>Ecstasy and Death</i>	53 people
<i>A Tribute to Nureyev</i>	63 people
<i>Le Corsaire</i>	60 people
<i>Lest We Forget</i>	71 people
<i>Coppélia</i>	70 people

Oxford hub participants also joined the London group on many of these visits. They are not included in the above figures.

Oxford (2013):

<i>Sleeping Beauty</i>	43 people
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Liverpool (2014):

<i>Le Corsaire</i>	21 people
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Ipswich (2015):

Nutcracker 26 people

Modern Masters 27 people

Many participants brought one or two guests with them to the theatre trips.

The theatre trips were very well received and participants were very enthusiastic about the wealth of knowledge they had learned both at the theatre and as preparation for the theatre in their dance sessions.

The rehearsal was amazing. You realise even for the best dancers, posture and balance is a work in progress and they work at that for several hours a day.

Exploring the ballet was something new for me that is equally enjoyable, getting knowledge of the ballet and seeing the costumes. It adds to the distinctiveness of the class.

Our trip to Manchester to see a performance of Le Corsaire was a highlight of the whole experience. Being able to see the beautiful costumes up close and listen to the history of the music scores was fantastic. We were looked after the whole day and nothing was too much trouble.

I felt very privileged to be able to go to something like that.

2.3 Hubs

i. Oxford

The Oxford hub was coordinated in partnership with Oxford City Council and its Dance Development Officer, Claire Thompson, and with the city centre venue, the Old Fire Station.

The Old Fire Station has a dance studio, theatre, gallery space and café. Locally based artists Katherine Hartley and Nia Williams were recruited to lead the sessions, with mentoring by London team members. The Oxford hub ran for 12 weeks from February to May 2013. They were introduced to *The Sleeping Beauty* during the classes and taken to the theatre.

Following the popularity of the 12-week project, funding was found to continue the project in the short term. Oxford City Council remain enthusiastic supporters of the programme. Fundraising is happening to continue the programme for the long term. The Parkinson's UK Oxford branch, endorsed raising the subscription to the class and subsidising the fee for anyone who cannot afford it. Two members from the branch, who participate in the dancing, have been key decision makers in supporting the framework to let the classes continue.

ii. Liverpool

The Liverpool hub was set up and delivered in partnership with MDI (formerly Merseyside Dance Initiative), a strategic dance organisation for the north east of England. The 12-week pilot took place from January – April 2014 at MDI's studio in Hope Street, in the centre of Liverpool. Two local artists, Helen Gould and Stephen Mannings, were recruited to deliver the sessions. Programme artists from London and Oxford co-led alongside them for different sessions and mentored them through the process. Participants were introduced to *Le Corsaire* over the 12 weeks and attended two Company performances.

Following the popularity of the sessions, funding was secured to keep the sessions running and fundraising is happening to help the class continue for the long term. MDI was enthusiastic about the outcome of the pilot and is keen to keep the relationship with English National Ballet.

We are thrilled with the numbers for the class...I think people will be really keen to continue and we are very keen to keep the sessions going...On a personal level, I'm really happy to have such a lively, positive and engaged group of people in the studio - it generates a great feeling of energy in me and in the building.

The relationship has had a knock on effect on MDI's other community classes. Rachel Rogers, Project Development Manager at MDI, noted that there is now, for the first time, a waiting list for the community ballet classes.

iii. Ipswich

The Ipswich 12-week pilot was run in conjunction with DanceEast and took place in one of the studios at DanceEast, January – April 2015. Two local artists, Sarah Lewis and Amy Mallett have led the sessions with some input from the London and Oxford programme teams. Participants were introduced to Modern Masters and were taken to London for two theatre trips. The programme is continuing for the near future and fundraising is being explored.

Again, as with MDI, DanceEast were very enthusiastic about hosting the sessions because of what the class brought to the organisation:

It's been a joy to organise because everyone's been so enthusiastic, so involved and involved in it. They don't feel like customers. They feel like part of the DanceEast family.

iv. Cardiff

The Cardiff 12-week pilot, run in conjunction with National Dance Company Wales started in April 2015. Artists Yvette Halfhide and Stacey Blythe were recruited locally with input from the London programme team. Participants were being introduced to the triple bill *Lest We Forget*. English National Ballet was not touring to Cardiff during the pilot, but National Dance Company Wales gave participants and their families the opportunity to see its show at the Wales Millennium Centre, where the *Dance for Parkinson's* sessions took place. The programme



is continuing and the dancers from National Dance Company Wales are very much a part of this when they are able to be there.

The hubs have been a way of embedding high quality *Dance for Parkinson's* practice within four regions of England and Wales. The sense of connection with English National Ballet is strong within each hub, with the high levels of support, enthusiasm and expertise demonstrated at a local level by partner organisations. It has demanded much administrative work, more so than for other community projects, but has been very popular with participants and serves as an excellent model for other touring companies who would like to foster meaningful and sustainable relationships with regional dance organisations, health professionals and with people who would like to dance.

2.4 Continuing Professional Development (CPD) Courses

One CPD two-day course was delivered in conjunction with each hub for dance artists, musicians and allied health professionals in each locality one month before the commencement of the pilot. The courses were very well received by delegates. Most rated the quality of the course as excellent. The workshops were delivered by the London and Oxford *Dance for Parkinson's* artistic teams. They were joined by Houston and McGill, a regional Parkinson's UK Education Officer and for Oxford, Liverpool and Ipswich, a freelance evaluator and facilitator Fern Potter. Evaluation forms were collated and assessed by the Programme team and by Potter.

The team honed the content and delivery of the courses over the three years, evaluating, reflecting and building on the feedback from each. The delegates were enthusiastic, and in the case of Oxford and Liverpool, six months after the course some delegates fed back that they were using the knowledge gained within their own classes.

Delegates not only came from each region, South Wales, Suffolk, Merseyside and Oxfordshire, but further afield around England and Wales and internationally. There was one person who attended in Cardiff who had also attended in Liverpool.

Most were experienced community dance artists and there were a few musicians who attended. In Cardiff nearly half of delegates were physiotherapists and occupational therapists. This indicates that the reach and influence of the workshops increased over the period in question.

An English National Ballet resource pack was produced for delegates and the European Parkinson Disease Association and Parkinson's UK also donated contextual literature.

The Programme team also co-delivered *Dance for Parkinson's* Network UK events. Working with *Dance for PD*[®], independent dance for Parkinson's artists and those from other organisations, English National Ballet contributed to summer schools based at University of Roehampton, London and De Montfort University, Leicester. London participants also took part in the summer school at Roehampton, participating in a demonstration class for delegates. The reach for these summer schools was international.

2.5 *Dance for PD*[®] Training

Three Associate Dance Artists, Jones, Hartley and Trevitt, from ENB *Dance for Parkinson's* programme have received training in New York from *Dance for PD*[®]. Derbyshire-Fox visited David Leventhal in New York in 2011.

[David Leventhal, Dance for PD® Director] is so good at explaining. That was the beauty of the course. It allowed us to go back to the beginning and hear his process. To go back to basics and talk about the philosophy behind why we do what we do with someone with his wealth of experience. Hearing the same feedback from participants [in New York] affirms the value of what we are doing. It was energising. It made me realise all the things I love about dancing that we're awakening in them.

The connection to *Dance for PD®* remains strong. David Leventhal, Director of *Dance for PD®* at Mark Morris Dance Group, visited English National Ballet in 2013 and led a session for the London class. His session was received enthusiastically by both the artistic team and the participants for his style of delivery, the content, and for his charisma as a dancer and facilitator.

I was engrossed in the slick and polish of his movement. I could have just sat there and watched him.

It was amazing how he got us doing West Side Story.

He's alive and vibrant. He's got a dynamic personality, but he also moves so well.

***We really enjoyed having him. It has affected how we've approached this term [Lest We Forget]. We've embraced bits of music outside of the rep.
(Dance for Parkinson's artistic team member)***

For participants, Leventhal's presence brought an exciting dimension to the programme as a dancer and teacher. For the *Dance for Parkinson's* artistic team, his way of delivering movement has influenced how they now think about working within a repertory context and how they might approach movement and music from the repertory in a more flexible way in order to create variety for participants and to push their own creativity in delivering repertory-based work. The programme was able to offer participants discounted tickets to see Mark Morris Dance Group perform at Sadler's Wells as an accompanying benefit.

Dance for PD® is very much still connected with English National Ballet's programme and is appreciated by teachers and participants alike. Leventhal's visit came at a time when new contemporary repertoire was being developed at English National Ballet and introduced into the *Dance for Parkinson's* programme and to the artistic team. His workshop was a catalyst for the team to spark different ways of creating and delivering repertory-based work that is meaningful to participants.

2.6 Volunteers

Volunteers have been important members of the *Dance for Parkinson's* sessions. Not only do they supervise the refreshments, but also help with demonstration and help individuals who might need additional support. One volunteer from the London group now runs her own dance for Parkinson's class and has not only used volunteering at English National Ballet as a basis for her professional development in leading dance for this population, but it was also her inspiration:

Assisting has made me choose to seek out being a teacher myself in order to facilitate classes to bring communities together....I never wanted to teach dance until now. There's a healing that happens. I feel it myself. I feel happy and fulfilled when I leave.

Several Company dancers from Artist to Soloist have attended sessions, many to demonstrate and speak about their role in the current production. Four dancers volunteered at various points over the three years to help out with the class, dancing with participants. In particular, Company Artist, Jennie Harrington, has been a key member of the programme for the whole of the three years. Other staff members from the orchestra, wig and costume departments and archive have given talks and demonstrations for the programme.

