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Songlines for Parkinson's: The Process of Co-Developing a New Music-and-Movement Group-Based Intervention to Improve Mood and Movement for Parkinson's

Dawn Rose[1], Marietta Ungerer[1,2], Sabrina Köchli[1], Paolo Paolantonio[3], Daria Dinacci[4,5], Amanda Foletti[5], Daniele Molteni[6], Andrew Greenwood[7], Maria Thomas[8], Lindsay Truran[2], Lucy E. Annett[2], Costas I. Karageorghis[9], Caroline Whyatt[2], Ellen Poliakoff[10], and Alison Short[11]

Abstract

Participatory research promotes inclusive practice and enables stakeholder expertise to be recognized as a valuable contribution throughout the research cycle. However, there is little guidance regarding how to disseminate these qualitative processes, and the methodological insights gained.

Based on preliminary research, we had developed a session framework for a new intervention using music to improve motor and non-motor symptoms for people with Parkinson's. Our next step was to work in a trans- and interdisciplinary way to further explore concepts (e.g., imagery) and to co-develop content (e.g., musical exercises). Through a synthesis of materials including video footage, worksheets, field notes, transcriptions of interviews and feedback forms derived though workshops and interviews with people with Parkinson's, a range of practitioners and healthcare professionals, and researchers in the UK (in English) and in Switzerland (in German and Italian), we developed a draft protocol for a 12-week course. This was then optimized through a final round of feedback with the stakeholders.

We gained direct methodological insights throughout these processes, including some that led to changes in protocol (addition of two new sections), and the revision (rhythmic exercises) and removal (e.g., singing and syncopation) of some planned content. We also changed our use of language. Indirect insights included the need for cultural and contextual sensitivity, and a new understanding of the bidirectional nature of impact.

A new group-based music and movement course, Songlines for Parkinson's, has been co-developed for and with people with

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[1] School of Music, Lucerne University of Applied Sciences and Arts, Lucerne, Switzerland
[2] Department of Psychology, Sport and Geography, University of Hertfordshire, Hatfield, UK
[3] Conservatorio della Svizzera Italiana, University of Applied Sciences and Arts of Southern Switzerland, Lugano, Switzerland
[4] Clinica Hildebrand Centro Ambulatoriale Lugano e Centro di Riabilitazione Brissago, Brissago, Switzerland
[5] Istituto Neurocentro della Svizzera Italiana, EOC, Lugano, Switzerland
[6] Istituto di Arti per le Terapie Camille Saint-Saens, Crosio della Valle, Italy
[7] Switch to Move, Tilburg, The Netherlands
[8] The Music Workshop Company, Knebworth, UK
[9] Department of Sport, Health and Exercise Sciences, Brunel University of London, London, UK
[10] Division of Psychology, Communication and Human Neuroscience, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK
[11] School of Humanities and Communication Arts, Western Sydney University, Penrith, NSW, Australia

Corresponding Author:
Dawn Rose, School of Music, Lucerne University of Applied Sciences and Arts, Arsenalstrasse 28a, Lucerne-Kriens 6010, Switzerland.
Email: dawn.rose@hslu.ch

Parkinson's. The methodological insights gained have not only shaped the protocol but also provided lessons that could be useful for planning and guidance in future participatory projects involving the Parkinson's community and extended to other groups.

Keywords

neurorehabilitation, Parkinson's disease, transdisciplinary, interdisciplinary, music, patient and public involvement, intervention, participatory medicine, inclusivity, insight

Participatory research encapsulates a research-to-action approach to engage people who, though not necessarily trained in research, either belong to or represent the people who are the focus for the research (Vaughn & Jacquez, 2020). Levels of engagement can begin with consultation and extend to co-researchers with equal power for decision-making, and the research has been described as ranging from community-informed to community-driven (Key et al., 2019). To provide context for the present paper, this study was produced in line with the 'patient and public involvement in research' (PPI) movement (Meinders et al., 2022). Public involvement in research aims to promote inclusive practice and enable key stakeholders to have their expertise recognized as a valuable contribution throughout the research cycle (i.e., from conception to dissemination). To try to ensure PPI work is representative rather than tokenistic, various bodies (e.g., NHS,[1] Parkinson's UK[2]) have designed guidelines to help researchers contemplate how to conduct themselves and address concepts such as knowledge exchange and use of language. Moreover, such bodies have encouraged and promoted the exploration of a range of collaborative possibilities for research projects.

The purpose of this paper is to focus on the collaborative processes involved in this project, and the methods employed in relation to their direct and indirect impact on the development of a new intervention. As identified by Wight and colleagues (2016), there is scarce guidance related to the development of interventions in comparison to the multiple guidelines provided for the evaluation of interventions. This is echoed by Vaughn and Jacquez (2020), who indicated that although there is a long history of participatory research across multiple fields, "…the nuts-and-bolts description of *how* to do this work is often minimal to non-existent." (p. 7). Accordingly, we share the processes involved in developing a new music-and-movement group-based intervention. These processes correspond with the first four steps presented in the 6SQuID framework (Wight et al., 2016).

Specifically, we begin (Step 1) by defining the problems and their causes (the introductory section of this paper describes how we can use music to help ameliorate specific symptoms of Parkinson's). In Step 2, we identify which contextual factors are malleable (the introduction also provides a review of available therapeutic approaches and associated mechanisms), followed by Step 3 (methods) expounding how we intend to bring about change (through a six-step plan for inclusive research practice). In Step 4 we demonstrate how we will deliver the change mechanism (i.e., the production of a revised protocol adapted from theory for practice through an inclusive process). The final two steps which involve testing, refining, and collecting evidence, will be the focus of a separate paper.

Parkinson's disease[3] is a neurodegenerative condition associated with a loss of dopamine producing cells (Bloem et al., 2021). The principal Parkinson's motor symptoms are bradykinesia/akinesia, tremor, hypertonia with rigidity and postural deficit (postural alignment and postural reaction); these symptoms, as well as cortical-subcortical automatic network impairment, are responsible for locomotion difficulties (shuffling, freezing, festination) that commonly lead to falls, and thus reduce both the quality and duration of life (Tolosa et al., 2021). Non-motor psychological symptoms are also common and include apathy, anxiety and depression, with cognitive decline occuring as the disease progresses (Bloem et al., 2021). Cases of Parkinson's doubled worldwide between 1990 and 2016 with conservative estimates suggesting over 12 million people will be diagnosed with the incurable condition by 2050 (Dorsey et al., 2018). Pharmacological and surgical treatments can temporarily ameliorate some motor symptoms, but they have no effect on postural symptoms, no effect on non-motor symptoms and have no impact on clinical progression; in this context, adjunct therapies are needed to reduce symptom severity and improve quality of life (Fox et al., 2018; Karageorghis et al., 2021).

