

Irish set dancing classes for people with Parkinson's disease: the needs of participants and dance teachers. *Shanahan, J et al. (2016)*

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Title: Irish set dancing classes for people with Parkinson's disease: the needs of participants and dance teachers

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Irish set dancing classes for people with Parkinson's disease: the needs of participants and dance teachers. *Shanahan, J et al. (2016)*

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Abstract

Objective: As the number of people diagnosed with Parkinson’s disease increases, there is a need to develop initiatives that promote health and wellbeing and support self-management. Additionally, as exercise may slow physical decline, there is a need to develop methods that facilitate greater engagement with community-based exercise. The aim of this study is to examine the needs of (1) people with Parkinson’s disease and (2) set dancing teachers to enable the development of participant-centred community set dance classes.

Methods: A mixed methods study design was used. Two consensus group discussions using nominal group technique were held to (1) identify factors pertaining to the needs of people with Parkinson’s disease from a set dance class and (2) the educational needs of set dancing teachers to enable them to teach set dancing to people with Parkinson’s disease. Group discussions began with silent generation of ideas. A round-robin discussion and grouping of ideas into broader topic areas followed. Finally, participants ranked, by order of priority (1-5), the topic areas developed. Final data analysis involved summation of participants’ ranking scores for each topic area.

Results: Rich information on the needs of people with Parkinson’s disease from a dance class and the educational guidance sought by set dancing teachers was gathered. Topic areas developed include “teaching method” for set dances and “class environment”.

Conclusion: Accessing community exercise programmes is important for this population. The results of this study will inform the development of an educational resource on

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Parkinson's disease for set dancing teachers. This resource may facilitate a larger number of teachers to establish sustainable community set dancing classes for people with Parkinson's disease.

Keywords: Community exercise programmes; Parkinson's disease; Dance; Education; Nominal group technique.

1. Introduction

Parkinson's disease is a progressive condition associated with functional disability,¹ social isolation and reduced quality of life.² Promoting regular participation in physical activity is one initiative recommended in the management of Parkinson's disease.³ Regular participation in physical activity may prevent secondary consequences of sedentary lifestyles,⁴ increase functional ability,⁵ improve quality of life⁶ and reduce referral into the health system.⁷ Unfortunately, the level of engagement in habitual physical activity is poor for those with Parkinson's disease as approximately 64% of this population are leading sedentary lifestyles.⁷ Lack of suitable service provision,⁸ low expectation and interest in the activities offered and low self-efficacy^{9,10} have been identified as barriers to exercise by people with Parkinson's disease. Physical limitations including postural instability and gait impairments may also deter exercise participation.¹¹ Enjoyable exercise interventions that respect the needs and abilities of people with Parkinson's disease may help overcome these barriers and encourage regular participation.

Irish set dancing along with Tango¹² and different forms of modern dance^{13, 14} maybe beneficial activities and encourage habitual participation in exercise in people with Parkinson's disease. Irish set dancing is a social and partnered form of cultural dance and may improve balance, mobility and quality of life^{15, 16} through the integration of complex motor skill learning patterns, dynamic balance practice,¹⁷ musical cueing and socialisation.¹⁸ Moreover Irish dance music has a predictable rhythmic beat which may improve the pattern of gait.¹⁹ Irish set dancing is popular worldwide and practiced in America, Australia and Europe.^{20, 21} Research has found Irish set dancing to be beneficial in Irish and Venetian people with Parkinson's disease.^{15, 16} In 2013, a national conference, "*Training course for Irish set dancing teachers and therapists: focusing on Parkinson's disease*" was held. The

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aim of this conference was to provide preliminary information about teaching set dancing to people with Parkinson's disease to lay community set dancing teachers and health care professionals. The conference provided symposium and workshop sessions, delivered by researchers, Consultant Neurologists and Chartered Physiotherapists with expertise in set dance and/ or Parkinson's disease. During this conference set dancing teachers noted that insufficient information was available to help them implement safe and beneficial set dancing classes for people with Parkinson's disease.

