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Development of best practice recommendations to enhance access to and use of formal community care services for people with dementia in Europe: a Delphi process conducted by the Actifcare project

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Title

Development of best practice recommendations to enhance access to and use of formal community care services for people with dementia in Europe: a delphi Process conducted by the Actifcare Project.

Abstract

Objectives

Home-dwelling people with dementia and their informal carers experience barriers impeding access to community care services. This study is a part of the Actifcare project where eight countries participated. The aim was to achieve consensus on best practice recommendations for enhancing access to and use of formal community care services.

Method

A Delphi consensus process was conducted. A total of 48 professional experts, 14 people with dementia and 20 informal carers rated the importance of 72 statements on a 7-point Likert scale. Consensus was based on the median and level of dispersion.

Results

An appointed contact person emerged as the main recommendation in *Recommendations to enhance access.* Coordination and flexibility in setting and type of services were among the *Recommendations to enhance use.* Training of health care personnel and person-centred care were central *Recommendations that can facilitate access or use indirectly.*

Conclusion

The Actifcare Best Practice Recommendations suggest practical measures that can be taken by decision makers to enhance access and use of community care services, and thereby enhance quality of care and quality of life for home dwelling people with dementia and their informal carers.

Keywords

Dementia, access, services, Delphi process, consensus, best practice

Background

Due to cognitive and functional decline, and the behavioral and psychological symptoms of dementia, people with dementia become progressively dependent on help and support (McLaughlin et al., 2010). This help is often provided by informal carers (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). The provision of informal care, which increases as the disease progresses, is often associated with higher levels of burden and distress that has an impact on carers' well-being and health (Hughes et al., 2014; Pinquart & Sorensen, 2003; Sorensen, Duberstein, Gill, & Pinquart, 2006). In a later stage of the dementia, informal care is often complemented with formal care. A systematic review found that older people with dementia used community services, such as home support, day care or respite care, less often than medical services, despite the fact that community services may be very useful for them and their informal carers (Weber, Pirraglia, & Kunik, 2011). Brodaty and colleagues found a lack of appropriate services and knowledge about the services that are available (Brodaty, Thomson, & Fine, 2005). Informal carers in the qualitative study of Peel & Harding (2014) regularly reported being unable to access appropriate services (Peel & Harding, 2014). Barriers to use of formal care for people with dementia and their informal carers have been identified in other studies: the perception that services or care are a threat to

independence and social life; the stigma that is attached to receiving dementia care services; and poor organization or functioning of services. Other reasons given for not using services are that the person with dementia does not find it necessary, and that the family finds that formal care services are not necessary yet (Brodaty et al., 2005; Kerpershoek et al., 2019; Stephan et al., 2018; Werner, Goldstein, Karpas, Chan, & Lai, 2014).

Actifcare (ACcess to TImely Formal CARE), is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The overall objective of the Actifcare project was to generate best practice recommendations for access to formal dementia care services that can be integrated into European health and social care systems (Kerpershoek et al., 2016). The aim of the present study was to achieve consensus on actions or measures that can be taken to enhance access and use of services. The Actifcare project defined formal community care services as 'home nursing care, day care services, in-home long-term medical nursing and, social care structures and processes'. The term 'social care structures and processes' was used to capture differences in systems or settings across countries. The term may include health services, as some countries define certain health services as social services. The project lasted from January 2014 to December 2017. The participating countries were Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Sweden and the United Kingdom.

Method

The aim of this study was to consult with multiple stakeholders to achieve consensus on how to make it easier for people with dementia and their informal carers to access formal care services. A Delphi process was the chosen method because it can be a useful tool to achieve convergence of opinion concerning real-world knowledge solicited from experts in the area in question (Dawson & Barker, 1995). A Delphi process applies a feedback process that consists of a series of structured questionnaire rounds (Powell, 2003). In this study, a three-round

modified Delphi procedure was used to seek the opinion of experts by experience (people with dementia and informal carers), health professionals, policy makers and academics.

Generation of statements

The Norwegian research team was responsible for the Delphi process. The process started with a preparatory meeting in the Actifcare consortium where the nature of the statements to be rated was discussed. This resulted in a template denoting the phrasing of the statements and the elements they should contain (table 1). The template was piloted by the Irish Actifcare team to test feasibility and clarity. Next, the eight Actifcare teams identified actions or measures that could be taken to enhance access and proposed statements using the template. The Norwegian team processed the statements; overlapping content was removed, and ambiguous statements were rephrased. When necessary, concepts were defined or specified in footnotes. The resulting list of statements was sent to the principal investigators of the eight research teams to be checked for inconsistencies. A version of the statements for the experts by experience was adapted according to language advice from the Alzheimer association's European Working Group of People with Dementia (EWGPWD) and translated by the national research teams in the non-English speaking countries (table 1).

Rating of statements

The two following survey rounds consulted both professional experts and experts by experience who rated the importance of the statements on a Likert scale from 1 ('not important at all') to 7 ('extremely important') (Powell, 2003) and provided comments (Rowe, Wright, & Bolger, 1991). The filled-in rating forms were submitted by e-mail. The ratings were aggregated and analyzed. The statements that had to be changed because they were perceived as unclear were marked. Results of the rating and the anonymized comments were distributed to all participants in the next round (table 1) (Hsu & Sandford, 2007).

(Please put Table 1 here: **The stages and rounds of the Actifcare Delphi process**)

Participants

No set standard of selecting Delphi participants exists in the literature. Hsu & Sandford (2007) state that Delphi participants should be highly trained and competent within the specialized area of knowledge related to the target issue (Hsu & Sandford, 2007).

The criteria for being defined as a professional expert in the present Delphi process were to have published national or international papers in the field (scientific expert); have extensive clinical experience in the field of dementia care and a minimum of bachelor degree (clinical expert); have special knowledge in the field and institutionalized authority to be influential in a relevant way (policy/administrative decision maker). The members of the Actifcare scientific advisory board, who fulfilled the criteria above, were also asked to participate as professional experts. Each national Actifcare team identified, contacted and recruited up to eight relevant experts in their country from national, regional, or local level. The professional experts communicated directly, in English, with the Norwegian research team during the rating rounds.

Two to four members from each national Actifcare team took part in the first round and proposed statements on behalf of their research team. All were researchers who qualified according to the criteria above. In the two following rating rounds, both professional experts and experts by experience took part (table 2 and 3). Experts by experience were defined as home dwelling people with a diagnosis of dementia and/or (former) informal carers. Each Actifcare country recruited three to six experts by experience among people who participated in the Actifcare cohort study, through the national Alzheimer association (AE), and in Norway also through local dementia coordinators. In addition, five members of EWGPWD were recruited through contact with staff members of AE who organized and supported when

necessary (https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia).