Volunteering has been a very rewarding process for many of the volunteers, some of whom have been there since the programme commenced.

I am so happy afterwards. That's why I come. I get an energy all week. I feel I belong to that community as well. To see them at the beginning of class and then how they are at the end, that inspires me to do more.

It's amazing how dance that is my passion can be helpful for other groups of people. I'm grateful that I'm here and I'm learning more how dance can help.

I never thought I'd be a teacher but after these classes I could be a teacher, but not to children but with other people. I would like to go back to Lithuania and create something there.

I don't think there's a better place to be on a Saturday. You get the most feel good factor.

It's a privilege to help. There's an amazing energy and it lifts the whole room.

It was noted by the *Dance for Parkinson's* artistic teams, particularly in the hubs where volunteers were new, that mentoring is vital to develop the confidence, awareness and understanding of what the role of the volunteer entails in this specialist setting and to nurture these skills. All volunteers were provided with a briefing paper and received additional mentoring from the artistic team or more experienced volunteers when needed.

3. THE RESEARCH

The research was conducted by a team from University of Roehampton led by Dr. Sara Houston, with Ashley McGill, Katherine Watkins and Cameron Donald and Professor Raymond Lee. Donald came from Brown University as a summer intern Research Assistant in 2013. McGill has used part of the research as the basis for completing her doctoral thesis.

The research used a mixture of qualitative and quantitative methods and remains the only dance for Parkinson's research to examine the subject from a physiological, social, emotional and artistic perspective. It remains the only study so far to explicitly recognise the importance of the World Health Organisation's (WHO) three levels of social integration: the physical, tasks of daily living and social participation.

The qualitative data was gathered through multiple interviews, focus groups and participant observation over the course of three years. This is the longest running study so far to examine qualitatively the perceptions and experiences of people with Parkinson's dancing giving unique insight into how participants are valuing the dance programme. The quantitative data was gathered through biomechanical measures, clinical rating scales, and questionnaires. A short-term and long-term analysis was then carried out for each measurement. The short-term analysis represents changes over a three-five month time period and the long-term analysis represents changes over a ten-12 month time period.

It was a controlled study that compared the results of those with Parkinson's who did not dance, with those who did. Since the research studied participants over a long period of time, we were able to examine dance's effect on people who had experience of dancing. We were not assessing beginners, apart from participants in Oxford and Liverpool, whose measurements were analysed separately.

Our study is one of a few longitudinal research studies in the field to date with many studies focusing on shorter durations of anywhere between two weeks and six-eight months. We suggest that across the duration of our study, the neurodegeneration that is inherent within Parkinson's has had an affect on the participants, which may not be as visible when looking at shorter-term studies.

3.1 Methods of Collecting Data

Semi-structured interviews

Conducted one-to-one, the interviews were conversations with set and spontaneous open questions. Questions and prompts included 'tell me about yourself', 'how has your week been', 'can you tell me more about those other groups you are involved in', 'tell me about your involvement in your Parkinson's UK support group', 'has your Parkinson's changed at all since we last spoke', 'how did you first get involved with the ENB class', 'why do you go to the classes', 'what did you think of the performance', 'can you talk more about your interests and hobbies'. Participants were allowed to diverge off topic to allow the researcher to get a sense of what interested people and to bring up other points. We interviewed participants several times over the three years. Themes coming through in the interviews were used as a basis for further questioning and theorising.

Focus and discussion groups

Focus groups were held with four-ten participants. There were set questions but participants were encouraged to discuss between themselves to bring out more nuance. Questions were similar to those asked in interviews, but had the added dynamic of discussion between participants.

Discussion groups were held with eight-12 London participants. A theme was set and then the discussion was based around the theme. Themes included community, imagination, is dancing different and watching past research film footage from class.

Diaries written by participants

Participants were encouraged to keep a diary of what they were doing, feeling or thinking during the week. Diaries were very individually structured but formed an important part of gaining insight into the experience of someone with Parkinson's who dances.

Unified Parkinson's Disease Rating Scale (UPDRS)

The Movement Disorder Society's Unified Parkinson's Disease Rating Scale (MDS-UPDRS) is a valid, reliable measurement that has been used in multiple studies dealing with this particular population. It is a 4-part scale looking at non-motor and motor symptoms that people with Parkinson's may experience. The individual administering the scale rates the severity of each symptom and changes are then noted across time to help determine progression of the condition (Goetz et al., 2008)..

Activities-Specific Balance Confidence Questionnaire (ABC scale)

The Activities-Specific Balance Confidence Scale (UK version) is a 16-item scale asking participants to rate how confident they feel at attempting various tasks that require some level of stability to complete, for instance, 'how confident are you that you can pick up something off the floor without losing balance'. The scale gave us an indication of participants' balance confidence in multiple everyday situations and was also compared to other stability measures (Powell & Myers, 1995; Parry et al., 2011).

***Dance for Parkinson's* Questionnaire**

The *Dance for Parkinson's* Questionnaire was created by Cynthia McRae, University of Denver and Robert Rubin, UCLA, in 2011. It is a 10-part scale compiled from a number of different validated questionnaires used to measure various symptom and quality of life issues for people with Parkinson's. These were the SF-36 (Ware and Sherbourne, 1992), UPDRS (Montgomery et al. 1994), Hoehn & Yahr scale (Hoehn & Yahr, 1967), Bandura & Lorig self-efficacy scale (Bandura, 2006; Lorig et al, 2001), free or restricted and quality of life global items found in several PD studies (McRae et al., 2004), Center for Epidemiologic Studies Depression Scale (Radloff, 1977), Intrusiveness in Illness scale (Devins et al., 2010), and the dance questionnaire by Quigora et al., 2010. It is a self-administered scale and participants had to comment on how they felt at their worst.

Health and falls information sheet

The participant health and information sheet asked about any other medical conditions that had arisen since participants were last seen for testing, number of falls since the last testing session, any changes to medications and in the first instance a full list of medications, general physical activity levels and any other activities they were taking part in. This information was then logged and noted when looking at other results. We did not ask participants to change or avoid taking certain medications or ask them to not take part in other physical activities. We simply recorded what was happening so that we could help explain the results at a later time.

Inertial sensors

Parkinsonian gait is characterised by a smaller step/stride length, increased time in double stance, decreased walking velocity, and instability with greater variability. This along with the fact that people with Parkinson's often find they have decreased clearance of the swinging leg from the floor can put them at risk of falling during dynamic situations. As a result, this study looked specifically at step/stride variability and the relationship between movement in the pelvis and thorax during gait, as these variables can provide an indication of the participants' dynamic stability, rigidity, and coordination during a walk. To look at these variables we used two inertial sensors placed on the back of the participant and secured with tape. Sensor one was located at S2 and sensor two was located at T1 along the spine. These sensors wirelessly sent information to a receiving box attached to a computer. Linear acceleration, angular displacement, and angular velocity data were gathered at a rate of 180Hz and this allowed for analysis of the variables described above. This method has previously been noted as a scientifically acceptable and robust assessment of gait variability and balance during walking (Brach et al., 2011; Esser et al., 2011; Moe-Nilssen & Helbostad, 2004).

Attendance record

Registers were taken for every class and these were tracked to look at adherence.

Participant observation

Some of the research team regularly attended sessions and theatre visits in order to immerse themselves within the *Dance for Parkinson's* group. A useful ethnographic tool, participant observation allows for the researcher to examine the sessions minutely and to engender trust between researchers and participants. Participant observation also allowed researchers to observe behaviours and reactions within the dance settings.

Filming

All classes attended by the researchers were filmed with two flip cameras on tripods.

Non-structured conversations with dance participants

As part of participant-observation researchers engaged in conversation where there was no particular question to be answered. This was useful in allowing participants to bring up anything that might not be brought up in an interview situation.

Reflective discussion with the *Dance for Parkinson's* artistic team and with Company staff and dancers

Houston led discussion with the *Dance for Parkinson's* artistic team on a regular basis. Intended to be reflective, observations and ideas were discussed as a way of keeping abreast of ideas, events, issues and changes and to offer observations and promote dialogue, as well as to gain insight into the experience of the facilitators. Discussions have centred on:

- how individual participants were coping with the class
- challenges and opportunities offered by the repertory, movement and music
- support for participants within the class setting
- coping with team absences
- logistical challenges and opportunities organising the other cultural activities, such as the visits to the theatre
- the challenges and strengths of administering the programme in London, as well as across the hubs

3.2 Participation in the Research Study

Participation in the research was voluntary and ethical clearance was gained from University of Roehampton Ethics Committee. With respect to quantitative measures, 24 people from the dance class in London were included in the final analysis for this report. A total of 27 people took part in these measures throughout the duration of the study but three were removed from analysis completely (one participant moved abroad, one participant did not feel well enough to continue attending, and one participant was not able to attend enough testing sessions). A total of 15 people were recruited for the control group, with the final control participant recruited in autumn 2013 (two years into the study). Because two measurements used electro-magnetic devices, those with Deep Brain Stimulation (DBS) were advised not to take part in the inertial sensor measurements. For these measurements there were fewer dance participants and controls taking part.

A total of 30 dance participants from London, 17 from Oxford, six from Liverpool took part in the qualitative research for the report.

The majority of participants were aged between 60 and 80.

