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USING HOME RECRUITMENT TO INCREASE PARTICIPATION AND REPRESENTATIVENESS IN RESEARCH AMONG INDIVIDUALS WITH PSYCHOSIS

ABSTRACT

The participation rates in epidemiologic cohort studies have declined in recent decades. We aimed to evaluate the effect of home recruitment on participation rate and non-response bias within the individuals with psychosis in a follow-up study. The baseline (1999-2001) and follow-up (2008-2010) studies in the Northern Finland Birth Cohort 1966 consisted of magnetic resonance imaging of the brain, cognitive testing and psychiatric assessment. The participation rates were 67% (54/81) for baseline participants, 10% (5/49) for baseline non-participants and 35% (48/136) for those who were diagnosed with a psychosis after the baseline study. In order to increase participation of the individuals who had participated at the baseline (n=81), those who would not have participated otherwise were offered to be interviewed at home. Altogether 18 follow-up participants were home-recruited. Several illness-related variables were compared between the home-recruited participants, standard protocol participants and non-participants. The home-recruited participants had more symptoms, lower functioning, cognition and total grey matter volume, and higher use of antipsychotics measured at baseline (absolute values of effect sizes 0.60-1.05), compared to standard protocol participants and non-participants. The same differences occurred between the home-recruited and standard protocol participants in the follow-up. By using home recruitment we were able to increase the participation rate and to avoid problems of non-response bias. Effective recruitment may need special efforts in population-based studies for individuals with psychosis.

Abbreviations: NFBC1966: The Northern Finland Birth Cohort 1966, CRHC: the Care Register for Health Care, PANSS: the Positive and Negative Syndrome Scale, CGI: the Clinical Global Impression, SOFAS: the Social and Occupational Functioning Assessment Scale, MRI: Magnetic Resonance Imaging, TGM: total grey matter volume, CVLT: the California Verbal Learning Test, VOLT: Visual Object Learning Test, AIM: Abstraction, Inhibition and Working Memory task.

KEY WORDS: NON-PARTICIPATION, NON-RESPONSE BIAS, PSYCHOSIS, RECRUITMENT

INTRODUCTION

Non-participation is a serious problem in research, reducing sample size and statistical power, compromising both internal and external validity and possibly introducing non-response bias. Non-response bias, i.e. bias resulting from limiting the survey analysis to the available data, may occur if participants and non-participants are different with respect to the study variables. However, a high participation is neither a necessary nor a sufficient condition for unbiased estimation, if the study sample is representative (1).

The participation rates in epidemiologic cohort studies have declined in recent decades and they are likely to decline even further (2,3). Participant dropout tends to increase with, e.g. multiple follow-ups and more complicated study designs becoming burdensome for the participants (3).

Participation in health studies is lower among people with severe mental health problems (4), and diagnoses of schizophrenia (5-7), psychosis and personality disorders (8) have been associated with non-participation. In the Health 2000 Study in Finland, the prevalence estimate of psychotic disorders was 12% higher when non-participants with a register diagnosis of psychosis were included in the calculations (9). In a five-year follow-up magnetic resonance imaging (MRI) study of schizophrenia cases, the participants of the follow-up had a shorter duration of illness and fewer negative symptoms at baseline than non-participants (10). Also, according to Candilis et al. (11) individuals with schizophrenia were more willing to participate in a hypothetical research protocol if they had less symptoms and higher decision-making capacity. In all, individuals with more severe psychotic illness tend to cumulate into non-participants.

We have previously reported that in a study of psychosis, including MRI of the brain, non-participants were more often patients with schizophrenia than with non-schizophrenic psychoses, they had more positive symptoms, and they had a higher number of hospitalizations than participants (7). In this paper we describe the participation of individuals with psychosis (cases) in a follow-up study. We specifically aimed to evaluate the effect of home recruitment of the baseline participants on participation rate and non-response bias. As far as we know, this is the first study evaluating the effect of home recruitment of individuals with psychosis in a population-based follow-up study.

MATERIAL AND METHODS

THE NORTHERN FINLAND BIRTH COHORT 1966

This study is based on the Northern Finland Birth Cohort 1966 (NFBC1966), which includes all live-born babies in Northern Finland with a date of birth during 1966 (n=12058; 12). Schizophrenia research in the NFBC1966 has been active since the mid-1990s (13). Altogether, 10932 subjects who lived in Finland at the age of 16 years have not denied the use of their data. Overall ethical permissions for the NFBC studies have been obtained from The Ethics Committee of the Northern Ostrobothnia Hospital District (EETTMK 94/11, 17th September 2012) and signed informed consents have been received from all participants.

