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Strategies for Successful Retention of Alaska Native and American Indian Study Participants

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Abstract

This paper reports the strategies used to track and follow 3,828 Alaska Native and American Indian study participants in the city of Anchorage and more rural areas of Alaska and provides characteristics of respondents and non-respondents. Over 88% were successfully followed-up, with 49% of respondents completed in three or fewer attempts. Follow-up completion rates were significantly higher for women, those living in a rural area, over age 55, married, employed, having a higher household income, and at current residence for more than five years. Follow-up of large numbers of Alaska Native and American Indian people living in geographically diverse areas is feasible, although challenging. Successful strategies to avoid attrition include using telephones as the primary method of contact; using a computerized contact relationship management system to track efforts and manage data; obtaining contact information from participant contact networks, medical records, and community networks; using local village interviewers to contact participants without telephone service; and mailing paper questionnaires to participants who are incarcerated or use social services.

Keywords

computer-based tracking; participant retention; longitudinal research; Alaska Native

Introduction

Longitudinal studies examine temporal relationships between exposure to known or suspected causes of disease and subsequent morbidity or mortality. To understand these relationships, it is necessary to follow study participants over time to monitor risk factors and health outcomes. Although response rates vary depending on a number of factors, it is vital to retain as many individuals as possible from the original cohort to increase statistical power and avoid response bias. Ineffective follow-up can affect internal validity and influence incidence estimates (Ribisl et al., 1996; Tooth et al., 2005). Participants lost to follow-up often differ from continuing participants in their basic demographics or health status (Cotter et al., 2005; Davis et al., 2002; McKenzie et al., 1999). Most of the research on retention examines why participants are lost to follow-up or whether participants lost to follow-up are similar enough to those who stayed in the study that results are not significantly biased (Dudley et al., 1993).

Considerable resources are devoted to tracking and follow-up of participants in longitudinal studies. Retention can be costly, but these costs are generally modest in comparison to those associated with participant enrollment (Cotter et al., 2005). The importance of retention has produced a body of literature outlining strategies to increase participant tracking and follow-up. Retention strategies suggested include: (a) building rapport between participants and study personnel at the time of enrollment and periodically thereafter; (b) using multiple tracking and follow-up strategies simultaneously; and (c) contacting participants during non-working hours (Goldstein et al., 1977; Hunt & White, 1998; Robinson et al., 2007; Sullivan et al., 1996; Tansey et al., 2007). Researchers also have reported on the successful use of community network groups for retention of study participants and have recommended the use of computerized tracking systems to help manage tracking follow-up efforts (Gilliss et al., 2001; Hunt & White, 1998). Although some reports have included specific strategies targeting minorities and hard-to-reach populations (Gilliss et al., 2001; McKenzie et al., 1999), a meta-analysis of recruitment and retention of minority research participants found that only 5% of articles focused on Native American people (Yancey et al., 2006), and no published research to date has suggested successful strategies for follow-up in the geographically diverse Alaska Native population. We report on the development of a computerized contact relationship management (CRM) system to successfully track a cohort of Alaska Native and American Indian research participants living in Alaska and follow them one to two years after study enrollment. We further describe the types of tracking information collected by the CRM system, tracking methods and results, retention strategies, and the characteristics of participants who completed the follow-up interview and those who did not.

Methods

Study Background

The Education and Research Towards Health (EARTH) Study is a multi-center study of Alaska Native and American Indian people designed as a prospective study to examine risk and protective factors related to chronic diseases. Details of the EARTH Study design, data collection methods, and baseline characteristics of participants in the pilot study

have been reported previously (Slattery et al., 2007). We present here data on the first follow-up (January 2006- August 2007) among 3,826 participants enrolled in Alaska from 2004 to 2006. The Alaska component of the EARTH study was conducted in 26 different communities statewide, which ranged in population size from 300 to 300,000. Many of the southwestern and southeastern Alaskan communities are located off the road system and are accessible only by airplane, boat, or seasonally by snow mobile or four-wheeler. In each community, enrollment was available to all persons who were Alaska Native or American Indian based on: (a) being eligible for care from the Indian Health Service; (b) being 18 years of age or older; (c) being able to give informed consent; (d) not being currently pregnant; and (e) not receiving chemotherapy. In addition to a monetary incentive, participants received items such as baseball caps, shirts, and water bottles with the study logo in order to create a sense of belonging to an important study project and to establish rapport between participants and study personnel.