4. RESEARCH RESULTS

4.1 Quantitative Data

The quantitative measurements consist of all gait measures, the Unified Parkinson's Disease Rating Scale, the Activities-Specific Balance Confidence scale, and the *Dance for Parkinson's* questionnaire. Descriptive statistics including mean changes and standard deviations have been calculated for the following report. Overall the results from the quantitative measurements show that there were no demonstrable changes for dancing or control groups which were of clinical significance for these aforementioned measures. These results are contrasted with the qualitative analysis where significant psychological, emotional, and social benefits are noted for the dancing participants.

The nature of the disorder with fluctuating clinical conditions led to high variability in the data. Furthermore, as researchers made a conscious decision to not interfere with participants' medication plans, we were seeing the participants at varying stages of their daily condition. The present study looked at the effects of a weekly ballet class for people with Parkinson's. While some quantitative measurements did not show significant change, it is unknown what the results would show with an increased frequency of classes per week.

4.2 Qualitative Data

Results were collated across the whole three years and the experiences of participants from London, Oxford, Liverpool and Ipswich are included in the anonymised documentation. Results show participant perceptions about their experience on the programme and about themselves and their Parkinson's. Results point to an experience that clearly has affected participants, often at a profound level, despite lack of change shown in the objective measures.

4.3 Triangulation of Results

The different methods of collecting data were chosen to allow the research team to triangulate results. Triangulation means cross-referencing one set of results from one method of data gathering with another. It enables the team to be more certain of the accuracy of results and gives a more rounded picture of what is going on.

Our results from all methods of data collection are presented below. They are set out triangulated and grouped in the areas that the results highlighted.

4.3.1 Fluency of Movement

Many participants have made note of a change in fluency of movement, not only for themselves but also when watching other participants in the dance class. Fluency can be defined as a smooth and controlled transition between actions, performed with seeming ease. Fluency may also be associated with fluid coordination of the body.

E. noted improvements in the coordination of his arms and legs during walking, although his dynamic stability was still not as strong with frequent stumbles and falls. His improvements

in coordination and fluency are consistent with observational findings so far. Many people (participants, carers, instructors, and researchers) perceive that walking is improving at least for the duration of the class. For example, two diary entries noted the change in another fellow participant, who was, arguably, the most disabled person in the class:

What's really struck me during the last two weeks is the fluidity. The real one is C. Last week he walked unattended. This week his strides were so big.

C., who had started back at the 'taster' session in a wheelchair and was helped out for a brief while, also managed a 'stride' across the room. Initially he had started by shuffling, but in his final turn he managed to put one foot in front of the other, with his helper walking alongside with just a hand under one elbow to keep him steady. We were nearly all in tears. It was very moving – almost like a miracle.

Although C's movement may not have been typically fluid, based on a normative perception of fluency, the improvement in how he was managing to stride down the room was so marked that other participants related to this as fluency.

Researchers also have noted this change in fluency and increased coordination when participants have been walking to a strong rhythm or pulse. However, it is interesting to note that some participants still perceive stability issues may be present even when arm and leg coordination has improved.

Interviews with participants demonstrate the common perception that music helps people to move in a more fluid and coordinated fashion. Some participants brought forward thoughts and questions about whether music acts as an auditory cue that is encouraging movement at a more automatic or unconscious level. In this way the participants are not having to concentrate too heavily on specific actions, but can allow the body to respond to what the music is suggesting. In doing so, we suggest that there could be an increasing ease and fluidity of movement.

The music seems to be a particularly important impetus when an individual is trying to initiate movement. The researchers have observed the dance artists and volunteers helping participants out of a freeze by singing a song or humming a tune, a tool that continues to work well for many people.

The dance made me feel more graceful, moving and flowing with the music, it made me feel that I had to move when the music started.

It is such good exercise, fun, and companionable, and the music enhances it. Really helps the coordination between movements combined with speaking, and helps mentally too.

It does show how important music is. We take it for granted that we've got the piano, but it really does help. Having it live seems to matter even more.

And it wouldn't be as good if it were a CD because the music comes when we need it, at the right point in the music, and it's the right speed, and everything else. It's fabulous, such a luxury. Well no, it's essential.

Music can be good with a CD, but it's not as sensitive as live music.

Music carries you on.

The comments also indicate how much they appreciate having live music to dance to. Musicians are able to alter tempo, pulse, quality and time signature in order to help dancers keep momentum and coordination.

In addition, researchers and participants have observed a more fluid sense of movement when participants are directing their focus and carrying out movement sequences with clear intention and purpose behind the actions.

Jon is teaching us how beats fit into bars to make different rhythms. It's all very thorough. We clap and tap the rhythms, getting them into our bodies as well as into our minds. Our bodies, of course, behave less precisely as the Parkinson's progresses and this feels like a way of fighting that progression.

Some discussion groups were shown extracts of research film footage from various classes. The following responses after watching fellow dancers on film illustrate how fluency of movement can be observed:

I am struck by the fact that I am not aware that anyone has Parkinson's. No one is struggling with illness, shaking in anyway.

They are quite fluid movements. Your movements are fluid R!

It looks as if we're supposed to be doing that. We're not lost anywhere.

It's interesting to see us move. I didn't realise how different we move. We do get it in walking, but there's just as big a difference in that [improvisation task] as well.

It looks slick, really good.

4.3.2 Balance and Stability

Stability has been assessed in multiple different ways in previous research. Many studies to date in the dance for Parkinson's field use clinical rating scales such as the Berg Balance Scale and the Fullerton Advanced Balance (FAB) Scale. In the pilot research study the FAB scale was used to assess changes to static and dynamic balance across a 12-week dance intervention and positive changes were noted (a total of six people were included in this pilot study result).

For the second phase of the research we decided to use methods based on work by Moe-Nilssen (1998) to assess balance during walking as it seems many of the issues around stumbles and falls happen when people are in motion. Furthermore, results from the pilot research study saw that participants were learning tools to help them carry out specific tasks within the FAB scale with more ease and efficiency. Questions then arose of whether these measurements were actually assessing changes to dynamic balance overall, or whether participants were simply becoming more efficient at carrying out those specific tasks.

Variability of accelerations of the centre of mass were assessed to understand changes to participants' walking patterns. With respect to this variable, the more consistent the gait rhythm, the more stable the individual is during walking. There were no demonstrable differences with respect to balance during walking across the duration of the study for dancing or control groups. However, many participants noted in interviews and focus group discussions that while they were not sure if or how their balance had improved, they felt that the



coordination of their arms and legs during walking had improved. This will be discussed later in the report.

When looking at the gait variability results in relation to perceived balance confidence as measured by the Activities-Specific Balance Confidence (ABC) scale, the results present a similar story with no demonstrable differences of clinical significance across the duration of the study.

Myers et al. (1998) suggests that an ABC total score between 50% and 80% is reflective of a moderate level of physical functioning whereas a score below 50% is indicative of a low level of physical functioning. When looking at the dancing participants, the group as a whole were within the 50% to 80% range, as were the control group. Both groups then stayed within this range throughout the duration of the study.

Lajoie and Gallagher (2004) suggest that an ABC score below 67% may indicate a higher risk of falls for older adults and is a predictor of future falls. When analysed as a group the control participants began the study at a confidence level slightly above 67% and fell lower in this range thus putting them at a higher fall risk, whereas the dancing group began the study above a 67% confidence level and remained above this value throughout.

Balance and stability were assessed in multiple other ways throughout this research study. Within part 3 of the UPDRS (also termed the motor subscale), postural stability is assessed by the administrator and rated on a 5-point scale with a higher score indicating more problems with stability. Within part 2 of the UPDRS (a participant questionnaire asking about ease of everyday activities), participants are asked if over the past week, they have usually had problems with walking and balance. Furthermore, within the *Dance for Parkinson's* questionnaire, section 3 asks about severity of symptoms, such as imbalance and problems with gait, when participants are feeling at their worst. We thought it would be useful to pull out these specific questions to take a deeper look at what is potentially happening with respect to postural stability and perceptions of stability.

When looking at postural stability as assessed through the UPDRS motor subscale, the dancing group showed stronger improvements in comparison to the control group. When looking at perceived changes to walking and balance as rated by the participants in part 2 of the UDPRS as well as perceived problems with imbalance in the *Dance for Parkinson's* questionnaire, there were no observable differences for either group across the duration of the study.

It is interesting to note the difference between results when looking at postural stability, as rated within the UPDRS, in relation to other biomechanical measures of stability during walking. It is possible that these two measures are accessing different information about balance and stability for the individual. While the postural stability task asks people to re-stabilise after

being placed off balance in more of a static situation, the gait variability measures are looking at consistency of step and stride pattern as an indication of dynamic stability.

The above results are particularly interesting when triangulating these quantitative measures to other qualitative accounts of perceived changes to balance and stability. Results from interviews and focus group discussions suggest that participants feel the dancing may be doing them some good in relation to balance and gait, though the specifics of what is exactly happening are difficult to verbalise and pin down.

I suffer from balance problems. I think it [dancing] is ideal for me. I've noticed a difference. It's improved but not disappeared.

I do have problems with balance and coordination and I do feel better for it although I can't pinpoint why.

It helps with balance, gait. When we dance it's not too bad is it?

In interviews and focus group discussions there has been mention of an improved sense of body awareness both inside and outside of the dance studio with participants also noting a lack of freezing, which is often a direct cause of falls for this population.

We don't look as if we have Parkinson's. C. looks so strong! M. has no hesitation and no one is freezing.

I get a bit of freezing in movement but I feel I'm less freezing when I come to class. I don't freeze here and when I go back home I don't freeze as often that day.

The strange thing I find, is my freezing movement has very much reduced. I don't freeze here and at home it's much reduced for at least two days after. If I keep moving a little bit it keeps the momentum going again.

