

Supplementary material 1– SURVEY QUESTIONS

Background information

- * 1. In what year were you diagnosed with Parkinson's disease?
2. Are you.... Male Female Prefer not to say
3. Which of the following age groups are you in?
- Under 18
 - 18-24
 - 25-34
 - 35-44
 - 45-54
 - 55-64
 - 65-74
 - 75+
4. How often do you see your Parkinson's Healthcare team? (e.g. neurologist, Parkinson's nurse, physiotherapist, speech and language pathologist, occupational therapist, social worker, geriatrician)
- Once a year
 - Twice a year
 - Three times a year
 - Four times a year
 - Other (please specify)
5. Do you live...
- With a spouse or partner
 - With other family members
 - With friends
 - Alone
 - Other (please specify)
6. What best describes where you live?
- Flat/Apartment/Bungalow
 - House
 - Residential care
 - Other (please specify)
7. In what country do you live?

"Health confidence" - confidence in controlling and managing your Parkinson's symptoms

*8. Adapted from John Wasson's health confidence tool, whenever you think about your Parkinson's and your Parkinson's care, how confident are you that you can control and manage most of your Parkinson's symptoms? (0 = not confident; 10 = completely confident)

0 1 2 3 4 5 6 7 8 9 10

*9. Has your health confidence changed in the past year?

- Improved
- Unchanged
- Worsened

*10. How has this change in health confidence impacted your life? Please tick all that apply

- Improved your interactions with your healthcare team Increased the quality of care and support offered Reduced the quality of care and support offered
- Increased the range of support and care offered (e.g. physiotherapy, speech & language support, occupational therapy) Decreased the range of support and care offered
- You are more likely to seek urgent or emergency care You are less likely to seek urgent or emergency care Changed the questions you ask about your health
- It has not impacted your life Other (please specify)

*11. What would it take to increase your confidence to manage your Parkinson's? Please tick all that apply (if you answered 10, please tick N/A)

- Better understanding of my disease
- Better communication with my healthcare team
- More frequent medical appointments
- Medical appointments when I need them (on demand)
- Ways of demonstrating patterns in your Parkinson's
- Ways to communicate easily my priorities and concerns with family, friends and clinicians
- If monitoring - understanding what the data shows
- Better communication with other people with Parkinson's
- Better resources and knowledge of the resources I can access
- Knowledge of best practice in terms of monitoring
- Better treatments
- N/A
- Other (please specify)

*12. Do you feel in control of your medication routine?

Yes/No

13. What would make you feel more in control of your medication routine? Please tick all that apply

- Better understanding of patterns of my disease, e.g. what triggers poor sleep?
- Clear understanding of the medications themselves - their interactions (e.g. with food, alcohol, other medication), their side effects, recommended routine etc.
- Predictability of medicine
- Predictability of personal routine
- More frequent medical appointments
- Understanding timing of doses
- Other (please specify)

14. Do you have the confidence to adjust your medication timing and doses as you need?

Yes/No/Sometimes

15. Do you work in partnership with your healthcare team to adjust your medication timing and doses?

Yes/No/Sometimes

16. Have you been given confidence by your healthcare team to adjust your medication timing and

doses?

Yes/No/Sometimes

*17. Do you think the medication you take influences your health confidence?

Yes/No

18. What Parkinson's medication do you take? Please tick all that apply

- NOT TAKING MEDICATION
- Ropinirole (e.g. Adartrel, REPREEVE, REQUIP, REQUIP XL, RONIROL, ZELAPAR)
- Selegiline (e.g. Anipryl, ELDEPRYL, EMSAN, L-DEPRENYL) Apomorphine pen/pump (e.g. APO-GO/APOKYN)
- Benzhexol/Trihexiphenidyl (e.g. ARTANE, PACITANE, PARKIN)
- Rasagiline (e.g. AZILECT)
- Orphenadrine (e.g. BANFLEX,
- BIORPHEN, BROCASIPAL, DISIPAL, DOLAN, FLEXON, ME PHENAMIN, NORFLEX, NORGESIC, ORFENACE)
- Benzhexol/Trihexiphenidyl (e.g. BROFLEX) Bromocriptine (e.g. BROTTIN, CYCLOSET, PARLODEL) Cabergoline (e.g. CABASER, CABERLIN, DOSTINEX)
- Pergolide (e.g. CELANCE)
- Bantzropine (e.g. COGENTIN) Entacapone (e.g. COMTAN, COMTESS) Procyclidine (e.g. KEMADRIN)
- Levodopa and Benserazide - Co-beneldopa (e.g. MADOPAR)
- Pramipexole (e.g. MIRAPEX, MIRAPEX ER, MIRAPEXIN, SIFROL)
- Rotigotine patches (e.g. NEUPRO)
- Carbidopa-Levodopa (e.g. SINEMET, DUODOPA/DUOPA, CO-CARELDOPA)
- Levodopa/Carbidopa and Entacapone (e.g. STALEVO) Amantadine (e.g. SYMMETREL)
- Tolcapone (e.g. TASMAR)
- OTHER e.g. non-proprietary or self-prescribed (please specify)

Sharing data

*19. If people with Parkinson's come together to share their data for research purposes, what information do you think would be the most useful to collect? Please tick all that apply