FIELD STUDIES ON PSYCHOSIS IN THE NFBC1966

In the NFBC1966, field studies on psychosis data were collected from individuals with psychosis and control subjects without psychosis. The control subjects (not used in this study) have been presented earlier by, e.g. Haapea et al. (14) and Veijola et al. (15).

Baseline study

The baseline study was conducted during 1999–2001 (mean age 34.2 years, standard deviation (SD) 0.8). It consisted of structural MRI of the brain (14,16), measures of cognitive functioning (17), psychiatric interviews (18) and questions relating to, e.g. use of antipsychotic medication (19), social background and substance use.

Sample detection. Cohort members with a psychotic episode by the end of year 1997 were detected using the Care Register for Health Care (CRHC). Additionally, two subjects were outpatients with a psychosis detected by non-systematic search of outpatient records in outpatient practice during the data collection. The diagnoses were validated according to DSM-III-R.

Participation. Altogether 91 (62%) cases participated and provided informed consent in writing. The data collection of the baseline study has been presented in detail previously (7).

Follow-up study

The follow-up study was conducted during 2008–2010 (mean age 43.7 years, SD 0.8). The follow-up study procedure was extended from the baseline study with also functional MRI and more measures of cognitive functioning (15,20-23). The

participants provided informed consent at the beginning of the study. The interviews, the MRI scans and the cognitive tests were to be conducted in the Oulu University Hospital, in most cases during one day. Completing all parts of the field study took about seven hours.

Home recruitment. In the early phase of the follow-up study we had problems in recruitment as many of the cases did not want to participate with standard protocol. To increase the participation of the cases who had participated at the baseline, they were offered to be interviewed at home and chauffeured to the Oulu University Hospital for the MRI scan and cognitive testing if they were not willing to participate with the standard protocol. Home interviews were arranged beforehand on the phone, and were conducted by two experienced psychiatric nurses, who always visited the interviewees together. Home interviews lasted for about 4–6 hours. The mean distance to the homes of the interviewees was 150km, maximum being 360km. The nurses chauffeured those who agreed to participate in the MRI scan to the Oulu University Hospital and back home.

Sample detection. In addition to those who had been identified as having a psychosis before the baseline study (baseline cases), we detected individuals (new cases) who had developed a psychosis between 1998–2008 according to the CRHC: those who had indications of a psychosis in the register data of the Social Insurance Institution of Finland by the end of year 2008 (i.e. sick leave or disability pension due to psychosis, or right for reimbursement for psychoactive medication); or who had reported having a psychosis or current high-dose (over 300mg chlorpromazine equivalents) antipsychotic use at 31 years of age in the questionnaire data. The diagnoses of those who participated were validated using DSM-IV.

Invitation. Addresses were received from the Population Register Centre. A maximum of four invitation letters were sent in which several examination dates were suggested. The suitable date was agreed during a phone call with a research secretary. In the invitation letter, the subjects were informed that associations between mental health, brain function and cognitive performance were to be studied. The procedure of the field study was introduced and a fact sheet presenting information on the MRI session was included. The subjects were told that they would have their travel expenses paid and that they would receive a daily allowance and refreshments. The possibility to participate in a shorter examination and to be interviewed at home was given for the cases who participated in the baseline study but would not have participated in the follow-up with the standard protocol.

Participation. We detected 277 individuals with a possible psychosis (81 baseline participants with already confirmed psychosis, 54 baseline non-participants and 142 new cases), of whom 266 with information on address were invited to participate (*Figure 1*). Fifty-four (67%) baseline participants, 5 (10%) baseline non-participants and 48 (35%) new cases participated. All participants provided informed consent in writing.

SPECIFICATION OF THE VARIABLES USED

The variables used in this study are presented in *Table 1*. As the home recruitment was offered for the baseline participants with psychosis we selected variables which were measured both in the baseline and follow-up studies.

