**Overview of proposed work on dementia with CLAHRC West - March 2015**

The aim of this document is to provide some background to the dementia bids submitted to CLAHRC West and possible forthcoming work in collaboration with the AHSN. The dementia research that is already taking place in and around Bristol will be described in order to demonstrate how the proposed research will complement the work that is already taking place. Until fairly recently, dementia research in the local area has concentrated on neuropathology, neuroepidemiology and clinical drug trials. However in recent years there has been a shift towards more psychosocial approaches to dementia, in terms of understanding the impact of the disease, as well as evaluating novel interventions and new models of service delivery.

**Dementia research in Bristol:**

### *University of Bristol*

For many years dementia research in Bristol was led by Gordon Wilcock, Professor of Care of the Elderly, who set up the Bristol Dementia Research Group. The Dementia Research Group is now led by Professors Seth Love and Pat Kehoe and comes under the umbrella of the University of Bristol (UoB) Institute of Clinical Neurosciences. The group conducts preclinical and clinical research in dementia, using molecular genetic, biochemical, cell culture-based and neuropathological approaches, as well as cognitive and neuroimaging studies in patients. The aim is to translate preclinical findings into applications that benefit patients with dementia. The research uses a number of complementary methods to examine brain tissue and DNA from one of the largest dementia brain bank collections in the world. The main areas of research are:

- The biology of Aβ and its role in the pathogenesis of AD
- The interplay between cardiovascular factors and AD
- The study of the neuronal microenvironment

In 2011 Dr Elizabeth Coulthard was appointed to Senior Clinical Lecturer in Neurology, UoB, with a remit to expand dementia research. She developed the ReMemBr group (Research in to Memory, the Brain and dementia) who are currently undertaking:

- Clinical trials in dementia including the RADAR trials and AFFECT trials
- Exploratory study of the effect of exercise and caffeine in dementia.
- Exploration of brain mechanisms underlying memory consolidation and the potential for memory enhancement
- Huntington's disease (HD) registry, Europe-wide EURO-HD and HD interventional trials
- MRI work in collaboration with CRIC (see below)

In 2011 the UoB Clinical Research & Imaging Centre (CRIC) was opened in Bristol, with a state-of-the-art 3T MRI scanner CRIC Bristol, and staff are developing projects in clinical & cognitive neurosciences. Within CRIC Professor Risto Kauppinen and his team are working on the project "Hippocampal Imaging in Alzheimer's Research". In collaboration with Siemens, this project is generating MRI sequences sensitive to early changes in medial temporal volume in Alzheimer's disease.

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Professor Yoav Ben-Shlomo is a Clinical Epidemiologist at UoB and has an established reputation in life course epidemiology with interests in ageing, chronic and neurodegenerative disease, and cohort studies including Caerphilly Prospective Study (CaPS) examining dementia risk.

Sarah Purdy, Professor of Primary Care at UoB, leads a research programme exploring predictors of, and interventions for, unscheduled care use and avoidable hospital admissions. She is Lead Director of the Avoidable admissions HIT (ITHAcA) which has identified admissions for people with dementia as a priority area for future work. ITHAcA is not currently undertaking any work in this area. Therefore, in collaboration with the Joint Working for Dementia HIT, ITHAcA is now expanding this area of research to include people with dementia, who have poor outcomes in acute hospitals but for whom there are few care alternatives.

### Avon & Wiltshire Mental Health Partnership NHS Trust

Dr Sarah Cullum is a Consultant in Old Age Psychiatry and Honorary Senior Clinical Lecturer at UoB. She co-leads the Bristol Joint Working for Dementia HIT with Dr Elizabeth Coulthard. Her research background is in epidemiology and health services research, and she is currently completing a suite of Cochrane systematic reviews of diagnostic accuracy of tests for dementia. She is leading on two of the three CLAHRC West dementia workstreams, and co-leading on the third (see below).

### University of the West of England

At the University of the West of England (UWE) Richard Cheston is Professor of Mental Health Research (Dementia) in the Department of Health and Social Sciences. He has a national and international reputation in post-diagnostic work with people affected by dementia, with a particular interest in developing psychotherapeutic interventions. Having previously worked as a Clinical Psychologist in a local Mental Health Care Trust (AWP) for 20 years, he has strong links with local providers of care. Amongst other collaborations, Professor Cheston is working with the Tavistock Institute for Couple Relationships on a programme to develop resilience in couples, one of whom has been diagnosed with dementia. He is one of a number of Professorial appointments at UWE which span clinical and academic roles.

