

ISSUE: 12 – December 2018<sup>□</sup>

Research & Innovation

newsletter



Sussex Community  
NHS Foundation Trust

We currently have opportunities for Sussex Community NHS Foundation Trust patients and staff to be involved in research in the following areas: **Children's Services, Mental Health, Neurological Conditions, Older People, Palliative Care & Rehabilitation Services**. For the full inclusion/exclusion criteria and further details please contact the team: [SC-TR.Research@nhs.net](mailto:SC-TR.Research@nhs.net)

## Children's Services

### Be on the TEAM: Teenagers against Meningitis

**Study Aim** - To determine if immunisation with 4CMenB (Bexsero) or MenB-fHBP (Trumenba) influences the carriage of pathogenic meningococci.

**What's involved?** 24,000 year 12 pupils attending schools and 6th form colleges in England, Scotland and Wales will be enrolled. Sites will act as one of three groups, vaccine with 4CMenB (Bexsero), vaccine with MenB-fHBP (Trumenba) or control. Participants will be assigned as such. In collaboration with Brighton and Sussex Universities Hospital Trust, Sussex Community NHS Foundation Trust will act as one of the control groups, visiting colleges and schools in the Brighton and Hove area. Participants will be seen at school / college and will be screened for carriage of meningococcus by oropharyngeal swab at the first visit and then again 12 months later. A course of 4CMenB will be offered to all participants in the control centres after the '12 month' swab has been taken.

**Who can take part?** Healthy male or female adolescents aged 16-19 years of age, attending year 12 in selected schools / 6th form colleges in England, Scotland and Wales.

### PIRATES 2: Accuracy Parameters of a Child Social Communication Assessment Tool

**Study Aim** - An automated story tool (in the form of a pirate adventure game) that scores emotional cognition in children has been developed. It is proposed that this could be used as an adjunct to current initial assessment of children referred to clinical services with social communication difficulties and possible Autism Spectrum Disorder (ASD). This study aims to test the use of the Pirate Adventure Social Communication Assessment Tool in 62 children already diagnosed with ASD compared with 62 children who are typically developing (i.e. not diagnosed ASD).

**What's involved?** Children will complete the Pirate Adventure Social Communication Assessment Tool with a member of the research team. The tool incorporates a number of psychometric tests used in diagnostic assessment of ASD and takes 10 minutes to complete.

**Who can take part?** Children diagnosed with ASD who attend Child Development Centres within Sussex Community NHS Foundation Trust and typically developing children who attend local mainstream primary schools (age range 4 -11 years).

## Children's Services *continued...*

### **Mini-EDACS: Eating and Drinking Ability Classification System for young children with cerebral palsy**

**Study Aim** - We aim to develop and validate a new version of Eating and Drinking Ability Classification System (Mini-EDACS) suitable for use with children with CP aged 18 to 36 months.

**What's involved?** Firstly we will invite parents, health professionals and research experts to examine and refine the proposed content of Mini-EDACS using an international Delphi Survey until 70% agreement. Then Speech and language therapists (SLTs) and parents will use Mini-EDACS independently to assign a level describing eating and drinking abilities of children with CP aged between 18 and 36 months. The reliability of Mini-EDACS will be assessed by comparing pairs of judgments made by pairs of SLTs or parents vs SLTs.

**Who can take part?** For full inclusion/exclusion criteria please contact Jess Baskerville (Clinical Researcher) on 01273 696011 ext. 8408 or email [jessica.baskerville@nhs.net](mailto:jessica.baskerville@nhs.net)

### **WINS - What I need in school: Developing Guidelines for Best Practice for Young People with Epilepsy in Schools in the UK**

**Study Aim** - To garner the views and experiences of school age children (6-15 years) with epilepsy, their parents and teachers regarding:

- Impact of epilepsy on school functioning.
- Current and desired educational supports for young people with epilepsy

**What's Involved?** Interviews and focus groups with parents, young people and teachers will be undertaken to understand experiences. These will focus on aspects such as learning difficulties, social and emotional functioning including bullying, reactions of others, support, educational progress, provision of Educational Health Care Plans (EHCP), and desired supports in the future. The young people, parents and teachers will also be asked to complete standardized measures to provide data on child development, behavioural functioning and quality of life.

**Who can take part?** School age children (6-15 years) with epilepsy, their parents/carers and teachers.

## Mental Health

### **LightMind2: Low - Intensity guided help through Mindfulness**

**Study Aim** - Comparing supported Mindfulness-based cognitive therapy self-help to supported cognitive behaviour therapy self-help for adults experiencing depression

**What's involved?** Six sessions of support from a psychological wellbeing practitioner. Participant measures to be completed at baseline, week 16 & week 42.

**Who can take part?** Patients referred into the North & Coastal SCFT psychological support services. Patients aged 18 years and over and that meet diagnostic criteria for mild-moderate anxiety and depression.

## Neurological Conditions

### **ProSec 3: A multi-centre evaluation of excessive saliva management in patients with Motor Neurone Disease.**

**Study Aim** - To estimate the incidence of excess saliva problems experienced by people with MND, document how they are currently managed and identify any side-effects, including their frequency, from those treatments.

**What's involved?** Completing some questionnaires at three monthly intervals over a period up to a year, coinciding with their neurological review.

**Who can take part?** People aged over 18 with a formal diagnosis of MND & known to one of the MND specialists working within SCFT.

## Older People

### **SPACEtoolkit: Managing care for older people in community hospitals to increase comfort and reduce distress: developing and evaluating a new toolkit SPACE – Symptom and Psychosocial Assessment and Communication Evaluation**

**Study Aim** - To improve communication and assessment for older people when admitted to a community hospital, particularly those facing uncertainty about their level of recovery, in order to reduce the anxiety and distress for them and their families. To also understand how to support older people in planning future care and how to communicate this to the health care professionals supporting them on discharge.

