

<b>Institution:</b> University of Worcester		
<b>Unit of Assessment:</b> 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
<b>Title of case study:</b> Improving the reach of post-diagnostic care for people and families affected by dementia		
<b>Period when the underpinning research was undertaken:</b> 2014-2017		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Professor Dawn Brooker	Professor of Dementia Studies	2009 - present
Dr Simon Evans	Principal Research Fellow	2011 – present
Dr Shirley Evans	Senior Research Fellow	2013 - present
Teresa Atkinson	Senior Research Fellow	2011 - present
Jennifer Bray	Research Assistant	2010 - present
<b>Period when the claimed impact occurred:</b> 2016-2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>1. Summary of the impact</b>		
<p>There has been limited support for those recently diagnosed with dementia and their families. Research examining a community-based dementia support model, the Meeting Centre Support Programme, demonstrated the benefits of the model for those recently diagnosed with dementia and for their families. It showed the implementation of Meeting Centres led to improved quality of life and better mental health. More than 200 Meeting Centres have subsequently been established or are in development across the world, bringing their benefits to thousands of people. The research has informed national and regional policy in the UK and in Italy and the Netherlands. It has also shaped the approach of charities supporting those living with dementia.</p>		
<b>2. Underpinning research</b>		
<p>The Meeting Centres Support Programme (MCSP) originated in the Netherlands. It provides a model for the delivery of locally tailored, post-diagnostic support, for people living with mild to moderate dementia and their family carers. The Meeting Centre (MC) “club” is offered 3 days per week, usually to 12 – 20 members per meeting in an easily accessible location (e.g. community centre). The typical MC is provided within a local community of around 5,000 older people and membership is open to people of all ages and types of dementia diagnosis and their family carers. Evidence-based post-diagnostic interventions are provided within the MC according to the needs of local members. MCs are facilitated by staff and volunteers trained in the ethos of person-centred dementia care and the Adaptation-Coping Model.</p> <p>Between 2014 and 2017, Prof Brooker and her team in the Association for Dementia Studies were co-investigators on MEETINGDEM, funded through the EU Joint Programme for Neurodegenerative Diseases (Grant 1), leading the work-package to evaluate effectiveness. MEETINGDEM was designed to adapt, implement and evaluate the MCSP across the UK, Italy and Poland (Reference 1).</p> <p>The research comprised:</p>		

- An exploration of pathways to care for each country and identification of key stakeholders for the MCSP, leading to the formation of groups of organisational collaborators and user representatives.
- Production of inventoried facilitators / barriers to implementing MCSP.
- Adaption of Dutch materials to develop country-specific implementation plans, practical guides and tools kits.
- Staff training for 9 new MCs (including 2 in the UK).
- A controlled trial with people living with dementia who attended the MCs and their family carers. The trial considered impact on behaviour, mood, quality of life for those living with dementia; sense of competence, mental health, loneliness, distress, experienced burden for family carers; a cost-effectiveness analysis and evaluation of user satisfaction
- An evaluation of facilitators and barriers to implementation of the MCs in each country.

The vision for the MCSP was successfully upheld across each country, with adherence to key components for MCs as outlined within the Dutch programme. Amendments were made to account for the national context of delivery including inclusion criteria, frequency of different components within the programme, and adoption of culturally relevant activities. Factors associated with successful implementation across different countries included enthusiastic local stakeholders, staff and project manager qualities, and availability of evidence of MC effectiveness (Reference 2). Barriers to implementation included competition between care providers and funding (Reference 3).

For people with dementia, attendance at MCs had a significant impact on their quality of life (feelings of belonging, self-esteem, positive affect) when compared to usual care. Higher attendance levels were associated with greater neuropsychiatric symptom reduction and increased feelings of support. For family carers, attendance at MCs reduced carer burden, distress and enhanced their overall mental health when compared to those receiving usual care (Reference 4 and 5).

People with dementia and their family carers were highly satisfied with the MCs and reported that they provided an important means for social and emotional adjustment post diagnosis (Reference 6).

The research concluded that MCs are a transferable method of post-diagnostic support for people with dementia and their family members across different countries, including the UK. Those attending MCs realise improvements to their quality of life and wellbeing against reasonable additional costs.

