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## Strategies to recruit and retain older adults in intervention studies: A quantitative comparative study

### 1. Introduction

The recruitment and retention of participants in Randomized Controlled Trials (RCTs) is challenging and raises issues of great concern, especially in studies involving the older population (Crome et al., 2011; Bayer & Tadd, 2000; McMurdo, Witham, & Gillespie, 2005). The characteristics of the sample in a given study should as much as possible reflect the characteristics of the population that is the subject of the enquiry. To obtain this, it is necessary to focus also on those who drop out of the studies at different stages and for various reasons. Differences between participants and non-participants might bias the results of an RCT. Biased research may lead to unreliable results, misleading or incomplete evidence (McMurdo et al., 2011). Participation bias is also shown in postal surveys (de Souto Barreto, 2012). Yet, many studies do not account thoroughly for different types of non-participation or discuss the generalizability and external validity of their sample. Thus, there is a need for further investigation into non-participation.

A greater understanding of the factors that lead to or predict non-participation may enable us to identify those at risk of dropping out (Slymen, Drew, Elder, & Williams, 1996; Elzen, Slaets, Snijders, & Steverink, 2008; van Heuvelen et al., 2005; Jacomb, Jorm, Korten, Christensen, & Henderson, 2002; Young, Powers, & Bell, 2006; Haring et al., 2009). Using relevant and targeted strategies to recruit and retain participants may lead to lower drop-out rates (McMurdo et al., 2011; Gardette, Coley, Toulza, & Andrieu, 2007; Treweek et al., 2010), and may also be useful in recruiting and keeping participants in rehabilitation programmes and treatment on a general basis. Relevant and targeted strategies should be considered at all stages of the studies, including the design and the approach used in recruiting participants. The traditional means of recruiting participants assumed that people were potentially willing to participate in RCTs, and that non-response to an initial approach could be followed up with further communication. This approach is called 'opt-out', as participants approached in this way actively choose not to take part in the study when they are unwilling to participate. For ethical reasons, the gold standard in recruitment at

present is the 'opt-in' approach, where potential participants are informed about the study and then have to communicate their willingness to participate actively; hence, choosing to be included in the study (Junghans, Feder, Hemingway, Timmis, & Jones, 2005; Vellinga, Cormican, Hanahoe, Bennett, & Murphy, 2011). Research has shown that one needs to approach a larger number of potential participants in order to get the required number of participants when applying an opt-in approach, compared to the former opt-out approach (Trevena, Irwig, & Barratt, 2006), and that selection bias can occur with the higher level of consent requirements of the opt-in approach (Buckley, Murphy, Byrne, & Glynn, 2007; Junghans & Jones, 2007; Hewison & Haines, 2006). However, an opt-out approach is often not possible, because of the more stringent ethical regulations imposed in recent years. The current study is part of an RCT which evaluated the effect of a lifestyle intervention programme on well-being, activity and social participation for persons over the age of 65 in a later stage of recovery after a mild to moderate stroke (Lund, Michelet, Sandvik, Wyller, & Sveen, 2012). The main aims of the study were to prevent depressive symptoms and social isolation among older persons with stroke resident in their own homes. The intervention started approximately 3 months after the stroke. All the participants were offered physical exercise in groups at senior centres once a week, while half of the participants, randomly selected, were to receive a group-based lifestyle intervention programme once a week, in addition to the physical exercise. Several strategies were used to improve inclusion and retention in the study in an effort to obtain a representative study sample.

Initially, an opt-out approach could not be used for ethical reasons. Stroke survivors had to consent explicitly before being approached by a researcher and having their medical records read. Thus, in this study of older stroke survivors, inclusion was performed in three steps further described in the methods section, in an attempt to reduce the barriers to participation. The aim of the study was to identify factors associated with participation in an RCT involving older stroke survivors.

## **2. Materials and methods**

### *2.1. Strategies used*

Throughout the RCT, different strategies to enhance participation were applied in the routines and in communication with the participants. We attempted to lower the demands made on potential participants wanting to opt into the study, by including in three steps, wherein the researchers (AL and MM) initiated the contact at all times. Among the strategies used to retain the participants once they had been included in the study, were: close contact with the recruits being kept by only two researchers; creating a project identity; giving thorough information that is easily understood; as well as running the groups at easily accessible local senior centres, and offering transport.

The inclusion criteria for the RCT were: at least 65 years of age, diagnosed with stroke or TIA, believed to be able to function in their own home eventually, and assumed ability to consent. Subjects who met these inclusion criteria were identified with the help of contact-persons in six hospitals in two communities in Norway. Figure 1 shows the flow of the participants in the RCT.

< insert figure 1 here >

Subjects identified by contact nurses at six different hospitals, who met the inclusion criteria, and consented to be contacted, were approached by one of the researchers (AL or MM), were given oral and written information and were asked if they agreed to receive a phone call 2–3 months after discharge. This was the first step of the inclusion, and 204 subjects gave their written consent to be contacted at step 2 (more than 95% of those who were approached). At step 1, participants did not actually consent to take part in the intervention or even the baseline interview, and it was made clear that they could leave the study at any time and that refusal would not result in negative consequences for them. Step 2 of the inclusion took place 2–3 months after step 1, when the researchers contacted the participants by phone to ask if they would take part in a baseline-interview including tests and questionnaires focusing on activity, depressive symptoms and anxiety, health related quality of life and functioning. The final 3rd step was consenting to be randomized into the intervention or the control group.