(Please put Table 2 here: **Participants in the e-mail-based second and third Delphi round**)

(Please put Table 3 here: **Characteristics of the participants of the Delphi-process)**

Analyses

Two criteria were used to measure the level of agreement and determine consensus; central tendency and level of dispersion. Central tendency was measured by the median score on the 7-point Likert scale. A statement reached consensus as important if the median score was 6 or 7, it was undecided if the median score was 3, 4 or 5, and regarded as not important if the median score was 1 or 2. Regarding dispersion, consensus was reached if the quartile deviation (the interquartile range divided by 2) was 0.5 or lower (≤0.5) and 75% of the ratings of a statement were within two adjoining values. Analyses were performed for three main groups; 'all experts', 'experts by experience', and 'professional experts'. The group 'experts by experience' consisted of the subgroups 'people with dementia' and 'informal carers'. The group 'professional experts' had the subgroups 'Actifcare experts' and 'external professional experts'. In the second round of the Delphi process, a statement had to be rated again if it did not reach consensus in all three groups. In the third round, a statement that reached consensus in the group 'all experts' was considered to have reached consensus. The numbers of participants were too small to allow for analysis of national differences. Subgroup analyses were performed after the third round despite the fact that these subgroups were very small. The purpose was to detect consistent differences in the rating between the subgroups which might require consideration.

Results

First Round; Statements

The eight Actifcare research teams suggested 74 statements in total which were processed into 72 statements in two categories. The first category described how to ensure access and overcome barriers. Examples were; a contact person for the person with dementia and the family; ways of providing information; how the general practitioner (GP) could promote access; how services could be integrated and health care personnel be trained to promote access. The second category described how to make services more attractive. Examples were; to focus on the perspective, needs and wishes of the person with dementia; home care services providing a timetable adjusted to the person's routine; and services for people with young onset dementia that fit their specific needs (table 5).

Second Round; Survey Round

Forty-eight professional experts submitted their rating, 54% of these were women. Twenty-three were scientific experts, 11 were clinical experts and 14 were policy makers /administrative experts. Of the scientific/clinical experts, 12 were members of the Actifcare project. Of the 34 experts by experience who took part in this second round, 11 were people with dementia, three were dyads of people with dementia and informal carers providing one common rating, 20 were informal carers, 66% were women (table 2 and 3). Of the 72 statements, 28 reached consensus in this round (tables 4,5).

(Table 5 Results for each statement in rounds 2 and 3 for the different groups of experts can be placed here, if possible, or at the end of the manuscript.)

Differences between 'Experts by Experience' and 'Professional Experts' in the second Round

The members of the group 'experts by experience' differed too much in their ratings to reach consensus (had too high levels of dispersion) on five statements (statements numbers

7,9,13,20,34, table 5). These statements concerned: the contact person's responsibility to provide information to the person with dementia; motivate for and facilitate referral to services; involving the person with dementia in decisions about care; and provision of information by specialized outpatient services. The group 'professional experts' reached consensus on these five statements.

The opposite was the case for eight other statements (statements numbers 6,19,35,53,57,65,66,71, table 5). The group 'professional experts' differed too much in their ratings on these statements, while the group of experts by experience reached consensus. These statements concerned: the contact person's responsibility to coordinate services; establish contact with the person with dementia and the informal carer as early as possible; coordination of structures of counselling; monetary support; transport; starting service use with a short term social introduction and offering a trial of the service being considered; and an adjustable time frame for services.

Third Round; Survey Round

Of the 48 professional experts who participated in the second round (table 2), 42 (88%) submitted their rating in the third round. Of these 42, 10 were members of the Actifcare project. Of the 34 experts by experience, 29 (85%) submitted ratings in this round.

In the third round, consensus was considered as reached regarding a statement if the criteria of dispersion and median score were fulfilled for all participants seen as one group. Of the 44 statements that were rated in the third round, 34 reached consensus as important. No statements reached consensus as 'not important'. Of the 10 statements that did not reach consensus, two had too low median rating, eight had too high levels of dispersion (tables 4 and 5).

The results of the rating of the group 'experts by experience' differed from the group 'all experts' on nine statements in the third round (table 5). The results of the rating of the group 'professional experts' differed from 'all experts' on two statements (statements number 56 and 58, table 5).

Differences between 'Experts by Experience' and 'professional Experts' in the third Round

As in the previous round, the experts by experience varied too much on how important they found statements number 9 and 13 about the contact person to reach consensus (table 5), i.e. the levels of dispersion were high. The professional experts reached consensus that these two statements were important.

In this round, these two groups of experts also differed in opinion regarding seven other statements belonging to different subcategories (table 5). The experts by experience did not reach consensus that these statements were important, while the professional experts did. The experts by experience reached consensus on statement number 54 about assistive technology (table 5), while the professional did not.

(Please put Table 4 here: **Results for the subcategories of statements in the second and third round**)

Differences within the Groups 'Experts by Experience' and 'Professional Experts'

Subgroup analyses were performed in the third round. The group 'experts by experience' consisted of the subgroups 'people with dementia' (n=10) and 'informal carers' (n=16). Three dyads, people with dementia who filled in the forms together with an informal carer, were not included in the subgroup analyses because they offered a combined perspective. The subgroups 'people with dementia' and 'informal carers' rated differently from each other on

three statements (statements number 9, 21, 49). The subgroup ‘people with dementia’ reached consensus on statement number 9: ‘(…) *provide information to people with dementia about relevant services at the right time for them’*, the subgroup ‘informal carers’ did not. The subgroup ‘informal carers’ reached consensus on statement number 21: ‘*Education about dementia should be provided in all parts of the education system’* and statement number 49: *‘All health care personnel assigned to dementia services should have knowledge of available community services’* , the subgroup ‘people with dementia’ did not (table 5).
The group ‘professional experts’ had the subgroups ‘Actifcare experts’ (n=10) and ‘external professional experts’ (n=32). The two subgroups differed in their rating on 10 statements in the third round. The subgroup ‘Actifcare experts’ did not reach consensus on these statements, the subgroup ‘external professional experts’ did (table 5).

