Empowering Partnerships

Preparing People with Dementia
to Partner with Researchers

INVOLVING PERSONS LIVING WITH DEMENTIA IN RESEARCH: PEER MODELS AND ISSUES OF CAPACITY

Literature Review

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PEER TO PEER MODELS OF SUPPORT

GASSAWAY, J., JONES, M. L., SWEATMAN, W. M., HONG, M., ANZIANO, P., & DEVAULT, K. (2017). EFFECTS OF PEER MENTORING ON SELF-EFFICACY AND HOSPITAL READMISSION AFTER INPATIENT REHABILITATION OF INDIVIDUALS WITH SPINAL CORD INJURY: A RANDOMIZED CONTROLLED TRIAL. *ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION*, *98*(8), 1526-1534.

Objective. To investigate the effect of intensive peer mentoring on patient-reported outcomes of self-efficacy and unplanned hospital readmissions for persons with spinal cord injury/disease (SCI/D) within the first 6 months after discharge from inpatient rehabilitation. **Design.** Randomized controlled trial. **Setting.** Nonprofit inpatient rehabilitation hospital specializing in care of persons with SCI/D and brain injury. **Participants.** Patients (N=158) admitted to the SCI/D rehabilitation program whose discharge location was a community setting. Participants (51% with paraplegia and 49% with tetraplegia) were 73% white and 77% men, with a mean age of 38 years. **Interventions.** Participants in the experimental group received initial consult/introduction with a peer support program liaison and were assigned a peer mentor, who met with the participant weekly throughout the inpatient stay and made weekly contact by phone, e-mail, or in person for 90 days postdischarge. Participants also were encouraged to participate in regularly scheduled peer support activities. Nonexperimental group participants were introduced to peer support and provided services only on request. **Main Outcome Measures.** General Self-efficacy Scale (adapted to SCI/D), project-developed community integration self-efficacy scale, and patient-reported unplanned rehospitalizations. **Results.** Growth rate for self-efficacy in the first 6 months postdischarge was significantly higher for experimental group participants than nonexperimental group participants. Experimental group participants also had significantly fewer unplanned hospital days. **Conclusions.** This study provides evidence that individuals receiving intensive peer mentoring during and after rehabilitation for SCI/D demonstrate greater gains in self-efficacy over time and have fewer days of unplanned rehospitalization in the first 180 days postdischarge. More research is needed to examine the long-term effects of this intervention on health care utilization and the relation between improved health and patient-reported quality of life outcomes.

DAVIDSON, L., CHINMAN, M., KLOOS, B., WEINGARTEN, R., STAYNER, D., & TEBES, J. K. (1999). PEER SUPPORT AMONG INDIVIDUALS WITH SEVERE MENTAL ILLNESS: A REVIEW OF THE EVIDENCE. *CLINICAL PSYCHOLOGY: SCIENCE AND PRACTICE*, *6*(2), 165-187.

This article reviews the history and potential effectiveness of peer support among persons with severe mental illness. Following a historical overview, we describe the three primary forms of peer support that have been developed to date by and for this population, and examine the existing empirical evidence of the feasibility, effectiveness, and utilization of each of these approaches in contributing to the recovery of individuals with psychiatric disabilities. These three forms are (1) naturally occurring mutual support groups, (2) consumer-run services, and (3) the employment of consumers as providers within clinical and rehabilitative settings. Existing studies of mutual support groups suggest that they may improve symptoms, promote larger social networks, and enhance quality of life. This research is largely from uncontrolled studies, however, and will need to be evaluated further using prospective, controlled designs. Consumer-run services and the use of consumers as providers promise to broaden the access of individuals with psychiatric disabilities to peer support, but research on these more recent developments is only preliminary and largely limited to demonstrations of their feasibility. We discuss issues entailed in participating in peer support for this population, and then close with a discussion of the implications for future policy, research, and practice.

DAVIDSON, L., CHINMAN, M., SELLS, D., & ROWE, M. (2006). PEER SUPPORT AMONG ADULTS WITH SERIOUS MENTAL ILLNESS: A REPORT FROM THE FIELD. *SCHIZOPHRENIA BULLETIN*, *32*(3), 443-450.

Peer support is based on the belief that people who have faced, endured, and overcome adversity can offer useful support, encouragement, hope, and perhaps mentorship to others facing similar situations. While this belief is well accepted for many conditions, such as addiction, trauma, or cancer, stigma and stereotypes about mental illness have impeded attempts on the part of people in recovery to offer such supports within the mental health system. Beginning in the early 1990s with programs that deployed people with mental illness to provide conventional services such as case management, opportunities for the provision and receipt of peer support within the mental health system have proliferated rapidly across the country as part of the emerging recovery movement. This article defines peer support as a form of mental health are and reviews data from 4 randomized controlled trials, which demonstrated few differences between the outcomes of conventional care when provided by peers versus non-peers. We then consider what, if any, unique contributions can be made by virtue of a person's history of serious mental illness and recovery and review beginning efforts to identify and evaluate these potential valued-added components of care. We conclude by suggesting that peer support is still early in its development as a form of mental health service provision and encourage further exploration and evaluation of this promising, if yet unproven, practice.

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, *20*(4), 392-411.

Background. Although mutual support and self-help groups based on shared experience play a large part in recovery, the employment of peer support workers (PSWs) in mental health services is a recent development. However, peer support has been implemented outside the UK and is showing great promise in facilitating recovery. *Aims.* This article aims to review the literature on PSWs employed in mental health services to provide a description of the development, impact and challenges presented by the employment of PSWs and to inform implementation in the UK. *Method.* An inclusive search of published and grey literature was undertaken to identify all studies of intentional peer support in mental health services. Articles were summarised and findings analysed. *Results.* The literature demonstrates that PSWs can lead to a reduction in admissions among those with whom they work. Additionally, associated improvements have been reported on numerous issues that can impact on the lives of people with mental health problems. *Conclusion.* PSWs have the potential to drive through recovery-focused changes in services. However, many challenges are involved in the development of peer support. Careful training, supervision and management of all involved are required.

Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: A metasynthesis of qualitative findings. *Psychiatric Rehabilitation Journal*, *36*(1), 28.

Objectives: Peer support involves people in recovery from psychiatric disability offering support to others in the same situation. It is based on the belief that people who have endured and overcome a psychiatric disability can offer useful support, encouragement, and hope to their peers. Although several quantitative reviews on the effectiveness of peer support have been conducted, qualitative studies were excluded. This study aimed to synthesize findings from these studies. **Method:** A qualitative metasynthesis was conducted, involving examination, critical comparison, and synthesis of 27 published studies. The experiences of peer support workers, their nonpeer colleagues, and the recipients of peer support services were investigated. **Results:** Peer support workers experiences included nonpeer staff discrimination and prejudice, low pay and hours, and difficulty managing the transition from “patient” to peer support worker. Positive experiences included collegial relationships with nonpeer staff, and other peers; and increased wellness secondary to working. Recipients of peer support services experienced increased social networks and wellness. **Conclusions and Implications for Practice:** The findings highlight training, supervision, pay, nonpeer staff/peer staff relationships, as important factors for statutory mental health peer support programs.

BELLAMY, C., SCHMUTTE, T., & DAVIDSON, L. (2017). AN UPDATE ON THE GROWING EVIDENCE BASE FOR PEER SUPPORT. *MENTAL HEALTH AND SOCIAL INCLUSION*, *21*(3), 161-167.