The study protocol was approved by the Alaska Area Institutional Review Board (IRB), the research and ethics committees and governing boards of each of the participating regional health corporations, and the tribal councils of each participating community. All participants provided informed consent to join the study. The consent form stated that participants would be contacted periodically to update contact information and health status. It was impractical to have study personnel revisit all 26 communities dispersed widely across the state of Alaska solely for the purposes of follow-up. Therefore a protocol was designed to conduct follow-up interviews primarily by telephone. Tracking and follow-up results described here were conducted by study personnel who had conducted the study enrollment visits in many of the communities. All study personnel completed the Collaborative IRB Training Initiative (CITI) certification program for protection of research participants.

Computer Tracking

Using Microsoft Office Access, study investigators and programmers developed and designed a computerized contact relationship management system, the “EARTH Tracker,” to record and display tracking and follow-up efforts. The EARTH Tracker is a comprehensive tracking database with information sharing capabilities designed to support multiple staff members conducting follow-up. All participant contact information was kept on a separate secure research server, and access to the server was password protected. The EARTH Tracker data was separate from the baseline study data. Access to the EARTH Tracker was limited to the three interviewers and the computer programmer who designed the database. Any written notes about participants were put into the EARTH Tracker database and then shredded.

Data elements in the EARTH Tracker included the participant’s name, date of birth, a maximum of five phone numbers, and two personal contacts who would know the location of the participant in the future. A log history of contact attempts was created with date and time stamps for each tracking effort. Log entries included information on specific method used and outcome of contact attempt. Possible choices of outcome included: (a) no answer; (b) left message with person or machine; (c) made appointment; (d) number not in service or wrong number; (e) undelivered; (f) deceased; (g) refused; (h) go to follow-up questions;

or (i) other result. The name of the staff member who made the follow-up effort was entered into the database. In addition to methods and results, study personnel could record comments to clarify or assist in the next attempt. Figure 1 shows an example of an EARTH Tracker screen including sample log entries.

Follow-up

Each EARTH participant was automatically added to the EARTH Tracker database, and the date of follow-up was set for 30 days before their first anniversary of the date of enrollment. On follow-up, participants first were asked to update their contact information and then to answer a short 16-question health status/risk behavior questionnaire. The first contact methods were to try personal telephone numbers (home, mobile, work, or message telephone), then email if an electronic address had been given. When these methods were unsuccessful, staff attempted to connect with the personal contacts listed by participants or their extended community network, including their tribal organization, local research staff, or other family and friends. After that a letter was sent by U.S. mail asking the participant to call a toll-free number or to return the follow-up questionnaire in a pre-stamped envelope. If necessary, staff checked the most recent patient demographic information within the comprehensive computerized medical record database utilized by tribal health care facilities throughout Alaska. In addition, research staff attempted to contact participants at multiple times during the day, as well as nights and weekends. A contact attempt was defined as any discrete act directed toward finding and interviewing the participant. There was no preset cut-off point on the number of contact attempts made. Respondents were defined as persons who were successfully contacted and completed the follow-up interview. Non-respondents were defined as persons who did not successfully complete the follow-up interview. Non-respondents were considered 'lost to follow up' if all contact methods were exhausted and no new useful information was obtained to continue to reach the participant.

Follow-up was conducted largely by EARTH research staff in Anchorage. Trained personnel were available to conduct the interviews in English or Yup'ik, which is the primary language spoken in the home in rural southwestern Alaskan communities. The questionnaire was not translated ahead of time, but all Yup'ik interviews were conducted by one trained medical translator at the Alaska Native Medical Center. No monetary incentive was offered for the follow-up interview, but each participant who responded was sent a thank you card with an EARTH pen or a magnet. During the one to two years between enrollment and first follow-up, the EARTH study team mailed two newsletters and a four-page community health report to each participant. These were sent with forwarding address requests in order to get notice of change of address.

Study staff developed a matrix of estimated average time per contact. This was used to create an estimate of total time to complete the follow-up based on all possible combinations of methods and results and of average time spent per respondent and non-respondent.

