



PRISM (Parkinson's Real-world Impact aSsessMent): an ongoing study of the burden of Parkinson's in Europe

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INTRODUCTION

Parkinson's affects approximately 1.2 million people across Europe¹ and places a significant burden on people with Parkinson's (PwP), their care-partners, healthcare and social care services².

While core healthcare resource use and drug spending in Parkinson's have been widely studied, there is a paucity of data on real-world treatment patterns, the wider use and costs of support and therapeutic services and the true burden that PwP and their care-partners live with for a substantial period of time.

By focusing on these issues, PRISM aims to:

- Better characterise the burden of Parkinson's; and
- Explore relationships between treatment patterns, symptoms, healthcare and social care resource utilisation and quality of life for PwP and their care-partners.

OBJECTIVE

The survey method and recruitment are outlined. Demographic data (age, gender) collected (including from a pilot study of UK respondents) are presented.

METHODS

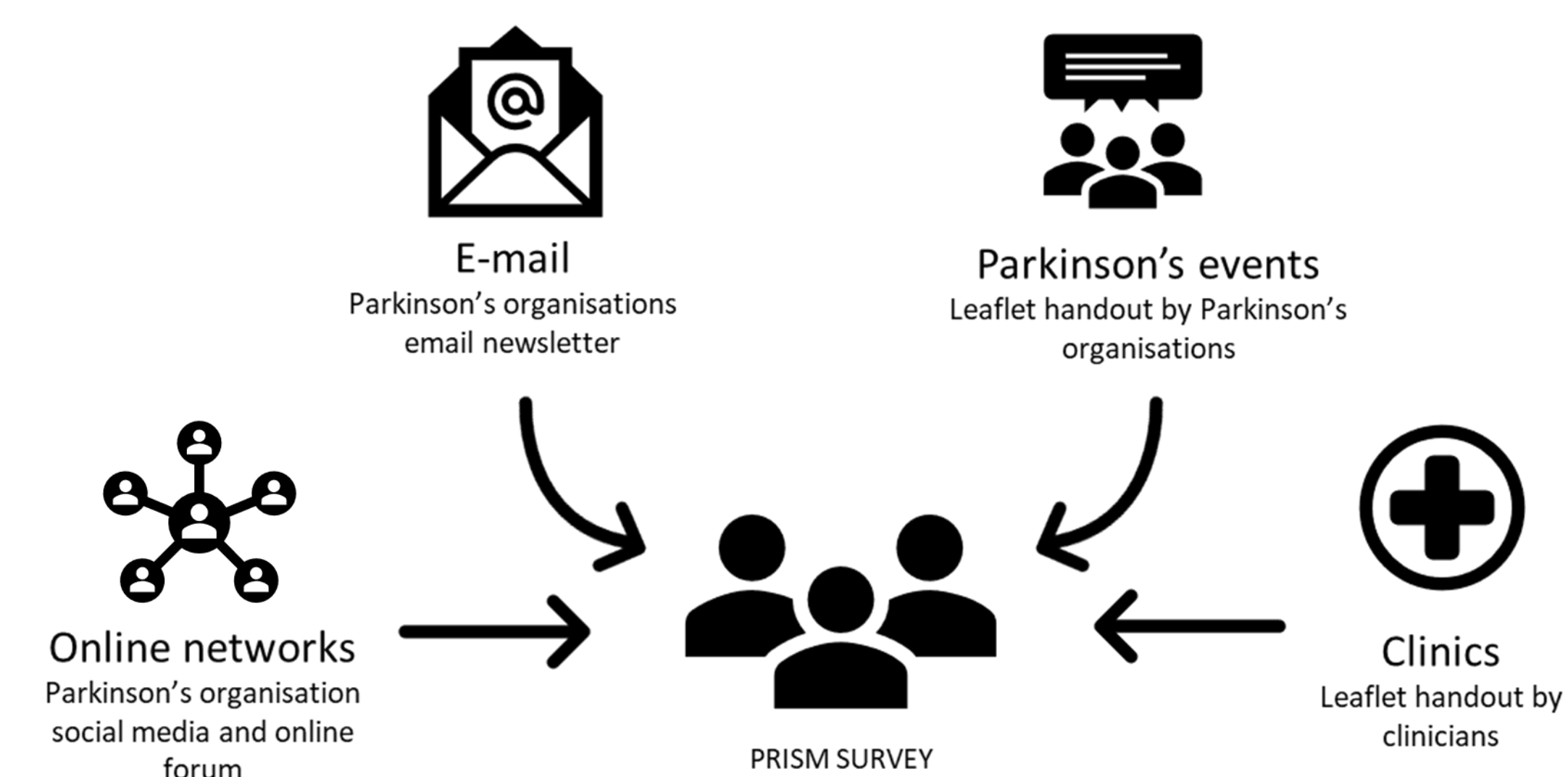
PRISM is a cross-sectional study conducted by a European team, fielded as a web-based survey. PwP were involved in survey development (information collected is summarised in Table 1). The potential limitation of self-reporting is mitigated by the use of validated patient-reported outcome measures, where available.