Physical therapy is commonly prescribed to help manage motor symptoms for people with Parkinson's (PwP; Morris et al., 2010). Frameworks of physical therapy designed for PwP recommend task-specific approaches (i.e., exercises related to functional mobility) using specific strategies to help support dysfunctional cortical-basal ganglia networks (e.g., King & Horak, 2009). As Morris (2000, p. 582) explained, PwP "…are reliant on cortical control mechanisms to initiate movements...and fronto-cortical 'attentional mechanisms' to sustain movements."

Studies have shown that such task-orientated programmes are effective in terms of improving functional mobility (i.e., balance, posture, gait, reaching and grasping) and that the benefits often extend to measures of health-related quality of life (e.g., Keus et al., 2007; Tomlinson et al., 2012). However, adherence to programmes is problematic; PwP tend to be ~30–70% less active per day compared to their peers (Ramaswamy et al., 2018). Moreover, whilst individual physical therapy programmes may be essential to tailor individual solutions, they are relatively expensive and do not address issues related to motivation, isolation and sustainability.

Conversely, therapeutic approaches using music, such as dancing, drum circles and/or singing in choirs are commonly group-based, thereby providing social support systems in a delivery model that has lower costs (because there is a higher facilitator-to-participant ratio), and the sessions are often provided in community spaces rather than clinical settings (e.g., Pantelyat et al., 2016; Tamplin et al., 2020). The group nature involved in these interventions was believed to encourage social cohesion and 'co-pathy' (i.e., social empathy) providing socialized support for PwP and their care partners (Koelsch, 2014; Prado et al., 2020).

As an overview, the mechanisms for change involved in such intervention strategies are based on the idea that music, as a specialized stimulus, has both motivational and organizational properties that can improve the efficacy of interventions by a) increasing the urge to move and continue to move (i.e., ergogenic effect, Terry et al., 2020), and b) providing auditory cues to regulate movement, as seen in specific neurologic music therapies such as Rhythmic Auditory Stimulation (RAS), where the beat provides temporal scaffolding that can improve aspects of gait, such as stride length (Bella et al., 2017; Thaut et al., 2019).

Neuroimaging studies have shown that multiple areas of the brain are stimulated by sound and music, leading researchers to suggest that music provides pathways for plasticity and neurorehabilitation throughout one's life (Altenmüller & Schlaug, 2015). Specifically, there are multiple neural pathways linking sound and movement that are thought to facilitate the activation of compensatory mechanisms, such as the cerebellar-thalamocortical networks, helping to bypass the putamen-SMA impairment and enable entrained motor actions (Zatorre et al., 2007). That is, the temporal regularity of rhythmic stimulus affords predictable auditory-motor coupling that can trigger the urge to move, enable entrainment, and guide the timing of a specific movement to a specific auditory reference point (i.e., sensorimotor synchronization; Janata et al., 2012; Grahn & Brett, 2009).

RAS is a neurologic music therapy technique that uses auditory cueing to improve gait for PwP (Thaut et al., 2015). It is based on the principle of auditory-motor coupling, whereby the perceptual regularities in the auditory scene (e.g., a metronome or emphasized beat in music) act as the external entrainment cues (Matthews et al., 2020). Through the adjustment of the 'temporal scaffolding' (i.e., changing the tempo of the metronome or music), clinical aims, such as increasing step length, can be achieved (Bella et al., 2017).

Music also has affective properties: people commonly select songs to modulate their mood (Koelsch, 2014), and music is often used to increase motivation for, as well as performance and enjoyment of, sport and exercise (Karageorghis, 2020). A recent study of the use of music among PwP in everyday life demonstrated that in addition to a general hedonic appreciation of music, PwP use music primarily for motivation and relaxation (Rose et al., 2023).

Many researchers concur that the rich and multifaceted nature of music, including its rhythms, melodies and meaning to individuals, offers avenues for neurorehabilitation (Grahn & Watson, 2013; Schaefer, 2014). However, some studies suggest that this may depend on peoples' rhythmic abilities (Bella, 2017), and it must be acknowledged that for some PwP, listening to music has a detrimental effect on walking due to the difficulties associated with dual-task processing (Brown et al., 2009). Nevertheless, interventions incorporating music and dance have successfully helped PwP (Barnish & Barran, 2020; Fox et al., 2018) and a variety of active music-making programmes for PwP have been piloted including interventions focusing on singing (Irons et al., 2020; Stegemöller et al., 2017; Tamplin et al., 2020), drum circles (Pantelyat et al., 2016), musical instrument improvisation (Pacchetti et al., 2000) and some that combine cognitive tasks and movement exercises with musical activities (Pohl et al., 2013).

One further way of experiencing music may provide beneficial avenues for therapeutic application: recently, studies of mental singing (i.e., singing inside one's mind) reported a larger decrease in gait variability when compared to singing out loud among PwP (Harrison et al., 2017, 2019). Other studies have also shown that PwP use 'internalized music' (i.e., remembered and/or imagined) to prime or maintain movement when external stimuli cease (Rose, Alessandri et al., 2019a). This phenomenon has been referred to as *carryover effects* in RAS studies (Thaut et al., 1996) or as "covert synchronisation" (Repp, 2005, p. 969) in timing studies, and is a type of internalized music is known as imagery.

Musical imagery (Zatorre & Halpern, 2005) has been described as a complex neuro-psychological and physiological experience engaging auditory, motor, frontal and limbic systems as well as the autonomic nervous system in ways that may be voluntary or involuntary (such as with earworms; Halpern & Bartlett, 2011). A recent study showed that PwP spontaneously use musical imagery to support movement (walking or exercise), to regulate their mood and/or to help with concentration (Poliakoff et al., 2023).

The relative success of these pilot studies has led to speculation that musical imagery training for PwP may provide further opportunities for engaging compensatory pathways (Schaefer, 2014). However, explicitly training transfer from external to internalized cueing strategies has yet to be incorporated into interventions. If such an approach is feasible, PwP could be empowered to overcome mobility issues (such as akinesia and/or freezing of gait) by accessing their own internalized jukebox of memorized musical cues. Together, the studies included in this introduction suggest that aspects of physical therapy, music therapy and music psychology could be combined in a range of therapeutic practices to improve movement and mood for PwP. Next, we present the processes involved in developing this concept from a theoretical framework to a working protocol.