Statistical Analysis

Descriptive statistics were calculated to provide an overview of the demographic and socioeconomic characteristics of participants. Demographic variables included sex, age,

residency, education, marital status, employment, income, language spoken at home, and perceived health status. Univariate associations between demographic characteristics and respondent status were evaluated using the chi-square test. Associations between methods of contact and regional location were evaluated using analysis of variance (ANOVA). All analyses were conducted with Statistical Packages for the Social Sciences (v. 15.0); p -values 0.01 were considered to be statistically significant.

Results

At the end of the follow-up period, 3,368 participants (88.0%) had completed the follow-up questionnaire. An additional 28 (0.7%) were known to be deceased. Interviewers estimated most follow-up interviews averaged four to seven minutes. Completion rates differed by demographic characteristics (Table 1). Demographic characteristics associated with a higher likelihood of responding were female sex; residence in the southwest region; older age; being married, being employed, higher household income; and having lived at his or her current residence for more than five years ($p < 0.01$ for each). Self-reported health status and language spoken at home were not significantly related to respondent status.

In the initial EARTH Study enrollment, participants were asked for contact information so that study personnel could reach them in the future. Table 2 shows contact information provided, changes to contact information at follow-up, and numbers of contact attempts. Among the total Alaska EARTH Study participants, about half (53%) gave two or more personal telephone numbers, one quarter (26%) gave an electronic mail address, and nearly all (91%) gave the name and telephone numbers of two people who would know where they were in the future. Types of contact information given during study enrollment varied by region, with the most information given by participants in the southeast region ($p < 0.01$).

Of the total respondents, 1,018 (31%) had address changes, 1,884 (60%) had changes in telephone numbers, and 1,235 (40%) made changes to persons and/or phone numbers of persons identified as contacts. Among respondents who gave electronic mail addresses, 231 (26%) had changes, with the majority (65%) of those changes being discontinued electronic mail accounts. Overall, 2,764 respondents (82%) had corrections to telephone numbers, electronic mail addresses, or mailing addresses. Changes were more likely for the most urban region (92%).

The computerized EARTH Tracker database captured contact attempt methods and which methods led to completion of the follow-up questionnaire. The tracking system demonstrated that for all three regions over half (52%) of the total number of contact attempts were calls to personal phone numbers. However, electronic mail was used more often in the southeast region, and electronic medical records look up was used more in the southcentral region. Attempts to make personal contacts and U.S. mail were used fairly equally among regions.

Table 3 shows some of the completion characteristics of the EARTH Study follow-up. Of the total follow-up respondents, 2,028 (60%) were reached by attempts to call personal telephone numbers, 807 (24%) were reached through one of their listed personal contacts or

extended community networks, 469 (14%) returned telephone calls, electronic mail or sent back the completed questionnaire via U.S. Postal Service, and 64 (2%) were completed by a local interviewer.

There were some differences in successful method of completion by region. About two-thirds of follow-up interviews with southeast region respondents (65%) and southwest region respondents (67%) were completed by telephone, whereas less than half of those with southcentral respondents (49%) were completed by telephone. About equal numbers of respondent interviews were completed by telephone calls or other methods in each of the three regions. Respondents in the southcentral region were two times as likely to return telephone calls, electronic mail messages, or U.S. mail sent to their addresses. A total of 53 respondents (3%) required Yup'ik language translation in order to complete the follow-up questionnaire.

On average, 22.5 minutes were spent to make contact with each respondent, whereas an average of 35.6 minutes was spent to reach each non-respondent. The mean number of contact attempts per respondent was five. Of those who completed the follow-up, 1,647 (49%) were completed in one to three attempts, 860 (26%) were completed in four to six attempts, and 861 (26%) were completed in seven or more attempts. Only a small percentage of the follow-up interviews (8%) were completed outside of regular business hours.

As of August 2007, we were unable to complete the first follow-up with 12% (460) of the total study population. Of the original cohort, 28 (0.7%) are known to be deceased through cross checking with State of Alaska death records, 24 (0.6%) requested no further contact, 166 (4.3%) were classified as lost to follow-up after exhaustive efforts to find their whereabouts, and 121 (3.2%) were unable to complete the follow-up interview at the time of analysis. Of those who were unable to complete the entire interview, 20 (0.5%) were known to be incarcerated or in halfway houses; 6 (0.2%) were serving extended periods in the military; 36 (0.9%) were believed to be homeless because the last known address was a substance abuse treatment center, women's shelter, and/or homeless shelter; and 59 (1.5%) were unable to complete follow-up for some other reason.