Researchers observed few incidents of freezing, despite several participants in each dance class claiming to have freezing as one of their symptoms.

4.3.3 Posture

A few comments from dancing participants, helps to bring forward ideas about posture in relation to dance and the difficulties they face in maintaining posture outside of the dance class in order to cause permanent change:

There was a strong emphasis on posture (corsets and armour) and this feels like a good basis for all exercise. I am sure we all benefited from this within the class, but old habits die hard at home. I am conscious that maintenance of posture is so important for PD subjects and Danielle and Kate presented examples of posture that made a positive imprint on the mind (even the tiniest movement was undertaken with grace and poise). I am sure that dance must be effective in the long term in improving confidence and maintaining posture. Ballet involves taking on roles, such as courageous princes that bring about a sense of confidence - and for a while you think you are walking tall and proud even if a glimpse in the mirror betrays you (or perhaps encourages you).

I think when I go off and I remember to walk so tall, and keep my head up, and swing my arms, just to do movement, and if I think I go dancing and sit up straight, and shoulders back, head up, it's a great image to hold on to.

My daughter comes to class. We're walking along the street and she says, 'come on: corset!' That's quite valuable.

These participant comments discuss the principle of maintaining an upright posture that is inherent within a ballet class and can be incredibly useful for this population. However, they also remind us that the postural work does not stop when the dance class finishes. Images brought forward in the dance class may be of use to them outside of the studio, so that they can continue to strengthen the appropriate muscles to cause more permanent adaptations.

4.3.4 Progression of Parkinson's

Recent research has questioned whether dancing has the potential to slow the progression of Parkinson's. In order to look at this more closely in the second phase of the research, we used the UPDRS rating scale along with a newly developed *Dance for Parkinson's* questionnaire.



As mentioned earlier, part 3 of the UPDRS focuses on a motor subscale that assesses severity of symptoms, thus providing an indication of stage and progression of Parkinson's. Part 4 of the UPDRS focuses on other motor complications such as dyskinesia, motor fluctuations, and dystonia.

There were no observable changes of clinical significance in the dancing or control group with regards to the motor subscale scores or motor complication scores across the duration of the study and this result correlates with the lack of demonstrable change seen in the Hoehn and Yahr (H&Y) score. The H&Y scale is commonly used to assess severity of condition and stage of Parkinson's. This scale is included as a separate score within the UPDRS outside of the motor subscale.

Many participants in both dancing and control groups were taking part in other activities outside of the dance class such as Tai Chi, Pilates, exercise classes, physiotherapy, rowing and swimming. The results above suggest that the dancing was not necessarily helping to slow the progression of Parkinson's more effectively than other activities

Section 3 of the *Dance for Parkinson's* questionnaire also asks participants about perceived severity of symptoms when they are feeling at their worst. Supporting the results above, findings show no observable changes across the duration of the study.

Interviews and focus group discussions show that participants have an improved sense of physical health.

I didn't realise that my neck and shoulders had got so stiff. I realise they're looser. I'm also stronger. I can now push a wheelbarrow across the garden now.

It's clearly done me good. The warm up is tremendous and I feel the benefit, no doubt.

However, multiple participants note that the physical changes may not be as obvious or distinctive as the mental benefits. As noted in the balance section, when asked about changes to physical symptoms, particularly balance and other physical fitness components, participants felt that the dancing must be doing them good, but specific perceived changes were not described.

Having been to classes...for three years I have found them extremely helpful. Hard pushed to say how or why.

Several described the general feeling of being energised, rather than more specific physical changes:

It's not just I'm in the mood, but physically I feel different. I don't think about it all the time, but suddenly I realise how much better I feel. More movement, more energy, certainly more energised....I want to stay positive and not think about Parkinson's.

Prospect of going back in to Oxford for the Dance for Parkinson's session at the Old Fire Station didn't seem appealing as I left. W. didn't want to come with me, and I felt a bit wan. But as soon as I'd negotiated the Park and Ride and got to the studio, and met everybody again, I thoroughly revived and enjoyed it (also the 'focus group' afterwards) and then I realised how much I enjoyed getting out of the house and meeting friends. Amazing how energetic "port de bras" is and marching up and down gets the blood going round. Then I was reluctant to go home!

Moreover, some participants made note of the fact that they do not attend the dance classes thinking about how the exercises will be doing them good. Several use the dance classes for reasons other than getting a good physical workout, such as expression of personality, social factors, or keeping the brain active.

In this way participants may sense an improved physical health that is not solely based upon changes to severity of motor symptoms and complications, but rather includes other factors that are important to them as individuals.

4.3.5 Cognitive Functioning

As discussed above, multiple participants in interviews and focus group discussions have made note of how the dance classes are mentally challenging. Some participants suggest that it is quite literally exercise for the brain as well as the entire neuromuscular system. It appears that some participants find the dance classes to be quite difficult with respect to remembering the movement sequences and being able to move different parts of the body simultaneously.

Particularly coordination with legs and arms needs lots of concentration.

I find it really difficult to learn because they are quite quick in framing what we are going to do next. Its coordination, and memory and detail-orientatedness.

With regards to psychological health, the main themes drawn from interviews and focus group discussions include an improved sense of self-esteem and confidence, a strong sense of a bonded community that is both meaningful to the participants and a key motivator to attend the sessions, a sense of achievement, and feelings of encouragement and support in a safe environment. These aspects are highlighted below, for instance, in Sections 4.3.8 and 4.3.10.

Part 1 of the UPDRS focuses on changes to cognitive functioning and non-motor aspects of experiences of daily living such as feelings of depression, apathy, and anxiety. In light of comments made above it is interesting to note that the dancing participants saw stronger trends towards improvement in this area with controls trending towards a decline.

These results help to strengthen points brought forward by participants in interviews and group discussions about dance helping to aid mental activity. These results also help to support comments made by participants that the dance classes are helping them to stay motivated and maintain, or improve, other non-motor aspects of daily life.

I do think it is good for you. The whole mental activity is on a different plane from physical activity.

I knew it was physically demanding, I was hoping that it would be, but I had forgotten that it was also taxing on the memory and that is what is brilliant. Having to remember the next step as well as doing the bit before that is very difficult, its good training really. And doing two things together. And of course we all came today for the cake.

The exercise is beneficial doing movements we wouldn't normally do. It's not like anything else I've ever done. Mentally it's liberating and refreshing.

It's the combination of movements, something which reactivates our brains.

4.3.6 Quality of Life

The *Dance for Parkinson's* questionnaire asks participants to rate their quality of life at the present time on a 5-point scale with the lower score showing a better quality of life. There were no observable changes of clinical significance for either group across the duration of the study.

Participants were asked what was important to them personally in maintaining a good quality of life. Their answers can be categorised into five separate areas:

- having confidence to do things
- having the ability to keep doing interesting activities
- having movement capability and stability
- being around loved ones
- having a religious belief

Given the physical results and progression of Parkinson's it is not surprising that both dance participants and controls were not seeing a large change in quality of life over the period of the research, given the importance attached to movement capability and stability. The ability of the dance participants to see slightly less difficulty than the controls in this area, however, suggests that the more positive results of non-motor aspects of daily living might be a factor.

4.3.7 Aid to Daily Life

As mentioned earlier in the report, part 2 of the UPDRS scale is a participant questionnaire that asks about ease of everyday activities such as bathing, walking, and eating. Section 2 of the *Dance for Parkinson's* questionnaire also asks about activities of daily living when participants are feeling at their worst. Both scales demonstrated no observable changes for either group with respect to activities of daily living in a usual week, or when feeling at their worst.

Despite these results, some dance participants noted in interviews that dance movement was helping them with specific challenges. A dancing participant makes note of how he uses an exercise from class to help alleviate rigidity and pain and improve mobility for everyday activities:

It is typically a matter of identifying the right exercises on each occasion to alleviate the various neuro-muscular afflictions. For my shoulder I noted during the classes that the 'lasso, arrow and sword' provided some temporary relief – so, I used a similar routine at home to improve mobility and it seems to work better than anything else I have tried (e.g. stretching and strengthening).

Moreover, although people may have been experiencing difficulties with tasks, such as bathing and dressing over the long period, these challenges did not stop them participating in other activities. While some of these activities commenced prior to the start of the project, others attempted new activities throughout the course of the study. For example, a group of participants started up their own choir. It appears that the dancing may have been helping to nurture both an active lifestyle, as well as continued positive social interaction despite difficulties with everyday tasks.

4.3.8 Motivation to keep coming to the English National Ballet *Dance for Parkinson's* programme

Given that people's Parkinson's progressed gradually in general over the three years, it is useful to explore why people kept attending the programme regularly.

The motivations people had to attend a dance class and to be a regular member of the *Dance for Parkinson's* programme were diverse. From the discussion in interviews and focus groups, as well as diaries, they can be categorised into nine separate areas of motivation. Together, they give insight into why people with Parkinson's dance, as well as why English National Ballet's programme has been so successful.

i. Inclusion and Community

The community being created through the dance programme has been increasingly important to participants. Parkinson's is a condition where social isolation can be a consequence. Dance participants have been keen to stress the importance of the programme as a place where they feel valued and where they feel they can make friends. Part of the success of creating a sense of community lay in the inclusivity fostered within the teaching methods and within the programme as a whole.

I didn't know anyone with Parkinson's before I came to these classes. I was all alone. It's not just about dancing, it's making friends and sharing.

No one feels we're a nuisance here.

I come here and feel that I can shake at will and not worry about it...I come here and feel relaxed.

