Inquiry into the provision of primary, allied and private health care, aged care and NDIS care services and its impact on the Queensland public health system

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Attention: Committee Secretary, Health and Environment Committee
Parliament House Brisbane

December 9 2021

Re: Submission to the inquiry into the provision of Primary, Allied and Private Health care, Aged Care and NDIS care services and its impact on the Queensland Public Health system.

Parkinson's Queensland Incorporated (PQI) is the peak body representing Queenslanders living with Parkinson's Disease (PD). In that role we present the following submission for consideration by the Committee.

Overview

It is estimated that there are in excess of 18,000 Queenslanders living with Parkinson's Disease (PD) and that number grows by approximately 2,000 new diagnoses each year across our state. PD is now the fastest growing neurological condition in the world with researchers predicting the number of people with the condition will double over the next 10 years. PD is progressive, degenerative and there is no cure, so its impact on the health system will only grow over time.

While 80% of those diagnosed are aged over 60 years, 20% (or 400 Queenslanders each year) are diagnosed with Young Onset Parkinson's. These are people in their 30s, 40s and 50s who are still working. Many have young families and many may be left to live with a life changing condition for 20 – 30 years.

Not enough is being done to provide Queenslanders living with PD with the support and care to optimally manage their condition, remain active and productive and keep them out of the public hospital system.

Queensland Health does not provide funding for Parkinson's related support through Parkinson's Queensland.

The Federal Government, through the Department of Social Services, provides modest funding equivalent to $50 per person per annum which allows Parkinson's Queensland to provide modest levels of support to approximately 2,500 Queenslanders, far short of what is required to meet the ever increasing demand.

PQI sought feedback from people living with PD and those caring for them and we are pleased to be able to share that feedback with the Committee in the hope that it will lead to an improvement in the access to appropriate care for Queenslanders living with PD.

Summary of Feedback from the Parkinson's community in Queensland

PQI asked Queenslanders living with PD, and those caring for them, to share their experiences across the areas of the health system outlined in the Inquiry's Terms of Reference:

a. primary and allied health care;
b. aged and NDIS care;
c. the private health care system;

72% of respondents were people living with PD and 28% were people caring for someone living with PD.

Services Accessed

We asked respondents to list the types of services they accessed on a regular basis and the percentage breakdown of services accessed is as follows:

Primary care and general practice: 92.11%

Allied health care: 23.68%

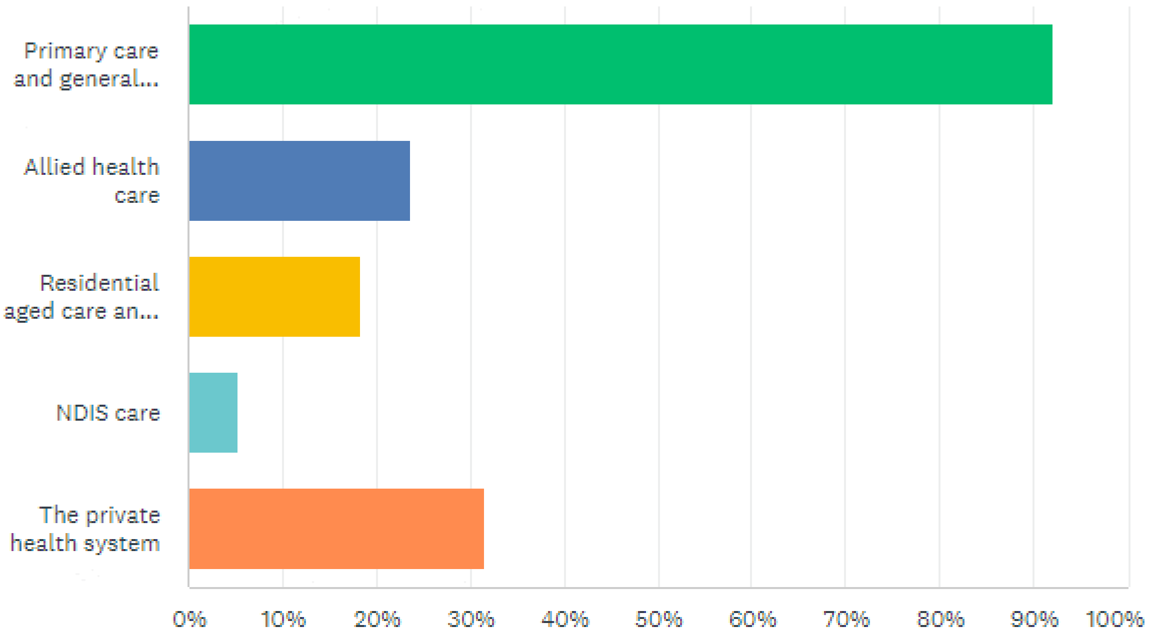
Residential aged care and My Aged Care: 18.42%