To the authors' knowledge, no guidelines or resources exist to provide set dancing teachers with comprehensive information about teaching set dancing to people with Parkinson's disease. The aim of this study is to identify the (1) educational needs of set dancing teachers and (2) elements required by people with Parkinson's disease from a set dancing class. The information gathered will inform development of an educational resource that will address specific needs of set dancing teachers and guide delivery of client-centred set dancing classes for people with Parkinson's disease in the community. Providing relevant information and educating set dancing teachers may be one meaningful and novel initiative to help combat the lack of suitable community dance and exercise programmes for people with Parkinson's disease, aforementioned. Educating set dancing teachers may also help establish supportive networks for people with Parkinson's disease as community peers work together to achieve common goals.

2. Methods

2.1. Design

This project was approved by the Education and Health Sciences Ethics Committee. The methodology for this study was developed in line with previous research.^{22, 23}

Two separate consensus group discussions, one with set dancing teachers and one with people with Parkinson's disease were conducted. Both group discussions used a nominal group technique.^{22, 23} This method allows for priority information in relation to a specific topic to be identified and prioritised through structured group discussion, thus ensuring the most useful and relevant information for inclusion in the resource was identified. A nominal group technique also gives each participant an equal opportunity to speak and prevents individuals from dominating the discussion.^{22, 23}

The aim of the discussion with set dancing teachers was to identify their educational requirements in order to teach set dancing to people with Parkinson's disease. For those with Parkinson's disease, the group discussion focused on identifying their needs for the structure of a set dancing class and the knowledge they would like set dancing teachers to have about Parkinson's disease. The consensus group discussions were held on a suitable day and time, in a location convenient to participants. A chairperson (J.S.) was present at both group discussions. All data collected was anonymized. Each group discussion began with a brief introduction to the session and silent generation of individual ideas. Following this, a round-robin sharing of ideas took place. In this part of the discussion, participants called out one item from their individual list of ideas. The chairperson wrote down all ideas shared on a full view flip chart and ensured each participant was given an opportunity to speak. The process of round-robin sharing continued until participants had shared all items on their lists.

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Participants then discussed all the items on the flip chart and with the help of the chairperson, related items were compiled, via group consensus, to create broader topic areas that represented similar factors pertinent to their needs. Finally, participants were asked to privately rank, by order of priority,^{22, 23} (1-5: 1 least important, 5 most important) the topic areas developed during the round-robin discussion.

2.2. Selection of participants

Set dancing teachers, were recruited by an email invitation. This invitation was sent via a gatekeeper, to set dancing teachers on a national database of set dancing teachers for people with Parkinson's disease. Those with Parkinson's disease were recruited by a postal invitation, distributed to people who participated in a study exploring the benefit of set dancing for people with Parkinson's disease.²⁴ This was done to ensure participants would have experience of set dancing and thus be able to contribute participant evidence to the study. All participants received a patient information leaflet and were required to provide written informed consent prior to participating in the study. Participants were also asked to provide an email address so a draft version of the resource could be emailed for review and feedback.

2.3. Data analysis for consensus group discussions

Demographic information for set dancing teachers was collected and presented descriptively. Descriptive statistics using SPSS version 22 were used to analyse demographic information for those with Parkinson's disease.

The final data collected from the group discussions was analysed by tabulating participants rank-ordering of items to be included in the educational resource. The most important item received the highest ranking score-(5).²³ Participants' top five ranking items were included in the educational booklet. This ensured in-depth information was provided on the topics identified as most relevant.

3. Results

3.1. Description of participants

Five set dancing teachers volunteered to participate. All participants taught set dancing in the community and had been involved in classes for people with Parkinson's disease. Participants had limited knowledge of the evidence-based information available in the area of dance for people with Parkinson's disease.

Six people with Parkinson's disease participated in the study. The demographic profile of participants is presented in Table 1.

3.2. Findings

Figure 1 and Figure 2 display a summary of the topic areas participants felt most important to include in this resource and the ranking results. The topic area that received the highest ranking score was deemed most relevant to participants. Topic areas with the same ranking score were deemed as having equal importance.

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Within each topic area, suggested factors and/or items for discussion in the educational resource were developed. These items were generated during the round-robin sharing of ideas and are presented in Table 2 and Table 3.

