MinD
designing for people with dementia
mindful self-empowerment and social engagement

Brief description about the Trust

Nottinghamshire Healthcare NHS Foundation Trust (NHT) is a major provider of mental health, intellectual disability and community healthcare services. The services by the trust especially include separate division for Mental Health Services for Older People (MHSOP)[1], including Nottinghamshire County and Nottingham City Specialist Working Age Dementia Services and Dementia Outreach Team[2], Memory Assessment Services for Older People (MAS)[3], Living Well with Dementia Group[4], Diversity within Dementia Communities of Interest (COI)[5], etc.

NHT realises the need to invest in learning, research, development, and innovation in order to continually improve its services and patient care. NHT is a partner in Institute of Mental Health (IMH), Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and hosts the East Midlands Leadership Academy[1].

The Trust's approach to dementia research

Nottinghamshire Healthcare NHS Foundation Trust has been collaborating with European and Australian partners in an exciting four-year programme called MinD[6]. This project focuses on personal difficulties with social interaction in people with dementia and environmental influences on their social engagement[7]. Its aim is to utilise the concept of mindful design to help empower people with dementia and improve their psychosocial wellbeing[8].

This project runs till 2020. It involves technology design projects and a series of 15-day exchanges in partner countries: the UK, Germany, the Netherlands, Luxemburg, Spain, and Australia[9]. The first exchange took place in May 2016 hosted by University of Wolverhampton and NHT. NHT hosted May4th, 5th, 9th, 10th, 11th, and 16th. The second visit was to Luxembourg where Alzheimer Europe, the non-academic partner in Luxembourg hosted a two-day event in Brussels. The first MinD symposium will be held on December 7th, 2016 in London, UK at Europe House[10].

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Specific Roles in MinD

The NHT end of the programme, comprising of the mindfulness and dementia activities in Nottingham[11], is led by Mindtech's Tom Dening (Professor of Dementia Research and old age psychiatrist at NHT) and Dr. Michael Craven (technology senior research fellow) along with consultant clinical psychologist and neuropsychologist Dr. Dons Coleston, Technical Advisor for Mind, Deborah C. de Oliveira, and MindTech's patient and public involvement team. The group is based at the Institute of Mental Health, University of Nottingham Jubilee Campus[6].

Following is a brief biographical note on the NHT team members:

Tom Dening, MA MD FRCPsych

Tom Dening was appointed in October 2012 as Professor of Dementia Research at the Institute of Mental Health, University of Nottingham; and Honorary Consultant in Old Age Psychiatry, Nottinghamshire Healthcare NHS Trust. He studied Medicine at Newcastle University and trained in Psychiatry in Cambridge and Oxford. From 1991 to 2012, he was a Consultant Psychiatrist in Old Age Psychiatry in Cambridge. From 1999 to 2002 was seconded part-time to the Department of Health as a Senior Professional Adviser, including work on the National Service Framework for Older People. From 2002 to 2011, he was the Medical Director of the Cambridgeshire & Peterborough NHS Foundation Trust. His interests include the epidemiology of mental disorders in older people, treatment of dementia and depression in older people, psychiatric services, dementia and technology, care homes and other clinical topics. He is one of the editors of the Oxford Textbook of Old Age Psychiatry, the leading international work in this field. He has also published papers on neuropsychiatry, psychiatric symptoms and the history of psychiatry.
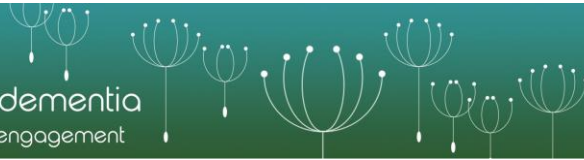
Michael Craven, Senior Research Fellow with NIHR MindTech

Dr. Michael Craven has over 20 years research experience spanning healthcare technology assessment, electronic engineering and computer science, and 5 years in teaching and learning. He is Senior Research Fellow with the NIHR MindTech Healthcare Technology Co-operative based in the Institute of Mental Health in Nottingham, UK. He is connected to Nottinghamshire Healthcare NHS Foundation Trust, Nottingham University Hospitals Trust (Centre for Healthcare Equipment and Technology Adoption) and the Faculty of Engineering Bioengineering Group at the University of Nottingham. Current research includes mobile self-monitoring & therapy, health-related games and assistive technologies. Expertise includes evaluation of medical devices and digital applications across physical & mental health and dementia, user-centred and human factors methods, and design experience including electronics, healthcare apps and game design. He is a member of the Centre for Dementia and the East Midlands Research into Ageing Network and is a trustee of Trent Dementia Services Development Centre (which runs the atdementia.org.uk website).

