

COMMUNICATION

Most hospitals will have experienced PR teams who can help with internal and external communication. Devising a communication plan will a) improve the way the trial is administered and b) improve the trial experience with people with Parkinson's (PwP)

Pre-trial:

Set up a Communications Committee alongside the Data Monitoring Committee and the Steering Group. Their role is to ensure that a robust communications plan for internal and external communication is developed, with materials written and evaluated by PwP to ensure they are relevant and use appropriate language. This committee's primary aim is to support recruitment and retention.

- What are the communication milestones?
- Identify who needs to know what, when (your network)
- Build a wider trial network via patient organisations, press releases (national, regional TV, Radio, internet, social networks), newsletters, blogs, patient forums, FoxTrialFinder, ClinicalTrials.gov and similar, internal channels, Parkinson's Networks such as Parkinson's Study Group
- Who will handle the communication?
- How will members of the public respond and what will happen to their query? Who will reply? Define the response timeframe and communicate this clearly to applicants? Are there tools such as TrialSpark that can help?
- The success of the communication plan can be quantified in the number of positive expressions of interest in the trial – capitalising on these by responding quickly and appropriately is vital.

Trial announcement including:

- What the trial is about, positioned within Parkinson's research arena, using motivating language to encourage PwP to take part
- Centres selected (if a multi-centre trial), contact details of how to take part.
- Quotes from PI, funders, PwP on the importance of the trial
- Q&A to address any potential queries from members of the public
- Is there any additional evidence needed from the wider Parkinson's community that can be collected by a relevant survey?
- Identified spokespeople
- Regional research meetings for PwP including the trial and how to take part

During trial:

A programme of newsletters distributed to the defined audiences and trial applicants updating on how the recruitment to the trial and the pre-defined trial milestones. This can be part of general research update from the centre ideally sent every six months.

Informing participants and centres about *when* to expect the results is important – this helps manage expectations whilst keeping people engaged.

Post trial:

Communication post-trial needs to be divided into key areas, and the relevant communication route should be used for each:

1. Publications, posters, conferences, peer-to-peer
2. Participant, staff and centres involved: provide the results via meetings, letters, newsletters, internet, webinar, social media
3. General public
 - Did the trial answer its question? How has it informed the wider Parkinson's research arena? What happens next?
 - Quotes from PI, PwP, funders on the results
 - Q&A to address any potential queries from members of the public
 - Identified spokespeople