



PEARL

Co-production with people with Parkinson's disease: making physical activity effective, meaningful and sustainable

Hunter, Heather; Gorst, Terry

Published in:

JBI Database of Systematic Reviews and Implementation Reports

DOI:

[10.11124/jbisrir-d-19-00088](https://doi.org/10.11124/jbisrir-d-19-00088)

Publication date:

2019

Link:

[Link to publication in PEARL](#)

Citation for published version (APA):

Hunter, H., & Gorst, T. (2019). Co-production with people with Parkinson's disease: making physical activity effective, meaningful and sustainable. *JBI Database of Systematic Reviews and Implementation Reports*, 17(4), 442-443. <https://doi.org/10.11124/jbisrir-d-19-00088>

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Wherever possible please cite the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

Co-production with people with Parkinson's disease – making physical activity effective, meaningful and sustainable

The tide is turning: service users are challenging the traditional bio-medical model, which focusses on illness treatment and neglects the role of patients in the provision of care. “We want person-centred care: people having as much control and influence over their care as possible – as patients, carers and members of communities” is the mission statement of National Voices.¹ Formed in England in 2008 from an alliance of 150 health and social care charities, the purpose of the alliance is to provide a forum for stakeholder involvement of service users and carers in developing national policy.¹ In the ongoing battle against Parkinson's disease, establishing the needs of people with this often debilitating and long term condition, and collaborating as equal partners to design appropriate physical activity interventions is essential. Doing so may go some way to ensuring this valuable intervention is fun, engaging and, most importantly, effective.

The benefits of physical activity for people with Parkinson's disease are widely recognized. Physical activity interventions may take many forms: structured exercise programs, leisure-based activities such as dance, tai chi and walking groups, and even occupational or household activities. Research efforts to date have understandably focussed primarily on the efficacy of structured exercise programs in people with Parkinson's, demonstrating improvements in neurophysiological, physical and functional outcomes.²⁻⁴

The research literature however often fails to evaluate whether participation in such programs encourages or facilitates sustained engagement once they cease. Most exercise program within research studies tend to be supervised and limited to a finite number of sessions over several weeks. Despite often revealing beneficial physical and mental benefits for participants, most studies have limited follow-up once the program ends and/or fail to consider its sustainability. Given the attrition rates from similar programs with other long term conditions, it is postulated that the benefits of time-limited programs for people with Parkinson's disease, while effective initially, are unlikely to be maintained indefinitely.^{5,6}

Given such issues with sustaining engagement, one might assume that people with Parkinson's do not value nor appreciate the multiple benefits of exercise and physical activity. This does not appear to be the case; a survey of 1500 people with Parkinson's found 87% felt exercise and physical activity was important to them.⁷ Improved health, slowing the progress of Parkinson's disease and maintaining independence were reported as the main reasons for this. Findings from our recent systematic review of qualitative studies of people with Parkinson's disease who were physically active demonstrated they also valued choice, enjoyment and an inclusive social group when engaging in physical activity.⁸ We suggest these factors should be integral to the design of interventions that aim to optimize sustained engagement.

To date, however, the optimal physical activity intervention that provides physical and functional improvements, and also encourages sustained engagement remains elusive. Investigation for our review⁷ prompted us to question whether, as well-intentioned researchers and clinicians, we have for too long focussed on designing interventions that prioritize addressing impairments, whilst potentially overlooking what people with Parkinson's really want, that is, interventions that are enjoyable, accessible and inclusive, as well as providing social and meaningful functional outcomes.

A recommendation from our review⁸ is the need to involve, and not just consult, people with Parkinson's in the design and commissioning of physical activity programs. This inclusive approach, known as co-production,⁹ requires service users, healthcare professionals and policy makers to work together as equal partners to develop a model of service design which is meaningful to people with Parkinson's. Such a paradigm shift requires people with Parkinson's, as experts in their own condition, to be empowered to make decisions and recommendations to transform services.¹⁰ Professionals and policy makers should therefore actively engage with people with Parkinson's as equal partners in that transformation. Co-production, sometimes referred to as Public and Patient Involvement (PPI), is receiving greater prominence within the healthcare arena. For example, in the UK, the NHS Long Term Plan calls for a "fundamental shift" in the way the NHS works with service

users. It highlights the need to create genuine partnerships with service users and their carers in a shared responsibility for health, as well as encouraging partnerships with non-NHS health and social care providers.¹¹ Despite its well-intentioned and somewhat familiar recommendations, critics¹² highlight a lack of detail concerning how this may be achieved. Perhaps this is a missed opportunity.

