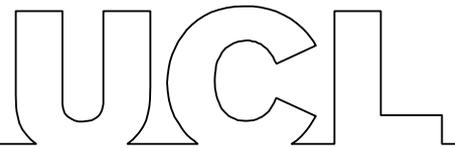




**SHIELD**

Support at Home:  
Interventions to Enhance  
Life in Dementia

North East London   
NHS Foundation Trust



# SHIELD Research Programme Newsletter

## June 2013

*Edited by Sandra Nolle, Dementia Research Centre Manager*

### 1. Introduction

Thanks to Sandra for organising the latest newsletter and to all the contributors. It is great to see such steady progress on all the studies. The results are beginning to emerge and we all look forward to some exciting statistics and qualitative analyses in the coming months!

Martin Orrell, Programme Director

### 2. Programme Details

The *Support at Home - Interventions to Enhance Life in Dementia* (SHIELD) project is a 5-year grant-funded NIHR programme on psychosocial interventions in dementia, led by Professor Martin Orrell at UCL/NELFT. This research programme aims to reduce disability, improve health outcomes, and enhance quality of life for people with dementia and their carers. NIHR funding for SHIELD was received in August 2007 and the research programme commenced in February 2008.

### 3. Research Project Updates

#### ***Maintenance Cognitive Stimulation Therapy***

The Maintenance Cognitive Stimulation Therapy (MCST) programme is exploring the long-term effects of a Maintenance CST programme v CST only for dementia. The mental stimulation groups for people with

dementia aim to improve cognition and quality of life.

#### ***MCST Work Package 4***

The maintenance Cognitive Stimulation Therapy (CST) implementation in practice study that comprises of three projects has completed recruitment. The staff training and outreach (STANDOUT) and monitoring and outreach (MONOU) trials differ in that staff members recruited into the STANDOUT trial were new to CST and received CST training as part of the research programme whereas staff members recruited into the MONOU trial had attended training or were already familiar with CST prior to their involvement in the trial. Participants in both studies were randomized to receive outreach support (email support, local supervision and online forum). There are 240 participants across both studies and all data will be collected by October of this year.

The observational study completed recruitment and there are 89 people with mild to moderate dementia completing minimal outcome measures (cognition and quality of life) before, during and after the CST and maintenance CST programme. All data will be collected by October 2013.

Between now and the data collection end point focus groups will be conducted with staff members to get their feedback on the delivery of the programme and their experience of being in receipt of outreach support.

#### **Visit to 24th Annual Saint Louis University Summer Geriatric Institute**

I was invited to the Institute in June 2013 as a plenary speaker and to run a workshop on



Cognitive Stimulation and its implementation in practice, with the intention of highlighting to staff a ready to use, evidence based, and effective therapy for people with mild to moderate dementia.

There were a high number of attendees from a variety of health backgrounds. A number of international speakers provided very interesting and thought provoking presentations ranging from malnutrition to delirium in older adults. My presentation was very well received with plenty of discussion after, specifically in relation to the inclusion criteria for group members. The workshop also had a good turnout with plenty of interaction and session planning to get people thinking in practical terms of getting groups implemented in practice.

In addition to the Conference I also ran two workshops for approximately 60 people on CST, one in a care home and another for the Alzheimer's Association. The feedback was extremely positive and all the attendees to these sessions considered it feasible to set up a CST programme in their care setting.

Amy Streater, Research Assistant/PhD student

### ***Individual Cognitive Stimulation Therapy (iCST) for Dementia Trial***

The aim of the iCST trial is to develop and evaluate an individualised version of Cognitive Stimulation Therapy (CST). iCST will be delivered by the carer of the person with dementia for 30 minutes, up to 3 times a week over 25 weeks.

The project is now in the final phase of recruitment. Our original target of 306 dyads has been extended to 340 due to the high loss to follow up rates at some sites. We are hoping to achieve our new target by the end of June with the assistance of the external sites (Bangor, Hull, Manchester, Lincolnshire, Norfolk & Suffolk, Devon, and Dorset). We are expecting all dyads to have completed participation by December 2013 or early January 2014.

We are now able to offer the iCST package to dyads allocated into the control group after they have completed their participation in the

study. All of our participants have been very keen to try the programme, so we are pleased that they will now have the opportunity to do so.

The team are now planning to produce an iCST training DVD for carers. Carers and people with dementia will be consulted about training needs in a series of focus groups scheduled to take place this summer.

Lauren Yates, Research Assistant/PhD student

### ***Carer Supporter Programme - Remembering Yesterday Caring Today***

The Carer Supporter Programme (CSP) is researching the impact of one-to-one peer support by family carers of people with dementia for family carers, alone and in combination with large group reminiscence (Remembering Yesterday Caring Today).

Data collection for the SHIELD Carer Supporter Programme was completed in February 2013, with 241 of the 291 dyads being seen for final follow-up, giving an 83% retention rate. Data entry on MACRO was completed in March 2013, and has since been audited for all sites. Data is currently being screened and cleaned ready for analysis by NWOORTH over the summer. In parallel, the health economics team at LSE are starting to cost the resources used.