Link: www.mindtech.org.uk

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Dons Coleston, CPsychol CSci AFBPsS

Dons Coleston is currently managing a large, multi-project research programme concerned with service provision for crisis in dementia at the Institute of Mental Health, University of Nottingham. Professionally she is a Consultant Clinical Psychologist & Neuropsychologist with specialist skills in the neuropsychology of dementia and cognitive assessment in later life, in addition to her broader therapy and systemic skills. She has a background in psychopharmacological research, particularly in the development of treatments for dementia, obtaining her PhD in this field in the 1980s when the area was still in its early stages. Drawing on her broad clinical experience in dementia and neuroscience, her wider interests include (among others) managing clinical complexity to prevent hospital admission and facilitate discharge, promoting therapeutic inpatient environments, and carer support. She continues to work clinically, across a broad range of older adult services, when opportunity arises.

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Deborah C. de Oliveira, Research Associate, Faculty of Medicine & Health Sciences

Deborah is the Project Manager for INDUCT (Interdisciplinary Network for Dementia Utilising Current Technology) and Technical Advisor for MinD (Designing for People with Dementia). Deborah is also a PhD student at the School of Health Sciences, University of Nottingham, due to completion on 2016. She has completed her MSc degree at the University of Campinas, Sao Paulo Brazil (2010-2012), where she also graduated as a General Practitioner Nurse in 2009. She has experience as a Palliative Care Nurse and Community Care Nurse, having worked for the National Health System and Private Health Sector in Brazil (2010-2013). Deborah has research experience with quality of life, family caregiving, dementia, older people, scale development and validation, psychometrics and mixed-methods research. Her PhD thesis is aimed at developing the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC), an age and dementia specific scale to measure the QoL of older family carers. She is also a member of INTERDEM, a well-established, interdisciplinary European collaborative research network of 130 leading academics and researchers in 20 European countries with an aim to improve early detection and timely psychosocial intervention in dementia.

Summary of the First Exchange Visit hosted by NHT

- **May 4th, 2016**

In the morning Dementia Care Session, Tom Dening described the structure of dementia services, including the distinction between health and social care. The distinction influences what people are expected to pay for themselves. He also talked about the contributions provided by hospitals, care homes, and community services. Finally, he gave a short summary about dementia research.

The afternoon session comprised of clinical visits to Nottingham Highbury Hospital, St Francis unit at City Hospital, and Lings Bar Hospital.

- **May 5th, 2016**

Michael Craven gave an introduction to design focus and WP4 and WP5. This was followed by an interactive workshop on ICT technologies available to mental health care and dementia care. Michael Craven made review of projects and ICT solutions (prototype or product).
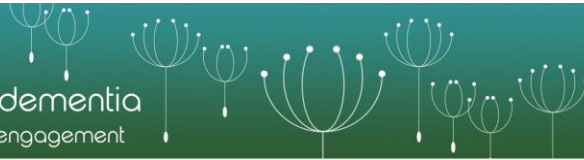
- **May 9th, 2016**

The day was focused on mindfulness framework. Participants helped with developing the themes for data collection, including (mindful) therapy, well-being, empowerment, and choice/decision-making. The relationship between the abstract mindfulness framework, existing approaches, best practice and challenges in dementia care and, also, the link to the aforementioned focus areas were explored.

- **May 10th, 2016**

In the morning, the group discussed the data collection methods and the following potential methodologies were considered to be most suitable in order to identify the obstacles and opportunities related to self-empowerment and social engagement, and, also, to understand the participants' lives: focus groups, observations, diaries, and interviews.

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The afternoon session comprised of visits to St Francis and Wren Hall Nursing Home.

- **May 11ᵗʰ, 2016**

It was last day of discussion on data collection. The group met in the Campus of Nottingham University and decided to collect data from elderly people with dementia and from their carers, including family, healthcare professionals and occupational therapists. During the first year, Germany, Netherlands, UK, and Spain are assigned to collect data. Four groups discussed how to use each of the four methodologies for data collection: focus groups, observations, diaries, and interviews.

In the afternoon session, the impact of nature on the wellbeing of the population, especially, people with dementia were discussed. Attenborough Wildlife Nature Reserve plans activities, such as walks, for people with dementia. Raising awareness about these events amongst the public was discussed.

- **May 16ᵗʰ, 2016**

Participants were invited to attend Patient and Public Involvement (PPI) in Dementia Research at the Institute of Mental Health (IMH). The IMH is in the process of establishing its own Dementia PPI group for the research project. The programme consisted of a series of workshops on how to get involved, research in care homes, and outreach to minority communities.

References:

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