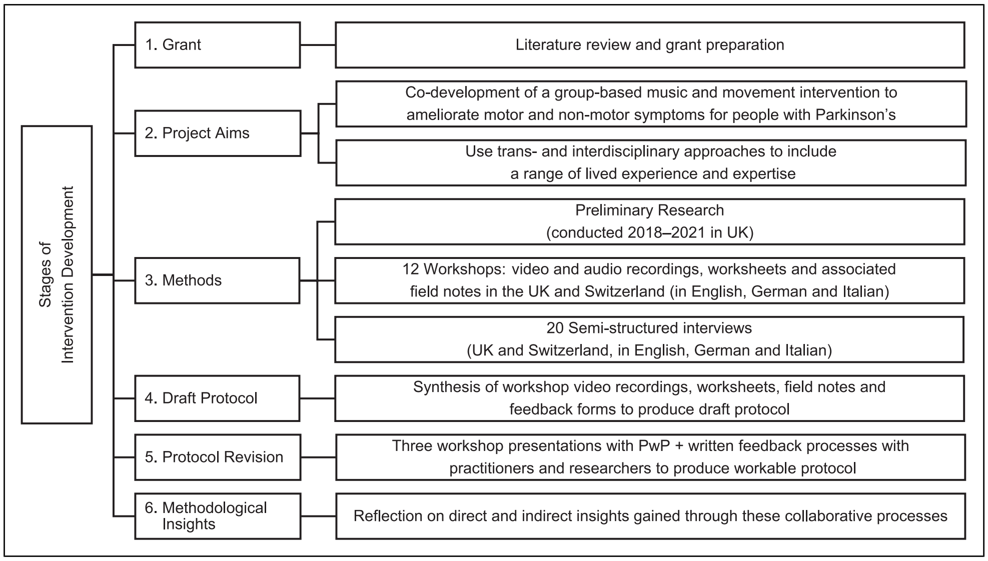

Figure 1. Illustration of the Steps Used to Co-Develop Songlines for Parkinson's, Resulting in Both Direct and Indirect Methodological Insights.

Aims

The aim of the project was to co-develop a new group-based course (i.e., intervention) integrating musical activities with task-based exercises to improve movement and mood for and with PwP. The aim of this paper is to report the methods and collaborative processes involved in this type of participatory research and share the methodological insights such work provides. The results of the qualitative analyses from the project will be reported in accordance with GRIPP2 checklists for PPI research (Staniszewska et al., 2017) in a separate paper.

Figure 1 illustrates the steps of the processes used for the intervention development resulting in the direct and indirect methodological insights reported herein, acting as a guide for this article: 1. The introduction provides a precis of the literature review conducted during the grant preparation; 2. The aims of the project are stated to provide context for this article; 3. The methods reported here include the preliminary research, workshops and semi-structured interviews; 4. The extrapolation and synthesis of data that were used to produce the draft protocol are described; 5. The processes involved in revision of the draft protocol are explained; 6. The methodological insights gained throughout these collaborative processes are shared.

Methods

Preliminary Research

Work to develop an agenda for research into music and Parkinson's began in 2018 as reported in Rose et al. (2022). That original research also produced a statement paper for healthcare professionals (Karageorghis et al., 2020). As part of the trans- and interdisciplinary research undertaken during that period, we planned to co-develop a new music and movement group-based intervention for and with PwP by a) continuing our PPI approach and b) expanding our interdisciplinary element further by including practitioners, therapists and scientists from a wider range of disciplines (Choi & Pak, 2006; Radder et al., 2020).

As already noted, consultation with PwP is a central tenet of the PPI research process (Sacristán et al., 2016). Such participatory models of medicine advocate shared decision making, illustrated by the 'nothing about me without me' phrase, demonstrating a fundamental shift in attitudes to empower patients as co-investigators rather than participants (Hewlett et al., 2006). In this instance, as opposed to researchers projecting a 'prescriptive' use of music onto PwP, we believed it was important to explore ways in which PwP use music (how, when and why they listen and imagine or remember music, see Rose et al., 2023; Poliakoff et al., 2023).

We took this approach to ensure the inclusion of the diverse voices of the people who would potentially participate in the intervention, and therefore, for whom intervention adherence would matter most (Schipper et al., 2014; Staniszewska et al., 2017). This approach has been successful in other studies; for example, co-designing the content for a new dance class with PwP, dance artists and physiotherapists (Bek et al., 2022). Ultimately, we aimed to ensure that the activities within the intervention would be desirable, practical and appropriate from the perspectives of PwP as the key stakeholders.

Stakeholders

Due to the inclusion of different stakeholders at various points during these processes, we provide herein an overview of the stakeholders, their roles in terms of participation, and the places in which the collaborative interactions took place

Table 1. Description of Stakeholders, Their Roles, and Record of Their Presence During the Development Processes.

		UK	Switzerland		Total
Stakeholders	Description of role	Stevenage	Lucerne	Brissago	*N*
PwP: Workshops	Volunteers who participated in the workshops to discuss concepts, try out ideas for content, and suggest new ideas/content	6	4	5	15
PwP: Interviews	Volunteers who participated in the workshops and provided time in a private setting to share their concerns and identify potential barriers to participation	6	4	1	11
Sport scientist	Took part in workshops to provide professional reflections on participation and use these to adapt measurement protocols	1	1	1	3
Systematic musicologist	Researcher who gathered and analyzed data and provided ideas on concepts and content for the intervention protocol, ran workshops in Lucerne (in German) and conducted interviews with PwP	1	1	1	3
Music psychologist	Principal investigator (grant holder) who designed original workshops, ran workshops in UK, conducted the final analyses and brought together the data and literature to create the draft and final intervention protocols	1		1	2
Music therapists	Led musical sections of the workshops and provided professional reflections on their participation and how to adapt concepts and exercises for the intervention		1	1	2
Music workshop facilitator	Led musical sections of the workshops and provided professional reflections on their participation and how to adapt concepts and exercises for the intervention	1		1	2
Occupational therapist	Led physical sections of the workshops and provided professional reflections on their participation, and how to adapt concepts and exercises for the intervention	1			1
Movement therapist	Led dance sections of the workshops and provided professional reflections on their participation and how to adapt concepts and exercises for the intervention		1		1
Physical therapist	Led physical sections of the workshops and provided professional reflections on their participation, and how to adapt concepts and exercises for the intervention			1	1
Physician	Took part in the workshops and provided professional reflections on how to adapt concepts and exercises for the intervention		1		1
Neuro-rehabilitation specialist	Took part in the workshops and provided professional reflections on how to adapt concepts and exercises for the intervention			1	1
Psychologist	Took part in the workshops and provided professional reflections on how to adapt concepts and exercises for the intervention	1			1

(Table 1). Working with PwP, we decided to record the workshops and conduct individual interviews to reduce the demand on their time and avoid reliance on written (or typed) work, which the PwP found rather arduous. The researchers, practitioners and allied health professionals tended to lead exercises that were in their area of expertise, and provided written reflections on their participation, as well as written formal guidance for the adaptation of exercises for the intervention protocol.