Purpose. As peer support services have become increasingly used in mental health settings as a recovery-oriented practice, so has the body of published research on this approach to care. The purpose of this paper is to provide an update on the current evidence base for peer support for adults with mental illness in two domains: mental health and recovery, and physical health and wellness. **Design/methodology/approach.** To provide a robust, non-redundant, and up-to-date review, first the authors searched for meta-analyses and systematic reviews. Second, the authors found individual studies not included in any of the reviews. **Findings.** Peer services are generally equally effective to services provided by non-peer paraprofessionals on traditional clinical outcomes. Although some studies found peer services to be effective at reducing hospitalization rates and symptom severity, as a whole, the current evidence base is confounded by heterogeneity in programmatic characteristics and methodological shortcomings. On the other hand, the evidence is stronger for peer support services having more of a positive impact on levels of hope, empowerment, and quality of life. **Research limitations/implications.** In addition to the need for further high-quality research on peer support in mental and physical health domains, the authors also question whether measures of hope, empowerment, and integration into the community are more relevant to recovery than traditional clinical outcomes. **Originality/value.** This paper provides an original, robust, and up-to-date review of the evidence for peer services.

LLOYD-EVANS, B., MAYO-WILSON, E., HARRISON, B., ISTEAD, H., BROWN, E., PILLING, S., ... & KENDALL, T. (2014). A SYSTEMATIC REVIEW AND META-ANALYSIS OF RANDOMISED CONTROLLED TRIALS OF PEER SUPPORT FOR PEOPLE WITH SEVERE MENTAL ILLNESS. *BMC PSYCHIATRY*, *14*(1), 39.

Background. Little is known about whether peer support improves outcomes for people with severe mental illness. **Method.** A systematic review and meta-analysis was conducted. Cochrane CENTRAL Register, Medline, Embase, PsycINFO, and CINAHL were searched to July 2013 without restriction by publication status. Randomised trials of non-residential peer support interventions were included. Trial interventions were categorised and analysed separately as: mutual peer support, peer support services, or peer

delivered mental health services. Meta-analyses were performed where possible, and studies were assessed for bias and the quality of evidence described. **Results.** Eighteen trials including 5597 participants were included. These comprised four trials of mutual support programmes, eleven trials of peer support services, and three trials of peer-delivered services. There was substantial variation between trials in participants' characteristics and programme content. Outcomes were incompletely reported; there was high risk of bias. From small numbers of studies in the analyses it was possible to conduct, there was little or no evidence that peer support was associated with positive effects on hospitalisation, overall symptoms or satisfaction with services. There was some evidence that peer support was associated with positive effects on measures of hope, recovery and empowerment at and beyond the end of the intervention, although this was not consistent within or across different types of peer support. **Conclusions.** Despite the promotion and uptake of peer support internationally, there is little evidence from current trials about the effects of peer support for people with severe mental illness. Although there are few positive findings, this review has important implications for policy and practice: current evidence does not support recommendations or mandatory requirements from policy makers for mental health services to provide peer support programmes. Further peer support programmes should be implemented within the context of high quality research projects wherever possible. Deficiencies in the conduct and reporting of existing trials exemplify difficulties in the evaluation of complex interventions.

SWARBRICK, M., GILL, K. J., & PRATT, C. W. (2016). IMPACT OF PEER DELIVERED WELLNESS COACHING. *PSYCHIATRIC REHABILITATION JOURNAL*, 39(3), 234.

Objective: People receiving publicly funded behavioral health services for severe mental disorders have shorter lifespans and significantly impaired health-related quality of life compared to the general population. The aim of this article was to explore how peer wellness coaching (PWC), a manualized approach to pursue specific physical wellness goals, impacted goal attainment and overall health related quality of life. **Method:** Deidentified archival program evaluation data were examined to explore whether peer delivered wellness coaching had an impact on 33 service recipients with regard to goal attainment and health-related quality of life. Participants were served by 1 of 12 wellness coach trainees from a transformation transfer initiative grant who had been trained in the manualized approach. **Results:** Coaching participants and their coaches reported significant progress toward the attainment of individually chosen goals, 2 to 4 weeks after establishing their goals. After 8 to 10 weeks of peer delivered wellness coaching, improvements were evident in the self-report of physical health, general health, and perceived health. These improvements were sustained 90 days later. **Conclusions and Implications for Practice:** PWC is potentially a promising practice for helping people choose and pursue individual goals and facilitating positive health and wellness changes. Rigorous controlled research with larger samples is needed to evaluate the benefits of peer delivered wellness coaching.

COATES, D., LIVERMORE, P., & GREEN, R. (2018). THE UNIQUE CONTRIBUTION OF OLDER PEOPLE WITH A LIVED EXPERIENCE OF MENTAL ILLNESS TO THE PEER WORKFORCE: OBSERVATIONS FROM OLDER PEER WORKERS. *EUROPEAN JOURNAL FOR PERSON CENTERED HEALTHCARE*, 6(1), 78-87.

Background: The development of peer work models that are integrated into health systems is at the heart of national and international reform agenda in mental health. Peer work differs from other mental health roles as it is provided by people who have a lived experience of mental illness and recovery and does not assume a medical model. Peer work in mental health services for older people is not well established and to address this gap we developed, implemented and evaluated a peer work model for older patients of a specialist mental health service. **Method:** The findings discussed in this paper are part of a broader evaluation and consist of qualitative observations made by the peer workers during focus groups. Three focus groups were conducted during the first year of the project to identify the peer workers' perspectives, feelings and thoughts around the developing peer work model and how they were impacted by the work. Data collection and analysis was inductive and informed by grounded theory principles. Observations from peer workers are discussed in relation to the literature as well as observations made by the researchers during project implementation. **Results:** Analysis suggests that older peer workers have a level of maturity and experience with recovery that benefit the peer workforce in a number of ways namely (a) significant experience with recovery to draw on when helping others; (b) a well-established sense of identity and coping strategies that support wellbeing and (c) ability to cope with ambiguity and uncertainty inherent in peer work practice. We propose that having a strong sense of self or personal identity may be important in peer work, particularly as the peer work role is often challenged, questioned and unclear. **Conclusion:** Older peer workers provide a valuable contribution to the peer workforce and bring with them an array of strengths that can help overcome some of the common peer work implementation barriers.

DALEY, S., NEWTON, D., SLADE, M., MURRAY, J., & BANERJEE, S. (2013). DEVELOPMENT OF A FRAMEWORK FOR RECOVERY IN OLDER PEOPLE WITH MENTAL DISORDER. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY*, *28*(5), 522-529.

Objective: To evaluate whether a conceptual framework of recovery developed for working age adults holds value for users of older people's mental health services, including those with dementia. **Method:** Thirty-eight qualitative interviews were undertaken with service users and carers from an older people's mental health service in South London and were analysed using grounded theory methods. **Results:** Components of recovery, which appear to be meaningful to older people with mental disorder include the following: (i) the impact of illness, (ii) the significance of personal responsibility, and (iii) specific coping strategies. Unlike their younger peers, older people did not aspire to a new and revised sense of identity, nor did they seek peer support from others with lived experience of mental illness. Three components of recovery were identified as being distinct to older people: the significance of an established and enduring sense of identity; coping strategies, which provide continuity and reinforce identity; and the associated impact of physical illness. Finally, two additional components of recovery were identified for people with dementia: (i) the changing experience over time and (ii) support from others. **Conclusion:** Mental health policy is increasingly framed in terms of 'recovery'. This paper provides empirical evidence of how it applies to users of older people's mental health services. Practice implications include the need to focus on the maintenance of identity, and embed the values of empowerment, agency and self-management within service delivery.

