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2024-25 Pre-Budget Submission

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About AbbVie

AbbVie is a research-based biopharmaceutical company committed to discovering, developing and delivering innovative new medicines with distinct and compelling benefits for people. In Australia, more than 90,000 patients currently benefit from our medicine, with over 2 million PBS prescriptions written for AbbVie products in the 2022-23 financial year. As a member of Medicines Australia, AbbVie actively contributes to ensuring Australians have access to sustainable innovative medicines.

Our therapeutic focus areas include immunology, oncology, eye care, virology, and neuroscience. Within our areas of focus, we build on a deep understanding of biology and unmet patient needs to pursue world-class medicines and solutions for a number of diseases and conditions including Parkinson's Disease.

In this pre-budget submission, we review the burden of Parkinson's Disease (PD) and propose actions that the Australian Government can take together with other stakeholders to minimise the future consequences of this devastating disease.

AbbVie also supports Medicines Australia's pre-budget submission that calls for 1) funding to support the implementation of their Roadmap for Health Technology Assessment (HTA) Reform over 3 years, and 2) enhanced reporting of investment in F1 medicines.

Recommendations

1. Increase the understanding & awareness of PD

    a) Commission the AIHW to conduct an in-depth study and ongoing reporting on PD, covering epidemiology, disease burden, social and economic impact, at national, state and regional level. Cost over the forward estimates: $0.5m
    b) Funding for a public awareness campaign on PD and General Practitioner education program (to be led by Parkinson's Australia).[1] Cost over the forward estimates: $2m over 2 years.

2. Address the complexity and capacity constraints associated with managing advanced PD patients

    a) Provide Medicare Benefits Scheme (MBS) subsidies for the initiation and titration of infusion-based therapies through new MBS items to reflect clinician and nurse workload.

Introduction

AbbVie welcomes the opportunity to provide input into the priorities for the 2024-25 Federal Budget. With more than three decades of experience in neuroscience, AbbVie's commitment to preserving the personhood of people living with neurological and psychiatric disorders is unwavering. We provide meaningful treatment options for patients today and are advancing innovation for the future through investment in research. We are committed to continuing to advancing outcomes for those impacted by neurological conditions. This submission focuses on PD, the fastest growing and second most prevalent neurological disorder after Alzheimer's disease.[2]

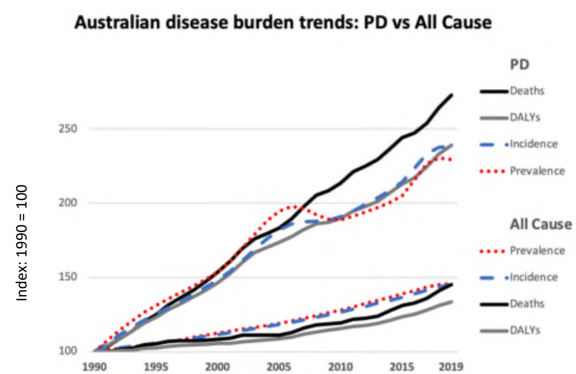
PD is a degenerative condition that affects movement, mood and cognitive function.[3] Increasing age is the main risk factor for the disease[3] however 10-20% of diagnoses occur in people under the age of 50.[4] The prevalence of PD is difficult to estimate given challenges in identifying and diagnosing people living with the disease. Australian figures vary from the Australian Institute of Health and Welfare's (AIHW) 2019 estimate of 60,252[5] to Deloitte's 2024 projection of 94,000[6] to a more recent script-based estimate of approximately 120,000 in 2022.[7] These estimates do not account for undiagnosed patients, and with an estimated 3 patients going undiagnosed for every 10 diagnosed, the number of patients with PD may be up to 30% higher.[6] A recent study of US data notes similar challenges with estimating PD prevalence and calculates that there may be 50% more PD patients in the US than previously thought.[8]

People living with PD face diminishing quality of life and independence as their disease progresses, relative to their peers. The median time from disease onset to death is 12.4 years.[6] While there is currently no cure for PD, effective clinical management and exercise can improve functioning and help patients live productive lives.[3,9]

Despite the significant burden that PD imposes on Australia's health, it is not currently recognised as a National Health Priority Area[10] nor is it included as one of the chronic diseases tracked within The Treasury's *Measuring What Matters* well-being framework.[11,12] As noted in the *Intergenerational Report*, population aging is one of the major forces shaping Australia's future.[13] The profound impact that PD will have on the lives of increasing numbers of Australian patients and their families needs urgent attention. In this submission, we review the burden of PD and propose actions that the Australian Government can take together with other stakeholders to minimise the future consequences of this devastating disease.

PD is imposing a growing burden on Australia

PD incidence, prevalence, disability-adjusted life year loss and death have all more than doubled in Australia over the past thirty years. This compares starkly with the all-cause disease burden where no measure has grown by more than 50%.[5] Most of the growth in the PD burden can be explained by Australia's aging population. However, even when mortality data is age standardised, PD death rates have still grown by around 10% since 1990 vs a *39% decline* for all-cause mortality.[14]



Source: IHME - Global Burden of Disease Study (2019)

In addition to its health impact, PD also has significant negative economic consequences. Deloitte estimated that PD cost Australia nearly $10b in 2014, of which $1b was the financial cost of treatment, care and employment loss, and $9b the economic loss that the disease burden imposes on patients.[6] The $1b in financial costs can be roughly equally split between:

- Residential aged care
- Medical care (medicines & services)
- Productivity losses, and
- Other costs, including informal carer costs and welfare payments.