Over the course of the trial the volunteers and Carer Supporter Coordinators have been gathering information on time, session content, expenses and satisfaction. This was collated by Shaheen Ahmad in Age Concern Havering before she completed her work with us in March this year. Volunteers' data is being used to look at the impact of volunteering on the volunteer and also the similarities and differences between carers using the peer support service and those who provided the service (Sullivan et al., 2013).

The Reminiscence intervention used in CSP-RYCT is based on the same intervention as was used in the REMCARE trial. The REMCARE trial threw up some unexpected



results, and we have therefore worked with Bob Woods in Bangor and Fiona Poland at UEA to carry out a qualitative evaluation of the experiences of carers attending the intervention. Preliminary results were presented in Florence (Crellin et al., March 2013), and the full findings will soon be submitted for publication.

The trial would not have been possible without the many organisations and volunteers involved in the provision of the Carer Supporter and Reminiscence Interventions. Grateful thanks are extended to them all, and we will be celebrating the involvement of all in the Carer Support intervention at our September Event.

Nadia Crellin, Assistant Trial Manager/PhD student

### **Norfolk Dissemination Event**

To mark the end of the CSP-RYCT project, the Norfolk site held a very successful dissemination event at the Costessey Centre in Norwich on the 22nd of March 2013. Around 35 stakeholders attended.

There were four presentations including researchers' experiences and an overview of SHIELD activities. There was also a poster display and photos of RYCT activity sessions. This was followed by a lively debate about the experiences of taking part as a participant and as a volunteer in the project.

All feedback was highly positive, with one volunteer saying that taking part had changed his life; he enjoyed the RYCT groups so much that he has now volunteered to join AGE UK Norfolk's reminiscence team of volunteers. A participant with dementia also found the RYCT groups and the CSP intervention very supportive and empowering, giving him a new lease of life and hope for the future.

These comments are typical of feedback about the interventions. We also had glowing references for Doreen Harrison and Diane Collins in their roles as coordinators and facilitators of the interventions.

Sandra Nolle, SHIELD administrator

### **Home Treatment Programme**

The purpose of the SHIELD Home Treatment Programme is to identify the best interventions to help people with dementia be managed at home during crises.

### **Systematic Reviews**

The Cochrane Systematic Review evaluating the effectiveness of case/ care management for people with dementia and family carers was submitted to the Cochrane Collaboration Group at the end of May 2013.

The systematic review and meta-analysis looking at causes of hospital admissions for people with dementia was published in the Journal of American Medical Directors Association in January 2013.

The systematic review on causes of nursing home placement for people with dementia is currently being completed by the research team. Data extraction and quality assessments have been completed, data analysis and review is currently underway. Expected date of completion is October 2013.

### **Discrete Choice Experiment**

The HTP discrete choice experiment was launched online at the beginning of August 2012. The online questionnaire link was circulated nationwide to healthcare professionals and carers with an overall target recruitment of 400. The online questionnaire was closed in March 2013 with an overall recruitment figure of 501 participants. Data analysis is currently underway and expected completion for analysis is October 2013.

Sandeep Toot, R&D Manager/PhD student

Further information on SHIELD can be found on the website: [www.ucl.ac.uk/shield](http://www.ucl.ac.uk/shield)



## **4. Publications & Presentations**

confidence. *Poster session presented at the 11th International Conference on Alzheimer's and Parkinson's Diseases, Florence, Italy.*

### **Publications:**

Burnell K, Selwood A, Charlesworth G, Sullivan T, Burnell K, Poland F, Orrell M. Involving service users in the SHIELD CSP programme for family carers of people with dementia. *Health Expectations*  
DOI: 10.1111/hex.12012 (2012)

Toot S, Devine M, Akporobaro A, Orrell M. Causes of hospital admission for people with dementia: a systematic review and meta-analysis. *Journal of American Medical Directors Association* 14, (7): 463-470 (2013)

Toot S, Hoe J, Ledgerd R, Burnell K, Devine M, Orrell M. Causes of Crisis and Appropriate Interventions: the views of people with dementia, carers and healthcare professionals. *Ageing & Mental Health* 17(3):328-35 (2013)

Charlesworth G, Burnell K, Hoe, J, Orrell M, Russell I. Acceptance Checklist for Clinical Effectiveness Pilot Trials (ACCEPT) a systematic approach. *BMJ Medical Research Methodology* 13:78 (2013)

### **Presentations:**

Sullivan, T., Ahmad, S., & Charlesworth, G. (2013). The Impact of Volunteering on Volunteers. *Oral presentation at the North East London NHS Foundation Trust Older Peoples Conference 2013.*

Sullivan, T., Charlesworth, G., and Ahmad, S. (2013). Do Family Carers of People with Dementia who accept a Peer Support Intervention differ from those who volunteer to provide Peer Support? *Poster presentation at the North East London NHS Foundation Trust's Research and Development Open Day 2013.*

Crellin, N. E., Melunsky, N., Charlesworth, G., & Orrell, M. (2013, March). Remembering Yesterday Caring Today reminiscence groups: The influence on family carer