Community Engagement Evidence Synthesis

A final report for Alzheimer's Society

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Executive summary

Introduction

In November 2015 we were commissioned to undertake a review of the evidence of community engagement for dementia and outcomes that can inform current work and future service development. Identifying which programme elements are key to achieving change, irrespective of setting, and which are context specific. This complements the theory of change work by NPC.

Community engagement can mean different things to different groups/organisations, Box 1 gives some examples of the variety of definitions. Alzheimer's Society does not have a specific definition, but groups certain activities (Dementia Friends, Dementia Friendly Communities, Dementia Action Alliance and Public Awareness) under the umbrella term.

For Alzheimer's Society: "Community Engagement includes; Dementia Friends, Dementia Friendly Communities and Dementia Action Alliance and Public Awareness."

For Local Government: "Approaches to involve communities in decisions that affect them"

For Public Health: "'Community engagement' is therefore 'an umbrella term encompassing a continuum of approaches to engaging communities of place and/or interest in activities aimed at improving population health and/or reducing health inequalities'"

For marketing & communications teams: ""What is state of our relationship with the community? Do people like us or do they hate us? If they like us, can we make them like us more? If they hate us, what do we need to do to turn that around?"

Box 1: Differing definitions of community engagement

It is important to understand what sort of community engagement activities are most likely to achieve positive change for people affected by dementia. As there is not a current body of research in this area we used a realist synthesis methodology to interrogate a wider grey literature and papers from other fields of study, not specifically dementia, to draw together current knowledge, learning and recommendations.

We conducted the review in two phases, the phase 1 report (Appendix 1) was delivered in February 2016 and is summarised briefly. Phase 2 findings form the main body of this report.

Phase one: How the candidate theories were identified and linked to NPC 'Theories of Change'

Phase 1 provided an overview of how community engagement with and awareness of dementia in the UK is perceived to work and how this is expressed in different community engagement activities. This overview complemented the stakeholder interviews completed by NPC and reviewed 94 UK and international documents (7 case studies, 8 policy papers, 19 briefings, 28 evaluation reports and 32 research papers). Community engagement clusters into a range of activities:

- Awareness raising to normalise the experience of living with dementia
- Co-ordination and integration of public and private services to be dementia aware and responsive to the needs of people with dementia
- Promotion of inclusion in culture and leisure activities to reduce social isolation
- Environmental adaptations
- Digital technology to support orientation and involvement of people living with dementia

Most of the literature reviewed was descriptive with overlapping definitions of what community engagement involves. Evidence for the impact of community engagement initiatives for people living with dementia was limited, but there was some evidence of processes that were more or less likely to promote engagement with communities and people living with dementia. Of the 28 evaluations reviewed, 11 had evidence of active input from people living with dementia.

At the end of phase 1 we derived three potential drivers or motivations for community engagement (Box 2). They all had as a common starting point the need for an awareness and understanding of dementia. These motivations were developed from the studies we had reviewed along with data from the NPC interviews about what worked well and why.

1. **COMPASSION** 'we must do something' driven by a recognition that living with dementia needed support to maintain involvement with their local communities
2. **UTILITARIAN** 'we must do something' driven by practical cost-benefit or utilitarian analysis of the need to ensure businesses and services are equipped to respond to the increasing numbers of people living with dementia
3. **RIGHTS-BASED** 'we should not be excluded' driven by a social justice/disability rights/citizenship based perspective that asserts the person with dementia's right to determine what they need to be an active member of their community.

Box 2 Three potential drivers or motivations for community engagement

These can be articulated as a set of if…then…statements:

IF there is a cumulative and growing common understanding that the increasing numbers of people living with dementia means there is a need for better understanding [of dementia] and for initiatives that support people to live well with dementia without fear of stigma or exclusion…

…THEN people in different **'experience'** communities will come together around initiatives that meet the need to support people to live well with dementia thus enabling people to have more social contact and be independent.

…THEN organisations will ensure that services and **systems** are supportive and accessible for people living with dementia so they can access support, health and social care and daily activities that are essential for living well (shops, banking, leisure) because this will keep people better for longer so they have less need for emergency services, high cost health and social care services/ and are active consumers for longer (shops/banks/leisure/employment).

…**THEN** through the process of making political the personal experiences of discrimination and social inequality organisations will see it as their (statutory) duty to provide services that are accessible to PLWD and thus enable people to have more social contact and be independent.

We represented these ideas schematically (Figure 1). Awareness raising becomes an essential foundation for community engagement that leads to understanding, empathy and reduced fear, enabling people and organisations to be active in reducing social isolation, promoting independence and improved quality of life for people affected by dementia. Phase 2 revisited the evidence and expanded the literature search to consider *how* the process of awareness raising triggers community engagement for dementia friendly initiatives and whether certain responses or mechanisms are more or less likely to trigger the desired outcomes. This review tests the ideas and assumptions of how these activities work in the empirical evidence, looking specifically at the extent to which responses to these activities or 'mechanisms' support outcomes that align with a rights based approach. This process uses the evidence to unpack the "black box" of how, when and why community engagement activities work for different groups of people.

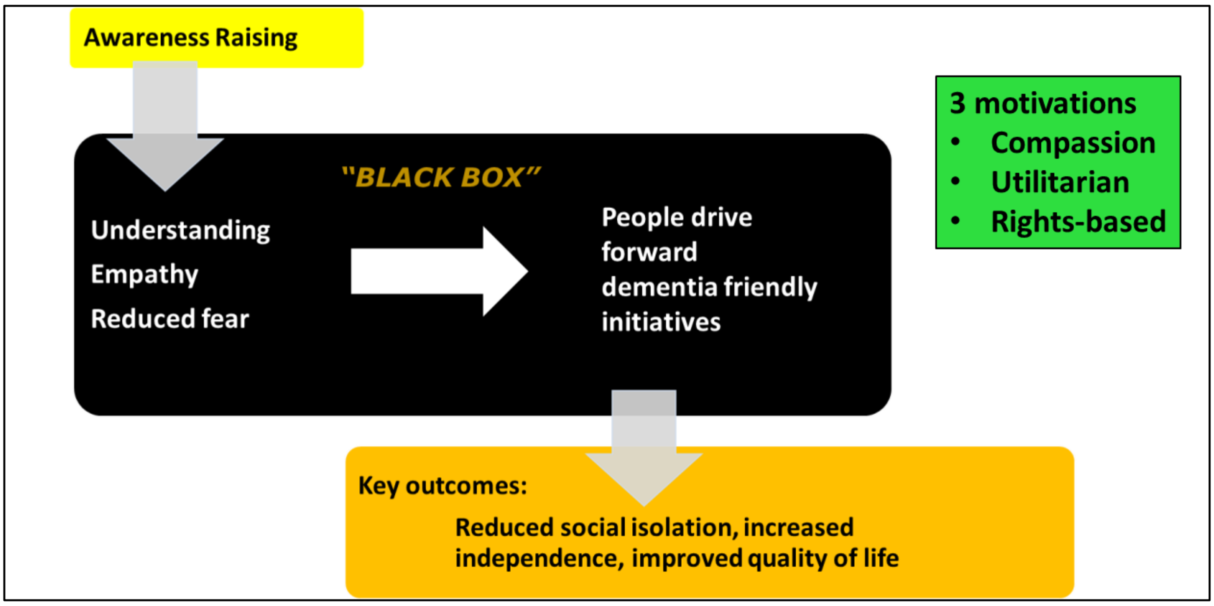

Figure 1: Schematic of the overarching theory to be tested in Phase 2

The review also links with the NPC theory of change schematics that have drawn out in detail specific activities that are proposed to work, based on interviews and focus groups.

Phase two

Approach

To gain a conceptual understanding of how community engagement works, a realist approach[1] to reviewing the literature was taken. We adopted a purposive search and inclusion strategy that could capture the underlying ideas and assumptions of community engagement. We looked beyond research that focused solely on dementia to include community engagement work with groups whose experience offered transferable learning about what works (or not). The process was iterative, as evidence was examined it raised new questions and new lines of enquiry.

Four source reviews (1–4), literature from phase one and theory driven accounts of how groups work (5,6) together generated 481 potentially relevant documents. Of these 121 were considered for inclusion. Figure 2 provides an overview of the different literature sources used in phase two. Unlike phase one we broadened our search to include research on community engagement that included learning disability, health inequalities and marginalised groups. They included twenty three empirical studies and eleven reviews of the literature which summarise knowledge in a specific area. Appendix 2 summarises these 34 sources in Table 1 and Table 2.

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[1] Realist review and synthesis asks the questions what works, for whom, under what circumstances, and why? Hypotheses, called Context-Mechanism-Outcome configurations (CMOcs) are proposed and evidenced from a variety of study designs in the literature. The focus on mechanisms and necessary conditions for success allows for rigour, even when raw contributing evidence is of variable quality. The process is guided by input from relevant stakeholders. The underlying premise is that the observed "demi-regular patterns" of interactions between the components that make up complex interventions in the evidence reviewed can be explained through theoretical propositions (programme theories). The iterative process of the review tests those theories that are thought to work against the observations reported in the evidence included in the syntheses. This enables us to take account of a broad evidence base as well as the experiential knowledge

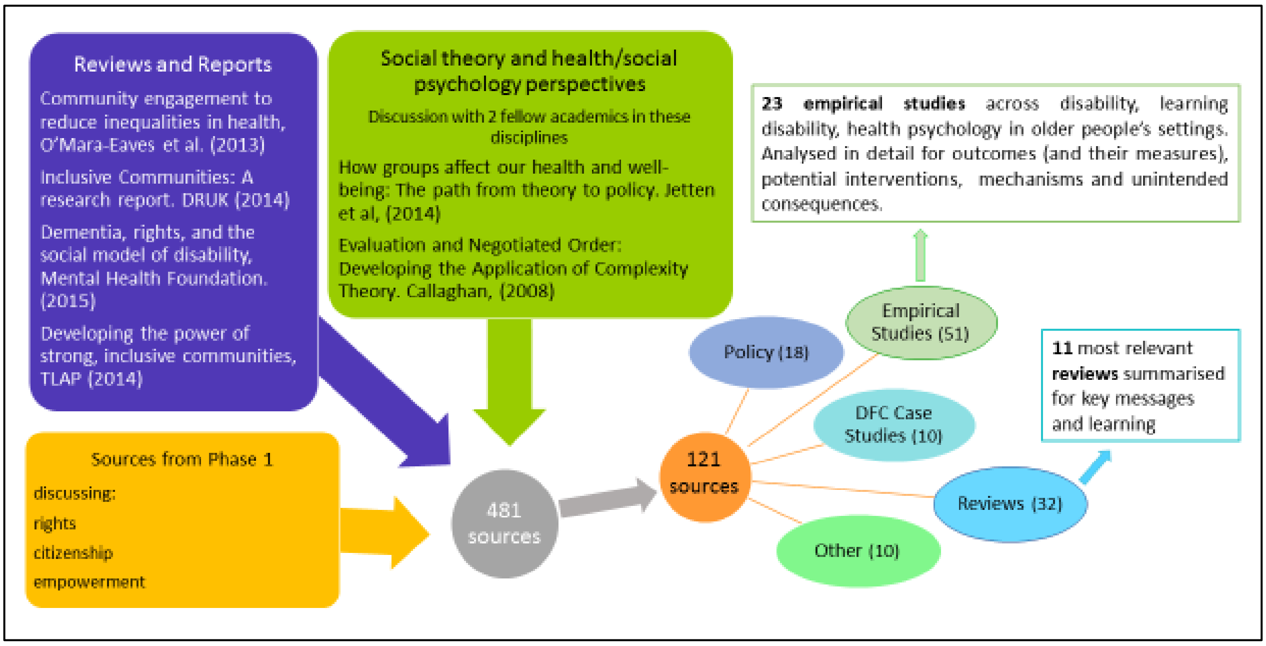

Figure 2: Community engagement evaluation: evidence synthesis

The focus for phase two emphasised a rights based approach to community engagement across different fields of study. We included case studies of community engagement initiatives, policy documents expressing the stance of various organisations towards engaging with people living with dementia or disabilities, briefing documents produced to inform and educate stakeholders and evaluation reports from individual interventions. We also tracked the online discussions and blogs and conference reports of those who are arguing for inclusion of and engagement with people living with dementia through pursuing a disability rights agenda (7–11).

