

# Sharing experiences of engaging Service Users



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# WHO ARE WE?

**The Clinical Research Coordinators (CRC) and Research Assistants (RA) are the participant's advocate and supporter.**

**We are the:**

- **local point of contact**
- **facilitator between the research team and the public, and**
- **A consistent source of support throughout the research process**

**Within our team we have varied roles, skills and backgrounds. Here are a few of us...**

# HERE'S WHAT WE DO

Sussex Partnership  
NHS Foundation Trust



## Clinical Research Coordinators (CRC's)

- Work specifically on NIHR Portfolio research studies
- Work on several different studies at once
- Coordinate studies locally including:
  - Promote and discuss studies
  - Recruitment of participants
  - Carry out assessments, clinical interviews
  - Data management, with adherence to data protection and confidentiality
- Liaising with **all** SPFT services, Primary Care, Universities, BSMS and 3<sup>rd</sup> sector organisations Sussex wide.
- Research link for each division of SPFT across the county

## Research Assistants (RA's)

- Work on a specific study, from beginning to end
  - Initial set-up (e.g. meeting and engaging local teams with the project)
  - Discussing the research with interested parties and recruiting participants
  - Conducting assessments, interviews and/or focus groups
  - Data input and protection, analysis and general admin
- Research link within Early Intervention teams for all other studies

# Memory Recall Activity

1. Cash
2. Tree
3. Packet
4. School
5. Hike
6. Picture
7. Solid
8. Shout
9. Hay
10. Flag
11. Photo
12. Swim
13. Brick
14. Cake
15. Night

# WHY WE DO IT

Knowing that you're contributing to something that will ultimately improve peoples' lives is massively rewarding

To help people share their stories to shape future services

I enjoy being in such a dynamic and exciting environment - what we do always feels so positive, there is a real sense of moving forwards with care and treatment options

To try and minimise the barriers to taking part to give everyone equal opportunity

I like being part of a team dedicated to increasing our understanding and improving our skills to help people with their mental health

To be part of exciting and innovative advancements in mental healthcare

We can facilitate the service user 'giving back' to the NHS in the form of participating in research

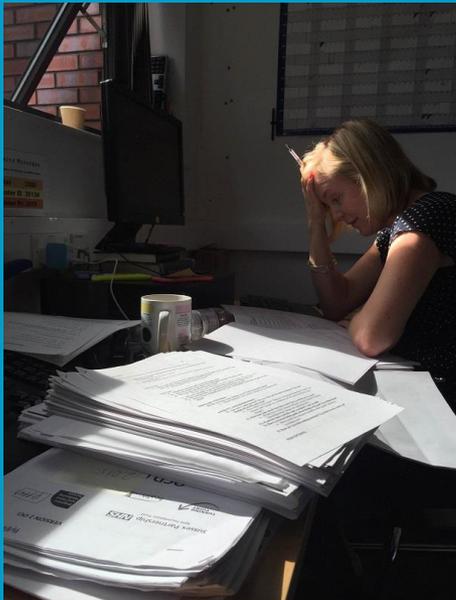
Putting compassion into action

# CHALLENGES

- Letting people know about the study
  - Hopefully helped by the Research Opt out
- Missed appointments
  - Phone call/text reminders the day before (ask participant what they would prefer)
- Limitations of research visit around potentially distressing topics
  - Check how participant is feeling on the day, let them know what the assessments will involve, work with clinical teams.
- Being part of the control group
  - Make participant fully aware of random 50/50 chance. The control group is just as important!

# WHAT DO WE DO WITH YOUR INFORMATION?

- Once data has been collected it is stored in secure locked cupboard
- Data is anonymised meaning participants cannot be identified
- **Randomisation**



- Data is then analysed – Which can be a long process!
- **Write up**
- **Results/Dissemination**

# MEMORY RECALL – DELAYED

1. Cash
2. Tree
3. Packet
4. Swell
5. Hike
6. Picture
7. Solid
8. Shout
9. Hay
10. Flag
11. Photo
12. Swim
13. Brick
14. Cake
15. Night

# WHAT CAN WE DO TO HELP YOU TAKE PART?

After feedback from previous participants, here are some of the ways we try to help make taking part easier:

- Contact you directly when new studies are available via post / email
- Offer appointments in your home, local SPFT clinic or non-NHS sites to meet (where possible)
- Be open and transparent about the time needed to complete tasks
- Arrange or assist travel (either paid or unpaid)
- Increase flexibility for appointment times (out of hours)
- Breakdown large sessions into smaller appointments

## **But what else can we do?**

Please use your feedback cards to give us more ideas and post in the red box.

# What participants have said...

“She was very well trained and wanted me to let her know if I had any requirements. She was very supportive...and I did not feel anything could have been done better”.

“I hope that research will help people and change the way they are treated, socially as well as medically”

“He was really friendly, I felt relax and like I was doing something to help others”

“They listened to what I said and I felt that they appreciated my comments”.

“I would obviously like to receive the intervention but I would still be happy if I was in the other group as I would feel like I am still contributing and giving something back to the services that have supported me”

**If you are interested in finding out more about how to get involved in SPFT research come and speak to one of us or check out the research table!**