



# The University of Bradford Institutional Repository

<http://bradscholars.brad.ac.uk>

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher's website. Access to the published online version may require a subscription.

**Link to publisher version:** <https://doi.org/>

**Citation:** Øksnebjerg L, Diaz-Ponce A, Gove A et al (2018) What are meaningful psychosocial interventions for people with dementia and how can they be captured in research? Report of a pan-European consultation. *Health Expectations*. Accepted for publication.

**Copyright statement:** © 2018 The Authors. This is an Open Access article distributed under the [Creative Commons CC-BY license](https://creativecommons.org/licenses/by/4.0/).



**What are meaningful psychosocial interventions for people with dementia and how can they be captured in research?  
Report of a pan-European consultation**

Journal:	<i>Health Expectations</i>
Manuscript ID	HEX-2018-2805
Manuscript Type:	Original Research Paper
Keywords:	Dementia, Consultation, Psychosocial, Patient and public involvement, Outcome measures, Quality of life

SCHOLARONE™  
Manuscripts

Review

## What are meaningful psychosocial interventions for people with dementia and how can they be captured in research? Report of a pan-European consultation

### Abstract

**Background:** People with dementia are often marginalized and excluded from influence, also in relation to dementia research. There is, however, a growing requirement for inclusion through Patient and Public Involvement (PPI), but there is still limited knowledge on how researchers can fully benefit from the involvement of people with dementia in the development and testing of psychosocial interventions. This paper describes the results of a pan-European consultation with people with dementia, synthesizing their views on outcomes of psychosocial interventions.

**Objective:** To involve people with dementia in establishing what are important meaningful outcomes when participating in psychosocial interventions.

**Setting and participants:** Consultations took place at four divergent sites across Europe, involving twenty five people with dementia from nine European countries.

**Methods:** The methods used for the consultation were developed through an iterative process involving people with dementia. Data from the consultation was analysed from a thematic analysis approach.

**Results:** The results suggested that people with dementia wish to participate in interventions that enhance their human rights, confidence, health, social participation and well-being. This highlights a need for improvements in psychosocial research to capture these outcomes.

**Discussion and conclusions:** Involving people with dementia in discussions of psychosocial interventions has enhanced our understanding about meaningful outcome measures in research and methods of data collection. This study suggests that new outcome measures in psychosocial research are needed where concepts of social health and positive psychology can guide innovation and outcome measurement.

### Key words

Dementia, consultation, methods, psychosocial, patient and public involvement, outcome measures, positive psychology, social health, quality of life.

## Main text

### Introduction

Living with dementia often leads to marginalisation by society. People with dementia are not included and adequately involved, even with issues directly related to their life situation. For instance, people with dementia are often not informed about their diagnosis and treatment<sup>1</sup> and when conducting research, or developing new health or social services, the opinions and experiences of people with dementia are seldom requested or shared<sup>2</sup>. Nonetheless, a shift in paradigm is evolving, giving people with dementia more opportunities to influence policies, practices and research. This shift is reflected in increased political awareness, e.g. giving rise to National Dementia Strategies<sup>3</sup> and emphases on dementia-friendly societies in many countries<sup>4</sup>. The shift has come about as a result of several initiatives, particularly the effort of individuals sharing their views and experiences of living with dementia and the united effort of stakeholders in NGOs<sup>5</sup>. There is also a growing emphasis on Patient and Public Involvement (PPI) when conducting research, but this is usually with respect to recruitment to studies<sup>6</sup> and not direct inclusion in the research process<sup>7</sup>.

To fully benefit from the involvement of people with dementia we need knowledge on how this might be best accomplished. Alzheimer Europe, together with INTERDEM and the European Working Group of People with dementia, has published a position paper on the involvement of people with dementia in research through PPI, reflecting on the benefits and possible challenges associated with this<sup>8</sup>.

Aligned to this, the overall objective of the consultation described in this paper was to have people with dementia involved in the development of methodology within the field of psychosocial intervention research.

Evidence is emerging for psychosocial intervention in dementia<sup>9,10</sup>, but sound methodology about outcome measures remains important<sup>11</sup>. Traditionally, outcome measures in dementia research have focused on cognition, functional ability and symptoms that demonstrate the gravity of the loss/deficit paradigm in dementia care<sup>11</sup>, but there is a need for outcome measures which truly mirror the concepts

of well-being and 'living well' with dementia<sup>12,13</sup>. These are essential in many psychosocial interventions, but rarely genuinely captured and reflected in outcome measures. Well-being and 'living well' with dementia is related to positive psychology, but this concept is not well defined or operationalized in relation to dementia<sup>14,15</sup>. It is also related to social health. Recently, a group of health care professionals have proposed a reformulation of the WHO definition of health that moves towards a more dynamic definition, based on the ability to physically, mentally and socially adapt and self-manage<sup>16</sup>. Within this framework, social health is characterized by having the capacity to fulfil one's potential and obligations, the ability to manage life with some degree of independence, despite a medical condition, and to participate in social activities<sup>16</sup>. This concept of social health has been operationalised within the field of dementia in a European consensus paper<sup>17</sup>, encompassing wellbeing at multiple levels, and emphasizing social health as a favourable framework within which to focus on positive outcome measures in dementia research.

We need to adopt these new understandings of the relationship between well-being and health when living with dementia and incorporate this into the field of psychosocial research.