While co-production is seen as the way forward in the design, delivery and evaluation of services, there is a lack of evidence about the best and most effective method of *how* to achieve this.¹³ Methodologies such as experience based co-design have demonstrated improvement in enhancing patient care in a number of clinical services such as cancer care, emergency medicine and mental health.¹⁴ Other methods include a “future workshop” approach, whereby relevant parties are invited to critique a current service and offer ideas and solutions to enhance the service, followed by a presentation of these ideas in a prototype form for checking and refinement.¹⁰ Embracing the co-production approach, Parkinson's UK and Sport England are collaborating to develop an innovative project: *Parkinson's Power*.¹⁵ Its aim is to help inactive people with Parkinson's disease become, and crucially stay, physically active. The project, informed by the findings of a two-day co-production conference, has involved a number of health and physical activity stakeholders, and crucially, people with Parkinson's and their families. We anticipate the findings with great excitement and hope the results will inform future service design.

Heather Hunter and Terry Gorst

School of Health Professions, University of Plymouth, Plymouth, UK;

The University of Plymouth Centre for Innovations in Health and Social Care: a

Joanna Briggs Institute Centre of Excellence.

References:

1. National Voices; [internet]. [accessed 13 March 2019] available at: www.nationalvoices.org.uk
2. Shu HF, Yang T, Yu SX, Huang HD, Jiang LL, Gu JW, et al. Aerobic exercise for Parkinson's disease: a systematic review and meta-analysis of randomized controlled trials. PLoS One 2014; 9(7): e100503.

3. Saltychev M, Barlund E, Paltamaa J, Katajapuu N and Laimi K. Progressive resistance training in Parkinson's disease: a systematic review and meta-analysis. *BMJ Open* 2016; 6(1): e008756.
4. Goodwin VA, Richards SH, Taylor RS, Taylor AH and Campbell JL. The effectiveness of exercise interventions for people with Parkinson's disease: a systematic review and meta-analysis. *Mov Disord* 2008; 23(5): 631-640.
5. Junker L and Carlberg EB. Factors that affect exercise participation among people with physical disabilities. *Advances in Physiotherapy* 2011; 13(1): 18-25.
6. Hendry M, Williams NH, Markland D, Wilkinson C and Maddison P. Why should we exercise when our knees hurt? A qualitative study of primary care patients with osteoarthritis of the knee. *Fam Pract* 2006; 23(5): 558-567.
7. The Parkinson's Alliance. Exercise and Parkinson's Disease with and without Deep Brain Stimulation; [internet]. [accessed 7 February 2019] Available at: www.parkinsonalliance.org/research-result/exercise-parkinsons-disease-with-and-without-dbs-a-closer-look-from-the-patients-perspective/
8. Hunter H, Lovegrove C, Haas B, Freeman J and Gunn H. Experiences of people with Parkinson's disease and their views of physical activity interventions JBI Database System Rev Implement Rep 2019; In press
9. Realpe AWL. What is co-production. *Health Foundation* 2010: 1-20.
10. Knowles S, Hays R, Senra H, Bower P, Locock L, Protheroe J, et al. Empowering people to help speak up about safety in primary care: Using codesign to involve patients and professionals in developing new interventions for patients with multimorbidity. *Health Expect* 2018; 21(2): 539-548.
11. DoH (UK) NHS long-term plan [internet]. [accessed 7 February 2019] Available at www.longtermplan.nhs.uk/
12. Charles A, Ewbank L, McKenna H and Wenzel L. The NHS long-term plan explained 2019 [internet] [accessed 7 February 2019]. Available at www.kingsfund.org.uk/publications/nhs-long-term-plan-explained#patients
13. Vennik FD, van de Bovenkamp HM, Putters K and Grit KJ. Co-production in healthcare: rhetoric and practice. *International Review of Administrative Sciences* 2015; 82(1): 150-168.
14. Bate P and Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care* 2006; 15(5): 307-310.
15. Parkinson's UK. Parkinson's UK and Sport England launch Parkinson's Power [internet]. [accessed 7 February 2019] Available at: www.parkinsons.org.uk/news/parkinsons-uk-and-sport-england-launch-parkinsons-power