## **Research Currently Recruiting in CNTW**

INDEX	
Mental Health Conditions	2
LD / Autism / Epilepsy Studies	2-3
Children and Young Adolescents Studies	3 - 4
Depression / Mood Studies	4 - 5 - 6
Drugs and Alcohol Studies	6
Case Register Information	7
Dementia Studies	8 - 9
Neurodegenerative Studies	9

#### **Useful Contacts**

#### CNTW NIHR Portfolio Research Delivery teams

Mental Health:	Jill Davison (Team Lead) 0191 2081356		
Dementia:	Jill Davison (Team Lead) 0191 2081351		
Neurology:	Lyndsey Duke (Advanced OT) 0191 287 5100		
Lorraine Henderson:	(Research Team Administrator) 0191 2081360 / 0191 2467388		
<u>R&amp;D</u>			
Simon Douglas:	(Joint Director of Research, Innovation and Clinical Effectiveness)		
Paula Whitty:	(Joint Director of Research, Innovation and Clinical Effectiveness)		
Lyndsey Dixon:	(Research and Development Manager) 0191 246 7221		
Bryony Stokes	(Quality Assurance Lead) 0191 246 7226		
Jahnese Hamilton:	(Research Funding Development Manager / CSO) 0191 246 7226		
Victoria Ternent:	(Research Coordinator) 0191 246 7228		
Ellie Drummond:	(Research Coordinator) 0191 246 7360		
Karol Adams:	(Research Secretary & Team Administrator) 0191 246 7222		



	Research into Mental Health Co	onditions	
<b>HWB</b> HEALTH AND WELLBEING	The aim of this survey is to provide information about the health and wellbeing of people with Severe mental illness (SMI). To follow approximately 10 000 adults in the UK who have severe mental ill health and to collect information about their health and general well being.	Principal Investigator: Dr Ambrina Roshi Research Nurse: Jamie Rea, 0191 2081367 / Jamie.rea@cntw.nhs.uk	Sponsor:
<b>CAP-MEM</b> Exploring the cause and prevalence of memory problems in people with mental health, neurodevelopmental and neurodegenerative disorders.	Exploring the relationship between dysfunction of the Autonomic Nervous System and cognitive impairment in a range of conditions. Recruiting people aged over 16 with conditions including schizophrenia, bipolar disorder, anxiety disorders, autism and dementia, and people with none of these health conditions.	Principal Investigator: Dr Niraj Ahuja Research Nurse: Jamie Rea, 0191 2081367 / <u>Jamie.rea@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
Suicide by Middle aged men	Examine the characteristics of middle-aged men who die by suicide; determine how frequently suicide is preceded by factors that are more often associated with suicide by men than by women (e.g. masculinities, socio-economic position, social disconnectedness, reluctance to seek help for both mental and physical health);examine the role of support services; and make recommendations to strengthen suicide prevention for middle-aged men.	Principal Investigator: Dr Tham Su-Gwam Research Nurse: Jamie Rea, 0191 2081367 / <u>Jamie.rea@cntw.nhs.uk</u>	Sponsor: The University of Manchester
Psychosocial assessments and psychological therapies following self-harm	Our main objective is to investigate the barriers and facilitators to mental health assessments and psychological therapies following self- harm. We will seek the views of staff, patients with personal experience of self-harm and their carers/ significant others to meet this objective. Our secondary objective is to explore patient and carer experiences and views on mental health assessments and psychological therapies following self-harm.	Chief Investigator: Dr Leah Quinlivan Research Nurse: Jahnese Hamilton, 0191 2081356 / <u>Jahnese.Hamilton@cntw.nhs.uk</u>	Sponsor: The University of Manchester
	Research into Learning Disability / /	Autism	
<b>PAT-A</b> Exploring the effectiveness of personalised non-pharmacological anxiety treatment for adults with autism	In this study, we will conduct a national autism and anxiety survey, gathering the views of autistic people and professionals. Using this information, we will adapt current NHS anxiety treatments to make them 'fit for purpose' for use with autistic adults and test their efficacy in a randomised control trial.	Principal Investigator: Dr Barry Ingham Research Nurse: Susan Wilson, 0191 2081356 / <u>Susan.wilson1@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland Tyne and Wear NHS Foundation Trus