### **Research aim and questions**

This study aimed to involve people with dementia in establishing what is meaningful when participating in psychosocial interventions and to identify ways to capture the essence of this through research. We also wished to increase our knowledge of how to involve people with dementia in research consultations in a meaningful way and fully benefit from their participation.

To accomplish the project aims we formulated the following research questions:

Opinions and experiences of people with dementia:

1. What psychosocial interventions do people with dementia consider meaningful?
2. What do people with dementia consider to be meaningful approaches to capture the essence of psychosocial interventions through research?

Methodological issues:

- 1  
2  
3  
4  
5  
6  
7
3. How can we consult people who are living with dementia in diverse circumstances about the development of new psychosocial interventions and research related to this?

## 8 **Methods**

9  
10 The consultation presented in this paper was part of a larger study funded by the EU Joint Programme on  
11 Neurological Diseases (JPND)<sup>18</sup>, where the overall aim was to chart new territory in psychosocial  
12 measurement outcome research.  
13  
14  
15  
16  
17

### 18 **Design and procedure**

19  
20 The methods and material used for the consultation were developed through an iterative process  
21 involving people with dementia. An initial exploratory consultation was conducted in one city in the UK,  
22 involving five people with dementia and four carers. They were all members of a group established to  
23 advise researchers on ideas and proposals for dementia research. This consultation identified a number of  
24 important factors for successful consultation with a group of people with dementia, such as the  
25 importance of the appropriate environment and setting, the need for familiarity with setting, enhanced  
26 facilitation and in some cases the need for support for communication.  
27  
28  
29  
30  
31  
32  
33  
34

35 The results of this pilot consultation, together with preparatory work carried out by Alzheimer Europe,  
36 were discussed at a workshop with 13 dementia experts from the pan-European Interdem network who  
37 had a special interest and expertise in the subjects of this study.  
38  
39  
40  
41

42 Based on this workshop, materials for further consultations were developed: an information sheet for  
43 participants and a guide for moderators of the group. The guide for moderators served as a common  
44 framework for conducting the consultation. It suggested topics and questions designed to uncover issues  
45 related to the key aims and objectives of the project, and a vignette (a short imaginary situation) was  
46 created to be used during the consultations to facilitate discussion<sup>19</sup>, see appendix 1. The material was  
47 developed in English, and later translated and adapted to fit cultural contexts in the countries  
48 participating.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 The process of preparing and conducting the consultation, and the data analyses, took place during 2015.  
2  
3 Afterwards two workshops took places during 2016. First 26 dementia experts from the Interdem  
4 network, who had a special interest and expertise in the subjects, met to debate the initial findings; and  
5  
6 later the authors met to shape the final results.  
7  
8  
9

### 10 **Settings**

11 The consultation took place at four sites in Europe. Groups had 3-9 participants, and they were brought  
12 together through a mix of purposeful and convenience sampling. This made it possible to have  
13 representatives with a common experience of living with dementia, but from a range of backgrounds,  
14 nationalities, ages and different types and stages of dementia, thereby giving a voice to people with  
15 different experiences, views and preferences.  
16  
17

18 One consultation was conducted in Belgium with a multinational group of people with dementia who  
19 were part of an ongoing advisory group facilitated by Alzheimer Europe. The three other consultations  
20 were conducted at an Alzheimer's Society office (UK), a meeting place used for group activities for people  
21 with dementia (Italy) and a memory clinic running post-diagnostic support programmes (Denmark). The  
22 settings and the professionals attending were familiar to the participants. In some cases the participants  
23 were also familiar with each other, e.g. attending the same group activity.  
24  
25

26 The overall study was designed to have separate consultations with groups of people with dementia and  
27 family caregivers respectively. This paper includes the results of consultations with people with dementia.  
28  
29 In the UK consultation, however, the groups decided not to split; all participants clearly indicated that  
30 they were comfortable with participating and giving their opinion in a joint group. The results of this  
31 consultation were carefully split during data analysis, and this paper only includes data generated from  
32 people with dementia.  
33  
34

35 In the Alzheimer Europe group three participants with slightly more advanced dementia had  
36 communication support from caregivers during the consultation, e.g. help to explain questions or  
37 elaborate responses.  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 The consultations ran for between 1 and 1.5 hours and were facilitated by one or two researchers at each  
2 site. At some sites, researchers were supported by additional staff.

3  
4  
5 In full agreement with all participants, the consultations were audio recorded.  
6  
7  
8  
9

### 10 **Participants**

11 Twenty-five people with dementia from nine European countries participated in the group consultations.  
12  
13 Participants were between 49 and 81 years old, with a majority of people being over the age of 65. There  
14  
15 were 14 women and 11 men, who were mild to moderately affected by dementia. The characteristics of  
16  
17 the participants and groups are presented in table 1.  
18  
19  
20  
21  
22  
23

### 24 **Procedure**

25 Consultations were facilitated by researcher AD and DG in the Alzheimer Europe setting, researcher GM in  
26 the UK, researcher RC in Italy and researcher LØ in Denmark. The consultation was based on a focus group  
27 approach, and the facilitators initiated the consultation by giving a short introduction of the general topic.  
28  
29 Next, the specific topics from the interview guide were introduced stepwise, supported by the short  
30 vignette to facilitate discussion. Topics and questions were addressed in a flexible way and adapted to the  
31  
32 pace of the group, and all participants were encouraged to speak. Some participants found it difficult to  
33  
34 relate to the general topics and challenging to go from the vignettes to more specific personal opinions  
35  
36 and discussions. In these cases, participants were encouraged to think about their personal experience of  
37  
38 an activity they knew, in order to give them the opportunity to relate to the topics in a more personally  
39  
40 meaningful and concrete manner.  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50

