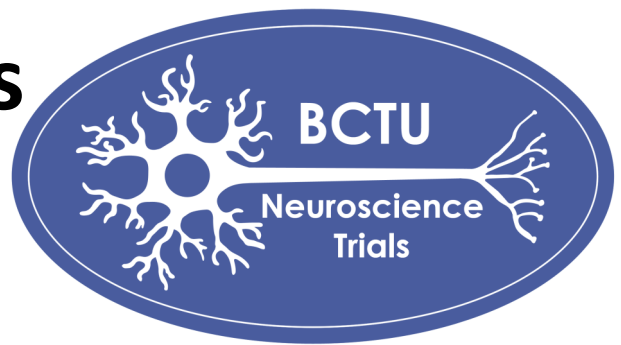


# Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit  
December 2019



Hello everyone! Welcome to another newsletter from the Neurosciences Trials Team at BCTU. In this newsletter, we will provide you with the latest news from PD MED and PD COMM.

Firstly though, we would like to give a big thank you to all of our participants, carers, collaborators and clinicians, who have been or will be completing their respective forms and returning them to us. We definitely wouldn't be able to complete our research without you!



## **PD MED to terminate follow-up in December 2019**

After 20 years, the PD MED study will be ending its collection of follow-up data on December 31, 2019. We are very excited by this and look forward to analysing the data. We, of course, would not be able to do this were it not for the hard work of the participants, their carers and the clinical staff at the participating sites. Because PD MED will be ending, we would like to stress to you the importance of completing the last forms for 2019. This last piece of data is very important for the overall conclusion of the study. As you are aware, PD MED is a longitudinal study analysing the long-term effects of treatment with 4 different classes of medicines for Parkinson's disease. The trial will have 20 years of follow up at the end of 2019, with everyone having been in the trial for at least 10 years. Because Parkinson's is a chronic condition, it is important to know what are the long term impacts from its treatment medications. To do this, we need your continued assistance by completing the final participant booklets, carer forms or annual follow-up forms. Your efforts have already made an initial impact: results published in 2014 resulted in NICE guideline changes for Parkinson's disease treatment. With your help and continued support in completing these forms, we hope to gain more information so that the future of Parkinson's disease treatment can be further improved.





## What is the PD COMM trial?

The evidence to support the use of speech and language therapy in Parkinson's is limited and yet patients feel that it is effective. The provision of this service in the NHS is patchy with some patients not receiving SLT when it may be appropriate. Following the success of the pilot study, a large-scale study was setup in 2015.

PD COMM is a multi-centre pragmatic randomised controlled trial to evaluate the clinical and cost effectiveness of two types of speech and language therapy (Lee Silverman Voice Treatment and Standard NHS therapy) for people with Parkinson's who have self-reported problems with voice in the NHS.

## Who is in the trial?

Over the past 4 years, 352 patients with Parkinson's who have self-reported speech or voice issues (and some of their carers too) joined PD COMM.

The eligibility criteria are kept broad to ensure the study include patients at difference stages of Parkinson's.

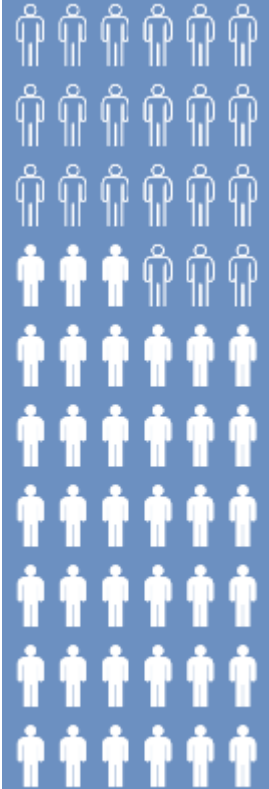
Our collaborating doctors, nurses, clinical studies offices and speech therapists from 42 NHS Trusts and Health Boards in the UK have approached over 10000 patients to take part!



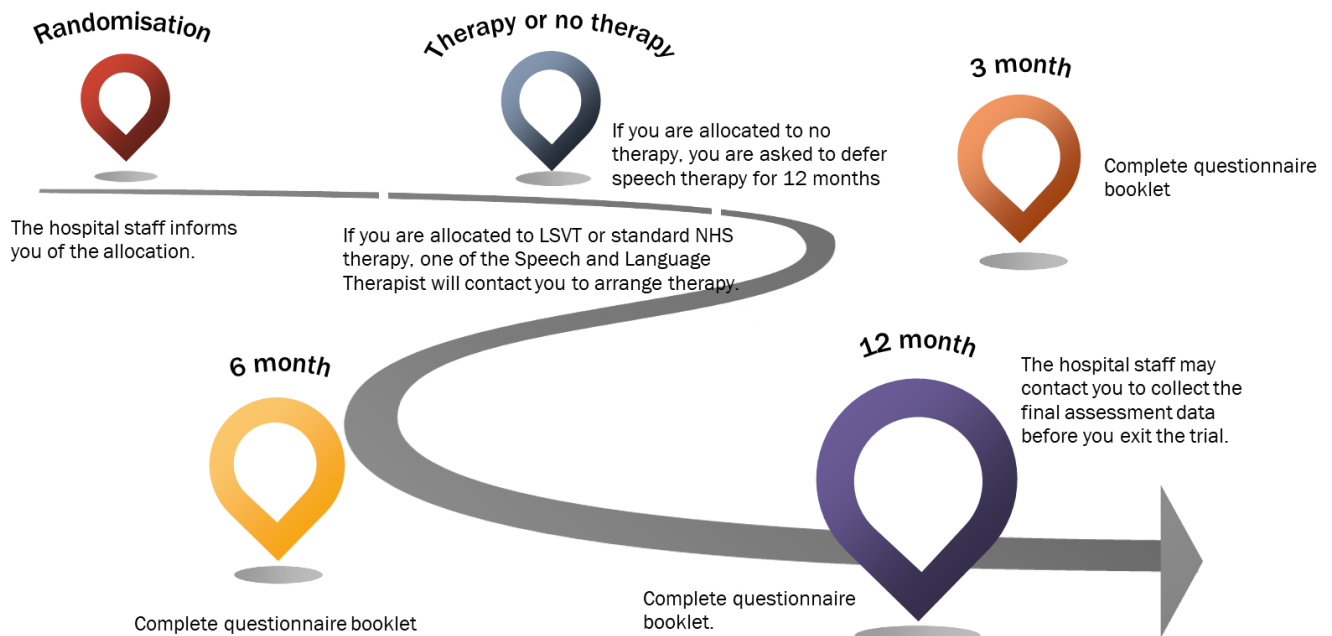
We cannot emphasise how important it is to the trial that you return the questionnaire promptly to us. Once again, a big thank you for your time in completing the questionnaires booklet at 3, 6 & 12 months from the time you have joined the trial. Your contribution will help to inform the standard management of people with Parkinson's who have reported voice problems, and to some extent, the future provision of speech and language therapy service for Parkinson's in the UK.