NDIS care: 5.26%

The private health system: 31.58%

These results clearly show that people living with PD are accessing a number of health services as they navigate the complexity of managing their condition.

Figure1. Areas of the health system accessed the most



Accessibility of health services

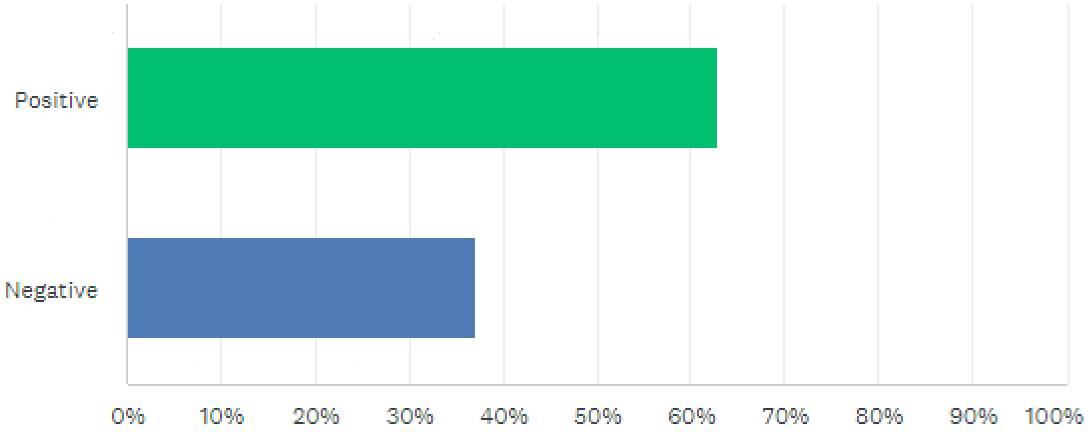
We asked respondents to rate their ability to access health services.

30% of respondents found it difficult or moderately difficult to access services, only 24% found it easy or moderately easy to access services while 46% found it neither easy nor difficult.

41% of respondents said that out of pocket expenses deterred them from accessing health services.

Overall, 63% of respondents had a positive experience when accessing health services, 37% had a negative experience. Based on feedback these figures were influenced by people's interactions with health staff.

Figure 2. Experience when accessing the health system



We then asked respondents to share more detailed information about their experiences accessing health services.

The main themes that emerged were:

1. A lack of knowledge about Parkinson's Disease within;
   - General Practice
   - NDIS Assessors
   - My Aged Care Assessors
2. A lack of Parkinson's Specialist Nurses in Queensland that can be readily contacted
3. Long wait times to access specialist Parkinson's health services
4. Travelling long distances to access Parkinson's specialist health services

The majority of respondents felt that GPs have little to no knowledge or understanding of PD. They also felt that accessing the NDIS and My Aged Care was made more difficult by the fact that Assessors have little to no knowledge or understanding of PD and its impacts on daily life.

Approximately one third of respondents raised the lack of Parkinson's Specialist nurses in Queensland. Some cited their experiences in the UK and WA with access to Parkinson's nurses and the benefits these interactions made on their PD journey. It is worth noting that Parkinson's Queensland has raised the need for Parkinson's Specialist Nurse Educators on several occasions with the Queensland Health Minister. While there are 6 Movement Disorder Nurse Navigators within the Hospital and Health Service, these roles are only available within the public hospital system. This means that people living with PD do not have access to them unless they have been admitted to a Movement Disorder Clinic. In states including WA, NSW and Tasmania, Parkinson's Specialist Nurses are funded by the respective State Governments through the Parkinson's peak bodies in each State. These nurses are in the community and play an important role in supporting, informing and educating the Parkinson's community.