Table 1: Information collected in the PRISM survey

Respondent characteristics	Country and region of residence
	Age (current and at Parkinson's diagnosis) and gender
	Education and employment status
	Rurality (distance from a specialist Parkinson's consultant)
	Other diagnoses (comorbidities)
Quality of life, motor and non-motor symptoms of Parkinson's	PDQ-39 (summary index score and individual domain scores)*
	Non-motor symptoms (NMSQuest#)
	Issues with impulse control
	Issues with sexual functioning
Healthcare service utilisation and out of pocket costs to PwP	Impacts of Parkinson's on relationships
	Medication use
	Hospital inpatient admissions
	Emergency Department attendances
	Consultations with neurologists, general practitioners and other healthcare professionals
Other financial costs to PwP	Mental health service use
	Community support service use
	Paid caregiver service use
	Aids, adaptations and supports
Ability to work and be active	Travel to access services
	Reduction in working hours or early retirement
Questions completed by care-partner	Reduction in daily activities
	Age, gender, relationship to PwP
	Zarit Burden Interview [†]
	Impact of Parkinson's on relationship with PwP
	Care-partner support service use

PwP=People with Parkinson's

Figure 1: Recruitment channels



RECRUITMENT

The PRISM survey will remain open over the European summer. It is available in English, French, German, Italian, Portuguese and Spanish. Recruitment is open to all PwP and their care-partners. Figures 2 and 3 provide a snapshot of recruitment at 10 May 2019.