During the step-wise inclusion, the researchers were able to stay in close contact with the participants and use several strategies to enhance participation. Such strategies are also outlined in the literature (Treweek et al., 2010; McMurdo et al., 2011; Gardette et al., 2007). During inclusion, stressful evaluations were avoided, the information given was clear and easy to understand. Also, attempts were made to create a project-identity for the participants, i.e. by drawing attention to the fact that this project was designed to aid stroke survivors and that the participants could contribute from their own experience as well as benefit personally. After initiating inclusion at step 2, frequent and personal contact was made with the participants with only two researchers working in the project at this stage. To maintain contact, track was kept of those patients who had moved or had stays at rehabilitation facilities. If the participants said they might go on to step 2 or 3, but not at that particular time, permission was asked to call again. When permitted, the researchers initiated all the phone calls, sometimes repeated calls during weeks or months until each participant chose either to be included in the next step, or to leave the study.

Baseline interviews were conducted in the participants' homes, avoiding travel problems for the participants on this occasion. These appointments were arranged taking into account the participants' schedules, i.e. fixed visits from home carers, and written confirmation and follow up calls were made to make sure the appointments were at a convenient time. To reduce the travel distances, the groups were held at local senior centres and every participant was offered transport to get to the centres.

The efforts made to improve participation resulted in 155 participants at step 2 – baseline, and of these 99 also consented at step 3 – randomization. Even if this was not required, most of the 56 who opted out between step 2 and step 3 explained their reasons for opting out, and these reasons were recorded. All the 99 who chose to participate at step 3 are considered as participants regardless of how long they stayed in the project after randomization. All the 56 who left the study at this step were treated as one group in the analyses, regardless of reason stated for not participating.

## *2.2. Measures at inclusion and at baseline (interviews) evaluation*

Data for the purpose of the current study were collected at time of inclusion (close to discharge from hospital) and the baseline evaluations (approximately 2–3 months post stroke). All the questionnaires were filled in under the guidance of the researchers (AL and MM), to make sure there were no misunderstandings, and that missing data would be kept at a minimum. At inclusion, questionnaires were filled in by the participant, hospital staff and one of the two researchers, in the hospital wards. At baseline, appointments were made and the researcher visited the participants' homes.

The RCT project was approved by the Regional Committee for Medical Research Ethics in the Eastern Health Region, Norway, with approval number 194-07084a1.2007.269. This approval also covered the current study.

### *2.2.1. Measures at inclusion*

Demographic information, the health of the patient before the stroke and type of stroke/localization were recorded. The Barthel ADL index was used to measure the participants' performance of basic functions and the activities of daily living (Mahoney & Barthel D.W, 1965). The score scale ranged from 0 to 20. Subjects with a score of 15 or more were included in the RCT. In this study the scores were dichotomized to 18 points and lower/19 points or higher, to distinguish between good and less good/fair functioning. This matched the median value found in our sample. The Mini Mental State Examination (MMSE) is a brief, well-established 30-point structured test used to screen cognitive function (Folstein, Folstein, & McHugh, 1975). It tests abilities, including mental arithmetic, memory and orientation. The ability to consent to participate in the RCT was assumed when the subject had a score of at least 23. A commonly applied cut-off point between good/normal performance and questionable or poor performance is 27 and less/ 28 or more (Engedal & Haugen, 2009), and this is also used to dichotomize the scores in this study. The Ullevaal Aphasia Screening (UAS) test is performed by health personnel and offers a short and valid screening of speech (Thommessen, Thoresen, Bautz-Holter, & Laake, 1999). The maximum score is 52 points and the scores in this study were dichotomized to 49 or lower/ 50 or higher to distinguish between normal speech and problems with speech, matching the median of our sample.

### *2.2.2. Measures at baseline*

Baseline evaluations were carried out in the participants' home. The Medical Outcomes Study 36-item Short Form Questionnaire (SF-36) is a measure of perceived health and well-being which consists of 8 subscales; mental health, vitality, bodily pain, general health, social functioning, physical functioning, role physical and role emotional (Ware & Sherbourne, 1992; Anderson, Laubscher, & Burns, 1996; Gandek, Sinclair, Kosinski, & Ware, Jr., 2004). The subscales were scored and transformed to a 0 - 100 scale with 100 as the highest level of health. When examined, the subscales mental health, vitality, general health and physical functioning proved to have an even distribution of the data and were initially analysed using t-tests. The remaining 4 subscales of the SF-36 (bodily pain, social functioning, role physical and role emotional) had unevenly distributed data and were initially analysed using Mann–Whitney U tests.