Best Practice Recommendations

All statements that reached consensus were included in a draft of the Actifcare Best Practice Recommendations. To reduce the number of recommendations, statements concerning the same recommendation for different targets groups, for instance people with dementia and informal carers, were merged into one recommendation mentioning both target groups.
The list of the statements that had reached consensus in the Delphi process, as well as the draft of the resulting recommendations, were presented and discussed in a meeting in March 2017 involving the three Actifcare boards: the Actifcare consortium consisting of the research teams of the eight countries who took part in the Actifcare project; the Actifcare scientific advisory board consisting of appointed international, multi-disciplinary researchers with expertise in this field; and the Actifcare consumer board, represented by a staff member of Alzheimer Europe. The statements that almost reached the set parameters for inclusion, in particular those which only reached consensus in the group of experts by experience, were

given much attention to make sure that the perspective of people with dementia and their informal carers was safeguarded. This process resulted in 23 final recommendations in three categories (see textbox 1).

Dissemination

The Actifcare recommendations were presented and discussed at national meetings in the eight Actifcare countries with representatives of policy makers, clinicians, researchers and insurance companies. The attendees were invited to provide feedback and indicate which recommendations should be prioritized in their country and suggest action points for their implementation. An example of the issues that came up in these meetings was the role of the GP. In some countries it was suggested that a primary care dementia team could have some of the responsibilities instead of the individual GP. Such a team could include registered nurses, social workers, psychologists and other relevant professions in addition to a GP.

(Please place Textbox 1 here)

Discussion

The Actifcare Best Practice Recommendations for access to community care services are the result of an elaborate Delphi process across eight European countries. An appointed contact person for each person with dementia emerged as the central recommendation in category A: 'Access to services'. Alzheimer's Association Dementia Care Practice Recommendations (2018) have a category called 'Practice Recommendations for Person-Centered Assessment and Care Planning' (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018), based on Molony et al (2018), which also underlines the need for a coordinator (Molony, Kolanowski, Van Haitsma, & Rooney, 2018). The Actifcare recommendations' category B concerns actions or measures that can be taken to help potential services users overcome barriers to use of

services, category C describes factors that enable access and use. Actions that can be taken which are central in categories B and C are in line with Alzheimer's Association Dementia Care Practice Recommendations' (2018) category 'Practice Recommendations for Staffing'. These recommendations are based on Gilster and colleagues (Gilster, Boltz, & Dalessandro, 2018) and recommend fostering of relationships between the person with dementia, staff, and family, and provision of person-centred care training for health care professionals. However, as far as we know, the Actifcare recommendations are the only practice recommendations that have enhancement of access to community services as their focus.

The results of this Delphi process are also supported by the findings of a scoping review conducted as a part of the Actifcare project which mapped interventions to enhance access to and use of community care services. Five types of interventions were identified, most interventions of all five types had positive effect. The type of interventions that was most studied was case management interventions (Rosvik et al., 2020). Case management involves a role which resembles that of the contact person described in the present Actifcare Best Practice Recommendations. The other types of interventions described in the scoping review are also reflected in the results of this Delphi process, for instance interventions focused on providing information and rising awareness of dementia, economic support to buy services, encouraging GPs to refer to services, and preparing the person with dementia and the family for use of relevant community services after discharge from hospital (Rosvik et al., 2020).

There were some differences in the results of the rating between the two main groups of experts that were consistent across the rating rounds of the Delphi process. The experts by experience maintained their high level of dispersion in both rounds of rating on two statements. These concerned some of the responsibilities of the contact person. The first statement concerned the contact person's provision of information about available services to the person with dementia. The subgroup analyses after the third round showed that the two

subgroups of the group ‘experts by experience’ had different levels of consensus on this statement. The subgroup “people with dementia” reached consensus. It might be that people living with dementia experience that health care personnel have a paternalistic attitude and tend to talk to their family members rather than directly to them. The subgroup ‘informal carers’ had too high level of dispersion to reach consensus. This may be seen in connection with the findings from two other studies of the Actifcare project where some informal carers reported that the person with dementia’s lack of awareness of their care needs was a hindrance for the uptake of formal care (Kerpershoek et al., 2019; Stephan et al., 2018). Informal carers who find themselves in such a situation may think that information to the person with dementia about formal care can cause more harm than good. The group ‘professional experts’ reached consensus regarding this statement in both rating rounds. The statement supports the view that people with dementia should, as long as possible, receive information and be included in decisions that concern themselves. This view is reflected in in Alzheimer’s Association Dementia Care Practice Recommendations (Alzheimer's Association, 2018; Molony et al., 2018)

The other statement which received different results of rating in the two main groups of experts in both rating rounds concerned the contact person’s responsibility to introduce, motivate for and facilitate referral to services. The group ‘professional experts’ reached consensus in the second round on this statement, the group ‘experts by experience” did not. The subgroup analyses showed that both subgroups of the group “experts by experience’ had high degree of dispersion on this statement. This result may be related to the findings of another part of the Actifcare study; some informal carers felt obliged to provide the care themselves, and some people with dementia considered formal care a threat to their individual independence and therefore only accepted services they perceived as absolutely necessary (Stephan et al., 2018). The experts by experience who felt this way may have found that this

statement implied more involvement in their lives by the contact person than they appreciated. Engagement with community support services can introduce the stress of what has been termed ‘ambiguous gain’; the services are understood as well intended, but not always entirely positive, interventions into their private worlds (Lloyd & Stirling, 2011). People with dementia may be afraid of stigma connected to receiving dementia services, the informal carers may be afraid of losing control of the care situation (Stephan et al., 2018).
The group ‘experts by experience’, and the subgroup ‘people with dementia’ in particular, represent views which require special attention and consideration in questions concerning the services they are offered. In the present Delphi process, difference in the results of the rating between the groups and subgroups did not necessarily mean that they strongly disagreed. Firstly, because the subgroup ‘people with dementia’ was so small, it only required a few participants to rate a statement as ‘medium important’ for this subgroup to end up with a high level of dispersion. The low degree of dispersion across the groups indicated that the statements presented a common understanding across Europe, shared by the different types of experts, about what needs to be done to enhance access and use of services. Secondly, nobody rated a statement as ‘not important at all’, only three of 72 statements received a rating that denoted undecided or low importance. Some participants commented that the statements almost stated the obvious by describing what they perceived as basic prerequisites for access.

The professional experts had two subgroups; ‘external experts’ and ‘Actifcare experts’. The ‘Actifcare experts’ constituted a quarter of the professional experts. It may be argued that this subgroup represented a risk of biased rating, as some of the participants had suggested statements in the first round. However, the Actifcare experts represented eight countries and a wide array of competence and experience from the field. These experts had also acquired extra knowledge of this particular field through the research they had conducted in the three-

year long Actifcare project. The subgroup analyses showed that ten of the 34 statements that were rated in the third round had too high degree of dispersion in the subgroup 'Actifcare experts' but reached consensus in the subgroup 'external professional experts'. These ten statements also reached consensus in the group 'experts by experience' and were included in the Actifcare recommendations. In other words, the dissenting rating result of the subgroup 'Actifcare experts' was not decisive for the end result for these statements.

