DEMENTIA OUTCOME MEASURES:
CHARTING NEW TERRITORY

Report of a JPND Working Group on Longitudinal Cohorts

October, 2015

JPND
research

This document is the final report from one of ten working groups commissioned by the EU Joint Programme – Neurodegenerative Disease Research (JPND) in 2014 through a peer-reviewed call for proposals. The working groups were established to address methodological challenges preventing current population- and disease-based cohorts being further exploited for ND research. All ten reports are listed below and are available to download on the JPND website by clicking on the website link at the bottom of this page:

- **HD-READy (High-Dimensional Research in Alzheimer's Disease)**
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- **Harmonization and innovation of cognitive, behavioural and functional assessment in neurodegenerative dementias**
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- **NETCALS (Network of Cohort Assessment in ALS)**
  Coordinator: Professor Leonard van den Berg, University Medical Centre Utrecht, Utrecht, Netherlands

- **21st Century EURODEM**
  Coordinator: Professor Carol Brayne, University of Cambridge, Cambridge, UK

- **Multi-centre cohort-studies in Lewy-body dementia: Challenges in harmonizing different clinical and biomarker protocols**
  Coordinator: Professor Dag Aarsland, Stavanger University Hospital, Stavanger, Norway

- **Developing a methodological framework for trials in presymptomatic neurodegenerative disease – the Presymtomatic Neurodegeneration Initiative (PreNI)**
  Coordinator: Dr Jonathan Rohrer, University College London, London, UK

- **BioLoC-PD: Harmonization of biomarker assessment in longitudinal cohort studies in Parkinson's disease**
  Coordinator: Professor Daniela Berg, Hertie-Institute for Clinical Brain Research and German Center for Neurodegenerative Diseases, Tübingen, Germany

- **Dementia Outcome Measures: charting new territory**
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- **Body fluid biobanking of longitudinal cohorts in neurodegenerative diseases**
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- **Realising the potential of cohort studies to determine the vascular contribution to neurodegeneration**
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JPND Website link: http://www.neurodegenerationresearch.eu/initiatives/jpnd-alignment-actions/longitudinal-cohorts/

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Summary

This work has been steered by the following objectives:

- Produce updated evidence based recommendations on the best outcome measures for psychosocial research across Europe
- Investigate the need for new measures to reflect changes in emphasis and the consequent needs of researchers and of services
- Involve early career researchers in the working group to increase the workforce capacity in dementia research.

Additionally we intended to hear the views of the type and nature of outcomes that should be developed by people living with dementia.

The first objective has been achieved through a comprehensive update of the paper by Moniz Cook et al (2008). A paper is ready for submission to *Aging and Mental Health*. Recommendations refresh concepts and measurements of quality of life and include additional domains of 'caregiver responses to dementia symptoms' and 'health related quality of life'.

Achieving the second objective has resulted in a list of potential existing outcomes to meet identified domains within the neglected construct of 'living well with dementia', a review of new measurement methodologies and construction of a research agenda, taking into account headlines from the end user consultation This output is in final draft for publication.

The extended stakeholder consultation to be reported fully in a third output has resulted in recommendations for involving people living with dementia in research as well as inclusion of the user voice in the above research agenda.

We have involved 18 early career researchers in this work, including publication authorship.

Introduction

Dementia is a global research priority (Prince et al, 2013) and while the focus remains upon identification of a cure, there is also widespread recognition of the importance of enabling people to live well with dementia. The Manifesto published by the EU group of experts in psychosocial dementia research; INTERDEM (Moniz-Cook et al, 2011) used research evidence to illustrate the growing interest in psychosocial interventions for dementia, highlighting the promising range of possibilities that are emerging and also stressing the need for rigorous research evaluation of clinical and cost effectiveness. This level of evidence is required by service commissioners and providers to build effective services to support and enable people to live well with dementia for as long as possible. A cure is not likely to be achieved in the foreseeable future. Therefore researchers must work in partnership with dementia services to improve the range and quality of psychosocial interventions and evaluate their success. The science of outcome measurement in dementia is of central importance to this developing agenda.