The Hospital Anxiety and Depression Scale (HAD) consists of 2 subscales; anxiety and depression, both ranging from 0 to 21, which is the highest level of anxiety or depression (Zigmond & Snaith, 1983). There is no set cut-off score to distinguish normal from pathological findings for this measure (cut-offs between 6 and 10 are commonly used (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000; O'Rourke, MacHale, Signorini, & Dennis, 1998; Bjelland, Dahl, Haug, & Neckelmann, 2002)) and in the analyses the data was divided into 4 categories according to the interquartile range of scores for the whole sample. The Canadian Occupational Performance Measure (COPM) shows change in self-reported occupational performance and satisfaction of up to five occupational issues rated on a scale from 1 to 10, where 10 is the highest score of performance or satisfaction (Kjeken, Slatkowsky-Christensen, Kvien, & Uhlig, 2004). Timed Up and Go is a measure of mobility where the person is timed getting up from a chair, walking 3 metres and back again to sit down again (Podsiadlo & Richardson, 1991). As done in the Balance Evaluation Systems Test (Horak, Wrisley, & Frank, 2009), scores on Timed Up and Go were dichotomized to 10 seconds or less/ 11 seconds or more, to distinguish between fast and slow walking. Trail Making Tests A and B were applied to evaluate cognitive function (Perianez et al., 2007). In Trail Making Test A the person is timed drawing a line between the numbers 1 to 25 spread out on a paper. In Trail Making Test B, the person is timed drawing a line between numbers from 1 to 13 and the letters A to L, visiting every number and letter alternately; 1A2B3C4D, etc. The most common cut-off score to distinguish between good performance and poor performance for adults above the age of 65 are 60 seconds for Trail Making Test A and 120 seconds for Trail Making Test B. In this sample, these cut-off scores are also applied when dichotomizing.

### *2.3. Analyses*

To pursue the aim of this study, we performed statistical comparisons of participants and non-participants, using logistic regression analyses, in order to identify and describe potential differences found in the demographics and various

measures of activity, anxiety and depression, health-related quality of life and performance (Altman, 1991; Pallant, 2001).

All the measures for which the missing data did not exceed 10 % were analysed. We had more than 10 % missing data on localization/type of stroke. On the Canadian Occupational Performance Measure, more than 10 % of the participants did not define any prioritized occupational performance problems. Therefore, these variables could not be included in the analyses. Initial analyses were performed using crosstabulations and chi-square tests for nominal variables, and t-tests and Mann–Whitney U tests for continuous data. The variable 'age' had evenly distributed data, and was initially analyzed using t-tests. To get a better picture of differences between the specific age groups, age was then transformed according to its interquartile range, making it a categorical variable. HAD anxiety and HAD depression scores as well as the Role Emotional subscale from SF-36 were also transformed according to their interquartile range. Such a transformation was attempted on the SF-36 subscale Role Physical. However, this was not possible, since more than 50% of the responders had the lowest possible score (0). Role Physical was, therefore, dichotomized at 0/1 - 100.

Correlation tests were performed on all the variables, resulting in the removal of the variable "assistance before the stroke", due to high correlation with "assistance after discharge". As one might expect the HAD anxiety scale and the HAD depression scale correlated with a Pearson value of 0.51, though this did not result in the removal of either from the model.

All variables where differences between participants and non-participants had a p-value less than 0.20 in the initial descriptive analyses were then entered into a bivariate logistic regression. Gender was also entered despite its p-value of 0.27. The variables with a p-value of less than 0.20 in the bivariate analyses were then entered into a multivariate logistic regression analysis using backward removal, removing the variable with the highest p-value from the model, until only variables with significance level below 0.05 were left.

### 3. Results

A total of 155 of the included stroke survivors agreed to take part in a baseline interview (step 2), after which they were offered participation in a group-based programme. Of those included, 99 chose to participate at step 3, taking part in the groups, and 56 of them chose not to do so. Different reasons were given for not participating in groups.

< insert table 1 here >

As shown in table 2, group participants were younger than non-participants, after the age of 80 years the participation rate declines. However, it is not until after the age of 85 that the difference is statistically significant (OR=0.30, p=0.03). The youngest quartile has a lower participation rate than the second youngest group. The

participation rate was 72 % in the age group 63-74, 77 % in age group 75-79, 54 % in the age group 80-84 and 50 % for subjects above the age of 85.

< insert table 2 here >

< insert table 3 here >

When using the backward removal method in the multivariate regression analysis, the variables were removed in this order: marital status, Barthel ADL-index, role emotional, HAD anxiety scale and gender. The logistic regression analysis (table 4) shows that persons with lower scores on the HAD depression scale (less presence of depressive symptoms) were less likely to participate. The presence of depressive symptoms indicated by a HAD depression scale score of 7 or higher seemed to predict participation in this study, with an odds ratio of 4.22 and a p-value of 0.02. Subjects with higher scores (1 - 100) on SF-36 "role physical", indicating good health in this domain, had a lower participation rate than those with poor score (0) on this subscale (OR=0.32, p-value 0.01). Furthermore, persons with assistance in their homes less than once a week, indicating good functioning in the home, were substantially (OR=4.88) and significantly ( $p < 0.01$ ) more likely to participate (45 % participation rate among subjects with assistance once or week or more versus 71 % participation rate among subject with assistance less than once a week).