CHAPIN, R. K., SERGEANT, J. F., LANDRY, S., LEEDAHL, S. N., RACHLIN, R., KOENIG, T., & GRAHAM, A. (2012). RECLAIMING JOY: PILOT EVALUATION OF A MENTAL HEALTH PEER SUPPORT PROGRAM FOR OLDER ADULTS WHO RECEIVE MEDICAID. *THE GERONTOLOGIST*, *53*(2), 345-352.

Purpose: *Stigma and lack of access to providers create barriers to mental health treatment for older adults living in the community. In order to address these barriers, we developed and evaluated a peer support intervention for older adults receiving Medicaid services.* **Design and Methods**: *Reclaiming Joy is a mental health intervention that pairs an older adult volunteer with a participant (older adult who receives peer support). Volunteers receive training on the strengths-based approach, mental health and aging, goal setting and attainment, community resources, and safety. Participant–volunteer pairs meet once a week for 10 weeks. Participants establish and work toward goals (e.g., better self-care, social engagement) that they feel would improve their mental health and well-being. Aging services agencies provide a part time person to*

manage the program, match volunteers and participants, and provide ongoing support. Outcomes evaluation for this pilot study included pre/postintervention assessments of participants. **Results**: *Thirty-two participants completed the intervention. Pre/post assessment group means showed statistically significant improvement for depression but not for symptoms of anxiety. Quality-of-life indicators for health and functioning also improved for participants with symptoms of both depression and anxiety.* **Implications:** *The Reclaiming Joy peer support intervention has potential for reducing depression and increasing quality of life in low-income older adults who have physical health conditions. It is feasible to administer and sustain the intervention through collaborative efforts with minimal program resources and a small amount of technical assistance.*

HILL, L., ROBERTS, G., WILDGOOSE, J., PERKINS, R., & HAHN, S. (2010). RECOVERY AND PERSON-CENTRED CARE IN DEMENTIA: COMMON PURPOSE, COMMON PRACTICE?. *ADVANCES IN PSYCHIATRIC TREATMENT*, *16*(4), 288-298.

With the launch of the Fair Deal for Mental Health campaign in 2008 the Royal College of Psychiatrists made a commitment to ensuring that ‘training for psychiatrists promotes the recovery approach’. National guidance emphasises the universal applicability of the recovery values for anyone of any age who has a significant mental health problem. Yet there has been little thinking as to whether the recovery approach is applicable to old age psychiatry and particularly to dementia care. This article explores the striking similarities between a recovery-oriented approach and person-centred care, the particular challenge posed in dementia care and the benefits of a collaborative approach in pursuit of common purposes.

COATES, D., LIVERMORE, P., & GREEN, R. (2018). THE DEVELOPMENT AND IMPLEMENTATION OF A PEER SUPPORT MODEL FOR A SPECIALIST MENTAL HEALTH SERVICE FOR OLDER PEOPLE: LESSONS LEARNED. *MENTAL HEALTH REVIEW JOURNAL*, *23*(2), 73-85.

Purpose. There has been a significant growth in the employment of peer workers over the past decade in youth and adult mental health settings. Peer work in mental health services for older people is less developed, and there are no existing peer work models for specialist mental health services for older people in Australia. The authors developed and implemented a peer work model for older consumers and carers of a specialist mental health service. The purpose of this paper is to describe the model, outline the implementation barriers experienced and lesson learned and comment on the acceptability of the model from the perspective of stakeholders. **Design/methodology/approach.** To ensure the development of the peer work model

met the needs of key stakeholders, the authors adopted an evaluation process that occurred alongside the development of the model, informed by action research principles. To identify stakeholder preferences, implementation barriers and potential solutions, and gain insight into the acceptability and perceived effectiveness of the model, a range of methods were used, including focus groups with the peer workers, clinicians and steering committee, consumer and carer surveys, field notes and examination of project documentation. **Findings.** While the model was overall well received by stakeholders, the authors experienced a range of challenges and implementation barriers, in particular around governance, integrating the model into existing systems, and initial resistance to peer work from clinical staff. **Originality/value.** Older peer workers provide a valuable contribution to the mental health sector through the unique combination of lived experience and ageing. The authors recommend that models of care are developed prior to implementation so that there is clarity around governance, management, reporting lines and management of confidentiality issues.

TILLY, J., WIENER, J., & CUELLAR, A. E. (2000). CONSUMER-DIRECTED HOME-AND COMMUNITY-BASED SERVICES PROGRAMS IN FIVE COUNTRIES: POLICY ISSUES FOR OLDER PEOPLE AND GOVERNMENT. *GENERATIONS*, *24*(3), 74-83.

This article analyzes the development, design, and experience of consumer-directed homecare programs in Austria, Germany, France, the Netherlands, and several states within the United States. The experiences of beneficiaries, caregivers, and workers are compared across all five countries.

VISSER, S. M., MCCABE, M. P., HUDGSON, C., BUCHANAN, G., DAVISON, T. E., & GEORGE, K. (2008). MANAGING BEHAVIOURAL SYMPTOMS OF DEMENTIA: EFFECTIVENESS OF STAFF EDUCATION AND PEER SUPPORT. *AGING AND MENTAL HEALTH*, *12*(1), 47-55.

This study was designed to investigate the impact of staff education on the behaviour and quality of life of residents with dementia and on staff members' attitudes about working with people with dementia and level of burnout. Staff from three aged care facilities participated in the study (*n* = 52). These facilities were randomly assigned to one of two intervention groups or a control group. Staff assigned to the intervention groups received an eight-week behaviourally-based programme. Staff from one aged care facility also participated in a peer support group designed to reinforce educational material and facilitate positive changes among staff members. Behavioural symptoms displayed by residents (*n* = 76) in each of the facilities were also assessed. Assessments were conducted at pre-intervention, post-intervention, three- and six-month follow-up.

The results of this study indicated that education or peer support was not associated with an improvement in resident behaviour or quality of life. Education or peer support also did not impact on staff members' level of burnout. There was, however, a change in staff members' attitudes about working with people with dementia. Possible explanations for these findings and implication for further research are considered.

DAVISON, T. E., MCCABE, M. P., VISSER, S., HUDGSON, C., BUCHANAN, G., & GEORGE, K. (2007). CONTROLLED TRIAL OF DEMENTIA TRAINING WITH A PEER SUPPORT GROUP FOR AGED CARE STAFF. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY: A JOURNAL OF THE PSYCHIATRY OF LATE LIFE AND ALLIED SCIENCES*, *22*(9), 868-873.

Objective: This study evaluated the impact of an eight-session training program for aged care staff in managing dementia-related challenging behaviours. Participation in the training program with an additional five-session peer support group was compared with both participation in training only and a wait-list control condition. **Methods:** Outcomes were evaluated for 90 participating staff members and 113 residents with challenging behaviours from six aged care facilities. Measures of staff attitudes and the behaviours of staff and residents were collected pre- and post-intervention, and at six month follow-up. **Results:** Staff members in both dementia training groups reported improved attitudes regarding their knowledge and skills in managing residents with challenging behaviours, immediately after the training and six months later. Facility supervisors rated the nursing performance of trained staff more positively, particularly those who participated in a peer support group. The dementia training programs, whether with or without the inclusion of peer support, did not impact on levels of staff burnout or substantially reduce the level of challenging behaviours among aged care residents.**Conclusions:** While training programs may impact positively on staff performance, organisational characteristics of aged care facilities, including low levels of management support for staff training initiatives, limit the potential outcomes. Methodological limitations are discussed. Copyright © 2006 John Wiley & Sons, Ltd.

