‘Exchanges’: A visual resource to inspire and support deeper conversations in the Parkinson’s community

Miratul Muqit1, Daksha Patel2, Sarah Patrick1,3, Nur Kocaturk1, Daniel Saarela1, Shalini Agarwal1, Gloria Shi1, Bill Carton1, Janet Niven3, Katrine Wreford3, Daryl Lawson4, Ian Keir5, Sharon Langlands4, Linda Donegan1, Anthony Knowles6, Sandra Knowles6, Joy Milne5,6, Thomas Giddens7, Paul Davies1

1MRC Protein Phosphorylation and Ubiquitylation Unit (MRC PPU), University of Dundee, Dundee, Scotland, UK, 2Artist Educator, England, UK, 3Science Communications & Public Engagement Consultant, Scotland, UK, 4Parkinson's patient, Scotland, UK, 5Parkinson’s carer, Scotland, UK, 6University of Manchester, England, UK, 7Dundee Law School, University of Dundee, Dundee, Scotland, UK

Introduction

Interactions between people with Parkinson’s (PwP), carers and researchers are often limited to research talks or visits to laboratories. These interactions are hugely beneficial to all involved and improve the understanding of research developments, but the opportunity for deeper conversations – particularly around the complexities and ambiguities of the lived experience of Parkinson’s and of the research process itself – can be limited in these settings.

Objective

To develop a creative resource that inspires deep, meaningful exchanges between research and lived experience of Parkinson’s to further increase patient involvement in research.

Results: co-created resources

‘Exchanges’, an interpretive art card activity with drawings that depict Parkinson’s research and symptoms alongside question prompts such as “What does Parkinson’s mean to you?” to support deeper conversations in the Parkinson’s community.

A webpage (accessed from a QR code on the card box) that enables translation of the instructions and questions cards to any language, ensuring accessibility.

Short film capturing some of the powerful exchanges between MRC PPU Parkinson’s researchers and people with lived experience of Parkinson’s using the ‘Exchanges’ interpretive art card activity.

www.ppu.mrc.ac.uk/parkinsons-exchanges

Key findings

• Initial experiences of the art card resource being used by a person with lived experience of Parkinson’s (PwP or a carer) and a Parkinson’s researcher generated striking levels of engagement, breaking down barriers and prompting deep, quality conversations about Parkinson’s.

• We discovered that the resource has an even greater/wider impact than originally anticipated – it is successful at prompting discussions about the emotional and physical challenges of Parkinson’s and of the research process itself.

• Unexpectedly, the resource also supports deep conversations in a group setting as well as in pairs, with participant feedback advocating future use at conferences, in support groups and clinical settings.

Future plans

• Who should we partner with to make these resources freely available to the wider Parkinson’s community?

• Where would you like the art card activity to be made available?

• Who would you like to use this art card activity with?

Please share your thoughts and feedback: Parkinons-Exchanges@dundee.ac.uk