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REVIEW ARTICLES

Systematic review identifies number of strategies important for retaining study participants

Karen A. Robinson[a,*], Cheryl R. Dennison[b], Dawn M. Wayman[c], Peter J. Pronovost[d], Dale M. Needham[e]

[a]*Division of Internal Medicine, School of Medicine, Johns Hopkins University, Baltimore, MD, USA*
[b]*School of Nursing, Johns Hopkins University, Baltimore, MD, USA*
[c]*Department of Epidemiology, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, USA*
[d]*Department of Anesthesiology and Critical Care Medicine, School of Medicine, Johns Hopkins University, Baltimore, MD, USA*
[e]*Division of Pulmonary and Critical Care Medicine, School of Medicine, Johns Hopkins University, Baltimore, MD, USA*

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Abstract

Objective: Loss to follow-up threatens internal and external validity yet little research has examined ways to limit participant attrition. We conducted a systematic review of studies with a primary focus on strategies to retain participants in health care research.

Study Design and Settings: We completed searches of PubMed, CINAHL, CENTRAL, Cochrane Methodology Register, and EMBASE (August 2005). We also examined reference lists of eligible articles and relevant reviews. A data-driven thematic analysis of the retention strategies identified common themes.

Results: We retrieved 3,068 citations, 21 studies were eligible for inclusion. We abstracted 368 strategies and from these identified 12 themes. The studies reported a median of 17 strategies across a median of six themes. The most commonly reported strategies were systematic methods of participant contact and scheduling. Studies with retention rates lower than the mean rate (86%) reported fewer strategies. There was no difference in the number of different themes used.

Conclusion: Available evidence suggests that investigators should consider using a number of retention strategies across several themes to maximize the retention of participants. Further research, including explicit evaluation of the effectiveness of different strategies, is needed. © 2007 Elsevier Inc. All rights reserved.

Keywords: Patient participation; Patient dropouts; In-person follow-up; Follow-up studies; Cohort studies; Systematic review

1. Introduction

Loss to follow-up of research participants threatens the internal and external validity of a study [1,2]. The study results may be biased by differential dropout between comparison groups or by differences between those participants who drop out and those that continue to participate. Loss to follow-up may also threaten the generalizability of a study, as well as its statistical power. Despite these threats, little attention has been paid to the optimal methods of maintaining participants in a study.

Much of the existing literature on strategies to retain participants in research studies is limited to descriptions of ''lessons learned.'' For example, based on their experiences in studies of people aged over 65 years, Cassidy et al. suggested that personalized attention, empathy, and support from study staff resulted in higher participant completion [3]. Shumaker et al. similarly drew on their own experiences to outline approaches to promote retention including screening out those likely to not remain in the study and early identification and tracking of study participants who are poor or nonadherers [4].

Coday et al. collected lessons learned from 14 NIH-funded behavioral change trials [5]. They elicited perceived barriers to participant retention and 61 retention strategies from the project staff and investigators from these trials. The retention strategies were categorized into eight themes which study personnel then ranked based on perceived effectiveness. The strategy category of flexibility followed

* Corresponding author. Divisions of Internal Medicine and Health Sciences Informatics, School of Medicine, Johns Hopkins University, 1830 East Monument Street, Room 8069, Baltimore, MD 21287, USA. Tel.: 410-502-9216; fax: 410-955-0825.

E-mail address: krobin@jhmi.edu (K.A. Robinson).

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by incentives, benefits, and persistence were rated as most effective by the study personnel.

Davis et al. completed a review of trials between 1990 and 1999 identifying 21 studies that included a description of retention strategies and retention rates [6]. The authors provided a table listing the trials rank-ordered based on the retention rate (specifics not provided) and suggested that those studies with higher retention were those using a combination of strategies. The paper combined discussion about retention and recruitment strategies as well as about studies with mail or telephone follow-up vs. those with in-person visits.

In the existing literature, we could not identify any explicit evaluation of the effectiveness of retention strategies, such as a comparison of follow-up rates using different strategies. To help comprehensively synthesize strategies for participant retention in research studies and to evaluate areas for future methodological research in this field, we conducted a systematic review of studies which described strategies for maximizing retention for in-person follow-up.

2. Methods

2.1. Searching and study selection

We sought English-language publications reporting research that described retention strategies for in-person follow-up and included actual retention rates. We reviewed only those published reports with a primary focus on retention strategies. We included studies that provided data on retention rates, described data from a primary study, and provided information regarding strategies used to retain participants. We searched PubMed (August 11, 2005), Cumulative Index of Nursing and Allied Health Literature (CINAHL) (August 8, 2005), the Cochrane Controlled Trials Register (CENTRAL) and the Cochrane Methodology Register (Issue 3, 2005), and EMBASE (August 11, 2005). The search strategies combined text words and controlled vocabulary words for concepts of ''attrition,'' ''retention,'' ''patient dropouts,'' and ''loss to follow-up.'' The specific search strategies are provided in Appendix A. We also examined the reference lists of eligible articles and relevant reviews [3,4,6–29].

