# **Dementia Services Development Centre Annual report**

Name of Centre / Institute	DSDC Wales
Lead College	CoHaBS
Director	Prof. Bob Woods
	Gill Windle (acting director from 31.7.17)
Staff Associated with the Centre	Staff NameDr Katherine Algar-SkaifeMaria CaulfieldBrenda Ellis (administration)Hannah JelleyDr Catrin Hedd JonesDr Catherine MacLeodDr Jennifer RobertsIona Strom (projects secretary)Dr Gill WindleDr Siôn WilliamsProfessor Bob Woods
PhD students	Laura O'Philbin         Robert Edmund Friedrich Jr         Sian Hughes
Master's Programmes and number of students	Conor Martin; Lynwen Hamer

# 1<sup>st</sup> September 2016 – 31<sup>st</sup> August 2017

# **Aims and Objectives**

The primary aim of the DSDC is to improve the quality of life and well-being of older people, people living with dementia and their supporters, by:

- Conducting and applying internationally recognised high quality research on developing and evaluating creative psychosocial interventions for people with dementia and their carers, and for studies on social exclusion, well-being and resilience in later life.
- Collaborating with <u>research networks</u> within Bangor University, across Wales and the other UK nations and internationally.
- Working closely with a variety of organisations and agencies, both statutory and independent who are committed improving the quality of services for older people, people living with dementia and their supporters in Wales.
- Developing and delivering training for and support for professional and family caregivers.

# Activities and achievements

DSDC Wales was awarded centre status by Bangor University in 1999. In 2011 it was accepted as a member of The Global Aging Research Network (GARN), led by the International Association of Gerontology and Geriatrics, in collaboration with the World Health Organization.

Since April 2015, DSDC had led Bangor University's contribution to the <u>Centre for Ageing</u> <u>& Dementia Research</u>, a collaboration with Swansea and Cardiff Universities as part of the <u>Health & Care Research Wales</u> research infrastructure. Our research represents multidisciplinary collaborations across UK and international research teams, and professional organisations.

### Highlight achievements over the past 12 months include:

- Early career researcher success Dr. Kat Algar awarded her first research grant from Health and Care Research Wales Social Care Award; Dr Catherine MacLeod awarded a fellowship from Health and Care Research Wales.
- Grant capture, including new arts and science research to the value of £1,290,345.00 (see 'external research funding').
- Evaluation of Age Cymru Wales cARTrefu programme across Wales nearly 20% of all care homes in Wales (122) took part and 1543 care home residents participated in one or more creative activity (KA).
- Bob Woods and Gill Windle are part of the Alzheimer's Society task force developing the first UK set of research goals for dementia care and support for future research funding priorities.

- Gill Windle is an academic member of the Welsh Government task and finish group developing the Wales dementia strategy (due to be launched Autumn 2017).
- Leading and contributing to 28 journal articles
- Presentations at national and international conferences
- Public engagement activities
- Achieving Centre Status with awarding body Agored Cymru for another year following annual review 26/04/2017 enabling continued training with Agored Cymru accredited courses.

## User engagement and impact; collaborations and partner involvement

- Organised with the Alzheimer's Society and DEEP (Dementia Engagement and empowerment Project) two consultation events for people living with dementia and those who care for them around the Welsh Dementia Strategy (18<sup>th</sup> Nov 16 and 12 Jan 17)
- Organised 'Living well with dementia: Implementing what we know' event on 5<sup>th</sup> April Reichel Hall, Bangor. This event was a partnership between CADR and Emerging Researchers in Ageing (ERA, part of BSG) aimed at early career researchers working in the field of dementia research. It brought together those starting out their careers in dementia research with key stakeholders (health and social care practitioners, community groups, third sector organisations and people living with dementia and those who support them) to foster lasting collaboration between researchers, those who participate in research and those who use research findings to improve their practice. Delegates ranged from ECRs from across the UK and members of the North Wales Dementia Network.
- We have worked in partnership with charities, private companies and social services, testing different approaches of embedding creativity in care practice, improving care and quality of life. Our practitioners' publication 'research informed approaches to visual arts programmes' (Parkinson, Windle & Taylor, 2017) was developed using a creative approach to intervention development (Windle et al., in press) and an electronic version is freely available. Between 1<sup>st</sup> February and 2<sup>nd</sup> May 2017, 3583 copies were downloaded.
- Following the cARTrefu project, which engaged with nearly 20% of care homes across Wales (122), a cARrefu Activity Pack was developed and distributed by *Age Cymru* to every care home in Wales (642) so that even the homes who hadn't received a cARTrefu residency would benefit. Fou rcARTrefu 'sharing events' were held in care homes and attended by 110 care staff across Wales. The pack will be