< insert table 4 here >

These analyses are based on data collected at inclusion and during the baseline interview. We performed similar analyses on inclusion data only; with the purpose of comparing those included at step 2, the baseline interview (n=155) to those who were included at step 1 but withdrew from the study before step 2 (n=46). The only significant difference between these two groups was education. Subjects with higher education (college/ university) were more likely (p-value 0.01) to take part in the baseline interview. This significant difference, however, disappeared when it came to the next step of inclusion; choosing to attend the groups or not.

#### **4. Discussion**

Information about participation bias in studies is crucial for evaluating the strength of study results (de Souto Barreto, 2012). The main findings of the current study address the factors associated with participation are age under 85 years, assistance in the home less than once a week, the presence of depressive symptoms and poor self-reported health on the SF-36 role physical.

Some of these findings are in line with earlier research. It is known that younger age and functioning independently at home predict participation in studies (Haring et al., 2009; van Heuvelen et al., 2005; Slymen et al., 1996; Jacomb et al., 2002; Chatfield, Brayne, & Matthews, 2005). What is interesting in the present study is the relatively small difference between participants and non-participants on the

other measurements and that males do not have a significantly larger participation rate, which has often been found in similar studies (Haring et al., 2009; Williams, Irvine, McGinnis, McMurdo, & Crombie, 2007; Slymen et al., 1996). Furthermore one would expect that the presence of symptoms of depression and a poor self-reported SF-36 role physical would predict non-participation (Young et al., 2006; Elzen et al., 2008; van Heuvelen et al., 2005). In this study, however, the presence of depressive symptoms as well as poorer self-reported health in the domain of role physical was associated with participation in the groups.

This study does not have a control group, as the recruitment strategies were used with all the potential participants. Therefore, we cannot know if these results would have been different had we not applied the strategies. However, considering how these results differ from earlier studies on participation, we consider it a possibility that an explanation for the findings may be the strategies applied to enhance participation, among them the inclusion over 3 steps. The 3-step inclusion allowed us to stay in touch actively with the participants, in order to motivate them to take part in the groups. When an opt-out approach is not ethically acceptable, this step-wise inclusion might reduce the barriers to participation that are often seen when using an opt-in approach. Inclusion at step 1 did not demand any commitment by the person at the time of inclusion and no initiative needed to be made by the subjects in order to participate. The subjects simply allowed us to call them 2 - 3 months after the stroke. During our phone-calls we were able to do some motivational work. If for some reason, subjects were slightly interested, but not at the time able to make a decision about participation, we often agreed to call them again some weeks later. We called back, as often as needed, until the participants decided whether they wished to consent to the next step or to withdraw. This was done to make it easy to participate, believing that rather than feeling coerced by several phone calls, people willing to participate may find it burdensome to take the initiative themselves (Junghans et al., 2005).

Studies of participation often report cognitive impairment to be associated with non-participation (Jacomb et al., 2002; Gardette et al., 2007; Chatfield et al., 2005). For the measures of cognition in our study (Mini Mental State Examination, Trail Making Tests A and B), no significant differences between the scores of participants and non-participants were found. This may also be due to the close follow-up, and the low demands put on the participants in the study.

Another explanation of our findings is the additional strategies we used after inclusion at step 1 to minimize attrition, among them frequent personal contact, and giving thorough information about the programme in order to create a project identity. The motivational work which was done over the phone may have contributed to a feeling that the patients actually needed this programme. This is a plausible explanation for people with depressive symptoms deciding to participate. They might feel a need for the social support this programme offered. Persons with depressive symptoms did not, as in other studies (van Heuvelen et al., 2005; Slymen et al., 1996), refuse to take part in the study. One of the aims of the RCT programme was to reduce social isolation and depressive symptoms. It is, therefore, a strength of this



trial that we actually were able to recruit participants with some depressive symptoms. Likewise, subjects with lower scores on the SF-36 role physical might feel that they needed the project's physical exercise programme.

The baseline interview was performed by a researcher visiting the persons' homes. This approach may have been especially suitable for the population targeted in this study; older stroke survivors living at home. Some of the subjects wished to participate but had practical difficulties in doing so, i.e. problems with transport due to poor mobility, trouble keeping track of the appointments, etc. Several efforts were made on our part to meet these needs, for example, providing transport when needed. This could be another explanation why subjects with poor self-reported health in the domain of role physical decided to participate.

The reasons for refusal, when given, were different. Approximately half of the subjects referred to reasons like not feeling a need for the programme, already having had enough follow-up after the stroke and not wishing to prioritize our programme. Maybe these subjects really did not need the intervention. However, the only measure showing that non-participants have significantly better functioning is on the SF-36 role physical, not in the measures of other physical or cognitive functioning (for instance Timed Up Go, SF-36 physical functioning, Mini Mental State Examination and Trail Making Test A and B). Analyses have not been done on the groups according to reasons for non-participation. Such a group-wise analysis might shed more light towards the aim of the current study. However, we considered that the material was insufficient for such a sub-group analysis.

The important point in following participants as closely as we did in this study was not to put pressure on the participants. Though we made a great effort to emphasize that the phone calls as well as participation was optional, we cannot completely exclude the possibility that our repeated phone calls were felt as pressure. There is, however, also a possibility that all the attention from us was something the participants found agreeable, that knowing we were concerned and interested in their experiences could itself be seen as an intervention. Attending some kind of intervention after a stroke might in itself have a positive effect on motivation to recover, and affect the quality of life (Carin-Levy, Kendall, Young, & Mead, 2009).