Research into Learning Disability / Autism				
EPILEPSY LD REGISTER		Principal Investigator: Dr Ian McKinnon	Sponsor	
A register for collecting/measuring outcomes of licensed Anti-Epileptic Drugs in patients with Epilepsy and Intellectual Disability and/or Pervasive Development Disorders	To ascertain the safety and impact of AEDs in PWE on individuals with ID and/or PDD with specific focus on the intensity and frequency of seizures and the side effects associated with their use and to compare these findings with data collected for a control group of PWE who do not have ID and/or PDD.	Research Nurse: Andrew Hamilton, 0191 2081356 / <u>Andrew.Hamilton@cntw.nhs.uk</u>	Cornwall Partnership NHS Foundation Trust	
MRB Managing Repetitive Behaviours	This study aims to test the effectiveness of the MRB intervention for parents of young children with ASD against Learning About Autism group sessions. The long-term objective is to enable parents to have a better understanding of why children with ASD may show several repetitive behaviours, and manage those behaviours which cause difficulty for the family.	Principal Investigator: Dr Victoria Grahame Research Nurse: Susan Wilson, 0191 2081356 / <u>Susan.wilson1@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	
BEAT-IT	Study will examine if Behavioural Activation can be adapted for adults with more severe intellectual disabilities and depression. Half the participants will take part in the Beat-It (behavioural activation) treatment, and half will receive usual NHS treatment. People who choose to take part will be involved for a maximum of six months.	Principal Investigator: Dr Andrew Cairrns Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor: NHS Greater Glasgow and Clyde	
	Research for Children and Young Ac	dolescents		
<b>EPICC-ID</b> Evaluation of Parent Intervention for Challenging Behaviour in Children with Intellectual Disabilities	This study is an intervention for parents of children with intellectual disabilities and challenging behaviour. It provides parents with information and support about how to manage such behaviours in their child. Trained therapists follow a manual and deliver the intervention in groups of 5-7 parents for 5 weeks, followed by 3 individual sessions and a final group meeting	Principal Investigator: Dr Adi Sharma Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor:	
<b>CAPRI-VOC</b> Children and Adolescents with Parental Mental illness: Measuring Vocal Brain Development in Babies of Mothers who have experienced Serious Mental Illness	The CAPRI-Voc study aims to discover biomarkers of abnormal language development in CAPRI using functional near infrared spectroscopy. Compare the emergence of voice recognition over time between groups at 12 and 18 months of age, using fNIRS.	Principal Investigator: Dr Andrew Cairns Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor: The University of Manchester	



Research for Children and Young Adolescents				
<b>EOD-UK &amp; ROI –</b> Early Onset Depression in the UK and ROI in children aged 3-13 years	It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by the particular mental health disorder or condition each year – this is called epidemiological surveillance. Doctors also gather information about the cases of a particular rare condition, so they can begin to understand what might have caused it, how to diagnose and treat the problem	Principal Investigator: Dr Adi Sharma Research Nurse: Joseph Horne, 0191 2081381 / <u>Joseph.horne@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	
<b>SSS - SPECIALIST SERVICES STUDY</b> A realistic process evaluation of the implementation and impact of Forensic Child and Adolescent Mental Health Services (F-CAMHS) and SECURE STAIRS	The aim of this study is to evaluate the effectiveness of two new service models being rolled out as part of routine practice across England. The study involves collecting data from young people and parents/guardians from 33 Specialist Services provided by Forensic Child and Adolescent Mental Health Services (G-CAMHS) and the Secure Estate	Principal Investigator: Dr Jack Kennedy Research Nurse: Emily Clare, 0191 2081356 / <u>Emily.clare@cntw.nhs.uk</u>	Sponsor:	
	Research for Depression / N	lood		
<b>TRIANGLE</b> Transition care in AN: Through Guidance on-Line from peer and carer Experts	A multicentre randomised controlled trial to examine whether the addition of a patient and carer skill sharing intervention improves long- term patient wellbeing following hospital treatment for Anorexia Nervosa.	Principal Investigator: Dr Caroline Reynolds Research Nurse: Jamie Rea, 0191 2081367 / Jamie.Rea@cntw.nhs.uk	Sponsor:	
LQD Lithium versus Quetiapine in Treatment Resistant Depression	Trying to work out which of two medications (lithium or quetiapine) added to an antidepressant is best in helping people with TRD. Patients in the LQD study will be given either lithium or quetiapine alongside their antidepressant.	Principal Investigator: Prof Hamish McAllister- Williams Research Nurse: Susan Wilson, 0191 2081356 / Susan.wilson1@cntw.nhs.uk	Sponsor:	
BLISS Bipolar Lithium Imaging and Spectroscopy Study	This study aims to find out if there are differences between responders and non-responders to lithium so that in the future, psychiatrists will have a better idea who should be offered lithium; patients will be able to make more informed choices.	Principal Investigator: Dr David Cousins Research Nurse: Jamie Rea, 0191 2081367 / Jamie.Rea@cntw.nhs.uk	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	