For me, the chance to spend quality time with my Mum and seeing her animated and enjoying the time at the studio are memories I will cherish. We have spent so much time over the past few years at hospitals and clinics. The Parkinson's Dance has given us the chance to share some special time together.

You think you are all alone with this situation but this dancing makes you realise you're not.

One of the chief pleasures of this course has been interacting with other people who have Parkinson's in a happy, easy-going atmosphere where we all have Parkinson's (of varying degrees) in common.

H. and I both spoke about how impressed we were with the sustained high standard achieved through the tutors. It is a very inclusive environment, support when needed is provided in an unobtrusive fashion. There is a very distinct sense of achievement throughout the group. We all comment on the comparison with the exercises that we achieve now as opposed to when we first started.

The vocal training was an excellent inclusion re control of muscles when producing vowel sounds. Also, the 'audience' was also taken into account by linking with the Liverpool dialect.

I chatted at length with two other members of the group, in particular, today. I found it interesting to get to know them more and hear about aspects of their lives which were not dominated by 'Parkinson's Disease', like past employment. We all seemed to enjoy simply having a 'normal conversation.

In addition, Nicolas Ephgrave, Information and Support Worker for Parkinson's UK, who attends the London dance sessions, has seen a difference in how the dancers relate to each other in the Parkinson's UK support group that many of them attend:

Some people may see each other at a monthly support group and say hello, but because of the intimacy of dance, real friendships have developed, more so than with any other support group I'm involved with.

Ephgrave's observation tallies with pilot study interviews that when the group started dancing they did not socialise at their Parkinson's support group in the same way and to the same extent as they did at English National Ballet.

ii. Group Motivation and Bonding

The classes continue to be a way of motivating people to move in a supportive group environment and to socialise.

I'm enjoying it immensely. I like the sensation of moving as a large number, encouraging each other. Group motivation is important.

I need someone to give me a cue. I can only do it with them.

Sometimes I think I'm so comfy at home that I don't want to make the effort to go out, or I feel miserable and dread going out. But without exception, when I have made the effort to get there I'm so glad I did, and being amongst everyone else is a great lift, and I arrive back home feeling really energised. It isn't nearly so much fun doing exercises by oneself. It doesn't re-energise you being on your own.

[Parkinson's] makes you want to give up but this [the ballet] make you want to do things.

It's a big step for me to go to a place where I'm defined by Parkinson's. It's a good thing for me at this stage. It's emotional. I feel quite moved.

My attitude towards myself has changed. This is so welcoming and a non-judgemental sort of atmosphere of welcoming and acceptance, me learning and possibilities. Here we are crooked and falling over and we're allowed to do it.

The chance to talk with people going through the same thing was invaluable. It helped people to bond and we became a good group.

iii. Expression

Much ability to express is lost with the progression of Parkinson's. People can lose expression in their faces, in their voices and in their movement. Added to this is often less opportunity to express themselves through, for example, a lessening of social engagements or an inhibition to move in the way that might highlight Parkinsonian symptoms.

I enjoy moving in a balletic way. - I'd call it that, no one else would. - It's a need to express myself.

I get the chance to express myself that otherwise I wouldn't get the opportunity to do. I wouldn't go to a club and I wouldn't be able to go to ballroom as I'd feel too self-conscious. It's very important to be able to express oneself.

I find it liberating. I can make a fool of myself and no one cares.

iv. Quality

Participants have been very clear about the high quality of the provision at English National Ballet and the specialness that the feeling of belonging to the organisation engenders.

I think it's excellent.

The people running class are very, very good, excellent.

The music is vastly superior and the level of tuition is brilliant.

By coming here it's a bit like going to play at Wembley. It's so special. It's like going out on pitch and training at Wembley.

You just feel so cared for.

They [staff] are so loving and caring. By example they teach us to be loving and caring with each other.

Danielle, Becky, Fleur, Sara, the music boys, and all the ENB team, were so welcoming and friendly and made us feel as though it was an honour to have us there. So many smiles. It was lovely.

I don't feel dumbed down. I want to know ballet etiquette. It feels respectful to us.

It is hard to choose my favourite part of the afternoon, but I think it's the anticipation, like Christmas Eve, getting there early and watching the musicians and dancers practising, the magic being planned, the lesson about to start. It is such a privilege to be so near them and watch and listen and learn.

v. Uniqueness

Participants are very motivated to come because of the uniqueness of the class. Its uniqueness is partly due to English National Ballet's brand and partly because of what ballet gives which is distinct from other physical activities. So although we suggest that dancing once a week does not give a more substantial physical workout than any other activity, there are other factors that promote the dance programme as a worthwhile activity for participants.

It's expressing mood, feeling and interpreting and has an interesting subject matter that we wouldn't ever otherwise experience.

English National Ballet have welcomed us in and want us here. That's quite unique. It's friendly.

People here don't have barriers whether male, female, tall, short. You don't get that in society generally.

You get a sense of occasion coming to this venue. It heightens the experience... it's so uplifting for me.

Everyone's fascinated that I'm training with English National Ballet. It gives us a tremendous boost.

With ballet specifically, you are entering into an imaginative world.

To have the opportunity to be taught by a ballet company is just for me – I wasn't going to go because I thought it's such an effort and I'm broke, but it's really an opportunity not to miss.

vi. Intellectual and Physical Challenge

Many saw the classes as a way of challenging themselves positively to stay physically and mentally alert. There was a strong belief that going regularly to the classes was helping them to stay as fit as they could and to give them confidence to keep moving. As suggested in Section 4.3.5 the intellectual challenge of the class was particularly welcome.

It's been a good term. They've been pushing us harder. It's more challenging and I can feel it more. I've got more stretch. Since starting dancing I can run a bit, running is easier than walking.

This has been my life line. It has kept me moving. I went to a Cabaret last night. There was lots of dancing and I got up and danced. I wouldn't have done that 18–6 months ago.

The best kind of exercises are those that make us speak (or shout or whatever) as we are moving. If Parkinson's is a brain and movement disorder, organising specific movements to specific words really reveals itself as one of the problems, and it's great to keep trying to get it right – I find it ridiculously difficult! (Patting the head and rubbing tummy syndrome??)

vii. Feeling Good and Feeling Capable

According to participants they gained a sense of feeling good about themselves and a feeling of being more capable, despite some worsening of symptoms. It is clear that these comments are about feelings developed during the dance sessions themselves, rather than as a general feeling of capability and well-being outside of the sessions. We suggest that the dance sessions became places and times where people could feel good about themselves even if they had had a difficult week.

Now I'm doing this I feel so capable.

I watch all the waltzing and tango on Strictly Come Dancing and I feel sad because I can't do that anymore, but coming here, I'm still a dancer, I still feel able.

It gives you a sense of elegance.

I feel graceful, yes graceful when moving. So often you do actions clumsily and now you aren't. It's a welcome change.

I love the room. It makes a difference. Coming here makes me feel good.

As our disease progresses we are gaining skills.

viii. Dance Education

Many participants wanted to learn more about dance and about ballet as a theatre art. It is significant that some people attended who did not attend Parkinson's Support Groups. They felt they did not feel ready to do this, but they felt that the dance programme would allow them to take part in an activity that was tailor made for them, but without the emphasis on Parkinson's, so apparent in the support groups.

The classes have broadened my cultural understanding.

I'm really enjoying learning about the technical side of ballet.

The focus of the activity is on art, not on Parkinson's. I don't think about Parkinson's from beginning to end. I don't think 'this is good for me' while I'm doing steps, I don't think I'm doing steps for my Parkinson's.

I had gained an appreciation from the D4P classes that various moves and postures have meaning in ballet.

I have learnt about ballet in general and attended performances for the first time in my life.

I enjoyed the performance very much. And I think I got more from it from even the little bit we did in class here, so that you could look for the mime and things, so I knew why that bit meant something. I felt a bit clever.

It certainly is very illuminating isn't it? Seeing the ballet movers do the dance and do the movements, it has given me insight into stuff that I never thought of, that I never realised.

ix. Music

As pointed out in Section 4.3.1, music is a key element of English National Ballet's programme and it was an important factor in motivating people to attend. Participants identified music as being a special element that distinguished the dance sessions from other activities (some of which provide recorded music). Although in Section 4.3.1 music was identified as a possible aid to fluency of movement, many more participants highlighted the emotional and uplifting aspect of ballet music as a motivating factor

It unites mind, body and soul, unlike anything. I play squash and workout in the gym. With music it makes it into something else.

The music cheers me up and allows me to go further. It's not like any other group I attend.

Music was brilliant and very motivating.

I do think the music is parallel. There's an emotional dimension to it.

The first time I walked in, the pianist was tinkling the ivories and it lifted my spirit.

When we had the first session of the Rite of Spring and there were two pianists playing it was so exciting. I felt this term is going to be magic and it was.

4.3.9 Certainty about the Future

Part 6 of the *Dance for Parkinson's* questionnaire looks at how certain participants feel about their future life with respect to maintaining social relationships, having hope for the future, continuing to learn new things and developing self-confidence.

With respect to this subsection of the questionnaire participants in the dancing group saw trends towards an improved certainty about future life, while the controls saw a trend towards a decreased certainty in the long term.

These results are supported by multiple comments in interviews, focus groups and diaries from participants about their experiences of dance in relation to certainty about the future.

The quotations below have been categorised into the various subsections seen in part 6 of the questionnaire.