Limitations

The experts that took part in this Delphi process were recruited by the research team in each Actifcare country. This convenience sampling may represent a risk of bias of opinion. However, the experts represented eight European countries, different types of professional experts in the field, people with dementia as well as informal carers. There was an imbalance in number of professional experts between the countries. It was agreed that the number to be recruited should be flexible because some research teams expected a high attrition rate and recruited more experts to compensate for this, and others had trouble recruiting enough experts. The low degree of dispersion indicates that the imbalance did not cause a biased result.

It is possible that some nuances in some statements were altered in the translation of the rating form for the experts by experience in the non-English speaking countries. This may have had an impact on their perception and rating of the statements. It should be noted that, to be able to give their opinion in a way that was not stressful, some of the experts by experience received help from their carer or the national Actifcare research team to fill in the rating form.

Conclusion

The Actifcare Best Practice Recommendations go beyond describing barriers to access by suggesting practical measures that can be taken to enhance access, based on the existing knowledge. The recommendations should be used by national decision makers who are in the process of reforming their health and social systems to enhance quality of care. The aim is better access to services and better quality of life for home dwelling people with dementia and their informal carers. The challenge is implementation of the recommendations in national settings.

Abbreviations

Actifcare: ACcess to TImely Formal Care

AE: Alzheimer Europe

EWGPWD: European Working Group of People With Dementia

GP: General Practitioner

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests

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To access the Actifcare Best Practice Recommendations and the country specific

recommendations for implementation please go to

https://www.alzheimercentrumlimburg.nl/actifcare

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Table 1 The stages and rounds of the Actifcare Delphi process

	STATEMENT GENERATION STAGE		
	What was done	**Participants**	**Interim processing and analysis**
Preparatory steps	Meeting with discussion of nature of statements to be rated Piloting of template	The eight Actifcare research teams The Irish Actifcare team	Preparation of template denoting elements and phrasing of statements
Round 1 Preparation of statements	Identification of actions or measures to be taken described using template: -Phrasing of statements: *"To enhance access and/or use of community care services …"* -Rationale for statement -Examples of use -Evidence base	The eight Actifcare research teams	Removal of overlapping content and rephrasing of ambiguous statements Preparation of rating form for survey rounds: -version for experts by experience -version for professional experts
	EVALUATION STAGE		
Preparatory steps	Recruitment of experts Piloting of rating form Language check Translation of rating form for experts by experience	The eight Actifcare research teams GPWD* The Irish Actifcare team The non-English speaking Actifcare research teams	Rephrasing of unclear statements based on feedback
Round 2 Rating of statements	Survey round: Rating of importance on a 7-point Likert scale Use of free text area for comments	Professional experts: -External professionals -Actifcare professionals Experts by experience: -People with dementia -Informal caregivers	Translation of comments from non-English speaking experts by experience Analysis of dispersion and median Rephrasing of unclear statements Preparation of individualized forms: : -The median score of each statement -How many experts had given each of the scores (from 1 to 7) -The participant's own score
Round 3 Rating of statements which did not reach consensus	Survey round: Use of individualized forms Rating of importance on a 7-point Likert scale Free text area for comments	Professional experts Experts by experience	Analysis of dispersion and median Statements which reached consensus processed into draft of Best Practice Recommendations
	BEST PRACTICE RECOMMENDATIONS CONCLUSION STAGE		
Preparatory steps	Actifcare project meeting with discussion of draft of Best Practice Recommendations	The Actifcare research teams Representatives from:	Preparation of final draft of Best Practice Recommendations

		Actifcare scientific advisory board Actifcare consumer board	
Conclusion	Feedback on the final draft	The primary investigators of the Actifcare research teams	Preparation of ratified final Best Practice Recommendations
Implemen-tation	National meetings with discussion of implementation in each Actifcare country: Which recommendations should be prioritized in their country and action points for their implementation	National decision makers in the eight Actifcare countries	Translation of Best Practice Recommendations in non-English speaking countries
Dissemi-nation	-Presentations at national and international conferences -Research publications -Best Practice	The eight Actifcare research teams	Recommendations are available at https://www.alzheimercentrumlimburg.nl/actifcare

Table 2 Participants in the second and third Delphi round

Country	Experts by experience Round 2	Professional experts Round 2	Total Round 2	Experts by experience Round 3	Professional experts Round 3	Total Round 3
The Netherlands	3	9	12	1	8	9
Germany	5	5	10	5	3	8
United Kingdom	3	3	6	2	3	5
Sweden	3	5	8	2	5	7
Norway	3	8	11	2	8	10
Ireland	3	6	9	3	5	8
Portugal	3	7	10	3	7	10
Italy	6	3	9	6	3	9
EWGPWD*	5	na	5	5	na	5
SAB**	na	2	2	na	0	0
Total	**34**	**48**	**82**	**29**	**42**	**71**

*European Working Group of People With Dementia
** Actifcare Scientific Advisory Board. One of the SAB members was also on a country's national list
na=not applicable

Table 3 Characteristics of the participants of the Delphi-process

Professional experts				
Type of expert	*Scientific*	*Clinical*	*Policy makers/ administrative*	*Comment*
	21	7	15	

Profession	*Nurse, social worker*	*Physician*	*Psychologist*	*Administrator/ economist*	
	9, 1	18	6	10	Missing information about profession for 4 of the experts (from DE, IE, SE, SAB)
Education	*Bachelor*	*Master*	*PhD*	*Other*	
	2	14	24		Missing information about education for 8 of the experts
Sex	*Female*	*Male*			
	26 (54%)	22 (46%)			
Age	Mean: 54 years				Based on information about age for 24 of the experts
Total in round 2	**48**				

Experts by experience

	Female	*Male*	*Age*	*Comment*
Person with dementia	4 (35%)	7 (65%)	Mean for national experts (n=6): 72 years Mean for EWGPWD (n=5): 64 years	
Informal carer	13 (65%)	7 (35%)	Mean: 64 years	Based information on 13 carers (of 20) from DE, PT, IE, NO
Educational level	*Less than secondary school*	*Secondary school*	*Bachelor's degree or higher*	
Person with dementia	1	5	5	
Informal carer	1	3	7	Based on information from DE, PT, IE, NO on 11 carers (of 20).
Informal carer currently providing care	*Yes*	*No*		Based on information from DE, PT, IE, NO on 11 carers (of 20)
	10	1		
Relationship to person with dementia	*Spouse*	*Daughter in law*	*Daughter/son*	Based on information from DE, PT, IE, NO on 11 carers (of 20)
	7	1	3	
Informal carer's occupational status	*Retired*	*Employed*		Based on information on from DE, PT, IE, NO 13 carers (of 20)
	5	6		
Living with the person with dementia	*Yes*	*No*		Based on information from DE, PT, IE, NO on 11 carers (of 20)
	9	2		
Total in round 2	**34**			