Jonathan Benger, Professor of Emergency Care at UWE is working with Sarah Voss (UWE) and Steve Illiffe (UCL) to develop interventions within emergency services to divert people with dementia away from potentially harmful hospital admissions into more appropriate alternatives. This integrates and complements the work of both the Dementia and ITHAcA HITs, hence the ongoing involvement of Sarah Cullum (AWP) and Sarah Purdy (UoB) in this project.

Also at UWE, Professor Myra Conway works in the Centre for Research in Biosciences, and is a protein biochemist with an interest in metabolism dysregulation, particularly with respect to glutamate and related signalling mechanisms in AD. Further work includes an interest in developing novel protein biomarkers for early AD detection. Her collaborators are both national and international spanning several areas ranging from metabolic biochemistry to neuroscience, imaging and biosensor technologies.

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### *Clinical trials*

Clinical drug trials have been carried out for many years at Kingshill Research Centre in Swindon (Avon and Wiltshire Mental Health Partnership NHS Trust, AWP) and at the Research Institute for the Care of Older People (RICE) in Bath.  Professor Roy Jones is an Honorary Professor at the University of Bath and Director of RICE, and in recent years has expanded his research interests to include studies on effectiveness of brief cognitive screening tools for diagnosing and monitoring dementia and MCI, cognitive rehabilitation techniques for relearning information and skills in AD and early FTD, assessing assistive technologies designed to improve quality of life and independence for people with dementia, and quality of life measures in dementia.

Appendix 1 summarises the research and service evaluation that is taking place in Bristol and Bath. The order does not reflect size of project or grant income; it is purely a snapshot of current activity.

**NIHR CLAHRC West bids:**

### *National, regional and local context*

The National Dementia Challenge was launched in March 2012 by Prime Minister David Cameron to highlight dementia care as a national priority in the context of an ageing population.  The Challenge has three key aims: improving health and care, creating dementia friendly communities and improving dementia research*.*  Thus the Joint Working for Dementia HIT has brought together local universities, health and social care organisations and the third sector whose goals are to transform local dementia care, enhance access to high quality research, and to help develop dementia friendly communities.  The specific objectives are to increase diagnosis rates and improve post diagnostic support for families affected by dementia (notably by developing dementia services in primary care), to minimise the adverse outcomes of the disease such as avoidable hospital admissions and institutionalisation, to improve public awareness of dementia and reduce stigma, and to improve involvement and recruitment in dementia research.  The chances of success have been boosted by the recent merging of Bristol and South Gloucestershire CCGs Joint Dementia Strategy Board with the Dementia HIT, which will enable collaborative working and allow us to disseminate and implement findings into practice with ease.

The recent NHS South of England review of the Dementia Challenge Fund programme (2014) highlighted several service initiatives aimed at reducing unplanned admissions to hospital by either improving coordinated care for people with dementia living in the community, increasing use of end of life care plans in care homes or by improving integrated care after discharge from hospital.  Some of these initiatives have built in a component of evaluation but none have reported outcomes as yet.

Several of the other 12 NIHR CLAHRCs are also working on dementia.  Of relevance to our bids is the work being done in Greater Manchester on responses in primary care to identify diagnose and manage dementia; Yorkshire & Humber are planning a scoping review of the evidence base on the range of psychosocial interventions available in first 2 years after dementia diagnosis and a survey of services available across Yorkshire and Humber, and Eastern England have published a useful integrative review on Research into Older people with Dementia and their carers' use of Emergency Services (RODES).  None appear to be working on unplanned admissions in dementia.

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*Dementia HIT research priorities*

The Dementia HIT research workstream has identified two areas of dementia research to be prioritised and expanded within the next five years: post diagnostic support and avoiding hospital admissions for people with dementia.  We have developed three workstreams, each of which will help extend evidence-based services locally and are also likely to have regional and national relevance.  Two bids were submitted to CLAHRC West in September 2014; these are described in workstreams 2 and 3 below and will form the basis of our future dementia research strategy.

In December 2014 we were advised by the NIHR CLAHRC West Research Advisory Panel that CLAHRC West will help us to prioritise specific aspects within workstreams 2 and 3 which can then be expedited by CLAHRC West staff in 2015.  This work will start in early 2015.

*Proposed CLAHRC West dementia workstreams*

Both the Joint Working for Dementia and ITHAcA HITs have identified avoiding hospital admissions in dementia as a priority area for research.  Thus the two HITs are working together in workstreams 1 and 2.  Workstream 3 is a stand-alone bid that builds on previous collaborative work between UWE and the Tavistock Institute, and potentially future collaboration with NIHR CLAHRC Yorkshire & Humber who are currently mapping post diagnostic psychological services in their region.