Conceptualisations of community engagement

The scope and reach of community engagement terms found in the wider literature is illustrated by Figure 3. This is taken from the review by O'Mara-Eaves et al (1) on community engagement for reducing health inequalities. They identify three models of community engagement that map broadly to the findings of phase one in how community engagement is enacted with and for people with dementia.

1. Classical or traditional interventions in which needs are identified and addressed by people outside the target group or community.
2. Varying degrees of collaboration, but need is still identified by those outside the community which then engages community members to in order to tailor the intervention.
3. Empowerment in which the community itself has identified the need and takes the lead in effecting the change. The latter is closest to the rights based approach that emphasises participation and inclusion.

The O'Mara review (1) argues that successful community [engagement] projects begin by identifying, through and with community members, the resources, assets and strengths of a community and building on those rather than identifying needs and seeking to rectify them.

The empowerment model resonates with the Think Local Act Personal consultation work (4) which found that "*'Dementia capable communities' nurture the assets that make a place safe, welcoming and enabling to people with dementia"*, (2, p9). The Inclusive Communities report from Disability Rights UK (3)expands on this emphasising the difference between **presence and participation** as a key indicator of inclusivity and defining participation in terms of power and decision making.

"…an inclusive community is one where all people can participate socially, economically and politically, and disabled people need appropriate levels of support to ensure that participation is possible; 'presence'

is not sufficient to ensure the participation of disabled people, full inclusion involves disabled people having decision-making power and participation with some degree of authority and certainty that our voices will be heard…", (3, p63)

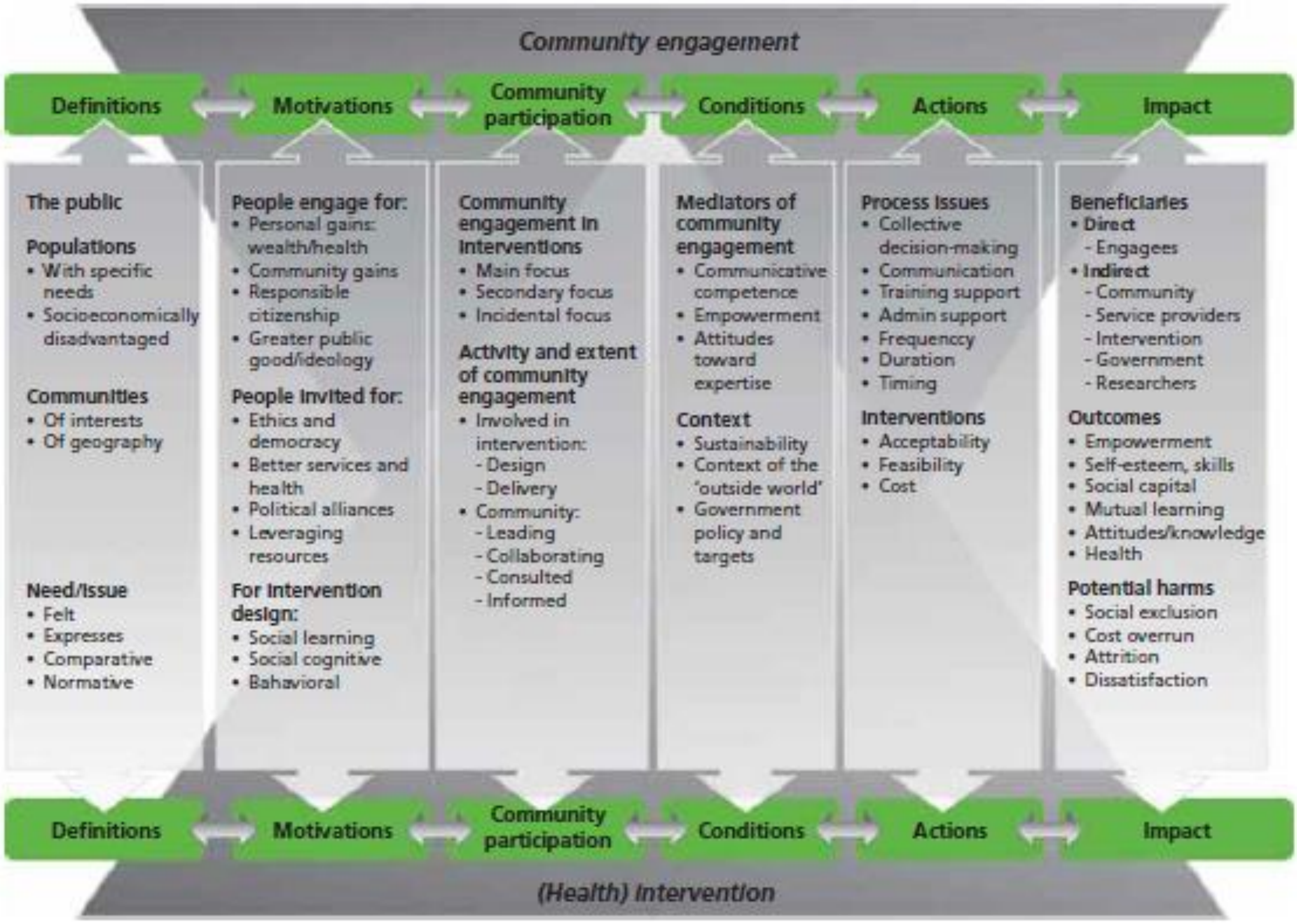

Figure 3: From O'Mara-Eaves (2013) conceptual framework for representing community engagement in interventions

Learning from the Dementia Community Engagement literature relevant to phase two

Phase one findings had identified within the community engagement literature the idea of the "space of possibilities" where "top-down-bottom-up" approaches meet to create change and achieve participation and inclusion. This section considers four points of learning that capture both the synergy between community engagement and ideas of empowerment and informed phase two thinking about how this is achieved within a rights based approach. These are:

- Strategies that secure appropriate and predictable resources for community engagement work over time
- The sharing rather than the delegating of responsibility between organisations for making Community Engagement work
- Moving beyond the immediate world of those living with dementia and their peers to engage with those unaffected and largely disengaged.
- Addressing how 'normal' and 'participation' are defined in a society that values a person's potential to be economically active and fit with ideas of what are desirable and acceptable behaviours/skills/attributes.

Grassroots community activity is seen as the "bedrock" of dementia friendly communities, and launching projects "cold" into a community is often problematic (12). However to ensure sustainability, to increase effectiveness and ensure that the right resources are available, strong strategic planning, commissioning and leadership is important (13). Engaging business leaders, local media and key community figures is recommended in order to secure more influence and power to a network. For example, councillors training as Dementia Friends will increase awareness considerably (13). Literature also recommends leveraging existing networks such as local DAAs (14), and sharing learning with other organisations and groups working in similar fields (15).

While ‘social prescribing’ and community engagement are seen as beneficial to the health and wellbeing of a person living with dementia, Menec et al (16) recognise that the creation of age-friendly (or dementia friendly) communities and the involvement of multiple players and organisations should not be seen by authorities as a “cost-cutting” measure, through which responsibility is passed onto volunteers and grassroots groups. This would risk creating distance and disengagement and ultimately become counterproductive.

Intergenerational work is identified as important to creating dementia friendly communities and promoting community engagement with people living with dementia. Williamson (17) suggests that the difference between the dementia rights movement and others, such as the disability rights movement, is that the other movements had more momentum as they involved younger generations who have more energy, and were less conservative, describing members of the DEEP network as not fitting “the stereotypical mould of ‘radical’ younger people involved in other disability groups/’causes’” (17). The challenge is how people with dementia are then represented to young people. Activities such as the “Million Hands” initiatives (The Scout Association) focus on rejecting stigmatisation and breaking down barriers to social inclusion.

Linked to this mobilisation of those not directly affected by dementia (e.g. “Million Hands”), Thomas & Milligan (18) argue that there are two perspectives of the relationship between people living with dementia and so-called ‘normal’ members of society: materialistic perspectives (capitalist economies only value the fully ‘able’) and poststructuralist perspectives (bodies and behaviours of people with dementia carry negative cultural meanings in our society, which values youth, beauty and celebrity, and rejects anything ‘abnormal’). To dismantle barriers for people living with dementia, therefore, changes are needed in the economic realm and in the ideas and knowledge realm. These ideas are closely aligned to how a rights based approach focuses on how rules and expectation for society and its members are articulated and discussed.

Evidence of outcomes of community engagement (summary tables in Appendix 3)

Rather than seeking out ‘evidence’ for specific theory of change outcomes we have surveyed the literature that addresses rights based approaches/activism to see how this aligns with the proposed theory of change.

The twenty three empirical studies reviewed included quantitative and qualitative data covering a broad range of outcomes related to community engagement. We have categorised these community engagement outcomes and mapped to the theory of change outcomes provided by NPC. These are,

- Awareness (Appendix 3: Table 3, Table 4)
- Attitudes (Appendix 3: Table 5, Table 6)
- Accessibility (Appendix 3: Table 7, Table 8)
- Social isolation/loneliness (Appendix 3: Table 10, Table 11)
- Involvement/Participation (Appendix 3: Table 13, Table 14)
- Quality of Life (Appendix 3: Table 16, Table 17)
- Other (Appendix 3: Table 19, Table 20, Table 21)

It would be misleading to suggest that these are discrete outcomes, for example loneliness is the opposite of social participation and quality of life is reliant on being valued. Nevertheless, listing the community engagement related outcomes this ways shows a) how the evidence informs how these outcomes are understood and measured and b) those that are more or less aligned with a rights based agenda.

