

# Positive Behaviour Support Recruitment Update

Clinical and Cost Effectiveness of Positive Behaviour Support: a multicentre randomised controlled trial

The Positive Behaviour Support Trial has now recruited a total of:  
**219 study participants**

Six month follow-up assessments have now been completed with:  
**114 of the study participants**

(As of the end of April 2014)

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## Staff Update

We would like to welcome Chris Anderson, our new part-time Administration Assistant to the team.

We would also like to introduce Lucy Fodor-Wynne. Lucy is an Honorary Research Assistant and has been tremendously helpful with various aspects of the study.

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## PBS—A clinical studies officer perspective

Hello my name is Imogen I am a CSO in Kent, I have been working on PBS since it opened in June 2013. We currently have the study running over two very enthusiastic sites. Over the last 7 months I have found that many of our patients and carers have really enjoyed being in the study. Carers have found it a good exercise to reflect on how their patients are and what areas they are already functioning well in and what areas need improvement, as a separate entity to the challenging behaviour. Patients have also feedback that they enjoyed getting to see CSOs and the research team and enjoy the extra level of input into their usual routine.

### **What made PBS successful in Kent**

I think what helped the study be successful in terms of initial uptake and retention to the PBS study, was the help of our eager and open local investigator, Dr Eyeoyibo. Dr Eyeoyibo and I worked together closely to identify potential participants early on. This meant we could open the study feeling confident that we could find eligible and interested patients and keep them involved for the full 12 months.

It was fairly easy to get staff on board with the study and by offering the possibility of free training for those involved it really helped with initial uptake. Many of our consultants also felt that new behavioural approaches can be helpful in clinical practice as well as contributing to a database of research.

During the initial stages of the study I committed my time solely to consenting participants and completing baseline assessments. This meant an extremely busy 2 months but also meant we were able to complete baselines for the majority of our participants before staff were potentially trained. This also made it possible for our follow ups to fall together as opposed to running over the year. Thus, making it easier to focus on the study for an allotted time and ensuring it was completed to time and over target.

The PBS team have been great to work with and highly understanding of any issues that we have come up against. They have been able to dedicate time to assisting us with follow ups which has meant that my time has been more freed up. I have enjoyed working on the study and hope that the hard work pays off and that we are able to collect some interesting findings about positive behaviour support.

Author: Imogen Bennetto , Clinical Studies Officer for PBS in Kent



# Service Users' Group Meeting

There was a service users' group meeting in April where the qualitative follow up study for the trial was discussed.

- Qualitative questions to be asked in follow up study were presented to service users
- Easy-read qualitative questions to be asked in follow up study were presented to service users
- Updates of changes made based on previous meeting were presented to service users (e.g. new carer's certificate)

The service users suggested some changes to wording and images of easy-read qualitative questions to increase accessibility.



What do you think  
challenging behaviour is?

Example qualitative question for service users

## What else are we doing?



One of our Research Assistants, Jessica, is also currently working on her MSc Psychiatric Research at UCL. For her dissertation she will be looking at the relationship between challenging behaviour and epilepsy in people with learning disabilities.

Since we don't do things by half measure here, she spent a week of her annual leave shadowing in the telemetry unit at the National Hospital of Neurology and Neurosurgery to get a closer understanding of epilepsy. She shadowed ward rounds and outpatient clinics, attended teaching for medical students and an MDT and even got the chance to watch brain surgery. Best 'holiday' ever.



# Other Learning Disability Research Conducted at UCL

**A feasibility study of a psychological intervention to address alcohol misuse for people with mild to moderate learning disabilities living in the community.**

There is much debate among the literature regarding prevalence estimates of substance misuse among the intellectually disabled (ID) population.

Alcohol is the most commonly used substance worldwide. The 1970's de-institutionalisation of those with an ID has significantly increased the risk of alcohol use among this population. Such individuals are now exposed to life stressors, along with ready access to alcohol, often used for coping.

Despite, the rise in vulnerability of this population, the issue has been somewhat overlooked. Due to the lack of robust research so far, there is a tendency among practitioners to underestimate the prevalence of this problem. Consequently, this population remain hidden with an absence of suitable interventions.

The current study is a first of its kind. It aims to develop a psychological intervention for individuals with a mild-moderate ID, who engage in hazardous-harmful drinking.

The intervention is an extended brief intervention (EBI), recommended by the National Institute of Health and Clinical Excellence. Its approach involves motivational enhancement therapy and behavioural methods tailored to meet the needs of those with ID. There is an abundance of evidence indicating the success of EBI within mainstream services.

The current study aims to establish whether EBI can be feasibly applied to community learning disability settings. Preliminary findings so far have provided insight into the drinking culture among this population, recruitment challenges and practitioner's attitudes and expectations.

Author: Sophie Nicholls, Research Assistant on the EBI study

The PBS website:

[www.ucl.ac.uk/positive-behaviour-support](http://www.ucl.ac.uk/positive-behaviour-support)



Twitter account:

[www.twitter.com/PBSstudy](https://www.twitter.com/PBSstudy)



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