4

Research for Depression / Mood			
<b>BDRN</b> Molecular genetic investigation of bipolar disorder and related mood disorder in nuclear families	The aim is to find genes and other factors, such as stressful life events, which make some people more likely than others to become ill. We hope that their study will improve the understanding of mental illness and help researchers find better treatments in the future.	Principal Investigator: Dr Andrew Cairrns Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor: CARDIFF UNIVERSITY PRIFYSGOL
<b>PSILOCYBIN</b> The Safety and Efficacy of Psilocybin in Participants with Treatment-Resistant Depression	The study will analyse the effects of a single administration of psilocybin at three doses (1mg, 10mg, 25mg) in 216 patients. All patients on antidepressants must taper off them within 3-6 weeks prior to baseline (the study team will manage this). The study includes 13-16 visits, two of which can be done remotely, over a 15-18 week period. A specially trained study therapist will support every participant before, during and after the psilocybin session. For further info: https://mood-disorders.co.uk/research/psilocybin-Study	Principal Investigator: Prof Hamish McAllister- Williams Research Nurse: Susan Wilson, 0191 2081356 / <u>Susan.Wilson1@cntw.nhs.uk</u>	Sponsor: COMPASSIONI Navigating Mental Health Pathways
<b>BRIGHTMIND</b> Brain image guided transcranial magnetic in depression	We are testing the effectiveness of a new approach to treat Treatment Resistant Depression (TRD) using magnetic stimulation applied via the scalp. Treatment resistant depression is depression that has not improved with at least two previous antidepressant treatments.	Principal Investigator: Prof Hamish McAllister Williams Research Nurse: Andrew Hamilton, 0191 2081356 / <u>Andrew.Hamilton@cntw.nhs.uk</u>	Sponsor: WHS Nottinghamshire Healthcare NHS Foundation Trust
RESTORE-LIFE	A Global Prospective, Multi-center, Observational post-market Study to assess short, mid and long-term Effectiveness and efficiency of VNS Therapy <sup>®</sup> as adjunctive therapy in real-world patlent's with difficult to treat depression.	Principal Investigator: Dr Hamish McAllister Williams Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor: LivaNova Health Innovation that matters
GAMECHANGE Improving lives through VR Therapy	The purpose of the trial is to find out whether our new Virtual Reality (VR) therapy helps people feel much less anxious in everyday situations.	Principal Investigator: Dr Rob Dudley Research Nurse: Jahnese Hamilton, 0191 2081356 / <u>Jahnese.Hamilton@cntw.nhs.uk</u>	Sponsor:



Research for Depression / Mood			
The PAX-BD study Double-blind, placebo-controlled, efficacy/mechanism study investigating the effect of adding pramipexole to antidepressant medication in patients with bipolar disorder.	The study will investigate whether pramipexole is a beneficial treatment to patients with BD who have depression that has not responded to other treatments.	Principal Investigator: Dr Stuart Watson Research Nurse: Emily Clare, 0191 2081356 / Emily.clare@cntw.nhs.uk	Sponsor: Cumbria, Northumberland, Tyne and Wear NH5 Foundation Trust
	Research into Drugs and Alco	hol	
MUP Impact of Minimum Unit Pricing in Scotland on harmful drinkers	To investigate the impact of implementing MUP on people who are alcohol dependent, in terms of consumption, expenditure, treatment seeking and unintended consequences and to identify potential strategies for minimising harms in this population.	Principal Investigator: Prof Eilish Gilvary Research Nurse: Susan Wilson, 0191 2081356 / <u>Susan.Wilson1@cntw.nhs.uk</u>	Sponsor The University Of Sheffield. :
SCIMITAR +	The Primary Objective is to establish the clinical effectiveness of a bespoke smoking cessation intervention for people with severe mental ill health. The secondary objectives are to establish the cost effectiveness of a bespoke smoking cessation intervention for people with severe mental ill health compared to usual GP care.	Principal Investigator: Paul Courtney Research Nurse: Jamie Rea, 0191 2081367 / Jamie.Rea@cntw.nhs.uk	Sponsor:
<b>EXPO</b> Extended-release Pharmacotherapy for Opioid Disorder	The primary objective of the study is to determine the difference in effectiveness (in terms of reduced non-medical opioids) for a head-to- head superiority comparison of Extended-release Buprenorphine and Buprenorphine/Methadone and the difference in effectiveness of a head-to-head comparison of Extended-release Buprenorphine plus Psychosocial Interventions and Buprenorphine/Methadone plus PSI during 6 months of trial treatment	Principal Investigator: Prof Ellish Gilvary Research Nurse: Jamie Rea, 0191 2081367 / <u>Jamie.Rea@cntw.nhs.uk</u>	Sponsor:



7

# **Dementias and Neurodegeneration Case Register**

To facilitate recruitment to studies we have a Case Register for people with all types of **dementia**, **mild cognitive impairment**, **Parkinson's disease**, **progressive supranuclear palsy and multiple system atrophy**. The Case Register holds information about patients interested in research. Members of the Case Register can be selected for suitable studies and asked if they would like to take part.

Patients throughout the region should have opportunities to take part in clinical research. For clinicians, referring to the Case Register can be a step on the way to research activity.

