



SEASONS GREETINGS!

IN THIS ISSUE

Positive decision from funders!

by Freya Stuart

The TYPPEX programme is funded by the National Institute for Health and Research ('NIHR'). Large grants are routinely released in two waves. To receive the second wave of funds it must be demonstrated in a written report that the research can be delivered safely, effectively and to budget. It is not unprecedented for studies to be discontinued.

We submitted our report to the NIHR in September 2019, which demonstrated that:

- ✓ There is a need for TYPPEX (approximately 30% of people participating in Improving Access to Psychological Therapies (IAPT) treatment have unusual experiences in addition to depression/anxiety)
- ✓ We have developed a comprehensive and acceptable training programme (ongoing staff and patient interviews will provide further feedback – see 'Process Evaluation' article, page 2)
- ✓ We can recruit and train 'enough' therapists (to show if there is a statistical effect on recovery)
- ✓ We can deliver TYPPEX therapy to 'enough' patients (again, to show a statistical effect)

- ✓ We can recruit 'enough' patients to complete the cost-effectiveness questionnaires at baseline (see 'Recruitment update' article, page 3)
- ✓ We can extract recovery data from IAPT computer systems

The report also included a patient and public involvement (PPI) impact summary, recruitment figures (targets surpassed), therapists' training scores (knowledge and confidence improved), and schedule and contingency plans for the main trial.

We are delighted to announce that on 28th October 2019, Peter Jones and Jesus Perez jointly received a letter from the NIHR approving the release of the second wave of funds!

We would like to thank all of our collaborators and contributors for supporting us to this point and we look forward to the next phase of the project with the main trial beginning in March 2020.



The 'Process Evaluation'

Staff and patient interviews are now underway.

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Meet our LEAP

Views on being on our lived-experience panel.

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Recruitment update

Find out the latest recruitment figures.

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Literature workshop

Five LEAP members attended this training research session.

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We want to hear from you!

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What do people on the ground think of TYPPEX? (The 'Process Evaluation')

by Freya Stuart and Vikki Charles

We've heard the process evaluation was delayed – why is that?

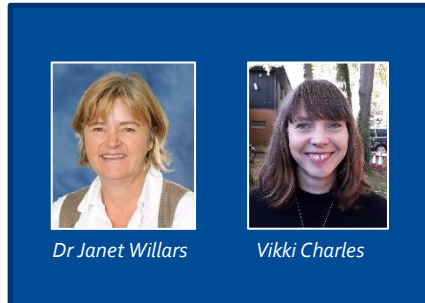
Due to staff turnover at THIS Institute, only a handful of service users were interviewed ahead of TYPPEX development. We are in the very fortunate position of having Vikki Charles on the TYPPEX team who has previous experience of conducting process evaluations and we are now managing this work in-house. Vikki will be supported by Dr Janet Willars of THIS Institute who has also carried out a number of process evaluations.

Who are you speaking to and why?

We will interview service users and therapists, as well as researchers about how they understand TYPPEX, what is effective and any areas that may need refining for the main trial.

How many interviews so far?

- ➔ 2 service users
- ➔ 5 therapists
- ➔ 1 IAPT manager



Dr Janet Willars

Vikki Charles

What will happen next?

The recorded interviews will be transcribed (typed up) and anonymised. The recordings are then deleted. Vikki and Mary-Dixon Woods, Director of THIS Institute and a co-applicant on TYPPEX, will 'code' the transcripts into categories that emerge from patterns in what people are saying. For example, there might be a category about patient-facing material. A final report will inform refinements to the training and therapy.

Will there be Patient and Public Involvement (PPI) input?

It's really useful to have the perspective of people with lived experience who might interpret things differently and be able to make sense of the data because they've had direct experience. We'll ask our PPI group to critically reflect upon any assumptions or themes constructed by the researcher to aid interpretation of the qualitative data.



Process evaluations often use interviews to collect qualitative data in the form of people's views and opinions.

Meet our LEAP

by Anjie Chhappia, TYPPEX Lived Experience Advisory Panel (LEAP) member

WHY I GOT INVOLVED

I was interested in this study as having used Improving Access to Psychological Therapies (IAPT) as a BAAME person with lived experience I fell through the net as IAPT locally did not offer what I required and there was not an appropriate service that could help my need. I felt this study would be close to filling that gap for people like me.

WHAT I'VE LEARNT

I have learnt to understand about the impact gaps in service provision can have by hearing about others experiences and I have helped in contributing by being part of this study by sharing experiences and I learn from other academics and peers. I was able to participate in contributing to develop this study and the training modules.