The results of this study indicate that a focus on recruitment and retention is important in intervention studies, especially when studying the older population who are more likely not to participate. When setting up a panel in an ethically acceptable way with the opt-in approach, one must perhaps pay even more attention to getting a large and unbiased sample. The strategies applied in the RCT "Lifestyle intervention for older adults in rehabilitation after stroke: Development, implementation and evaluation", at inclusion and during the study may have contributed to getting a larger and less biased sample, as well as including subjects who seemed to meet the aims of the intervention.

### **Clinical message**

- A focus on recruitment and retention is important in intervention studies, especially when studying the older population, who are more likely not to participate.
- Targeted strategies in recruitment and retention may contribute to less biased samples, and the inclusion of subjects who meet the aims of the intervention.

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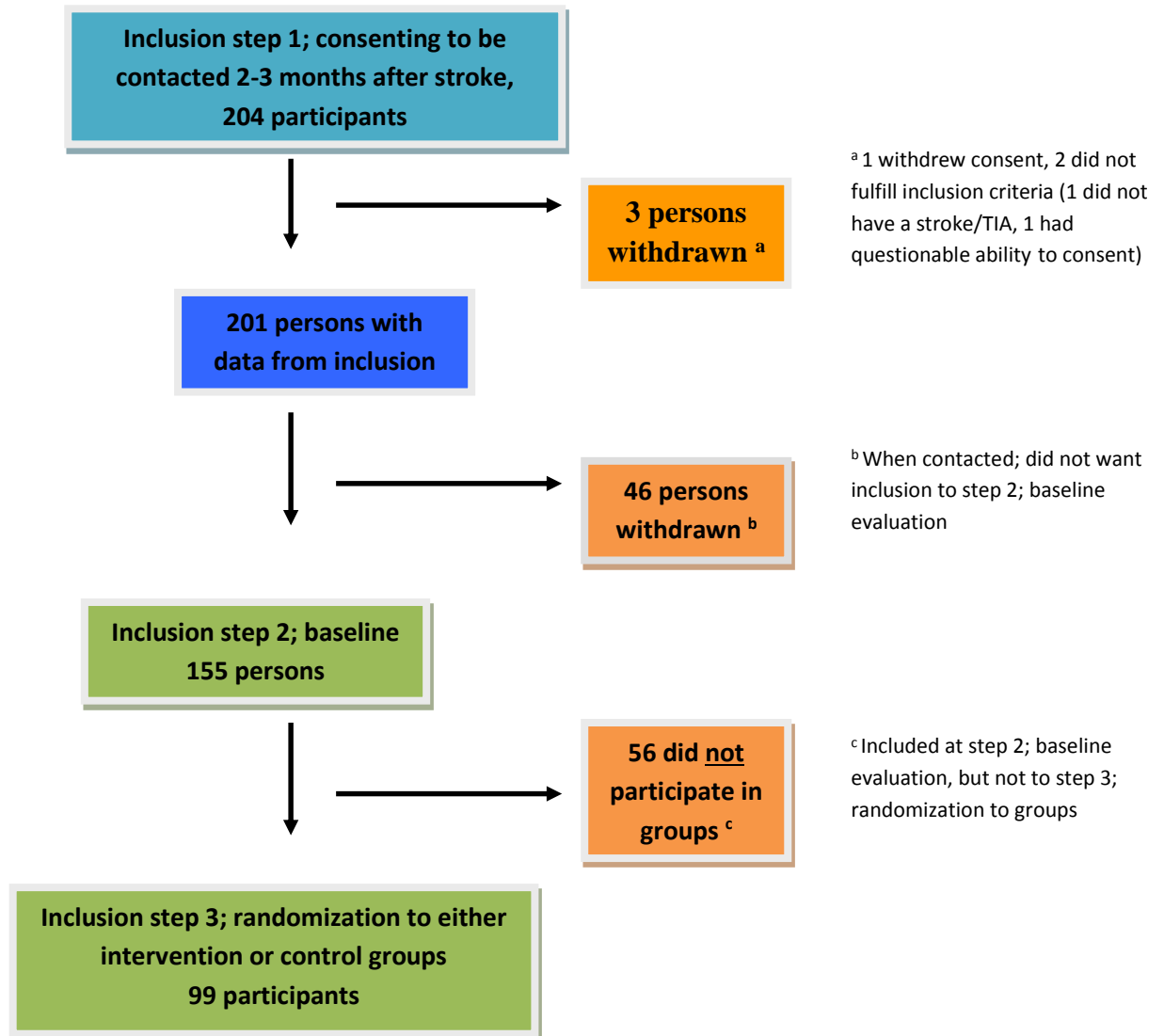
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### **Conflict of interests**

The authors declare that there are no financial or personal conflicts of interest to the present study.

