

## Patient and Public Involvement (PPI) Funding Award

Josephine Wallinger – 23.05.23

### **Young people and adults' experiences of developmental language disorder in the workplace: a life narrative and co-design study**

Developmental language disorder (DLD) is a common condition in childhood, that has received little research funding. Hence, there is limited research evidence on the long-term impact and support needs when DLD persists into adulthood. DLD and reading difficulties frequently co-occur, causing hidden challenges for individuals in education, training and at work.

This study will document the life stories of young people and adults with DLD, exploring their life experiences, with a particular focus on work.

Thank you for this SPCR PPI funding. It has enabled me to work with a PPI Advisor, over six sessions, to plan, prepare and set up the main component of my DPhil research.

PPI has been key in planning and preparing this study, which will also invite study participants to participate in co-design.

#### **The impact of PPI on my project**

This qualitative study is part of a patient-led project in which I draw on my own profile of Dyslexia and Developmental Co-ordination Disorder. These conditions can co-occur with DLD and cause me persistent and hidden difficulties at work.

My PPI Advisor brought their lived experience of language difficulties to the project and helped me to prepare study recruitment materials, interview processes and plan a co-design workshop.

I particularly enjoyed working alongside someone else with a shared experience and understanding of the study topic. We were able to combine our similar and differing perspectives, of language and literacy difficulties, with the aim of preparing materials and approaches to include and support a range of eligible participants.

Working together also helped me to consider how I will work with people in the study, focusing my own preparation as a qualitative researcher and as a partner in the co-design process.

## **The impact of PPI on me as a researcher**

My PPI advisor brought so much thought, care and insight to the project and helped me to view the project from the perspective of potential participants.

They particularly directed me to highlight (in various ways) the most important information to study participants.

This project is about persistent language disorder, in people's own home language/s, and language difficulties can be hidden. This makes applying for work and carrying out some tasks more challenging. There is poor awareness of DLD in adulthood and so it is not easy for people to gain accommodations or reasonable adjustments at work.

My PPI advisor thought seriously about the tasks that people would be asked to do in this study. I am so grateful for their focus. This is an example of a situation where someone experiencing language difficulties could be a more effective colleague than another person without the same level of commitment, insight and experience.

## **The impact of PPI on my PPI contributor**

In their own words:

*"My role as the PPI Contributor on this project is something impressive that I can add to my CV.*

*This process has helped increase my confidence in expressing my opinion and offering advice.*

*The suggestions I made about highlighting sections of the text, adding pictures and formatting the text allowed me to demonstrate my IT skills, which have not always been recognised. This has validated my confidence in my IT skills.*

*As I have not been to university, being part of a project at a prestigious university such as Oxford, made me feel really good about myself."*

## **Next steps for using the PPI in the study**

The PPI sessions directly contributed to a successful application for ethical approval to conduct the project. This represents progress in including an **underserved** group in research. As a result, people with Developmental Language Disorder will be invited to talk about their lives in relation to education, training and work. Once all the stories are summarised participants will be invited to a **co-design** session, with the aim of influencing future development of services and support.

Now that ethical approval has been gained, the next steps are to **pilot** the participant information and interview approaches that we have prepared in these sessions. The first two or three study participants will act as a pilot group. Study materials will then be reviewed and further adjustments may be made.

## **How we spent the funding**

We allocated the funding to 6 PPI sessions, run two at a time, with a 30 to 40 minute break between each session.

We ran these double sessions 3 times to increase the number of sessions the budget would allow for, while reducing travel expenses. This enabled a good workflow in the sessions and ensured that we could have more PPI sessions than would have been possible had we spent more of the budget on expenses. We used the full funding allocation.