Discussion

The EARTH Study is the first large-scale prospective cohort study designed to measure protective and risk factors and eventual health outcomes among Alaska Native and American Indian people living in Alaska. The one-to-two-year EARTH Study follow-up of this hard-to-reach population was highly successful, with over 88% of the original population of Alaska Native and American Indian people enrolled in the study completing the follow-up questionnaire. The EARTH Study retention rate was similar to the 88% reported over the 10-year period of the Strong Heart Study, a multi-community study of cardiovascular disease among American Indians living in Arizona, Oklahoma, and the Dakotas (Sambo, 2001). To date no other studies have reported retention rates or follow-up strategies for Alaska Native people, especially those living in remote areas. The EARTH Study found that those with higher education, higher household income, and older persons were more likely to complete the follow-up questionnaire, which is similar to trends in African-American and Caucasian

urban adult populations reported by other researchers (Dudley et al., 1993; Pirzada et al., 2004; Russell et al., 2001). Retention rates ranged from 93% in the southwest and 88% in the southeast regions, which comprised the smallest and most close-knit communities that participated in the study, to 83% of those in the southcentral region, which included people living in or around the largest city in Alaska. The EARTH Study was able to build on the initial trust and cooperation generated during the participant enrollment phase to find participants in these communities during the follow-up phase. It should be noted that because this study used multiple retention strategies, it is not possible to report on the efficacy or cost effectiveness of specific methods of follow-up.

Tracking research participants in a prospective cohort study is difficult, and the EARTH Study faced the additional challenge that the majority of participants enrolled resided in geographic areas that were difficult to access and which would have been prohibitively expensive to revisit solely for the purpose of updating contact information or for each periodic follow-up questionnaire. The EARTH Study population appears to be highly mobile. The 3,828 participants had numerous contact updates and address changes across Alaska, and in some cases had moved to other U.S. states after enrollment. Numerous contact attempts that required detailed logs of contact efforts were made per participant. The computerized contact management relationship system, “EARTH Tracker,” was instrumental in reducing tracking errors and keeping organized records of all follow-up attempts. Additionally, extensive contact information identified during enrollment, extended community networks, and access to hospital medical records for updated contact information, were especially valuable for contacting hard-to-reach participants.

Also valuable in participant retention was the community-based, culturally tailored approach used by the EARTH Study following models developed by Israel, Minkler and Wallerstein (Israel et al., 2005; Minkler & Wallerstein, 2003). Key principles of community-based participatory research that guided the EARTH Study included building on the strengths and resources of the community by hiring community members for jobs within the study; developing and maintaining community/research partnerships; and regular knowledge dissemination on research findings back to study participants and local community leaders (Israel et al., 2003; Minkler & Wallerstein, 2003; Smith, 1999). This foundation enabled study staff to utilize relationships and rapport established in the original EARTH Study enrollment with community members and organizations to obtain further contact information for hard-to-reach participants.

Conclusion

There is no consensus as to how many contact attempts should be made in order to contact study participants for follow-up, only that investigators need to remain persistent (Cotter et al., 2005). Davis et al. (2002) reported that the estimated number of contacts to locate participants for follow-up ranged from three to seven attempts, with many cases requiring far greater effort to secure participation. A 2003 study found that nine contacts were needed for 75% and 20 contacts were required for 95% of the study population to reach a final outcome (Rogers et al., 2004). Cotter et al. (2005) reported that 65% of study participants were retained with 10 or fewer contacts, and a substantial amount (12%) of participants required

20 or more contact attempts to retain. Comparability between the EARTH Study and other studies' follow-up methods is difficult because of methodological differences. However, the EARTH Study found that almost half (49%) of respondents were successfully contacted with three or fewer contact attempts; whereas only 10% of participants required more than 10 contact attempts for completion. Furthermore, the majority of EARTH Study respondents (92%) were accessible by telephone during daytime hours (8 AM- 5 PM) and on weekdays, in contrast to other studies that have reported difficulty in reaching participants during standard business hours (Russell et al., 2001).