### 51 **Data analysis**

52 Each audio-recorded consultation was separately transcribed and subsequently coded using a common  
53  
54 framework. This coding framework was created through an iterative process between the researchers  
55  
56 who had facilitated the consultations.  
57  
58  
59  
60



1 Initially, to set out a preliminary common framework for analysing the consultations, the Alzheimer  
2 Europe consultation was used as benchmark, and two of the researchers (AD and DG) carried out an open  
3 coding on the transcription of this consultation. Secondly, these codes were used to develop a common  
4 framework of pre-determined categories, which was discussed and adapted by all researchers involved in  
5 the consultations. Thirdly, these categories were used as a common framework to code all consultations.  
6 Coding was, however, not restricted to these pre-determined categories of the common coding  
7 framework. Researchers were free to add new codes and categories if necessary, in order to capture the  
8 varied experiences and views represented by all participants, and to avoid neglecting important details.  
9 The initial coding process was done in the original language, and at the final stages the essential parts of  
10 the transcripts from the Italian and Danish consultations were translated into English.  
11 The results of the four consultations were discussed and processed by the researchers at two workshops,  
12 first to synthesise initial findings and then to shape the definitive conclusions.

## 29 **Results**

30 The research questions in relation to opinions and experiences of people with dementia, described in  
31 section 1.1, are used as a framework to summarize the results from the consultation. The research  
32 questions serve as headlines, and are followed by subheadings of themes that emerged from the  
33 consultations. Key constructs summarize the subsequent narratives and related quotations.

34 **Research question: What psychosocial interventions do people with dementia consider meaningful?**

35 **Theme: Individual needs and rights**

36 **Key constructs:** Preconditions for participating, accepting risk, equal rights, individual needs and well-  
37 defined activities.

38 **Narrative:** Participants mentioned several requirements that should be met before they would consider  
39 taking part in any activities or research. These included feeling safe and that their needs were understood  
40 by a professional who has a sufficient understanding of dementia.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

*'Before I would even consider attending any sessions, be it art or singing or anything, I would need to feel that I was going to be in a safe, secure place, where people would know what my needs were, that there would be a quiet room...so the people who are holding the session actually knew what my needs were, rather than as I've had in the past. I turn up to do something, looking forward to it, and to find out that people don't even understand dementia'.*

*'It would be a bad experience for me if something was too overwhelming....if there were too many. Too many who contributes with input...it is confusing'.*

Whilst feeling safe was mentioned, the right to take risks was also emphasised. Some participants were concerned that people with dementia were sometimes denied the right to do activities where they could risk injury (e.g. cutting oneself whilst doing woodwork).

At the core of the preconditions for taking part was the desire to be treated like a human being who wants to feel good and enjoy life rather than as an "animal", "object" or "specimen" "under a microscope".

Some participants also emphasised that they expected specific information on the interventions they were invited to participate in, in order to decide if it was the right thing for them. *'One would also like to know how it works...for instance if it makes your better at remembering or something. You just need to tell how it can help us'.*

### **Theme: Social participation**

**Key constructs:** Social engagement, socialising, social inclusion, dignity, reciprocity, sharing and tailored activities.

**Narrative:** The importance of socialising with other people and social engagement was described in the context of a desire for companionship and understanding from others. The joy of engaging in social relations, both familiar and new, was illustrated in different ways.

Examples partly reflected the need to feel included in social contexts. However, issues of reciprocity and social dignity were also identifiable in the discussions. For example, participants emphasized the importance of being an equal member of a group, *'being part of everything that's not dementia'* and not

1 being treated as *'special'*, but nevertheless having appropriate attention paid to their needs. One  
2 participant spoke about the importance of activities which help to overcome the feeling that *'I am useless'*  
3 and *'a lesser person'* in relation to others. Beliefs about inherent dignity were reflected in a plea to  
4 researchers to treat people with dementia as human beings who like to feel good. As one participant  
5 stated, *'I am not an animal, I am a human being..... I don't want to feel like an object'*. Another explained,  
6 *'Music makes me feel needed; able to join in with people'*.  
7  
8  
9  
10  
11  
12  
13  
14  
15

16 The issue of reciprocity was raised several times in relation to individuals, groups, the community and  
17 researchers. Participants described their perception of receiving something which they enjoy or  
18 appreciate (e.g. yoga classes or walking with other people) and giving something back by educating  
19 people about dementia, contributing towards changing perceptions of dementia and contributing  
20 towards research efforts. The importance of having access to activities that are tailor-made for people  
21 with dementia was also discussed. Activities that gave them an opportunity to meet other people in a  
22 similar situation, sharing their situation and enjoying shared activities and interests. Some participants  
23 also emphasized the benefits of being in an environment that fitted their needs.  
24  
25  
26  
27  
28  
29  
30  
31  
32

33 *'And the beauty of this place is... and the various things that happen, it fills an empty diary but it also*  
34 *produces friendly people every time, supportive friendly people'*

35  
36  
37 *'I can talk here, everyone can have his say, I like it.*

38  
39 *'We like... I mean we are a bit boring aren't we in life.. and it would be nice to get together with people*  
40 *like.. you know.. a group of us sort of thing. Because when we are all together and mix.. we all understand*  
41 *each other, so in a similar group altogether - it would be ok'.*  
42  
43  
44  
45  
46  
47