## Recruiting and retaining the elderly in intervention studies



**Figure 1**  
Flowchart of the RCT until inclusion in step 3

## Recruiting and retaining the elderly in intervention studies

**Table 1**

Reasons given for not participating in groups (n=56)

Reason given	%
Being too busy, or being happy with the follow-up they already have and not wanting to prioritize attending something new.	52
Health issues or poor mobility and other reasons for reduced functioning, including aphasia.	25
Did not wish to attend, without stating further reasons.	16
Having an ill spouse.	5
Died after baseline and before having decided whether or not to participate in groups.	2

## Recruiting and retaining the elderly in intervention studies

**Table 2**

Mean/median scores of continuous variables; participants and non-participants and difference between the two

Characteristics	Participants Mean (SD)	Non- participants Mean (SD)	Mean difference	95 % Confidence interval	p-value
Age at inclusion (n=99/56)	77.6 (6.9)	80.9 (7.1)	3.3	1.0 - 5.6	0.01
SF-36 Mental health (n=96/51)	72.9 (19.2)	74.4 (17.3)	1.4	-4.9 – 7.8	0.66
SF-36 Vitality (n=97/51)	45.7 (20.7)	48.7 (20.7)	3.0	-4.1 – 10.1	0.40
SF-36 General health (n=97/51)	59.4 (23.4)	62.3 (22.3)	3.0	-4.9 – 10.8	0.46
SF-36 Physical functioning (n=97/51)	52.6 (25.8)	51.8 (28.5)	-0.8	-10.0 – 8.3	0.86
Characteristics of unevenly distributed variables	Participants Median	Non- participants Median			P-value
SF-36 Bodily pain (n=97/51)	62	52			0.28a
SF-36 Social functioning (n=97/51)	63	75			0.14a
SF-36 Role physical (n=97/51)	0	25			0.04a
SF-36 Role emotional (n=96/51)	33	67			0.07a

aUneven distribution; Mann Whitney U test.

## Recruiting and retaining the elderly in intervention studies

**Table 3**

Descriptive data and percentage choosing to participate, of categorical variables with less than 10 % missing data

Characteristics	Total number ( % )	% who chose to participate (n=99)	p-value
Gender (n=155)			
Men	70 (45)	69	0.27
Women	85 (55)	60	
Education: (n=151)			
Primary school	39 (26)	59	ref
Secondary school	62 (41)	63	0.69
College/ university	50 (33)	68	0.38
Marital status (n=155)			
Living alone	80 (52)	58	0.09
Living with spouse	75 (48)	71	
Stroke or TIA (n=151)			
Stroke	141 (93)	63	1.0a
TIA	10 (7)	60	
First time stroke (n=154)			
Yes	91 (59)	62	0.39
No (earlier stroke(s))	63 (41)	68	
Barthel ADL index at inclusion (n=155)			
19 points or higher	95 (61)	71	0.03
18 points or lower	60 (39)	53	
MMSEb during hospital stay (n=151)			
28 or higher	80 (53)	65	0.84
27 or lower	71 (47)	63	
UASc during hospital stay (n=152)			
50 or higher	138 (91)	67	0.25a
49 or lower	14 (9)	50	
Discharged to n=150)			
directly to own home	92 (61)	63	0.76
rehabilitation or other institution	58 (39)	66	
Assistance after discharge: (n=155)			
once a week or more	42 (27)	45	0.01
less than once a week	113 (73)	71	
TUGd at baseline (n=152)			
10 seconds or less	57 (38)	67	0.76
11 seconds or more	95 (63)	64	
TMTe A at baseline (n=147)			
60 seconds or less	66 (45)	67	0.75
61 seconds or more	81 (55)	64	
TMTe B at baseline (n=147)			
120 seconds or less	42 (29)	69	0.55
121 seconds or more	105 (71)	64	
HADf anxiety scale at baseline (n=153)			
0 - 1	40 (26)	55	ref
2 - 4	46 (30)	59	0.73
5 - 7	42 (28)	71	0.13
8 - 16	25 (16)	76	0.09
HADf depression scale at baseline (n=153)			
0 - 2	44 (29)	57	ref
3 - 4	44 (29)	61	0.67
5 - 6	29 (19)	62	0.66
7 - 18	36 (24)	79	0.05

aFisher's exact test.

bMini Mental State Examination.

c Ullevaal Aphasia Screening.

dTimed Up and Go.

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eTrail Making Test.

f Hospital Anxiety and Depression scale.