### 3. References to the research

1. Dröes, R. M., Meiland, F. J. M., Evans, S.C., Brooker, D., Farina, E., Szcześniak, D., L. D. Van Mierlo, M. Orrell, J. Rymaszewska & Chattat, R. (2017) Comparison of the adaptive implementation and evaluation of the Meeting Centers Support Program for people with dementia and their family carers in Europe; study protocol of the MEETINGDEM project. *BMC geriatrics*, 17(1), no.79. <https://dx.doi.org/10.1186%2Fs12877-017-0472-x>
2. Mangiaracina, F., Chattat, R., Farina, E., Saibene, F.L., Gamberini, G., Brooker, D., Evans, S.C., Evans, S.B., Szcześniak, D., Urbańska, K., Rymaszewska, J., Hendriks, I., Dröes, R.M. and Meiland, F.J.M. (2017) Not Re-inventing the Wheel: the Adaptive Implementation of the Meeting Centres Support Programme in Four European Countries. *Ageing & Mental Health*, 21 (1). pp. 40-48. <https://doi.org/10.1080/13607863.2016.1258540>
3. Van Mierlo, L.D., Chattat, R., Evans, S. B., Brooker, D., Saibene, F.L., Gamberini, G., Farina, E., Scorolli, C., Szcześniak, D., Urbańska, K.M., Rymaszewska, J., Dröes, R.M. and Meiland, F.J.M. (2017) Facilitators and Barriers to Adaptive Implementation of the Meeting Centers Support Program (MCSP) in Three European Countries; the Process

Evaluation Within the MEETINGDEM Study. *International Psychogeriatrics*, 30(4), 527-537. <https://doi.org/10.1017/S1041610217001922>

4. Brooker, D., Evans, S.C., Evans, S.B., Bray, J., Saibene, F.L., Scorolli, C., Szcześniak, D., D'Arma, A., Urbańska, K., Atkinson, T., Farina, E., Rymaszewska, J., Chattat, R., Henderson, C., Rehill, A., Hendriks, I., Meiland, F. and Dröes, R.M. (2018) Evaluation of the implementation of Meeting Centres Support Programme: The impact on people living with dementia in Italy, Poland and UK; exploration of the effects on people with dementia. *International Journal of Geriatric Psychiatry*, 33(7), 883-892. <https://doi.org/10.1002/gps.4865>
5. Evans, S.B., Evans, S.C., Brooker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Rehill A., Saibene, F.L., d'Arma, A., Scorolli, C., Chattat, R., Farina, E., Urbańska, K., Rymaszewska, J., Meiland, F. & Dröes, R.M. (2018) The impact of the implementation of the Dutch combined Meeting Centres Support Programme for family caregivers of people with dementia in Italy, Poland and UK, *Aging & Mental Health*, 24(2), 280-90. <https://doi.org/10.1080/13607863.2018.1544207>
6. Szcześniak, D., Rymaszewska, J., Saibene, F.L., Lion, K.M., d'Arma, A., Brooker, D., Evans, S. B., Evans, S.C., Chattat, R., Scorolli, C., Meiland, F., Hendriks, I., Drees, R.M. and Farina, E. (2019) Meeting Centres Support Programme highly appreciated by people with dementia and carers: a European cross-country evaluation. *Ageing & Mental Health*, 25(1), 149-59. <https://doi.org/10.1080/13607863.2019.1683814>

#### Grants

1. Dröes R-M., **Brooker, D.**, Orrell, M. Chattat, R. Rymaszewska, J., MEETINGDEM : Adaptive Implementation and Validation of the positively evaluated Meeting Centres Support Programme for people with dementia and their carers in Europe. EU Joint Programme for Neurodegenerative Disease (funded in the UK by the Economic and Social Research Council), €1,199,819 (2014-2017).

References 2, 3 4 and 5 are included in the unit's output submission for REF2021.

#### 4. Details of the impact

There is currently little statutory care provision across Europe to meet the needs of people living with dementia. This reflects a significant gap for those newly diagnosed with dementia and their families. People living with dementia are recognised as a 'hard to reach' group, given the ongoing isolation and stigma often surrounding a dementia diagnosis. The research has highlighted the benefits of Meeting Centres (MCs) for this group: improved quality of life, enhanced feelings of belonging, increased self-esteem and positive affect. It has also highlighted the benefits for carers who attend MCs: they experience less burden, distress and better mental health. MCs yield high levels of satisfaction for people with dementia and their family members providing an important, and impactful, resource for social and emotional adjustment post-diagnosis. This is emphasised not only through the research but also through testimonies of people living with dementia and their families (Source A). It is further elaborated by the organisations who run the MCs (Source B).