**Workstream 1: Risk factor s for admission to acute hospital in people with dementia**

Dr Sarah Cullum, Director on both Dementia and ITHAcA HITs, has started developing a systematic review of physical and psychosocial risk factors for admission to hospital in people with dementia with Dr Rachel Churchill, Reader in Psychiatric Epidemiology, University of Bristol.

The review will build on work on risk of admission and interventions to reduce admission in general populations of older people previously carried out by Prof Sarah Purdy and ITHAcA, the avoidable admissions HIT, and will inform both of our CLAHRCWest bids outlined below (workstreams 2 and 3).

**Workstream 2: Reducing unplanned hospital admissions in people with dementia.**

Led by Dr Sarah Cullum, with Prof Sarah Purdy and Prof Yoav Ben Shlomo.  The aim of workstream 2 is to carry out a) systematic review of acute interventions to reduce unplanned hospital admissions in dementia; b) analyses of Clinical Practice Research Datalink (CPRD) with the aim of identifying individual, practice or local geographical factors that reduce or increase the risk of someone with dementia requiring hospital care as compared to being cared for in their own home or in a care home; c) qualitative study of a sample people and families living with dementia to obtain more in-depth knowledge about the circumstances leading up to admission which will enable us to develop an intervention that addresses the needs of people with dementia and their caregivers at the point when admission is highly likely.  We will also attempt to identify risk factors for local hospital admissions by linking with the "Connecting Care" Programme. We aim to use this data to inform a grant application to NIHR HS&DR, requesting funding for the development and evaluation of an alternative to hospital care for people with dementia.  The alternative is likely to be a rapid response health and social care team in keeping with the multispecialty community provider (MCP) model as suggested in the NHS Five Year Forward View (2014).

**Workstream 3:  Post diagnostic support for people affected by dementia.**

Led by Prof Rik Cheston, with Dr Sarah Cullum.  The aim of workstream 3 is to improve the evidence base for post-diagnostic interventions for people with dementia and their families, and to develop a

targeted intervention aimed at improving family resilience early on in the course of the disease. Our aim is to a) carry out a review to identify the personal and social factors which predict those families affected by dementia who are at risk of poorer outcomes; b) work with West of England AHSN to carry out a regional survey to identify best practice in post-diagnostic psychosocial dementia services; c) use expert panels to develop and refine an algorithm aimed at identifying families affected by dementia at highest risk of adverse outcomes that might benefit from targeted post diagnostic psychological interventions; d) use qualitative methods to explore the acceptability of using the algorithm in families affected by dementia. These data will inform two NIHR applications to a) fund a national mapping of post-diagnostic psychosocial services in dementia, and b) carry out a pilot evaluation of the intervention aimed at improving resilience in high risk families affected by dementia.

**Expected outputs from workstreams:**

1. Identify from systematic reviews of people and families affected by dementia: reasons for admission to hospital; effectiveness of interventions to reduce unplanned hospital admissions; psychosocial risk factors which predict poorer outcomes.
2. Map regional post-diagnostic psychosocial services in dementia and identify best practice; and, with successful NIHR funding, repeat on a national scale.
3. Development of an algorithm aimed at identifying families affected by dementia at highest risk of adverse outcomes that might benefit from targeted post diagnostic psychological interventions
4. Data-derived evidence for reasons for hospital admission in people with dementia, which, combined with other ongoing led by local CCGs, will inform the development of novel interventions aimed at reducing avoidable hospital admissions, such as the multispecialty community providers suggested in the Five Year Forward View.
5. Preliminary data from 1-4 above will inform two future NIHR applications for evaluation of interventions aimed at a) improving resilience and b) reducing avoidable hospital admissions in people living with dementia.

**Dissemination and implementation**

The Joint Working for Dementia HIT has been working closely with local commissioners and health and social care providers to design improved models of service delivery informed by good quality research. Thus the pathways are already in place to facilitate dissemination and implementation of evidence provided by CLAHRC-assisted and/or NIHR-funded projects. The Dementia HIT encourages its partner organisations to embed service evaluation from the start and to identify useful outcome measures from routinely collected data. The aim is to facilitate the implementation of new service models which can then be evaluated within current systems and thus without difficulty or extra cost. The Dementia HIT also has close links with the South West Dementia Strategic Clinical Network, South West Dementia Partnership and the West of England Academic Health Science Network, which will further facilitate mutual learning and knowledge mobilisation.

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