Anjie Chhappia, LEAP member.

WHAT I'VE ENJOYED

I've enjoyed being part of this group and the supportive environment from the start. The communication in between sessions and during the sessions with others has been good and it's been rewarding to be able to share experiences. I've enjoyed the Cambridge meetings.

WHAT I'VE FOUND CHALLENGING

Some of the technical bits at the beginning and during the rushed presentation of the training modules were challenging.

ANOTHER LEAP MEMBERS SAYS:

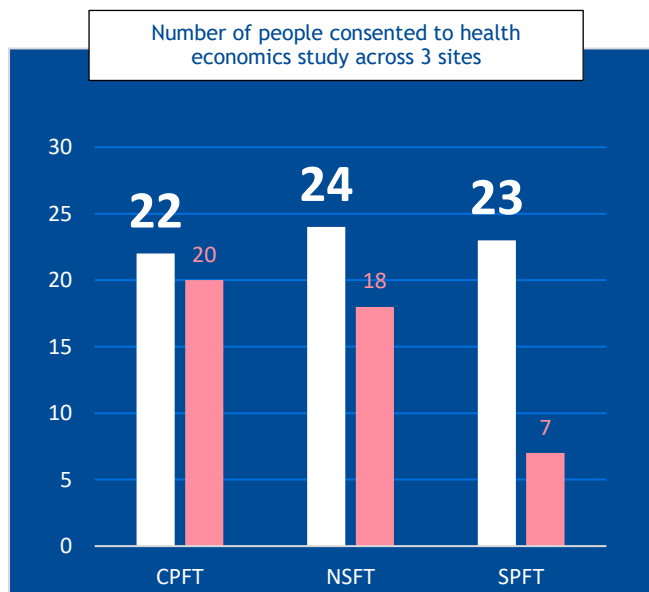
"I got involved with the TYPPEX LEAP because I have lived experience of a mental health condition and have used CBT before. I would like CBT to improve. I have learnt that a lot of work goes into the study and can be quite hard at times. I have enjoyed meeting and talking with new people. I hope going forward that the study is completed successfully and that CBT used from this study is helpful for patients." – Anonymous, LEAP member.

How many people are completing our health economics questionnaires? (Recruitment update)

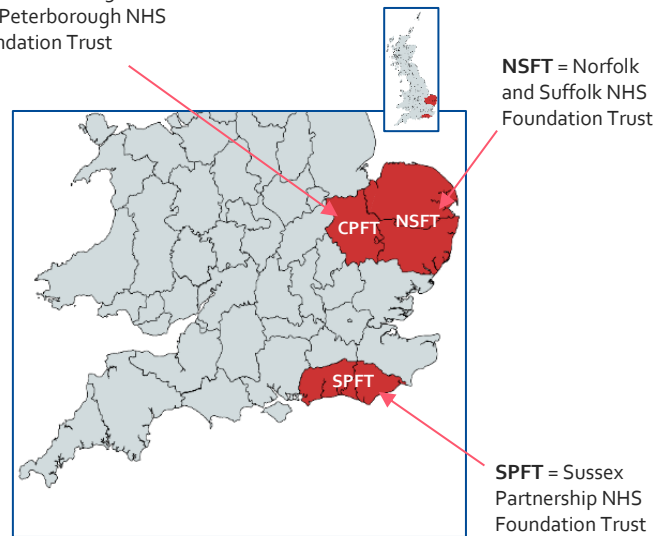


by Freya Stuart and Clare Knight

We trained 10 therapists in Peterborough (CPFT) in early April 2019, 13 therapists in Ipswich (NSFT) in late April 2019, and 12 therapists in Lewes (SPFT) in early June 2019. Recruitment to the cost-effectiveness (health economics) part of the study could only begin after TYPPEX training and was therefore staggered. The recruitment target was 15 and we have exceeded this at all 3 sites (see white bars, below). Pink bars show recruitment as reported in the August newsletter: the two lagging sites have now caught up.