There is a hierarchy of outcomes that begins with increased awareness and changes in attitudes and beliefs about what people living with dementia could and should be able to do and be as members of their communities

Awareness

Although the overall aim is to raise awareness of dementia, there are multiple themes around what public awareness is and how it might be measured. Our more detailed review of the wider literature reinforced the findings from phase one that public awareness was an important precursor to activism and engagement activities.

- Increasing the number of people in the general population who know that dementia affects a lot of people, for example the Dementia Friends initiative, (19,20). Whilst numbers of people attending sessions can be measured it is acknowledged that, as an outcome measure, this constitutes a limited proxy for impact and change.
- Awareness of minority groups: For example, dementia diarists from BAME communities tell of the shame of a dementia diagnosis in their home countries, (21,22). Peel and McDaid (23) observed that LGBT people living with dementia seek reassurance that service providers will treat them as *people* and not judge them due to the dementia diagnosis or their sexual orientation, (23). The term used is, *signalling safety*, not compassionate safety, but rights-based safety.
- Awareness of the rights of people living with dementia, for example, Dementia Alliance International (8) which lays out the basic human rights of all people under international laws and conventions; Kate Swaffer and De Rynck et al., (10,24) both argue for an alteration **in the language** used to discuss dementia and the Dementia Action Alliance (25) calls for a paradigm shift in the way people in England respond to dementia from interpersonal contact to organisational policy. See also Philly Hare on impact of negative language https://www.youtube.com/watch?v=1Qk3-gonW-U
- Evidence of how people with dementia are shaping the narrative through digital media and collective accounts of the everyday experiences of living with dementia is a possible proxy measure of exposure and uptake. For example: Wendy Mitchell blogs on her day to day experiences of living with dementia https://whichmeamitoday.wordpress.com/

Attitudes

Awareness and strategies that seek to change the language of dementia are linked to attitudes and how this affects behaviour of individuals, services and organisations.

People living with dementia have given clear indications that they expect to be treated with the same consideration as anyone else, whether they are talking to a consultant or taxi driver, (23,26–28). The language used to talk about dementia has also been challenged and guidance given for improvement, (24,29) moving away from suggestions of suffering to acknowledgement of living to the fullest extent. There are a number of models and frameworks for amending organisational attitudes to dementia and people living with dementia, (15,30–33), some suggest measures or goals to help assess the level or rate of success, (30,31). There are also local area plans which show how local circumstances are being incorporated into dementia friendly initiatives, (34,35) and initiatives for specific groups for example carers and people in a particular business, (36,37).

Underpinning all of these initiatives is the idea that society’s negative attitude towards dementia is potentially the greatest limitation for people living with dementia, Milton, Gilliard, Grue and the Mental

Health Foundation all suggest that societies could (and should) be the greatest asset for people living with dementia. (2,38–40).

Accessibility

Difficulty with navigation is a barrier experienced by many people living with dementia and has life limiting consequences. Limitations are experienced in a range of ways, e.g. landmark recognition, spatial awareness, and functional ability. Wendy Mitchell gives a clear account of the difficulties of planning and accomplishing a journey by bus, (41) while Dean et al., (42) evaluate the endeavours of the 'Dementia Friendly York' initiative.

The broader literature that addresses accessibility for people with disabilities, offers some transferable learning; online resources that can provide information about accessibility, (43,44) and the wider benefits to the community of accessible environments, (3). An important resource for outcome measurement is the advice about the adaptation of services, organisations and environments which is drawn from the knowledge and experience of people living with dementia, (12,15,45,46).

Social isolation/loneliness

The issues of loneliness and social isolation are common themes in the lives of people living with dementia, (45,47). Cacioppo, Fowler and Christakis (48) identify the ability to choose and associate freely with friends as central to a feeling of belonging which precludes or diminishes loneliness, this holds true regardless of the strength of family bonds. It is this freedom to mix with others by choice which can be absent for many people living with disabilities, (49–51). For people living with dementia this is experienced over time (52–54). A study among LGBT people affected by dementia highlights the issues of loneliness, stigma, caution and safety and to be oneself without fear of judgement, (23). The issue of loneliness, as outlined above, should be factored in when considering the significance of community participation (see below) for people living with dementia, although there are wider implications as communities which value all their members tend to be more cohesive and have fewer social problems (4).

Initiatives based on the over-arching concept of 'dementia friendly communities' include improving public space for people living with dementia, improvements to assist way-finding around a city centre to consultation about redecoration of the shared areas in a residential home (12,42,55–57) The challenge for outcome assessment is how to differentiate between presence in a community or activity and participation in that community or activity that is comfortable, meaningful and on their own terms (23,26,33,38,49,58).

Involvement/Participation

Much of the information about community presence, participation, involvement and inclusion comes from literature about people with physical, learning or developmental disabilities. While there are similarities, for example stigmatisation and lack of consultation, there are important differences.

- People living with dementia are often householders, have jobs or have retired from paid employment, they have a prior history of full participation and engagement
- Dementia will alter their capacity to interact and participate in the same ways as before. The issue is about not about gaining access to mainstream activities it is about being excluded from activities and relationships where they were formerly involved. The importance of their ongoing participation as social citizens is critical to their wellbeing and quality of life, and to that of their care partners
- Participation (and with that activism) is temporal, it will change over time and activities need to recognise and support that, particularly as dementia progresses.

When assessing a person's level and depth of participation in society it is important to understand the nature of the interactions, who was involved and what the outcomes of such interactions were for the person living with dementia and their families/care partners e.g. opportunities and confidence to make a contribution to society. There was an emphasis in the evidence reviewed that 'community presence' is not the same as social inclusion.

A clear message from people living with dementia is that they have the same rights as other people (10,59,60) which means to be consulted and treated as capable until (and if) the dementia trajectory reduces their capacity to signal what they want and make decisions, (60,61). Continuing to live life independently and/or meaningfully may require new social connections such as joining the DEEP organisation (62) or finding a local group (59,63) to give and receive peer support and maintain a voice in the community.

The concept of citizenship for someone living with dementia is one way of framing a linked outcome for participation and inclusion. Being a citizen is both a status and a practice, where people living with dementia are often positioned as passive. Bartlett takes an individualised approach considering the interactions (and opportunities) which occur in day to day life and serve to maintain the respect of others, (60,64), whereas Brannelly's starting point is that all people have the same rights under the law, (33) rendering stigmatisation or dehumanisation as violation of those rights.

One under explored vehicle for effecting positive change is to enable community members to identify the strengths and needs within their community, and then begin building on the strengths to address the needs and seeking external assistance as and when required, (4,12,15,26,45,46). Levasseur et al. (65) enumerate six levels of community involvement (Figure 4), an individual may engage differentially with depending on the situation. Knowing the motivation for the activity is important and social participation can range from an activity done in preparation for connecting with others, to be with others, to those activities that are about making a tangible contribution to society.

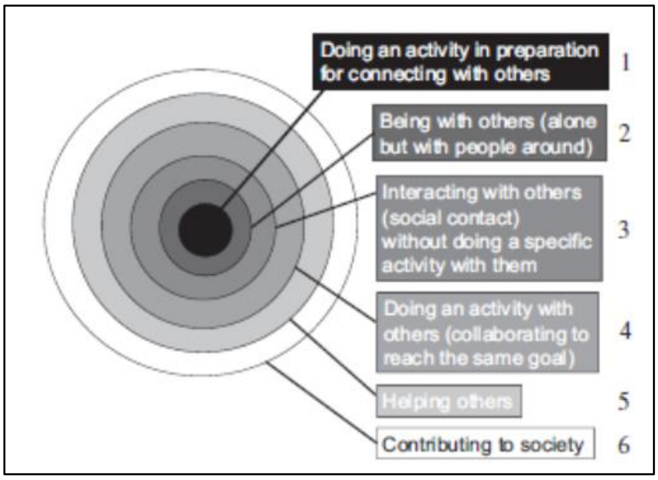

Figure 4: Proposed taxonomy of social activities based on (1) levels of involvement of the individual with others and (2) goals of these activities

Lin & Lewis (1, p242) argue that for a society to be truly inclusive and empowering for people living with dementia the three concepts of Dementia Friendly, Dementia Capable, and Dementia Positive must be embraced. They argue that without dementia positivity, society will merely "tolerate or respect differences" and will not view all members as equal contributors, and therefore it is neither fully socially inclusive nor empowering.

One possible outcome measure is the number and variety of networks available to a person with dementia. Through building personal, professional and organisational networking, with partnerships that include all areas of society, from local authorities to schools to health care professionals to businesses, a ‘dementia movement’ is created. Building such a movement will increase sustainability, influence, morale and will allow learning to be shared (12). This is likened to the civil and gay rights movement (62), as well as the disability rights movement as mentioned earlier.

Quality of Life

Quality of life as an outcome for people living with dementia arising from their community engagement linked activities is possibly too broad an outcome as it is invariably dependent on a person’s ability to continue with preferred activities. That is, it is a measure of their level of participation, and social isolation (see above). Lloyd and Stirling (52) report that quality of life for people with dementia living alone, is bound up with the altered effects of sensory input. For example, busy streets which have been part of everyday life for many years can become alarming and confusing. Von Kutzleben and colleagues (26) frame quality of life in terms of knowing what people living with dementia need or want recognising them as experts best placed to understand the issues and solutions and in doing so educate other people. Similarly the knowledge that they are respected and valued is linked to social participation and the notion of being valued and not disregarded as a citizen.

Other outcomes

In this section we have grouped together other outcomes that do not map between the empirical evidence and the NPC outcomes. Cost/resource use (Table 19) and general health (Table 20) outcomes do not feature in the NPC schematics, and some of the organisational outcomes (Table 21) around training, policies, following the lead of other organisations and the individual outcome of ongoing engagement with Alzheimer’s society did not have corresponding outcomes in the literature we reviewed.

The O’Mara-Eaves review of community engagement (1) found only a small number of studies (across a very broad range of community engagement activities and focuses) that included an economic evaluation, and only 3 were empowerment based models (neighbourhood based, Finland, USA, UK). They also noted the negative impact that poor cash flow and worries about long-term sustainability can have. These findings are mirrored in the wider literature we reviewed (50,61,62).

The clarity of reporting of costs and resources in the evaluation report for the dementia diaries project (66) is to be commended and it would be good to require all projects to report this clearly. They acknowledge the contribution of volunteers and “good-will” noting this is not included in project costs. O’Mara-Eaves et al also make the point that volunteers are often treated as a ‘free’ resource (66, p105).

A small number of studies looked at health outcomes which are related to wider quality of life measures. Some in care homes and in the evaluation of a health promotion programme for people with disabilities looked at self-report measures. One study, specifically focussed on self-management for people living with dementia, used some well validated measures for quality of life in dementia and anxiety and depression. There could be the temptation to use already developed measures as these, but these measures often come from a health service/medical perspective and may not be appropriate. A recent report from the EU Joint Programme: Neurodegenerative Disease Research (JPND) gives recommendations for the best measures for psychosocial research in dementia (30) but also touches upon the issue that many current measures do not address the “‘neglected construct of ‘living well with dementia’” (30, p3).