48 **Theme: Confidence, positive emotions and sense of competence**

49  
50 **Key constructs:** Enjoyment, feeling good, reaching or touching emotions, creation, mastery and  
51 achievement.  
52

53  
54 **Narrative:** A recurring issue throughout the consultations was that people with dementia want to enjoy  
55 themselves, have fun and feel good. Participants expressed interest in activities, programmes or forms of  
56  
57  
58  
59  
60

1 support which help them to do so, and the desire to judge the success of such interventions mainly on the  
2 basis of whether they result in enjoyment, having fun and feeling good. As one participant put it, *"If I am  
3 smiling, then it is a success."*

4  
5  
6  
7  
8 Several references were made to certain activities/interventions that touch a person's emotions (e.g.  
9 music, arts) and enable the person to access emotional memories which would otherwise not have come  
10 to the surface, creating an emotional reaction. One person emphasised that it was not about triggering  
11 factual memories, but about emotional memory and emotional happiness.

12  
13  
14  
15  
16 Many examples were given of activities that the participants were able to do, and how being able to do  
17 them meant a lot to them in terms of personal satisfaction, the sense of being able to master something  
18 and having a sense of control. One person said that joining the group activity for people with dementia  
19 gave him the opportunity to be completely independent for a while, autonomous and free to express his  
20 point of view.  
21  
22  
23  
24  
25  
26  
27  
28

### 29 **Theme: Health**

30  
31 **Key constructs:** Cognition, functional ability, mental health and physical health.

32  
33 **Narrative:** Participants varied in their opinions on whether interventions should be applied to try to make  
34 a difference to their cognitive and functional ability. Some wanted specific personalized ways of coping  
35 with memory problems and to be able to participate in daily activities, and they mainly emphasised a wish  
36 to maintain functioning rather than improve it.  
37  
38  
39

40  
41 *"I don't want to lose memory, sometimes I have something like memory loss, and I think that interventions  
42 like this one can be useful for my memory"*

43  
44  
45  
46 *'I don't want to be like my husband, sitting all day long in front of the television... if I can, I want to  
47 continue to exercise my mind'.*

48  
49  
50 The importance of doing something because it affects physical and mental health was also highlighted.

51  
52 *'Now that we are talking about music... that has to do with feelings. It makes you recognize...you don't  
53 remember.. but you recognize the feelings and it makes you feel good'.*  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

*'For example, I was always anxious before I joined the group, I always had the need to check my purse looking for something. Now I don't do it anymore, the intervention reduced my tension and I really appreciate that'.*

Specific physical health-related outcomes included improving balance, having a strong core, preventing falls and remaining mobile.

*'I joined a walking group ... I find it twofold, one that I find myself feeling very well, after I walk seven or eight kilometres ... And so I feel that this has an impact on my life because I am forced to talk to a lot of people, some I know, some I don't know, some have an understanding of the illness, some don't'.*

### **Theme: Well-being**

**Key constructs:** Coping, sense of control, confidence, identity, self-esteem, quality of life and well-being.

**Narrative:** Participants emphasised that coping with dementia did not necessarily mean effectively managing various everyday situations, but rather about feeling OK about having dementia, being emotionally able to deal with any difficulties which may arise and focusing on what was still possible. Some participants spoke with great enthusiasm about activities which gave them a sense of control and a feeling of confidence as a result of being able to achieve or create something (e.g. training dogs, doing woodwork, playing an instrument and singing). Being able to produce or create something was linked to self-esteem and self-respect.

*'to give me a sense of "me" again, a sense of identity...'*

*'They want me to be part of the group, not because I have the illness, but because I am...[person's name]..'*

*'Just feeling well, at peace with yourself, perhaps for a while not dwelling on problems, and you get some period of comfort... It is just joy. And I love it'.*

In general, participants took it for granted that problems occurred in daily life. Quality of life and wellbeing seemed to be a reflection of 'getting on with life' despite problems that might arise. Some participants referred to living well with dementia in the context of doing something which makes them feel good and happy, being part of the wider social group not dwelling on problems, but getting on with life and coping with setbacks and difficulties.

1  
2 *'...just feeling well at peace with yourself, perhaps for a while not dwelling on problems and you get some*  
3 *period of comfort. I mean I get absolute joy from walking the dog in woods, just being back with nature,*  
4 *that there is nothing there other than nature and the birdsong and watching my dog enjoying herself. It is*  
5 *just joy. And I love it'.*

6  
7  
8  
9  
10 *'Sometimes I need a 'change of scenery'- I leave behind my family for a while and all my worries'*

### 11 12 13 14 **3.2. Research question: What do people with dementia consider to be meaningful approaches to** 15 **capture the essence of psychosocial interventions through research?**

#### 16 17 **3.2.1 Theme: Views on evaluation and outcomes**

18  
19 **Key constructs:** Momentary versus long-term outcomes, authenticity, accuracy of feedback, emphasis on  
20 predominantly qualitative methods and resistance to self-report instruments and questionnaires.

21  
22 **Narrative:** The consultations revealed various views and opinions on what would be the most ideal way to  
23 capture the essence of interventions and how to evaluate them. However, some participants found it  
24 difficult to conceptualise outcome measurement. They were encouraged to refer to their own experience  
25 of participating in an activity to help them relate to the issue in a more concrete manner. As a result, the  
26 debate in the four different settings of the consultation to some degree reflected features of the specific  
27 local activities.