THOMPSON, C. A., SPILSBURY, K., HALL, J., BIRKS, Y., BARNES, C., & ADAMSON, J. (2007). SYSTEMATIC REVIEW OF INFORMATION AND SUPPORT INTERVENTIONS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA. *BMC GERIATRICS*, *7*(1), 18.

Background: Dementia is an important health and social care problem and is one of the main causes of disability in later life. The number of families affected by dementia will dramatically increase over the next five decades. Despite the implications for health and social care services in the future, the overwhelming majority of care for people with dementia takes place away from health care settings. Providing informal care for someone with dementia can be psychologically, physically and financially expensive and a range of health service interventions aimed at supporting and providing information to these carers has developed to help carers meet these demands. This review examines whether information and support interventions improve the quality of life of people caring for someone with dementia. **Methods:** A systematic review examining evidence from randomised controlled trials in which technology, individualised or group-based interventions built around the provision of support and/or information were evaluated. **Results:** Forty-four studies were included in the review. Controlling for the quality of the evidence, we found statistically significant evidence that group-based supportive interventions impact positively on psychological morbidity. However, whilst the improvement was unlikely to be due to chance, the clinical significance of this finding should be interpreted tentatively, due to the difficulties in interpreting the standardised mean difference as a measure of effect and the complex aetiology of depression. No evidence was found for the effectiveness of any other form of intervention on a range of physical and psychological health outcomes. **Conclusion:** There is little evidence that interventions aimed at supporting and/or providing information to carers of people with dementia are uniformly effective. There is a pressing need to ensure that supportive interventions at the development stage are accompanied by good quality randomised evaluations in which outcomes that are important to clinicians and carers are measured.

KEYES, S. E., CLARKE, C. L., WILKINSON, H., ALEXJUK, E. J., WILCOCKSON, J., ROBINSON, L., ... & CATTAN, M. (2016). “WE’RE ALL THROWN IN THE SAME BOAT…”: A QUALITATIVE ANALYSIS OF PEER SUPPORT IN DEMENTIA CARE. *DEMENTIA*, *15*(4), 560-577.

Peer support is well established in fields such as the disability movement and mental health and is increasingly recognised as one way of enabling support by and for people with a diagnosis of dementia and their immediate carers. It was central to the implementation of the National Dementia Strategy (NDS) for England, when 40 demonstration sites were established. This mixed-methods study included in-depth qualitative interviews with people living with dementia (*n* = 101) and staff/stakeholders (*n* = 82) at 8 of the 40 sites. Data analysis was a five-stage process: coding framework developed (using 25 transcripts); further development of the framework (using a further 70 transcripts); development of emerging themes; modelling of themes and verification of models based on the entire data set. Peer support had positive emotional and social impact that was rooted in identification with others, a commonality of experience and reciprocity of support. There was also a contrast between the quality of peer support and support from professionals. This emphasises the significance of lived experience and promoting a strength-based approach to interpersonal support that is enabling and challenges a deficit approach to understanding dementia.

CHARLESWORTH, G., BURNELL, K., BEECHAM, J., HOARE, Z., HOE, J., WENBORN, J., ... & ORRELL, M. (2011). PEER SUPPORT FOR FAMILY CARERS OF PEOPLE WITH DEMENTIA, ALONE OR IN COMBINATION WITH GROUP REMINISCENCE IN A FACTORIAL DESIGN: STUDY PROTOCOL FOR A RANDOMISED CONTROLLED TRIAL. *TRIALS*, *12*(1), 205.

Background: Peer support interventions can improve carer wellbeing and interventions that engage both the carer and person with dementia can have significant mutual benefits. Existing research has been criticised for inadequate rigour of design or reporting. This paper describes the protocol for a complex trial that evaluates one-to-one peer support and a group reminiscence programme, both separately and together, in a factorial design. **Design:** A 2 × 2 factorial multi-site randomised controlled trial of individual peer support and group reminiscence interventions for family carers and people with dementia in community settings in England, addressing both effectiveness and cost-effectiveness. **Discussion:** The methods described in this protocol have implications for research into psychosocial interventions, particularly complex interventions seeking to test both individual and group approaches.

PILLEMER, K., & SUITOR, J. J. (2002). PEER SUPPORT FOR ALZHEIMER'S CAREGIVERS: IS IT ENOUGH TO MAKE A DIFFERENCE?. *RESEARCH ON AGING*, *24*(2), 171-192.

This study tested a social support enhancement intervention for caregivers to relatives with Alzheimer's disease. Theory and empirical research on life-course transitions and social support suggest that support from an experientially similar peer (i.e., a person who has undergone the same stressful transition) will lead to positive outcomes among caregivers. The intervention differed from previous programs for caregivers by isolating social support enhancement as the intervention mechanism, without simultaneously providing education, counseling, or direct services. Using a randomized, control-group design, no main effects were found. At the level of interactions, a modest buffering effect was found for persons in more stressful caregiving situations. However, the overall pattern of the results suggests that social support alone is not a sufficient intervention to improve the experience of caregivers. Implications for future research and planning of interventions are discussed.

DAVIES-QUARRELL, V., HIGGINS, A., HIGGINS, J., QUINN, P., QUINN, M., JONES, G., ... & MARLAND, P. (2010). THE ACE APPROACH: PROMOTING WELL-BEING AND PEER SUPPORT FOR YOUNGER PEOPLE WITH DEMENTIA. *THE JOURNAL OF MENTAL HEALTH TRAINING, EDUCATION AND PRACTICE*, *5*(3), 41-50.

This article describes the evaluation of the ACE club, a service for younger people with dementia in North Wales. The evaluation was conducted by the ACE club members and conducted through a relationship-centred approach expressed through the Senses Framework (achievement, belonging, continuity, purpose, security, significance) (Nolan et al, 2006). Members of the ACE club found the sense of significance to be the most important and meaningful 'sense' in helping to structure their evaluation and use of the ACE club. The clinical interventions outline is shared within the text to help provide a grounded and inductively generated practice structure. The funding of 'normalising' activities for younger people with dementia is an area of dementia care that needs urgent attention.

CLARKE, C., KEYES, S., WILKINSON, H., ALEXJUK, J., WILCOCKSON, J., ROBINSON, L., ... & CATTAN, M. (2013). HEALTHBRIDGE: THE NATIONAL EVALUATION OF PEER SUPPORT NETWORKS AND DEMENTIA ADVISERS IN IMPLEMENTATION OF THE NATIONAL DEMENTIA STRATEGY FOR ENGLAND.

This report, commissioned by the Department of Health, provides evidence on the importance of post diagnostic support for people with dementia and their carers, and the role that dementia advisers and peer support networks can provide in this.

Important messages from the report are:
- people with dementia and carers saw dementia advisers and peer support networks as having a positive impact on their wellbeing and quality of life
- demonstrator sites provided evidence of both dementia advisers and peer support networks filling a gap in service provision that often occurs after diagnosis but before there is a need for more intensive support
- both initiatives were seen as having resource saving implications for the local health and social care economy

CHARLESWORTH, G., BURNELL, K., CRELLIN, N., HOARE, Z., HOE, J., KNAPP, M., ... & ORRELL, M. (2016). PEER SUPPORT AND REMINISCENCE THERAPY FOR PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS: A FACTORIAL PRAGMATIC RANDOMISED TRIAL. *J NEUROL NEUROSURG PSYCHIATRY*, JNNP-2016.

