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| Newsletter Issue 1 March 2019  **IST-ID**  **Clinical and cost evaluation of Intensive support teams (IST) for adults with intellectual disabilities and challenging behaviour** |  |
| **Prof Angela Hassiotis-Chief Investigator**  Welcome to the first IST-ID newsletter. We are a national study funded to evaluate if different models of intensive support teams produce comparable outcomes for people with intellectual disabilities and challenging behaviour.  **Background to the study**  About 17% of people with learning disabilities (LD) living in the community display challenging behaviour such as aggression to others or property, self-injury or hyperactivity. There are concerns that adults with LD and challenging behaviour over-use medication, spend large periods of time in hospital, and miss out on living in the community. Hospital care is expensive, and costs are increasing.  NHS England has produced guidance about Intensive Support Teams (ISTs) proposing that they should be part of all community ID services in England.  ISTs are specialist services for adults with LD and challenging behaviour, which aim to support individuals through interventions such as positive behaviour support and other psychosocial approaches, to promote recovery, leading to reduction in severity and frequency of challenging behaviour and preventing restrictions of liberties such as inpatient admissions.  S:\MHS_Hassiotis\IST-ID\Logos\ucl logo.pngHowever, there is currently very little evidence about how effective ISTs are. The people who pay for Health and Social Care services (commissioners) would like more information about outcomes, and this project aims to provide this. | **Contents**   1. **Introduction** 2. **Background to the study** 3. **The project** 4. **Recruitment update** 5. **Our Co-applicants** 6. **UCL Research team and contact details** 7. **Patient and Public Involvement** |
| **The project**  We propose to do a project over 36 months. It will be in two parts.  **Stage 1**: First we will find out about how many, and what type of ISTs exist in England, by asking service managers about their service, their staff, and the work they do. With this information, we will identify different models of ISTs  **Stage 2**: We will look at various services in each model to compare how they work with people with ID and other local services. We will collect data twice over 9 months to see which model(s) work best. We will also carry out interviews with people who use ISTs, family and paid carers, and referrers to ISTs to find out about their experiences of these services, and how happy they are with them.    **Recruitment update**  Stage 1 of the study has been completed and we are currently in Stage 2. We have identified **two** models of ITSs in England and we have calculated that we need to collect information from eight sites per model. 15 out of 16 sites have given approval to recruit participants and so far we have recruited 49 out of our target of 226  .  **We are actively looking for more participants**!  **IST-ID Team**    **Chief Investigator**  **Prof Angela Hassiotis** -Professor in intellectual disability in the Division of Psychiatry at UCL and honorary consultant Psychiatrist at the Camden Learning Disability Service  **Co-applicants**  **Dr Elisabeth Victoria Crossey – NHS Lothian**  **Dr Ken Courtenay – BEH Mental health NHS trust**  **Dr Brynmor Loyd Evans – University College London**  **Dr Renee Romeo – King’s College London**  **Dr Vincent Kirchner- Camden and Islington Foundation Trust**  **Dr Ian Hall – East London Foundation Trust**  **Dr Nicola Morant – Independent Research Consultant**  **Dr Peter Langdon – University of Kent**  **Dr Laurence Taggart – Ulster University**  **Miss Rebecca Jones – University College London**  **Research Staff**  IST-ID Project Manager Dr Victoria Ratti [v.ratti.11@ucl.ac.uk](mailto:v.ratti.11@ucl.ac.uk)  Research Assistant Jessica Budgett [j.budgett@ucl.ac.uk](mailto:j.budgett@ucl.ac.uk) | |
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**Patient and Public Involvement**

**What is public involvement in research?**

The NIHR INVOLVE defines patient and public involvement in research as research being carried out ‘**with**’ or ‘**by**’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, participating in study steering groups and offering advice to researchers, supporting researchers to develop study materials, providing feedback and interviewing participants.

The term ‘public’ refers to patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Their role is distinct to that of professionals in health and social care services.

Exemplars of public involvement in our study are family carers and persons with intellectual disabilities.

**Family carer group**

The Challenging Behaviour Foundation has supported us to recruit family carer representatives (Jan, Lorna and Narender) that have been involved in our research study, providing valuable input and advice on study related issues and topics. Their contribution through regular meetings is highly valuable and we look forward to continue working together for the duration of the study.