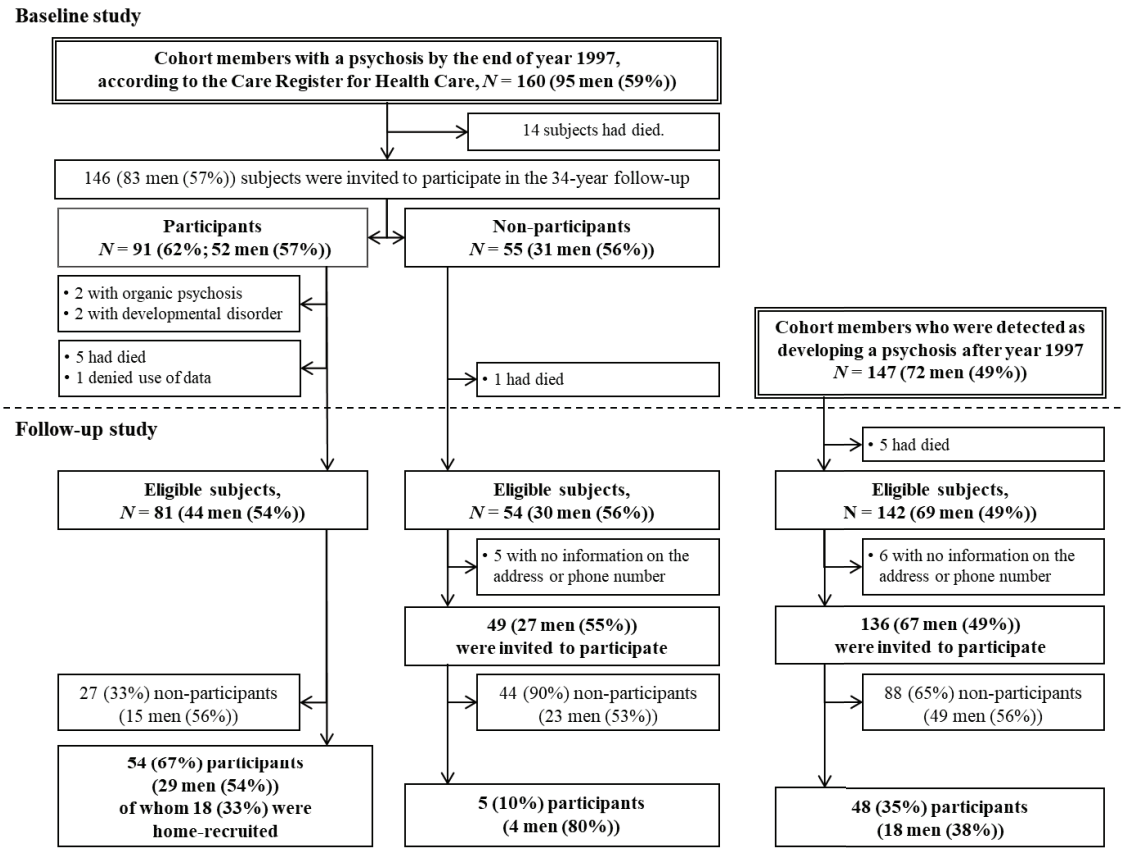

Figure 1. Flowchart of the participation of the individuals with a psychosis in the follow-up study on psychosis at the age of 43 years.

Variables used	Additional information on the variables
The following for all subjects:	
Participation	
Follow-up (2008-2010)	Participated vs. not. Separately for the home-recruited baseline participants, i.e. those who were interviewed at home and/or chauffeured to the MRI scan; the standard protocol baseline participants, i.e. those who participated without extra effort; the baseline non-participants and the new cases.
Baseline (1999-2001)	Participated vs. not.
Demographic	
Gender	Men vs. women.
Education	Basic, secondary, tertiary level in the end of 1997 (at the age of 31). Information from Statistics Finland.
Geographic area	Oulu Region, Northern Ostrobothnia (other than the Oulu Region), Kainuu or Lapland, other parts of Finland.
Illness-related	
Diagnosis	Schizophrenia (including schizophrenia spectrum diagnoses) vs. non-schizophrenic psychoses. Information from the Care Register for Health Care, the Social Insurance Institution of Finland and self-report.
The following for the participants with psychosis of the baseline study:	
Psychiatric assessments	
Psychiatric symptoms (PANSS)	The Positive and Negative Syndrome Scale interview (24); higher scores indicate more symptoms. Subscales of positive, negative and general psychopathology, as well as the total score of all PANSS items.
Illness severity (CGI)	The Clinical Global Impression (25); scale from 1 to 7, higher scores indicate more severe illness.
Social and occupational functioning (SOFAS)	The Social and Occupational Functioning Assessment Scale (26); scale from 0 to 100, lower scores indicate worse functioning.
Cognitive ability	
CVLT, total recall	Verbal learning and episodic memory in general from the California Verbal Learning Test (27); lower scores indicate impairment.
VOLT	Visual Object Learning Test (28); lower scores indicate impairment and scores less than half of the maximum scores are considered as below chance and are excluded.

AIM	Abstraction, Inhibition and Working Memory task (29); two outcome measures are used (total score on the abstraction trials and total score on the trials involving abstraction and memory); lower scores indicate impairment and scores less than half of the maximum scores are considered as below chance and are excluded.
Antipsychotic medication	
Dose years	Dose years in chlorpromazine equivalents until the baseline and follow-up studies. Logarithmic transformations were used in analysing the statistical significance. Information from the hospital and outpatient notes for the baseline participants only.
Brain volumes	
Volume of total grey matter	Volume of total grey matter acquired from the structural MRI data.