Given the previous poor diagnostic rates, early intervention is a relatively new area for service delivery. However extent of supporting research evidence for psychosocial interventions remains patchy and there is a pressing need for rigorous evaluation through randomised controlled trials. Although these are emerging across Europe, many well designed psychosocial intervention studies have failed to demonstrate effectiveness for a number of reasons; one being the appropriateness of existing outcome measures and the validity of the concepts that underpin them. For example measurement of the static concept of health related quality of life has overlooked the growing acknowledgement of the importance of social health which embraces the ability of people with dementia to adapt to the condition and self manage (Huber et al., 2011). Another reason concerns the methods of who reports the detail for the outcome measured. For exampe the continuing use of proxies rather than direct self-report for quality of life measures (Moyle et al., 2012) can be problematic given growing reports that proxy (carer) ratings remain discrepant from those of the person's own perspectives (Thorgrimsen et al 2003)

The present work has aimed to both recommend existing measures for use in studies and in practice and explore needs for new measures and methods of application, using both the user voice and existing evidence drawn from a range of paradigms and perspectives to achieve this.

Context

- The guidelines are for researchers across Europe engaged in psychosocial research in deemntia care, with a focus on the efficacy of psychosocial interventions designed for people with dementia and their supporters/ carers.
- The guidelines may contribute towards UK work which is currently being commissioned on the identification of a common set of outcome measures for dementia research
- The guidelines have also taken the needs of clinicians into account, identifying measures that are as far as possible cost neutral and can be routinely applied in practice.

Terminology

Interdem: a Pan-European network of researchers collaborating in research on and dissemination of timely and quality psychosocial interventions in dementia aimed at improving the quality of life of people with dementia and their supporters across Europe.

Methods

Background to Methods
This study used an iterative collaborative, evidence-based approach across different European experts to identify and recommend the best currently available dementia outcome measures for European psychosocial intervention research. The methodology was first applied in 2008 by Moniz-Cook et al (2008) and incorporated a series of consensus workshops, systematic reviews of peer reviewed outputs published between June 2005 and February 2007 (see also Appendix 1) and rigorous evaluation of identified measures against agreed criteria (see Appendix 3). The present study replicated this methodology, evaluating evidence published since 2006 for new and existing measures. Using the same agreed criteria as in the 2008 publication, with the same focus upon utility across Europe, feasibility of use for research and in routine clinical practice, and sensitivity to change in psychosocial intervention research. Experts from twelve European countries (The Netherlands, Germany, Ireland, Italy, Luxembourg, The Czech Republic, Finland, Denmark, Norway, Spain, Austria and the UK) (as listed) contributed to the workshops and scientific literature searches. Additionally there were several face-to-face meetings between members of the project leadership group.

An initial one-day workshop was held in Glasgow in October 2014 during the Alzheimer's Europe annual conference. This was open to the Interdem membership and involved PPI representatives nominated by Alzheimer's Europe [www. alzheimer-europe.org] and early career researchers as well as senior academics and practitioners. It involved authors of key psychosocial intervention studies published by the pan-European network of experts INTERDEM (www.interdem.org) and original authors of the 2008 paper (Moniz-Cook et al 2008). Requirements for updating the original conceptual domains were discussed in detail as well as new potential domains and outcome measures across these domains. From this we agreed to: review the 2008 Global domain in depth; add the Health Related Quality of Life (HrQoL); add Resource Use (costs); and examine measures of behavioural problems in terms of both the behaviour as well as the caregivers reaction or response to this (Bird and Moniz-Cook, 2008). Domains were agreed and leads established to work with co-leads from the INTERDEM network (see Appendix 2).