28  
29 Participants found that recording outcomes and reactions in the moment, both during activities or just at  
30 the end of them, was important and should be the main focus. Various ways of doing this were proposed  
31 such as interviewing, filming or audio recording, observing body language and expression and taking note  
32 of reactions.

33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
*'In the moment' evaluations were described as being most authentic and most accurately reflecting what*  
*people actually think and feel, and therefor easier for people with dementia to manage.*

*'I am worried that I wouldn't remember many things if researchers would ask me questions some weeks*  
*after the intervention''*

*'I think 'in the moment' is the most honest you're gonna get....I think filming is a good way because...we*  
*would forget what you filmed... as everybody does...and you get the real reactions'.*

Another commented that what is measured 'in the moment' such as happiness might also have a lingering effect and is just the trigger, suggesting that long-term effects should also be measured.

Several participants highlighted potential difficulties and complex issue of obtaining 'in the moment' feedback. Difficulties included social desirability (e.g. wanting to please, just saying what the researchers might want to hear), being too tired to respond, or being put on the spot and feeling under pressure to respond. On the other hand, they also recognised the problem of being asked later and having forgotten how they felt about the intervention. It was acknowledged that the same method for obtaining feedback might not be suited to everyone across all disabilities due to dementia.

The importance of getting information and observation from other people (for example family caregivers) was discussed. Some found it particularly important if changes over a period of time are to be measured.

One participant suggested: *'You could also ask the relatives. I have experienced that you get a lot of input from them. Sometimes it is hard to see the little changes...you don't see it yourself'*.

Some participants were very critical of questionnaires.

*'If you talk with someone, you can really share your thoughts, your idea. I don't think that word and pencil questionnaires can grasp what you really think'*.

Participants in general agreed that people with dementia should be more involved in the preparation of interventions so as to ensure that they correspond to their individual needs and preferences.

It was also suggested that users should be involved in the analysis and interpretation of observations and measurements, e.g. video recordings, to make sure that the analysis came to the right conclusions. *'You need to involve the people who were there, you need to know what they were actually feeling...right then'*.

## **Discussion**

### **Main findings**

1 The consultation was conducted to embody the voices of people with dementia in understanding what  
2 they consider to be meaningful aspects of psychosocial interventions, including the identification of  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

An essential aim of the project was to include a broad variety of people living with dementia, and to present all their views. The consultation took part at four sites across Europe, with participants representing various experiences of living with dementia, and researchers found a number of common themes among participants. There were of course also contrasting views, and these may reflect the various contextual features of the four groups, and the differing experiences of living with dementia among participants.

In general, the findings showed that the people with dementia who were consulted favoured psychosocial interventions that imply social engagement and inclusion, and that they wanted to be involved in settings and activities where they sensed respect for dignity and reciprocity. Various views on what they found important to gain from interventions and activities were presented. Activities that imply enjoyment and reaching or touching emotions were in general emphasized, including activities that give a sense of mastery and achievement. In this way, some activities and accomplishments seem to have a symbolic function linked to self-esteem and identity, rather than being simply ways to pass time or keep active. These themes strongly relate to the concept of social health, as defined by Huber et al.<sup>16</sup>, and operationalized in relation to people with dementia by Droes et al.<sup>17</sup>, and to a positive psychology approach to living with dementia<sup>15</sup>. These new concepts are essential in the future development of meaningful interventions within the field of psychosocial interventions in dementia.

Understanding the contextual influents on participant reports is an important consideration in psychosocial research<sup>20</sup>. When discussing actual outcomes, participants had varying views on the importance of outcome measures on cognition and ability, perhaps reflecting differing contexts of the four study sites<sup>21</sup>. Some questioned the relevance of cognitive and functional ability to their overall quality of life. Those in favour of outcome measurements that address cognition and ability stressed the



1 importance of emphasizing the maintenance of function rather than improvement. Mental health was  
2 described as a positive outcome measure that was generally sought. In particular having confidence and a  
3 sense of control was emphasized. This is in line with the lack of convincing evidence that the level of  
4 cognitive impairment is associated with lower quality of life, whereas depression is consistently  
5 associated with decreased quality of life<sup>22</sup>. It also underlines how other factors such as choice, self-  
6 determination and maintaining independence influence the quality of life of people with dementia<sup>23,24</sup>.  
7  
8 These results are also consistent with the concepts of social health and positive psychology, and they  
9 underline the need to develop new outcomes that reflect these positive constructs, and leave behind  
10 outcome measures that focus on deficits which negate the possibility of living well with dementia.  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22

23 Participants also stressed the importance of activities to meet the individual and various special needs of  
24 people with dementia. There were, however, various opinions on this, underlining the need to delicately  
25 balance the need for activities and settings where people with dementia feel safe, with their right to  
26 accept risks and have equal access to activities that are meaningful and rewarding at a personal level.  
27  
28 Such reflections reinforce a continued discussion on human rights and ethics related to dementia when  
29 designing and applying psychosocial interventions. It also underlines the essential involvement of people  
30 with dementia in this discussion.  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51

52 When discussing the actual application of outcome measures both momentary and long-term outcomes  
53 were mentioned, and there was a preference for momentary outcomes bringing more authenticity and  
54 accuracy to the feedback of people with dementia. There was also an emphasis on qualitative methods.  
55  
56 These views underline the importance of using mixed methods when assessing the outcomes of  
57 psychosocial interventions in dementia<sup>25</sup>.  
58  
59  
60