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**Table 4**

Logistic regression; bivariate and multivariate

Characteristics	Bivariate analyses - odds			Adjusted – multivariate analyses		
	OR <sup>a</sup>	95% CI <sup>b</sup>	p-value	OR <sup>a</sup>	95% CI <sup>b</sup>	p-value
<b>Age at inclusion</b>						
63 – 74	Ref			Ref		
75 – 79	1.29	0.48 – 3.51	0.62	1.00	0.34 - 2.98	1.00
80 – 84	0.46	0.18 – 1.18	0.11	0.37	0.13 - 1.10	0.07
85 - 95	0.39	0.15 – 0.97	0.04	0.30	0.10 - 0.88	0.03
<b>Gender</b>						
Living with partner	1.46	0.83 – 2.55	0.19			
Barthel at inclusion, cut-off point 18/19	1.78	0.92 – 3.47	0.09			
Barthel at inclusion, cut-off point 18/19	2.09	1.07 – 4.1	0.03			
Assistance less than once per week	2.94	1.41 – 6.1	0.01	4.88	1.92 - 12.44	< 0.01
<b>HAD anxiety scale</b>						
0 – 1	ref		ref			
2 – 4	1.16	0.49 – 2.74	0.73			
5 – 7	2.05	0.82 – 5.10	0.13			
8 - 16	2.59	0.85 – 7.86	0.09			
<b>HAD depression scale</b>						
0 – 2	ref		ref	ref		ref
3 – 4	1.21	0.52 – 2.83	0.67	1.07	0.40 - 2.82	0.89
5 – 6	1.24	0.48 – 3.24	0.66	1.08	0.36 - 3.23	0.89
7 - 18	2.66	0.99 – 7.13	0.05	4.22	1.28 - 13.94	0.02
<b>Role physical</b>						
Role physical	0.47	0.24 - 0.92	0.03	0.32	0.14 - 0.73	0.01
<b>Role emotional</b>						
0	ref					
1 - 34	1.23	0.46 - 3.29	0.68			
35 - 99	0.71	0.24 - 2.09	0.53			
100	0.49	0.19 - 1.23	0.13			

a OR = Odds Ratio.

b CI = Confidence Interval.



## References

- Altman, D. G. (1991). *Practical statistics for medical research*.
- Anderson, C., Laubscher, S., & Burns, R. (1996). Validation of the Short Form 36 (SF-36) health survey questionnaire among stroke patients. *Stroke*, 27(10), 1812-1816. Retrieved from PM:8841336
- Bayer, A., & Tadd, W. (2000). Unjustified exclusion of elderly people from studies submitted to research ethics committee for approval: descriptive study. *BMJ*, 321(7267), 992-993.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. [Review] [86 refs]. *Journal of Psychosomatic Research.*, 52(2), 69-77.
- Buckley, B., Murphy, A. W., Byrne, M., & Glynn, L. (2007). Selection bias resulting from the requirement for prior consent in observational research: a community cohort of people with ischaemic heart disease. *Heart*, 93(9), 1116-1120.
- Carin-Levy, G., Kendall, M., Young, A., & Mead, G. (2009). The psychosocial effects of exercise and relaxation classes for persons surviving a stroke. *Canadian Journal of Occupational Therapy - Revue Canadienne d'Ergotherapie*, 76(2), 73-80.
- Chatfield, M. D., Brayne, C. E., & Matthews, F. E. (2005). A systematic literature review of attrition between waves in longitudinal studies in the elderly shows a consistent pattern of dropout between differing studies. [Review] [32 refs]. *Journal of Clinical Epidemiology.*, 58(1), 13-19.
- Crome, P., Lally, F., Cherubini, A., Oristrell, J., Beswick, A. D., Clarfield, A. M. et al. (2011). Exclusion of older people from clinical trials: professional views from nine European countries participating in the PREDICT study. *Drugs & Aging*, 28(8), 667-677. doi:<http://dx.doi.org/10.2165/11591990-000000000-00000>
- de Souto Barreto, P. (2012). Participation bias in postal surveys among older adults: The role played by self-reported health, physical functional decline and frailty. *Archives of Gerontology and Geriatrics*, 55(3), 592-598. Retrieved from <http://www.sciencedirect.com/science/article/pii/S0167494312000817>
- Dennis, M., O'Rourke, S., Lewis, S., Sharpe, M., & Warlow, C. (2000). Emotional outcomes after stroke: factors associated with poor outcome. *Journal of Neurology, Neurosurgery & Psychiatry*, 68(1), 47-52.
- Elzen, H., Slaets, J. P., Snijders, T. A., & Steverink, N. (2008). Do older patients who refuse to participate in a self-management intervention in the Netherlands differ from older patients who agree to participate? *Aging Clin.Exp.Res.*, 20(3), 266-271. doi:4667 [pii]. Retrieved from PM:18594195
- Engedal, K., & Haugen, P. (2009). *Demens - fakta og utfordringer [Dementia - facts and challenges]*. Tønsberg.(in Norwegian)
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198. doi:0022-3956(75)90026-6 [pii]. Retrieved from PM:1202204
- Gandek, B., Sinclair, S. J., Kosinski, M., & Ware, J. E., Jr. (2004). Psychometric evaluation of the SF-36 health survey in Medicare managed care. *Health Care Financing Review*, 25(4), 5-25.
- Gardette, V., Coley, N., Toulza, O., & Andrieu, S. (2007). Attrition in geriatric research: how important is it and how should it be dealt with? *Journal of Nutrition, Health & Aging.*, 11(3), 265-271.

