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Parkinson's UK - Initiatives to help connect the research community, design research and increase participation

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Before Parkinson's UK went through its rebrand in 2010, we asked our members how we were perceived. The results highlighted the need for us to communicate, collaborate and involve people affected by Parkinson's in more areas of our work. Today everything we do as an organisation includes people affected by Parkinson's. Within the research directorate we have focused on 3 key initiatives over the last decade; the Research Support Network, Research Involvement and Participation. The Parkinson's UK Research Support Network (RSN) is an online network of currently over 5,500 people affected by Parkinson's who are interested in research; getting connected to the latest research news and events and finding opportunities to take part in and shape research. Through consulting with our RSN, our other important work streams and initiatives have come about. Research Involvement has now become the cornerstone of good research. We have developed and deliver a comprehensive PPI package that teaches researchers how to do meaningful involvement and links them to our Research Involvement Volunteers. We have also created a Research Involvement Award to help support meaningful involvement. Without participation, research would not happen. In 2015 we surveyed our membership and discovered 70% of them wanted to take part in research but only 24% had. Many Parkinson's researches trials have failed to recruit participants to time and target, causing the research to go over budget and sometimes fail to reach significance. To address this, we worked with 3 key stakeholder groups; people affected by Parkinson's, Health Care Professionals and Research Professionals. From this data we developed the Participation work stream that helps researcher to connect with potential participants and people to find research in their area using our Take Part Hub. We have just published our report showing the impact of these work streams and future plans.

Biography

Amelia Hursey joined Parkinson's UK as Senior Research Participation Officer 1 July 2015 and has since been promoted to Research Participation Lead. She is responsible for initiative to increase research participation for people affected by Parkinson's, health care professionals and researchers. She is responsible for creating the innovative Parkinson's UK Take Part Hub. Before working with Parkinson's UK, Amelia obtained an MSc in Cognitive Neuropsychology from Oxford Brookes University. She worked with DeNDRoN East Anglia as a Clinical Trials Practitioner at the Norfolk and Norwich Hospital for 5 years, specialising in Parkinson's clinical research. Working with Dr Paul Worth, she supported the creation and development of an extensive Parkinson's research portfolio spanning Clinical Research Trials Phase's 2-4, observational and longitudinal research.

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