Table 4 Results for the subcategories of statements in the second and third round

Sub Category	A. Contact person	B. Aware-ness	C. Infor-mation	D. Integration	E. The GP	F. Training	G. Various	H Accept - ability	Total
Number of state-ments	20	3	7	10	7	2	11	12/11*	**72**
Too high dispersion Second/ third round	11/1	3/1	3/0	9/2	4/1	1/0	6/3	4/0	**41/8**
Too low median score Second/ third round	0/0	0/0	0/0	0/0	3/2	0/0	0/0	0/0	**3/2**
Consensus Second/ third round	9/10	0/2	4/3	1/7	0/4	1/1	5/3	8/4	**28/34**

*Statements number 65 and 66 were merged before the third round

Textbox 1 THE ACTIFCARE BEST PRACTICE RECOMMENDATIONS

A. RECOMMENDATIONS TO ENHANCE ACCESS

Recommendations that can enhance access to services directly

1. People with dementia and their carer/family should have a named contact person

The contact person may be the general practitioner, a case manager, or someone working inside the care system. The contact person may also be part of a team specialising in dementia.

The contact person should:

- **1.1. be trained in dementia and person-centred care, which implies focusing on the perspective, needs and wishes of the person with dementia**
- **1.2. have sound knowledge of the available dementia services**
- **1.3. be easy to reach**
- **1.4. cooperate closely with the primary care clinics and hospitals (inpatient and outpatient units) in their area to arrange the services people need at home**

2. The contact person or other personnel delivering services should:

- **2.1. establish contact with the person with dementia and the carer/family at a timely point in the disease process, that is, at the right moment in accordance with the wishes of the person with dementia and the informal carer**
- **2.2. establish and continuously maintain contact proactively**
- **2.3. regularly assess the needs of the person with dementia and his/her carer/family, including psychosocial needs**
- **2.4. provide individualised information about dementia and available services to people with dementia and their carer/family**
- **2.5. provide continuous support and advice to the people with dementia and their carer/family**

2.6. encourage people with dementia and their carers/families to consider referral to services that may be relevant to them and facilitate referral, if wanted
2.7. discuss decisions about service use with the person with dementia and his/her carer/family

3. Services should be affordable and monetary support should be offered when needed

4. Information about dementia and dementia services should be accessible
4.1. Information about dementia and dementia services should be available to people with dementia and carers/families in a way that is easily understood and accessed.
4.2. An online information platform should be established with updated information about available care services in all communities. This platform should:
i. be easy for people with dementia and carers/families to access
ii. provide health care personnel with updated information

5. Other parties of the health care system should have knowledge and provide information about available community services as well as ensuring referrals
Memory clinics/specialised outpatient services, general practitioners and other health care professionals assigned to work in dementia services should have knowledge and provide information about available community care services. They should also refer to services, or to the contact person/ other relevant health care personnel in the community who can refer to services

6. There should be appointed personnel, well-defined pathways* for referral to services, and coordination of advice
**A pathway is a set stepwise procedure to be applied in a certain situation, e.g. when someone has been diagnosed with dementia.*

6.1. In each country, there should be a well-defined pathway to community care services, that includes admission to and discharge from acute care/hospitals
6.2. In all hospital units where older people are commonly admitted, there should be an appointed health care professional who cooperates with the community to arrange the services needed at home
6.3. In each country/state, there should be a well-defined pathway for general practitioners' referrals for treatment of persons with dementia who have severe psychological distress and other urgent cases
6.4. When services are provided by both communities and private health and social care providers, advice regarding the services should be coordinated

7. Psychoeducation should be provided following a diagnostic disclosure
The diagnostic disclosure should always include psychoeducation about what dementia entails and practical advice on how services can help people with dementia and their family/carers cope with dementia.

B. RECOMMENDATIONS TO ENHANCE USE
Recommendations that can enhance use of services

8. Transportation to and from dementia services and help to get ready for transportation should be available to people with dementia if they need it

9. Coordination of services should be ensured, and cooperation between people with dementia, their families, professionals, and volunteers should be enhanced

10. Use of services should begin with a social introduction between staff and the person with dementia/ family, and the use may be gradually built up over time

11. Services assigned to people with dementia should be flexible rather than set and detailed regarding setting, type, and amount of services granted. For instance, respite should be provided at home as well as in institutions

12. There should be continuity of staff and a timetable should be provided and adjusted to the person's routine, indicating when staff from home services are coming and which staff should be expected

13. People with dementia should have access to dementia-specific services provided by specially trained personnel appointed to these services

14. Services should aim at enhancing independence in people with dementia and in carers

C. ENABLING FACTORS
Recommendations that can facilitate access or use indirectly

15. Access to services should be equitable and needs driven

16. Support groups for people with dementia and their carers/families should be facilitated locally

17. Service providers should ensure that proper training for health care professionals is provided

18. Health care personnel should undertake training in safeguarding dignity and showing empathy and respect for people with dementia

19. Health care personnel should receive training in how to deal with conflict regarding care decisions between people with dementia and their significant others

20. General practitioners should have specific dementia training to enable them to diagnose dementia at the right time for the person and the family, and to recognize when an advanced diagnostic assessment of dementia is required

21. General practitioners (GPs) should have an overview of the situation of the person with dementia

22. The provision of care should build on the principles of person-centred care*
- **22.1. Services should focus on the perspective, needs and wishes of the person with dementia**
- **22.2. Services for people with young onset dementia should fit their specific needs**

** Person-centred care as described in 1.1 and 22.1 also encompasses ethnic and cultural factors.*

23. Awareness about dementia should be increased
- **23.1. Education about dementia should be provided at all levels of the educational system**
- **23.2. Mass media should be used to disseminate information about dementia to the general public in order to combat stigma**

The references to the evidence base for the recommendations are accessible at https://www.alzheimercentrumlimburg.nl/actifcare

NB: table 5 below (horizontal page format)

Table 5 Results for each statement in rounds 2 and 3 for the different groups of experts