How rights are articulated in the literature

The human rights agenda is deeply rooted in a post war, post holocaust narrative that sought to stress the unity and inherent dignity of the human race. A human right as Perry (67) notes is the basis on which governments are held to account about how they treat their citizens.

Charlton (68) on disability rights movements outlines how they grow from a place of resistance and rejection of the status quo. They are based on a recognition that people with disabilities are marginalized economically and politically, that there are culture and belief systems that stereotype, pity and promote fictional and misleading beliefs about people with disabilities and that people with disabilities internalize their oppression and remain alienated from themselves and others (68). The parallels with the experience of people with dementia, as our review has shown are being increasingly discussed and tested. There are differences however, and the review has considered to what extent the assumptions of a rights based approach, and activities that support empowerment and inclusion fit with current and proposed approaches to Community Engagement and are supported by the evidence.

The 'rights-based' perspective is clearly articulated in the recent report from the Mental Health Foundation (MHF). Their publication "Dementia, rights, and the social model of disability" discusses the implications of viewing dementia as a disability in the social/rights based model (2).Dementia friendly communities are cited as a current manifestation of the social model in practice (communities adapting to make it easier and more inclusive for people living with dementia to be an active citizen). It frames the discussion within a social model of disability. They acknowledge that dementia requires a particular understanding as there is a trajectory of decline.

> *"Given that the majority of people with dementia frame dementia as an illness or disease (with some rejecting the concept of it being a disability because of the negative connotations this can imply), a more nuanced and less radical model of disability may be more appropriate to engage. It can certainly be argued that the lived experience of people with dementia is usually articulated as the impairment itself causing a disability. Therefore, a disabling factor may be intrinsic to the condition. In these instances, the social model needs to take account not only of the external barriers, but also of the social and psychological obstacles that exclude or restrict full participation in society. Lived experience, as well as societal responses, may also vary significantly depending on the severity, perceived 'stages' and, the type of dementia."* (2, p15)

The social model of disability is based on an underpinning human-rights approach. There are five principles to this approach developed by the Scottish Human Rights Commission. These are,

- **P**articipation
- **A**ccountability
- **N**on-discrimination and equality
- **E**mpowerment
- **L**egality of rights

Clearly these link to some but not all of the outcomes identified in the NPC ToC models.

The report (2, p25) particularly highlights a different role for organisations such as Alzheimer's Society and other dementia focused charities, providing leadership and support in solidarity with people with dementia, so changing the power dynamics.

Two themes of ***elevating voice*** and ***language*** are discussed in the section on lived experience. The examples they give are:

- Disability rights work was based on building a critical mass of leaders from within the 'disabled' community and building collective momentum in terms of activism.
- Changing language, e.g. from terms such as 'sufferers', 'living death' and 'ticking time-bomb' to more positive or assets based terms.

The role of organisations, such as Alzheimer's Society is highlighted as needing to change (2, pp29-29) to 'actively support people to engage in activism'. The report acknowledges that people living with dementia may not wish to embrace rights-based principles or activism, and that the 'disability' label could be stigmatising (along with dementia and associated ‘ageing’ stigmas).This is a theme that Bartlett and colleagues (64) also address and suggest that people living with dementia can be activists in their everyday encounters and social world as opposed to activists as portrayed here.

The MHF report concludes with a quote from Professor Gerard Quinn, who is a human rights lawyer and one of the architects of the UN Convention on the Rights of Persons with Disabilities: *“It seems to be that the history of human rights is really a history of gradually admitting all of humanity, group by group, into its fold.”* And the MHF report concludes, ***“Perhaps now there is an opportunity, through the social model of disability, for people with dementia to be welcomed into the fold.”*** (2, p30).

There is a synergy between these arguments and our review and synthesis of 23 empirical studies (just one of which is cited in the MHF report) that include disability, learning disability, health psychology in older peoples settings, and dementia care perspectives.

Our review takes these arguments further to review the empirical basis for these propositions and unpick some of the meanings and discussion. Rights-based approaches are the accumulation of years of experience from different groups working in and with communities and the review of community engagement to reduce inequalities in health.

O’Mara-Eves et al, 2013 (1) provide a helpful definition of community engagement relating to people living with dementia. A continuum from peer-led interventions to ‘engage’ communities based on an assessment of needs by outsiders to, more sustainable models of empowerment which come from the community itself and have drawn on community needs and assets. The DAAs and DFCs have the potential to fit with this model, but could be critiqued as still being characterised as “needs assessed by outsiders”. From our perspective, evaluations of the impact of a rights based approach to community engagement are key and need to record:

- Who is involved (and why),
- Who is leading the initiative
- What is the balance of participation between people living with and affected by dementia or others?

The rights based literature does not explicate the role and type of public awareness needed (2,3,29,64). It is taken as a given that the activism of people with dementia and their advocates will create a recognition that living with dementia does not exclude you from the ability to make decisions about your care and support or reduce your rights to be an active participant in society. Our analysis of the empirical studies would suggest that this recognition or awareness is foundational for any initiative designed to promote inclusion. It needs to include an appreciation of a person’s assets not just needs, and that these should be articulated by people living with dementia. This raises a question for outcome measurement and how people with dementia are involved at each stage and level of community engagement.

Laws and legal reform are often represented as the keystone of rights based approaches, for example the recognition of the legality of gender reassignment for transgender groups (69). However, for people living with dementia, who have acquired a new (stigmatised) status associated with care and dependency, there is a need to create an awareness and appreciation of people with dementia, who are independent of those who support them. This is arguably an important contextual precursor in establishing their rights to social inclusion.

Two very recent publications do articulate this and specifically creating awareness that living well with dementia is linked to the opportunities people with dementia have to be an active social agent, a social citizen. They highlight the importance of creating safe spaces for people living with dementia where there are opportunities for them to speak apart from their carer. Underpinning these discussions is the recognition that for people with dementia ‘one size doesn’t fit all’.

- Wiersma, E. C. et al. Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. Dementia 15, 414–433 (2016).
- Bartlett, R. Scanning the conceptual horizons of citizenship. Dementia 15, 453–461 (2016).

A move towards elevating voice, particularly from campaigners such as Kate Swaffer, is shaping the language (10). We are also seeing a move in language from ‘carers’ to ‘care partners’ and other more personal terms e.g. Kate Swaffer’s use of the term “BUB” (back-up brain) for her husband (70). This is a positioning of the person living with dementia as the person who cannot be side-lined or be spoken for.

How rights based approaches can be expressed as useful Context – Mechanism – Outcome configurations (CMOs) based on the evidence reviewed

The CMO configurations of realist synthesis provide a helpful way to theorise how interventions may work, what are the important contexts and potential expected outcomes. The following CMO table seeks to unpack how using a rights based approach could contribute to the achievement of social inclusion and meaningful social participation for people living with dementia. The underpinning resource is an awareness in communities not only of what dementia is and the challenges of living with dementia, but also awareness that people living with dementia could and should be able to participate and be citizens. Enabling contexts are articulated and the types of mechanisms that may be in play to produce the outcomes aspired for. This way of thinking enables us to spot essential resources and contexts which if missing could trigger different responses (mechanisms) and therefore different (unwanted/unintended) outcomes. For example, tokenistic involvement (presence rather than participation) could trigger reduced confidence that people will be listened to and increase feelings of isolation and exclusion.

Resource	Context	+	Mechanism	+	Outcome patterns	Evidence
Awareness of the experience of living with dementia that is shared by Individuals, public and commercial services and local communities Awareness that people living with dementia have the capacity to participate and contribute	Funding of programmes and people (including those with dementia) to affirm that people with dementia are part of their community A language of inclusion		A sense of shared identity		Attitudinal shift. Language and services that defines people with dementia as "other" are unacceptable	(71,72)
	Initiatives involve people with dementia (rather than their presence) and meaningful participation e.g. creativity		Expectation of involvement and making a contribution to how services are offered. Networks of support to sustain the meaningful involvement of people with dementia Confidence that they will and should be listened to		Quality of life Socially "regarded" Treated with respect Recognisable as "citizens" within their communities	(62,64)
	Continuity of support including personnel, technology resources, places and spaces for people with dementia to be that promote their needs and abilities Importance of individualised activities and spaces where people can feel comfortable		People with dementia feel supported and comfortable Able to take risks		Normalises people with dementia's rights to take choices about day to day living Reduction in "evidence of deep isolation and boredom when collective sources of support are removed and not replaced or reimagined"	Lack of current evidence around the normalisation of choice making. Qualitative accounts about what people hope for or would like
	Activities identify gaps and failings in provision for people with dementia		Sense of injustice Lobbying for change		Funding	Needs testing, not evident from the studies we looked at
	Investment in new technology and assistive technologies to enable engagement		Access to public spaces and navigation		participation	The evidence we have is more for engagement than assistive living, (73,74)

What needs to be thought about and what is not known

This review has articulated some new ideas and potential mechanisms. What it does not do is offer a set of fully evidenced based interventions that will work. It offers important questions, ways forward, and ways to test potential programmes, and potential measures or important data to collect.

Gaps

There are a number of gaps in the evidence

Costs and/or lack of resources (funding, time)

Costs of interventions are not well described, if at all. Many of the studies are qualitative, yet this does not mean the interventions being investigated are cost neutral. The costs of driving a rights based agenda, and how financing decides what aspects of the rights agenda is prioritised, have not been discussed in the evidence reviewed.

A recommendation would be that all studies of interventions should include transparent, simple costings. The Dementia Diaries evaluation report (an internally produced report, not a peer-reviewed study) offers a good example of this clarity and transparency (66). The report also clearly states that there was much goodwill and volunteering which is not accounted for monetarily. This is important especially in the light of the finding that sustainability of projects is such a key issue.

Crampton et al.,(42) argue that creating dementia friendly communities need not be costly or resource-intensive but Litherland, cautions that despite low financial cost the “status and long-term preservation is insecure”, (62, p9). In order for groups to be wholly sustainable, a range of voices needs to be included from a range of organisations with constant recruitment and the development of a business case needs to structure activity, (62). In order to secure funding for community engagement projects for people living with dementia, groups need to demonstrate positive impact.

The Scottish Working Group (75) for example, is a campaigning group run by, and for, people with dementia or a related condition. It is supported by a committee and five members of staff who support the Group’s activities.

The personal connection as motivation

From our personal reflections while conducting this synthesis, we have noted that nowhere is the motivation that comes from knowing someone living with dementia noted as driving engagement. It would however, based on the qualitative accounts in the literature resonate as a potential mechanism to collect data on.