The Clinical Research Network: North East and North Cumbria can help you by:

- Promoting research in your clinics
- Signing your patients up to the Case Register
- Identifying suitable patients for your research studies
- Taking patient consent and providing information about studies and trials
- Carrying out research including study set-up
- Managing the Case Register
- Sending regular newsletters to Case Register members

Send the contact details of patients you have discussed research with to us. Either write, copy us in to a clinic letter, telephone, or email. We will send out information and obtain consent.

## How to refer patients

#### Please contact us at

Clinical Research Network North East and North Cumbria Dementias and neurodegeneration (DeNDRoN), St Nicholas Hospital Jubilee Road, Gosforth Newcastle upon Tyne, NE3 3XT

Copy us in to a clinic letter Phone: 0191 246 7388 or Email: <u>dendron@cntw.nhs.uk</u>

## Data protection and confidentiality

- All data is stored securely on a CNTW Server
- The database is used by approved members of the Clinical Research Network only
- Patient information is only released with the patient's agreement
- Patients are free to withdraw from the Case Register at any time; we inform you of their withdrawal or death and remove their details from the database



Research into Alzheimer's / Dementia			
Supporting Memory Services to enable people with dementia and their families' timely access to Assistive Technology. (Lisa Newton)	This project aims to determine current practice of professionals working in MS in the provision of information on, and access to, AT for families living with dementia.	Principal Investigator: Lisa Newton Research Nurse: Barbara Wilson, 0191 2081337 / <u>Barbara.Wilson@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
<b>SYMBAD</b> Study of Mirtazapine for Agitation in Dementia	The overall trial aim is to assess the safety, clinical and cost effectiveness of Mirtazapine and Carbamazapine in the treatment of agitation in Dementia	Principal Investigator: Dr John Paul-Taylor Research Nurse:, Bryony Storey, <u>Bryony.Storey@nhs.net</u>	Sponsor: UNIVERSITY OF SUSSEX
Graduate 2 Study Gantenerumab in patients with prodromal to mild AD	The purpose of this study is to find out the effects, good or bad, of Gantenerumab (this is a monoclonal antibody which aims to reduce amyloid burden in the brain), compared to a placebo (an inactive substance that looks like the study drug).	Principal Investigator: Dr Bob Barber Research Assistant: David Green, 0191 2081348 / <u>David.green@cntw.nhs.uk</u>	Roche
<b>DLB Genetics</b> Detecting Susceptibility Genes for Dementia with Lewy Bodies	The objective of this study is to collect a large and therefore well statistically powered DLB (Dementia with Lewy Bodies) cohort for the investigation of genetic risk factors for disease.	Principal Investigator: Dr Bob Barber Research Assistant: David Green, 0191 2081348 / <u>David.green@cntw.nhs.uk</u>	Sponsor:
<b>PATHFINDER</b> Problem Adaption Therapy for Individuals with Mild to Moderate Dementia and Depression	Our principal aims are to develop an adapted PATH intervention, suitable for use with people with mild and moderate dementia for delivery within the NHS, and to design and conduct a trial to answer the question posed by the HTA's commissioning brief:	Principal Investigator: Dr Charlotte Allan Research Nurse: Barbara Wilson, 0191 2081337 / <u>Barbara.Wilson@cntw.nhs.uk</u>	Sponsor: Camden and Islington NHS NHS Foundation Trust



8

	Research into Alzheimer's / Dementia			
<b>Determind</b> Determinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers	The study intends to investigate inequalities in care provision and outcomes, their causes, and their links to individual circumstances, including health and social care needs and strengths.	Principal Investigator: Dr Tim Williams Research Nurse:, Bryony Storey, Bryony.Storey@nhs.net	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	
<b>COGSLEEP</b> Understanding the relationship between cognitive fluctuations, sleep and arousal in Dementia with Lewy Bodies.	The Overall aim of the study is to better understand cognitive fluctuations in Dementia with Lewy Bodies(DLB)	Principal Investigator: Dr Charlotte Allan Research Nurse: Emily Nuttall, 0191 2081350 / <u>Emily.Nuttall@cntw.nhs.uk</u>	Sponsor: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	
	Research into Huntington's	Disease		
<b>ENROLL-HD</b> Is a multi-centre, multi-national, prospective observational study of Huntington's Disease	The 3 main aims are to, To better understand HD as it happens in people to give insight into developing new drugs. To improve the design of clinical trials to rapidly provide clear outcomes – better, smarter, faster clinical trials will identify effective treatments as quickly as possible. To improve clinical care for HD patients by identifying the best clinical practices across all sites around the world and ensure that all families receive that standard of care.	Principal Investigator: Dr Suresh Komati Research Nurse: Sarah Edwards, 0191 246 7392 / <u>Sarah.edwards@cntw.nhs.uk</u>	Sponsor:	



9