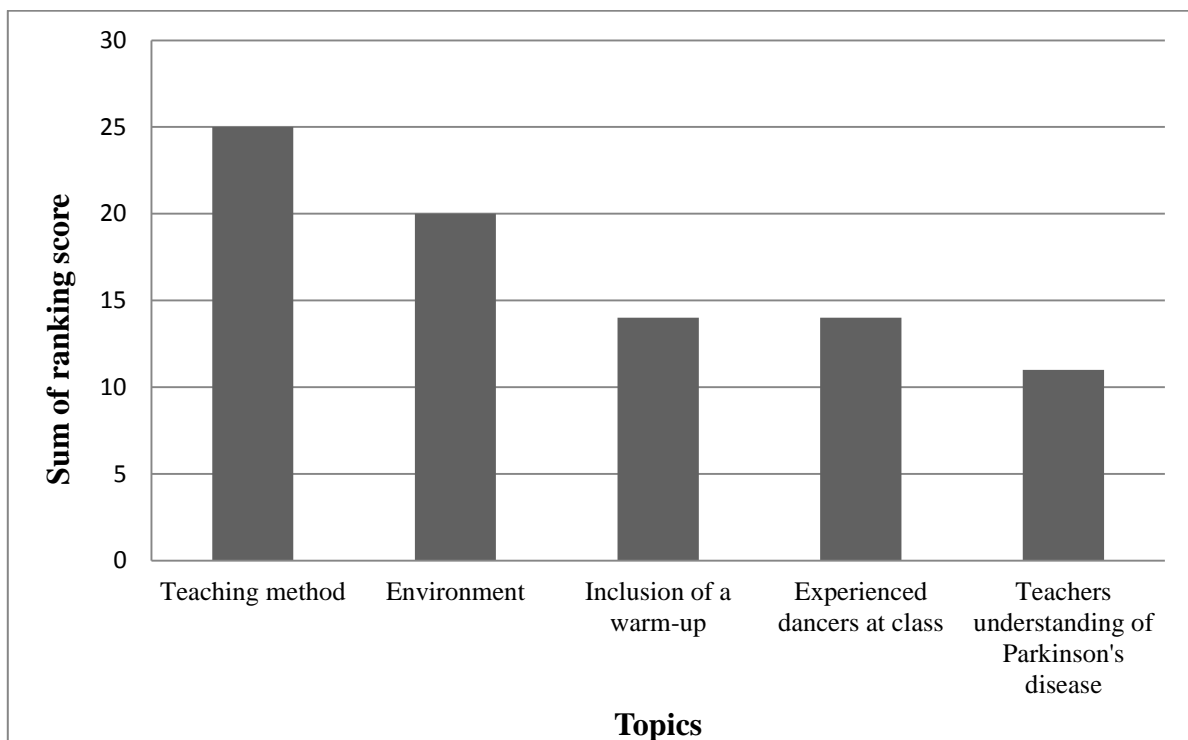
Table 1 Demographic Characteristics of participants with Parkinson's disease

Demographic Characteristic (n=6)	Values
Age (years)	70.5±8.5 (66, 79)
Hoehn and Yahr	2±1.13 (1, 2.5)
Gender (male/female)	4:2
Duration of disease (years)	9.5±13.75 (2, 18)
UPDRS-3	13.5±12.5 (7, 39)

Values are median± interquartile range (minimum, maximum values), UPDRS-3=Unified

