

Learning to listen at Parkinson's UK

By Claire Stephenson

Public involvement in organisational change

Before Parkinson's UK rebranded in 2010, we asked our members how we were perceived. The results were quite surprising with words like 'disempowering' and 'not representative' used. The steps we took to rectify this were bold, innovative and changed everything about the way we work as an organisation.

For the first time we started talking about meaningful involvement.

We introduced a user involvement team and employed people with Parkinson's to work across each department to support teams to improve the way they involve people in their work. Meaningful involvement was introduced as a team performance measure and recruitment, induction programmes and on-going training now had a strong user involvement focus. This new approach was championed by our Board of Trustees as one of our core values.

We wrote involvement into our organisational five year strategy:

"Everything we do will be informed by the views and experiences of people living with Parkinson's, their families and carers."

As a result our members, volunteers and the patient community found a more supportive, representative and dynamic charity that responds to and reflects their needs and views.

And whilst our vision for research “to find a cure and better treatments for Parkinson’s” remained, we focused on working with people with Parkinson’s to achieve this:

“We’ll ensure our research programme is shaped by and accountable to people with Parkinson’s.”

“We will develop and support a global network to allow people affected by Parkinson’s to be involved in a variety of research activities.”

In 2011, the Parkinson’s UK Research Support Network (RSN) was born. Its aim: to bring together people driven to help find a cure and better treatments for Parkinson’s.

Parkinson’s UK Research Support Network

The Parkinson’s UK Research Support Network (RSN) is an online network of people interested in Parkinson’s research. It’s a way to bridge the gap between people affected by Parkinson’s and the research community. Instead of passively hearing about Parkinson’s research at an event, the RSN mobilises them to take it further, find out more, participate and also get involved in research.

Over 95% of our Research Support Network members are people with Parkinson’s, their carers, family members or friends. With over 1,300 members, our RSN affords us an ideal opportunity to gain opinion, insights, case studies, participants and volunteers as well as help people affected by Parkinson’s to feel in control as their voice is heard by the research community.

We know that almost 60% of our RSN members are interested in taking part in research and 43% joined to be able to work with the research community to help shape Parkinson’s research.

What difference has public involvement made?

The Research Support Network is the only network of its kind focused on Parkinson's research. It gives us the unique position of accessing both a diverse and rich pool of experience of people affected by Parkinson's to help us at different stages of the research cycle.

Examples of the work of our RSN members includes:-

- helping us to identify unanswered research questions in the day-to-day care and management of Parkinson's
- advising us on our developing research strategy for 2015-2019
- working with us to decide which research we fund
- working with the Parkinson's UK Brain Bank to decide which projects receive brain tissue
- advising researchers on study design, protocol and recruitment methods
- becoming members of research project steering groups
- helping us to disseminate research by talking about research across our branches and groups nationally.

The Research Support Network has transformed the way we do research. It has inspired us, given us confidence and leverage, helped us attract new members and it has made us more attractive for researchers and funders.

We have also been able to develop our relationship with researchers. Researchers work with our RSN at all stages, and this is not exclusive to research that we fund. Members of our RSN join us at conferences worldwide, including the World Parkinson's Congress and Grand Challenges in Parkinson's. We also have RSN speakers at our upcoming annual researcher conference. It is vital to keep that sense of urgency alive in the research community, and no one can do that better than

people affected by this condition.

Finally, the RSN has made a difference to people affected by Parkinson's. In a condition that has taken away their control, our RSN allows them to seize some of it back:

“I wanted to be proactive and to find out as much as possible about available research opportunities; it seemed to be more upbeat and of interest to younger and newly diagnosed people with Parkinson's and I just wanted to be involved and help to find better outcomes for treating Parkinson's. It helps sustain my hope for the future.

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