Risk

One benefit of social participation is the reduction of risk to the person, because there are more people who will respond if they are lost or need help. We found minimal discussion of this as an outcome from community engagement. In Japan, the SOS Walkabout Network offers training to community members on how to talk to people living with dementia who are lost, and how to respond to them when they are found. When registered with the Network, people living with dementia are found on average within 2.5 hours, compared to 5.5 hours for unregistered people, (76).This kind of support, Hayashi argues, reflects a shift towards inclusion and dignity for people living with dementia, (76). Across Europe, some countries are using GPS trackers and developing new protocols with police for missing persons to address the issue of finding people living with dementia who become lost, (77). Some barriers to schemes like these, however, are data protection measures and issues of consent. We found no evidence of how this could be used to promote social inclusion and engagement.

Potential unintended consequences of rights based approaches

Role of care partner

What happens to the 'carer' in this rights-based narrative? Optimally the rights of all are observed, but there is a danger of 'side-lining' a group who have perhaps been the dominant voice till recently. Bartlett (64) identifies the need for people with dementia to have their own space to talk freely but equally acknowledges that the carers need fora to participate. An unintended consequence of privileging the voice of people living with dementia is that carers can feel excluded from the debate.

Who speaks for whom?

The literature on rights in relation to dementia, so far, has not considered those who may not want to exercise choice, voice and control in the ways advocated by leaders in the rights debate. It is noticeable that some of the keenest advocates have young onset dementia. Research with older people around decision making about future care, identifies that often they want to involve others and do not want the responsibility or fatigue that involvement might require (78) Bartlett and colleagues also highlights that the right to participate in the domestic rather than the public sphere, is how some people with dementia want to be activists (64). The issue therefore is one of choice; the choice of whether or not to participate and whether or not to let others speak on behalf of the person living with dementia.

The potential benefits or unintended consequences for people living with dementia

Does dementia diagnosis lead to opening of doors or increase the risk of 'social death' by focusing more attention on people living with dementia? For people who are already marginalised such as members of the LGBT community, diagnosis can either provide a tight group identity or compound some of the prejudice already encountered (23).

One study with people with learning disability suggested that some activities designed to achieve better outcomes, such as employment, could create the impression that all things were possible and not acknowledge that this was not always the case. The authors contrasted this with the reported benefits of participation in supportive peer groups who acknowledged the day to day challenges of having a learning disability (61.)

It takes, time, energy and resource for people to 'engage'. There are potential negative impacts (1,61); distress, exhaustion, becoming disengaged, cynical or feeling embittered (particularly due to failed or unsustainable community engagement projects). These are not often reported on. We would suggest these maybe unintended outcomes that it would be important to be alert to and document.

Stages of the disease trajectory

There is also a question of how a 'rights-based' approach applies beyond the early stages of dementia. This is acknowledged but largely untested. The impression is that it is those with young onset dementia or in the early stages of the disease who participate, and do so with the certain knowledge that they have limited time. One mechanism from this may be to think about when people with dementia are identified and supported to join community engagement activities.

Authors/studies/initiatives to keep an eye on

The following schematic (Figure 5) provides an overview of where we might expect the next waves of evidence on rights based approaches to be coming from. There are two directions of research endeavour we have observed. One group of studies is looking at community support and active and independent living for people living with dementia (79–81), including a very recent call from JPND to investigate ICT-based solutions addressing the specific aspirations and challenges of people living with dementia and their communities ((82)). These studies tend to be underpinned by a 'service' perspective. The other direction of inquiry takes the perspective of activism, citizenship and inclusiveness and tends to have a sociological focus. The authors, initiatives and groups identified are good examples of these

(10,34,64,74). However, these strands of enquiry come together round the concept of inclusive and supportive communities. The Neighbourhoods and Dementia funded study is one example of a development in this area (83).

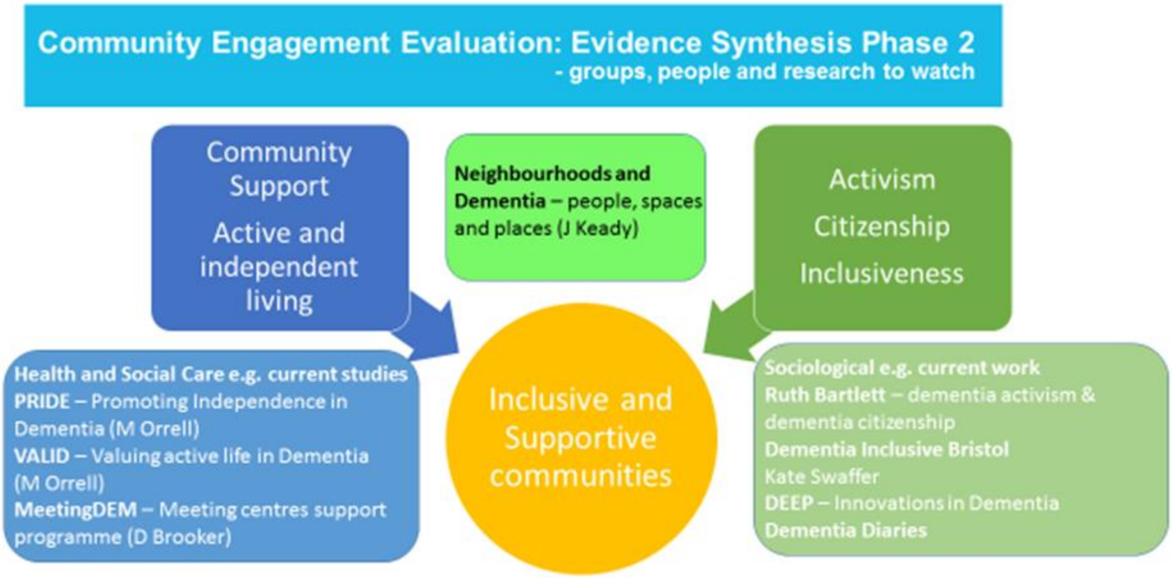

Figure 5: Groups, people and research to watch

We would suggest that the concept of a social citizen as put forward by Bartlett and colleagues (64) is very useful. It redefines activism as a domestic activity with particular, dementia specific goals and differentiates between the similar but different needs of people with a disability and those with dementia.

The patient and public involvement literature

We looked to community engagement activities that involved people who were stigmatised and excluded because of disability and social inequality.

There are other literatures, such as patient and public involvement in research that could and should be considered. A clear message from this review is the challenge as to how people living with dementia are meaningfully included in community engagement planning and implementation.

The literature on Public and Patient Involvement in Health Care Research offers a detailed account of the move from tokenism to full participation and patient led research. One recent study (84) that considered how PPI can become normalised into every day research practice concluded that six salient actions are required for effective PPI; these are listed below and parallels for community engagement for people living with dementia are suggested in brackets:

- A shared understanding of moral and methodological purposes of PPI (Dementia awareness)
- A key individual co-ordinating PPI (Resources and co-ordination to ensure it happens)
- Ensuring diversity (People living with dementia who represent a range of experiences and backgrounds)
- Researchers positive about PPI input (Wider engagement about the person living with dementia's right to participate and lead)
- Involvement based on relationships that are established and maintained over time (A continuum of involvement that builds up over time)

- PPI being evaluated in a proactive and systematic approach (The need to be able to measure effective engagement)

Potential digital tools for engagement

As yet there are few studies which use digital technologies to gather information from people living with dementia or people living with disabilities, two projects which do are PhotoVoice and Dementia Diaries (73,74). From email correspondence with an author of a study investigating health promotion for people with disabilities (71) technology that enables in the moment assessment and capture of experience would seem to offer potential. The methods used are called ‘experience sampling’ or ‘ecological momentary assessment’ because they capture the lived experience. There are a number of programmes developed for use on smartphones, though not specifically for use by people living with dementia. Thus some co-produced development would be required.

While assistive technologies such as memory support systems and GPS systems “show potential to support people with dementia to stay at home”, (81, p37) there are several notes of caution, namely that “technology can promote further isolation of people already excluded from social interaction if it is a substitute for human contact; some technologies, especially those which offer surveillance and monitoring require sensitive evaluation of potential intrusiveness and threats to autonomy; some technologies have been designed without input from users and may reflect the needs of service providers. Attention needs to be paid to the possibility that cost saving in one area (e.g. health) simply shifts costs to another sector (e.g. social care or informal care)" (82, p20).

JPND have a recent call (March 2016) with the objective to advance the contribution of ICT to integrated solutions that enable the well-being of people living with dementia and their communities, including their family, caregivers, neighbourhood, service providers and care system (82).

Discussion

This review asked what kind of community engagement works for whom in what circumstances and with what outcomes.

The first phase provided an overview of what is known and the growth of literature on the topic that is largely descriptive. Phase two considered these activities using in terms of how they might advance a rights based agenda that supports the inclusion and participation of people with dementia.

It is apparent that the range and interchangeable nature of terms and phrases that describe social integration, inclusion and citizenship pose challenges for the policy maker and the evaluator. We are not proposing that Alzheimer’s Society have fixed definitions for these terms, rather it is the operational definitions of the related outcomes that are important and specification as to whether they are specific to individuals, groups or organisations.

The proposed C-M-O configurations are the building blocks based on the evidence reviewed of a theory of what and how a rights based agenda for people with dementia may work. It clearly needs further testing but the evidence from health and disability literature would provide an empirical basis for the argument that activities that focus on empowerment do increase participation and activism. Key mechanisms are those activities and initiatives that offer: a language of inclusion, a collective/shared identity apart from those that provide support and care, an expectation that the person with dementia should and could participate and that their contribution is valued, that support people with dementia to articulate their choices and provide them with the space and time to do this. These mechanisms are generated by an underpinning awareness of the lived experience of dementia and that presence is not participation, an infrastructure of funding, design and support and continuity of service provision that can anticipate the different demands of living with dementia.

A rights based approach is a promising strategy and deserves to be pursued and evaluated as currently evidence for efficacy is weak. There is a need for a literature that references the particular experiences of becoming a person with dementia.

The evidence reviewed provides a partial explanation of how rights based interventions can work to empower people living with dementia to be citizens of their local communities and wider society. Awareness of what it is like to have dementia is an important precursor or context that can generate responses and activities designed to change or renegotiate the social order to one where people with dementia are an active player in decisions and activities that affect them. Keeping an acute awareness of the role and shifting balance of power and facilitating their negotiation and re-negotiation maybe a key leadership role for Alzheimer's Society.

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Appendix 1: Phase 1 Report and Phase 1 appendix 1

This is submitted as two separate PDF documents: [2016-02-29 Work package 3 - Interim Report], [Phase 1 Appendix 1 AS CE WP3]

Appendix 2: Evidence summaries

The following tables set out the evidence reviews used, their focus and recommendations and the detail of the individual studies on community engagement that were included in the review.