12% of people with PD live in residential care facilities; between 2005 and 2014 the number requiring residential care increased by 55%.[6] The lifetime cost of PD was $161,300 per person in 2015, higher than the lifetime cost for cancer patients.[6] Deloitte calculated that most costs are incurred in the later stages of the disease, which is supported by a recent study of PD patients in Melbourne showing that the health costs of patients with moderate to severe disease were four times greater than those with mild PD.[15]

The Deloitte study was completed before the full implementation of the National Disability Insurance Scheme (NDIS). While the NDIS isn't available to over 65s there would still be

thousands of working aged people living with PD that would currently be eligible. Overall, Deloitte calculated that the financial costs of PD more than doubled in the nine years between 2005 and 2014.[6] It is quite possible that they doubled again in the nine years to 2023.

The $9b estimate of economic loss arising from PD's burden is unsurprising given the high levels of disability associated with the disease. While this is an estimated value rather than an actual cost incurred by government or households, it is still an important metric as it shows the profound burden that people living with PD carry and quantifies the potential benefit that alleviating this suffering could deliver.

Australia needs better understanding and awareness of PD

As noted earlier, the official estimate of PD prevalence[5] in Australia is three times lower than a commonly referenced study.[7] This represents a concerning evidentiary gap given epidemiological and disease burden data plays an essential role in prioritizing the level and allocation of health system resources.[8] The most cited PD disease burden reference in Australia is the Deloitte study[6] which was commissioned by Parkinson's Australia and is nearly a decade old. The paucity of data is particularly acute for regional and rural Australia,[16] which could be the areas most vulnerable to the disease given the lack of movement disorder specialist physicians outside of metro areas and the identification of exposure to agricultural chemicals as a potential risk factor.[7]

In last year's pre-budget submission, The National Neurological Alliance recommended that the Department of Health allocate funding to the AIHW for a scoping study and data report to address gaps in neurological data.[17] AIHW has conducted similar initiatives recently for Alzheimer's Disease and Epilepsy. This submission supports this recommendation.

Recommendation

1a) Commission the AIHW to conduct an in-depth study and ongoing reporting on PD, covering epidemiology, disease burden, social & economic impact, at the national, state and regional level. Cost over the forward estimates: $0.5m

Despite the rising incidence,[2] patient advocates lament that PD is not yet large enough to command the attention given to Alzheimer's or diabetes, but "not rare or unique enough to draw a media following".[1] Given the evidence that 3 patients go undiagnosed for every 10 diagnosed, the PD population may likely to be up to 30% greater than currently estimated.[6] The perception that PD is an old person's disease is also problematic: members of the public might overlook PD symptoms in younger people, even though under 50s make up 10-20% of PD diagnoses.[4] If more people were aware of the early warning signs of PD, rates of diagnosis as well as time to diagnosis could potentially be improved. This could lead to enhancements in the quality of life of these patients and their families.

A two-year National Awareness Campaign and an Education Campaign for GPs and Allied Health Professionals was proposed in last year's Pre-Budget Submissions by Parkinson's

Australia, and again in 2024-25 with the inclusion of a Lived Experience project. This project will tell the stories and distil the priorities of patients living across urban; rural, regional and remote areas; culturally and linguistically diverse communities; and indigenous communities.[1] Given the growing prevalence of PD in Australia and the importance of early symptom recognition in leading to diagnosis and intervention, this submission is also supportive of this recommendation.

Recommendation

1b) Funding for a public awareness campaign on PD and General Practitioner education program (to be led by Parkinson's Australia). Cost over the forward estimates: $2.5m over 2 years.

Address the complexity and capacity constraints associated with managing advanced PD patients

The clinical management of advanced PD patients is inherently complex, given that patients are likely to have lost both motor and non-motor function and are no longer independent in their daily activities.

The medical approaches which can be taken to improve the symptoms of advanced PD include deep brain stimulation (DBS), and the delivery of medication via intestinal or subcutaneous infusion. While the procedures associated with the placement and ongoing adjustment required for DBS are claimable via the MBS, no there is no similar provision for the initiation and ongoing maintenance of infusion-based therapies, despite the resource-intensive nature of managing patients who are receiving these therapies. This is an example of inconsistency across procedures and therapies, which was a key theme identified in the MBS Review 2015-2020.[18] Patient and carer education around how to use the device, as well as ongoing dose-optimisation requires large amounts of clinician and nurse time. This is challenging given the well-acknowledged capacity constraints of the multidisciplinary PD workforce and creates an inequitable system for both clinicians and patients which may ultimately negatively impact patient outcomes. Furthermore, the current lack of MBS items for infusion-assisted therapy-related procedures is not aligned with contemporary clinical evidence and practice as per the objectives of the MBS Review 2015-2020.[18]

This submission therefore recommends that MBS items be instated to reflect the complexity and resource requirements of initiation, ongoing titration and management of advanced PD patients on infusion-based therapies, allowing clinicians to claim a Medicare benefit for these procedures without increasing the cost to the patient.

Recommendation

2a) Provide Medicare Benefits Scheme (MBS) subsidies for the initiation and titration of infusion-based therapies through new MBS items to reflect clinician and nurse workload.

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