Table 1. Variables used in the study.

STATISTICAL METHODS

Participation rates in background variables were analysed separately in baseline participants, baseline non-participants and new cases using chi-square test. Sample characteristics were analysed using chi-square test between the baseline participants, baseline non-participants and new cases, and between home-recruited and standard protocol participants within the baseline participants. The follow-up participation of the baseline participants was studied in detail. Separate analyses were conducted for evaluating illness severity as follows: 1) home-recruited (those who were interviewed at home and/or chauffeured to the MRI scan) vs. standard protocol participants (those who participated without extra effort); 2) home-recruited participants vs. non-participants; 3) standard protocol participants vs. home-recruited and non-participants (i.e. comparison of what difference between the participants and non-participants would have been without home recruitment), and 4) all participants (home-recruited and standard protocol participants) vs. non-participants (i.e. the real situation in our data). Effect sizes (Hedge's g; 30) were calculated to compare PANSS symptoms, CGI, SOFAS, cognitive ability (CVLT, VOLT and AIM), antipsychotic medication use (dose years) and total grey matter volume (TGM). Significance of the differences was tested by t-test. TGM was also analysed using analysis of variance, adjusted for gender. The same variables measured in the follow-up were compared between the home-recruited and standard protocol participants, between the home-recruited participants and the new cases, and between the standard protocol participants and the new cases, using the same methods as in the baseline comparisons. IBM SPSS Statistics 25.0 was used to conduct the analyses.

RESULTS

PARTICIPATION RATES

Overall, 107 (40%) cases participated in the follow-up study. The participation rates between the baseline participants, baseline non-participants and the new cases differed significantly (67%, 10% and 35%, respectively, p<0.001; Table 2). Without home recruitment participation rate within those who also participated in the baseline study would have been only 44% instead of 67%, as out of the 54 individuals who participated both in the baseline and follow-up studies, 18 (33%) were home-recruited (*Figure 1*). Within the baseline participants, those with a secondary education had the highest participation rate, and within the new cases, women participated more actively than men, those living in the Oulu region more actively than those living in other parts of Finland, and those having non-schizophrenic psychosis more actively than those having schizophrenia (*Table 2*).

SAMPLE CHARACTERISTICS

The baseline participants, baseline non-participants and the new cases did not differ in demographic characteristics (*Table 2*). The baseline cases had more often schizophrenia than non-schizophrenic psychosis, whereas the new cases had more often non-schizophrenic psychosis than schizophrenia (p<0.001; Table 2).

Within those who participated both in the baseline and follow-up studies, 33% were home-recruited from the Oulu Region and 67% from the Northern Ostrobothnia, Kainuu or Lapland. The geographic area for the standard protocol participants was the Oulu Region for 39%, Northern Ostrobothnia, Kainuu or Lapland for 36%, and other parts of Finland for 25% (p=0.031; *Table 2*).

COMPARISON OF THE BASELINE MEASUREMENTS BETWEEN THE HOME-RECRUITED PARTICIPANTS, STANDARD PROTOCOL PARTICIPANTS AND NON-PARTICIPANTS

Compared to the standard protocol participants, the home-recruited participants had more negative and general psychopathology symptoms and higher total score in PANSS (effect sizes (g)=1.05, 0.74 and 0.95, respectively), higher CGI score (g=0.60), lower SOFAS score (g=1.02) and lower levels of CVLT total recall (g=0.98) and VOLT score (g=0.87). They had used more antipsychotic medication (g=0.75) and had smaller TGM (g=0.77) (*Table 3*). The difference in TGM was also significant when adjusted for gender (p=0.035).

Compared to the non-participants, the home-recruited participants had more negative symptoms in PANSS (g=0.70), higher CGI score (g=0.62) and lower SOFAS score (g=0.85), lower levels of VOLT score (g=1.05) and AIM scores (g=0.78 for AIM without memory and g=0.76 for AIM with memory). They had used more antipsychotic medication (g=0.98) (Table 3).

When the standard protocol participants were compared with a pooled group of home-recruited and non-participants, i.e. all those who would have been non-participants without the home recruitment, the standard protocol participants had less negative symptoms in PANSS (g=0.46), their SOFAS score was higher (g=0.50), level of CVLT total recall was higher (g=0.65), and they had larger TGM (g=0.49) at baseline (*Table 3*). Non-participants did not differ from pooled home-recruited and standard protocol participants in their baseline illness severity.