To the best of our knowledge, three PwP were taking part in a local dance for Parkinson's class in the UK, and seven were participating in 'Big Movers', an exercise class for Parkinson's (also based in the UK) that does not involve music. From this point forward, we will refer to Parkinson's collaborators, research collaborators and professional collaborators to best represent the roles undertaken by each of these three groups.

From previous work (Rose et al., 2022), we knew that our Parkinson's collaborators were 'fed up with being told what they couldn't do' and that they wanted to focus on what they could do, and what would help. Following exploratory research conducted on playing in a drum circle in a motion capture laboratory (Rose et al., 2019b), our Parkinson's collaborators from that project had told us that using the traditional Djembe drums in that format (i.e., a circle) was too singular a focus. Instead, they wanted to try out different types of percussion instruments, make big movements, and explore how different rhythms made them feel. They also explained that, in any future intervention, they would need time to rest, but that they did not want to "sit around doing nothing" and especially not "moan [complain] about Parkinson's". Consequently, even at the conceptual stage we sought to include these points and seek strategies that would encourage adherence by providing enjoyable and sociable contexts. To this end, a preliminary session plan was developed as a conceptual starting point (Table 2), bringing together ideas PwP had told us they would like to try, with

Table 2. A Systematized Preliminary Session Plan Describing Targeted Activities, Related Outcomes and Measures.

Time (min)	Task	Actions and accompaniment	Mechanisms	Therapeutic objectives	Related measure
0–5	Warm up	Directed body mobility (stretches) and vocal exercises to slow instrumental music	Rhythmic and melodic associations with speech and movement	Improve symptoms of dysarthria, functional mobility and mood	Affective states, functional reach and postural stability
5–15	Active rhythmic engagement	Self-generated sounds using percussion and body drumming in repetitive patterns at varying tempi	Small to large movements using various parts of the body (e.g., from rain to thunder sounds on djembe)	Auditory-motor associative exercises to support perception-action feedback/ forward systems	Motion-capture and gait mat measures
15–20	Rest 1 - music education	Explore rhythms, music and from around the world	Videos or live musicians playing examples of different musical rhythms (e.g., polka, clave, Afro-Cuban music)	Thinking about how words, music and movement are used to communicate - what works for you (individualized empowered exploration)?	Psychoeducation and self-reflection (qualitative data)
20–30	Musical navigation	Partnered task using musical motifs to guide movement through an obstacle course	Similar to ceilidh dancing, a set of directions are called to direct movement to music	Cognitive and vocal exercise for one partner, auditory directed action for the other. Support activities of daily living and adaptive walking (e.g., standing from seated, turning, bending to lift)	Motion-capture and gait mat measures
30–40	Rest 2 - message stick	Weekly song-sharing and open discussion	Emotional engagement through music listening	Fosters pro-social behaviours, emotional relatedness (co-pathy) and group cohesion	Music and lyric analysis (qualitative data related to affective state and quality of life)
40–50	Improvise and imagine	Create music/lyrical motifs to initiate and regulate movements	Transfer external to internalized cues using memorable phrases (e.g., like marching songs)	Using musical mnemonics, develop an internalized jukebox of musical imagery to enable overcoming freeze of gait and improve functional mobility	Motion-capture and gait mat measures
50–55	Consolidate	Recap and remember	Led by therapist to enable practise of key skills	To reflect achievement back to group members and set weekly goals	Motion-capture and gait mat measures, and quality of life
55–60	Relax and restore	Restorative energy, gentle movement and breathing exercises (e.g., Tai chi cloud hands)	Anxiolytic effects of music	Non-beat based, de-arousal and relaxation	Affective state

physical therapies developed for Parkinson's (King & Horak, 2009; Morris, 2000), blended with aspects of successful music-based therapeutic approaches (Fox et al., 2018; Raglio, 2015; Zhou et al., 2021).

Workshops

The next step in the co-development process entailed conducting a series of workshops to explore concepts (e.g., musical imagery) and generate content (i.e., by trying out various musical exercises such as 'call and response'). Additionally, we wanted to identify practical and logistical considerations (e.g., how long sessions should last, which types of venue would be suitable, and what instruments should be used). This work was carried out during 2021 and 2022 in the UK (in English) and in Switzerland (in German and Italian). Switzerland is a confederation of 26 cantons with four official languages and associated regional cultures. Our aim was to explore any regional adaptations that would be necessary to accommodate (potentially) different cultural uses of music (Rössel & Schroedter, 2015). Resource restrictions meant that it was only possible to include two distinct regions,

Table 3. Task-Based Workshops for Co-Creating Content for Songlines for Parkinson's Intervention.

Workshop	Themes for intervention goals	Description of activities
1	Music, identity and emotions	Introductory session: a) why music is meaningful to humans in terms of lived experience (including autobiographical elements), and b) exploring how music makes us feel, (including tempo, dynamics, mode, lyrics and melody)
2	Auditory perception and musical engagement	Listening and hearing session: a) Interpreting sounds and tracking rhythms (including difficulties associated with Parkinson's), and b) ways of engaging with music, including issues related to music production abilities
3	External and internal cueing strategies	Exploring what makes us move when, where, how and why, a) in the environment (i.e., external auditory senses), and b) exploring musical imagery to developing internalized musical cues
4	Rhythm	Practical session (four parts): Exploring effects of rhythmic music on movement and relaxation in terms of a) repetition, b) tempo, c) synchronization and d) syncopation
5	Intervention protocol	Stakeholders will provide feedback on the 12-week intervention protocol, which will then be adjusted to provide the final intervention protocol

German-speaking central Switzerland and Italian-speaking southern Switzerland.

A series of five task-based workshops (Table 3) was devised as creative processes designed to provoke discussion/promote interaction and provide content for the intervention itself. The first three workshops were conducted in a similar manner: the workshop leader/s presented short segments of information (5–10 min) followed by the discussions between the Parkinson's, professional and research collaborators and the completion of tasks based on those ideas (approx. 20 min).

The fourth workshop was a practical session conducted in four parts to explore the rhythmic themes of repetition, tempo, synchronization and syncopation with musical instruments. We asked the Parkinson's and professional collaborators to try out various musical instruments gaining feedback on which had enjoyable sounds and felt good/practical to handle. This resulted in a list of musical instruments that were then purchased for the intervention sessions according to the preferences of the Parkinson's and professional collaborators.