**What's involved?** Patients and/or informal carers will be asked to complete a questionnaire asking what might be their priorities and preferences with regard to planning their future care.

**Who can take part?** Patients aged 65 or over who are currently in a participating community hospital within SCFT and their informal carer/relative.

### **The experience of older adults being discharged home from a community hospital**

**Study Aim** - To gain a greater understanding of how hospital discharge is experienced by older adults in order to contribute to increased empathy and understanding amongst health care professionals. This may contribute to improved patient centred care.

**What's involved?** Participants will be interviewed in their home about their experience of being discharged. This will be a one-off interview lasting approximately one hour.

**Who can take part?** Male or female adults aged 75+ who have been an inpatient for at least 72 hours in duration and have been discharged home to their usual residence.

## Palliative Care

### **MePFAC: Methylphenidate versus placebo for fatigue in advanced cancer**

**Study Aim** - This is a randomized, double-blind, placebo-controlled drug pilot study, to estimate the clinical effectiveness of methylphenidate versus a placebo, for cancer-related fatigue in patients receiving specialist palliative care.

**What's involved?** Patients will need to have a blood test as part of confirming their eligibility to take part in the study. If successful they will then need to be reviewed weekly by one of the medical & research team over a period of 10 weeks, which will include checking for side-effects of the medication and completing questionnaires with regard to their health and level of fatigue.

**Who can take part?** Patients known to the Specialist Palliative Care Team at Midhurst, with a diagnosis of advanced cancer, experiencing fatigue.

## Rehabilitation Services

### **EDUCAT Research study: An Assistive Powered Wheelchair. Stage 1 - Evaluating Users' Driving Characteristics (a non-interventional study)**

**Study Aim** - Sussex Community NHS Foundation Trust (SCFT) is supporting EDUCAT ('Empowerment of Disabled people through the User Coproduction of Assistive Technology'), which is a European project focussed on the development of an assistive powered wheelchair ([www.educat2seas.eu](http://www.educat2seas.eu)). This research study (Stage 1) aims to find out whether it is possible to monitor the well-being of powered wheelchair users, how well they are coping with driving their powered wheelchair and the effect of medication on their driving by recording and analysing joystick movements.

**What's involved?** This study (Stage 1) will be carried out in NHS clinics and/or in participant's homes. A device that records joystick movements will be attached to the participant's powered wheelchair for a trial period of five days. Participants and/or their carers will also be asked to keep a diary to record the location in which the powered wheelchair was driven; feelings of well-being and medication taken. Participants will also take part in an interview to obtain an understanding of their experiences of using (or supporting people using) powered wheelchairs.

**Who can take part?** Adult (18 yrs. +) powered wheelchair users will be recruited through SCFT Clinical Services including Wheelchair Services and the Chailey Communication Aid Service.

### **RETAKE: RETURN to work After stroke - Early vocational rehabilitation compared with usual care for participants: an individually randomised controlled multi-centre pragmatic trial with embedded economic and process evaluations**

**Study Aim** - To establish whether Early Stroke Specialist Vocational Rehabilitation (ESSVR) plus usual care is more effective than usual care alone at improving participants self-reported work outcomes 12 months after randomisation.

**What's involved?** Participants are recruited within 8 weeks after having a stroke. Participants will be randomised to receive either usual stroke care, or ESSVR and usual care. They will be asked to complete 3 questionnaires over a year. The Community Neuro Rehabilitation Team Occupational Therapist's will be delivering the ESSVR.

**Who can take part?** Adults who are admitted to hospital with a stroke; who are in work, and intend to return to work.

## Research News

SCFT are involved in **EDUCAT**, a project funded by the European Union, to develop a technological system that provides a variable level of assistance for powered wheelchair users. An additional part of the project is the development of an international digital platform called **ITCH!** [www.letsitch.eu](http://www.letsitch.eu). The platform invites individuals, carers, healthcare professionals, researchers, companies & manufacturers to share ideas about needs or problems that require tech solutions within the health field. Collectively through the platform tech solutions can be co-created, adapted, customised and made operational to meet the needs expressed.



## Young People's Advisory Group

The '**Young People's Advisory Group**' for Kent, Surrey & Sussex recently celebrated its first year and marked the occasion with a graffiti art-based activity...and cake! The group is for those aged 8 to 18 years who want to make research better for children and young people. Parents/carers are welcome to attend a parallel group. The next meeting for researcher presentations will be Saturday 19<sup>th</sup> January 2019. To attend or for further information please email: [ypagkss@nihr.ac.uk](mailto:ypagkss@nihr.ac.uk)

## Award Winner

Congratulations to Dr Diane Sellers, speech & language therapist and research fellow at Chailey Clinical Services who received the **SCFT Research & Innovation Award 2018**. And a huge well done to all the shortlisters & finalists in this category. You are all winners! Diane was also recently announced Allied Health Professional **Research Champion** for Kent, Surrey & Sussex. The scheme has been created by the National Institute for Health Research (NIHR) and the Council for Allied Health Professions Research (CAHPR). The Champions will link with others across the country, acting as role models for AHP research, encouraging more awareness of research and the work of the NIHR.



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Research & Innovation, Brighton General Hospital, Elm Grove, Brighton BN2 3EW

01273 696011 | [www.sussexcommunity.nhs.uk](http://www.sussexcommunity.nhs.uk) | [SC-TR.Research@nhs.net](mailto:SC-TR.Research@nhs.net)

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