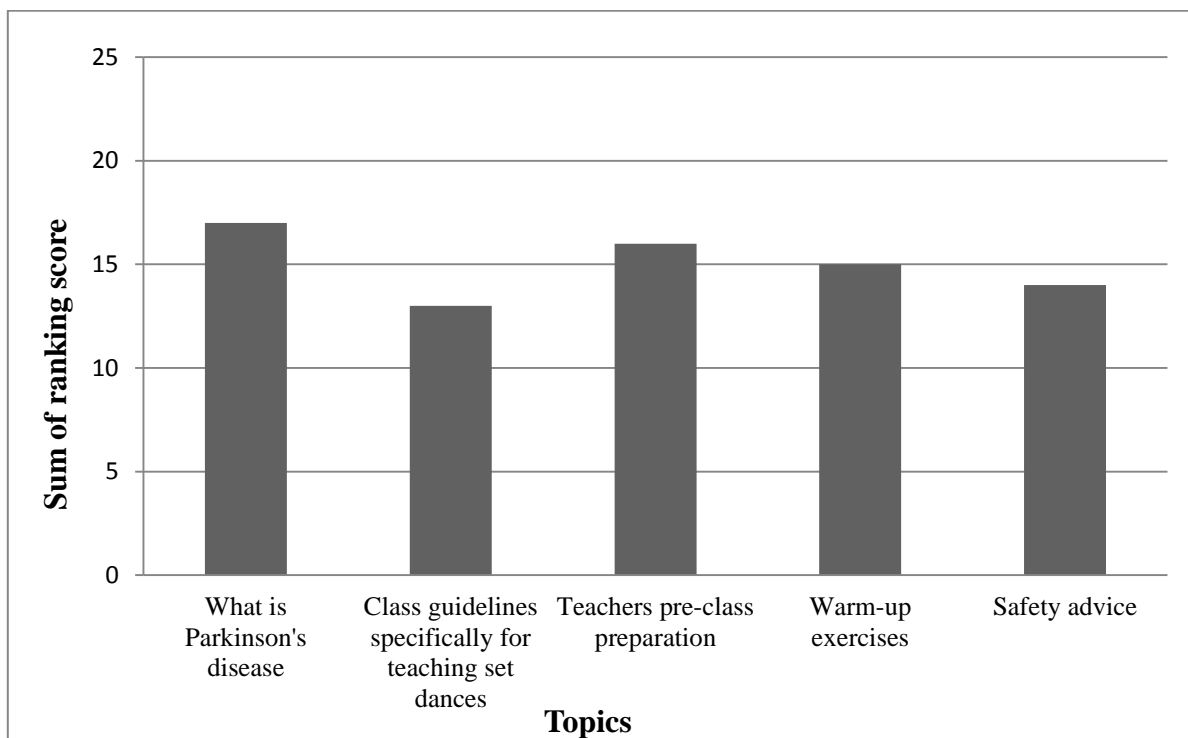
Parkinson's Disease Rating Scale Motor Section

Figure 1 Topic areas selected by people with Parkinson's disease



Numbers presented are sum of participant's ranks. Highest score represents most relevant topic. 30 was the highest achievable score.

Figure 2 Topic areas selected by set dancing teachers



Numbers presented are sum of participant's ranks. Highest score represents most relevant topic. 25 was the highest achievable score.

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Table 2 Topic areas and associated factors and/or items relevant to people with Parkinson’s disease

Topic area	Associated items for discussion
Teaching method	<ul style="list-style-type: none"> • Teacher should be familiar with all dancers past dancing experience • Steps and movements must be simplified into individual elements • Progress complexity of material in line with dancers ability • Never lose patience if some individuals are having difficulty learning steps/movements • Make all dancers feel “welcome” by modifying usual teaching method/ movements to each individual’s ability
Environment	<ul style="list-style-type: none"> • Teacher should create a relaxed atmosphere • Teacher should let conversation and friendships develop • Dancing class should be a pleasure to attend and dancers want to look forward to it • Teacher should not be strict and rigid when it comes to perfection of sets
Inclusion of warm-up	<ul style="list-style-type: none"> • Warm-up helps one “to get going” and moving • Needs to be enjoyable and exercises should be specific for people with Parkinson’s disease • Progression and new exercises increase motivation but complex exercises should be avoided
Experienced dancers at	<ul style="list-style-type: none"> • Helps with learning steps/ movements through observation

<p>class</p>	<ul style="list-style-type: none"> • Provides support • Provides motivation to learn set dancing • Nice to meet new people and mix with a wider social group
<p>Teachers understanding of Parkinson's disease</p>	<ul style="list-style-type: none"> • Teachers understanding is connected to the teaching methods they will use • Teachers knowledge of Parkinson's disease must be used to inform their teaching methods • Teachers should understand the individuality of symptoms associated with Parkinson's' disease and the different barriers they might have to overcome to help a dancer learn what is been taught • Teachers should understand that an individual's severity of Parkinson's disease may affect their ability to complete certain movements/steps. (Teachers should be able to modify in order to help these individuals achieve and learn) • Teachers should understand that practice is the key to motor learning for people with Parkinson's' disease • An individual's age should also be considered when devising a teaching plan

Table 3 Topic areas and associated factors and/or items relevant to set dancing teachers