To capture these processes as data, we used a combination of audio and video recordings, written work (e.g., flip charts, pictures of white boards, short worksheets), and observational field notes made by the research and professional collaborators. Workshops included PwP, a range of therapists and practitioners (including community music workshop facilitators and musicians, two music therapists, an occupational therapist, a movement therapist, a physical therapist, a psychologist who specializes in Parkinson's research, music psychologist and psychotherapist, two medical doctors, one of whom is a neuro-rehabilitation specialist, a sport scientist and a systematic musicologist (see Table 1)). Despite the restrictions imposed during the Covid-19 pandemic, we were able to conduct all the workshops in person. However, for some, wearing masks was required and this may have compromised interpersonal communication to a degree.

Semi-Structured Interviews

Twenty interviews were conducted in one-to-one settings to provide a safe space in which to discuss potential barriers against participation and/or other private thoughts for both the Parkinson's collaborators (n = 11) and professional collaborators (n = 9). The interview schedule included the following three items based on the participants' expertise:

1. Which aspects of music and dancing sound appealing to you?
2. Which aspects of music and dancing sound off-putting to you?
3. What types of activities do you think are appropriate and/or troubling?

Additionally, collaborators who took part in the interviews were invited to discuss any other concerns or ideas. Due to Covid-19 pandemic restrictions imposed in the UK and Switzerland at this stage, all interviews were conducted online (nine in English, seven in Swiss German and four in Italian).

Preparation of Draft Protocol

Following the completion of the fourth in the series of workshops (in total, 12 from all sites), and the interviews, the data in the form of video and audio recordings of the workshops and associated field notes, transcriptions of the interviews, worksheets and written feedback from the Parkinson's and professional collaborators was extrapolated and synthesized to produce a draft protocol. This process involved conducting a content analysis in line with guidance in the literature (Kuckartz, 2012, 2019; Mayring, 1994; Potter & Wetherell, 1987), based on the following research questions:

- What content could be used for the intervention?
- What topics/activities are appropriate for the intervention?

- What makes participation problematic?

Several members of the research team are multilingual (PP, MU, SK) and so, where possible, coding was conducted in the native language of the participants. If necessary (for example to resolve issues of conflict for dual-coding), data were translated into English and then back-translated into the original language to establish authenticity of meaning. Full details of the content analysis are documented among the articles of registration on the Open Science Framework: https://osf.io/329gh/?view_only=95cd9414c8264c48bb303c397ad39b6b

A version of the resultant protocol was then created for participants and distributed in advance of a fifth and final workshop at each of the three sites to gain feedback on the protocol from the PwPs. A separate protocol was created for practitioners (which included notes and guidance based on the literature) who provided their perspectives on this draft protocol in written format. The section that follows describes the direct and indirect methodological insights that resulted from these processes, including areas of agreement and/or conflict between collaborators, and the removal/addition of parts of the planned intervention that was presented as Table 2.

Methodological Insights

Here we share two types of methodological insight: direct and indirect. Beginning with the former, and based on the outcomes of the content analysis, a range of linguistic, logistic, practical and conceptual points were developed, and subsequent adjustments made to the original intervention session plan. These are now described in relation to the methodological insights they provided, and how they supported production of the final 12-week protocol, *Songlines for Parkinson's*.

Direct Insights

Use of Language. Several language-based adjustments were necessary during the co-development processes. Our Parkinson's collaborators explained that the words *disease* and *intervention* were associated with medicalization and negative impressions. For them, participation in this project was an act of empowerment, not only to support their own sense of agency, but also to act as advocates for other PwP who could not take part. After discussion on acceptable alternatives, and in line with guidance provided by Parkinson's UK, we agreed upon using *Parkinson's* throughout the lay documents and in practice. Similarly, the word 'intervention' was replaced with 'course' and other terms such as 'end-user' (or similar nomenclature), which were experienced as a depersonalization of participants, were consciously avoided by the research team. From the practitioners' perspective, the use of terms such as 'African music' was considered too general. Consequently, we adjusted the language in the protocol booklets to better reflect the places of musical and historical origin.

Choice of Instruments. Given that PwP had stated in the 2018 research that they wanted to use a variety of percussion instruments with which they could, potentially, make big movements, the fourth workshops included time to try out a variety of instruments to explore this idea. In addition to finding sounds and shapes that were pleasing to hear and hold, we included alternative versions of instruments to accommodate the needs of PwP. For example, in an earlier study, participants had described Djembe drums as too heavy and uncomfortable to use, both in terms of postural positioning and hand strikes, so we ordered some lightweight fibre glass djembe drums for participants to try out. Table 4 shows the instruments we included in the fourth workshops, those which were liked/disliked, and those that did not seem to elicit positive or negative comments. It is possible that people preferred to use a new or unfamiliar instrument, as it reduced the degree of comparison with experiences prior to having Parkinson's, but we did not ask about this specifically.

Singing. During the workshops, our Parkinson's collaborators mentioned that they felt anxious that they would be 'made to sing'. This appeared to be a general inhibition rather than a fear of anything specific. Consequently, to enable us to include exercises from speech and language therapies to help with vocal fitness (and thus communication skills), we suggested beginning sessions with non-singing strategies (e.g., humming, vowel sounds and breathing-type exercises). However, as many studies have suggested that singing can be beneficial to PwP on many levels (e.g., Irons et al., 2021; Stegemöller et al., 2017; Tamplin et al., 2020) we believe practitioners and therapists can offer alternative approaches to singing that may be helpful and specific to the group and/or individuals and context. Therefore, we support the inclusion of singing according to each group of intervention participants and the practitioner. This is with the proviso that there are no individual performance or execution-related requirements on individuals. The central goal is always to support a rehabilitative task through music in a way which enhances the individual's overall wellbeing.

Cathartic Experience. Our Parkinson's collaborators clearly stated a preference for a positivity in the sessions, with an expressed desire to 'feel good' rather than focus on their negative feelings, which they said could lead to the course 'feeling more like a therapy session'. In contrast, the music therapists had expressed concern about the lack of time and space in the draft protocol assigned to exploring music as a vehicle for expressing sadness, anger and loneliness, and to enable bitter-sweet nostalgic feelings of connection to one's past. It is notable that such feelings have been found to form part of the ways in which PwP use music in everyday life

Table 4. List of Musical Instruments Considered, and Preferences of People With Parkinson's Discovered During the Fourth Workshops.

