



	<p align="center">Quality Control Criteria for Alzheimer Cafés Voluntary self-assessment survey (2009 – 2010)</p> <p align="center">For your interest – summary information of previous Dutch AC self-evaluation is given in colour, at the start of each section, below. See also *</p>	
Item	<p>Section A - definition of ‘AC purpose’</p> <p>The Alzheimer Café is a safe, low-threshold, pleasant environment, for people with dementia, their family/carers, friends or neighbours to attend - in the presence of a variety of health care professionals, volunteers and members of the local Alzheimer’s Society or other local dementia support group. It offers support and information, opportunities to socialize, and works towards achieving more openness about dementia.</p> <p>The 2006 survey findings of 68 Dutch ACs found that the ACs are virtually unanimous in supporting the vision and goals. These results bid us anchor the vision and goals of the AC concept into the existing Quality Control Criteria, hereafter, unchanged.</p> <p>Additional comments:</p>	
AC Quality Control Criteria	<p>Instructions:</p> <ul style="list-style-type: none"> . A ‘five word scale’ is provided for each item . For each item, circle the word that best corresponds with your AC experiences - over the past year’s programme . If possible, provide a percentage figure to correspond to the word circled (in the box to the right of each item) 	Percentage achieved at ACs held in the past year’s programme
	<p>Section B - the guests</p> <p>The 2006 survey findings of 68 Dutch ACs found that: Average attendance was: 9% of guests visiting the ACs are people with dementia 50% are family members 19% are volunteer helpers 22% are involved in another capacity</p> <ul style="list-style-type: none"> . Most ACs are held in the evenings. Attendance at the ACs drops as the season progresses [in the darker winter months]. . ACs start with an average of 43 attendees; this drops to an average of 31, with 37 being the overall annual average participation per AC. <p>Extrapolating the mean responses to this evaluation, and to these values for all 103 Cafes, 3000 people with dementia and 16,500 family members of persons with dementia participate in ACs in the Netherlands. This means that about 2% of people with dementia are being supported by Alzheimer Cafés.</p> <p>12% of all interviews at the ACs were with people with dementia 24% were with a family member 88% of ACs had at least 3 different types of health care professionals present 51% of all ACs recorded that people with dementia participated in the questions or dialogue</p>	

	<p>85% of ACs saw volunteer helpers participating in responses and reactions to questions.</p> <p>The help of the volunteers is enormous: they are present and active at 90% of meetings and also respond to questions from other attendees at the Café.</p> <hr/> <p>Recommendations on the basis of the 2006 survey:</p> <ul style="list-style-type: none"> - extra attention for keeping the AC 'low threshold' and easy to join for persons with dementia -extra attention for the 'surplus value' of interviewing persons with dementia in the AC, and for techniques to help prepare persons to be interviewed -extra attention for the 'surplus value' of making persons with dementia and their families known to the public and the caregivers in the region -discussion about the overall impact of the ACs. 2% of the target group is being reached per year. Is that enough? How many people with dementia and their families is it realistic and possible to reach? -updating evaluation forms of ACs to more accurately record the different categories of attendees -discuss with volunteers the best way to record the various types of attendees 	
QCC Item		
1	<p>A minimum of 5% of those present at an AC are people with dementia.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
2	<p>People with dementia and their family/carers participate noticeably during AC gatherings.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
3	<p>Those present at an AC also include local, care-giving professionals, who have a variety of backgrounds (a minimum of 3 types). They also have local-regional area knowledge and psycho-social knowledge about the impact of dementia.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
4	<p>Care-giving professionals who participate at an AC, answer questions and respond to the issues raised by people with dementia and their family/carers present.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
	<p>Further queries relating to this section:</p> <p>Do you ever have people with early-onset dementia attending?</p>	
	<p>Have younger people with dementia and their family/carers been comfortable with the older age group?</p>	
	<p>Have you had students, student volunteers and children present at the AC?</p>	
	<p>Which health and social care professionals have been the most difficult to encourage to attend your AC? E.g.:</p> <ul style="list-style-type: none"> registered general nurses in hospital settings/ nursing homes community nurses / community psychiatric nurses care-giving staff from local care homes and day centres/services social workers/ occupational therapists/ physiotherapists psychologists/ family therapists/ counselors/ family doctors/ geriatricians/ old age psychiatrists family and carer support (outreach) workers 	