A two-day workshop for invited delegates was convened in London in January 2015. The first day focussed on the review work to meet objective (1). It involved 13 researchers (domain leads and their teams) who presented interim findings from examination of each domain for discussion. It also involved one of the scientific reviewers who provided an external perspective. Lists of measures were refined to exclude those with costs or those that did not have strong evidence.
Delegates for the second day also included an additional number of invited individuals, thereby increasing the workshop to 25 attendees. The second day was comprised of a series of invited interactive presentations of relevant innovative work by Interdem members both on new concepts for outcomes and new methods of measurement to meet objective (2) with external scientific review being available as before.

Final one-day workshop: The main goals of this event were to reach expert consensus regarding the constructs/ domains and methods of measurement that reflect new paradigms and the voice of people with dementia

(objectives 2 & 3). New domains were discussed further and existing measures for these domains identified (see appended list). The workshop also involved a member from another UK research group that had been involved in convergent work and one of the named Australian collaborators. The consultation process with people living with the condition was also agreed and sites identified.

One day analysis workshop: This was convened in Brussels in June with the explicit goal of agreeing and applying a common framework to focus group data obtained through the consultation with people with dementia and with carers. Four senior researchers organised and attended this workshop, which agreed methods to validate analyses.

Consultation
Methods for a pan European consultation with people with dementia were agreed in the final workshop. Five people with dementia (one early onset) and four carers participated in an initial exploratory group in Sheffield, UK in April 2015. Findings from this pilot together with conclusions drawn from workshop discussions led to materials being prepared by Alzheimer's Europe for use by participating sites. A common methodology was then applied across all sites with acknowledgement of the need for flexibility to accommodate specific needs. Twenty-five people with dementia and 18 carers then participated in group consultations, with participants being from the UK, Denmark, Italy, Finland, Norway, Slovenia, Ireland, Jersey, Germany, Czech republic, England and Scotland. Findings have been used to add to the body of evidence and knowledge regarding need for new outcome measures for psychosocial research and practice; thereby contributing to output (2). They are also being used to prepare a third publication on the process of user engagement, which will present full analysis and discussion of the findings.

Desk-based work
Following the first workshop, a methods document was circulated to domain reviewers.They then examined reviews relevant to their domain, sytematically searching for measures that may have gathered evidence since the previous review. Thus authors reached a shortlist of new measures to which the quality rating checklist (Appendix 3) was applied. This checklist was weighted toward psychosocial interventions studies, with standards raised for Proxy versus Self Report measure given the body of research in the intervening period suggesting that proxy ratings do not reflect the experiences of people with dementia themselves. We also weighted against measures that required detailed in –home or care come observations or those that required extensive training or incurred costs. Expert reviewers for the project validated outputs. In the latter stages of the project, authorship of the first output (1) was finalised with authors then having the usual editing responsibilities. The collation of material to meet objective (2) involved using workshop outputs, asking specific members for reviews within certain topics/ domains or concepts, undertaking reviews of existing outcome measures which may address identified domains and integrating the findings from the user consultation (detailed below) to create a draft output.

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SUMMARY RECOMMENDATIONS: OBJECTIVE 1

Summary of Results

Domain Reviewers (Appendix 2) located all reviews relating to a domain between 2006 and March 2015, and then examined single studies where relevant. For example for the Carer Mood and Carer Burden domains, 41 reviews were located and 73 single studies were examined; and Quality of life (for the person with dementia) domain, eight reviews were located and 31 single studies were examined.   In most cases original recommended measures were retained apart from where they required detailed observation; or training; or in some cases where they represented costs for use that could be avoided through use of an equivalent measure; or as in the case of the staff domain, the General Health Questionnaire -GHQ (Goldberg 1978) for staff was seen as conceptually poor in the measurement of staff 'morale' following a closer look at studies since 2006.