Table 1: Table Summaries of the eleven review papers

Source	Citation	Summary
Initial search	Amado AN, Stancliffe RJ, McCarron M, McCallion P. Social inclusion and community participation of individuals with intellectual/developmental disabilities. Intellect Dev Disabil. 2013;51(5):360–75.	Provides a framework for assessing social inclusion as assessed through literature focusing on people with learning disabilities. Highlights the overlap but lack of clarity about the differences between terms such as integration, inclusion, participation, and community belonging. Participation or integration can often be seen as physical integration but not social integration or inclusion. Unclear if different terms reflect different experiences. Raises problems for measurement e.g. individual preferences/how this is facilitated by others. Questions relevant for people living with dementia: how to move from community activities to a sense of belonging/ can social media promote inclusion?/as there is increased participation how to continue to work against stigma and prejudices/what does social inclusion mean for families? Conclude: *One of the most provocative avenues is extending beyond individuals with disabilities and the services system to understanding and impacting the larger community itself.*
Initial search	Simplican SC, Leader G, Kosciulek J, Leahy M. Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. Res Dev Disabil [Internet]. Pergamon Press; 2015 Mar;38:18–29. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0891422214004223	Provides definitions and analysis of how social inclusion has been defined in the last decade and how it could and/or should work. NB very useful figure of social inclusion (see appendix). Offer a model that separates the definition of social inclusion from the processes that may achieve it and the subjective feelings that may result from inclusion. Characterise involvement as as presence, encounter, and participation. Highlight an important issue relevant for people living with dementia Narrow definitions undercut the social and political purposes of social inclusion, vast definitions become too demanding, thus inviting some to conclude that social inclusion may be for some people, but not all. Recommends future focus should be on quantity and quality of social inclusion
Initial search	People Opportunities. Identification of best practice for inclusion: a report for Alzheimer's Society. 2015.	Identifies barriers to inclusion and adjustments which can remove them.
Initial search	Dementia Alliance International. The Human Rights of People Living with Dementia: from Rhetoric to Reality DEMENTIA [Internet]. 2016. Available from: http://www.dementiaallianceinternational.org/human-rights/	Written by people living with dementia, the document lays out the rights of people living with dementia. "A right gives you authority to speak for yourself and to join with others whose rights are not respected or abused" Source docs/authors Bryden, C. (2015). Nothing About Us Without Us. London: Jessica Kingsley. Swaffer, K. (2016). What the Hell Happened to My Brain?: Living beyond dementia. London: Jessica Kingsley/ Taylor, R. (2007). Alzheimers From the Inside Out. Baltmore, Md: Health Professions Press. 5th printng 2015/ Whitman, L. (ed) (2015). People with Dementa Speak Out. London: Jessica Kingsley.

Source	Citation	Summary
MHF	Mittler P. What can we learn from the disability movement? In: Batsch N, Mittelman M, editors. World Alzheimer Report 2012: Overcoming the stigma of dementia. London: ADI; 2012. p. 68-9.	Advocates the joining of dementia rights campaigning with general disability rights campaigning locally, nationally and internationally.
MHF	Swaffer K. Dementia: Stigma, Language, and Dementia-friendly. Dementia [England; 2014 Nov;13(6):709–16.: http://dem.sagepub.com/cgi/doi/10.1177/1471301214548143	The perspective of a person living with dementia on the subject of stigma and rights. Rejection of a biomedical view of living with dementia
Forward citation	Bartlett R. Scanning the conceptual horizons of citizenship. Dementia [Internet]. 2016;15(3):453–61. Available from: http://dem.sagepub.com/cgi/doi/10.1177/1471301216644114	Articulates citizenship as a core concept for dementia research and practice. This is predicated on a right of those who are not politically engaged to participate in the everyday activities and have equality of opportunity. Framed as a " collective" struggle addressing where injustices occur in the ordinary and domestic experience of living with dementia
Initial search	Bartlett R. The emergent modes of dementia activism. Ageing Soc [Internet]. Cambridge University Press; 2013;34(November 2012):623–44. Available from: http://eprints.soton.ac.uk/344600/\nhttp://journals.cambridge.org/abstract_S0144686X12001158	Commentary and study of people with dementia engaged with activism (mostly young onset). Analysis framed from literature on social movement/creation of a collective identity. Emphasises how the social environment adversely affects someone with dementia Offers a typology of three distinct modes of dementia activism: 'protecting self against decline' mode, '(re) gaining respect' mode and' creating connections with other people with dementia' mode. Argues that social linkages provide the structure for activism and to become politicized Activism pervaded by a sense of elapsing time and living with a progressive disease "no time to lose and everything to gain when one is a 'patient with dementia'p14. Suggests this is why **equality and respect is important**" time is a finite social resource for ageing 'activists'; A sense of elapsing time seems to explain/trigger participation. Argues post diagnosis is a critical time for activism and asks if it can protect against decline (linked papers from this study activism can servie to relocate the person in the world of work, but they are affected by how they are perceived by others (emotional oppression), terrified of forgetting things. Also difficult to be an activist when you do not conform to ideas of dementia e.g. ability to speak in public.(Is this a prerequisite for activism? See our argument about the foundational nature of awareness)
Initial search	von Kutzleben M, Schmid W, Halek M, Holle B, Bartholomeyczik S. Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. Aging Ment Health [Internet]. 2012 Jan [cited 2015 Sep 9];16(3):378–90. Available from: http://www.scopus.com/inward/record.url?eid=2-s2.0-84859712836&partnerID=tZOtx3y1	Another insight into the perspectives of people living with dementia, and the underlying theme of wanting to be taken seriously. Needs and demands do not differ significantly from those of other groups of patients with chronic conditions. Coming to terms with the disease and maintaining normality important

Source	Citation	Summary
Initial search	Levasseur M, Richard L, Gauvin L, Raymond É. Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. Soc Sci Med [Internet]. Elsevier Ltd; 2010;71(12):2141–9. Available from: http://dx.doi.org/10.1016/j.socscimed.2010.09.041	Social participation is deconstructed to expose various levels or degrees of engagement. The study looks at older people rather than people living with dementia. Identified 43 definitions of social participation from a range of disciplinary traditions. Found that social participation mostly focused on the narrower activity person's involvement in activities, less on participation leading to being productive. Essential the person is specifically involved with others but how others should be involved is not specified. For future research and measurement conceptual definitions of social participation are very important most do not do this
Initial search	Lin S-Y, Lewis FM. Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future. Gerontologist [. 2015;55(2):237–44. http://gerontologist.oxfordjournals.org/cgi/doi/10.1093/geront/gnu122	Discusses the conceptual and behavioural differences between dementia-friendly, -capable and -positive.

Table 2: Summaries of evidence from the twenty three empirical studies

Source	Citation	Summary
DRUK	Sendi R. An Interactive Web Tool as a Social Innovation that Ensures Greater Efficiency in the Realization of the Rights of People with Disabilities to Barrier-free Access. Soc Sci [Internet]. 2013;2(4):142. Available from: http://www.sciencepublishinggroup.com/journal/paperinfo.aspx?journalid=202&doi=10.11648/j.ss.20130204.11	Highlights the limitations of laws to promote inclusion, argues interactive web tool is a product of a bottom up social innovation that can address problems of access that can mobilise citizens to act and challenge barriers to participation. Ultimately to promote inclusive environments.
DRUK	Schleien S, Green F, Stone C. Making Friends Within Inclusive Community Recreation Programs. J Leis 1999;26(3). http://lin.ca/sites/default/files/attachments/making-friends-within-inclusive-community-recreation-programs.pdf	Articulates levels of inclusion in leisure activities and the risk of misinterpreting each of them as full participation. Inclusion viewed as a continuum that includes three levels of acceptance. Physical integration, Functional inclusion, Social inclusion. Defines latter ability to gain social acceptance and/or participate in positive interactions with peers It cannot be legally mandated contingent upon internally motivated acceptance by peers
DRUK	Schleien SJ, Brake L, Miller KD, Walton G. Using Photovoice to listen to adults with intellectual disabilities on being part of the community. Ann Leis Res. 2013;16(3):212–29.	Using technology to facilitate the inclusion of people of people with learning disabilities within communities. Documenting their lives through photography identified concerns about community access and linking with the larger community Highlighted desired independence, limited connections to the community and a wish to be treated as adults

Source	Citation	Summary
DRUK	Greig R, Chapman P, Eley A, Watts R, Love B, Bourlet G. The Cost Effectiveness of Employment Support for People with Disabilities Final Detailed Research Report [Internet]. 2014. Available from: http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf	Evidence around cost effectiveness of employment support for people with learning disabilities or mental health problems. Highlight problems of equality of access to employment support, stereotyping and low expectations may affect careers advice people get, and 'cherry picking' clients to meet targets;
DRUK	Clement T, Bigby C. Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability. J Appl Res Intellect Disabil. 2009;22(3):264–75.	Examination of community participation for people with profound learning disabilities, the findings look transferable for people living with dementia, (includes staff perspectives). Considers what it means to occupy a distinct social space highlights difference between " presence" and participation" NEEDED engagement and belief of staff,
Jetten	Knight C, Haslam S. A, Haslam C. In home or at home? How collective decision making in a new care facility enhances social interaction and wellbeing amongst older adults. Ageing Soc [Internet]. 2010;30(08):1393–418. Available from: http://dx.doi.org/10.1017/S0144686X10000656	A UK study in which care home residents were consulted about the redecoration of communal areas within the home, the findings encompass the benefits of collective decision making, 'ownership' and increased socialisation within the communal spaces.
Jetten	Cacioppo JT, Fowler JH, Christakis NA. Alone in the Crowd: The Structure and Spread of Loneliness in a Large Social Network. J Pers Soc Psychol. 2009;97(6):977–91.	Potential mechanisms around loneliness; crucially the ability to choose friends reduces the risk of loneliness irrespective of the strength of family bonds.
Jetten	Gleibs IH, Haslam C, Haslam SA, Jones JM. Water clubs in residential care: is it the water or the club that enhances health and well-being? Psychol Health [Internet]. 2011;26(10):1361–77. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21598183	Examines social engagement in care homes and how peer support can lead to change in behaviour includes measures for dementia.
	Brannelly T. Sustaining citizenship: people with dementia and the phenomenon of social death. Nurs Ethics [Internet]. 2011 Sep [cited 2015 Nov 9];18(5):662–71. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21893577	An empirical study exploring the 'social death' which can accompany a diagnosis of dementia. Considers citizenship as a status and a practice, where PWLD are positioned as passive. Inclusion is represented as knowing a person's preferences, maintaining social regard. May need practitioner facilitation to ensure the person is seen as socially alive and a social actor :"transformative citizenship"

