Engaging patients in research

Case studies from an
Applied Dementia Care Research Programme

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Leeds 28 April 2014
Before ‘Portfolio’ studies
1991 - mid 2000’s
Collaborative studies 2007 onwards
3000+ patients/families/staff

**REMCARE** Reminiscence groups for people with dementia & their family care-givers: national 8-centre trial of joint reminiscence v usual treatment, NIHR HTA Trial (Lead: Bangor University; Bob Woods). 132 accruals

**Challenge Demcare** Management of Challenging Behaviour in Dementia at Home & in Care Homes, NIHR Programme Grant (Esme Moniz-Cook, Humber NHS FT).

- **Challenge ResCare** CRT of an e-Learning training course and decision support tool for care home staff to deliver functional analysis-based interventions for challenging behaviour in dementia. 2454 accruals

- **Challenge FamCare** Cohort study of people with dementia and challenging behaviours living at home and their carers. 94 accruals

**iCST** individualised Cognitive Stimulation Therapy for dementia trial, NIHR HTA Trial (Martin Orrell, NE London NHS FT) 90 accruals

**PROMs** Using Patient Reported Outcome Measures to Improve Dementia Care. NIHR Policy Programme (Sarah Smith, London School of Hygiene & Tropical Medicine) 183 accruals

**PrOVIDe** Prevalence of Visual Impairment in Dementia. NIHR Health Services Research Programme (Lead: Mr Michael Bowen College of Optometrists) 42 accruals

**VALID** Valuing Active Life in Dementia - Development Phase NIHR Programme (Martin Orrell NE London NHS Foundation Trust / UCL) 158 accruals (ongoing)
Dementia Collaborative Research
Academic support

**SHIELD:** Support at Home - Interventions to Enhance Life in Dementia, NIHR Programme (Martin Orrell NE London NHS FT)

**WHELD:** an optimized person centred intervention to improve mental health & reduce antipsychotics amongst people with dementia in care homes, NIHR Programme (Ms Jane Fossey/Prof Clive Ballard Oxford NHS/ KCL)

**Life story work:** Improving care for people with dementia: development and initial feasibility study for evaluation of Life Story Work in dementia care. NIHR HS&DR Kate Gridley U of York

**PRIDE:** PRomoting Independence in Dementia. ESRC/NIHR (Martin Orrell UCL)

**INTERDEM:** a pan-European network of researchers on early detection and psycho-social interventions in dementia – 3 JPND dementia studies; 3 ESRC/NIHR dementia studies
MRC complex interventions
Craig et al 2008
Engaging patients/families/staff in research – what helps?

• Clinical Academic Leadership. PI is actively engaged in the research and can discuss this with every patient

• Clinical Reputation. PI has overview and may take responsibility for addressing participants’ needs outside the study protocol (Ross 2014 BMJ 348 p26)

• Reciprocity. Patients often willing to support studies if they appreciate the work of the PI/Clinician (Moniz-Cook, Vernooij-Dassen, Woods, Orrell, INTERDEM manifesto Aging and Mental Health, 2011)

• Active support from PI to grow local topic-specific patient groups

• Experienced Topic Specific Research manager with local staff – sustaining funding for manager and RAs

• Persistence. Keep reminding practitioners? Electronic reminder

• Develop a local NHS Centre and a research register where every patient is offered the opportunity to contribute – example Memory Clinics
Engaging Patients and Families in Research – an Example from VALID

• Patients and Carers recruit for research - by telling their friends - Friends of the Memory Clinic (ongoing)

• Patients and Carers coordinated a focus group in Hull

• Patients and Carers attended a Consensus meeting in London – 16 September 2013
Some Cautionary notes

• Providing research funding / backfill to clinical teams does not guarantee recruitment (e.g. FamCare/VALID)

• Providing Incentives such as training is a good idea but clinical teams often haven’t the time to attend (ResCare)

• Motivation. Support costs from local CRNs do not fully cover recruitment time (only get paid for those who actually enter the study, e.g. PrOVIDe)

• Experienced Research Management is costly- not covered by studies

• Extra Treatment Costs for care studies

• National Initiatives can have a undesirable impact on the quality of real world research methodology – e.g. Research ready care homes may not be representative of all care homes.

• Local Practices can have a undesirable impact on the quality of real world research methodology - using the same participants to contribute to consecutive studies
Centre of Dementia Research and Practice

Officially launched Jan 2014 by MPs
Rt Hon Alan Johnson and Diana Johnson


www.challengedemcare.com
Acknowledgements

Humber NHS FT/University of Hull
Bangor University
University College London/NEL FT
Kings College London/Oxford Health

INTERDEM –www.interdem.org
Yorks & Humber CRN – research staff at Humber
June Cooke and Linda Monday - PPI Dementia Care/fundraisers
Alzheimer’s Society [Hull and East Riding of Yorkshire]
Hull Memory Clinic
Humber NHS FT –communications/media/press office
Local MP’s in Hull –particularly Rt Hon Alan Johnson [from 1999]
Cathyrn Hart –Research manager and her team