Thirty three measures across 11 domains were shortlisted as potential relevant measures for psychosocial intervention research (Table 1); of these, 16 measurement scales are strongly recommended with at least one of these in each domain – see Table 1. The present set of outcome measures may be useful for future web-based electronic data sharing of research into psychosocial intervention outcome measures. This also has potential to inform research on which measures might be useful for particular research questions in the future. The presnet review could not recommend any Global Measures for the measurement of outcome in psychosocial research, but a final set of global measures may be considered for staging of the journey through dementia, outcomes of goals identified by people with dementia and 'needs assessment'.However the conceptual rationale for needs assesment as a global measure for outcome requires future examination.

Conclusion

The aspiration from this work is to recommend a set of measures that can be used to collate data from cohorts of people with dementia and carers across Europe, who participate in psychosocial research; thus preparing the way for data sharing from existing and future studies. This will enable us to better understand what might work for people and carers across the dementia trajectory in Europe.

TABLE 1: RECOMMENDED MEASURES FOR PSYCHOSOCIAL INTERVENTION RESEARCH

NAME OF MEASUREMENT SCALE	DOMAIN (and reference to measure)	COMMENTS (* **Recommended** equivalent to gold standard or most commonly used in research)
PERSON WITH DEMENTIA (PwD) Mood		
Cornell Scale for Depression in Dementia - CSDD	Alexopoulos GS, Abrams RC, Young RC, Shamoian CA (1988) Cornell Scale for Depression in Dementia. *Biological Psychiatry* 23,271–284	'Clinician' /observer rated using information from proxy, person with dementia and interview. **Recommended**
Geriatric Depression Screening Scale - GDS-15	Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, et al. (1983) Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37–49	Self- report measure, designed for older adults; severity of cognitive problems compromises reliability of the measure. May be used in mild dementia
Rating Anxiety in Dementia - RAID	Shankar KK,Walker M, & Frost, D (1999) The development of a valid and reliable scale for rating anxiety in dementia (RAID). *Aging & Mental Health* 3, 39–49.	Clinician' /observer rated using information from proxy, person with dementia and interview
Person with Dementia (PwD) Quality of Life		
Quality of Life in Alzheimer's Disease - QOL-AD	Logsdon R, Gibbons L, McCurry S, Teri L (1999) Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging* 5, 21-32	Can be use as Self- report, Proxy. For home and institutional settings **Recommended**
The Dementia Quality of Life Instrument – DQOL	Brod M, Stewart A, Sands L, & Walton P (1999) Conceptualisation and measurement of quality of life in dementia: The Dementia Quality of Life Instrument (DQOL). *Gerontologist* 39, 25–35.	See 2008 paper
QUALIDEM	Ettema T, Dröes R-M, de Lange J, Mellenbergh G, and Ribbe MW (2007) QUALIDEM: development and evaluation of a dementia specific quality of life instrument: validation. *International Journal of Geriatric Psychiatry* 22, 424–430 Ettema T, Dröes, R-M de Lange, J. Mellenbergh G and Ribbe MW. (2007) QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *International Journal of Geriatric Psychiatry* 22, 549–556	In – depth, evaluation of quality of life. **Recommended -2015**
DEMQoL	Smith SC, Lamping DL, Banerjee S, Harwood RH, Foley B, Smith P, Cook JC, Murray J, Prince M, Levin E, Mann A, Knapp M. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine* 37, 737-46.	So far validated with people with dementia and Proxy informal (family) carers living at home. Can be used in people with severe dementia. Ongoing work exists to develop this as a utility measure
QUALID	Weiner M, Martin-Cook K, Svetlik D, Saine K, Foster B, Fontain C. (2000). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association* 1, 114-116.	Only used in institutional settings