	Participation sample characteristics						Whole sample characteristics				Participation method for the baseline and follow-up participants, *n* = 54		
	Baseline participants, *N* = 81		Baseline non-participants, *N* = 49		New cases, *N* = 136		Baseline participants, *N* = 81	Baseline non-participants, *N* = 49	New cases, *N* = 136		Home-recruited, *N* = 18	Standard protocol, *N* = 36	
	n (%)	*P*[1]	*n* (%)	*P*[1]	*n* (%)	*P*[1]	*n* (%)	*n* (%)	*n* (%)	*P*[2]	*n* (%)	*n* (%)	*P*[3]
Participation in the follow-up study	54 (66.7)		5 (10.2)		48 (35.3)								
Gender		>0.999		0.362		0.050				0.666			0.154
Men	29 (65.9)		4 (14.8)		18 (26.9)		44 (54.3)	27 (55.1)	67 (49.3)		7 (38.9)	22 (61.1)	
Women	25 (67.6)		1 (4.5)		30 (43.5)		59 (45.7)	22 (44.9)	69 (50.7)		11 (61.1)	14 (38.9)	
Education		0.013		0.396		0.132				0.484			0.701
Basic	9 (64.3)		0 (0.0)		7 (20.6)		14 (17.3)	11 (22.4)	34 (25.0)		4 (22.2)	5 (13.9)	
Secondary	45 (71.4)		5 (14.3)		36 (40.0)		63 (77.8)	35 (71.4)	90 (66.2)		14 (77.8)	31 (86.1)	
Tertiary	0 (0.0)		0 (0.0)		5 (41.7)		4 (4.9)	3 (6.1)	12 (8.8)		-	-	
Geographic area		0.135		0.819		0.028				0.066			0.031
Oulu Region	20 (69.0)		1 (12.5)		14 (53.8)		29 (36.7)	8 (17.8)	26 (20.2)		6 (33.3)	14 (38.9)	
Northern Ostrobothnia, Kainuu or Lapland	25 (78.1)		2 (8.0)		27 (39.1)		32 (40.5)	25 (55.6)	69 (53.5)		12 (66.7)	13 (36.1)	
Other parts of Finland	9 (50.0)		2 (16.7)		7 (20.6)		18 (22.8)	12 (26.7)	34 (26.4)		0 (0.0)	9 (25.0)	
Diagnosis of psychosis		>0.999		>0.999		0.009				<0.001			0.704
Schizophrenia	46 (66.7)		5 (11.1)		11 (21.2)		69 (85.2)	45 (91.8)	52 (38.2)		16 (88.9)	30 (83.3)	
Non-schizophrenic psychoses	8 (66.7)		0 (0.0)		37 (44.0)		12 (14.8)	4 (8.2)	84 (61.8)		2 (11.1)	6 (16.7)	

Significance [1] between the participation rates, [2] between the baseline participants, baseline non-participants and new cases, and [3] between the home-recruited and standard protocol participants from Chi square test.

Table 2. Participation by background variables separately for the baseline participants, baseline non-participants and the new cases; the sample characteristics of the baseline participants, baseline non-participants and the new cases; and the participation method (home-recruited vs. standard protocol) within those who participated both in the baseline and follow-up studies.

	Home-recruited participants, *n* = 18		Standard protocol participants, *n* = 36		Non-participants, *n* = 27		Home-recruited and non-participants, *n* = 45		Home-recruited and standard protocol participants, *n* = 54		Effect sizes (Hedge's *g*)			
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	*g*[1]	*g*[2]	*g*[3]	*g*[4]
PANSS														
Positive symptoms	17	13.8 (5.8)	36	11.6 (4.6)	26	11.5 (4.6)	43	12.4 (5.2)	53	12.3 (5.1)	0.44	0.46	-0.16	0.17
Negative symptoms	17	21.1 (11.5)	36	12.1 (6.9)	26	13.5 (10.5)	43	16.5 (11.4)	53	15.0 (9.5)	**1.05**	**0.70**	**-0.46**	0.15
General psychopathology	17	27.8 (9.6)	36	22.4 (5.9)	26	23.8 (9.7)	43	25.4 (9.7)	53	24.2 (7.6)	**0.74**	0.42	-0.36	0.04
Total	17	62.8 (23.3)	36	46.2 (14.1)	26	48.8 (21.7)	43	54.3 (23.1)	53	51.5 (19.0)	**0.95**	0.63	-0.42	0.14
CGI	18	5.1 (1.8)	36	4.1 (1.5)	27	4.1 (1.5)	45	4.5 (1.7)	54	4.5 (1.7)	**0.60**	**0.62**	-0.23	0.22
SOFAS	18	40 (19)	36	57 (15)	27	54 (15)	45	48 (18)	54	51 (19)	**-1.02**	**-0.85**	**0.50**	-0.17
CVLT, total recall	15	39.5 (13.5)	36	51.7 (12.0)	26	45.2 (14.6)	41	43.1 (14.3)	51	48.1 (13.6)	**-0.98**	-0.40	**0.65**	0.21
VOLT	14	54.6 (7.5)	35	61.3 (7.8)	24	61.7 (6.2)	38	59.1 (7.5)	49	59.4 (8.2)	**-0.87**	**-1.05**	0.29	-0.30
AIM														
Without memory	15	21.4 (3.2)	35	23.1 (3.0)	22	23.5 (2.4)	37	22.7 (2.9)	50	22.6 (3.2)	-0.56	**-0.78**	0.15	-0.32
With memory	13	20.0 (2.3)	35	20.9 (3.6)	22	21.9 (2.5)	35	21.2 (2.6)	48	20.7 (3.3)	-0.28	**-0.76**	-0.07	-0.38
Dose years	15	43.0 (45.8)	29	18.4 (23.8)	20	12.1 (13.1)	35	25.4 (34.7)	44	26.8 (34.5)	**0.75**	**0.98**	-0.23	0.50
Total grey matter	17	593 (60)	33	642 (64)	26	623 (61)	43	611 (62)	50	625 (66)	**-0.77**	-0.49	**0.49**	0.04