Topic area	Associated items for discussion
What is Parkinson's disease	<ul style="list-style-type: none"> • Pathology • Symptoms • Different stages of disease and how to recognize those with different stage of disease • How dancing helps people with Parkinson's disease
Class guidelines specifically for teaching set dances to people with Parkinson's disease	<ul style="list-style-type: none"> • List of set dancing movements that are most beneficial • Suggested methods for teaching set dancing steps and movements
Teachers pre-class preparation	<ul style="list-style-type: none"> • Methods to adjust class material to suit varying degrees of ability • Suggestions toward communicating benefits of exercise and dance to people with Parkinson's disease to promote participation • Tips on how to ascertain if an individual is suitable based on observational assessment • Method for participants to identify improvements e.g. self-administered questionnaire of health/quality of life • Class scheduling required for benefit e.g. number of recommended sessions or weeks to run dance classes,

	suitable class times
Warm-up exercises	<ul style="list-style-type: none"> • A comprehensive list of exercises suitable for all stages of disease and progression ideas • Recommended warm-up time
Safety advice	<ul style="list-style-type: none"> • Strategies to help manage symptoms while dancing eg. Ways to overcome freezing of gait • Description of set movements/exercises that maybe problematic for people with Parkinson's • Suggestions for communicating with individuals who you feel may be unsuitable for set dancing

4. Discussion

4.1. Findings in context

For people with Parkinson's disease, participation in many daily and social activities as well as exercise and hobbies can be negatively affected by motor and non-motor impairments.^{9, 11, 25, 26} Community participation in exercise has been advocated to increase quality of life and socialisation. Notable, community involvement for this population may be difficult due to mobility limitations, poor balance, falls or lack of community infrastructure with respect to suitable amenities and services.^{7, 8, 27} To the authors' knowledge, factors important to the delivery of community led dance classes for people with Parkinson's disease are not known. As such, this study determined the needs of people with Parkinson's disease and lay community set dancing teachers in order to inform an educational resource and aid development of a community set dancing infrastructure for people with Parkinson's disease. The results show participants have multidimensional needs with respect to dance including personal, environmental, physical and knowledge-based factors. The identification of these needs will help to better understand participants' requirements from a dance class and ensure development of a participant-centred educational resource and dance classes. While this study focused specifically on set dancing, many of the factors identified are pertinent for delivering satisfactory classes in other dance genres and may be used by researchers or dance professionals involved in multiple community or rehabilitation dance programmes.

The results show that set dancing teachers require more information on the pathology of Parkinson's disease, the symptoms associated with the condition and the effect symptoms may have for learning and performing set dancing. This is an important finding as it shows the need for researchers and health professionals to engage, educate and empower community

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1 members to use their skills and develop dance programmes for people with Parkinson's
2 disease. Researchers and clinicians should consider the potential role of community-
3 healthcare partnerships,^{7, 27} whereby health professionals or researchers train or provide
4 educational resources to community experts to deliver community dance and exercise
5 programmes for people with Parkinson's disease. This approach may improve service
6 availability encourage community involvement, broaden social networks and increase
7 community knowledge so that dance and exercise programmes pertaining to the needs of
8 those with Parkinson's disease are made available. Providing adequate knowledge and
9 awareness will enable community experts such as set dancing teachers to make informed
10 decisions regarding appropriate dance material for those with Parkinson's disease or readily
11 modify dances to suit physical capacities, prevent falls and acknowledge the needs of each
12 individual.

13 Until now, little was known about environmental factors pertaining to the needs of
14 people with Parkinson's disease from a dance class. The findings of this study suggest people
15 with Parkinson's disease are very concerned with the social and emotional environment of
16 dance classes. People with Parkinson's disease ranked environmental factors higher than the
17 disease-specific knowledge of set dancing teachers (Figure 1). However, this may indicate
18 desires for dance classes that focus on enjoyment rather than disease related issues. In this
19 way, dance classes may help reduce anxiety²⁸ and fears about social interaction in people
20 with Parkinson's disease.⁷ Kleiner-Fisman et al²² also found people with Parkinson's disease
21 had greater emotional and social needs in relation to factors affecting quality of life than
22 disease-specific parameters. Therefore, to create participant-centred dance classes,
23 researchers, dance instructors and health professionals should identify strategies to optimise
24 participants' social experience and emotional satisfaction. The class environment appears to
25 be particularly important as Allen and Morey²⁹ found higher levels of adherence were