Person with Dementia Health Related QoL (HrQOL)		
EQ-5D	EuroQol Group ((1990). EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy* 16, 3,199-208.	Self -Report **Recommended -2015**
Person with Dementia (PwD) ADL/IADL		
Lawton – PSMS & IADL	Lawton MP, & Brody E M (1969). Assessment of older people: Self maintaining and instrumental activities of daily living. *Gerontologist* 9, 179–186.	Self -report **Recommended**
KATZ	Katz S, Ford AB, Moskowitz RW, Jackson BA & Jaffe MW (1963). Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA* 185,12, 914-919	Proxy rated
Alzheimer's Disease Cooperative Study – Activities of Daily Living Inventory - ADCS-ADL	Galasko D, Sano M, Ernesto E, Thomas R, Grundman, M, and Ferris S (1997) *Alzheimer Disease and Associated Disorders* 11,S33-S39	Proxy rated; derived for and used mostly in pharmacological studies
Bristol Activities of Daily Living Scale - BADLS	Bucks RS, Ashworth DL, Wilcock GK, et al (1996) Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. *Age and Ageing* 25, 113-120.	Used in pharmacological studies Proxy Rated
The disability assessment for dementia - DAD	Gelinas I, Gauthier L, McIntyre M & Gauthier S. (1999) Development of a functional measure for persons with Alzheimer's disease: The disability assessment for dementia. *American Journal of Occupational Therapy* 53, 471–81	Proxy rated
Behaviour (Rated by informal/family carer separated for Staff Carer		
Revised Memory and behaviour problems checklist - RMBPC	Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, & Vitaliano PP (1992) Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychol Aging* 7, 4, 622-631.	Derived from problems and concerns of family caregivers **Recommended for family care settings**
Neuropsychiatric Inventory - NPI	Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, et al. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 44, 2308–2314.	Derived from neuro psychiatric symptoms observed by psychiatrists/neurologists **Recommended for neuropsychiatric symptoms-family care settings**
Neuropsychiatric Inventory (Nursing Home) -NPI – NH	Wood S, Cummings JL, Hsu M-A, Barclay T, Wheatley MV, Yarema KT, Schnelle JF. (2000) The Use of the Neuropsychiatric Inventory in Nursing Home Residents. *American Journal of Geriatric Psychiatry* 8,1, 75-83	Derived from neuro psychiatric symptoms observed by psychiatrists/neurologists **Recommended for neuropsychiatric symptoms - institutional/ Nursing Homes**
CAMI	Cohen- Mansfield J, Marx MS, & Rosenthal AS (1989). A description of agitation in a nursing home. *Gerontologist* 44,3, M77-84.	Derived from problems reported by staff caregivers in Nursing Homes **Recommended for institutional / Nursing Homes**
Reaction to Behaviour (Rated by informal/family carer separated for Staff carer)		
Revised Memory and behaviour problems checklist – RMBPC –	Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, & Vitaliano PP. (1992). Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychol Aging* 7,4, 622-631.	**Recommended for family care settings**