In addition to emphasizing the opinions and experiences of people with dementia in relation to the  
research questions, the project also addressed the methodological issues of how to consult people living  
with dementia under different conditions and from various backgrounds and have them contribute. The

1 design of this study gave access to the experiences and opinions from a broad spectrum of people living  
2 with dementia. Through an iterative process, involving both people with dementia, we succeeded in  
3 developing a structured methodology that, with minor cultural adaptations, could be applied in an  
4 international setting with a varied group of people with dementia. This structured framework gave us the  
5 opportunity to gather rich and diverse data, which could be condensed to answer the research questions  
6 that we set out to address in this study.  
7  
8  
9  
10  
11  
12  
13  
14  
15

### 16 **Limitations**

17 Despite the broad recruitment of participants for this study there are still limitations with regard to the  
18 variety of people with dementia represented in the study. For instance, people with dementia who do not  
19 take part in psychosocial activities or advisory groups were not represented among participants. Also,  
20 people with severe dementia were not included in this study. These limitations could have implications  
21 for the generalizability of results. If people with severe dementia had been included a different design  
22 would have been needed and special efforts made to elicit their views<sup>26,27</sup>.  
23  
24  
25  
26  
27  
28  
29  
30

31 Another limitation to this study is the variation of caregiver involvement at the four sites. As part of the  
32 overall project, caregivers were invited to participate in a separate consultation addressing their  
33 involvement in and views on psychosocial activities. The results from this consultation form a separate  
34 study. However, at one of the settings (UK) caregivers took part in the consultation together with people  
35 with dementia, since people with dementia and caregivers decided not to split into separate groups.  
36 Caregivers were also present to support communication for three of the participants in the Alzheimer  
37 Europe working group consultation. They were not directly involved in the discussion. Still, in both  
38 situations, it is possible that the mere presence of caregivers may have influenced the results of the  
39 consultations. On the other hand, having a trusted person provide support to a person with dementia can  
40 be facilitating and empower a person with more advanced dementia to follow the discussion and  
41 contribute. This discussion underline the importance of achieving the appropriate balance between carers  
42 supporting people with dementia to have a voice, and carers speaking for the person with dementia and  
43 inhibiting the person's own contribution.  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 A further limitation is that people with dementia were not directly involved in the processing or  
2 interpretation of results of this consultation. It can seem paradoxical, since such involvement was  
3 requested by some participants in the consultation. We acknowledge that this should have been  
4 considered as part of the original design of the study, but for practical reasons it was not possible to  
5 change the design during the study.  
6  
7  
8  
9  
10

11 In the light of the above limitations, we recommended that future research also involves people who are  
12 not already participating in interventions. We acknowledge the need to include people with a more  
13 severe degree of dementia. Future studies need to be designed to meet the special needs and ethical  
14 considerations related to their participation. We also recommend that future research explores how  
15 consultations with people with dementia can be fully co-processed and endorsed by people with  
16 dementia.  
17  
18  
19  
20  
21  
22  
23

24 These considerations are further elaborated and discussed in Alzheimer Europe's position paper on PPI  
25 (patient and public involvement)<sup>8</sup>. This position paper is related to the current study, and the European  
26 Working Group of People with Dementia, who contributed to the consultation in this study, also took part  
27 in the collaboration on the position paper. The position paper outlines the potential challenges, risks and  
28 benefits of the much needed and meaningful involvement of people with dementia in research, ranging  
29 from consulting people with dementia at various stages of research to more comprehensive involvement  
30 in research.  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40

#### 41 **Conclusion**

42 The results of this study clearly underline benefits of involving people with dementia when planning and  
43 conducting psychosocial interventions research. The views expressed by people with dementia supports  
44 the position that in addition to consideration about maintaining health and cognition, activities and  
45 interventions could focus on enhancing dignity through social engagement, reciprocal contribution to  
46 society, and should take into consideration individual needs, preferences and rights. These values are  
47 embedded in concepts of social health and positive psychology, which are emerging within the field of  
48 psychosocial interventions for people with dementia.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 This consultation also demonstrates that, given the opportunity and taking into account special needs,  
2  
3  
4 people living with dementia within a variety of settings across Europe can contribute to research on  
5  
6 psychosocial interventions in dementia.  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For Peer Review