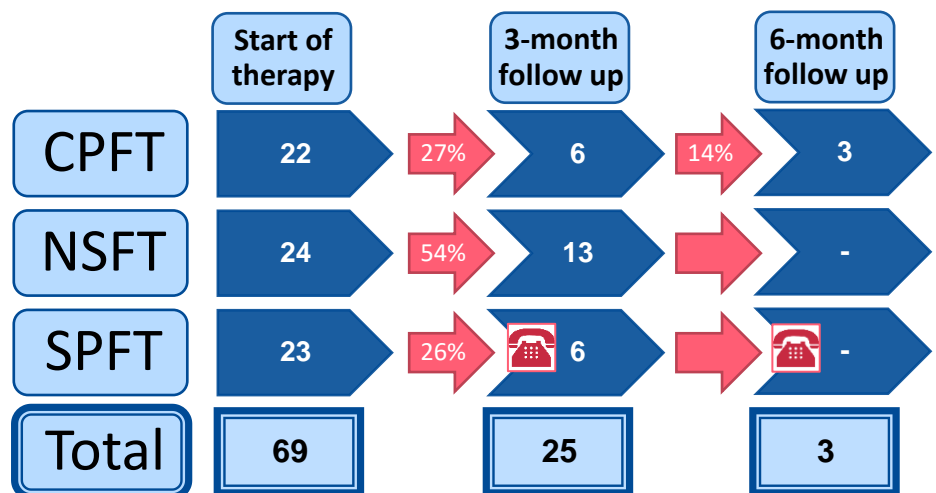
CPFT = Cambridgeshire and Peterborough NHS Foundation Trust



Recruitment has now ended and we are currently monitoring the number of follow-up questionnaires completed (requested via email at 3 and 6 months). The chart below shows how many people have completed the initial ('start of therapy') and follow-up questionnaires so far (the pink arrows show the percentage that continued to participate). As you can see there is a bit of a drop-off (although the training lag means that we haven't got the complete picture yet).

From data collected so far, we've noticed that some people complete the shorter of the two questionnaires but give up on the longer one (known as the Adult Service Use Schedule or ADSUS). Thank you to members of our PPI group who provided feedback on how the online interface of the ADSUS could be improved—we're working on it.

We also think more people might complete both questionnaires if given a phone reminder and we're testing this method in SPFT. We'll keep you updated!



= phone reminder

Meet the team: Debra Russo, Research Assistant

by Debra Russo (interview by Freya Stuart)

HI DEBRA – YOU ARE A RESEARCH ASSISTANT ON THE TYPPEX PROGRAMME. HAVE YOU ALWAYS WORKED IN HEALTH RESEARCH?

No, I came to health research late in life, almost accidentally. I did my degree with the aim of becoming a counselling psychologist, but I loved the research modules and caught the research bug! I managed to land a job here at the University of Cambridge as a research assistant in April 2008 – I've been here ever since, working on various projects.

WHAT MOTIVATES YOU TO WORK IN MENTAL-HEALTH RESEARCH IN PARTICULAR?

If my children ever need help with their mental health, I would want effective treatments to be available. Research is the best way to improve outcomes for people – everything we know and do is based on research conducted in the past. Most funding supports research on the causes of mental health, much less goes on detection, prevention, and development of treatments. That's why TYPPEX is so great – we've identified a group of people who are not best-served by current services and now we're working to develop a treatment to help them. This real life application of academic research is important to me. It's a job worth getting out of bed for!

WHAT IS YOUR ROLE ON THE TYPPEX STUDY? COULD YOU DESCRIBE A TYPICAL DAY?

No one day is the same in my role. Here's a selection of things I might be working on at any one time...

- ➔ *Out in the field supporting therapists in the feasibility (pilot) study*
- ➔ *Helping the TYPPEX Trainer and Therapy Development Lead, Ushma Patel, with the content and formatting of PowerPoint training presentation*
- ➔ *Printing and collating participant invitation packs*
- ➔ *Conducting a systematic review with Research Assistant, Emma Soneson*
- ➔ *Contributing to academic papers*
- ➔ *Helping out with some of the Lived Experience Advisory Panel (LEAP) meetings*

IF YOU WEREN'T A RESEARCHER, WHAT WOULD YOUR DREAM JOB BE?

I would own my own book shop with a resident cat or two!



HOW DO YOU LOOK AFTER YOUR OWN MENTAL HEALTH?

- ✓ *Try to surround myself with people who genuinely care about me.*
- ✓ *Ask for support if I need it.*
- ✓ *Take a little bit of time out every day – shut down my tabs! (My son always describes it as like shutting down all the windows you have opened on your computer during a busy day!)*

APART FROM WORKING ON SUCH AN AMAZING RESEARCH PROJECT (!), WHAT BRINGS YOU THE MOST JOY IN LIFE?