Retention literature has emphasized the labor and expense of telephone follow-up and suggested that the most economical method of tracking is to send multiple waves of mailed questionnaires (McKenzie et al., 1999; Russell et al., 2001). The EARTH Study is currently in its second wave of follow-up, with mailed questionnaires being used as the first contact method. Preliminary results show that return rates for this second wave of follow-up are about 10%. This is much lower than the 55–73% reported return rate by other studies using the same method and time period (Russell et al., 2001; Sheikh, 1986). In many Alaska Native cultures, strong relationships between people are an important traditional value, and a healthy community can be seen as a circle with all members interconnected (Napoleon, 1996; Oleska, 2005). It may be that these social values, along with small community sizes, contribute to the higher success rate of more personal forms of follow-up used in the EARTH Study. Although seemingly more labor intensive, telephone contact was highly effective for completing follow-up with EARTH Study participants, required fewer attempts than reported in other studies, and was a viable method even during regular business hours.

We suggest the use of the telephone as the primary retention method for long-term follow-up in this population. Telephone interviews combined with a computerized tracking system have provided effective follow-up in this cohort. This combination of retention techniques may decrease duplication of contact efforts and is ideal for research programs that seek to follow Alaska Native and American Indian participants over a long period of time.

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Display Follow-up records

Selected region is **EARTH FOLLOW-UP**

Return to Follow-Up Form Exit System Find by Last Name
Find Home Phone

Sex Approximate Age Date Exit Completed

TID Name Date of Birth

Other Names SSN

Spouse

Telephone Numbers

Home Mobile Work Other Message

E-Mail

Mailing Address

Physical Address

How long at address Years
at Residence Unit

Follow-Up Contacts

1st Listed	2nd Listed
Name <input type="text"/>	Name <input type="text"/>
Phone# <input type="text"/>	Phone# <input type="text"/>
Address <input type="text"/>	Address <input type="text"/>
City/State/Zip <input type="text"/>	City/State/Zip <input type="text"/>

Open Comments

Follow-Up Method: Call Home # Call Mobile # Call Work # Call Message Call Other # E-Mail
 US Mail RPMS Death list Returned call/mail

Follow Up Results: No answer Left Msg Perso Left Msg Machin Made appointment NIS/Wrong# Go to Questions
 Undelivered Dead Do Not Call Again Other FollowUp Failed

TID	Date Time	Who Did	Method	Result	Note
<input type="text"/>	9/22/2006 12:26:05 PM	<input type="text"/>	Sent USMail	Other	<input type="text"/>
<input type="text"/>	9/22/2006 12:16:51 PM	<input type="text"/>	Called home	Other	NH try mail, crt address
<input type="text"/>	9/15/2006 2:31:03 PM	<input type="text"/>	Called home	No answer	<input type="text"/>

Record: of 15

Figure 1.
Example of a Participant Follow-up Log, Alaska *Education and Research toward Health* (EARTH) Study, 2004–2007.

Table 1

Demographic Characteristics of 3,828 Study Follow-up Respondents and Non-respondents, Alaska EARTH Study, 2007

	Total (N=3828) N	Respondents (n=3368) N (%)	Non-Respondents (n=460) N (%)	<i>p</i> -value [†]
Sex				<0.001
Male	1507	1239 (82)	268 (18)	
Female	2321	2129 (92)	192 (8)	
Region				<0.001
Southcentral	1397	1156 (83)	241 (17)	
Southeast	887	780 (88)	107 (12)	
Southwest	1544	1432 (93)	112 (7)	
Age in years				0.004
18–34	1442	1251 (87)	191 (13)	
35–54	1729	1514 (88)	215 (12)	
55+	657	603 (92)	54 (8)	
Education				0.060
Less than high school	889	766 (86)	123 (14)	
High school or higher	2936	2599 (89)	337 (12)	
Marital Status				<0.001
Married/Living as married	1633	1526 (93)	107 (7)	
Separated/Divorced/Never married	2180	1829 (84)	351 (16)	
Employment status				<0.001
Employed or self-employed	1719	1583 (92)	136 (8)	
Not currently employed	2095	1775 (85)	320 (15)	
Income				<0.001
\$15,000	1343	1115 (83)	228 (17)	
>\$15,000	1925	1773 (92)	152 (8)	
Length of time at residence				<0.001
5 years	1737	1460 (84)	277 (16)	
> 5 years	2028	1854 (91)	174 (9)	
Language spoken at home				0.017
Native only/Both	1264	1135 (90)	129 (10)	
English only	2560	2230 (87)	330 (13)	
Self-reported health status				0.151
Excellent/very good/good	2867	2535 (87)	332 (13)	
Fair/Poor	957	829 (88)	128 (12)	

Note.