Objective The objective of this study was to evaluate peer support and reminiscence therapy, separately and together, in comparison with usual care for people with dementia and their family carers. **Design** Factorial pragmatic randomised trial, analysed by treatment allocated, was used for this study. **Setting** The trial ran in Community settings in England. **Participants** People with dementia and their family carers were the

participants. **Interventions** Treatment as usual (TAU) plus one of the following: one-to-one peer support to family carers from experienced carers (Carer Supporter Programme; CSP), group reminiscence therapy (Remembering Yesterday, Caring Today; RYCT) for people with dementia and carers, both or neither. **Main outcome measures** Primary outcomes included health-related quality of life (SF-12) for carers and quality of life (QoL-AD) for people with dementia; secondary outcomes included quality of relationship for carers and people with dementia; both were collected by blinded assessors at baseline, 5 and 12 months (primary end point). **Results** Of 291 pairs recruited, we randomised 145 (50%) to CSP (71% uptake) and 194 (67%) to RYCT (61% uptake). CSP and RYCT, separately or together, were not effective in improving primary outcomes or most secondary outcomes. For CSP versus 'no CSP', adjusted difference in means was 0.52 points on the SF-12 (95% CI −1.28 to 2.32) and −0.08 points on the QoL-AD (95% CI −1.70 to 1.56). For RYCT versus 'no RYCT', the difference was 0.10 points on the SF-12 (95% CI −1.72 to 1.93) and 0.51 points on the QoL-AD (95% CI −1.17 to 2.08). However, carers reported better relationships with the people with dementia (difference 1.11, 95% CI 0.00 to 2.21, p=0.05). Comparison of combined intervention with TAU, and of intervention received, suggested differential impacts for carers and persons with dementia. **Conclusions** There is no evidence from the trial that either peer support or reminiscence is effective in improving the quality of life.

BANERJEE, S. (2010). LIVING WELL WITH DEMENTIA—DEVELOPMENT OF THE NATIONAL DEMENTIA STRATEGY FOR ENGLAND. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY*, *25*(9), 917-922.

LEUNG, P., ORRELL, M., & ORGETA, V. (2015). SOCIAL SUPPORT GROUP INTERVENTIONS IN PEOPLE WITH DEMENTIA AND MILD COGNITIVE IMPAIRMENT: A SYSTEMATIC REVIEW OF THE LITERATURE. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY*, *30*(1), 1-9.

Objectives. Despite the large number of studies evaluating social support groups for people with dementia, there are no systematic reviews of current evidence. The aim of this study was to evaluate the effectiveness of social support group interventions for people with dementia and mild cognitive impairment. **Methods.** A systematic review was performed. We searched electronic databases for randomised controlled trials. Two reviewers worked independently to select trials, extract data and assess risk of bias. **Results** A total of 546 studies were identified of which two met the inclusion criteria. We were not able to pool data for further analyses, as the interventions tested in the studies meeting the inclusion criteria were too dissimilar in content. The first trial (*n* = 136) showed a benefit of early-stage memory loss social support groups for depression and quality of life in people with dementia. The second trial (*n* = 33) showed that post-treatment self-reported self-esteem was higher in the group receiving a multicomponent intervention

of social support compared with that in the no intervention control group. **Conclusions** Limited data from two studies suggest that support groups may be of psychological benefit to people with dementia by reducing depression and improving quality of life and self-esteem. These findings need to be viewed in light of the small number, small sample size and heterogeneous characteristics of current trials, indicating that it is difficult to draw any conclusions. More multicentre randomised controlled trials in social support group interventions for people with dementia are needed.

WILLIS, E., SEMPLE, A. C., & DE WAAL, H. (2018). QUANTIFYING THE BENEFITS OF PEER SUPPORT FOR PEOPLE WITH DEMENTIA: A SOCIAL RETURN ON INVESTMENT (SROI) STUDY. *DEMENTIA*, *17*(3), 266-278.

Objective: Peer support for people with dementia and carers is routinely advocated in national strategies and policy as a post-diagnostic intervention. However there is limited evidence to demonstrate the value these groups offer. This study looked at three dementia peer support groups in South London to evaluate what outcomes they produce and how much social value they create in relation to the cost of investment. **Methods:** A Social Return on Investment (SROI) analysis was undertaken, which involves collecting data on the inputs, outputs and outcomes of an intervention, which are put into a formula, the end result being a SROI ratio showing how much social value is created per £1 of investment. **Results:** Findings showed the three groups created social value ranging from £1.17 to £5.18 for every pound (£) of investment, dependent on the design and structure of the group. Key outcomes for people with dementia were mental stimulation and a reduction in loneliness and isolation. Carers reported a reduction in stress and burden of care. Volunteers cited an increased knowledge of dementia. **Conclusions:** This study has shown that peer groups for people with dementia produce a social value greater than the cost of investment which provides encouraging evidence for those looking to commission, invest, set up or evaluate peer support groups for people with dementia and carers. Beyond the SROI ratio, this study has shown these groups create beneficial outcomes not only for the group members but also more widely for their carers and the group volunteers.

TANNER, D. (2012). CO-RESEARCH WITH OLDER PEOPLE WITH DEMENTIA: EXPERIENCE AND REFLECTIONS. *JOURNAL OF MENTAL HEALTH*, *21*(3), 296-306.

Background: There is growing evidence that people with dementia want to participate in research and benefit from their involvement. However, little attention has been given to date to the potential to involve people with dementia as co-researchers, not just participants. **Aims:** The paper discusses the implications for people with dementia of

involvement in research as co-researchers. **Method:** Older people with dementia participated in planning the research methods, conducting interviews and making sense of the findings. **Results:** The project found that it is possible to involve older people with dementia in a meaningful way in research processes and that both co-researchers and participants can benefit significantly from their participation. **Conclusions:** The project has wider implications for the development of participatory research with people with dementia and for interventions based on peer support.

Mather, L. (2006). Memory Lane Café: follow-up support for people with early stage dementia and their families and carers. *Dementia*, *5*(2), 290-293.

VAISHNAV, N. H., & CHIONG, W. (2018, OCTOBER). INFORMED CONSENT FOR THE HUMAN RESEARCH SUBJECT WITH A NEUROLOGIC DISORDER. IN *SEMINARS IN NEUROLOGY* (VOL. 38, NO. 05, PP. 539-547). THIEME MEDICAL PUBLISHERS.

The doctrine of informed consent sits at the intersection of law, ethics, and neuroscience, posing unique challenges for human subject research involving neurological patients. These challenges are compounded by the variegated nature of both neurological injury and the law governing research consent. This article provides a framework for investigators likely to encounter subjects with some degree of neurological impairment, whose capacity to consent requires scrupulous assessment prior to enrollment in research trials. We consider several researches and disease contexts-from emergency epilepsy research to long-term dementia research-and clarify the ethical and legal principles governing consent for participation in each. We additionally explore empirical research on consent capacity and survey several areas of emerging ethical import that will require the attention of investigators in decades to come.