	<p>chaplains or pastoral care workers other: please name or comment</p>	
	<p>Section C - Leadership for the themed discussions and interviews</p> <p>The 2006 survey findings of 68 Dutch ACs found that: 76% of all ACs had a consistent 'duo' 24% of ACs do not have a fixed 'duo' who lead the discussions. It will be important to see whether and by how much, this affects the continuity of the ACs. 93% discussion of the themes demonstrated multi-[health care] disciplinary knowledge and input 94% of discussions demonstrated practical experience with interactions and support 83% of discussion demonstrated good 'role modeling' of interactions</p> <hr/> <p>Recommendations:</p> <ul style="list-style-type: none"> - extra attention for the continuity of discussion leaders - what are the reasons why some ACs don't work with 'duos'? - is it necessary to work with a duo, or, is it sometimes not helpful to work with a duo? - what do other ACs do to reduce the vulnerability of, and decrease the work-capacity of single discussion leaders? 	
5	<p>The themed discussions/ interviews are in the hands of a consistent MC / Interviewer ('duo' pair); to ensure familiarity and continuity for the guests. Never---rarely---usually---mostly---always Additional comments:</p>	
6	<p>The themed discussions/interviews demonstrate multi-disciplinary knowledge about dementia and dementia care. Never---rarely---usually---mostly---always Additional comments:</p>	
7	<p>The themed discussions/interviews demonstrate practical experience in interacting with and guiding people with dementia and their family/carers. Never---rarely---usually---mostly---always Additional comments:</p>	
8	<p>The themed discussions/interviews role-model how to interact with and communicate with people with dementia. Never---rarely---usually---mostly---always Additional comments:</p>	
	<p>Further comments or queries relating to this section:</p>	
	<p>Is the interviewer relaxed, comfortable, and able to put interviewees and speakers at ease?</p>	
	<p>Do they have the ability to keep the flow of the discussion, and summarize or paraphrase material if the speaker was unclear?</p>	
	<p>Section D - Content of the annual AC programme</p> <p>Original themes What's the matter? How is dementia diagnosed How does memory work and what happens in dementia? It's getting a bit much: feelings of powerless, adapting communication What kind of help is there? Who can I turn to for help? May I say I need help? [Where, When, How to start to get help] Day care / residential care How is the decision made?</p>	

	<p>How does it affect everyone involved?</p> <p>Additional topics also in use</p> <p>The value of breaking through denial; why is it so difficult to do sometimes? The range and purpose of human emotions; what is their purpose? Anger and Fear: the lion emotions Why can they get out of control? How to understand them better. The purpose of communication, the range of communication options. Which are used most/ least? Stress How can it sneak up on you unawares? Ways of coping with it Grieving and guilt: How guilt can delay grieving? Understanding reasons for behaviour changes in dementia - including visuoperceptual mistakes Living with dementia, after hitting the brick wall of the diagnosis</p> <ul style="list-style-type: none"> - 87% of ACs had formalized programmes of year's topics ready starting each new AC season - 68% of ACs follow that cycle of year themes which match the dementia process (listed above) - 80% of ACs place more emphasis on psychosocial aspects than medical aspects of discussion - 69% of interviews are with/done by health care professionals - 7% of interviews are of a person with dementia - 21% of interviews are with a family member - 82% of ACs portion the timings at the Café into 30 minute portions <ul style="list-style-type: none"> (eg. 30 mins. Socializing with refreshments 30 mins. interview or talk 30 mins. socializing and refreshments 30 mins. questioning about interview and additional discussion 30 mins. socializing and refreshments) - 76% of ACs use guest speakers from their own region <hr/> <p>Recommendations:</p> <ul style="list-style-type: none"> - Uniformity between ACs is relatively large. A small number of ACs are departing from the criteria. It would be good to emphasize the 'content arguments' for the choice of the themes at the courses for interviewers/discussion leaders - Also, extra attention for the importance of the order of the themes (which follow the dementia process) during the annual cycle of the AC. Is this really necessary? What are the reasons for not doing so? - The visibility and participation of people with dementia at ACs is important. The 'surplus value' to AC attendees, of an interview with a family member or a person with dementia, is worth discussing during the courses for interviewers/ discussion leaders, and at the new courses for volunteers 	
9	<p>The annual AC programme is already set out, in large measure, at the start of each new year.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
10	<p>The programme follows a yearly cycle wherein the themes chosen, broadly reflect the course of the dementia process (i.e. obtaining the diagnosis, learning about dementia, getting assistance, learning how to live with it and making ongoing adaptations, including communication and care for later stages).</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
11	<p>During AC meetings, 'psycho-social aspects' of dementia are given more attention than the 'medical aspects'.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
12	<p>The 'psychological education' part of the AC, takes place primarily in the form of interviews and interactive discussions - with professionals, carers and people with dementia (led by the interviewer/discussion leader).</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
13	<p>The discussion of the evening is usually divided into half-hour blocks.</p> <ul style="list-style-type: none"> - half hour socialization with the AC guests 	