PANSS = Positive and Negative Syndrome Scale, CGI = Clinical Global Impressions Scale, SOFAS = Social and Occupational Functioning Assessment Scale, CVLT = California Verbal Learning Test, VOLT = Visual Object Learning Test, AIM = Abstraction, Inhibition and Working Memory task.
[1] Home-recruited vs. standard protocol participants. [2] Home-recruited vs. non-participants.
[3] Standard protocol participants vs. home-recruited and non-participants, i.e. comparison of what difference between participants and non-participants would have been without home recruitment. [4] All participants vs. non-participants, i.e. the real situation in the data.

Table 3. Illness severity measured at the baseline in the home-recruited participants (n=18), standard protocol participants (n=36) and non-participants (n=27); and pooled groups of home-recruited with non-participants (n=45) and home-recruited with standard protocol participants (n=54).

COMPARISON OF THE FOLLOW-UP MEASUREMENTS BETWEEN THE HOME-RECRUITED PARTICIPANTS, STANDARD PROTOCOL PARTICIPANTS AND NEW CASES

At the time of the follow-up, compared to the standard protocol participants, the home-recruited participants had more negative and general psychopathology symptoms and higher total score in PANSS (g=1.11, 0.74 and 0.83, respectively), higher CGI score (g=0.74), lower SOFAS score (g=-0.74), and lower level of VOLT score (g=-0.94) (Table 4).

Compared to the new cases, the home-recruited participants had more positive, negative and general psychopathology symptoms and higher total score in PANSS (g=1.19, 1.47, 1.58 and 1.64, respectively), higher CGI score (g=0.88), lower SOFAS score (g=0.75), and lower level of VOLT score (g=1.11). The standard protocol participants had more positive and general psychopathology symptoms and higher total score in PANSS (g=0.82, 0.66 and 0.59, respectively) and larger TGM (g=0.57) compared to the new cases (*Table 4*).

DISCUSSION

MAIN RESULTS

Home recruitment substantially increased the participation rate of the individuals who also participated in the baseline study (from 44% to 67%). The home-recruited participants had more severe illness than the standard protocol participants at the baseline and follow-up. The non-participants did not differ from the pooled standard protocol and home-recruited participants based on the baseline data. However, compared to the home-recruited participants, the non-participants had less severe illness and better social and occupational functioning.

INTERPRETATION OF THE RESULTS

Due to the home recruitment we were able to collect data on people with a psychosis, who otherwise would not have participated in the follow-up study. Without the home recruitment the estimates of severity of psychotic symptoms or estimates of, e.g. changes in cognitive functioning or brain volumes over time in our sample would have been different and possibly biased. The home-recruited participants had the most severe illness followed by the non-participants, the standard protocol participants having the least severe illness. In population-based studies the aim is that data represent the whole population. Our data include individuals with varying severity and phase of psychotic illness. Unlike in many other studies (e.g. 8,31), we do not have the non-participants with more severe illness than the participants, which would have been the case without the home recruitment. In our study, the final non-participants seem to have slightly less severe illness than those who were home-recruited. It might be that the individuals with less severe illness may also be unwilling to participate, which may cause bias to direction of worse estimates of illness severity and outcome.

Participants were required to visit the Oulu University Hospital for the MRI scan and cognitive tests, which may have been difficult for some people. Oulu has good access by public transportation. However, from remote parts of Northern and Eastern Finland connections are not frequent and travelling may require extra effort and time which may be very challenging to individuals with a psychosis. Attitudes of individuals with schizophrenia towards participating in psychiatric research have been shown to depend on the type of research protocol: psychosocial research has been favoured over biological, and interviews and questionnaires over more invasive methods, e.g. imaging (3,32,33). Participation in our study was demanding with the MRI scan, cognitive testing and psychiatric interviews.