My daughter and son bring me the greatest joy – especially seeing the amazing adults they have become

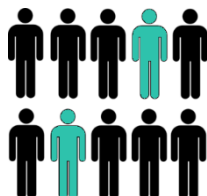
Stats corner

by Freya Stuart



We often talk about the 'prevalence' of unusual experiences but what exactly does this mean? Prevalence is defined as: "The total number of cases of a given condition/symptom in a specified population at a designated time."

For example, if we took the members of our LEAP (our population) and asked whether they currently (i.e. at a designated time) had a cold (our condition) we could calculate the prevalence.



Let's suppose 2 members out of 10 said that they had a cold.

The prevalence would be calculated as follows:

$$2/10 = 20\%$$

In reverse, we can bring to life what a prevalence percentage means. For example, in a sample of 2042 people accessing IAPT talking therapy, prevalence of unusual experiences was 30%.

What does this mean? How many individuals had these experiences?

$$2042 \times 30\% = 613 \text{ people}$$

That's a lot of people who could be better supported by TYPPEX!

Literature search workshop

by Freya Stuart



Our 'big idea'

In early November 2019, we put on a workshop to provide training for some of our Lived-Experience Advisory Panel (LEAP) members in conducting an online literature search. We wanted to find out how common unusual experiences are with the aim of using our findings to create a normalisation leaflet.

We got the idea from a similar leaflet used with people who have obsessive compulsive disorder. The leaflet shows how common different intrusive thoughts are in the general population (known as their 'prevalence' – see *Stats Corner* on page 4). For example, 54% of people in the general population experience intrusive thoughts about insulting a stranger*. The theory is

that people will feel less troubled by these thoughts if they know that lots of other people think in this way too. If the prevalence of unusual experiences in the general population is high, then this may be reassuring for people.

What did we do?

Five LEAP members attended the workshop that provided an overview of health and medicine literature followed by a practical session on carrying out a literature search using a database called PubMed.

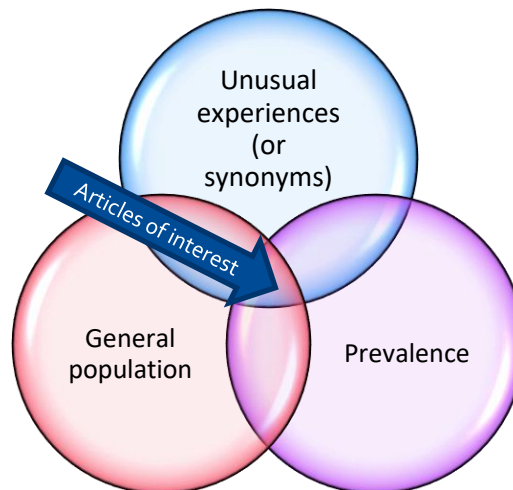
We worked together to build a search using computer language to make our search

both inclusive (to capture articles that use different words to describe unusual experiences) and specific (to focus on prevalence in the general population). Then we learnt how to navigate around our results. After reviewing a couple together, our members were soon off on their own, sifting through articles: a total of 17 potentially relevant articles were identified!

What's next?

The research team will review the articles and pull out any prevalence data. We'll ask our lived-experience panel how reassuring these statistics could be to support normalisation. If our panel thinks it would be helpful, we'll co-design a patient handout.

Thanks to all who attended for making this a success!



'Thank you, I really enjoyed the workshop, it made me feel like I was really managing to contribute something useful to the research even when not mentally very stable.' – LEAP member

'That was a really good presentation, nice atmosphere and practical experience. Thank you :)' – LEAP member

*Purdon C. & Clark D. *Obsessive intrusive thoughts in nonclinical subjects. Part 1 Content & relation with depressive, anxious & obsessional*

We want to hear from you!

by Freya Stuart

What do you think?

We want the newsletter to provide content that our readers are interested in. Is the TYPPEX newsletter useful and interesting to you? What do you like? Not like? What do you want to read more about?

Do you want to contribute to the newsletter?

Are you involved in the TYPPEX study? We want to hear from you! We are looking for content from our collaborators and contributors: our PPI members, co-applicants, research staff,

therapists and anyone involved in the project.

We welcome all content: articles, drawings, personal reflections, events, conferences and training attended.

INVOLVEMENT OPPORTUNITY

If you have any feedback, or would like to be involved in providing content or producing the newsletter, please contact the PPI research coordinator:

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For more information about TYPPEX: <https://www.fundingawards.nihr.ac.uk/award/RP-PG-0616-20003>.

For more information about the feasibility study: <https://doi.org/10.1186/ISRCTN16318194>

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