Liked	Indifferent	Disliked
Tambourines	(Small) bells	Xylophones and metallophones with small keys
Bongos	Rattles	Sleigh bells
Shakers of all kinds (e.g., maracas, egg shakers)	Castanets (they are light, but difficult to play)	Triangles
Percussion/big drums and large drum sticks/beaters, also those possible to play with bare hands or only one stick	Boom whackers (good if there is a choreography)	Piano
At least one melodic percussion instrument such as a tongue drum or handpan (using numbers rather than musical notes to play a melody)	Doumbek and djembes (traditional versions of the drums were too heavy)	Violin
Junk instruments (e.g., upturned washing baskets, Brissago only)	Guiros (Stevenage only)	Guitar/ukulele and all string instruments
	Cymbals (Stevenage only)	Wind instruments (too likely to spread infection)

(Rose et al., 2023). To resolve this area of conflict, we refocused one of the sections planned in the conceptual framework, the Message Stick. Originally, the aim had been to simply share songs each week to foster group connectedness. As a direct result of the input of the music therapists, we adjusted the facilitation guidance that PwP should freely choose a piece of music they wanted to share for any reason, thereby handing them the power to decide on their level of engagement in terms of the valence of the music and subsequently, the group's affective state.

Difficulty With Concept of Musical Imagery. Through analysis of the third workshop on external and internal cueing strategies, it became clear that we had not been able to properly convey the concept of musical imagery. Our Parkinson's collaborators were unsure if we were asking them to remember a video for a song, recall the lyrics, or think about where and when they had been when they first heard the song. The concepts of auditory imagery, motor imagery, musically evoked autobiographical imagery (Jakubowski, 2022), earworms and general memory for music had become conflated. Crucially, our Parkinson's collaborators wanted to know how this would help them with everyday tasks. Other studies have also found distinctions between these concepts difficult to convey, requiring more time and different types of materials to enable comprehension than originally planned (Bek et al., 2021; Lambert et al., 2024). This issue resulted in two new developments for the intervention protocol.

Firstly, we included more sensory tasks to try to increase imagery knowledge and ability. Specifically, we changed from a basic warm-up to a 'weather scene warm-up' where we planned to use sounds and images to conjure up different types of weather whilst warming up participants' bodies and voices. Secondly, we decided to ask course participants to prioritize which symptoms of Parkinson's that had not, thus far, been associated with the therapeutic use of music (e.g., sleeping, apathy). We planned to operationalize this by adding a list of symptoms (plus space for other suggestions) during the recruitment/screening stage. This change resulted in the addition of a section that we labelled 'Hive Mind' to capture the notion – from the social media phenomenon – of reaching out for ideas (or 'life hacks') to explore how music could help with particular Parkinson's symptoms that, thus far, had not been considered. The idea was to create time and space within each session for discussion between the participants and the facilitators, and as such, the whole group would become co-researchers for these novel topics.

Exercises for Active Rhythmic Engagement Section. During the fourth workshop, which was a practical session on exploring aspects of rhythm, it became clear that key concepts such as tempo, repetition and synchronization were understood and could be practised by our Parkinson's collaborators across a range of group activities. However, we noticed that exercises that involved syncopation (e.g., multipart rhythms, such as would be used in a Samba band) seemed to cause confusion and did seem enjoyable for our Parkinson's collaborators. Nevertheless, call and response-type exercises did prove viable and so were included as part of the Active Rhythmic Engagement section. Similarly, it became clear (from dyad-based vs. group work comparisons) that being able to copy actions provided important visual cues for our Parkinson's collaborators. This resulted in a circular room set-up for the intervention so that participants could see the session facilitator.

Noise Levels and Over-Stimulation. It also became clear during the fourth set of workshops that having a group of people engaged concurrently in different musical tasks was too noisy and irksome for most of our Parkinson's collaborators. Consequently, we removed the section planned as the Musical Navigation (see Table 2) and instead incorporated some of those ideas into a new Movement to Music section that would allow for the practice of different types of movement by way of weekly musical themes. For example, the first week would focus on marching to help the group learn to coordinate their movements according to instructions. The second week would explore music and dance steps from different parts of Africa, specifically enabling the inclusion of clock-steps to promote safe turning (e.g., practising first turning heads, then shoulders, then body to reduce turning *en bloc*), improve functional mobility and reduce falls (i.e., practising head–body placement when stepping to sideways, as well as backwards and forwards). To try to ensure a smooth transition into this newly devised music and movement section, we switched the content of the first and second rest periods. This meant the ‘Rhythms from Around the World’ section, which was planned as an exploration of different types of music and dance rhythms, would precede the next section of the intervention, Music and Movement, thereby facilitating the learning of dance steps and sequences according to the different types of music for each theme.

Choreography. At this stage in the protocol development, it became clear that we would need to engage a choreographer to provide content and a framework for the more specialized music and movement dance sequences. This was important not only in relation to the different cultural references, but also regarding a specialist knowledge of the challenges related to inclusive practice for Parkinson’s, such as the need for seated alternatives to adapt standing dance moves. Consequently, we engaged a renowned choreographer (Author AG) with over 20 years’ experience working with PwP. He helped us to choose appropriate music and designed movements for many parts of the Rhythms from Around the World ‘journey’ (see, e.g., Supplemental File 1, Flamenco Week Floor Map and Supplemental File 2, Explanation of Flamenco Moves).

Indirect Insights

Some of the insights we experienced were less explicit. We have clustered them here under two subtitles: Recognizing the Need for Cultural and Contextual Sensitivity, and Bidirectional Impact.

Recognizing the Need for Cultural and Contextual Sensitivity. Although we had considered the possibility that different cultures would relate to different types of music in different ways, we had not anticipated the need for cultural sensitivity in working practices, logistical and social contexts. In the UK, we had an established participatory research group, not only supported by the University of Hertfordshire, but also by Parkinson’s UK, a charity that offers a wealth of resources for researchers (e.g., assistance promoting studies and participant recruitment). However, in central and southern Switzerland (Lucerne and Brissago respectively), we were initiating relationships from the Lucerne University of Applied Sciences and Arts, not only with PwP and Parkinson Schweiz, but also professionally with other researchers, practitioners and clinicians based at Clinica Hildebrand in Brissago.

To provide further context, Swiss citizens play an important part in shaping their society through direct democracy, with referendum voting taking place three or four times per year on whichever issues citizens wish to raise, and an average voter turnout of up to 50% (Swiss Federal Chancellery, 2023[4]). However, as Selby and colleagues (2022) point out, the Swiss Healthcare system is highly decentralized, making it hard to establish how much PPI work is being conducted. Although there is a push towards participatory approaches, for example with the Swiss Clinical Trials Organisation[5] now providing guidelines and fact sheets, Selby et al. (2022) found evidence of only five clinical studies that incorporated PPI work in their study of research being conducted in Switzerland.

The Swiss PwP we worked with were initially very reserved and rather sceptical about this type of participation. However, the longer we worked together, the more trust and mutual respect we developed as we explored ways of using music that might be beneficial. As with earlier PPI work conducted in the UK (Rose et al., 2022), we found that music acted as a conduit (because we are all experts in our own musical preferences), enabling more in-depth dialogue about personal matters (e.g., narrating why certain songs have such meaning) that perhaps would not have been possible otherwise.

