A Quality Improvement project to identify and address research participants’ feedback when their study involvement ends

Jemima Littlejohns1, Sugandika L. Gajaweera1,2, Deborah Moll1,2, Amanda Colston1,2, Michael Howard3

1 Research and Development, Warneford Hospital, Oxford Health NHS Foundation Trust; 2 NIHR Oxford Health Clinical Research Facility, Research and Development, Warneford Hospital, Oxford Health NHS Foundation Trust; 3 Expert by experience

Background

Ending study participation can be a big milestone for participants. It is important that they feel appreciated and informed. There is limited guidance about researchers’ roles in supporting participants during these transitions, and existing literature on this topic has minimal patient and public involvement (PPI).

This Quality Improvement project aimed to work with PPI contributors, as well as research delivery and clinical staff, to promote smooth transitions for participants.

Methodology

Discovery phase:
- PPI contributor groups were conducted at the project start (n=6) and midway through (n=6), and a patient research champion joined the project working group.
- A qualitative focus group was conducted with 8 staff members, including research delivery nurses (n=2), research allied health professionals (n=1), research assistants (n=2), research engagement staff (n=1), and clinical nurses (n=2). Data was analysed thematically using the framework method.
- A scope of existing aftercare guidance yielded limited results.

This supported the development of five change ideas, which are being implemented and monitored using Plan-Do-Study-Act (PDSA) methodology.

Results

Staff focus group themes

Variability in the nature and duration of research participation
Identifying boundaries and responsibilities of clinical and researcher roles
Managing and supporting participant expectations
Barriers and facilitators in supporting aftercare in research
Alternative ways to support research participants after participation

PPI contributors feedback and suggestions

Variability in participant experiences of ending study participation
The need to be informed and supported
Ending research participation is a big milestone

"...letting people know how they could get involved with research outside of participation..."

PDSA Cycle for change idea 1: create a co-produced ‘after research’ resource

Act
- To adopt the ‘after research’ leaflet as a resource for study co-ordinators to utilise
- Create an easy read version of the leaflet
- Create translated language versions of the leaflet
- To update resource based on continuous feedback

Plan
- Collect feedback from participants on ‘after research’ leaflet
- Monitor annual Participant in Research Experience Survey (PRES) findings

Study
- Importance of feeling valued and connected to the research community
- Expectation management of study result timelines
- Draw upon existing resources
- Collect PPI feedback on resources created

Do
- Create a co-produced after research leaflet

Conclusions

There was a potential mismatch between participant expectations of researchers’ roles and researchers’ views of their own roles. This project highlights two broad areas for consideration to support participants as they end study participation:
- Clear and effective communication about their next steps and options
- The need for appropriate care and support following research participation

It is anticipated that these change ideas will enhance participant experiences of research, attitudes towards future participation, and understanding of resources available.

Further change ideas

- Develop a researcher’s toolkit for keeping participants informed
- Organise informal research events
- Establishing a results poster repository
- Increasing the number of published results available on the Trust’s online study results repository

Acknowledgements

This project is supported by the National Institute for Health and Care Research (NIHR) Nursing and Midwifery. The views expressed are those of the author(s) and not necessarily of the Department of Health and Social Care.

Authors would like to thank the ENGAGE (NIHR Oxford Health Clinical Research Facility Patient and Public Involvement Group), NIHR Clinical Research Network Thames Valley and South Midlands Research Champions, and Parkinson’s UK: Staying Connected toolkit

References:
1. Health Research Authority (2022). Ending your project. Available at: Ending your project - Health Research Authority (hra.nhs.uk)