COMPARISON WITH PREVIOUS STUDIES

In the epidemiologic survey of all the members of the NFBC1966 at age of about 31 years, women participated more actively than men in all phases of the survey, i.e. postal questionnaire, clinical examination and additional psychometric assessments (34). In general, women tend to participate in studies more actively than men (e.g. 4,6,35). In the baseline study, there was no difference in participation rates between men and women (7), which is concordant with the participation of men and women within the baseline participants in the follow-up study. However, within the new cases women participated more actively.

Having a high level of education has been associated with active participation in some studies (6,31,35). In the epidemiologic survey of the NFBC at age of about 31 years, however, among subjects with a psychiatric disorder those who had a tertiary education participated less commonly than those who had a secondary education (34). In some studies, education has shown not to affect the participation activity (4,7). In this study, within the baseline participants none of those who had tertiary education participated.

Over one third of the baseline participants lived in the Oulu region compared to about one fifth of the baseline non-

	Baseline participants						Effect sizes (Hedge's *g*)		
	Home-recruited *n* = 18		Standard protocol *n* = 36		New cases n = 48				
	N	Mean (SD)	*N*	Mean (SD)	*N*	Mean (SD)	g^1	g^2	g^3
PANSS									
Positive symptoms	18	16.3 (7.5)	34	14.1 (6.0)	46	10.1 (4.0)	0.33	**1.19**	**0.82**
Negative symptoms	18	26.7 (10.7)	34	16.0 (8.9)	46	14.8 (6.8)	**1.11**	**1.47**	0.16
General psychopathology	18	42.2 (15.5)	34	32.2 (12.3)	46	25.6 (7.9)	**0.74**	**1.58**	**0.66**
Total	18	85.2 (31.3)	34	62.4 (25.1)	46	50.4 815.8)	**0.83**	**1.64**	**0.59**
CGI	18	5.0 (1.4)	36	3.8 (1.7)	48	3.7 (1.6)	**0.74**	**0.88**	0.12
SOFAS	18	44 (15)	36	57 (19)	48	57 (19)	**-0.74**	**-0.75**	0.03
CVLT, total recall	16	39.3 (15.8)	36	45.0 (15.5)	47	46.7 (11.6)	-0.37	-0.58	-0.13
VOLT	11	55.1 (7.8)	32	62.5 (7.9)	47	63.1 (7.1)	**-0.94**	**-1.11**	-0.09
AIM									
Without memory	11	21.8 (3.0)	34	23.4 (2.8)	48	22.7 (3.2)	-0.57	-0.27	0.26
With memory	10	20.2 (3.9)	29	21.2 (3.3)	45	22.2 (3.2)	-0.30	-0.61	-0.31
Dose years	15	75.0 (69.5)	29	41.6 (41.4)	-		0.64	-	-
Total grey matter	13	576 (54)	32	599 (55)	35	570 (47)	-0.42	0.14	**0.57**

PANSS = Positive and Negative Syndrome Scale, CGI = Clinical Global Impression, SOFAS = Social and Occupational Functioning Assessment Scale, CVLT = California Verbal Learning Test, VOLT = Visual Object Learning Test, AIM = Abstraction, Inhibition and Working Memory task.
[1] Home-recruited vs. standard protocol baseline participants. [2] Home-recruited baseline participants vs. new cases.
[3] Standard protocol baseline participants vs. new cases.
Effect sizes in bold letters are statistically significant according to t-test.

Table 4. Illness severity measured in the follow-up study between the home-recruited and standard protocol participants and new cases.

participants and the new cases. In the Health 2000 Survey, people living in the catchment area of Oulu University Hospital had the highest participation rate (4). In the baseline study of psychosis in the NFBC1966, people living in the city of Oulu had the highest participation rate (7). In our study, home recruitment increased markedly the participation of those who lived in Northern Ostrobothnia, Kainuu or Lapland (i.e. in the remote areas of northern Finland) within the baseline participants. Within the new cases, the highest participation rate was for those who lived in the Oulu region.

It has been suggested that people with schizophrenia may not be willing or able to participate in interviews (36). Our cohort was about 34 years old at the time of the baseline study and about 43 years old at the time of the follow-up study. Due to onset age of schizophrenia being generally between 20 and 29 years (37), the proportion of individuals with schizophrenia was higher among the baseline cases compared to the new cases. Also, compared to the baseline cases, the new cases were detected using more comprehensive registers which detected persons treated solely in outpatient care. This is one reason why the non-schizophrenic psychoses were more likely to be found. In some previous studies non-participation has been shown to accumulate into the group of schizophrenia patients (5-7). In our study, the participation rates did not differ between people with schizophrenia and non-schizophrenic psychoses within the baseline participants and baseline non-participants, but within the new cases those with schizophrenia participated less actively.