Family Carer Reaction Domain		
Neuropsychiatric Inventory with Caregiver Distress Scale NPI – D – Family Carer Distress Domain	Kaufer DI, Cummings JL, Christine D, Bray T, Castellon S, Masterman D, et al (1998). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The neuropsychiatric inventory caregiver distress scale. Journal of the *American Geriatrics Society* 46,2, 210-215.	**Recommended for neuropsychiatric symptoms – family care settings**
Neuropsychiatric Inventory in Nursing Homes - NPI – NH – Occupational Disruption Domain	Wood S, Cummings JL, Hsu M-A, Barclay T, Wheatley MV, Yarema KT, Schnelle JF. (2000) The Use of the Neuropsychiatric Inventory in Nursing Home Residents. *American Journal of Geriatric Psychiatry* 8 ,1, 75-83	**Recommended for neuropsychiatric symptoms- Institutional /Nursing Homes**
Informal (Family) Carer Mood		
Hamilton Depression Rating Scale - HADS	Hamilton M (1960) A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry* 23, 56-62	May incur costs **Recommended**
General Health Questionnaire - GHQ	Goldberg DP, Williams P (1988) A User's Guide to General Health Questionnaire. Windsor: NFER-NELSON	See 2008 paper
Centre for Epidemiological Studies – Depression Scale - CES-D	Radloff LS, Teri L (1986) Use of the Center for Epidemiological Studies – depression scale with older adults. *Clinical Gerontologist* 5, 119-37	See 2008 paper
Informal (Family) Carer Burden		
Zarit Burden Interview - ZBI	Zarit et al. (1980) Relatives of the impaired elderly: correlates of feelings of burden, Gerontologist, 20,6, 649-55; Zarit (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study, *Gerontologist* 26, 260-266.	Few psychosocial intervention studies demonstrating sensitivity to change- See outcomes paper 2008
Sense of competence scale -,SCQ (27) Short sense of competence scale- SSCQ (7)	Vernooij Dassen MJ FJ, Persoon JMG, Felling AJA (1996) Predictors of sense of competence in caregivers of demented persons, *Soc Sc & Med*, 43, 41-49 Vernooij-Dassen MJ, Felling AJ, Brummelkamp E, Dauzenberg MG, van den Bos GA, Grol R (1999) Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: a Short Sense of Competence Questionnaire suitable for clinical practice *JAGS* 47,256-7.	Demonstrates sensitivity to change in some psychosocial intervention studies **Recommended measure of choice - 2015**
Relative Stress Scale -RSS	Greene JG, Smint R, Gardiner M, Timbury GC (1982): Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study, *Age Ageing*, 11, 121-126	Few studies demonstrating sensitivity to change See 2008 paper
Informal (Family) Carer Health Related QoL (HrQoL)		
SF 12-36	Ware J & Sherbourne C. (1992) The MOS 36-Item Short-Form Health Survey (SF-36): Conceptual framework and item selection. *Medical Care*, 30, 473–83.	See 2008 paper
WHOQoL-Bref	WHOQOL Group (1998) Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine* 28, 551–558.	See 2008 paper

EQ-5D	EuroQol Group (1990) EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy*, 16, 3, 99-208.	**Recommended measure of choice**
Resource Utilisation (Costs)		
Client Service Receipt Inventory - CSRI	Beecham J, Knapp M. (1992) Costing psychiatric interventions) In: Thornicroft G, Brewin CR, Wing J, editors. Measuring Mental Health Needs, 2nd edition: Gaskell//Royal College of Psychiatrists	Used in psychosocial intervention studies in the UK; it requires adaptation to tailor the measure to the context of each study.
The Resource Utilization in Dementia (RUD) Instrument	Wimo A, Nordberg G, Jansson W, Grafstrom M (2000) Assessment of informal services to demented people with the RUD instrument. *International Journal of Geriatric Psychiatry* 15, 969-71	**Recommended measure of choice for pan-European studies**
Staff Carer Morale		
Maslach Burnout Inventory - MBI	MASLACH C, JACKSON, SE, LEITER, MP (1996) Maslach Burnout Inventory Manual. *Consulting Psychologists Press* Palo Alto, CA.	**Recommended**

SUMMARY RECOMMENDATIONS: OBJECTIVE TWO

Conceptualising wellbeing in dementia

There is no single theory that currently provides an adequate basis for defining wellbeing in dementia. However perspectives on dementia within the biomedical, psychological and social models of disability provide different meanings, interpretations and assessments of constructs relevant to wellbeing such as independence, participation and quality of life.

One of the few reviews of definitions of wellbeing proposes a new interpretation which describes the state of balance that can be positively affected by life events or alternatively challenged by them (Dodge et al, 2012). Enabling people living with dementia and their families to live well require us to step outside the medical loss/deficit paradigm of dementia care. It demands move away from a narrow interpretation of health related quality of life and towards a broader concept of wellbeing. Our work identified the following challenges and associated research recommendations.

