# **Enhancing Knowledge Co-production Between** Neurodivergent Young People & Academic Researchers to Enrich Experimental Neuroscience







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## **INTRODUCTION:**

- Basic experimental science traditionally lacks a participatory research (PR) element.
- The RE-STAR project establishes new ground by co-designing an electroencephalography (EEG) study with neurodivergent young people who have a diagnosis of autism and/or ADHD.
- Here we describe first phase project progress, which aimed to develop an ethically approved research protocol for the study.

## **METHODS:**

- 9 weekly online research planning meetings and workshops
- 2 academic and 5 RE-STAR Youth Researcher Panel (Y-RP) researchers
- Reflective journaling and live reflective sessions throughout

## **PROJECT TIMELINE:**



#### **INTRODUCTION TO QUANTITATIVE RESEARCH** METHODS

Understanding the components of quantitative research: hypothesis testing, study design, and data collection



#### **DESIGNING THE STUDY, PART 2**

Selecting measures of research experience and engagement, reviewing measures of EEG data quality, designing





#### WRITING UP A RESEARCH **PROTOCOL**, **PART 2**

Gathering critical feedback on and finalising the protocol



**APPLYING FOR RESEARCH ETHICS & WRITING UP A RESEARCH PROTOCOL, PART 1** 

Learning about ethics in research, and research protocol write-up



Making joint decisions on EEG tasks, discussing the eligibility criteria for the study, deciding qualitative interview analysis

**COLLECTION & ANALYSIS** 



## **REFLECTIVE THEMES:**

## WHAT MAKES IT WORK

POWER

#### **FACILITATION / SUPPORT**

"...And the academic team facilitates that well." (YRP-R)

#### EQUITABLE WORK

"I feel respected and included and like my contributions do matter, which is standard for RE-STAR..." (YRP-R)

#### FREE EXPRESSION

"I feel free to express my ideas with the team." (YRP-R)

#### FAMILIARITY

"...We've met and collaborated before, this experience has been very positive for me." (YRP-R)

## **CONCLUSION:**

• The study has been fully approved on 26/10/2023 by the KCL Health Faculties Research Ethics Subcommittee (HR/DP-23/24-39713)

#### • Co-production research has

#### **POWER DYNAMICS**

*"I still don't consider myself to be on equal footing to* the academic researchers, but I'm not sure that's ever interview questions

**DISCUSSING DATA** 

DYNAMICS

really achievable in this kind of work." (YRP-R)



CHALLENGES

REWARDING

EXPERIENCE

## **EXCHANGE OF KNOWLEDGE/ EXPERIENCE**

"I have gained more insights about the reflections of the young people [...] i.e., the mental load of having a dual role of being a learner and a teacher [...] definitely resonate with my experience." (Academic-R)

## SCIENTIFIC CONTRIBUTION

"All of the PR team members shared good ideas about the study that will impact its design." (YRP-R)

## **DIFFERENT KNOWLEDGE BASE**

"I have got confused a few times what our aims are and what we are meant to be researching [...] with timeframe things can get lost in conversation." (YRP-R)

## **FAST-PACED**

*"It definitely has felt quite the crash course and very"* fast paced." (YRP-R)

enriched the development of our EEG study.

• YRP members will be involved fully as co-researchers through their participation in the data collection, analysis, and dissemination phase of the study.

### FULFILMENT

"I found it very fulfilling, by the end I felt well integrated into the team and like my contributions were helping." (YRP-R)

#### ENJOYMENT

"I really enjoy being part of this group. As a researcher I find the collaboration very fruitful." (YRP-R)



**\*\*The RE-STAR Participatory Research Team is:** Maciej Matejko, Dorian Poulton, Luke Harvey-Nguyen, Tiegan Boyens, Isabel Jackson (independent youth researchers), Edmund Sonuga- Barke, Susie Chandler, Eloise Funnell and Steve Lukito (KCL); Georgia Pavlopoulou (Anna Freud Centre and UCL), Sylvan Baker & Lauren Low (Royal Central School of Speech and Drama).



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