Category 1: How to ensure access and overcome barriers

Subcategory A – Contact person

Statement	SECOND ROUND			THIRD ROUND		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
Statements, as they were phrased in the second round:	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
1. People with dementia and their carer/family should be appointed a named contact person[a] [a]The contact person can be a case manager, or a general practitioner (GP) / health care professional	**7/ 0.5/ 90.1**	**7/ 0.5/ 93.6**	**7/ 0.5/ 88.9**			
2. The contact person* should initiate contact with people with dementia and their family/carer *If no contact person is appointed, other personnel delivering services should ensure that the functions assigned to the role of a contact person are safeguarded	*6/ 1/ 57.9*	*6/ 1.5/ 64.5*	*6/ 1/ 53.3*	**6/ 0.5/ 85.9**	**6/ 0.5/ 79.3**	**6/ 0.5/ 95.5**
3. The contact person* should have the resources needed to fulfil their role	**7/ 0.5/ 85.5**	**6/ 0.5/ 87.1**	**7/ 0.5/ 84.5**			
4. The contact person* should be trained in dementia and person-centred care[b] [b]Person-centred care is to focus on the perspective, needs and wishes of the person with dementia	**7/ 0.5/ 90.8**	**7/ 0.5/ 87.1**	**7/ 0.5/ 93.3**			
5. The contact person* should have sound knowledge of available dementia services	**7/ 0.5/ 93.4**	**7/ 0.5/ 96.8**	**7/ 0.5/ 91.9**			
6. The contact person* should co-ordinate services from health and social care as well as from volunteers	*6/ 1/ 68.4*	**6/ 0.5/ 83.9**	*6/ 1/ 57.8*	**7/ 0.5/ 91.5**	**7/ 0.5/ 86.2**	**6/ 0.5/ 95.2**
7. The contact person* should provide individualised information about dementia to person with dementia	**6/ 0.5/ 76.3**	*6/ 1/ 74.2*	**6/ 0.5/ 77.8**	**7/ 0.5/ 91.4**	**7/ 0.5/ 82.7**	**7/ 0.5/ 97.6**
8. The contact person* should provide individualised information about dementia to carers/families	**7/ 0.5/ 88.1**	**7/ 0.5/ 93.5**	**6/ 0.5/ 84.4**			
9. The contact person* should provide individualised information about available services to the person with dementia when he/she is ready for it	*6/ 1/ 69.7*	*6/ 1/ 58*	**6/ 0.5/ 77.8**	**7/ 0.5/ 84.5**	*7/ 1/ 69.0*	**7/ 0.5/ 95.2**

10. The contact person* should provide individualised information about available services to carers/families when they are ready for it	**7/ 0.5/ 81.5**	**7/ 0.5/ 77.4**	**7/ 0.5/ 84.5**			
11. The contact person* should regularly assess the needs of the person with dementia	**7/ 0.5/ 78.9**	**7/ 0.5/ 80.6**	**7/ 0.5/ 77.8**			
12. The contact person* should regularly assess the needs of carers/families	*6/ 1/ 68.5*	*7/ 1/ 61.3*	*6/ 0.88/ 73.3*	**7/ 0.5/ 91.4**	**7/ 0.5/ 89.3**	**7/ 0.5/ 92.8**
13. The contact person* should introduce, motivate for and facilitate referral to services required by the person with dementia	*6/ 0.88/ 75*	*6/ 1/ 67.7*	**6/ 0.5/ 80**	**7/ 0.5/ 83.9**	*7/ 1/ 71.5*	**6.5/ 0.5/ 92.5**
14. The contact person* should introduce, motivate for and facilitate referral to services required by carers/families	**6/ 0.5/ 79**	**7/ 0.5/ 77.4**	**6/ 0.5/ 80**			
15. The contact person should provide help with applying for financial support to pay for services when needed*	*5.5/ 1/ 50*	*6/ 1.5/ 58.1*	*5/ 0.5/ 44.5*	*6/ 0.5/ 63.3*	*6/ 1/ 72.4*	*6/ 0.5/ 66.7*
16. The contact person should be easy to reach	**7/ 0.5/ 89.5**	**7/ 0.5/ 90.3**	**7/ 0.5/ 88.9**			
17. The contact person should provide continuous support and advice to people with dementia	*6/ 1/ 63.1*	*6/ 1/ 58.1*	*6/ 1/ 66.7*	**6/ 0.5/ 77.5**	*6/ 1/ 72.4*	**6/ 0.5/ 81.0**
18. The contact person should provide continuous support and advice to carers/families	*6/ 1/ 63.8*	*6/ 1/ 64.5*	*6/ 1/ 66.7*	**7/ 0.5/ 84.3**	**7/ 0.5/ 86.2**	**6/ 0.5/ 82.9**
19. The contact person should establish contact with the person with dementia and the carer/family as early as possible	**6.5/ 0.5/ 80.3**	**7/ 0.5/ 87.1**	*6/ 0.75/ 75.6*	**7/ 0.5/ 91.6**	**7/ 0.5/ 89.7**	**7/ 0.5/ 92.9**
20. Decisions about care should be taken after discussions between the person with dementia, their carer/family and the contact person	**7/ 0.5/ 78.9**	*7/ 1/ 71*	**7/ 0.5/ 84.5**	**7/ 0.5/ 90.1**	**7/ 0.5/ 79.3**	**7/ 0.5/ 97.6**

Subcategory B – Awareness

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
21. Education about dementia should be provided in all parts of the education system	*6/ 1/ 60.5*	*6/ 1/ 67.8*	*6/ 1/ 55.5*	**6/ 0.5/ 76.1**	*7/ 1/ 72.4*	**6/ 0.5/ 78.6**
22. Dementia information campaigns should be launched regularly	*6/ 1.75/ 61.8*	*6/ 1/ 64.6*	*6/ 0.5/ 66.2*	*6/ 1/ 73.3*	*6/ 1/ 69*	*6/ 0.13/ 76.2*
23. Mass media should be used to combat stigma	*6/ 1/ 64.5*	*7/ 1/ 74.2*	*6/ 1/ 57.8*	6/ 0.5/ 77.5	*7/ 1/ 68.9*	6/ 0.5/ 83.2