## References

1. Woods B. The experience of carers of a diagnosis of dementia: Results of a five-country survey. Alzheimer Europe; 2017; Berlin.
2. Dupuis SL, Gillies J, Carson J, Whyte C. Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia* 2012;11(4):427-452. doi:10.1177/1471301211421063
3. Alzheimer Europe. National Dementia Strategies. Updated Tuesday 23 May 2017; <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies>. Accessed January 3, 2018.
4. Alzheimer's Disease International. Dementia Friendly Communities - Resources. <https://www.alz.co.uk/dementia-friendly-communities/resources>. Accessed January 3, 2018.
5. Bartlett R. The emergent modes of dementia activism. *Ageing and Society*. 2012;34(04):623-644. doi:10.1017/s0144686x12001158
6. Iliffe S, McGrath T, Mitchell D. The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies. *Health Expectations*. 2013;16(4):351-361. doi:10.1111/j.1369-7625.2011.00728.x
7. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*. 2014;17(5):637-650. doi:10.1111/j.1369-7625.2012.00795.x
8. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Ageing Ment Health*. 2017;1-7. doi:10.1080/13607863.2017.1317334
9. Olazarán J, Reisberg B, Clare L, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord*. 2010;30(2):161-178. doi:10.1159/000316119
10. Winblad B, Amouyel P, Andrieu S, et al. Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet Neurology*. 2016;15(5):455-532. doi:10.1016/s1474-4422(16)00062-4
11. Moniz-Cook E, Vernooij-Dassen M, Woods R, et al. A European consensus on outcome measures for psychosocial intervention research in dementia care. *Ageing Ment Health*. 2008;12(1):14-29. doi:10.1080/13607860801919850
12. Moniz-Cook E, Vernooij-Dassen M, Woods B, Orrell M. Psychosocial interventions in dementia care research: the INTERDEM manifesto. *Ageing Ment Health*. 2011;15(3):283-290. doi:10.1080/13607863.2010.543665
13. Testad I, Corbett A, Aarsland D, et al. The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: a systematic review. *Int Psychogeriatr*. 2014;26(7):1083-1098. doi:10.1017/S1041610214000131
14. Stoner CR, Orrell M, Spector A. Review of Positive Psychology Outcome Measures for Chronic Illness, Traumatic Brain Injury and Older Adults: Adaptability in Dementia? *Dement Geriatr Cogn Disord*. 2015;40(5-6):340-357. doi:10.1159/000439044
15. Wolverson EL, Clarke C, Moniz-Cook ED. Living positively with dementia: a systematic review and synthesis of the qualitative literature. *Ageing Ment Health*. 2016;20(7):676-699. doi:10.1080/13607863.2015.1052777
16. Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ*. 2011;343. doi:10.1136/bmj.d4163
17. Droes RM, Chattat R, Diaz A, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Ageing Ment Health*. 2017;21(1):4-17. doi:10.1080/13607863.2016.1254596
18. <http://www.neurodegenerationresearch.eu/wp-content/uploads/2015/10/JPND-Report-Fountain.pdf>.

19. Spector A, Hebdtich M, Stoner CR, Gibbor L. A biopsychosocial vignette for case conceptualization in dementia (VIG-Dem): development and pilot study. *Int Psychogeriatr*. 2016;28(9):1471-1480. doi:10.1017/S1041610216000338
20. Vernooij-Dassen M, Moniz-Cook E. Raising the standard of applied dementia care research: addressing the implementation error. *Aging & Mental Health*. 2014;18(7):809-814. doi:10.1080/13607863.2014.899977
21. Bunn F, Sworn K, Brayne C, Iliffe S, Robinson L, Goodman C. Contextualizing the findings of a systematic review on patient and carer experiences of dementia diagnosis and treatment: a qualitative study. *Health Expectations*. 2015;18(5):740-753. doi:10.1111/hex.12162
22. Banerjee S, Samsi K, Petrie CD, et al. What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *Int J Geriatr Psychiatry*. 2009;24(1):15-24. doi:10.1002/gps.2090
23. Moyle W, Fetherstonhaugh D, Greben M, Beattie E, AusQo Lg. Influencers on quality of life as reported by people living with dementia in long-term care: a descriptive exploratory approach. *BMC Geriatr*. 2015;15:50. doi:10.1186/s12877-015-0050-z
24. Stewart-Archer LA, Afghani A, Toye CM, Gomez FA. Subjective quality of life of those 65 years and older experiencing dementia. *Dementia (London)*. 2016;15(6):1716-1736. doi:10.1177/1471301215576227
25. Windle G, Newman A, Burholt V, et al. Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ Open*. 2016;6(11). doi:10.1136/bmjopen-2016-011634
26. Goodman C, Amador S, Elmore N, Machen I, Mathie E. Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *Int J Nurs Stud*. 2013;50(12):1639-1647. doi:10.1016/j.ijnurstu.2013.06.008
27. Iréne E, Ingrid H, Sofia K. Sliding interactions: An ethnography about how persons with dementia interact in housing with care for the elderly. *Dementia*. 2011;10(4):523-538. doi:10.1177/1471301211409376

**Appendix 1:****Vignette and questions from the discussion guide for moderators of the group consultation involving people with dementia****Vignette about people with dementia participating in a research project:**

*Imagine.... In connection with you having dementia, you have been offered the possibility to attend a series of "singing and remembering" sessions....*

(It was pointed out to researchers that this was just an example. They were free to use other examples that might include exercise routines, cognitive stimulation etc.).

*...Please try to imagine the impact that such sessions might have on your life, health, condition or wellbeing (both at the time and afterwards). Please also think about how you would personally assess whether or not they were successful or beneficial.*

**Suggested themes and questions:**

- In connection with the series of "singing and remembering" sessions, what impact do you think they might have on your quality of life, health/condition or social contact with others?
- Which aspect of having/living with dementia would you like to see improved as a result of taking part in a research activity, programme or intervention. In other words: if you took part in a session, in which areas of your life would you hope to see an improvement?
- On what basis (or "according to which criteria") do you think researchers should assess whether or not a particular programme or intervention was successful/effective?

(It was pointed out that researchers were free to split, reformulate, adapt and add questions and emerging themes).