How certain are you that you can...

i. Make some positive changes in your life and manage your situation so you can continue to do the things you enjoy

I was on my own for two years. I was almost housebound and on your own your mind wanders. I put on 67lbs in weight. It was the dancing, the euphoria, or I don't know, the adrenaline, made me realise there's still life to live for. There's more to live for. I go to the cinema, theatre, opera and ballet. I'm a member of Sadler's Wells [dance house]. I was on my own for two years. I was almost housebound and on your own your mind wanders. I put on 67lbs in weight. It was the dancing, the euphoria, or I don't know, the adrenaline, made me realise there's still life to live for. There's more to live for. I go to the cinema, theatre, opera and ballet. I'm a member of Sadler's Wells [dance house].

ii. Have hope for the future

I recognise that I lead my life with the cards I'm dealt rather than wallow in self-pity. It's rewarding for me to see me do what I'm doing.

You need to know there is a future and you need to know there's people who've got talents and ability to help you and to give you hope. The dancing is enhancing and enriching.

iii. Enjoy learning new things

Having learned things about ballet over the past few weeks, I was able to appreciate the skills of the dancers. My enjoyment was enhanced by being invited earlier in the morning to listen to some of the people involved in the production. The orchestra, costumes and production of the musical score from the original was clearly explained and was absolutely fascinating many thanks to all.

iv. Have a sense of achievement

It's wonderful; they have me running across the room. It's amazing; I am running across a room.

v. Develop more confidence

Working alongside others the same, you feel confident.

Alexis [a dance for Parkinson's teacher and ENB volunteer] is doing class in between [ENB terms]. I wouldn't have gone had I not had got the confidence coming here. I couldn't have gone if I hadn't come here.

vi. Have fun and make new friends

One of the chief pleasures of this course has been interacting with other people who have Parkinson's in a happy, easy-going atmosphere where we all have Parkinson's (of varying degrees) in common. And you all make it such fun, so merry, there is such a lot of laughter.

vii. Develop a sense of community with others with Parkinson's

It's a communal activity. We develop as a family.

4.3.10 Interference of Symptoms on Everyday Life

Section 8 of the *Dance for Parkinson's* questionnaire looks at how much the participants feel that their illness interferes with various aspects of their life such as the ability to express their personality, personal relationships, sense of well-being, and their sense of independence. The questions in this survey relate to quality of life and as such are very different to the ones asked about daily life in the UPDRS, which are mainly about functional capability.

With regards to this particular subsection of the questionnaire, the dancing participants consistently saw trends towards less interference, whereas the control participants consistently saw trends towards their illness interfering more with aspects of their life.

Interviews and focus group discussions after the first year of the project indicated that many of the participants were still feeling fairly independent and continued to attempt to do things on their own or with their partner. When asked about taking part in active homemaking or doing

things that they would normally like to do such as going to the cinema or the theatre, there was a general feeling that although participants may have to make adjustments to where they would normally sit or how they would get there (i.e. transportation) they would still make an effort to go and take part.

Some participants noted that they have family members close by that insist on helping out with things and this may lead to them not doing as many house chores, etc., but this is quite different from avoiding participation all together due to their Parkinson's. As such it appears that the group were already fairly independent and active at the start of the project.

The results from section 8 of the *Dance for Parkinson's* questionnaire are supported by multiple comments from participants. The quotations below have been categorised into the various subsections seen in part 6 of the questionnaire.

My illness interferes with my...

i. Ability to express my Personality

With Parkinson's you can lose sight of the individual and that person who you are inside.

As shown in Section 4.3.8, expression is a key element of dancing. In the quotations from diaries below, the sense specifically of how the dance exercises were encouraging personal expression is highlighted. In particular, these three illustrative descriptions indicate the change in how participants are able to express themselves and are particularly evocative of personalities coming through:

The class's version of 'Pass the Parcel' was illuminating too. We first did this a few weeks ago, all standing round the edge of the studio, receiving from the person in front of us, and passing on to the person behind, a present, which could be whatever we decided it was, different in size and weight and shape when we passed it on from when we had received it. We played it again this week. I would not have believed we could have come so far in such a short time. Everyone's movements were much freer, more individual and more exaggerated, we were much more inventive and had more confidence, and it was more obvious what more of the presents were. I got down on the floor to wrap a jumper, and tried to show how much difficulty I had in tying a ribbon in a bow. I felt I had done it rather clumsily, but to my surprise three people came to me afterwards and said how well I'd done the mime. At least, two of them did.



The third, J. said Christmas must be chaos in my house if I really wrapped parcels like that! (It is).

What a buzz there was in the class today. It started quietly, as usual, with breathing and posture, but when it came to movement with words – ‘Look at me, not at him’ things became very lively. Especially noticeable with one side of the room tried to outperform the other in gestures and volume. Everyone seemed to forget their infirmities or self-consciousness, and threw themselves whole heartedly into it. When it came to the theatrical marching head up, shoulders back, superior expression, flaunting our own importance! – the change in people went up several notches.

When it came to handing on a gift at the end of class, again everyone seemed more relaxed and inventive. Gestures were expansive, everyone was looking animated – either because of what they were going to give or what they were receiving – or watching what everyone else was doing. That seemed to counteract one of the most depressing symptoms about Parkinson’s – a ‘frozen’ face..

ii. Relationships

As noted in Section 4.3.8, the ability of the dance class to bring people closer together was a feature within interviews, discussion groups, and diaries. These participants felt that attending the dance class offered them the chance not only to talk to others, but also offer them the opportunity to get to know people better. For some this has resulted in meeting up outside of the dance time. For others it has allowed them to take part in an activity that is welcoming, where they feel a sense of belonging.

Everyone comes early to ENB. Some from a long way. That’s why I come early and sit down and talk. I like the camaraderie... The dancing] gave me a little nudge to get on with life. Parkinson’s is an anti-social disease. People drop you as a friend, but the camaraderie here is very solid. Here I enjoy meeting people.

After the seated part of the class, learning the movements, and involved hilariously in inventing new ones, we move round the room greeting each other by name (labels are great), and work with, and physically touch, different random partners, people we would not normally have got so close to so quickly. Hot drinks and biscuits, like break at school, encourage us to talk to other people we do not know well. At three of the classes so far I have exchanged email addresses with people, one of whom emailed me recipes good for people with Parkinson’s, another I have e-mailed with details of the gym for ‘neurologically challenged’ clients. We are learning to help each other.

Doing ballet (I hesitate to call what I do ‘dancing’, though, heavens, ‘ballet’ sounds even more sophisticated than ‘dancing’, and I don’t think what I do in class is sophisticated in the least) is bringing us, the pupils, closer to each other. We have partners for some activities, and for one of them I found myself partnering A., a tall man who I had never seen smile, I think we were both a bit frightened of each other, but after about several minutes working together, we were laughing.

I found dance to be quite an intimate process, where it was necessary to break down personal barriers in order to act out roles and interact with others. The shared difficulties were a constant source of humour...I just felt it opened up so many opportunities to get to know some really nice people.

I like the social side. I’m dating one of the women. We went to see a play the other day.

iii. Sense of well-being

A feeling of contentment and happiness is characteristic of the way many participants reply to questions about the dance class. This comment summed up how the dance class promoted a feeling of well-being.

[After class one feels] happy, warm, relaxed and ready for anything but not terribly energetic... [warm] means more than one thing. It means happy, content, positive, at one with nature, happy with the world really. You can convince yourself that everything is right.

iv. Independence in Society

Some participants wanted to highlight how the dance programme was creating more confidence and reason to do things. Continuing independence was a key aim for many and indicated in the key quality of life categories.

Working alongside others the same, you feel confident.

You lose a lot of freedom with this disease. At one stage I was afraid of leaving the house. I was afraid of falling down. I started to be afraid all the time. Coming here I have a sense of freedom that I can move and share with others who have the disease. I go out now. I'm still afraid, but I know I can do it.

Life starts to feel quite normal again. There's a reason to get up, go out, join in with people and achieve and meet lots of other people in the same boat.

Fear of losing independence is something that was reinforced in the discussion groups. In the following exchange between two participants the idea of staying independent within a supportive environment is evoked in the vision described:

I visualise an apartment building for each of us with lifts.

A sort of commune.

We'd each have individual flats. We'd have a notice on the door saying leave me alone, but communal area where we could put on music. My son wants me to live with him. I can't imagine a worse thing. I'd lose my independence.

They don't know.

Here I don't need to put up a front, but with friends I put up a front because they don't let me be myself, because my speech is slower it is associated with senility.

What comes across in this exchange is how much one of the speakers values the dance programme as place of understanding, where she can feel independent, yet supported within the community of dancers.

There is still a debate about whether dancing only attracts those who are already positive about their situation. The following comments indicate that some participants feel that they are a positive group:

So many people when diagnosed they give up and it's an inevitable decline. We all have positive attitudes. My one is that I'm not going to let this get me down and it does make a difference.

The sense of coming here is heightened with positive attitude. We got off our backsides to dance. It takes confidence to do that compared to other people with Parkinson's. It's uplifting to be around others with confidence.

Yet other comments about gaining in confidence through dancing and the results of the *Dance for Parkinson's* questionnaire in this area suggest that dancing as a group has lifted their positivity further. One Parkinson's UK member and dance participant noted that it took the ballet being provided in her town to convince other branch members of the positive effects of being active. Half the *Dance for Parkinson's* class now consists of branch members, who were not confident about dancing initially.

4.3.11 Freedom

Section 4 of the *Dance for Parkinson's* questionnaire asks participants to rate on a scale from one to seven how free or restricted they feel in doing what they want to do (one indicating they can still do all the things they would like and seven indicating that they can no longer do the things they wish to do). There were no observable changes of clinical significance for either group with regards to this particular question.