Subcategory C – Information

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
24. Information about dementia should be available for people with dementia in a way that is easily understood	**7/ 0.5/ 84.2**	**6/ 0.5/ 77.4**	**7/ 0.5/ 88.9**			
25. Information about dementia should be available for carers/families in a way that is easily understood	**7/ 0.5/ 88.7**	**7/ 0.5/ 100**	**7/ 0.5/ 97.7**			
26. Information about dementia services should be available for people with dementia in a way that is easily understood	**6/ 0.5/ 88.7**	**6/ 0.5/ 77.4**	**7/ 0.5/ 88.9**			
27. Information about dementia services should be available for carers/family in a way that is easily understood	**7/ 0.5/ 96.1**	**7/ 0.5/ 96.7**	**7/ 0.5/ 95.6**			
28. An online information platform with information about available care services in all communities should be established	*6/ 1/ 59.2*	*6/ 1.5/ 54.9*	*6/ 1/ 62.3*	**6/ 0.5/ 76.1**	**7/ 0.5/ 79.3**	**6/ 0.5/ 76.2**
29. An online information platform with information about available care services should be easy to access for people with dementia and carers/families	*6/ 1/ 64.4*	*6/ 1/ 67.8*	*6/ 1/ 62.2*	**6/ 0.5/ 80.3**	**7/ 0.5/ 79.3**	**6/ 0.5/ 81.0**
30. An online platform should provide health care personnel with updated information about dementia and available services	**6/ 0.5/ 75**	*7/ 0.63/ 76.7*	*6/ 0.75/ 75.6*	**7/ 0.5/ 84.5**	**7/ 0.5/ 86.2**	**6.5/ 0.5/ 83.3**

Subcategory D – Integration

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
31. There should be a well-defined pathway to community care services	*6/ 1/ 69.7*	*6/ 1/ 67.7*	*6/ 1/ 71.1*	**7/ 0.5/ 85.9**	**6/ 0.5/ 79.3**	**7/ 0.5/ 90.4**
32. A well-defined pathway to community care services should include admission to and discharge from acute care/hospital	*6/ 1/ 68.4*	*6/ 1 / 61.3*	*6/ 1/ 73.3*	**7/ 0.5/ 84.5**	**6/ 0.5/ 79.3**	**7/ 0.5/ 88.1**
33. Cooperation should be enhanced between persons with dementia, their families, professionals and volunteers	*6/ 1/ 73.7*	**6/ 0.5/ 77.5**	*6/ 1/ 71.1*	**6/ 0.5/ 91.6**	**6/ 0.5/ 86.2**	**6.5/ 0.5/ 95.2**

34. Memory clinics/specialised outpatient services should provide information about available community care services and refer to services when necessary	**6/ 0.5/ 76.3**	*6/ 1/ 70.9*	**6/ 0.5/ 80**	**7/ 0.5/ 88.6**	**7/ 0.5/ 86.2**	**7/ 0.5/ 90.2**
35. Structures and processes of counselling from communities and health and social care insurance should be coordinated	*6/ 1/ 67.1*	**6/ 0.5/ 80.6**	*6/ 1/ 57.8*	**6/ 0.5/ 85.8**	**6/ 0.5/ 83.7**	**6/ 0.5/ 87.8**
36. In all hospital units where older people are commonly admitted. there should be an appointed health care professional who cooperates with the community to arrange the services they need at home	**7/ 0.5/ 89.4**	**7/ 0.5/ 93.6**	**7/ 0.5/ 86.7**			
37. In primary care/GP clinics. there should be an appointed health care professional who cooperates with the community to arrange the services people with dementia need at home	*6/ 1/ 61.8*	*6/ 1 / 61.3*	*6/ 1/ 62.2*	*6/ 1/ 74.6*	*6/ 1/ 72.4*	*6/ 1.26/ 76.2*
38. In geographical areas with many primary care clinics there should be a team specialised in dementia. This team should cooperate with the community to arrange the services people need at home	*6/ 1/ 64.5*	*6/ 1/ 67.7*	*6/ 1/ 62.2*	**6/ 0.5/ 78.5**	*6/ 0.75/ 75.9*	**6/ 0.5/ 80.5**
39. An ambulatory team of health care staff specialised in dementia should be established in each hospital. This team should cooperate with the community to arrange the services people need after discharge	*6/ 1/ 67.1*	*6/ 1/ 74.2*	*6/ 1/ 62.3*	*6/ 0.66/ 75.7*	*6/ 0.75/ 75.8*	*6/ 0.75/ 75.6*
40. There should be a well-defined pathway for GPs' treatment of persons with severe psychological distress and other urgent cases	*6/ 1/ 73.7*	*6/ 1/ 71*	*7/ 0.75/ 75.5*	**7/ 0.5/ 93**	**7/ 0.5/ 89.7**	**7/ 0.5/ 95.2**

Subcategory E – The responsibility of the General practitioner (GP)

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts

41. Incentives for ensuring diagnostic disclosure should be provided to GPs or specialists	*5/ 1.5/ 38.1*	*5/ 1.63/ 43.4*	*5/ 1.5/ 35.6*	*5/ 1.125/ 40*	*5/ 1.5/ 37.9*	*5/ 1.25/ 48.8*
42. Incentives for post diagnostic dementia care should be provided to GPs	*5/ 1.38/ 43.5*	*5/ 1.88/ 42.9*	*5/ 1.38/ 46.7*	*5/ 1/ 47.9*	*5/ 1.5/ 41.4*	*5/ 0.63/ 59.6*
43. GPs should take part in every phase of the patient's process of accessing and using services	*6/ 1.5/ 52.6*	*6/ 1.5/ 61.3*	*5/ 1.5/ 46.7*	*6/ 1.5/ 62*	*6/ 1/ 65.5*	*6/ 1.0/ 59.5*
44. GPs should know which community care services are available	*6/ 0.88/ 75*	*6/ 1/ 74.2*	*6/ 0.75/ 75.6*	**6/ 0.5 / 90**	**7/ 0.5/ 86.2**	**6/ 0.5/ 92.7**
45. GPs should communicate with their colleagues and other professionals regarding their patients with dementia	*6/ 1/ 73.7*	*6/ 1/ 70.9*	*6/ 0.75/ 75.6*	**6/ 0.5/ 87.3**	**6/ 0.5/ 79.3**	**6/ 0.5/ 92.8**
46. GPs should have specific dementia training enabling them to diagnose dementia at the right time for the person and the family	*6/ 1/ 73.7*	**7/ 0.5/ 80.6**	*6/ 1/ 68.8*	**6/ 0.5/ 85.9**	*7/ 0.75/ 75.9*	**6/ 0.5/ 92.8**
47. GPs should receive training that enables them to refer for advanced diagnostic assessments	*7/ 0.88/ 75*	**7/ 0.5/ 80.7**	*6/ 1/ 71.1*	**7/ 0.5/ 94.4**	**7/ 0.5/ 93.1**	**7/ 0.5/ 92.2**

Subcategory F – Training of Health care personnel

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
48. To enable all health care professionals who are in contact with people with dementia and their carers/families to fulfil their role, service providers should ensure proper training is provided	**7/ 0.5/ 90.8**	**7/ 0.5/ 87.1**	**7/ 0.5/ 93.3**			
49. All health care personnel assigned to dementia services should have knowledge of available community services	*6/ 1/ 71*	**6/ 0.5/ 80.6**	*6/ 1/ 64.4*	**7/ 0.5/ 83.1**	*6/ 1/ 72.4*	**7/ 0.5/ 90.5**