**352 patients  
have joined so  
far.**

**Need another  
194 patients to  
join!**



## What happens during the trial?



## Where is the trial taking place?



**42 Centres in the UK are taking part.**

**Recruitment ends 30<sup>th</sup> Nov 2020.**

Aneurin Bevan University Health Board  
Basildon and Thurrock University Hospitals NHS Foundation Trust  
Bath and North East Somerset Community Health and Care Services  
Betsi Cadwaladr University Health Board  
Blackpool Teaching Hospitals NHS Foundation Trust  
Brighton & Sussex University Hospitals NHS Trust  
Cardiff and Vale University Health Board  
Central London Community Healthcare NHS Trust  
East Cheshire NHS Trust  
Gloucestershire Hospitals NHS Foundation Trust  
Great Western Hospitals NHS Foundation Trust  
Guy's and St Thomas' NHS Foundation Trust  
Harrogate and District NHS Foundation Trust  
Homerton University Hospital NHS Foundation Trust  
Hywel Dda University Health Board  
Lancashire Teaching Hospitals NHS Trust  
Leeds Teaching Hospitals NHS Trust  
London North West Healthcare NHS Trust  
Manchester University NHS Foundation Trust  
NHS Ayrshire and Arran  
NHS Dumfries & Galloway  
NHS Forth Valley  
NHS Greater Glasgow and Clyde  
NHS Highland / Argyll and Bute  
NHS Lanarkshire  
NHS Lothian  
NHS Tayside  
Norfolk and Norwich University Hospitals NHS Trust  
Norfolk Community Health and Care NHS Trust  
North Bristol NHS Trust  
Northern Lincolnshire and Goole NHS Foundation Trust  
Pennine Acute Hospitals NHS Trust  
Powys Teaching Health Board  
Royal Devon & Exeter NHS Foundation Trust  
Sandwell and West Birmingham Hospitals NHS Trust  
St Helens And Knowsley Hospitals NHS Trust  
Taunton and Somerset NHS Foundation Trust  
The Walton Centre NHS Foundation Trust  
Torbay and South Devon NHS Foundation Trust  
University Hospitals Birmingham NHS Foundation Trust  
University Hospitals Bristol NHS Foundation Trust  
Wye Valley NHS Trust

## When should I be completing the questionnaires?

Please complete your set of questionnaires as soon as you receive them.

- Whether you are allocated to receive LSVT, Standard NHS therapy or no therapy, you will receive a questionnaire booklet from us at the time point 3, 6 and 12 month as shown on the diagram to the left.
- The time point will ALWAYS count from the day when you join the trial (i.e. the day when you completed your first set of baseline questionnaires with the researcher).



*\*Take home message*

**Please promptly complete and return the questionnaire booklet to us when you get them!**

## **PD COMM related recent publications:**

We mentioned earlier about the pilot study, which the results was published in 2018 (DOI: 10.1186/s40814-017-0222-z). A more recent paper published based on the data collected from this pilot study is:



Rating the intelligibility of dysarthric speech amongst people with Parkinson's Disease: a comparison of trained and untrained listeners. Clinical Linguistics & Phonetics, DOI: 10.1080/02699206.2019.1604806.

## **PD COMM Speech and Language Therapists' Meeting:**

The meeting took place on Tuesday 19th November 2019 in Manchester.

Speech Therapist Representatives from recruiting centres across the UK have joined us in this educational day. The Big CACTUS Chief Investigator was there to tell us about the outcome of the trial. Two fantastic participants, who took part in PD COMM, shared their experience of Parkinson's and being in clinical trials with the Speech Therapists. Everyone had a great time learning from each other during the workshop session, where they had the opportunity to ask each other questions about the structure of their services and their local practice.



Thank you to all of the Speech Therapists who were able to join us that day and contributed in the discussions.



Tweet @PDCOMM\_trial

## **The newsletter needs your help!**

Hopefully, you have enjoyed reading your copy of the BCTU Neuroscience Trials newsletter. If you would like to submit an article to the next newsletter, please let us know. We will be very happy to publish it. Articles may be on any subject which you find interesting and which may be interesting and helpful for others with Parkinson's. If you would like to share your experiences as a person with Parkinson's or as a carer or if you are interested in writing about your experiences as a research nurse conducting studies with Parkinson's patients, all stories are welcome!

## **Contact Details**

Please submit your articles, stories or experiences to:

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