The results from this section of the questionnaire are different to the comments made in interviews and focus group discussions about the multiple ways that dance has encouraged a sense of freedom for these participants. With regards to the *Dance for Parkinson's* questionnaire, the participants are asked about freedom to do all the things that they would like to do. This was quite different from how freedom is discussed in relation to dance as seen in interviews and focus group discussions.

In interviews, focus groups, discussion groups and diaries participants talked about freedom in different ways, specifically in relation to dancing, rather than everyday life. Firstly, participants noted how the dance programme gave them time away from thinking about Parkinson's. Secondly, some participants valued the dance programme as a place where they did not have to hide or explain their Parkinsonian symptoms. Thirdly, dancing gave them some control from some symptoms to conduct more focused movement and grant them some freedom from disordered movement. Fourthly, dancing gave some a sense of being agents in the wider world again.

The ballet is wonderful. It gives me a feeling of organised freedom, of being able to do something new and different, however badly.

In class when it gets to the point of doing walks, I'm not someone who changes dramatically with walks, but to look at others and see them free from something. I think of freedom when I see them.

It's a freedom thing. I'm less afraid to move and to do things. That's positive for me.

Most noteworthy thing is that we forget that we have Parkinson's.

It frees you up. It freed me up. I'm a bit self-conscious as I'm not doing it right and I'm the only new person there. Then I push that to one side. I enjoyed the dancing, the movement on the chair. It was more like interacting with the music and doing the movement in a group and circle. I could identify with the group more. That probably made the difference – it was easier to keep it all in the background. You free up. When I first started I was thinking was I doing it right? Then I threw myself into it. It was fun. It was doing something different. No one looking at you.

I do enjoy it so much. I'm using parts of my body I don't normally use. When I leave here I've almost got a spring in my step. I can't put it into words how I enjoy it, but I do.

It can make me feel very free, wonderfully free. And it is wonderful to be made to move in ways that one does not normally move.

It's definitely helpful for the movement. I feel better after class....I can see in other people how it is helping them....from the beginning of the class to the end of the class, I can see them loosening up, which is lovely really.

4.3.12 Social Participation

As mentioned in Section 4.3.7 on Aid to Daily Life, interviews and diaries pointed to how dance participants were taking part in other activities. Some of these activities were the result of participation in the dance programme and socialising with other likeminded people. Some of these activities have been influential in helping others with Parkinson's.

It has also encouraged me to try Pilates classes for the first time.

We've started this choir...in Pimlico every two weeks. Grenville with a guitar. It's amazing the sound we make.

I also started another drop-in come to think of it, which is based in a pub on King's Road. It is for people just to come at lunch time if they want to have a bit of a break.

Participation in cultural activities have been prominent. For example, a couple of participants from the Oxford hub decided to set up another dance class closer to home in Banbury and English National Ballet has played a role in providing support with live music for the class in the initial stages, and inviting participants to the theatre trips. Others have realised their interest in dance performance through the theatre trips and now go more regularly to see dance shows.

5. LIMITATIONS

Throughout the course of this research many of our participants experienced positive life changes outside the context of the study (for instance, moving to a new, friendly neighbourhood or taking part in exciting family events such as a wedding). Several of our participants also experienced difficult and stressful times such as losing a partner or loved one. For many people with Parkinson's stress aggravates Parkinsonian symptoms. Embedded in our research design is the understanding that we need to take these personal contextual factors into consideration and not ignore these important life changes as they can, and probably have had a significant effect on our results.

Due to time constraints and space availability, adjustments were made to testing protocols to allow for all participants to be measured at the end of each term. All questionnaires and health information sheets were sent in a research package via post to each participant prior to their testing sessions. Participants were asked to complete the questionnaires prior to their visit. They were asked to make note of any queries or uncertainties about particular questions that could be addressed with the researchers during testing sessions.

While most questionnaires did not present difficulty for participants and any queries were easily addressed during the sessions, some questions did present confusion. Participants



sometimes felt that they did not fit in to any of the given options on some scales and others felt that their ratings would be completely different if they were rating themselves in certain situations. For example, when asked about the ease of getting out of a bed, car, or deep chair in part 2 of the UDPRS, a participant made notes about how this may differ depending on whether the car is next to a curb or how deep the chair actually is.

This same issue arose again in the Activities-Specific Balance Confidence scale with respect to different answers for when participants are in an 'on' state or 'off' state. However, a note was provided at the top of the questionnaire asking participants to rate themselves in 'on state' if they experience motor fluctuations.

Biomechanical measures can provide accurate and detailed information about physical changes. However, that accuracy is dependent upon a variety of factors including correct placement of sensors, how well the sensors attach to the body, interference from other electronic devices in the environment, and how the participant responds to the activity or measurement. Achieving accuracy on all things for each session, for each trial, and for each person can be quite difficult when testing in the field and not in a controlled, laboratory setting.

Furthermore, participants were provided with special t-shirts that would allow some coverage while the researchers could access the spine for the various sensors. Individual comfort levels and difficulties with dressing meant that not everyone was able to wear this clothing and thus the measurements became difficult to complete with accuracy in these particular situations.

In gaining participant perceptions of the class through interviews, focus groups, discussion groups and diaries, the range of different qualitative methods allowed researchers to cross-check opinions and follow up comments. Sustaining the writing of a diary proved very difficult for most people and most diaries were written over the course of four or five months. The

long-term picture in the diaries was not captured in general, although sustained use of multiple interviews, focus groups and discussion groups helped researchers analyse participant perceptions over the long-term.

6. CONCLUSION

Can I add, I've identified about eight or ten words to describe what we're doing: imagination, creativity, language, colour, music, rhythm. And I've not come across anything, anything in my diverse life, which combines all those things. The breadth and depth of what is going on downstairs [in the studio] is significant.

As this comment from a dance participant indicates, the dance programme offers an activity and cultural experience that is multifaceted. Participants engage with the programme for many reasons and find great significance in attending regularly. The programme is rich in what it offers and in what participants take from it.

The dance programme was examined from several angles and with different methods in order to explore the impact on participants, looking not only at the physical, but also the psychological, emotional and social sides of the participant experience.

We conclude that dancing helps people with Parkinson's nurture an active lifestyle, not just physically, but also socially.

Dancing seems to provide some physical benefit, but in general no more than other physical activities taken once a week, as illustrated by the control group in this study. We suggest that to see greater physical benefit, participants would need to take part in at least two classes a week. Results show that changes to postural stability may be an exception to this point with dancing participants improving more than controls on this particular variable. Dancing takes its place as a useful physical activity alongside other activities provided for people with Parkinson's.

The main benefits of dancing with Parkinson's are in the mental activity it provides and in emotional and social health and well-being. Scales and focus groups that looked at non-motor activity, such as cognitive functioning, psychological health, relationships and participant interaction indicated that the dance programme was providing particularly strong support for participants. We can conclude that dancing is a good and challenging mental workout for people with Parkinson's and allows some participants to cope better with symptoms and disability. It offers a positive environment where there is a community of support through dance, allowing participants to nurture positive attitudes to the future and a sense of independence. Dancing is a meaningful activity to participants and is valued highly by them.

It was also evident that the dance class was a place to experience freedom and capability in spite of what was happening in participants' daily lives, but which had the potential to expand into everyday life.

There was an overwhelmingly positive response given by participants to the programme. Dropping out was very rare. Dancing as a group to music within an inclusive atmosphere was key to generating motivation and the will to keep dancing. We can conclude that although dancing only offers participants a physical activity that is commensurate with other physical

activities, its specialness comes in its ability to offer an activity that resonates deeply on intellectual, social and emotional levels. With person-centred facilitation methods that put emphasis on inclusion and individual needs, together with a happy, positive atmosphere, people could participate in a programme that they felt was theirs collectively and one of immense value.



7. CREDITS

English National Ballet (ENB)

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English National Ballet *Dance for Parkinson's*:

London participants, 2011-2014

Oxford participants and artists, 2013

Liverpool participants and artists, 2014

Cardiff participants and artists, 2015

Ipswich participants and artists, 2015

ENB Associate Dance Artists

Helen Gould (Liverpool), Yvette Halfhide (Cardiff), Katherine Hartley (Oxford),

Danielle Jones (London), Sarah Lewis (Ipswich), Rebecca Trevitt (London)

ENB Associate Musicians

Stacey Blythe (Cardiff), Amy Mallet (Ipswich), Stephen Mannings (Liverpool),

Jon Petter (London), Nathan Tinker (London), Nia Williams (Oxford), Helen Woods (Cardiff)