Source	Citation	Summary
	Liddle J, Scharf T, Bartlam B, Bernard M, Sim J. Exploring the age-friendliness of purpose-built retirement communities: evidence from England. Ageing Soc [Internet]. 2013;34(9):1–29. Available from: http://www.journals.cambridge.org/abstract_S0144686X13000366	Includes interviews of older people in one specific village. Good design improves access but of itself does not guarantee accessibility location alone is not enough to facilitate social participation. Sees age-friendliness not as a number of specified tasks, rather an on-going, strategic process. Requires commitments from both staff and residents to engage with planning, implementing, evaluation and continual improvement.
	Litherland R. Developing a national user movement of people with dementia: learning from the dementia engagement and empowerment project (DEEP) [Internet]. York: Joseph Rowntree Foundation; 2015. Available from: https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia	Detail of the learning from DEEP.
	Lloyd BT, Stirling C. The will to mobility: life-space satisfaction and distress in people with dementia who live alone. Ageing Soc [Internet]. 2014;35(9):1–20. Available from: http://www.journals.cambridge.org/abstract_S0144686X14000683	Addresses experiences of 7 people with dementia living alone, aimed to identify unmet service needs in this vulnerable population. Key concepts of 'the will to mobility' and 'life-space expressed as the importance of having access to public space,
	Martin F, Turner A, Wallace LM, Bradbury N. Conceptualisation of self-management intervention for people with early stage dementia. Eur J Ageing [Internet]. 2013 Nov 7 [cited 2015 Nov 9];10(2):75–87. Available from: http://www.scopus.com/inward/record.url?eid=2-s2.0-84876907613&partnerID=tZOtx3y1	This study acknowledges people experience a "care gap" post diagnosis, takes a strengths approach to addressing the problems faced by people living with dementia and argues there are strong parallels with self-management literature and long term conditions.
	Milner P, Kelly B. Community participation and inclusion: people with disabilities defining their place. Disabil Soc. 2009;24(1):47–62.	Personal experiences of people with disabilities in the community.
	Peel E, McDaid S. "Over the rainbow": lesbian, gay, bisexual and trans people and dementia project: summary report [Internet]. 2015. Available from: http://dementiavoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf	A UK report which explores the difficulties of engaging with community activities for people from seldom heard groups living with dementia; facilitated by representatives of the lesbian, gay, bisexual and transgender community.

Source	Citation	Summary
	Roe B, McCormick S, Lucas T, Gallagher W, Winn A, Elkin S. Coffee, Cake & Culture: Evaluation of an art for health programme for older people in the community. Dementia [Internet]. 2014;1–21. Available from: http://dem.sagepub.com/content/early/2014/03/25/1471301214528927.abstract	Evaluation of a specific community engagement initiative.
	Teri L, McKenzie G, Logsdon RG, McCurry SM, Bollin S, Mead J, et al. Translation of two evidence-based programs for training families to improve care of persons with dementia. Gerontologist [Internet]. 2012 Aug [cited 2015 Nov 9];52(4):452–9. Available from: http://www.scopus.com/inward/record.url?eid=2-s2.0-84863974338&partnerID=tZOtx3y1	Considers the adaptation to a community setting of interventions for families originally developed to assist families to care for relatives living with dementia.
MHF	Popperwell I, Connett J. Bristol Dementia Inclusion Programme Jan Connett , Public Health Bristol Dementia Inclusion Programme You ' ll hear about : Our approach Examples of how the approach has impacted on our actions. 2014. p. 1–26.	PowerPoint presentation with interesting data and ideas around the need for a culture and language shift to rights and citizenship.
OME	Bolam B. Using New Media to Build Social Capital for Health: A Qualitative Process Evaluation Study of Participation in the CityNet Project. J Health Psychol [Internet]. 2006;11(2):297–308. Available from: http://hpq.sagepub.com/cgi/doi/10.1177/1359105306061188	This UK study among disadvantaged groups of people explores the interplay of power within the group with the personal confidence and self-esteem of group members.
OME	Ravesloot CH, Seekins T, Cahill T, Lindgren S, Nary DE, White G. Health promotion for people with disabilities: Development and evaluation of the Living Well with a Disability program. Health Educ Res. 2007;22(4):522–31.	An evaluation of living well with disability, includes outcome measures.

Source	Citation	Summary
MHF ref follow up	Power A, Bartlett R, Hall E. Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. J Intellect Disabil [Internet]. 2016;20(2):183–93. Available from: http://jid.sagepub.com/cgi/doi/10.1177/1744629516634561	Examining peer support, argues that an over focus on an individual's need for support can have the unintended consequence of social isolation by reducing opportunities for meeting peers for solidarity, friendship and building informal networks of support. Argues that peer groups offer spaces of hope, resilience and cohesion. (**NB for rights based approaches**)Warns that this space should not filled by "cruel optimism" that people will be able to become active participants in welcoming communities and able employees. Rather, the peer led approach offers people with intellectual disabilities the opportunity to honestly and safely build their own pathway to a life in the community based on their own aspirations, needs and abilities
DEEP follow up	On Our Radar, Final Report: Keeping Track Pilot (dementia diaries), 2014	The evaluation report for Dementia Diaries, includes cost information

Appendix 3: Outcomes tables – NPC Theory of Change outcomes and empirical research outcomes by outcome category

The following tables group together outcomes from the NPC ToC schematics with outcomes found in the empirical papers by the categories; awareness, attitudes, accessibility, social isolation/loneliness, involvement/participation, quality of life and other.

Notable is the difference in the conceptualisation of outcomes related to involvement/participation. The empirical studies are very much about the involvement and participation of people living with dementia or other disabilities at the micro or meso level. The NPC outcomes seem to differentiate between ‘people’ and ‘people affected by dementia’ and outcomes are also directed at the macro level (being part of a movement, influencing change).

Awareness

Table 3: NPC outcomes (yellow = individual, orange = organisational) that relate to awareness

Awareness
People recognise (early) signs of dementia
Increased understanding of the rights of PAD
Increased understanding of dementia and how it affects a person
People understand how their action can make a difference
PAD have increase awareness of available support
Increase in awareness and empathy
Organisations understand their legal duties to PAD
Organisations leaders recognise the financial benefits of becoming dementia friendly
Organisations understand the difference that they can make
Staff have increased awareness of dementia
Staff understand rights/needs of people affected by dementia

Table 4: Outcomes from the empirical literature that relate to awareness

Outcomes described/discussed	**Measures**
Raising awareness of why friendships are important (for people with disabilities) and strategies for 'successful' friendships (87)	Reference to methods for assessing and measuring friendship (early 90's)
Media 'reach'(66)	numbers of viewers/users/page views etc
Changing perceptions (in this case for senior managers and politicians) People with LD working in visible settings (50)	Descriptive, qualitative evidence
Easier to collect and find information about how accessible your building/service is Lack of awareness by people without condition (43)	Not measured
A way of signalling "LGBT friendly" services (23)	A kitemark proposed (a bit like dementia friendly)
Awareness of what inclusion means (or lack thereof) (72)	Interview data about what staff understood by "inclusion"

Attitudes

Table 5: NPC outcomes (yellow = individual, orange = organisational) that relate to attitudes

Attitudes
Increased confidence interacting with PAD
Increased empathy towards PAD
Improved perception of PAD
Recognition of the rights of PAD as equals
People see making change for PAD as their responsibility
People feel motivated to act
People challenge misconceptions & stigma
Staff feel motivated to take action

Table 6: Outcomes from the empirical literature that relate to attitudes

Outcomes described/discussed	**Measures**
Positive stories about living with dementia (66)	Language used
Staff attitudes (34)	Approaches to Dementia Questionnaire (ADQ), developed by Professor Bob Woods, University of Bangor, with amendments for use outside of care settings negotiated by Ian Popperwell. (Approaches to Dementia Questionnaire – ADQ; Lintern, Woods & Phair, 2000)
A place of safety/respite (importance of having places to escape public gaze and a respite from feeling different) (51)	Descriptive, qualitative evidence
Changing perceptions (in this case for senior managers and politicians) People with LD working in visible settings (50)	Descriptive, qualitative evidence
An outcome observed as part of the research "There were times when the practitioners and family members were surprised at the ability of the person with dementia to understand and con- sent to the research process." Social regard is measured (33)	Social regard: Practitioner attempts to include person with dementia as normal, acts in accordance with the perceived preferences of the person Decreased social regard: Practitioner attends to person with dementia as required Little social regard: Practitioner pays only slight attention socially to person with dementia Social disregard: Person with dementia ignored if present, practitioner reports no point acknowledging
Negative attitudes and feelings of discrimination (23)	Descriptive, qualitative evidence
Perception of friendship (87)	No measure
Links to accessibility and involvement/participation Staff attitudes specifically to what "inclusion" means (72)	Descriptive, qualitative evidence

Accessibility

Table 7: NPC outcomes (yellow = individual, orange = organisational) that relate to accessibility

Accessibility
PAD can access the services & activities they want to
Activities are revised & restored
Org.s adjust services to ensure equal access for customers/ service users
Dementia-friendly products, services & resources
Customers/ service users continue to access the services & activities they want to
Dementia-friendly changes to working environment
Employees with dementia continue at work for as long as they want/ are able

Table 8: Outcomes from the empirical literature that relate to accessibility

Outcomes described/discussed	**Measures**
Making informed choices and avoiding distress in telephone (call-centre specifically) encounters Generated particularly valuable insights (66)	No measures as yet, rather the "dementia diaries enabled people...to share their experiences...on their own terms, without being guided by our (BT's) questions and preconceptions…"
Ability to access information about dementia (88)	A qualitative question about a person's satisfaction with ability to access information
Access problems (not further defined, about perception & experience) Equipment failures (not further defined) (71)	Rating scale used to capture loss of independent activity and frequency 0 = Not experienced during the past year or insignificant problem (rarely or never limits activity) 1 = Mild or infrequent problem (limits activity 1 to 5 hours per week) 2 = Moderate or occasional problem (limits activity 6 to 10 hours per week) 3 = Significant or chronic problem (limits activity 11 or more hours per week)
Not specifically discussed in detail in the report. More about accessibility to support and services, not environmental accessibility (50)	No measures
Issues around difficulty in access noted (an old Victorian building, transport) (89)	No measures

Table 9: Outcomes from the empirical literature that relate to accessibility continued

Outcomes described/discussed	**Measures**
Ability to fully participate in mainstream life (61)	No measures
Fear of accessing services (because LGBT) (23)	No measures
"Barrier -free access" (built environment and communication) (43)	Talks about an inspection list taking into account all legal requirements and current standards. There are UK accessibility measures that could be used
Right to access Inclusion (87)	Define 3 types of inclusion, but no specific measures Physical integration Functional inclusion Social inclusion
Satisfaction (in achieving "expressions of the will to mobility") Security Continuity Access to public space (52)	No measures, qualitative data Feeling of safety (e.g. too much traffic or feeling at home and being happy to go out)

Social isolation/loneliness

Table 10: NPC outcomes (yellow = individual, orange = organisational) that relate to social isolation/loneliness

Social isolation /loneliness
PAD feel comfortable in their communities
People facilitate the inclusion of PAD

Table 11: Outcomes from the empirical literature that relate to social isolation/loneliness

Outcomes described/discussed	**Measures**
opportunity for social encounter (61)	No measure but note "An unintended consequence of personalisation agenda is the individualisation of people's lives and the de-collectivisation of spaces of care"
"There is a mass of anecdotal evidence from within the DEEP network that staying connected, and having a role and a sense of purpose has long-term health and wellbeing outcomes for people with dementia" (62)	Anecdotal evidence
Talks about friendships developing among residents and staff seeing residents in a different social context beyond a care context (89)	No measures
Improved communications within families and communities was an unexpected outcome of the dementia diaries Enabled direct communication with friends and family for people unable to hold direct phone conversations (66)	Qualitative data

