

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

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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.



JAN - APR 2022

MRC PPU researchers worked with the artist to create art card drawings to represent their Parkinson’s research and the Parkinson’s symptoms observed by Prof. Miratul Muqit in his Consultant Neurologist role.



MAY 2022

17 researchers and 9 people with lived experience of Parkinson’s (inc. a carer) reviewed the art card drawings and co-created our interpretive art card activity, ensuring our final resource meets the needs of the Parkinson’s community:

- Discussed how to better represent their research or lived experience through the drawings
- Decided black and white drawings were preferred over colour to support personal interpretation of the art cards
- Input what new art cards were needed to include all participants’ experiences of Parkinson’s
- Tested different ways to use the art cards with question prompts such as “What does Parkinson’s mean to you?” to support deeper conversations.



JUN - AUG 2022

Designed, tested and produced packs of the final ‘Exchanges’ interpretive art card resource packs.



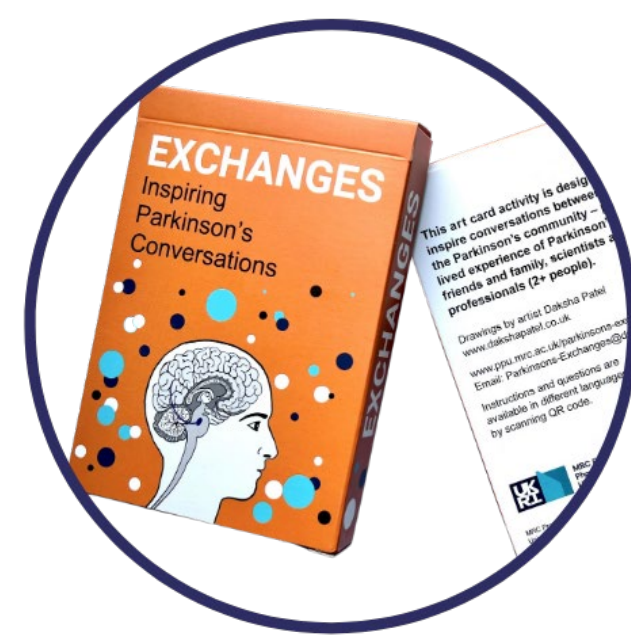
SEPT 2022

MRC PPU researchers and those with lived experience of Parkinson’s tested the final resource together in pairs.

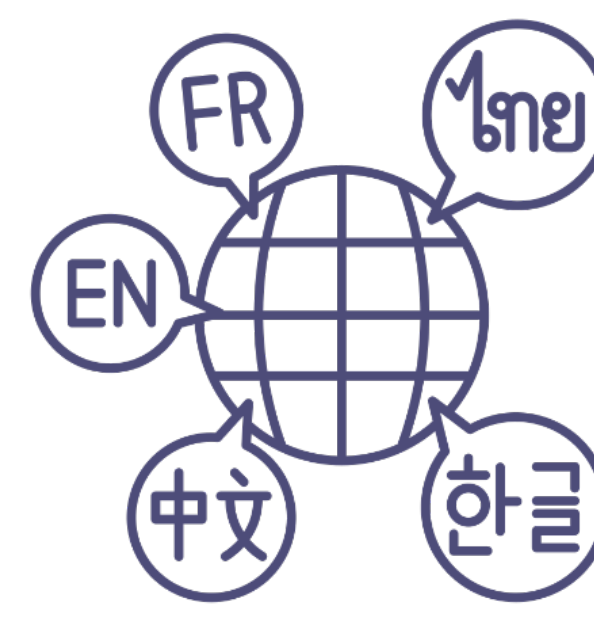
We captured the resulting, powerful exchanges on film.

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 amongst people with lived experience of Parkinson’s (PwP and carers) without the presence of researchers too.
- Unexpectedly, the resource also supports deep conversations about Parkinson’s 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:
Parkinsons-Exchanges@dundee.ac.uk