[†]*p*-value for differences in proportions by respondent status by chi-square test.

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Table 2

Contact Characteristics, Alaska EARTH Study Follow-up, 2007

	Region [†]			
	Total N (%)	Southcentral N (%)	Southeast N (%)	Southwest N (%)
Contact information (% of overall population)				
Participants who gave 2 personal phone numbers	2018 (53)	806 (58)	539 (61)	673 (44)
Participants who gave an email address	988 (26)	238 (17)	463 (52)	287 (19)
Participants who gave 2 contacts names with phone numbers	3482 (91)	1167 (84)	845 (95)	1470 (95)
Changes to contact information (% of respondents)				
Address	1018 (31)	505 (44)	222 (29)	291 (21)
Telephone number	1884 (60)	795 (73)	390 (55)	699 (52)
Contact people	1235 (40)	423 (44)	222 (30)	590 (43)
Electronic mail	231 (26)	64 (29)	109 (27)	58 (21)
Any changes to contact info	2764 (82)	1060 (92)	587 (75)	1117 (78)
Attempt methods for respondents (% of attempts)				
Personal numbers (home, cell, work, message, other)	10814 (52)	3512 (46)	3133 (51)	4169 (59)
Electronic address	728 (4)	190 (3)	429 (7)	109 (2)
Electronic medical record	1925 (9)	943 (12)	532 (9)	450 (6)
Personal contacts and extended community networks	6150 (30)	2454 (32)	1713 (28)	1983 (28)
U.S. Mail	1208 (6)	528 (7)	324 (5)	356 (5)
Total number of attempts	20825 (100)	7627 (37)	6131 (29)	7067 (34)

Note.

[†]All differences in proportions between regions for contact information and changes to contact information were significant at $p < 0.01$.

Table 3

Completion characteristics of EARTH Study Follow-up, 2007

	Region			
	Total (N=3368) N (%)	Southcentral (N=1156) N (%)	Southeast (N=780) N (%)	Southwest (N=1432) N (%)
Method of Completion (% of respondents)				
Call to personal telephone numbers	2028 (60)	567 (49)	504 (65)	957 (67)
Call to personal contacts or extended community networks	807 (24)	320 (28)	168 (22)	319 (22)
Participant returned electronic mail, US mail, or telephone call	469 (14)	269 (23)	91 (12)	109 (8)
Local interviewer	64 (2)	--	17 (2)	47 (3)
Completion Data				
Interviews completed outside of normal business hours/days (% of respondents)	259 (8)	82 (7)	63 (8)	114 (8)
Average minutes spent per respondent, <i>mean</i> (SD)	22.5 (14)	22.2 (13)	26.7 (17)	20.5 (12)
Average minutes spent per non-respondent, <i>mean</i> (SD)	35.6 (21)	31.8 (18)	47.6 (23)	32.3 (18)
Number of tries required to complete interview, <i>mean</i> (SD)	4.95 (4)	4.92 (4)	6.10 (5)	4.33 (4)
Number of tries required to complete interview (% of respondents)				
1-3	1647 (49)	560 (48)	305 (39)	782 (55)
4-6	860 (26)	302 (26)	211 (27)	347 (24)
7+	861 (26)	294 (25)	264 (34)	303 (21)
Reasons for non-completion (% of original cohort)				
Deceased	28 (0.7)			
Declined to participate	24 (0.6)			
Lost to follow-up [†]	166 (4.3)			
Unable to complete follow-up	121 (3.2)			
Incarcerated	20 (0.5)			
Military service	6 (0.2)			
Shelter	36 (0.9)			
Other	59 (1.5)			
Total Non-completion	460 (12.0)			

Note.

[†]Lost to follow-up was defined as all possible sources of contact information exhausted and nothing known further about participant whereabouts.