Figure 2: Respondents by country, 10 May 2019

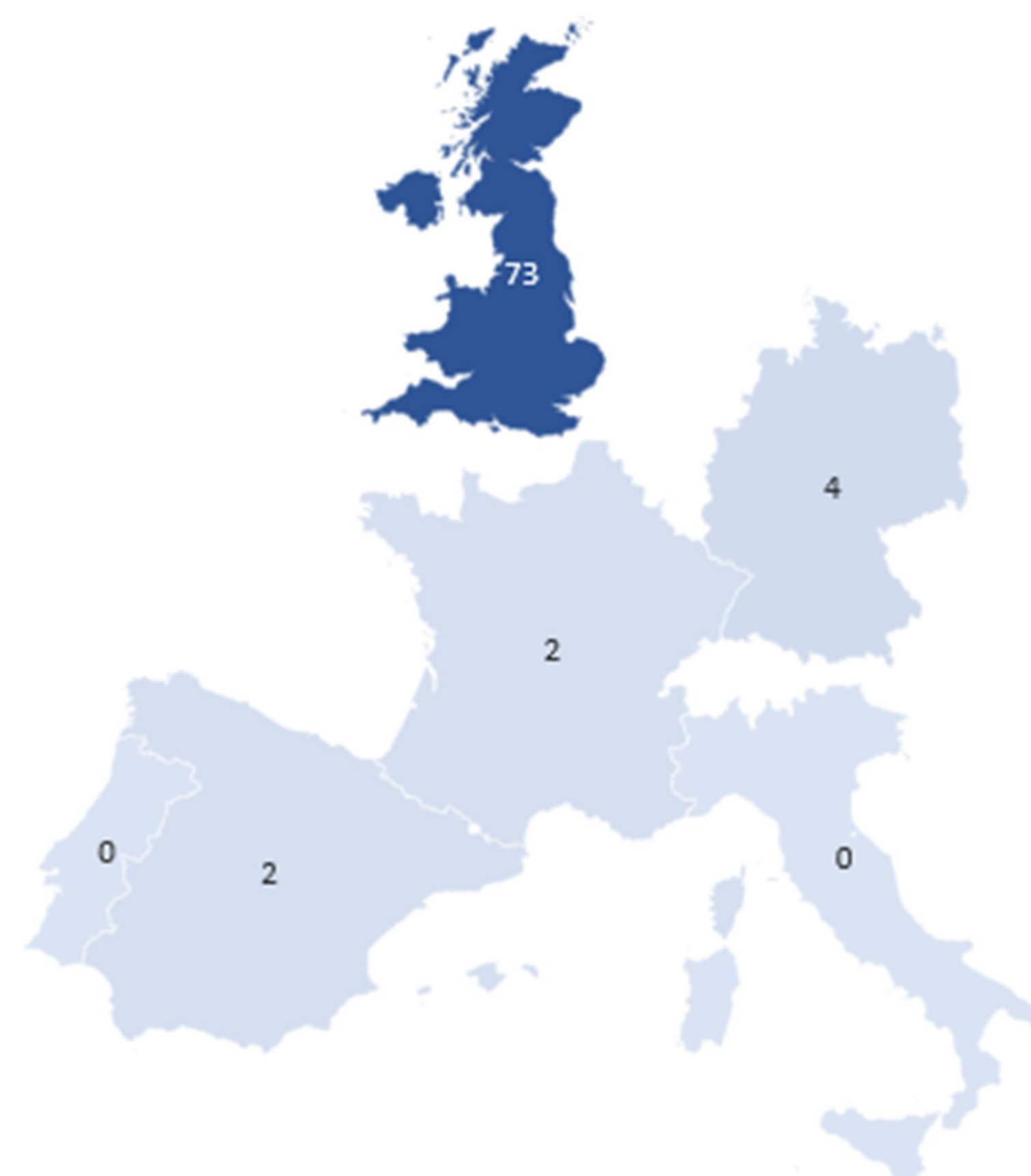
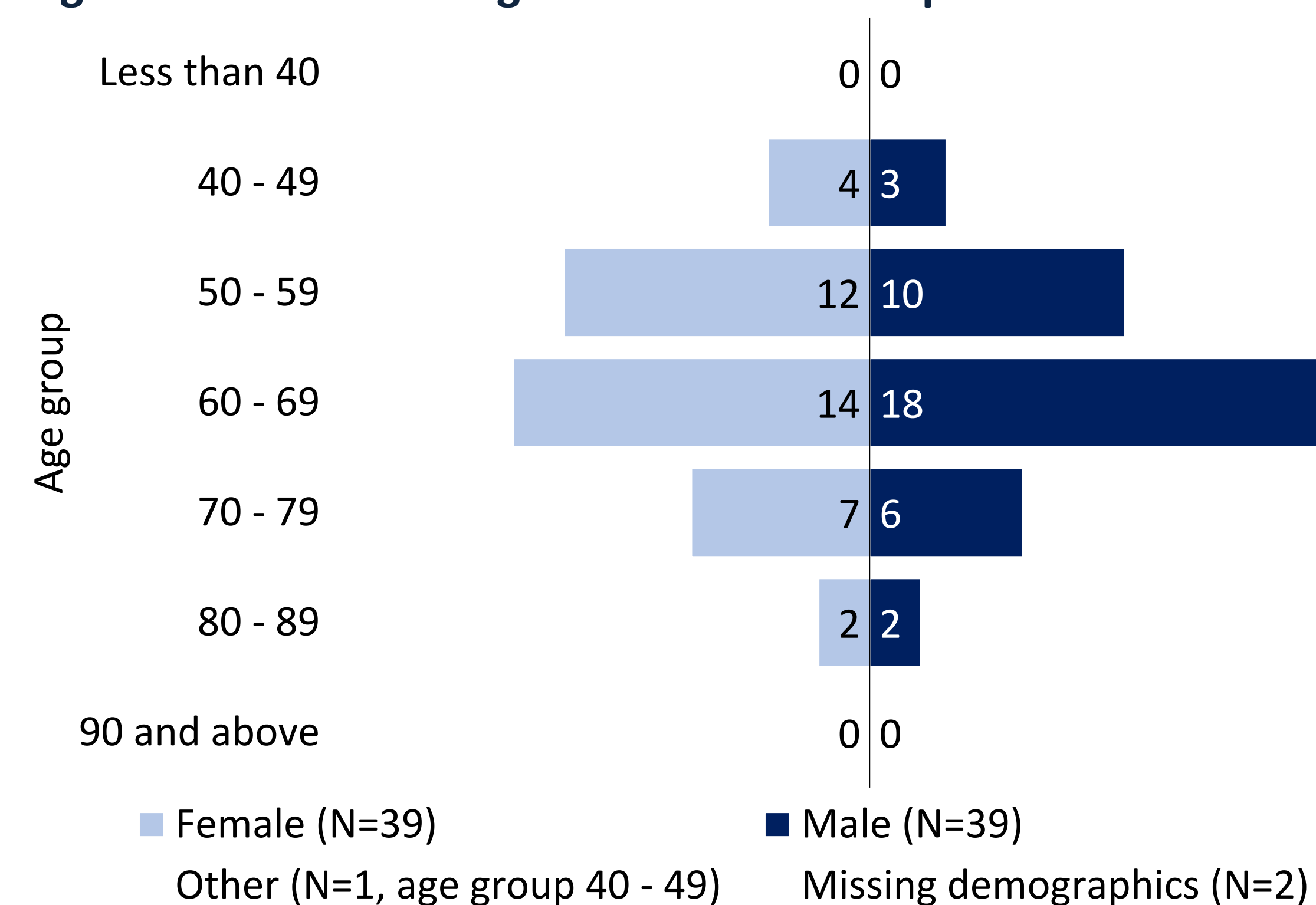


Figure 3: Gender and age breakdown of respondents



54% Have completed some university education

82% Live within 50km of their Parkinson's specialist

COMMENT

Data collection remains in the early stages. The majority of respondents reached the survey through internet-based advertising. They are a relatively young, well-educated and urban demographic of PwP, with balanced gender.

Additional channels, such as those indicated in Figure 1, are being explored to recruit a broad representation of PwP and to expand reach to France, Germany, Italy, Portugal and Spain.

Anticipated data (at least 100 participants are sought from each country) may inform improvements in Parkinson's management and evidence-based resource allocation.

NOTES AND REFERENCES

* PDQ-39 © Copyright, Oxford University Innovation Limited 1993. All Rights Reserved. The authors, being Professor Crispin Jenkinson, Professor Ray Fitzpatrick and Ms Viv Peto, have asserted their moral rights.

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† Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit.

1 Collaborators GPsD. Global, regional, and national burden of Parkinson's disease, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2018;17(11):939-953.

2 Gustavsson A, Svensson M, Jacobi F, et al. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol.* 2011;21(10):718-779.

Abbreviations: UK, United Kingdom

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