On the practical side, during the initial ‘getting-to-know-each-other’ phase, we can recommend one exercise that we found effective; we simply asked each person involved to introduce themselves by way of a song, or a single slide with a picture (cf. Rose et al., 2022). One PwP for example, showed a picture of their garden and explained that they found gardening a calming activity, which helped ameliorate their symptoms. One professional collaborator showed a picture of themself fencing and explained that this was something they loved to do in their ‘other life’, but it was also something that inspired their training as a physical therapist. Finally, one of the researchers showed a video of the song Jungle Drum by Torrini, 2009 and shared with the group that their background as a professional drummer had inspired their research exploring how rhythm and music can help PwP. This introductory exercise allowed people to share some of their lived experience and provide context for their participation, rather than overly focusing on their ‘qualifications’. As well as being fun and allowing for some creativity, it equalized any assumed or attributed hierarchy and provided avenues for further conversation throughout the project.

King & Gillard (2019) suggest that the development of rapport in participatory research and the cohesion of the team are important factors in sustaining morale and motivation. In this vein, the NIHR guidelines suggest ‘blurring roles’ as a way of reducing boundaries between professionals and ‘service users’. However, compared to what we had experienced in the UK, we found different cultural expectations regarding hierarchical structures in professional settings (such as clinics and universities) in Switzerland; not only when working with members of the public, but also interpersonally. With hindsight, our sometimes clumsy attempts to fast-track friendly relations resulted in a sense of uneasiness and, at times, even mild distress. Moreover, we realized we had taken for granted the role of the charities as conduits for 'cultural brokerage' (Aabe et al., 2019). Our schedule should not have detracted from taking the necessary time to develop trust and gently forge new relationships.

Nevertheless, we found that clinicians in both Lucerne and Brissago were open to participatory research, and indeed organized annual patient forums with the Swiss charity Parkinson Schweiz. Although there was no Swiss-wide platform for recruitment as in the UK, Parkinson Schweiz, the hospitals, clinics and healthcare professionals played pivotal roles in the success of the project by inviting us to give talks about the project. This essentially provided an important personal recommendation, known as Vitamin B colloquially in Switzerland, that opened the way to developing the networks, not only with clinicians but also with Swiss PwP. Moreover, the attention to detail we had shown regarding the choice of foods (including catering to specialist diets and being aware of foods that interfere with Parkinson's medications), and the choosing of small but thoughtful gifts, or taking the time to write individual cards, was highly appreciated and generated further good will.

Bidirectional Impact. When we think of impact as researchers, it often feels as if it must be on a large scale, and that makes it 'important', and we are often guided towards considering the impact we have on the public rather than on individuals, or ourselves. However, through this project, as has been evidenced in other long-term research partnerships (Sullivan & Poliakoff, 2023), we were able to re-evaluate this and understand how truly valuing *lived experience* can help strengthen people's sense of agency, feelings of belonging and develop new skills. As one of our Parkinson's collaborators explained:

> "The Songlines Project has been an exciting adventure for me, and I have enjoyed being part of it so much. Apart from rekindling my love of music, it has given me more confidence to step out of my small world and embrace new opportunities. Who would have thought that at my age, with Parkinson's, I would take a small but active role in such a project? Thank you for the wonderful opportunity to meet like-minded people, some of whom have become good friends too."

Songlines for Parkinson's Intervention Protocol

Through this project and within these processes, we were able to welcome people and invite their participation not only as experts in living with Parkinson's, but also as practitioners, therapists, clinicians and researchers. Especially important in this context, people were able to contribute as experts in their own relationship with music in ways that aptly reflected their complex identities. Although we did not address issues of power openly, we took care to try to preserve personal dignity, use non-patronizing tones and provide a safe space wherein collaborators could enjoy the processes of exploration and discovery that continues as we further develop our programme of research.

The final protocol that emerged from the processes described herein, and which forms the framework for each session of Songlines for Parkinson's, is presented in Table 5. During the co-development process, we tried out several names for the course, eventually deciding upon '*Songlines for Parkinson's*' because, as one Parkinson's collaborator said, "All you have to do is remember a line from a song, and then you can sing it inside your mind to get you moving." Secondly, because we wanted to make a tribute to the indigenous peoples of Australia, where the term *Songlines* has been used to describe ways of navigating space and time using music in its many forms.

In sum, through these processes, we were able to devise a new protocol for a co-developed intervention in which weekly themes are explored across a 12-week course. To provide an overview, the first few weeks focus on marching, followed by music and dance moves from the continent of Africa. We then travel (metaphorically) to Latin America, exploring Salsa and how learning those steps can improve our balance. Next, we return to Europe and delve into Flamenco, considering how the articulation of hands and feet can help both fine and gross motor control. Similarly, we experiment with European folk music (specifically Swiss and British traditions), using stick dancing to practise stepping and coordination, before venturing to the South Pacific where we learn how to do a Haka to help express our emotions and reduce facial masking (i.e., hypomimia).

The Participant and Practitioner booklets for *Songlines for Parkinson's* explain the weekly themes in detail, demonstrating how music can be incorporated into daily practice to help ameliorate symptoms for PwP. These documents were prepared in advance of the recruitment process to provide as much transparency as possible for interested participants and practitioners to help them decide whether to take part in the ensuing trials. These documents are also available among the articles of registration on the Open Science Framework: https://osf.io/329gh/?view_only=95cd9414c8264c48bb303c397ad39b6b

Discussion

In the present paper, framed within the first four of the 6SQuID guidelines according to Wight and colleagues (2016), we have reported the methods and processes used to co-develop a new rehabilitation course designed to ameliorate motor and non-motor symptoms specifically for PwP. We have also shared the direct and indirect methodological insights gained, and we now take the opportunity to discuss three issues that have arisen as a result of undertaking this work. Firstly, the tension between theory and practice in relation to impact and transdisciplinary research; secondly, acknowledgment of the limitations of our co-development process, and thirdly, the

Table 5. Overview of Weekly Songlines Sessions for Parkinson's Protocol.

Duration (min)	Session section	Name of activity	Brief description	Adaptation
0–5	1	Weather scene warm up	Stretching exercises	Include sensory/imagery exercises
5–15	2	Active rhythmic engagement	Guided percussion (body/instrument)	Variety of instruments chosen. Do not include syncopation exercises. Set up as a circle
15–25	3	Message stick	Active rest; shared listening and reflection	Enable safe space for personal/emotional sharing
25–35	4	Hive mind	Group symptom problem-solving using music cues + music and motor imagery	New section included to specifically deal with symptoms not currently addressed by music interventions
35–45	5	Rhythms from around the world	Active rest; mini lecture about music and dance according to weekly theme	Moved from earlier in the session to just before music and movement section
45–65	6	Music and movement	Practical section using music to improve functional mobility	Choreographer engaged
65–70	7	Restore and relax	Cool down to music	Rather than gentle martial arts, use music from the theme of the week
70–90	8	Refreshments	Socializing	Lunch (rather than coffee and cake) preferred due to timing of sessions, which needed to be held late morning

necessity to continue such work using trans- and interdisciplinary approaches to ensure key stakeholders are included at every stage.

