Involving PPI in Tic Disorder Research: Lessons Learned and Recommendations for Future Research

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BACKGROUND

Patient and Public Involvement (PPI) plays a vital role in shaping research through the lived experiences of those affected by tic disorders. Despite progress, more needs to be done to embed PPI as a core part of the research process. Across three diverse projects involving those with experience of living with or caring for someone with tics, we have explored how to best engage PPI as true research partners. Here we present both challenges and effective strategies, offering practical guidance to enhance collaboration in future research partnerships.

PROJECTS
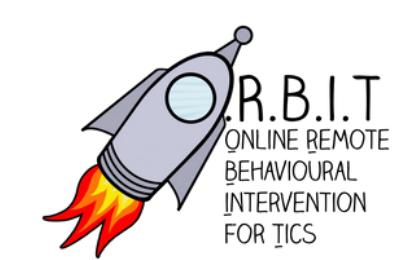
ORBIT: Online Remote Behavioural Intervention for Tics

INTEND: Improving Tic Services in England

'Tourettes Hear Us!": Qualitative study exploring the experiences of people with tics and Tourette Syndrome (TS) trying to access healthcare

HOW DO I INVOLVE PPI THROUGHOUT MY RESEARCH?

"I loved how it was facilitated and everyone was able to get views through and all treated as valid"

"The chat is useful as not as confident to talk, yet!"

RECRUITMENT

Verification

! Recently we have seen an increase in 'non-genuine' panel members, who may find PPI opportunities online and sign up with the hopes of financial gain. Verifying members during recruitment ensures the group is a safe space and membership places are reserved for those with genuine lived experience.

We had several non-genuine panel members sign up to the ORBIT PPI group. Asking for proof of address is a quick way of identifying these individuals. Organising an induction phone call during recruitment also helps to learn more about the individual and their lived experience.

Representation

? How do I recruit a diverse and representative PPI group?

Online meetings can allow for wider reach and national representation

Holding space for those with 'living experience' of tics, who may have ongoing struggles, ensures all voices are heard and that the PPI group reflects the full spectrum of experiences—not just those who are high-functioning or well-adjusted.

WAYS OF WORKING

Tics in Meetings

? In what ways can tics have an impact in meetings? What can I do to accomodate this?

A typical meeting rule might be 'don't interrupt others'. One PPI member told us tics make this rule hard to follow and it can be triggering. Allow members to feel comfortable ticcing freely. Since tics can be suggestible, there's concern members might pick up each other's tics. In our experience, this hasn't been an issue in online meetings, as members usually mute or turn off their cameras while ticcing.

Communication

? How can I best communicate with my PPI group?

Our group told us that they can sometimes experience 'information overload'. To streamline communication, we found 'little and often' is best, for example discussing just one task per email.

Facilitation

? How can I best facilitate PPI involvement?

Some panel members found it hard to get their views across during online meetings. We now ensure that order of 'hand raising' is followed, and allow members to share feedback via the meeting chat, or an email post-meeting if they prefer.

We facilitated involvement by allowing participation via chat if microphones weren't available, allowing members to contribute in their preferred way, through speaking or writing.

We use group agreements so that everyone has the opportunity to shape how the group looks and feels, and allows us to keep some order to the group.

IMPACT & DISSEMINATION

Co-Authorship

? Acknowledging PPI in research publications is important, but we often face challenges such as the time commitment for their continued involvement in the publication process, maintaining engagement through multiple (potential) rejections from journals, or ensuring appropriate compensation for their contributions.

From the outset, be open and honest about the timelines of authorship processes and expectations. We find that panel members really value being invited to be involved in publications or being acknowledged in them. Ensuring that you have enough in your PPI budget to ask members to review at least once to allow for authorship credit.

Impact

? How can I keep my PPI group motivated to stay involved when research can take years to produce tangible outputs?
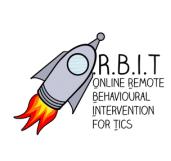
Share updates of interest that are outside of your projedct, e.g. there might be interesting studies or policy changes that are relevant to the PPI group – you can tell them about these in and between meetings e.g. newsletter

PIRIT Impact Tracking tools allow for systematic tracking of impact that PPI panel has had on decisions/progress of study

SUSTAINED ENGAGEMENT

Feedback

? How do I know if my group are enjoying PPI? What can I do to improve?

Collecting anonymous feedback via Microsoft Forms after every session gives members the space to tell us what they really think of how we run things, whether that is positive or negative! This feedback helps us to navigate what works best for the group and continually improve our involvement activities.
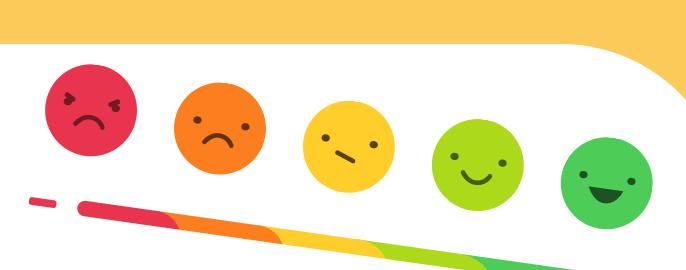
Accommodating Busy Lives

? How do I keep my PPI group engaged, even when their lives get busy?

Ensuring resources are shared in multiple, accessible formats to accommodate panel members. This includes sending both a meeting summary Word document and a recording of the meeting that they can watch in their own time if they weren't able to attend.

It's important to remember than panel members usually have full time jobs, family commitments, or could be in school! Using polls to find meeting times that suit everyone is key. Allow members to join meetings from wherever they are, on any device that works for them. This could range from joining on a phone whilst in the car, or on a tablet whilst cooking dinner.
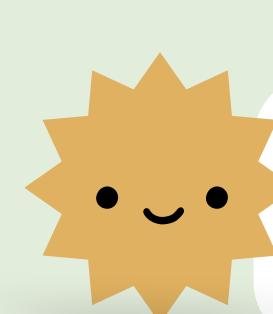
We're delighted that our work at the University of Nottingham has been recognised by national and institutional awards. We hope sharing our lessons will help others passionate about involving lived experience voices.
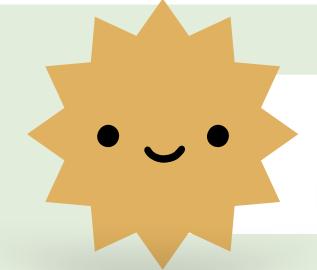
These are a few key insights we felt would be valuable to share, but please ask us if you have any other questions about PPI!