Table 12: Outcomes from the empirical literature that relate to social isolation/loneliness continued

Outcomes described/discussed	**Measures**
Improved social connectedness observed (90)	Qualitative data
Participants recorded a number of 'secondary conditions' that affected them, one is relevant: Isolation (71)	Measured on a 4 point anchored rating scale used to capture loss of independent activity and frequency 0 = Not experienced during the past year or insignificant problem (rarely or never limits activity) 1 = Mild or infrequent problem (limits activity 1 to 5 hours per week) 2 = Moderate or occasional problem (limits activity 6 to 10 hours per week) 3 = Significant or chronic problem (limits activity 11 or more hours per week)
Psychological well-being (88)	Bath Assessment of Subjective QoL in Dementia (BASQID)
Social identity measures Identity Personal Identity Strength (91)	Identity - Social Identification scale (Doosje, Ellemers & Spears, 1995), Personal Identity Strength (Jetten 2010)
Social isolation may be exacerbated (23)	No measures
Making friends (87)	Reference to methods for assessing and measuring friendship (early 90's)
Perceived Social Support Social identification (63)	“I get the emotional support I need from other people”, “I get the advice I need from other people”, and “I get the help I need from other people" rated on 5 point Likert scale Four measures for social identification, “Do you see yourself as part of the care home”, “Are you pleased to be part of the care home”, “Do you feel strong ties with others in the care home?”, “Do you identify with others in the care home?” (reliability of measure questioned)
Liking of fellow residents and staff and observed 'citizenship' (57)	Identification with the staff with two items, i.e. ‘I like the care staff in this home’ and ‘I like the care home managers’ identification with residents was measured by a single item, ‘I like my fellow residents’. Staff observations: citizenship was measured with two items, i.e. ‘has been helpful to other residents’ and ‘has been helpful to staff'

Involvement/Participation

Table 13: NPC outcomes (yellow = individual, orange = organisational) that relate to involvement/participation

Involvement/Participation
People understand how their action can make a difference
People feel that they belong to a movement bigger than just them
People take action
People influence their communities to become dementia friendly
People facilitate the inclusion of PAD
PAD are able to participate in their communities in their own terms
People (including PAD) share learning & experiences
Increased likelihood of PAD seeking help with general health matters
Buy-in and commitment to act
Customers/service users influence change
Customers/service users continue to access the services they want to

Table 14: Outcomes from the empirical literature that relate to involvement/participation

Outcomes described/discussed	**Measures**
"This idea of being comfortable with others" (61)	No measure, from qualitative data
Involvement and participation described as leading to other outcomes, enriched lives, well-being, quality of life (89)	Numbers participating collected and number of sessions attended
Unintended outcome - taking care services language into the community can increase stigma (e.g. using the term 'carer') confidence self-esteem willingness to participate in activities (34)	An 'experiential' questionnaire specific to the project, that seeks to measure differences in attributes such as confidence, self-esteem and willingness to participate in activities. This tool has been developed in collaboration with Rik Cheston, UWE
Having a role and purpose (intermediate outcome) Unintended outcome: organisations 'use' the network (DEEP) for their own purposes, i.e. tokenistic rather than true engagement (62)	No measure, from qualitative data
"social distance and proximity" Unwanted people "watching out for you" (52)	No measure, from qualitative data
Involvement in a group with a care partner can have negative consequences as well as positive consequences (88)	Qualitative data

Table 15: Outcomes from the empirical literature that relate to involvement/participation continued

Outcomes described/discussed	**Measures**
Level of visibility (51)	Measure - suggests measure of visibility not a good measure of inclusion
Participation rates (66)	Amount/regularity of content per participant
Difficulty in 'reaching' some groups (23)	No measures
Alternative definitions and criteria for friendships and relationships (87)	Reference to methods for assessing and measuring friendship (early 90's)
"Full" participation in society (43)	No measure for "full" participation
Perceived Social Support Social identification (63)	“I get the emotional support I need from other people”, “I get the advice I need from other people”, and “I get the help I need from other people" rated on 5 point Likert scale Four measures for social identification, “Do you see yourself as part of the care home”, “Are you pleased to be part of the care home”, “Do you feel strong ties with others in the care home?”, “Do you identify with others in the care home?” (reliability of measure questioned)
Community presence Activities being done in the community (72)	No measures, qualitative data
Participation and social interaction (57)	Resident self-report measures; Identification with staff & Identification with residents identification with the staff was measured with two items, i.e. ‘I like the care staff in this home’ and ‘I like the care home managers’ identification with residents was measured by a single item, ‘I like my fellow residents’

Quality of Life

Table 16: NPC outcomes (yellow = individual, orange = organisational) that relate to quality of life

Quality of Life
PAD are treated with dignity and respect
PAD feel in control and able to make choices
Customers/ service users are comfortable in organisations premises
Customers/service users are treated with dignity and respect
Employees affected by dementia are understood & supported
Employees affected by dementia have flexibility & support to meet needs
Employees affected by dementia able to balance work & care

Table 17: Outcomes from the empirical literature that relate to quality of life

Outcomes described/discussed	**Measures**
confidence self-esteem willingness to participate in activities (34)	An 'experiential' questionnaire specific to the project, that seeks to measure differences in attributes such as confidence, self-esteem and willingness to participate in activities. This tool has been developed in collaboration with Rik Cheston, UWE
"There is a mass of anecdotal evidence from within the DEEP network that staying connected, and having a role and a sense of purpose has long-term health and wellbeing outcomes for people with dementia" (62)	Anecdotal evidence
Relationship with family Maintaining an active lifestyle (88)	Psychological well-being (Hospital anxiety and depression scale) Measure: Bath Assessment of Subjective QoL in Dementia (BASQID)
Quality of Life (63)	Four item measure, "In the last few months the quality of my life has improved"; "In the last few months, the quality of my life changed for the worse" (reversed) "Have your life experiences changed you for the better?" "All things considered, are you happy with your life?"). The scale had acceptable reliability both pre- and post-intervention
Participants recorded a number of 'secondary conditions' that affected them, some are Qol relevant Fatigue Joint and muscle pain Sleep problems/disturbances Eating or weight problems Sexual dysfunction (71)	Measured on a 4 point anchored rating scale used to capture loss of independent activity and frequency 0 = Not experienced during the past year or insignificant problem (rarely or never limits activity) 1 = Mild or infrequent problem (limits activity 1 to 5 hours per week) 2 = Moderate or occasional problem (limits activity 6 to 10 hours per week) 3 = Significant or chronic problem (limits activity 11 or more hours per week)

Table 18: Outcomes from the empirical literature that relate to quality of life continued

Outcomes described/discussed	Measures
Well-being measures Life satisfaction Anxiety & Depression (91)	Life satisfaction (Andrews & Whitney 1976) Anxiety & Depression (HADS, Zigmons & Snaith 1983)
Comfort Environmental Satisfaction Physical well-being (57)	Resident self-report measures for comfort with four-items, e.g. 'This home is a pleasant place in which to live' The residents' experience of the home environment was assessed using two, three-item scales: environmental satisfaction, e.g. 'I would rather live here than move to a new home' and physical wellbeing, e.g. 'Conditions in this home are responsible for many of my minor illnesses and ailments'

Other: Cost/resource use

No NPC outcomes

Table 19: Outcomes from the empirical literature that relate to cost/resource use

Outcomes described/discussed	Measures
Alluded to, potentially an outcome around sustainability of funding for projects (cuts to funding resulting in peer advocacy groups being cut or amalgamated) (61)	No measure but potentially a measure about long-term security of project funding
£60K for a 9 month project supporting 31 people living with dementia and 26 link people (66)	Basic cost data along with details of numbers in programme, staff etc. A good example of clear, simple, transparent programme cost and resource use
Health care utilization (71)	Four items used to measure health care utilization, including frequency of physician visits, emergency room visits, outpatient surgeries and hospital days, using a 2-month retrospective recall.
Resources are used in just sustaining a group (i.e. finding continued funding) (62)	Qualitative data "Involvement groups are not costly and yet, for many, their status and long-term preservation is insecure. Energies are expended on sustaining the group, potentially limiting the work that the group is able to do."
Cost-effectiveness - basic cost-effectiveness calculation (overall investment and numbers getting/keeping jobs) Paid employment (as an outcome) (50)	Used 'realist style' evaluation Numbers receiving employment support, Numbers supported gaining (or retaining) paid jobs, demographic data, type of job, hours worked, amount earned, numbers eligible for employment support, job retention, complexity of disability, changes in use of health & social care services, changes in type and cost of employment support for individuals over time.
Use of health services (GP calls specifically) (63)	Number of GP calls

Other: General Health

No NPC outcomes

Table 20: Outcomes from the empirical literature that relate to general health

Outcomes described/discussed	**Measures**
Cognitive ability – No significant improvement in cognition for either sex (91)	Cognitive ability – Addenbrooke's Cognitive Examination Revised (ACE-R)
"There is a mass of anecdotal evidence from within the DEEP network that staying connected, and having a role and a sense of purpose has long-term health and wellbeing outcomes for people with dementia" (62)	Anecdotal evidence
Maintaining an active lifestyle Psychological well-being (88)	Psychological well-being (Hospital anxiety and depression scale) Measure: Bath Assessment of Subjective QoL in Dementia (BASQID)
The number of "unhealthy days " were recorded Participants recorded a number of 'secondary conditions' that affected them, some are health relevant Fatigue Joint and muscle pain Eating or weight problems Arthritis Contractures Circulatory problems Sexual dysfunction Injuries due to loss of sensation Anaemia (71)	Measured on a 4 point anchored rating scale used to capture loss of independent activity and frequency 0 = Not experienced during the past year or insignificant problem (rarely or never limits activity) 1 = Mild or infrequent problem (limits activity 1 to 5 hours per week) 2 = Moderate or occasional problem (limits activity 6 to 10 hours per week) 3 = Significant or chronic problem (limits activity 11 or more hours per week)
Use of health services (GP calls specifically) (63)	Number of GP calls
Physical health & physical well being (57)	Self- report for physical health and staff observed report for physical well being

Other: NPC outcomes

We did not find related outcomes (measured or not) in the literature other than descriptions in the DFC literature summarised in phase 1

Table 21: NPC outcomes (yellow = individual, orange = organisational) that did not have corresponding outcomes in the literature

Other
Ongoing engagement with Alzheimer's Society
Organisations encouraged to follow the lead of other businesses
Organisations provide relevant training and information
Organisations introduce policies and practices to support staff affected by dementia
Organisations work with others at local/national level to promote dementia-friendliness
Organisations promote/ defend the rights of PAD
Organisations support wider positive change for PAD