GRISSO, T., APPELBAUM, P. S., & HILL-FOTOUHI, C. (1997). THE MACCAT-T: A CLINICAL TOOL TO ASSESS PATIENTS' CAPACITIES TO MAKE TREATMENT DECISIONS. *PSYCHIATR SERV*, *48*(11), 1415-1419.

APPELBAUM, P. S., & GRISSO, T. (2001). MACARTHUR COMPETENCE ASSESSMENT TOOL FOR CLINICAL RESEARCH (MACCAT-CR). PROFESSIONAL RESOURCE PRESS/PROFESSIONAL RESOURCE EXCHANGE.

The MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) is a structured interview schedule for assessing decision-making abilities relevant for judgments about subjects' competence to consent to participation in research. It is derived from a companion instrument, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T; T. Grisso and PS Appelbaum, 1998b).

MARSON, D. C., CODY, H. A., INGRAM, K. K., & HARRELL, L. E. (1995). NEUROPSYCHOLOGIC PREDICTORS OF COMPETENCY IN ALZHEIMER'S DISEASE USING A RATIONAL REASONS LEGAL STANDARD. *ARCHIVES OF NEUROLOGY*, *52*(10), 955-959.

Objective: To identify neuropsychologic predictors of competency performance and status in Alzheimer's disease (AD) using a specific legal standard (LS). This study is a follow-up to the competency assessment research reported in this issue of the Archives. **Design:** Univariate and multivariate analyses of independent neuropsychologic test measures with a dependent measure of competency to consent to treatment. **Setting:** University medical center. **Subjects:** Fifteen normal older control subjects and 29 patients with probable AD. **Main Outcome Measures:** Subjects were administered a battery of neuropsychologic measures theoretically linked to competency function, as well as two clinical vignettes testing their capacity to consent to medical treatment under five different LSs. The present study focused on one specific LS: the capacity to provide "rational reasons" for a treatment choice (LS4). Neuropsychologic test scores were correlated with scores on LS4 for the normal control group and the AD group. The resulting univariate predictors were then analyzed using stepwise regression and discriminant function to identify the key multivariate predictors of competency performance and status under LS4. **Results:** Measures of word fluency predicted the LS4 scores of controls (R^2=.33) and the AD group (R_2=.36). A word fluency measure also emerged as the best single predictor of competency status for the full subject sample (n=44), correctly classifying 82% of cases. Dementia severity (Mini-Mental State Examination score) did not emerge as a multivariate predictor of competency performance or status. Interestingly, measures of verbal reasoning and memory were not strongly associated with LS4. **Conclusions:** Word fluency measures predicted the normative performance and intact competency status of older control subjects and the declining performance and compromised competency status of patients with AD on a "rational reasons" standard of competency to consent to treatment. Cognitive capacities related to frontal lobe function appear to underlie the capacity to formulate rational reasons for a treatment choice. Neuropsychologic studies of competency function have important theoretical and clinical value.

Carabellese, F., Felthous, A. R., La Tegola, D., Piazzolla, G., Distaso, S., Logroscino, G., ... & Catanesi, R. (2018). Qualitative analysis of the capacity to consent to treatment in patients with a chronic neurodegenerative disease: Alzheimer's disease/Analisi qualitativa sulla capacità a prestare consenso al trattamento in pazienti con malattie cronico degenerative neuropsicoorganiche: Demenza di Alzheimer. *International Journal of Social Psychiatry*, *64*(1), 26-36.

Objective: Informed consent is an essential element in doctor–patient relationship. In particular, obtaining valid informed consent from patients with neurocognitive diseases is a critical issue at present. For this reason, we decided to conduct research on elderly patients with Alzheimer's disease (*Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5) to assess their capacity to make treatment decisions. **Methods:** The experimental group comprised 70 Alzheimer patients who were admitted to the Neurodegenerative Disease Unit of the University of Bari. The control group consisted of 83 elderly patients without neurocognitive disorders who were hospitalized in the Geriatric Unit at the same university. After providing written consent to participate in the research, each subject underwent the following assessments: (a) assessment of comprehension sheet, (b) Neuropsychiatric Inventory (NPI) and Global Functioning Evaluation (GFE), (c) neurological evaluation, (d) neuropsychological assessment with a full battery of tests, (d) The MacArthur Treatment Competence Study (MacArthur Competence Assessment Tool for Treatment (MacCAT-T); understanding, appreciating, reasoning and expressing a choice) and (e) a semi-structured interview administered by the patient's caregiver. **Results/conclusion:** The present survey was designed to analyze possible qualitative and quantitative correlations between cognitive functioning and capacity to consent in relation to different degrees of severity of the neurodegenerative disorder. A large portion of the patients in our experimental sample did not appear to have the capacity to provide a valid consent. The authors present initial results of this study and discuss their possible implications.

MILNE, R., BUNNIK, E., TROMP, K., BEMELMANS, S., BADGER, S., GOVE, D., ... & RICHARD, E. (2017). ETHICAL ISSUES IN THE DEVELOPMENT OF READINESS COHORTS IN ALZHEIMER'S DISEASE RESEARCH. J PREV ALZHEIMERS DIS. 2017;4(2):125-131. DOI: 10.14283/JPAD.2017.5

There is growing interest in the development of novel approaches to secondary prevention trials in Alzheimer's disease to facilitate screening and recruitment of research participants and to reduce the time and costs associated with clinical trials. Several international research collaborations are setting up research infrastructures that link existing research cohorts, studies or patient registries to establish 'trial-ready' or 'readiness' cohorts. From these cohorts, individuals are recruited into clinical trial platforms. In setting up such research infrastructures, researchers must make ethically challenging design decisions in at least three areas: re-contacting participants in existing research studies, obtaining informed consent for participation in a readiness cohort, and disclosure of Alzheimer's disease-related biomarkers. These ethical considerations have been examined by a dedicated workgroup within the European Prevention of Alzheimer's Dementia (EPAD) project, a trans-European longitudinal cohort and adaptive proof-of-concept clinical trial platform. This paper offers recommendations for the ethical management of re-contact, informed consent and risk disclosure which may be of value to other research collaborations in the process of developing readiness cohorts for prevention trials in Alzheimer's disease and other disease areas.

PALMER, B. W., HARMELL, A. L., DUNN, L. B., KIM, S. Y., PINTO, L. L., GOLSHAN, S., & JESTE, D. V. (2018). MULTIMEDIA AIDED CONSENT FOR ALZHEIMER'S DISEASE RESEARCH. *CLINICAL GERONTOLOGIST*, *41*(1), 20-32.

Objectives: Optimizing the research consent process simultaneously fosters respect for autonomy and protection of those with diminished capacity for autonomy. This study evaluated the effectiveness of an enhanced research consent procedure, employing multimedia disclosure and corrective feedback, in improving decisional capacity among 114 people with mild-to-moderate Alzheimer's disease (AD) and 134 non-psychiatric comparison (NC) subjects. **Methods**: Participants were randomized to consent type (routine versus enhanced) and protocol type (lower versus higher risk). Outcomes included a 5-item questionnaire assessing immediate comprehension, MacArthur Competence Assessment Tool for Clinical Research assessing four components of decision-making capacity, and categorical decisional capacity (based on a cut-score established in reference to expert judgments for a subset of participants). **Results**: There was no significant effect of the enhanced consent procedure, relative to routine consent, on immediate comprehension or decisional capacity. **Conclusions**: Multimedia tools do not appear to be the solution to better consent for AD research. **Clinical Implications**: Given the ethical primacy of informed consent and issues of justice for impaired populations who might be harmed by an absence of research-based treatment advances, continued search for ways to more meaningfully engage people with AD in the consent or assent process is warranted.