- Information about motor symptoms e.g. balance, tremor, movement
- Information about non-motor symptoms e.g. sleep patterns, pain, fatigue
- General health information e.g. heart rate, weight
- Personal information e.g. age, gender, ethnicity, location, age of onset
- Genetic information
- Medical history e.g. other previous and current conditions
- Not sure
- Other (please specify)

*20. What would motivate you to share your data for this purpose? Please tick all that apply

- Assured anonymity of the data shared
- Understanding exactly how the data will be used
- Knowing exactly who will access the data
- Gaining personal insights from the data
- Not sure
- Other (please specify)

*21. What are the most useful tools to collect data? Please tick all that apply

- Wearable activity trackers
- Mobile Apps
- Online surveys
- Electronic diaries
- Written diaries
- Not sure
- Other (please specify)

*22. How could this information improve care? Please tick all that apply

- It helps your healthcare team understand your type of Parkinson's
- It helps you understand your experience with Parkinson's
- It allows for a more personalised treatment plan
- It allows monitoring of fluctuations and progression
- It would not improve care
- Not sure
- Other (please specify)

*23. What is the most important question that could be answered by people with Parkinson's sharing data about their disease in a big data resource?

24. What other questions (if any) do you think could be answered by sharing data in this way?

*25. How could this information improve research? Please tick all that apply

- May provide a better understanding of Parkinson's disease and possible non-motor symptom sub-types
- May provide a means of monitoring individuals remotely during clinical trials
- It would not improve research
- Not sure
- Other (please specify)

*26. Are you willing to share information/data about your Parkinson's with researchers?
Yes/No/Undecided

*27. Are you currently sharing any information about your Parkinson's for research purposes?
Yes/No/Don't know

Sharing data – For those sharing their data

28. With whom are you sharing data?

29. Do you use personal technology (e.g. a Smartphone) to collect and share information about your Parkinson's with researchers?
Yes/No

30. Do you feel your data is fully anonymised?

- Yes - all of it
- Yes - some of it (please specify in comment box)
- No - none of it
- Don't know

- Comments (please specify)

31. Who do you think owns your data?

- You
- Whomever you share it with
- The platform it is shared on
- Don't know
- Other (please specify)

32. Who do you think should be able to access it? Please tick all that apply

- You
- Clinicians
- Researchers
- Other health care professionals
- Other people with Parkinson's
- Everyone
- Not sure
- Other (please specify)

*33. Should you be informed when your data is used?

Yes/No

34. How should you be informed?

- By post
- By email
- By telephone
- By text
- Not sure
- Other (please specify)

Sharing data – For those not sharing data

35. Is there a reason why you are not sharing information about your Parkinson's for research purposes? Please tick all that apply

- Never been asked
- Concerns about security of personal information
- Issues associated with using technology
- Other (please specify)

Future correspondence

36. If you would like to receive the results of this survey, please supply your name and email address so that The Cure Parkinson's Trust can contact you.

37. We may have further questions relating to monitoring Parkinson's which will provide vital information for us. Would you be happy, in principle to take part in further surveys?

Yes/No

Supplementary material 2 – SUMMARY SLIDES PRESENTED TO FOCUS GROUPS

Aims of the survey

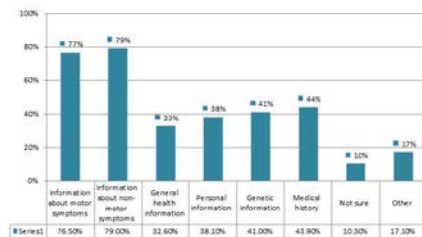
- To find out:
 - What information do people share?
 - How does this information influence decision making in healthcare and research?

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Sharing data for research purposes, what would be the most useful information to collect?



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How could this data improve care and research?

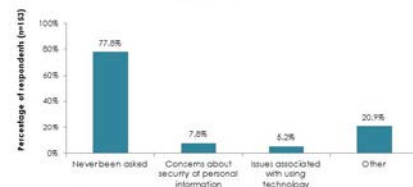
- Allow **Personalised treatment** (72%)
- Help PwP **understand** their experience with Parkinson's (68%)
- Help healthcare team **understand their patient's** type of Parkinson's (67%)
- Allow **monitoring** of fluctuations and progression (63%)
- Improve **understanding** of Parkinson's and the possible non-motor subtypes (84%)
- Provide a means for **monitoring the disease remotely** during clinical trials (62%)

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Why are people not sharing their data?



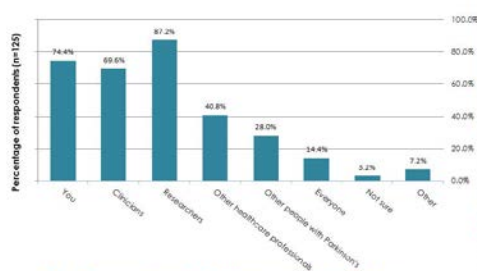
- Other answers included:
 - Too busy/time constraints
 - Have done in the past

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



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Summary

- People are generally willing to share their data for research purposes
- Fewer people are actually doing so
- It is unclear in many cases:
 - Whether data is fully anonymised
 - Who owns the data that people share
 - Who is accessing the data

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