PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Continuous engagement - working with researchers to enable them to stay engaged with participants.

1. Introduction - what is continuous engagement and why are we doing this project?

Participation in research is essential in the search for better treatments and a cure for Parkinson's. At Parkinson's UK we assist people, with and without Parkinson's, to take part in research, from questionnaires to trialling new treatments whatever people are ready for. But we know there is work to be done to help improve this experience.

We are looking at how communication can be improved after people have taken part in research ¹²³. But there is limited work looking at the communication people receive at this point and before the researcher has completed their write up ready for publication. This is where the concept of continuous engagement comes in.

Continuous engagement is maintaining regular communication with participants throughout the research cycle, from recruitment to publication.

This is an area that needs to be addressed - people affected by Parkinson's have told us at events, through our surveys and in emails that they infrequently receive feedback from researchers after taking part in research. 2. Methods - gathering opinions of people affected by Parkinson's

We asked our Research Support Network - a group of people affected by Parkinson's who are signed up to receive regular emails about research - to fill in a survey to help us understand the current situation and what people would like to see in the future with regard to continuous engagement.

• The survey was produced through Smart Survey and the questions were refined by our Participation Steering Group. This group is made up of - people affected by Parkinson's, researchers and healthcare professionals who help steer the work Parkinson's UK are doing with regard to people taking part in research.

• We had **334 responses to our survey** from people who had taken part in a variety of research. The graph below shows how many research studies our respondents had taken part in, over half had taken part in multiple studies.



In this project we wanted to assess what engagement people are currently receiving and understand what updates and information are important for them to hear about. From this information we plan to create a toolkit and educational package to assist researchers to stay continuously engaged with participants.

3. Results - what were the main findings from the survey?

3. 1 People are not getting feedback after taking part in research

3.2 People want to receive more information after they have taken part in research

Our survey highlights that there is currently a gap in communication after people have taken part in research.

- 72% of people did not receive feedback after taking part in research.
- Of the small percentage of those that did, **45% were not satisfied with the information**.

"I get email updates only fairly rarely, and mainly when the project will be requiring something new from participating subjects. Updates don't give much on findings or conclusions..." survey respondent How often do people want to hear from the researchers after they have taken part?

The results from our survey highlight that **people want to be empowered to find out more information** and have different expectations of how often they would like to hear from the researchers.

Survey question: How frequently do you want to receive updates from the researchers after you have taken part in research?

100

What information do people want?

The survey results show that people want

• Only 11% of people contacted the researchers for more information after taking part in a study.

This shows that although researchers are meant to feedback to participants after they have taken part, this is often not happening. There is no current best practices to support continuous engagement and we are hoping to change this.

Did you know that researchers are very happy to hear from anyone who's taken part in their research?

Whenever you have a question about any research you've taken part in, you can get in touch with the researchers. They will be able to answer all your queries and keep you in the loop as to when their research will be published. If you're not sure where to find their contact details, they are always on the Participant Information Sheet you read before you signed the consent form to take part in the research.

Take control of the research you've taken part in, contact the researchers for information.

3.3 Continuous engagement would encourage people to take part in research!

Our results show that over **80% of people would be more likely to take part in future research if they received more communication** from researchers after taking part.



to know more about the research they have taken part in. The table below summarises what information people want to receive, starting with the item that came out as the most important at overall rank 1. The total score helps us understand how the overall rank was determined and how strong the preferences are between items.

Survey question: What information would you want to receive from the researchers after taking part in research? The following items were ranked in terms of preference (1 most interesting, 11 least interesting)

ltem	Total Score	Overall Rank
More information about the research project itself	3130	1
The time point the research is at currently	2781	2
Future plans for the research	2579	3
Links to information about symptoms covered in this research	2497	4
How many people have taken part in the research	2242	5
Other research that they could take part in	2024	6
Connections to the wider research community	1746	7
What benefit do people gain from taking part in research	1587	8
What happens in research trials - the research activities	1153	9
The history of research	957	10
The structure of clinical research in general	952	11

4. Discussion





"I do realise it is time consuming for the researchers to update the research participants, but if I do not get any feedback it makes me less likely to volunteer! As an ex nurse I realise how vital research is to find ideally the optimum is a cure for PD but also some research studies will help alleviate some of the multiple distressing symptoms that we encounter too!! An email update would be useful." survey respondent

Acknowledgements

We would like to thank everyone who completed the online questionnaire we circulated in June 2019 and the Participation Steering Group for their input and guidance on this project.

References

- 1. Long, C. R.; Stewart, M. K.; McElfish, P.A. Health research participants are not receiving research results: a collaborative solution is needed. Trials. 2017, 18:449.
- 2. Return of Aggregate Results Toolkit. Multi-Regional Clinical Trials (MRCT). 2017, version
- 3. Schroter, S.; Price, A.; Malički, M.; Richards, T.; Clarke, M. Frequency and format of clinical trial results dissemination to patients: a survey of authors of trials indexed in PubMed. BMJ Open. 2019, 9:e032701

- The overarching message from our findings is that very few people are receiving feedback from researchers and the information that is shared is sporadic and varied in quality.
- Researchers have identified that communicating with participants about their findings is not something they have been trained to do³. We cannot expect changes in research practice to happen without help, support and guidance.
- By helping researchers preplan the information they are going to share with participants and giving them simple and effective templates, we can make it more likely that people who have taken part in research will receive information from the researchers.

5. Next steps: developing templates and tools to assist with continuous engagement

- Create templates and tools in consultation with people affected by Parkinson's and researchers
- Work with researchers to see how we can make continuous engagement part of their normal research activity
- Work with the wider research community to help spread continuous engagement as best practice in research