**Table 1: Details on consulted groups, participants and consultations**

<b>Groups and participants</b>							<b>Consultations</b>		
<b>Group location</b>	<b>Setting</b>	<b>Group characteristics</b>	<b>Participant characteristics<sup>§</sup></b>	<b>Moderator(s)</b>	<b>Duration</b>	<b>People with dementia only or mixed group</b>	<b>Support for people with dementia</b>		
Alzheimer Europe	Hotel meeting facility in Brussels	Members of the European Working Group of People with dementia. <sup>†</sup> Participants were familiar with each other, except 1 new member.	9 people with dementia Age: 56-71 M/F: 3/6	Psychologist/PhD Social Worker/PhD Both familiar to group/participants	1 ¼ hours	People with dementia only	3 family carers were present to support 3 group members. Flip chart record of the discussion and printed handouts.		
UK	Local Alzheimer's Society offices	Members of the SHINDIG group. <sup>‡</sup> Participants were familiar with each other.	4 people with dementia Age: 1: 61, 3 >65 M/F: 3/1 3 caregivers (all spouses)	Lead researcher Senior clinical nurse PhD student All familiar to group/participants	1 ½ hour	Mixed group	Flip chart record of the discussion.		
Italy	Local Alzheimer's Society offices	Members of a cognitive stimulation group. Participants were familiar with each other.	7 people with dementia Age: 72-79 years M/F: 3/4	3 psychologists 2 other professionals All familiar to the participants	1 hour	People with dementia only	None		
Denmark	Memory clinic	Members of a group support programme for PwD. Participants were familiar with each other.	5 people with dementia Age: 49-81 years M/F: 3/2	1 Psychologist Familiar to group/participants	1 hour	People with dementia only	Framework of the consultation presented on power point slides. Flip chart record of the discussion.		

<sup>†</sup>The EWGPWD is comprised of people with dementia. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with its own Board and agenda of activities. Nationalities of members: Germany, Czech Republic, England, Scotland, Ireland, Jersey, Norway, Finland and Slovenia.

<sup>‡</sup>The SHINDIG group is a city wide forum which provides opportunities for those living with dementia to give views and opinions on local services and developments.

<sup>§</sup>Level of details differs due to the nature of the different group settings.  
All participants were diagnosed with dementia, and were living with dementia at a mild-moderate stage.



**Table 1: Details on consulted groups, participants and consultations**

<u>Groups and participants</u>			<u>Consultations</u>				
Group location	Setting	Group characteristics	Participant characteristics <sup>§</sup>	Moderator(s)	Duration	People with dementia only or mixed group	Support for people with dementia
Alzheimer Europe	Hotel meeting facility in Brussels	Members of the European Working Group of People with dementia. <sup>†</sup> Participants were familiar with each other, except 1 new member.	9 people with dementia Age: 56-71 M/F: 3/6	Psychologist/PhD Social Worker/PhD Both familiar to group/participants	1 ½ hours	People with dementia only	3 family carers were present to support 3 group members. Flip chart record of the discussion and printed handouts.
UK	Local Alzheimer's Society offices	Members of the SHINDIG group. <sup>‡</sup> Participants were familiar with each other.	4 people with dementia Age: 1: 61, 3 >65 M/F: 3/1 3 caregivers (all spouses)	Lead researcher Senior clinical nurse PhD student All familiar to group/participants	1 ½ hour	Mixed group	Flip chart record of the discussion.
Italy	Local Alzheimer's Society offices	Members of a cognitive stimulation group. Participants were familiar with each other.	7 people with dementia Age: 72-79 years M/F: 3/4	3 psychologists 2 other professionals All familiar to the participants	1 hour	People with dementia only	None
Denmark	Memory clinic	Members of a group support programme for PwD. Participants were familiar with each other.	5 people with dementia Age: 49-81 years M/F: 3/2	1 Psychologist Familiar to group/participants	1 hour	People with dementia only	Framework of the consultation presented on power point slides. Flip chart record of the discussion.

<sup>†</sup>The EWGPWD is comprised of people with dementia. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with its own Board and agenda of activities. Nationalities of members: Germany, Czech Republic, England, Scotland, Ireland, Jersey, Norway, Finland and Slovenia.

<sup>‡</sup>The SHINDIG group is a city wide forum which provides opportunities for those living with dementia to give views and opinions on local services and developments.

<sup>§</sup>Level of details differs due to the nature of the different group settings.  
All participants were diagnosed with dementia, and were living with dementia at a mild-moderate stage.

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

27

28

29

30

31

32

33

34

35

36

37

38

39

40

41

42

43

44

45

46

47

**Appendix 1:****Vignette and questions from the discussion guide for moderators of the group consultation involving people with dementia****Vignette about people with dementia participating in a research project:**

*Imagine.... In connection with you having dementia, you have been offered the possibility to attend a series of "singing and remembering" sessions....*

(It was pointed out to researchers that this was just an example. They were free to use other examples that might include exercise routines, cognitive stimulation etc.).

*...Please try to imagine the impact that such sessions might have on your life, health, condition or wellbeing (both at the time and afterwards). Please also think about how you would personally assess whether or not they were successful or beneficial.*

**Suggested themes and questions:**

- In connection with the series of "singing and remembering" sessions, what impact do you think they might have on your quality of life, health/condition or social contact with others?
- Which aspect of having/living with dementia would you like to see improved as a result of taking part in a research activity, programme or intervention. In other words: if you took part in a session, in which areas of your life would you hope to see an improvement?
- On what basis (or "according to which criteria") do you think researchers should assess whether or not a particular programme or intervention was successful/effective?

(It was pointed out that researchers were free to split, reformulate, adapt and add questions and emerging themes).