8. REFERENCES

- Bandura A (2006) Guide for constructing self-efficacy scales. In: Pajares F, Urdan T, Greenwich CT (eds) *Self-Efficacy beliefs of adolescents*. Information Age Publishing. pp. 307-337
- Brach et al. (2011). Validation of a measure of smoothness of walking. *J Gerontol A Biol Sci Med Sci*, 66A(1):136-141.
- Devins GM (2010) Using the illness intrusiveness ratings scale to understand health-related quality of life in chronic disease. *J Psychosom Res* 68(6):591-602.
- Esser, P, Dawes, H, Collett, J, Feltham, MG, & Howells, K (2011). Assessment of spatio-temporal gait parameters using inertial measurement units in neurological populations. *Gait and Posture*, 34:558-560.
- Goetz, CG et al. (2008). Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale presentation and clinimetric testing results. *Movement Disorders*, 23(15):2129-2170.
- Hoehn MM, Yahr MD (1967) Parkinsonism: onset, progression and mortality. *Neurology*. 17(5):427- 442
- Lajoie, Y & Gallagher, SP (2004). Predicting falls within the elderly community: comparison of postural sway, reaction time, the Berg balance scale and the Activities-specific Balance Confidence (ABC) scale for comparing fallers and non-fallers. *Arch Gerontol Geriatr.*, 38(1):11-26
- Lorig K, Chastain RL, Ung E, Shoor S, Holman, HR (1989) Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis Rheum* 32(1):37-44.
- McRae C, Cherin E, Yamazaki TG, et al. (2004) Effects of perceived treatment on quality of life and medical outcomes in a double-blind placebo surgery trial. *Arch Gen Psychiatry* 61(4): 412-20.
- Moe-Nilssen, R & Helbostad, JL (2004). Estimation of gait cycle characteristics by trunk accelerometry. *Journal of Biomechanics*, 37:121-126.
- Moe-Nilssen, R (1998). A new method for evaluating motor control in gait under real-life environmental conditions. Part 2: Gait analysis. *Clinical Biomechanics*, 13(4-5):320-327.
- Montgomery EB, Lieberman A, Sing G, Fries JF (1994) Patient education and health promotion can be effective in Parkinson's disease: a randomized controlled trial. *Am J Med* 97(5):429- 435
- Myers, AM, Fletcher, PC, Myers, AH, & Sherk, W (1998). Discriminative and evaluative properties of the activities-specific balance confidence (ABC) scale. *J Gerontol A Biol Sci Med Sci.*, 53(4): M287-94.
- Powell, LE & Myers, AM (1995). The Activities-specific Balance Confidence (ABC) Scale. *J Gerontol A Biol Sci Med Sci*, 50A(1):M28-34.
- Parry, SW, Steen, N, Galloway, SR, Kenny, RA, & Bond, J (2001). Falls and confidence related quality of life outcome measures in an older British cohort. *Postgrad Med J*, 77:103-108

Quiroga Murcia C, Kreutz G, Clift S, Bongard S (2010) Shall we dance? An exploration of the perceived benefits of dancing on well-being. *Arts and Health: An International Journal for Research, Policy and Practice* 2(2): 149-163

Radloff LS (1977) The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1(3):385- 401

Ware JE, Sherbourne CD (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 30(6): 473-83.





Appendix: Research Dissemination

PRESS AND MEDIA FEATURES

English National Ballet along with Houston and McGill have become commentators for dance for Parkinson's in the media, broadcast, online and paper. Notable features include: World Ballet Day, 1 October 2015, BBC World's Health Check, 13 March 2013 and BBC1's *Inside Out*, 16 January 2012.

Channel 4 News feature, Matthew Cain, *Ballet Therapy for Parkinson's Sufferers*, 2010

BBC1 Inside Out short documentary on the London programme and research, 16 January 2012 <https://www.youtube.com/watch?v=mTvsYweRZCA>

Channel 4 Random Acts short dance film by the BalletBoyz shot in Tate Britain, <http://www.balletboyz.com/videos/dance-for-parkinsons/> 2012

BBC World 'Health Check' feature, 13 March 2013 <http://www.bbc.co.uk/news/health-21682196>

Judith Mackrell's Dance Blog, The Guardian, *Dance is just what the doctor ordered*, 20 November 2015 <http://www.theguardian.com/stage/dance-blog/2014/nov/20/dance-for-parkinsons-disease-capturing-grace-therapeutic-benefits>

ITV Diversity Live short feature shot in London and featuring the full programme within a live show hosted by Diversity, January 2015

English National Ballet *Dance for Parkinson's*, World Ballet Day, 1 October 2015 <https://youtu.be/0UqtB6QU4AY>

Presentation of delivery model English National Ballet presented at:

Dance for Parkinson's Network UK: two-day CPD course at University of Roehampton, 21-22 June 2013

Bristol International Culture, Health and Well-being conference, 24 June 2013, <http://www.culturehealthwellbeing.org.uk/>

Westminster Arts - Arts of Well-being Festival, 13 December 2013

Dance for Parkinson's Network UK: two-day CPD at People Dancing Summer School, 10-11 July 2014

University of Bedfordshire, 28 February 2014 and 2 October 2014

People Dancing International Conference – Wales Millennium Centre, 13-15 November 2014

Elixir Festival - The Art of Age Conference at Sadler's Wells Theatre alongside Dr. Sara Houston, 15 September 2014

Festival of the Brain, Folkestone, 22 May 2015

Dancing More; Living More, City Hall, 5 October 2015

PUBLICATIONS

Houston, Sara. (2015) *Dancing with Parkinson's*, Blog for BioMedCentral, 29 April 2015. <http://blogs.biomedcentral.com/on-health/2015/04/29/dancing-parkinsons/>

Houston, Sara. (2015) Feeling Lovely: An examination of the value of beauty for people dancing with Parkinson's, *Dance Research Journal*, April Vol.47 (1), 26 - 43. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9702823&fileId=S0149767715000042>

Houston, Sara. (2014) Moved to Dance: Socially Engaged Dance Facilitation. In Mary Elizabeth Anderson & Doug Risner (eds), *Hybrid Lives of Teaching Artists in Dance and Theatre Arts: A Critical Reader*. New York: Cambria Press, pp. 133 – 154. <http://www.cambriapress.com/cambriapress.cfm?template=4&bid=603>

McGill, Ashley, Houston, Sara & Lee, Raymond. (2014) *Dance for Parkinson's: A new framework for research on its physical, mental, emotional, and social benefits*. *Complementary Therapies in Medicine*. <http://www.sciencedirect.com/science/article/pii/S0965229914000363>

Houston, Sara & McGill, Ashley. (2013) A Mixed-methods Study into Ballet for People Living with Parkinson's. *Arts & Health: An International Journal for Research, Policy and Practice*, 5:2, 103-119. <http://www.tandfonline.com/doi/full/10.1080/17533015.2012.745580> (A summary of this article appears on Culture Case.) <http://www.culturecase.org/research/2014/04/helping-parkinsons-sufferers-through-ballet/>

Houston, Sara. (2011/12) The Methodological Challenges of Researching Dance for People Living with Parkinson's. *Dance Research*, vol. 29, part 2, 329-351 <http://www.eupublishing.com/doi/abs/10.3366/drs.2011.0019>

Jones, Danielle, and Sara Houston (2011) Researching *Dance for Parkinson's*. *Animated*, Autumn, 23–25. <http://www.communitydance.org.uk/DB/animated-library/researching-dance-for-parkinsons.html?ps=knrJ6gb1rmc93mQ247-TGyxTAqPRg1&lib=15280>

A summary of the pilot research appears in: Arts Council England (2014) *The Value of Arts and Culture to People and Society: an evidence review*. See pp. 26-27. <http://www.artscouncil.org.uk/what-we-do/research-and-data/value-arts-and-culture-people-and-society-evidence-review/>

In addition, Houston has been contracted to Intellect Books to publish *Dancing with Parkinson's: Art, Community and Wellbeing* in 2017/18.

PUBLIC TALKS

Two public talks at the Wellcome Collection Rhythm is a Dancer seminar series. Houston gave two talks in November 2012 and January 2013 along with other scientists and artists for the general public at the Wellcome Collection in London on the *Dance for Parkinson's* research. Approximately 270 people attended in total.

Public talk at St Andrew's United Reformed Church Chesterfield, October 2012. Houston together with Danielle Jones gave a talk on the Programme and research to the general public, including GPs, nurses and occupational therapists. Approximately 50 people attended.

Houston gave *Dance for PD*[®] telephone seminar for the Mark Morris Dance Group in November 2012. This was for all *Dance for PD*[®] members worldwide, including many dance artists teaching dance for Parkinson's groups around the world.

Houston presented at the Art of Wellbeing day at the Cochrane Theatre, London with English National Ballet as part of a taster workshop, summer 2013.

McGill, Donald and Houston gave a research presentation at the *Dance for Parkinson's* Network UK summer school, London, in June 2013 and McGill and Houston in Leicester, 2014.

Macclesfield Literary and Philosophical Society, Macclesfield, invited Houston to present on the research October 2014

Houston and McGill gave presentations at each English National Ballet CPD weekend course in Oxford (2012), Liverpool (2013), Ipswich (2015) and Cardiff (2015).

CONFERENCES

Houston gave a keynote speech to the Artists and Scientists in Partnership research symposium at Brown University in Rhode Island, USA on the *Dance for Parkinson's* research in March 2013. In addition, Brown University student, Cameron Donald, joined the research team as a summer intern in May 2013.

Houston gave a paper at the International Culture, Health and Wellbeing conference, Bristol in June 2013 on the research. It was streamed live on the internet.

McGill gave a poster presentation at the International Association of Dance Science and Medicine conference in Seattle, USA, October 2013.

Houston gave the keynote speech at the Brain Dance conference in Freiburg, Germany in March 2014 and contributed to several roundtable discussions and panels at the four day conference.

PRIZES

Houston and McGill were Finalists in the National Engagement awards, run by the National Co-operating Centre for Public Engagement in June 2014, for their work in engaging the public about the *Dance for Parkinson's* research.

Houston and McGill received the Bupa Foundation Vitality for Life Prize 2011.

CONSULTANCY

Houston and the English National Ballet team have also been actively involved on the Advisory Board for Queensland Ballet's *Dance for Parkinson's* programme, Australia.

Houston is Education and Development Consultant for Dance for Health and Parkinson, Rotterdam, The Netherlands.

LECTURES

Both Houston and McGill have given lectures on the research to MSc and PGDip students at Trinity Laban, BA and MA students at University of Roehampton and University of Bedford.





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