made available online so it can be shared more widely and to meet demand from health and care professionals across Wales, the UK and wider. The evaluation by Kat Algar was integral to learning important implications for future projects, leading to the project receiving funding for a further 2 years.

- As a consequence of the research partnership in Dementia and Imagination, *Denbighshire county council* obtained funding to deliver further arts and dementia services in North Wales.
- Our partnership with *Flintshire social services and Dementia Positive* as part of the Creative Conversations project will enable the development of the social care work force through a novel, creative approach to staff development. The project includes an implementation phase where local facilitators are trained to deliver the intervention within three homes, enabling a legacy through further roll-out across the county by the local authority, to inspire others across Wales and beyond.
- Our arts and science collaborations have been important for public engagement activities. By taking dementia to a different audiences, we have had hundreds of conversations with the public about dementia. We have worked with artists to visually represent our research in an engaging way. This led to installations featuring at various national festivals including the Green Man Festival in 2016, which counted 820 conversations with people, leading to 108 signing up to the mailing list.
- We have professionally curated some of the work generated by participants in our visual arts interventions and so far held seven exhibitions in public galleries and libraries in England and Wales, encouraging the public to see dementia differently. Visitor figures suggest that a touring exhibition in North East England were in view of 33,494 people. We have produced five films, which are used in our public engagement work. We have established an online community of practice with 554 members which enables us to continually share our work and engage with others, and to date we have circulated 12 newsletters. As of July 2017, our D&I website has over 19,000 users since its launch in January 2014. Twitter had 1702 followers on 05/07/2017.
- The impact of DSDC research was showcased in the house of Commons at the launch of the Academy of Social Sciences booklet *Making the Case for Social Sciences, No. 11, Dementia* "Professor Bob Woods FAcSS [...] carried out research which looked at how life story work helps preserve a person's identity and, in doing this, enhances the level of care they receive. [...]This research has now been widely adopted using a variety of media, including digital apps as well as conventional books. The Department of Health funded the Life Story Network to train over 500 health and social care staff, family carers and volunteers in life story work, arising from the

national dementia strategy. Organisations such as the Social Care Institute of Excellence (SCIE), major charities including Dementia UK and Alzheimer's Society, and professional organisations such as the Royal College of Nursing (RCN) Life story work DEMENTIA have also promoted the approach as good practice. A joint Alzheimer's Society / RCN brief life story template 'This is Me' is used in general hospital wards across the country to help staff quickly get to know the person and their preferences, contributing to person centred care for thousands of people with dementia."

- Reference https://www.acss.org.uk/wpcontent/uploads/2016/03/AcSS\_MTC11\_Dementia.pdf
- Catherine MacLeod and Catrin Hedd Jones are members of the North Wales Ageing Well Network, meeting regularly with representatives from local councils, emergency services, and third sector agencies to stay informed of current policies and programmes taking place across North Wales, exchange knowledge, and discuss existing needs related to ageing.
- The collaboration with a TV company based in Wales led to a new research development looking at the impact of intergenerational care. Children attending preschool nurseries have been part of the Hen Blant Bach/ Care Share programme of activities and the collaboration between DSDC staff and academic in the School of Education secured KESS2 funding for a Masters by Research studentship in partnership with the TV company. A commissioned series will be aired on S4C and BBC Wales in December 2017.
- North Wales Dementia Network established through Impact Acceleration Award (building on Dementia and Imagination and CFAS Wales) to Dr Catrin Hedd Jones. A series of meetings have been hosted across the region and t the network currently has over 170 members.