- Haring, R., Alte, D., Volzke, H., Sauer, S., Wallaschofski, H., John, U. et al. (2009). Extended recruitment efforts minimize attrition but not necessarily bias. *Journal of Clinical Epidemiology*, 62(3), 252-260.
- Hewison, J., & Haines, A. (2006). Overcoming barriers to recruitment in health research. [Review] [16 refs]. *BMJ*, 333(7562), 300-302.
- Horak, F. B., Wrisley, D. M., & Frank, J. (2009). The Balance Evaluation Systems Test (BESTest) to differentiate balance deficits. *Physical Therapy*, 89(5), 484-498.
- Jacomb, P. A., Jorm, A. F., Korten, A. E., Christensen, H., & Henderson, A. S. (2002). Predictors of refusal to participate: a longitudinal health survey of the elderly in Australia. *BMC Public Health*, 2, 4.
- Junghans, C., Feder, G., Hemingway, H., Timmis, A., & Jones, M. (2005). Recruiting patients to medical research: double blind randomised trial of "opt-in" versus "opt-out" strategies. *BMJ*, 331(7522), 940.
- Junghans, C., & Jones, M. (2007). Consent bias in research: how to avoid it. *Heart*, 93(9), 1024-1025.
- Kjeken, I., Slatkowsky-Christensen, B., Kvien, T., & Uhlig, T. (2004). Norwegian Version of the Canadian Occupational Performance Measure in Patients With Hand Osteoarthritis: Validity, Responsiveness, and Feasibility. [Article]. *Arthritis & Rheumatism*, 51(5), 709-715.
- Lund, A., Michelet, M., Sandvik, L., Wyller, T. B., & Sveen, U. (2012). A lifestyle intervention as supplement to a physical activity programme in rehabilitation after stroke: a randomized controlled trial. *Clin Rehabil*, 26(6), 502-512. doi:10.1177/0269215511429473
- Mahoney, F. I., & Barthel D.W. (1965). Functional evaluation: The Barthel Index. *Md State Med.J.*, 14, 61-65. Retrieved from [PM:14258950](#)
- McMurdo, M. E., Roberts, H., Parker, S., Wyatt, N., May, H., Goodman, C. et al. (2011). Improving recruitment of older people to research through good practice. *Age & Ageing*, 40(6), 659-665.
- McMurdo, M. E., Witham, M. D., & Gillespie, N. D. (2005). Including older people in clinical research. *BMJ*, 331(7524), 1036-1037.
- O'Rourke, S., MacHale, S., Signorini, D., & Dennis, M. (1998). Detecting psychiatric morbidity after stroke: comparison of the GHQ and the HAD Scale. *Stroke*, 29(5), 980-985.
- Pallant, J. (2001). *SPSS Survival manual - a step by step guide to data analysis using SPSS version 12*.
- Perianez, J. A., Rios-Lago, M., Rodriguez-Sanchez, J. M., drover-Roig, D., Sanchez-Cubillo, I., Crespo-Facorro, B. et al. (2007). Trail Making Test in traumatic brain injury, schizophrenia, and normal ageing: sample comparisons and normative data. *Archives of Clinical Neuropsychology*, 22(4), 433-447.
- Podsiadlo, D., & Richardson, S. (1991). The timed "Up & Go": a test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society*, 39(2), 142-148.
- Slymen, D. J., Drew, J. A., Elder, J. P., & Williams, S. J. (1996). Determinants of non-compliance and attrition in the elderly. *International Journal of Epidemiology*, 25(2), 411-419.
- Thommessen, B., Thoresen, G. E., Bautz-Holter, E., & Laake, K. (1999). Screening by nurses for aphasia in stroke--the Ullevaal Aphasia Screening (UAS) test. *Disability and Rehabilitation*, 21(3), 110-115. Retrieved from [PM:10206350](#)

- Trevena, L., Irwig, L., & Barratt, A. (2006). Impact of privacy legislation on the number and characteristics of people who are recruited for research: a randomised controlled trial. *Journal of Medical Ethics*, 32(8), 473-477.
- Treweek, S., Pitkethly, M., Cook, J., Kjeldstrom, M., Taskila, T., Johansen, M. et al. (2010). Strategies to improve recruitment to randomised controlled trials. [Review] [67 refs][Update of Cochrane Database Syst Rev. 2010;(1):MR000013; PMID: 20091668]. *Cochrane Database of Systematic Reviews*.(4):MR000013, 2010.,(4), MR000013.
- van Heuvelen, M. J., Hochstenbach, J. B., Brouwer, W. H., de Greef, M. H., Zijlstra, G. A., van, J. E. et al. (2005). Differences between participants and non-participants in an RCT on physical activity and psychological interventions for older persons. *Aging Clin.Exp.Res.*, 17(3), 236-245. doi:2183 [pii]. Retrieved from PM:16110738
- Vellinga, A., Cormican, M., Hanahoe, B., Bennett, K., & Murphy, A. W. (2011). Opt-out as an acceptable method of obtaining consent in medical research: a short report. *BMC Medical Research Methodology*, 11, 40.
- Ware, J. E. Jr. P. \*, & Sherbourne, C. D. P. (1992). The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual Framework and Item Selection. [Article]. *Medical Care*, 30(6), 473-483.
- Williams, B., Irvine, L., McGinnis, A. R., McMurdo, M. E., & Crombie, I. K. (2007). When "no" might not quite mean "no"; the importance of informed and meaningful non-consent: results from a survey of individuals refusing participation in a health-related research project. *BMC Health Services Research*, 7, 59.
- Young, A. F., Powers, J. R., & Bell, S. L. (2006). Attrition in longitudinal studies: who do you lose? *Australian & New Zealand Journal of Public Health.*, 30(4), 353-361.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica.*, 67(6), 361-370.