STORMOEN, S., TALLBERG, I. M., ALMKVIST, O., ERIKSDOTTER, M., & SUNDSTRÖM, E. (2017). DECISIONS AND ATTITUDES REGARDING PARTICIPATION AND PROXY IN CLINICAL TRIALS AMONG PATIENTS WITH IMPAIRED COGNITIVE FUNCTION. *DEMENTIA*, 1471301217737413.

Background. Medical decision-making capacity is impaired in Alzheimer's disease and mild cognitive impairment. Medical decision-making capacity depends on many different cognitive functions and varies due to situation and cognitive, social, and emotional status of the patient. Our aim was to analyze dementia patients' capacity to estimate risks and benefits in different clinical trials and determine how cognitive decline affects their attitude toward possible participation and proxy consent. **Methods:** Groups: Alzheimer's disease (n = 20), mild cognitive impairment (n = 21) and healthy controls (n = 33). Two hypothetical clinical trials, a standardized interview and three visual analogue scales were used to investigate decisions, estimations, reasoning, and attitudes. **Results:** A general positive attitude toward participation in clinical trials was shown among all groups. Both patients and controls motivated possible participation as "own-benefit" in the low-risk trial and to "help-others" in the high-risk trial. Individuals who accepted to participate in the high-risk trial scored lower in medical decision-making capacity in comparison to participants who would not have participated ($p < .01$). Patients in the Alzheimer's disease but not mild cognitive impairment and healthy control groups underestimated risks and overestimated benefits in the high-risk/low-benefit trial ($p < .05$). A family member was most frequently chosen as possible proxy (91%). **Conclusions:** Medical decisions and research consent should be interpreted with caution in patients who are already in early stages of dementia, as the patients' acceptance to participate in high-risk trials may be due an insufficient decisional capacity and risk analysis, accelerated by a general desire to make good to society. We emphasize the use of a standardized tool to evaluate medical decisional capacity in clinical research.

ROBILLARD, J. M., & FENG, T. L. (2017). WHEN PATIENT ENGAGEMENT AND RESEARCH ETHICS COLLIDE: LESSONS FROM A DEMENTIA FORUM. *JOURNAL OF ALZHEIMER'S DISEASE*, *59*(1), 1-10.

The importance of patient engagement in research has been gaining recognition since the turn of the 21st century. However, little is known about the perspectives of people with dementia on the process of discovery. To fill this gap and to inform priorities in patient engagement in the context of dementia research, the Clinic for Alzheimer Disease and Related Disorders at the University of British Columbia hosted an interactive session for members of the patient community and of the general public to share their views on various ethical aspects of the research process. Results from the session indicate that several current research ethics policies and norms in dementia research are not in line with participants' preferences. Here we discuss the importance of bridging the gap between researchers and patients and call for reforms in current standards of dementia research.

PALMER, B. W., HARMELL, A. L., PINTO, L. L., DUNN, L. B., KIM, S. Y., GOLSHAN, S., & JESTE, D. V. (2017). DETERMINANTS OF CAPACITY TO CONSENT TO RESEARCH ON ALZHEIMER'S DISEASE. *CLINICAL GERONTOLOGIST*, *40*(1), 24-34.

Objective: Investigators conducting Alzheimer's disease (AD) research need to consider participants' capacity to consent. Cognitive functioning is a significant predictor of decisional capacity, but there is a dearth of information on the influence of neuropsychiatric symptoms in AD on decisional capacity. We examined the rates of decisional capacity associated with two types of research protocols, and the association of capacity with neuropsychiatric symptoms and other participant characteristics.

Methods: We comprehensively evaluated decisional capacity among 64 patients with mild-to-moderate AD and 70 healthy comparison (HC) subjects randomized to consider either a medium-risk or higher-risk hypothetical research protocol. Additional measures included sociodemographics, cognitive deficits, and neuropsychiatric symptoms. **Results**: Twenty AD patients (31.3%) and 67 HCs (95.7%) were deemed capable; 44 AD patients (68.8%) and 3 HCs (4.3%) incapable of consent. Age, education, and severity of cognitive deficits were associated with incapable status; there were no significant associations with severity of neuropsychiatric symptoms or protocol risk level. **Conclusions**: Findings highlight the importance of understanding of capacity and its assessment among people with AD, rather than treating AD diagnosis as synonymous with impaired capacity. As novel treatments move from bench to bedside, methods of assessing and addressing capacity impairment must similarly advance. **Clinical Implications**: In assessing research consent capacity, use structured assessments interpreted in the context of the person's background including education, culture, and language. Individuals should be encouraged to execute research proxy documents when able.

PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH (PPI)

GOVE, D., DIAZ-PONCE, A., GEORGES, J., MONIZ-COOK, E., MOUNTAIN, G., CHATTAT, R., ... & EUROPEAN WORKING GROUP OF PEOPLE WITH DEMENTIA. (2018). ALZHEIMER EUROPE'S POSITION ON INVOLVING PEOPLE WITH DEMENTIA IN RESEARCH THROUGH PPI (PATIENT AND PUBLIC INVOLVEMENT). *AGING & MENTAL HEALTH*, *22*(6), 723-729.

This paper reflects Alzheimer Europe's position on PPI (patient and public involvement) in the context of dementia research and highlights some of the challenges and potential risks and benefits associated with such meaningful involvement. The paper was drafted by Alzheimer Europe in collaboration with members of INTERDEM and the European Working Group of People with Dementia. It has been formally adopted by the Board of Alzheimer Europe and endorsed by the Board of INTERDEM and by the JPND working group 'Dementia Outcome Measures - Charting New Territory'.

Alzheimer Europe is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of PPI, by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective. Topics covered include, amongst others, planning involvement, establishing roles and responsibilities, training and support, managing information and input from PPI, recognising the contribution of people with dementia involved in research in this way, promoting and protecting the rights and well-being of people with dementia, training and support, and promoting an inclusive approach and the necessary infrastructure for PPI in dementia research.

KELLY, S., LAFORTUNE, L., HART, N., COWAN, K., FENTON, M., & BRAYNE, C. (2015). DEMENTIA PRIORITY SETTING PARTNERSHIP WITH THE JAMES LIND ALLIANCE: USING PATIENT AND PUBLIC INVOLVEMENT AND THE EVIDENCE BASE TO INFORM THE RESEARCH AGENDA. *AGE AND AGEING*, *44*(6), 985-993.

Background: the James Lind Alliance (JLA) created an approach to elicit the views of those under-represented in research priority exercises. Building on this, the JLA Dementia Priority Setting Partnership was set up as an independent and evidence-based project to identify and prioritise unanswered questions ('uncertainties') about prevention, diagnosis, treatment and care relating to dementia. **Methods:** a survey was widely disseminated to stakeholders with an interest in the needs of the older population. Thematic analysis was used to identify themes from the large amount of questions collected from which research questions were developed using PICO framework (Population, Intervention, Comparator, Outcome). Each question was checked against an extensive evidence base of high-quality systematic reviews to verify whether they were true uncertainties. **Findings:** one thousand five hundred and sixty-three questionnaires were received, from people with dementia, carers/relatives, and health and care professionals; 85 uncertainties were identified from other sources. Questions were refined and formatted iteratively into 146 unique uncertainties. An interim prioritisation process involving diverse organisations identified the top 25 ranked questions. At a final face-to-face prioritisation workshop, 18 people representing the above constituencies arrived by consensus at the top 10 priority questions. The impact of patient and public involvement on the priorities is discussed. **Interpretation:** the long (146 questions) and top 10 lists of dementia research priorities provide a focus for researchers, funders and commissioners. They highlight a need for more research into care for people with dementia and carers, and a need for high-quality effectiveness trials in all aspects of dementia research.

