NEWSLETTER ISSUE

August 2022

Welcome to our fourth PETAL newsletter!

We are a national study (across England, Scotland and Northern Ireland) that has developed and will test a personalised intervention for aggressive challenging behaviour for adults with learning disability, which, if effective, can be rolled out in the NHS.

Chief InvestigatorProfessor Angela Hassiotis





Co-Chief Investigator Dr. Afia Ali

CO-APPLICANTS

Prof. Umesh Chauhan
Prof. Sally-Ann Cooper
Ms. Vivien Cooper
Prof. Richard Hastings
Ms. Rachel Hunter
Prof. Andrew Jahoda
Mr. Brendan Leahy
Dr Louise Marston
Prof. Craig Melville
Dr Penny Rapaport
Dr Elizabeth Steed
Prof Laurence Taggart

University of Central Lancashire
University of Glasgow
Challenging Behaviour Foundation
University of Warwick
University College London
University of Glasgow
Camden Disability Action
University College London
University of Glasgow
University College London
University University of London
Ulster University



Personalised Treatment Packages For Adults
With Learning Disabilities Who Display
Aggressive Challenging Behaviour In
Community Settings

We split our work into 4 different workstreams:

Workstream 1a: Rapid Realist Review

We carried out a review of existing literature and developed theories to determine what works in intervention programmes for aggressive challenging behaviour, for whom and in what circumstances. Emerging theories include emotion regulation and skill development; valuing, understanding and listening to those receiving therapy; engaging, mentoring and supporting therapists; and improving communication with paid and family carers.

Workstream 1b: Qualitative Interviews

We completed 42 interviews with service users, carers, and professionals about the barriers and facilitators associated with treatment outcomes. Participants were recruited from 7 sites across England, Scotland, and Northern Ireland.

Key themes of facilitators of positive outcomes were identified as therapeutic alliance, intervention related factors (such as catering towards individual needs and tools to manage behaviour), streamlining and collaboration of support, and person-centred support and environment. The main barriers of positive outcome were structural and organisational issues, such as inadequate support, lack of resources and organisational culture and attitudes.

Workstream 2: CRIS

We used a mental health database called CRIS (Clinical Record Interactive Search) to identify patient profiles that are more likely to come to contact with crisis services due to aggressive challenging behaviour, and to explore what happens as they move through the clinical pathway.

The results showed that patients with aggressive challenging behaviour were more likely to contact such services if they had a diagnosis of a personality disorder or common mental health disorder (anxiety, depression), if they experienced episodes of agitation and if they were having more contact with professionals of mental health services. People with a pervasive and specific developmental disorders diagnosis, however, were less likely in need of crisis interventions.

Workstream 3: Intervention Development

The personalised intervention has been developed through coproduction with adults with learning disability, their family and paid carers. Seven meetings were held to design the intervention, which was also informed by the findings from Workstreams 1 and 2.

CONTACT INFORMATION FOR THE RESEARCH STAFF

Rachel Royston

Research Programme Manager (London) r.royston@ucl.ac.uk

Nancy Kouroupa

Clinical Trial Manager (London) athanasia.kouroupa.12@ ucl.ac.uk

Peter Mulhall

Research Associate (Northern Ireland) p.mulhall@ulster.ac.uk

Tamara Ondruskova

Research Assistant (London) t.ondruskova.16@ucl.ac.u k

Bori Vegh

Research Assistant (London) borbala.vegh@ucl.ac.uk

Address

University College London, Division of Psychiatry, 6th Floor, Maple House, 149 Tottenham Court Road, London, W1T 7NF

Website

https://www.ucl.ac.uk/ps ychiatry/research/epidem iology-and-appliedclinical-researchdepartment/petalprogramme-nihr-idnihr200120 We are finalising the intervention manual for therapists, the workbooks for carers and participants, and the therapist training programme. We would like to say a special thank you to PhD student Sarah Ashley for designing the workbooks for participants with learning disability and family and paid carers.

The intervention includes modules on understanding behaviour, improving communication, emotional regulation, calming/relaxation activities, carer wellbeing and healthy habits. The intervention will be delivered flexibly over 14 weeks.

Workstream 4: Clinical Trial

We will conduct a large trial to test whether the PETAL intervention reduces aggressive challenging behaviour in adults with learning disability and how cost effective it is. We plan to test the feasibility of the intervention with 3-4 sites beginning this autumn, with the main trial scheduled to start in early 2023. After recruiting participants, half of the participants will receive the PETAL intervention along with their usual care and half of them will receive just usual care, which will allow us to compare the effectiveness of the intervention.

We are currently looking for sites across England, Northern Ireland and Scotland to participate.

Implementation

Our implementation work is about understanding barriers and facilitators of adopting the PETAL intervention in services and how to overcome these.

Patient and Public Involvement

Both our family and service user advisory groups facilitated by Afia Ali, Viv Cooper and Brendan Leahy have been meeting regularly to support the programme.

We would like to thank all the services and participants in the 3 UK countries, who have taken part in our research so far. We couldn't do it without you!

MEET THE NEW MEMBERS OF **OUR RESEARCH TEAM**



Nancy

I'm the Trial manager in the PETAL study. I have worked with autistic people and/or people with learning disability since 2014 and I very much enjoy working with parents/carers and people with neurodevelopmental conditions to improve access to services and interventions as well as bridging the gap between clinical and research practice.



Bori

I am a research assistant of the PETAL study. I had worked with adults with learning disability in the social care sector since 2018. I have recently completed my MSc in Social Psychology, and I am committed to work on projects that facilitate positive change and make a difference to the lives of people with learning disability.



Tamara

Hi everyone! I am the new research assistant at the PETAL study. I previously worked on a trial (EPICC-ID), which was looking into an intervention for parents of children with intellectual disabilities who display challenging behaviour. I hope that my work can contribute to improving lives of children and adults with learning disabilities.