	<ul style="list-style-type: none"> - half hour interview or interactive talk - half hour interlude with music - half hour session for further questions/ comments from the guests - half hour further socialization <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
14	<p>At least 70% of the professionals who are used as AC guest-speakers must work in the local region.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
	Further queries relating to this section:	
	Have you adapted the timing of the half-hour sections? (E.g. combining the interview with the question and discussion section)	
	How many of the listed themes were incorporate into your AC this past year?	
	Have you encountered any difficulties with the knowledge/comfort/choice of language, used by professionals being interviewed about these themes?	
	Have you been able to find professionals to speak on the [above] themes or have you been forced to substitute topics?	
	Have you had success (i.e. good participation) with any other themes or topics?	
	Any other comments or queries related to this section?	
	<p>Section E - Organization of AC meetings</p> <ul style="list-style-type: none"> - 72% of ACs hold more 10 or more meetings per year - 86% of AC meetings saw the sound system working satisfactorily - 66% of ACs meetings had 'live music' - 29% ACs had music on CDs - 97% of ACs had an 'Information Table' - 80% of ACs had special information for guests about the theme topics and a programme - 94% of ACs had a representative of the local Alzheimer Society' at the Information Table - 46% of ACs were held at Residential or Nursing Care Homes <p>ACs held in these Care settings had an average of 7% attendees with dementia. ACs held in other locations had 11% persons with dementia.</p> <ul style="list-style-type: none"> - 56% of ACs do not ask for financial contributions for their expenses - in 96% of ACs, Volunteers greet people with dementia on arrival, leaving, and care for them if they become sad, restless or don't know what to do with the information - 78% of AC workgroups (steering committees) are organized in cooperation with the local Alzheimer's Society Branch and representatives of at least 3 other health care professional sectors (care-giving, nursing, SW, psychologists, OT, speech and language or physiotherapists, family support workers, outreach workers, home care workers, pastoral care workers or chaplains) - 71% of the organizing partners for ACs actively participate in the AC work group (steering group) - 96% of ACs have a permanent 'contact person' appointed by the local Alzheimer's Society - 84% of ACs had folders and the logo of the Dutch Alzheimer's Society visible - 82% of ACs hold at least 2 activities per year to get the attention of the local press <p>The professional input 'most missed' by AC steering groups, were Pastoral Care Workers, home care workers, local hospital staff, day care centre staff, nursing home staff and GPs.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> - extra attention could be given to inviting/ working with Pastoral Care Workers and other professionals who have been less present at the ACS. This could be done at the National Annual 	

	<p>AC Meeting.</p> <ul style="list-style-type: none"> - extra attention could be given to 'press publicity for ACs' at the National Annual Meeting. - the use of music at the ACs is intended to make such evenings pleasant, not just informative. It helps to generate amusement and frame the different sections of the evening. Is it too difficult for some ACs to organize music, or do they not find it important? 	
15	<p>An AC has a minimum of 10 yearly meetings.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
16	<p>The meetings are held on a fixed day of each month; e.g. 1st Tues. of month.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
17	<p>There is a good sound-system in the room with microphones for the discussion leader, the person being interviewed, and others in the room in the event they wish to ask questions.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
18	<p>During the 'non-discussion parts' of the evening there is music playing.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
19	<p>An 'Information Table' is present in the room, with a wide assortment of printed information and material [from the Alzheimer Society and other reputable, known sources], aimed at the average person who would attend an AC.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
20	<p>The Information Table is manned by a volunteer from the Alzheimer's Society (or other local dementia support group).</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
21	<p>The room chosen to hold an AC in, is in an environment which is as non-threatening as possible (low threshold) for people in the beginning stages of dementia. (Nursing and care homes are not the most appropriate venue.)</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
22	<p>Attending an AC is free-of-charge for guests. No donations are asked for, during the AC.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
23	<p>Volunteers greet and attend to guests on arrival, on leaving, and if they are sad, restless, or don't know what to do with the information communicated.</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p> <p>Additional comments:</p>	
24	<p>An AC is organized together with the local branch/division of the Alzheimer's Society (or other local dementia support group), and volunteers from a minimum of 3 different professional sectors (e.g. care assistants, nurses, day care and care home staff, supportive family carers, pastoral care workers, carer support workers, social workers, OTs, physiotherapists, psychologists, doctors...).</p> <p style="text-align: center;">Never---rarely---usually---mostly---always</p>	

