



parkinson's
australia

Ecosystem of Parkinson's in Australia Project

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for Parkinson's Australia, January 2024

Part 1: Scoping Study

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Executive Summary

As the national advocate for the Australian Parkinson's community, Parkinson's Australia prioritises the need to work with our stakeholders to raise national awareness of Parkinson's, educate and empower the community about Parkinson's and ultimately create better outcomes for all those impacted by Parkinson's in Australia. To achieve these goals there is a need to the best possible evidence base to support our advocacy.

The Board of Parkinson's Australia commissioned the Ecosystem of Parkinson's in Australia Project with the aim to gather the best available information about the current impact of Parkinson's in Australia, to identify critical gaps in the available evidence base and to recommend, where needed, potential new directions of investigation that might enable this information to be collected and disseminated.

The project is multifaceted and ongoing. It is intended that various parts of the project would be released as individual report documents addressing specific issues. Ultimately Parkinson's Australia hopes that the Ecosystem Project will promote better community awareness, advocacy and connection, and reduce the burden of Parkinson's in Australia.



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Parkinson's Facts

Parkinson's is the second-most common neurological condition in the world, but remains one of the least understood.



52% are
male



48% are
female



Cost to economy
>\$10 billion p/a



Part One

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1. Part one summary

Part one of this report series sets out the history and initiation of the Parkinson's Australia-commissioned Ecosystem of Parkinson's in Australia Project.

This scoping study is designed to set out some critical questions that require formal research to address issues of importance for future efforts to advocate for people living with Parkinson's in Australia. It highlights specific areas of interest where limited information currently exists and provides a basis for future efforts to address these areas.

This is the first part of a multifaceted project, results of which will be released in due course.



PART ONE

Ecosystem of Parkinson's in Australia Project

2. Background & purpose

In March 2022, the Board of Parkinson's Australia agreed to conduct a scoping study to investigate the Ecosystem of Parkinson's in Australia with a view to gathering important information critical for the organisation's planning and advocacy as the peak national body representing people affected by Parkinson's disease (PD) across Australia. Parkinson's Australia previously commissioned reports from consultants (Deloitte Access Economics, see refs 1, 2, 3) to provide information on the impact of PD and related disorders to Australia in terms of financial and social burden.

The first of these reports, published in June 2007, was funded by an unrestricted grant from a number of industry stakeholders including Mayne Pharma, Medtronic Australasia, Novartis and Pfizer. The report provided the first national analysis of the burden of Parkinson's, summarising information for 2005. Subsequent updates, funded independently by Parkinson's Australia, were published in 2011 and 2018. Each provided very similar information, corrected for the changing demographics of the Australian population at that time.

These reports continue to be a source of useful evidence that has been widely used for awareness raising and advocacy to all levels of Government and other societal stakeholders nationally.

Recent discussions at the Parkinson's Australia Board level and elsewhere highlighted a significant need to gather additional and updated information as a basis for future efforts to forward our organisation's [Strategic Plan](#) (see Ref 4):

- Priority 1 to work collaboratively with other organisations.
- Priority 2 to raise national awareness of Parkinson's and its impact.
- Priority 3 to educate and empower key stakeholders.

3. Project initiation

Defining the aims of the project

The scoping study was launched to fill in some crucial knowledge gaps. The project aims to establish a framework that includes specific recommendations for future research. The goal is to prioritise key questions that require attention, identify applicable methodologies, and potential collaborators. This will ensure that the resulting information is the most rigorous, influential, and world-leading in this field.

Specific questions

Despite the important modelling provided in the previous Access Economics Reports (Deloitte, 2007, 2011, 2015), there has been very little evidence testing to determine the veracity of the estimations and assumptions made in these analyses. Whilst these estimates have been made using the best available data, these data are significantly limited by methodological difficulties and a paucity of local information. The Parkinson's community has settled on a mantra of "there are more than 100,000 people living with Parkinson's in Australia" with limited solid data to be more precise. Parkinson's Australia presents as fact a series of figures generated from the previously commissioned reports (see Figure on the next page).

Other groups use these or their own estimates, some of which may differ significantly, based on unpublished or uncertain evidence. It is crucial that there is a firm basis from which our advocacy can be promoted and the information we provide should be up-to-date and of the highest possible quality.

Variations in Parkinson's figures across Australia



FIGHT PARKINSON'S VIC
219,000



PARKINSON'S NSW
84,000 TO 212,000



PARKINSON'S QLD
130,000



PARKINSON'S TAS
200,000



PARKINSON'S WA
100,000



SHAKE IT UP FOUNDATION
200,000

PER THEIR STATISTICS ON WEBSITE AS AT 5/2/2024

Specific questions continued

There are also many questions that require rigorous investigation to provide satisfactory answers. These include:

1. How many people develop PD and Parkinsonism in Australia every year?
2. How many people live with PD and Parkinsonism in Australia?
3. Where do they reside?
4. How many live in Regional, Rural and Remote Australia?
5. How many are from low socio-economic communities?
6. What is the distribution of PD and Parkinsonism in diverse social Australian communities including: First Nations Communities; Polynesian and Melanesian Communities; Asian Communities; Other Immigrant Groups?
7. How does the disparate background of Australians Living with Parkinsonism influence their access to diagnosis, treatment and general care? Does this influence their Parkinson's journey? What is the economic and societal impact of these issues?

Adjunct questions

There are also many questions that require rigorous investigation to provide satisfactory answers. These include:

1. Have there been any recent updates to the previous work done to examine prevalence and incidence of PD in Australia and internationally? What methods can be used and what are their advantages and limitations? What is known about the distribution of people at different stages of PD and the transitions between stages?
2. What is currently known about the population distribution of Australia in terms of different social groups and community clusters (e.g. regional, rural, remote)? How is this reflected in the distribution of PD across these areas?
3. What do we already know about the challenges for health care in these different social groups? How are these manifest for people living with Parkinson's?
4. Have researchers in other relevant areas previously addressed societal differences in prevalence, incidence and outcomes in similar conditions for defined groups? How have they done this?

4. Structure of the Ecosystems Project

This project is multifaceted and will consist of a variety parts, each of which will be released as completed. Among the initial documents is a systematic literature review around the current state-of-play with respect to the incidence and prevalence of Parkinson's internationally with a focus on studies from Australia. A separate document will, for the first time provide detailed modelling of the incidence and prevalence of Parkinson's in Australia by State, Statistical Area (as defined by the Australian Bureau of Statistics) and by Federal Government Electoral Division. This analysis will generate some projections of incidence and prevalence for future time periods. It will also provide the justification for the statistics used in Parkinson's Australia's "Parkinson's Facts".

Other report documents will be released in due course and can be found on our website at www.parkinsons.org.au.

5. References

1. Living with Parkinson's Disease: Challenges and Positive Steps for the Future, Report by Access Economics Pty Limited for Parkinson's Australia, Published 18 June 2007.
2. Living with Parkinson's Disease – Update, Report by Deloitte Access Economics, Published October 2011.
3. Living with Parkinson's Disease – An updated economic analysis 2014, Published 2015
4. Parkinson's Australia Strategic Plan, 2024-2026



We thank you for your continued support
in our efforts to contribute to knowledge
about Parkinson's.



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