ILIFFE, S., MCGRATH, T., & MITCHELL, D. (2013). THE IMPACT OF PATIENT AND PUBLIC INVOLVEMENT IN THE WORK OF THE DEMENTIAS & NEURODEGENERATIVE DISEASES RESEARCH NETWORK (DENDRON): CASE STUDIES. *HEALTH EXPECTATIONS*, *16*(4), 351-361.

Aims (i) To describe patient and public involvement (PPI) in a network promoting research in dementia and neurodegenerative diseases, in terms of activity at the different stages of the research cycle and within the different levels of the research network. (ii) To use case studies to try and answer the question: what benefits (if any) does PPI in research bring to the research process? **Background** PPI in health research is a central part of government policy, but the evidence base underpinning it needs strengthening. PPI allows exploration of feasibility, acceptability and relevance of hypotheses, assists in the precise definition of research questions and increases accrual to studies. However, the measurement of outcomes is methodologically difficult, because the impact of lay researchers may occur through team interactions and be difficult to untangle from the efforts of professional researchers. Opportunities for PPI in rapidly progressive diseases may be limited, and involvement of people with marked cognitive impairment is particularly challenging. **Design** (i) Description of PPI within the DeNDRoN network. (ii) Case studies of three research projects which asked for extra help from centrally organized PPI. **Results** PPI in research projects on the DeNDRoN portfolio may function at different levels, occurring at project, local research network and national level. Case studies of three research projects show different roles for PPI in research and different functions for centrally organized PPI, including contribution to remedial action in studies that are not recruiting to target, solving problems because of the complexity and sensitivity of the research topic, and linking researchers to PPI resources. **Discussion** The case studies suggest that centrally organized PPI can have 'diagnostic' and remedial functions in studies that are struggling to recruit and serve as reinforcement for study-level PPI in the complex and sensitive research topics that are typical in neurodegenerative diseases research. PPI may be actively sought by researchers, but the infrastructure of PPI is not yet so widespread in the research community that lay researchers are easy to find; a centrally organized PPI resource can assist in this situation.

BRETT, J., STANISZEWSKA, S., MOCKFORD, C., HERRON-MARX, S., HUGHES, J., TYSALL, C., & SULEMAN, R. (2014). MAPPING THE IMPACT OF PATIENT AND PUBLIC INVOLVEMENT ON HEALTH AND SOCIAL CARE RESEARCH: A SYSTEMATIC REVIEW. *HEALTH EXPECTATIONS*, *17*(5), 637-650.

Background: There is an increasing international interest in patient and public involvement (PPI) in research, yet relatively little robust evidence exists about its impact on health and social care research. **Objective:** To identify the impact of patient and public involvement on health and social care research. **Design:** A systematic search of electronic databases and health libraries was undertaken from 1995 to 2009. Data were extracted and quality assessed utilizing the guidelines of the NHS Centre for Reviews and Dissemination 2009 and the Critical Appraisal Skills Programme (CASP). Grey literature was assessed using the Dixon-Woods *et al*. (2005) checklist. **Inclusion criteria:** All study types that reported the impact PPI had on the health and/or social care research study. **Main results:** A total of 66 studies reporting the impact of PPI on health and social care research were included. The positive impacts identified enhanced the quality and appropriateness of research. Impacts were reported for all stages of research, including the development of user-focused research objectives, development of user-relevant research questions, development of user-friendly information, questionnaires and interview schedules, more appropriate recruitment strategies for studies, consumer-focused interpretation of data and enhanced implementation and dissemination of study results. Some challenging impacts were also identified. **Conclusion:** This study provides the first international evidence of PPI impact that has emerged at all key stages of the research process. However, much of the evidence base concerning impact remains weak and needs significant enhancement in the next decade.

DARLING, E., & PARRA, M. A. (2013). INVOLVING PATIENTS AND THE PUBLIC IN RESEARCH. *NURSE RESEARCHER*, *20*(6).

Aim To present the actions taken by the Scottish Dementia Clinical Research Network (SDCRN) to comply with Scotland's National Dementia Strategy (SNDS) on patient and public involvement (PPI). Background Tackling priorities in dementia research is paramount to success in planning and delivering effective health services. Identifying such priorities is a task that should involve patients with dementia and their carers. Aware of the potential importance that the public has in shaping the future of dementia research, the Scottish Government has launched an initiative that places PPI at its core. The SDCRN, funded by the Chief Scientist Office, has responded to this initiative and has developed a strategic PPI agenda. Data sources Experience of developing and implementing an extensive range of PPI activities with patients with dementia and their carers in Scotland. Review methods This is an informative paper. Discussion The paper discusses the strategy that the SDCRN has adopted to comply with government PPI priorities, thus supporting the strategic agenda for Scottish topic-specific research networks. Conclusion The challenges that researchers face when engaging with patients with dementia and their carers can be overcome by promoting a culture that supports dementia research. Through the development of the PPI strategy, the SDCRN has encouraged and enabled the public to become active partners in research. Implications for practice/research Involving the public in dementia research is a priority. This paper highlights how this can be achieved through extensive partnership working, collaboration and the implementation of various PPI activities to allow the public to play a major influential role in the development of future dementia services.

ROBILLARD, J. M., & FENG, T. L. (2017). WHEN PATIENT ENGAGEMENT AND RESEARCH ETHICS COLLIDE: LESSONS FROM A DEMENTIA FORUM. *JOURNAL OF ALZHEIMER'S DISEASE*, *59*(1), 1-10.

The importance of patient engagement in research has been gaining recognition since the turn of the 21st century. However, little is known about the perspectives of people with dementia on the process of discovery. To fill this gap and to inform priorities in patient engagement in the context of dementia research, the Clinic for Alzheimer Disease and Related Disorders at the University of British Columbia hosted an interactive session for members of the patient community and of the general public to share their views on various ethical aspects of the research process. Results from the session indicate that several current research ethics policies and norms in dementia research are not in line with participants' preferences. Here we discuss the importance of bridging the gap between researchers and patients and call for reforms in current standards of dementia research.

STANISZEWSKA, S., HAYWOOD, K. L., BRETT, J., & TUTTON, L. (2012). PATIENT AND PUBLIC INVOLVEMENT IN PATIENT-REPORTED OUTCOME MEASURES. *THE PATIENT-PATIENT-CENTERED OUTCOMES RESEARCH*, *5*(2), 79-87.

This paper considers the potential for collaborative patient and public involvement in the development, application, evaluation, and interpretation of patient-reported outcome measures (PROMs). The development of PROMs has followed a well-trodden methodological path, with patients contributing as research subjects to the content of many PROMs. This paper argues that the development of PROMs should embrace more collaborative forms of patient and public involvement with patients as research partners in the research process, not just as those individuals who are consulted or as subjects, from whom data are sourced, to ensure the acceptability, relevance, and quality of research. We consider the potential for patients to be involved in a much wider range of methodological activities in PROM development working in partnership with researchers, which we hope will promote paradigmal evolution rather than revolution.