Another theme that emerged was the long wait times to access Parkinson's specialist services including Neurology. It's worth noting that 41% of respondents also commented that out of pocket expenses had deterred them from accessing health services. Therefore anyone unable to afford private health services would have a longer wait for public services. Parkinson's Queensland Inc. (PQI) has received anecdotal evidence that some Queenslanders with Parkinson's are waiting anywhere from 8 – 18 months to see a Neurologist through the public health system. Given the progressive and degenerative nature of PD, these wait times are unacceptable.

Feedback from the Queensland medical community

We received feedback from members of the medical community, some working within the public health system. They identified a distinct gap in support for PD patients, in particular for those who are newly diagnosed with PD.

Patients who are newly diagnosed are largely left to their own devices with little to no support. If they find PQI we can provide them with some initial information and support however our limited resources mean that we can only support around 370 of the 2,000 Queenslanders newly diagnosed each year. Queensland Health does not provide adequate support to newly diagnosed patients and does not fund PQI to provide that support.

The gap is particularly acute in rural and regional Queensland. By way of example, there are only two Neurologists who specialize in Parkinson's across the whole of Far North Queensland (FNQ). Many newly diagnosed patients have to travel to Brisbane for treatment. Many Parkinson's patients in FNQ have their disease managed by a GP who has little knowledge of PD. There is one Movement Disorder Clinic in FNQ that runs once a month for just 3 hours and can only see 14 patients a month, this is means many people are missing out on treatment.

In a region where we know there is a large Parkinson's population there needs to be more access to Parkinson's specialist services. There are also no Parkinson's specialist nurses in FNQ, something PQI has also highlighted to the Queensland Health Minister. PD specialist nurses could take on some of the education, information and support roles for those who are newly diagnosed, as well as those who are already on a PD journey, helping to improve their wellbeing and quality of life and keeping them out of an already stretched hospital system.

On the Sunshine Coast, Maleny Soldier's Hospital ran a very successful Movement Disorder Clinic which made a significant difference to the lives of people living with PD. That clinic has been moved to the Sunshine Coast University Hospital and its services significantly reduced. This means that people living with PD on the Sunshine Coast have significant wait times to access the clinic.

Overwhelmingly, the feedback has been that people living in rural and regional parts of Queensland have little to no access to Parkinson's specialist services and many have to travel to Brisbane to receive treatment and support.

Summary

The feedback received by Parkinson's Queensland highlighted some key gaps which are leading to suboptimal services and treatment options for people living with PD. The lack of knowledge amongst General Practitioners is extremely concerning as GPs are on the front line and are the first contact point for a person living with PD.

A lack of knowledge of PD and its impacts amongst NDIS and My Aged Care assessors means that people living with PD are missing out on support because their condition is misunderstood and under-estimated by assessors.

Queenslanders living with PD need the services of Parkinson's Specialist Nurses. Having 6 Movement Disorder Nurse Navigators in the hospital system is not enough, especially as they are not available in the community to support, inform and educate.

Long wait times to access services and having to travel long distances to access services were other major issues raised by the Queensland Parkinson's community.

While we acknowledge that some of these issues are impacted by the Federal Government, the Queensland Government cannot shirk its responsibility for the provision of Parkinson's specialist health services. There is a need to ensure access in equitable across the state. That people living with PD can access the services they need without lengthy wait times or having to travel long distances. People with PD should not be put in a position where they cannot afford to access much needed health services.

PD is now the fastest growing neurological condition in the world and numbers are set to double over the next 10 years. That means that by the time the 2032 Olympics come around, the number of Queenslanders living with PD will be equivalent to the capacity crowd at the Gabba likely to be watching the opening ceremony. If nothing is done to provide appropriate support and services now, the impact of PD to the Queensland Hospital system and to the health budget will be severe. Based on figures in a 2015 Deloitte Access Economics Report on the impacts of Parkinson's, the cost of the condition in Queensland could be as much as AUD $4 billion over the next 10 years.

While there is no cure for PD, more needs to be done to ensure that the thousands of Queenslanders living with PD and the thousands who will be diagnosed into the future, have access to specialist health services, treatment and support when and where they need it. By doing more to support them in their journey we can improve their wellbeing, quality of life and minimise the impact on the hospital system by keeping them out of Emergency Departments.

For and on behalf of Parkinson's Queensland Incorporated

Miguel A. Diaz MBA, FGIA

Chief Executive Officer