Impact through research, is said to occur "…when research generates benefits (health, economic, cultural) in addition to building the academic knowledge base." (p. 1, Greenhalgh et al., 2016). Impact is important because researchers should be 'accountable' and funders have a need to demonstrate value, but to whom and how should that accountability manifest? Policy makers and the public are faceless descriptions of such bodies, but participatory research and community engagement are personal and essential aspects that facilitate impact, providing a way to develop relations with key stakeholders, in turn lending legitimacy to the application of scientific findings (Farr et al., 2021). This provides a mandate for academics to engage in applied research, yet it remains unusual to find a suitable outlet to share the complex processes (as we have tried to do here), rather than simply reporting and disseminating results.

By sharing the methods and processes involved in this project, we must acknowledge that despite in-depth planning, we had to adapt dynamically in response to the needs of the team and the time. Even within the rare context of a fully funded project, the trade-offs between quality, completeness, timeliness and rigour were uncomfortable. Undoubtedly, we have not been able to honour the contribution of everyone involved in this report, and despite our best efforts to encourage diversity and make the project accessible, people of colour were not well represented, ultimately detracting from the project overall. There is more work to be done to address this, and lessons to be learned from our acknowledged shortfalls.

The processes described herein did ensure participation was transformative rather than dialogical; together we not only created a new 'course', but due to our improved understanding across perspectives and between disciplines, we were able to define what that course provides. It is a toolbox of music-based strategies that people with Parkinson's can learn, choose and use to improve their mood and movement. According to a policy statement by Parkinson's UK (2010),[6] the personalization of treatment is one of the top priorities for PwP and being empowered to exercise choice is one of the core principles of social care. What we have developed together is not a therapy, though it *can* be delivered by therapists. It is not prescriptive, because it has been designed to adapt to the facilitators' individual knowledge base and preferred practices, yet it is a protocol that is amenable to evaluation.

The present study contributes to participatory and interdisciplinary research by providing a selection of procedures and processes that could be adapted to help design interventions for other conditions, such as developmental coordination disorder (DCD). Each community and context have their own needs and in-built expertise, making it possible to adapt the methods reported herein to explore music-based exercises for other conditions. For example, people who wish to collaborate to help people with DCD could work with the young people, their families and friends, as well as specialists in developmental disorders, community artists and musicians. Together they could explore strategies to produce a new toolbox of treatment possibilities specific to DCD. According to Vaughn and Jacquez (2020) "…there is no prescription for the right way to do participatory research; instead, research partners must collaborate to prioritize what's the most important and choose methods that best represent stakeholder interests and maximize the potential for real-world impact." (p. 5).

For our next steps, we have begun the process of testing, optimizing and evaluating Songlines for Parkinson's using mixed methods to ensure the voices of all our stakeholders remain central during the evaluation stage. We are in the process of conducting a within-subjects experimental trial of the intervention, measuring at baseline, pre and post intervention, and include a follow up, but we are also open to exploring ways in which these processes of participatory research might take us. Impact, as we have discovered, works in a reciprocal manner, and our lives as researchers have been irrevocably touched by working together in this way (Staley, 2017).

Conclusions

A new music and movement course, Songlines for Parkinson's, that aims to ameliorate motor and non-motor symptoms for people living with Parkinson's has been co-developed by an international interdisciplinary team using participatory research. The processes used have provided important methodological insights, which we have shared with the hope they will be of benefit to other researchers, practitioners, and future projects. The most illuminating aspects of this project have been firstly, not to underestimate the length of time needed to establish relations with key stakeholders. The earlier in the process that dialogue can begin, the more meaningful any changes to planned activities and desired outcomes will be. Secondly, initiating participatory research requires nuanced cultural and contextual sensitivity and this can only be achieved at the pace of trust. Lastly, we find it important to emphasise our insight that impact can be bidirectional. We, as researchers, have not only learned more about the practicalities and sensibilities of inclusivity by working with PwP, but we have also learned about the pressures clinicians face and the differences between how universities and hospitals work as institutions. These lessons should help with the planning of future projects, though we are sure there are many more lessons to be learned.

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ORCID iDs

Dawn Rose https://orcid.org/0000-0003-2945-9491
Paolo Paolantonio https://orcid.org/0000-0001-7421-5256
Lucy E. Annett https://orcid.org/0000-0003-2082-1650
Costas I. Karageorghis https://orcid.org/0000-0002-9368-0759
Caroline Whyatt https://orcid.org/0000-0003-4589-7280
Ellen Poliakoff https://orcid.org/0000-0003-4975-7787
Alison Short https://orcid.org/0000-0002-0175-4563

Ethical Approval

The Health and Human Sciences Ethics Committee with Delegated Authority [Protocol aLMS/SF/UH/04396] at the University of Hertfordshire approved the parts of this study that were conducted in the UK. The Ethics Committee of Lucerne University of Applied Sciences and Arts approved the parts of the study that were conducted in Switzerland [Protocol EK-HSLU 002a M 22].

Consent to Participate

Participants were provided with a full itinerary of the events to enable them to make an informed decision about taking part, including assurances of anonymity for the analyses of video and audio recordings. Participants were made aware that they could withdraw at any point without further obligation, then provided written consent prior to engaging in the study.

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Conflicting Interests

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Data Availability Statement

Due to issues of anonymity (e.g., with the video recordings) we are only able to make parts of the data available, which we will do on request.

Supplemental Material

Supplemental material for this article is available online.

Notes

1. Health Research Authority: Public Involvement. https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/
2. https://www.parkinsons.org.uk/sites/default/files/2018-11/PPI_Guidance_for_Researchers.pdf.
3. We prefer to use the term Parkinson's only to refer to the condition in deference to our participants with Parkinson's who do not like to use the word disease. This is in line with guidance from Parkinson's UK: https://www.parkinsons.org.uk/information-and-support/what-parkinsons#:~:text=We_call_it_Parkinson's.,t_catch_Parkinson's_from_someone.

4. https://www.ch-info.swiss/en.
5. https://www.scto.ch/en/patient-and-public-involvement.html.
6. https://www.parkinsons.org.uk/about-us/control-choice-and-personalised-services-health-and-social-care.

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