

## **Rallying 2016: Data, Data, Data – Survey Results**

Three hundred and eighty nine people with Parkinson's (PwP) completed our 2016 Rallying to the Challenge survey which explored what information people with Parkinson's share and how that information can influence decision making in healthcare and research.

### **Sharing data**

Firstly, people with Parkinson's were asked if they are prepared to share their health information and secondly what would be the most useful information to collect.

79% reported that details about non-motor aspects of Parkinson's would be the most useful, closely followed by movement aspects of the condition (76%), medical history (43%) and genetic information (41%).

Responders believe that recording such information would improve care in the following ways:

1. Contribute to the development of a personalised treatment plan (72%)
2. Help them understand their individual experience with Parkinson's (68%)
3. Help their healthcare team understand their type of Parkinson's (67%)
4. Allow monitoring of fluctuations and progression of the disease (63%)

In addition 84% thought collecting such data would improve research by providing a better understanding of Parkinson's and the possible non-motor subtypes, and 62% reported that it would provide a means for monitoring the disease remotely during clinical trials. A small proportion of respondents (4%) suggested that this information would neither improve research nor care.

Although a significant majority 93% (n=310) are willing to share information/data about their Parkinson's for research purposes, only 41% are currently doing so. 8% of respondents reported that they don't know whether they are sharing any information in this way.

78% of those that are not currently sharing their data for research purposes (n=153) reported that this was because they have never been asked to. However, it was reported that gaining personal insights from the data (71%), understanding exactly how the data will be used (56%), assured anonymity of the data shared (47%) and knowing exactly who will access the data (40%) would motivate respondents to share their data in this way.

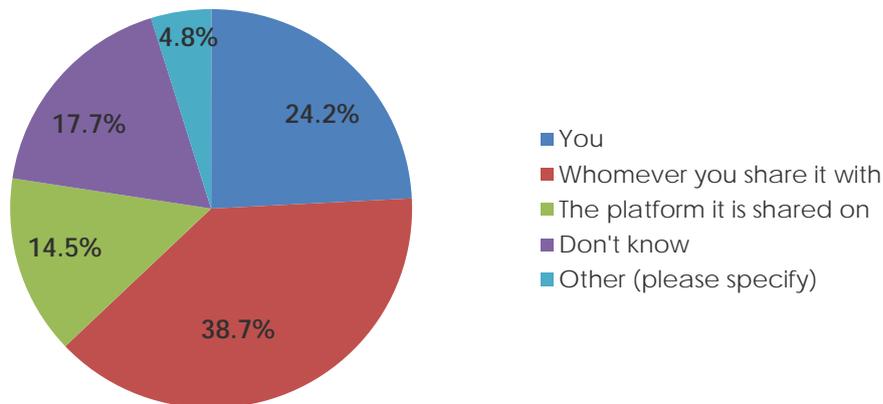
Of the 128 respondents who are currently sharing data, 39% do this via personal technology such as a smartphone.



## Data use

60% feel their data is fully anonymised but a worrying 30% of respondents don't know whether it is anonymised or not. There were mixed views on who owns their data (figure 1A) and who should be able to access their data (figure 1B). However, the majority (67%, n=126) believe they should be informed when their data is used, most conveniently via email (83%).

### A. Who do you think owns your data?



n=124

### B. Who do you think should be able to access your data?

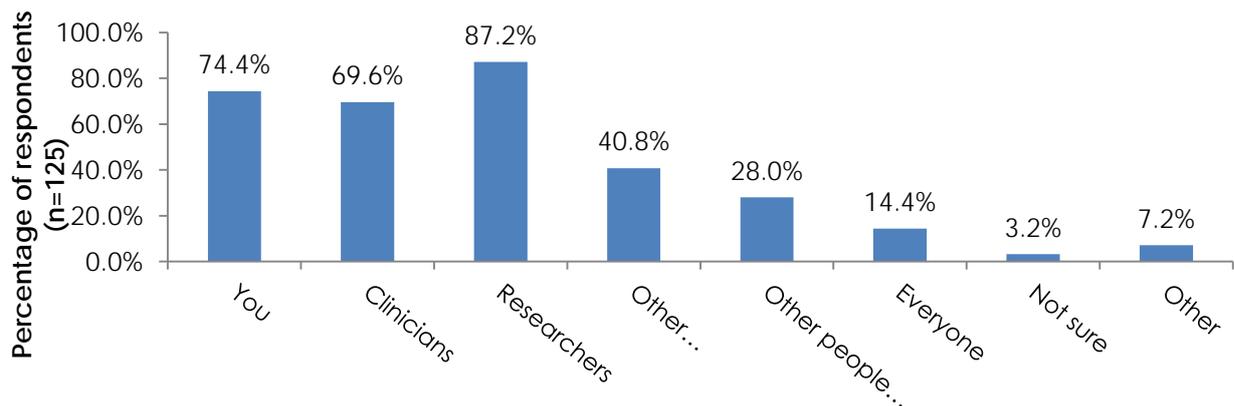


Figure 1. Responses to the questions who do you think owns your data (A) and who do you think should be able to access your data (B).

## Confidence in controlling and managing Parkinson's Symptoms

Using the John Wason Health Confidence scale, 60% (n=372) of respondents were highly confident (choosing seven or above out of 10) that they can control and manage most of their Parkinson's symptoms, however 47% reported that their health confidence had worsened in the last year. They reported that this resulted in a change in the questions they ask about their health (43%), increased the range of support and care offered to them (23%) and increased the likelihood that they would seek emergency care (20%).

The top four ways respondents (n=353) thought would increase their confidence to control and manage their Parkinson's were:

1. Better treatments (50%)
2. Medical appointments on demand (29%)
3. Better communication with their healthcare team (28%)
4. Better understanding of *my* disease (28%)

A significant 87% (n=353) reported that they feel they successfully manage their medication routine. The 45 respondents that did not feel in control of their medication routine reported that the following might make them feel more in charge:

- Better understanding of the medications and their interactions (58%)
- Better understanding of patterns of their disease (49%)
- Predictability of medication (47%)
- More frequent medical appointments (36%)
- Better understanding of timing and doses (33%)
- Predictability of personal routine (20%)

Although 51% (n=344) reported that they work in partnership with their healthcare team and have been given the confidence by them to adjust their medication timings and doses, 61% reported to have the confidence to adjust their medication timing and doses as they need and a further 23% report that they sometimes have the confidence to do this.

## Demographics

There were 198 (53%) female 173 (47%) male respondents (n=372). Respondents (n = 344) were predominantly from the UK (28%), USA (24%) and Canada (22%). There were respondents from 20 countries and 5 continents, the majority of which are English speaking. The majority of respondents (n=375) were aged between 55 and 74 years (range 25-75+) and the year of diagnosis ranged from 1994-2016 (n=394). 57% of respondents see their neurologist once or twice a year but see other healthcare professionals (for example, physiotherapist, Parkinson's nurse, speech therapist) more regularly.