#### **Consultations:**

- Welsh Government Dementia Strategy-Consultation response form: Together for a Dementia Friendly Wales (2017-22)
- Patient and Public Involvement (PPI consultations)- Creative Conversations PPI and advisory group meetings
- Hospital Design Consultations- BW and HJ consulting with Llandudno hospital regarding ward design, initial meeting with HJ and follow up planned for October 2017.

## **Training:**

Training Wrexham Maelor Hospital and Penrhos Stanley staff level 3 courses (HJ) Delivery of three Cognitive Stimulation Therapy course for BCUHB staff (HJ and BW)

# International collaboration (visitors, joint projects, etc.)

Dr Gill Windle was awarded a **knowledge exchange fellowship from Alzheimer's Society UK and Alzheimer Nederland, £12,500** (November 2016 for 12 months). To facilitate collaborations with a) Martijn Huisman, Professor of Epidemiology and scientific director of the Longitudinal Aging Study Amsterdam (LASA) to explore collaborative data analysis between LASA and CFAS Wales; and b) Rose-Marie Dröes, Professor of psychosocial care of people living with dementia to explore implementation of arts interventions in dementia care.

# **External Research funding**

### Grants funded within reporting period/active grants:

'Created out of Mind': Shaping perceptions of dementia through art and science. The Wellcome Trust Residency Hub, £1,087,059.00. October 16-July 18 (**Gill Windle co-director**; PI Sebastian Crutch; other core team include Fergus Walsh, Philip Ball, Charlie Murphy, Julian West, Nick Fox).

Creative Conversations: An exploratory study of an arts in health approach to embedding person-centred care and improving communication between care staff and people living with dementia. £203,286.00 Health and Care Research Wales Social Care Award. October 16-May 18 (Algar, K., Windle, G., Killick, J. & Davies, J. Pickering-Jones, L.)

Can the arts influence care staff representations and assumptions of advanced dementia? £15,236.00. The Wellcome Trust Residency Hub. April 17-July 18 (**Gill Windle, Kat Algar**, John Killick, Hannah Zeilig).

Centre for Ageing & Dementia Research. **Health & Care Research Wales**, £1.8 million. April 2015-March 2018 with Swansea and Cardiff Universities (Bangor funding: £463,150)

Building the Resilience and Wellbeing of Older People in Wales study for **Mind Cymru**/**Ecorys.** Woods, B. £2500 1 August 2016 to December 31 2018

Building the Mental Health Resilience and Wellbeing, 2016-2018 for Age UK / MIND / Ecorys. Woods, B. £1500 1<sup>st</sup> January 2017 – 31<sup>st</sup> March 2018.

Creating a dementia supportive practice community. **£21,416.00, ESRC IAA fund.** (Catrin Hedd Jones, Gill Windle). April 2016-March 2017.

Dementia and Imagination: Connecting communities and developing well-being through socially engaged visual arts practice. **Arts and Humanities Research Council/Economic and Social Research Council, £1.2m** July 2013- 31<sup>st</sup> August 2017 (GW lead investigator, BW co-investigator).

Dementia care training for Healthcare Support Workers. **Betsi Cadwaladr UHB**. April 2016 –July 2017; **Woods, B** £20,000.

Survey of carers across 5 European countries – diagnosis of dementia. Alzheimer Europe, Woods, B. £23,000. April 2016-October 2017.

Maintaining independence through goal-oriented cognitive rehabilitation: GREAT into Practice (GREAT-iP). Clare, L. (PI, Exeter University) , Lawrence, S., **Woods, B.,** McCormack, B., Oyebode, J., Knapp, M., et al. January 2018-December 2020. **Alzheimer's Society Implementation Grant,** £400,000.

Social exclusion and use of care services in Wales: Experiences of people with cognitive impairment and dementia. Social care fellowship funded by Welsh Government through Health and Care Research Wales. £269,306. October 2017- September 2020. MacLeod, C.A.