	Additional comments:	
25	An AC is organized by a steering committee or workgroup, at which all people [specified in point 24], can actively participate. This group comprises of a fixed number of people who organize the AC meetings/gatherings. Never---rarely---usually---mostly---always Additional comments:	
26	A designated contact person at the Alzheimer Society Branch (or other local dementia support group), will be responsible to appoint a fixed contact person, local to an AC, on behalf of the group, to the steering committee. Never---rarely---usually---mostly---always Additional comments:	
27	The steering committee of an AC is responsible for the quality of an AC and accepts responsibility for maintaining the QCC. Never---rarely---usually---mostly---always Additional comments:	
28	The logo of the Alzheimer's Society, or other dementia group supporting the AC is clearly visible in all information about the AC, Public Relations events, in the annual AC programme, and in general. Never---rarely---usually---mostly---always Additional comments:	
29	The steering committee undertakes at least 2 activities per year to attract regional press publicity to promote the AC. Never---rarely---usually---mostly---always Additional comments:	
	Further queries relating to this section:	
	Are the local press aware of your AC?	
	Are they supportive?	
	<p>Section F - Evaluation of the meetings</p> <p>- 75% of ACs evaluate each AC gathering. This is done either through asking for individual or collective feedback, or through providing a comment book or evaluation forms - 66% of ACs have already evaluated a the functioning of their AC in a previous year - 10% of ACs have only started evaluating their ACS as a result of this Evaluation Survey, which now constitutes their first evaluation of their AC, and which they can build upon</p> <p>Two ACs said that they did not wish to evaluate their AC, but did fill out the Evaluation Survey of ACs, there are others who see 'evaluating' as a tiresome chore</p> <p>82% of ACs hold successful events which are reported in the regional press. However, in the 'Client Panels' held by the National Dementia Programme (Dutch), it appears that a large number of people are still unaware of their Local Alzheimer Café. This is reason to see if ongoing, local AC contacts with the press, can be improved.</p> <hr/> <p>Recommendations:</p> <p>At the next National Meeting, discuss ways to make evaluating ACs easier and more informative for those of the Dutch Alzheimer Society and their partners in the AC steering committees.</p>	
30	Guests at an AC are always invited to evaluate the AC in verbal or written form [e.g. in a Comments Book]. Never---rarely---usually---mostly---always	

	Additional comments:	
31	An estimate of the numbers of guests are made at each meeting [persons with dementia, family members, friends, caregivers, others] Never---rarely---usually---mostly---always Additional comments:	
32	The AC steering committee evaluates the atmosphere, content, discussions and Information Table at the AC, at least once every two or three years. Never---rarely---usually---mostly---always Additional comments:	
33	The AC steering committee voluntarily self-evaluates their AC each year, according to these QCC criteria, and sends their evaluation in to those collating the information at the AC. Never---rarely---usually---mostly---always Additional comments:	
	Further queries relating to this section:	
	Do you evaluate your AC gatherings each month?	
	What other criteria do you use to evaluate your AC gathering?	
	Do you provide a registration or 'sign in' book to help with your evaluations?	
	Do you provide a 'comments book'?	
	Any miscellaneous queries, suggestions, observations	
	About fund-raising	
	About getting medical professionals and others to refer people to the AC	
	About interest in attending a 2 day for AC coordinators and interviewers	
	About interest in holding courses for AC volunteers	
	Do you already have, or need the AC UK artwork (logo and banners)	
	About others wishing to start an AC?	

Please use additional pages if necessary, to make any further comments or queries. Based on:

. Jones GMM, Redwood K, Harding JW, Bullock P (2008) Comparing UK and Dutch Alzheimer Cafés against new quality control criteria. *J of Dementia Care*. 16:1 (Jan/Feb) pp34-38.)

• Meerveld J, in collaboration with B Miesen (2005/2006; version- March 2006) Seizoensevaluatie met kwaliteits criteria Alzheimer Cafés. Bunnik: Stichting Alzheimer Nederland, pp28. [translation of the Quality Control Criteria and the a summary of the Dutch Evaluation report findings, by GMM Jones, available on the Website www.alzheimerscafe.co.uk.]

Thank you for contributing to this survey to help promote UK ACs.