Participants with schizophrenia from a 5-year follow-up MRI study were shown to have a shorter duration of illness and fewer negative symptoms at baseline than the non-participants (10). We have previously found that in our baseline study, having more positive symptoms associated with lower participation rate (7). The non-participants in our

follow-up study did not differ significantly in their symptoms compared to all participants, but compared to the home-recruited participants they had lower CGI and higher SOFAS scores, higher scores in VOLT and AIM, and they had used less antipsychotic medication.

There are ways to encourage and increase participation in research, e.g. monetary incentives (38). Our participants received a daily allowance, their travel expenses were paid and they were offered refreshments during the day. According to the Medical Research Act no payment shall be made for research participants in Finland, but an appropriate remuneration may be paid to cover expenses or any other inconvenience suffered as a result of the research (39). In the Health 2000 Survey, home interviews were an essential part of the survey, and to maximize the participation, telephone interviews or interviews at the most convenient place for the interviewees were offered (4). In the Health 2000 Study the participants, if necessary, were also offered to be chauffeured to the health examination clinic or their taxi fares reimbursed. We offered the home interview and pick up for only the cases who participated in the baseline study.

The importance of informed consent should also be notified. When research is clearly explained to the subjects, with the risks and benefits of participation, participation is less likely to suffer from uncertainty issues (40). All the invited subjects were given information about the study in the invitation letter and they were able to inquire about the study from the research secretary by phone.

METHODOLOGICAL ISSUES

Population-based studies are important in order to achieve a more extensive understanding of psychotic illnesses. In population-based samples subjects may have widely heterogeneous diseases in terms of severity of the illness and they may be in different phases of the illness. If the most severely ill patients drop out, differences between patient and control groups may be affected, as well as the estimates of illness course. Non-response bias may occur especially if participants and non-participants are different with respect to the survey variables (41). By comparing the standard protocol participants with pooled group of home-recruited participants and non-participants, we were able to evaluate that without the home recruitment non-participation might have caused non-response bias in several estimates calculated from the follow-up data.

Non-participation also causes decrease of power by reduced sample size. We aimed to invite all the members of the NFBC1966 with a possible psychosis. In this birth cohort setting, the number of cases is limited and the sample size of the baseline study was reasonably small. Therefore, it was crucial to try to have as many participants of the baseline study as possible participate in the follow-up. We were able to increase the sample size of the follow-up by one third by using the home recruitment.

Home interviews were conducted by two experienced psychiatric nurses. They always visited the participants together. Home interviews were time-consuming, required staff and were therefore reasonably expensive. The moderate extra costs were due to salaries of the nurses and expenses caused using their own car. The psychiatric nurses were able to build a trustful atmosphere in the interview at the participants' homes and no difficulties, e.g. threat of violence or negative reactions from the interviewees, occurred during the interviews.

STRENGTHS AND LIMITATIONS

The NFBC1966 is a large population-based study with the opportunity to utilise data from nationwide registers. We have the same register information on non-participants as we have on participants. We also have information collected at the baseline, which we could use in evaluating symptoms, illness severity, functioning, cognition, use of antipsychotic medication and brain volumes between the home-recruited participants, standard protocol participants and non-participants.

Altogether our sample size is reasonably small. However, we tried to recruit as many cases as possible. Without the home recruitment the non-response bias would be of more concern, and it would be more difficult to attain adequate statistical power in comparisons in time between the cases and controls. However, it is also possible that those with less severe illness were unwilling to participate and the data might lead to too pessimistic conclusions. Home recruitment increased the participation, but it was offered only for the baseline participants. The geographical differences between the samples, i.e. larger proportion of baseline participants living in the Oulu Region compared to the baseline non-participants and the new cases, may also have affected the participation activity, especially the low participation rate of the new cases.

CONCLUSIONS

By using home recruitment we were able to increase the participation rate and the sample size in the follow-up study and collect reasonably non-biased data in terms of severity of illness. In population-based studies for individuals with psychosis, effective recruitment may need special efforts like home recruitment. Higher participation rates and more representative sample will improve the reliability and validity of the research.

ACKNOWLEDGEMENTS

This work was supported by the grants from the Academy of Finland (grant numbers 268336 and 316563), the Sigrid Jusélius Foundation, the Jalmari and Rauha Ahokas Foundation, the Juho Vainio Foundation, and the NARSAD: Brain and Behaviour Research Fund (Dr Mortimer D. Sackler Developmental Psychobiology Research Programme). These foundations provided no input into the analyses or presentation of these data.

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