Subcategory G – Various

Statement	SECOND ROUND	THIRD ROUND
	Median/quartile deviation/% of the ratings within two adjoining values	Median/quartile deviation/% of the ratings within two adjoining values

	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
50. Access to services should be equitable	**7/ 0.5/ 92.1**	**7/ 0.5/ 87.1**	**7/ 0.5/ 95.6**			
51. Access to services should be needs driven	**7/ 0.5/ 92.1**	**7/ 0.5/ 87.1**	**7/ 0.5/ 95.6**			
52. Services should be affordable	**7/ 0.5/ 90.8**	**7/ 0.5/ 93.6**	**7/ 0.5/ 88.9**			
53. Monetary support should be offered when needed	**7/ 0.5/ 80.3**	**7/ 0.5/ 90.4**	*7/ 1/ 73.4*	**7/ 0.5/ 84.5**	**7/ 0.5/ 82.8**	**7/ 0.5/ 87.7**
54. Health care personnel should offer assistive technology early in the trajectory of the dementia	*6/ 1/ 55.2*	*6/ 1/ 67.8*	*5/ 0.5/ 57.8*	*6/ 0.5/ 73.2*	**6/ 0.5/ 82.8**	*6/ 0.5/ 69.1*
55. The diagnostic disclosure should always include psychoeducation about what dementia entails, and practical advice on how services can help people with dementia and their family/carers deal with the dementia	**6.5/ 0.5/ 78.9**	**7/ 0.5/ 80.6**	**6/ 0.5/ 77.8**			
56. The professionals should use the care that the person is already receiving for other health problems to enhance access to formal dementia care	*6/ 1/ 59.2*	*6/ 1/ 67.7*	*6/ 0.5/ 62.2*	*6/ 0.5/ 71.8*	*6/ 1/ 72.4*	**6/ 0.5/ 80.9**
57. Transport to and from dementia services and help to get ready for transportation should be available to people with dementia if they need it	**6/ 0.5/ 82.9**	**7/ 0.5/ 93.6**	*6/ 0.75/ 75.6*	**7/ 0.5/ 85.9**	**7/ 0.5/ 79.3**	**6/ 0.5/ 90.5**
58. Health care professionals should seek to involve the wider family in matters regarding services to the person with dementia	*6/ 0.5/ 57.9*	*6/ 1.5/ 54.8*	*6/ 0.5/ 60*	*6/ 0.5/ 72.5*	*6/ 1.38/ 57.1*	**6/ 0/ 82.9**
59. Health care personnel should be trained on how to deal with conflict regarding care decisions between people with dementia and their significant others	**6/ 0.5/ 78.9**	**6/ 0.5/ 77.4**	**6/ 0.5/ 80**			
60. Support groups for people with dementia and their carers/families should be facilitated locally	*6/ 1/ 71.1*	*7/ 1/ 67.7*	*6/ 0.88/ 73.3*	**6/ 0.5/ 87.1**	**6/ 0.5/ 79.3**	**6/ 0.5/ 92.7**

Category 2: Acceptability
Statements directed at the services, aiming to make them acceptable, e.g. how to make services more attractive to people with dementia

Statement	SECOND ROUND			THIRD ROUND		
	Median/quartile deviation/% of the ratings within two adjoining values			Median/quartile deviation/% of the ratings within two adjoining values		
	All experts	Experts by experience	Professional experts	All experts	Experts by experience	Professional experts
61. Services focus on perspective, needs and wishes of the person with dementia	**7/ 0.5/ 88.1**	**7/ 0.5/ 80.6**	**7/ 0.5/ 93.3**			

(Round 3: Statement 62 was divided into two statements: 62A, 62B) 62A. Services should be dementia specific	*6/ 1/ 60.2*	*6/ 1/ 71*	*6/ 1/ 51.1*	**6.5/ 0.5/ 84.3**	**7/ 0.5/ 86.2**	**6/ 0.5/ 82.9**
62B. Services for people with dementia should be given by specially trained personnel appointed to services				**7/ 0.5/ 90.2**	**7/ 0.5/ 89.6**	**7/ 0.5/ 90.4**
63. Home care services should provide a timetable adjusted to the person's routine indicating when staff from home services are coming	**6/ 0.5/ 80.2**	**7/ 0.5/ 83.9**	**6/ 0.5/ 77.7**			
64. Home care services should provide a timetable indicating which staff are coming	**6/ 0.5/ 82.9**	**7/ 0.5/ 83.9**	**6/ 0.5/ 82.3**			
(Round 3: Statement 65 and 66 were merged into one statement) 65. Service use should begin with a short-term social introduction and gradually be built up over time, if needed	*6/ 1/ 71.1*	**6/ 0.5/ 83.9**	*6/ 1/ 62.2*	**6/ 0.5/ 88.7**	**7/ 0.5/ 93.1**	**6/ 0.5/ 85.7**
66. People with dementia and their carers/families should be offered a trial of the service being considered, so that they can decide whether the service is suitable and meets their requirements	*6/ 1/ 69.8*	**6/ 0.5/ 77.5**	*6/ 0.5/ 64.4*			
67. Health care personnel should undertake training in safeguarding dignity and showing empathy and respect for people with dementia	**7/ 0.5/ 89.5**	**7/ 0/ 87.1**	**7/ 0.5/ 91.1**			
68. Services should aim at enhancing independence in people with dementia	**7/ 0.5/ 90.8**	**7/ 0/ 96.8**	**7/ 0.5/ 86.6**			
69. Services for people with young onset dementia should fit their specific needs	**7/ 0.5/ 94.8**	**7/ 0.5/ 90**	**7/ 0.25/ 100**			
70. There should be continuity of staff	**7/ 0.5/ 82.9**	**7/ 0.5/ 83.9**	**7/ 0.5/ 82.2**			
71. Services assigned to people with dementia should have a time frame that can be adjusted by the local staff, rather than set and detailed regarding the type and amount of services granted	**6/ 0.5/ 76.3**	**7/ 0.5/ 80.6**	*6/ 0.88/ 73.4*	**7/ 0.5/ 92.9**	**7/ 0.5/ 89.6**	**6/ 0.5/ 95.2**
72. It should be possible to deliver a service in different settings depending on needs. For instance. respite can be provided at home as well as in institutions	**7/ 0.5/ 81.6**	**7/ 0.5/ 83.9**	**6/ 0.5/ 80**			

Cursive: NOT consensus
Bold font: consensus