The reach of this research is global. As of December 2020, over 200 MCs have been established or are under development across the world because of this research. 30 new MCs have already opened across Europe, including 13 in the UK. MCs have opened or are planned in Spain, Chile, USA, Aruba, Singapore, Japan and Australia (Source C).

The Association for Dementia Studies has been fundamental to the UK implementation of the MC model. The team worked closely with the community to develop the two UK demonstrator MCs, Droitwich and Leominster, and to retain these centres (Source B). Both MCs are now

established Charities which have raised more than £500,000 to fund activities for their own local communities as well to support the development of new MCs. During the initial project, the team outlined the mechanisms to successful implementation for community support of this nature. In 2018 the team were awarded a National Lottery implementation grant (£587,601) to establish new MC sites across the UK between 2018-2021, and to share learning about the benefits and key factors associated with successful implementation. As part of this project, the team established a UK-wide Meeting Centres National Reference Group, including people affected by dementia, representatives from Public Health England, Health Education England, the Association of Directors of Adult Social Services (ADASS), care organisations and the charitable sector, to inform the roll-out of MCs across the UK, with a goal of the MC approach becoming a routine source of post-diagnostic support for people and families. In 2019 there were 74 new enquiries made directly to the team which have resulted in 20 new MCs being planned across England and Scotland. Learning has been exchanged through 8 UK workshops and a national conference. These events have directly enabled the setting up of 4 new MCs (MCs in Purbeck, Oldbury, Cheltenham and Newtown). It is expected that at least another 15 MCs will be established in 2021 across the UK. The team have also supported those running MCs across the UK with a Community of Learning and Practice. During the Covid-19 pandemic, this has been a lifeline for MCs to continue their work and has provided a central location to sustain learning about dementia.

The research has impacted on policy at a national and regional level, and internationally. The MC model has informed the Dementia Action Plan for Wales 2018-2022 and the Powys Dementia Action Plan (Source D). It is also a core part of Worcestershire County Council's long-term adult social services strategy (Source E). It is investing £540,000 initially to set up 9 MCs across the county by 2023 with the direct support of the Association for Dementia Studies which will lead on the implementation and evaluation of these MCs. Internationally, the Dutch Ministry of Health has pledged that 80% of people affected by dementia will have access to a MC by 2030 (Source H). The impact of the research internationally is elaborated by co-investigators on the original project: for example, 17 MCs have been established in Italy through government funding and the model has been embedded in the Regional Dementia Plan (Source I).

The research has also impacted on policy in the charitable sector. The Shaw Foundation has funded Project Officers in Liverpool and Bristol, to evaluate the barriers and facilitators associated with successful MC implementation in large urban areas (Source F). The Life Changes Trust has funded a Meeting Centres Collaboration to further implement MCs across Scotland (Source G), building on the success of the Kirriemuir MC.

## 5. Sources to corroborate the impact

A: Video testimonials from people living with Dementia and their Families

- Droitwich Spa Meeting Centre: [https://www.youtube.com/watch?v=Eu\\_6zuntrJ0](https://www.youtube.com/watch?v=Eu_6zuntrJ0)
- Wroclaw Meeting Centre: <https://www.youtube.com/watch?v=VFy8LxEtqi8>
- Adjustment to change model: [https://www.youtube.com/watch?v=MQad3mf76Tg&list=PL3YSBzgHauB9\\_rfEUybbRtYlMhZz24DoG&index=6](https://www.youtube.com/watch?v=MQad3mf76Tg&list=PL3YSBzgHauB9_rfEUybbRtYlMhZz24DoG&index=6)

B. Letters from organisations operating Meeting Centres

- Chair of Droitwich Spa Meeting Centre, Worcestershire
- Chair of Leominster Meeting Centre, Herefordshire
- Chief Executive of Kirrie Connections Meeting Centre, Kirriemuir

C. MeetingDem Newsletter (December 2020) outlining the global reach of the MC model

D. Letter from Chief Officer, Dementia Matters, Powys.

E. Letter from Assistant Director of Children, Families and Communities, Worcestershire County Council

F. Letter from Director of Evidence and Influencing, Dementia Programme, The Life Changes Trust

G. Letter from Chair of the Grants Committee, The Shaw Foundation

H. Letter from Minister of Health, Wellbeing and Sports, Netherlands

I. Letters from MEETING DEM co-investigators outlining the impacts in Poland and Italy