1 reported in exercise programmes fostering a sense of social cohesion and support. Socially
2 stimulating environments may increase neuroplasticity,³⁰ and help activate limbic areas and
3 non-dopaminergic neurotransmitters associated with fatigue, depression and other non-motor
4 symptoms linked with Parkinson's disease.³¹ Furthermore, the cultural context of Irish set
5 dancing may enhance these qualitative aspects as common cultural interests and identities can
6 foster a sense of togetherness and friendships.^{32, 33} For non-Irish populations, knowledge of
7 the cultural heritage associated with set dancing may stimulate nostalgia and conversation
8 with respect to their native traditions and create a sense of common understanding, safety and
9 aid development of social networks.

10 Notably, this study shows the degree to which set dancing teachers and people with
11 Parkinson's disease concur about teaching methods. In particular, participants were
12 concerned with the aspect of breaking down dance steps and movements. The use of
13 appropriate teaching methods in dance is very important to reduce falls risk, prevent
14 festinating and freezing of gait, facilitate movement and enhance motor skill learning.³⁴ It is
15 also important for those involved in dance interventions to know which aspects of dance may
16 exacerbate these movement difficulties aforementioned and understand the teaching
17 strategies that may minimize their occurrence. Research has shown movement strategy
18 training can be used to facilitate motor learning and correct execution of movements.³¹
19 Notably, the suggestion from participants to "break down movements" is comparable with
20 the principles of movement-strategy training and thus maybe one approach for teaching set
21 dancing and other dance forms to people with Parkinson's disease. Additionally, the use of
22 music in set dancing may act as an external cue and facilitate movement by entraining motor
23 output to the rhythmic beat of Irish music.¹⁹ Music may have positive implications for
24 symptoms of depression in people with Parkinson's disease as it activates the mesolimbic-

1 striatum network³⁵ and the Amigdala, that is the neural substrate where emotional reactions
2 to music are processed.³⁶

3

4 *4.2. Wider implications and transferability*

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6 In this study the authors sought to establish the needs of people with Parkinson's
7 disease and set dancing teachers in order to inform the content of an educational resource for
8 set dancing teachers. This may enable development of community set dancing classes for
9 people with Parkinson's disease and help prevent secondary consequences of physical
10 inactivity.⁴ With acknowledgment of the recognised link between physical activity and health
11 in those with chronic diseases,^{5, 37, 38} future studies may use similar approaches in order to
12 develop the infrastructure of safe and sustainable community dance and exercise programmes
13 for people with Parkinson's disease. Involving both service users and providers in the
14 development of the current educational resource was necessary to enhance relevance, value
15 and usability and maybe an important methodological consideration for future studies
16 developing health communication material.³⁹ Exploring the needs of set dancing teachers will
17 ensure appropriate information is available to help facilitate safe and beneficial dance classes.
18 Conversely, informing set dancing teachers of the needs and opinions of people with
19 Parkinson's disease is equally important to foster long-term participation and satisfaction in
20 set dancing. Ultimately, this may reduce reliance on the health system and promote health
21 and wellbeing through the neuro-protective effect of exercise.³¹

22 A limitation of this study is the small sample size. However, a low number of
23 participants in each group was preferable to allow in-depth exploration of topics and
24 encourage active involvement from all participants.²²

25

1 **5. Conclusion**

2

3 Community physical activity programmes are important in the self-management of
4 Parkinson's disease. Unfortunately, access to resources or the availability of community
5 physical activity programmes for those with Parkinson's disease can be limited. This paper
6 examined the needs of people with Parkinson's disease and set dancing teachers in relation to
7 set dancing. The inclusion of service users and providers in this study will allow the needs of
8 both groups to be represented in an educational resource that aims to guide set dancing
9 teachers delivering set dancing classes to people with Parkinson's disease. This approach
10 may help sustain interest, enjoyment and motivation in set dancing. Furthermore, this study
11 enables the provision of guidelines to enhance the experience of those engaging with set
12 dancing for Parkinson's.

13

14 **Declaration of Interest**

15

16 The authors report no declarations of interest.

17

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