TABLE 2: RECOMMENDATIONS FOR RESEARCH INTO NEW OUTCOMES

Challenge	Research recommendation
Lack of conceptual model of wellbeing in dementia	• Prioritisation of the views of people living with dementia for model development • Consideration of new concepts (in the context of dementia) within this model; for example social health, positive psychology and successful ageing
Reduction of complex constructs such as quality of life to single questions	• New outcome measure construction which takes complexity and response shift into account • Development of methods of measurement that can reliably record 'in the moment' benefits
Focus upon deficits which negate the possibility of living well with dementia	• Development of new outcome measures that reflect positive constructs • Avoidance of negative labelling and terminology within measures
Use of proxies to obtain the views of people with a dementia diagnosis	• Development of outcome measures for self-completion by people (early/moderate stages of dementia);Development of innovative outcome measurement including use of technology and visual methods to capture the views of those in more severe stages of the condition
Inappropriate presentation and application	• Presentation that reduces rather than amplifies the impact of cognitive loss and any sensory impairment

Achieving the above recommendations will demand a significant culture shift on the part of research funders and the research community, and in particular for studies such as randomised controlled trials where robust

outcome measures are required and therefore the tendency is to use well established instruments which will reflect the established deficit approach.

Workshops and review work identified the value of the following as a starting point for initiating this significant change:
1. Using the constructs identified from existing measures and interpreting them in a positive light (so for example caregiver burden becomes reciprocity in the relationship)
2. Using positive psychology as an alternative to a disease model; thereby measuring constructs such as hope, humour and resilience
3. Adopting a model of successful ageing with dementia, which includes maintaining engagement in physical and social activities, operationalising the construct of social health, and promoting citizenship.

The results of consultation with people with dementia and with carers in four sites across Europe (objective 3: which will be fully documented in a third output) reflected value of the above. The most significant issue echoed by those who participated was the need for social participation; a 'full diary'. Dislike was also expressed of the methods of existing methods of taking outcome measures.

Existing measures for an asset based approach

As part of this work we identified existing instruments that take an asset based rather than deficit approach which might be considered by new studies and by services. The following table provides a summary of those developed for application with older people or where there is evidence of application with this group. It should be noted that this list requires further validation with Interdemn experts. The full list of all identified measures and details of their properties is appended.

TABLE 3: EXISTING MEASURES FOR WELLBEING THAT MAY HAVE UTILITY FOR PSYCHOSOCIAL STUDIES WITH PEOPLE WITH DEMENTIA

Domain	Identified measure	Target group/ use
Overall wellbeing	CASP 19; Quality of life in 4 domains -Hyde et al, 2003	Older people aged 65-75
Overall wellbeing	ICECAP-O ; Quality of life for older people rather than healthCoast et al, 2008	Older people :Developed as an index which can be used for economic analysis
Overall wellbeing	Physical and psychological functioning of low functioning older people COOP/ WONCA charts Kempen et al, 1997	Developed for use within the minimum data set (van Weel et al, 2012)
Overall wellbeing	Self-management ability scale: SMAS-30;Schuurmans et al, 2005	Community living older people
Positive psychology	General Self-Efficacy GSE; Schwarzer & Jerusalem, 1995	Developed for the general population but has been used with older people and in dementia

Participation	Impact on participation and autonomy of older persons IPA-Q; Ottenvall Hammar et al, 2014	Adapted from the IPAQ for use with people with chronic health conditions
Informal carer support	The Inventory of Social Supportive Behaviors SSB; Barrera, 1981	Initially developed for use with young people Has been applied in a range of studies
Informal carer support	Interpersonal Support Evaluation List ISEL;Cohen et al, 1985	Student and general population versions
Informal carer role	Preparation for caregiving/ Mutuality scale-Archbold et al, 1990	Informal/ family carers ; identify capacity for caring
Staff attitudes	Approach to dementia questionnaire ADQ-Lintern et al, 2000	Staff working in care home settings
Staff understanding	Person-centeredness in acute care of older people (with cognitive impairment) POPAC scale - Edvardsson et al 2013	Staff working in acute care settings

Capacity building

As can be seen from the participant list, as well as attracting researchers with an international profile in dementia research, we have also involved 18 early stage – mid stage career researchers (doctoral and post-doctoral), thereby contributing to capacity building across Europe.

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Acknowledgments

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