EEG Neurofeedback to improve motor function in Parkinson's. Betsi Cadwaladr University Health Board. £56,385. October 2016-March 2018. Hindle, J., Pritchard, A., Cooke, A., Martin-Forbes, P., Linden, D., Bracewell, M. & **MacLeod, C.** 

Pilot evaluation of a Music Therapy group **Lottery funded**, Jones, CH and Ifan, G.£875 2017.

Intergenerational care research funding via **Darlun TV** Jones, CH.£6,300

National Assembly Research Service Knowledge Exchange Fellowship, **IAA, ESRC**. Jones, CH £8,077.

Conference funding by Coleg Cymraeg Cenedlaethol Jones, C.H £2,000

Developing Dementia Network in North Wales Dementia Innovations Jones CH. £6,846

Studentships:

KESS 2 – with Fairways Care / Drapers Company: Sept 2016 – Sept 2019 (PhD - Sian Hughes). Bob Woods, Kat Algar-Skaife, Hannah Jelley.

KESS 2 – with Darlun TV: June 2017 – June 2018 (Masters – Lynwen Hamer) Catrin Hedd Jones, Nia Williams, Bob Woods

## Publications 2016-2017

- Ballard, C., Orrell, M., Sun, Y., Moniz-Cook, E., Stafford, J., Whitaker, R., Woods,
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- Burholt, V, Windle, G., Morgan, D. (2016). A Social Model of Loneliness: The Roles of Disability, Social Resources and Cognitive Impairment" *Gerontologist* 2016 gnw125. doi: 10.1093/geront/gnw125
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- Charlesworth, G., Burnell, K., Crellin, N., Hoare, Z., Hoe, J., Knapp, M., Russell, I., Wenborn, J., Woods, B. & Orrell, M. (2016) Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial. *Journal of Neurology, Neurosurgery & Psychiatry*. Published Online First:[12<sup>th</sup> August 2016] doi:10.1136/jnnp-2016-313736
- Clare, L., Toms, G., Thomas, E., Hindle, J.V., and Woods, R.T. (2017). Gweld y Gair: standardisation and clinical application of a Welsh language measure for estimation of premorbid intellectual functioning. *FPOP Bulletin*, 139, July, 17-26
- Clare, L., Wu, Y-T., Teale, J.C., **MacLeod, C**., Matthews, F., Brayne, C., **Woods, B**. on behalf of the CFAS-Wales study team (2017). Potentially-modifiable lifestyle factors, cognitive reserve and cognitive function in later life: a cross-sectional

study. PLOS Med, e1002259. doi:10.1371/journal.pmed.1002259

- Janssen, E.P., de Vugt, M., Köhler, S., Wolfs, C., Kerpershoek, L., Handels, R.L., Orrell, M., Woods, B., Jelley, H., Stephan, A. and Bieber, A. (2016). Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health. *Aging & Mental Health*, pp.1-9. <u>http://dx.doi.org/10.1080/13607863.2016.1255716</u>
- Joling, K.J., Windle, G., Dröes, R.-M., Meiland, F., van Hout, H.P.J., MacNeil Vroomen, J., van de Ven, P.M., Moniz-Cook, E., Woods, B. (2016) Factors of resilience in informal caregivers of people with dementia from integrative international data analysis *Dementia & Geriatric Cognitive Disorders*, 42:198-214 DOI:10.1159/000449131
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- MacLeod, C.A., Ross, A, Sacker, A., Netuveli, G., Windle, G. (In Press). Re-thinking social exclusion in later life: A case for a new framework for measurement. *Ageing & Society.*
- Mountain, G., Windle, G., Hind, D., Walters, S., Keertharuth, A., Chatters, R.,
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- Newman, Andrew, Baber, Michael O'Brien, Dave Goulding, Anna Jones, Catrin Hedd Howson, Teri Jones... **Windle, Gill**. (2016). Carrying out research across the arts and humanities and social sciences: developing the methodology for Dementia and Imagination. *Cultural trends*, 25(4), p.218-232
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relationships in dementia: a randomized controlled trial. *PLOS Med* 14.3 (2017): e1002269.

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