All retrieved citations were screened independently by two authors to determine eligibility. Results of the search and screening processes were maintained in a citations database (ProCite, ISI, Berkley, CA).

2.2. Data abstraction and synthesis

Two reviewers abstracted information about the study, including design, location, and target population and health condition. We also abstracted all retention strategies and retention rates at all follow-up time points. Abstracted data were entered into a relational database (Microsoft Access, Redmond, WA).

We completed a data-driven thematic analysis of the retention strategies [30]. Using an iterative, multistep process, we reviewed all abstracted retention strategies to identify themes and to classify each strategy within these themes. Initially, two authors independently reviewed the strategies and identified themes. Second, a third author reviewed these independent results, reconciled differences, and proposed a list of common themes. Third, this list of themes and categorization of strategies was discussed at a team meeting and we developed consensus on a final list of themes. Fourth, two authors independently re-reviewed the strategies and assigned each strategy to one of the themes from the final list. Finally, a third author adjudicated all assigned themes. Any remaining disagreements were discussed and resolved at a team meeting.

3. Results

3.1. Review process

Our search identified 3,068 potentially relevant citations of which 115 were considered further at the full-text level. Of these 115, we excluded an additional 94 primarily because the article did not describe a primary study (e.g., article was a review or commentary) or because the article did not describe specific retention strategies. There were 21 articles that met our eligibility criteria. Fig. 1 summarizes the results of our search and selection processes.

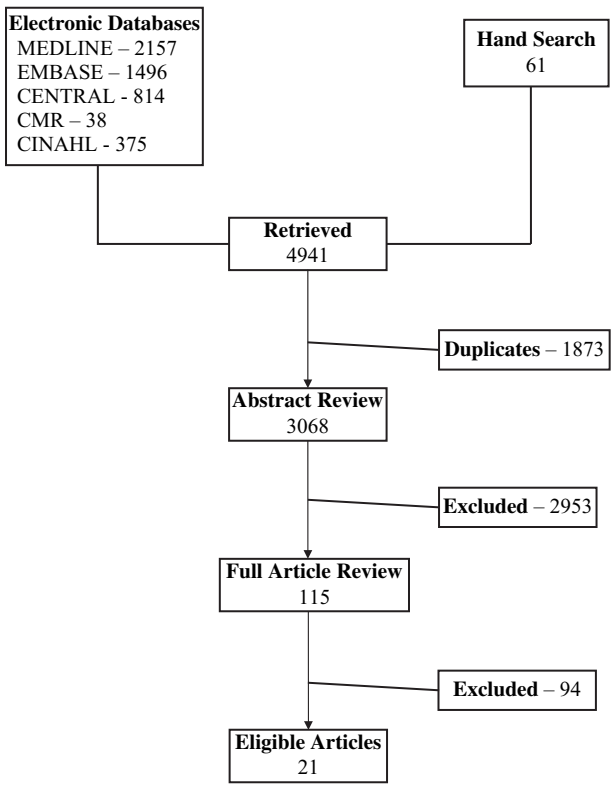

Fig. 1. Summary of search and screening results.

3.2. Study characteristics

The 21 studies in this review included 18,782 participants (mean = 894) (Table 1) [31–51]. Only one study was conducted entirely outside of the United States. Thirteen of the studies were randomized controlled trials and the remaining eight were prospective cohort studies. Of the trials, seven included behavioral interventions, four were of a drug intervention, two combined behavioral and drug interventions, and one involved a surgical intervention. Six of the studies examined substance abuse, with four of these including a behavioral or drug intervention. Other populations or health conditions included mothers and individuals with cancer, heart disease, and AIDS.

No study explicitly compared the effectiveness of different retention strategies. The average follow-up time of the studies was approximately 30 months with a range from 3 months to 9.5 years. Nine of the studies included a total follow-up time of 1 year or less. Twelve studies reported retention rates for only one follow-up point at the end of the study; though the range among the studies was 1–5 visits (mean = 2). The mean retention rate at the last, or only, follow-up time was 86% (range 59%–99%).

3.3. Synthesis of retention strategies

We abstracted 368 retention strategies from which we identified 12 themes. Table 2 lists the themes based on the order that the strategies would most likely be implemented. For instance, the theme ''Community involvement'' is listed first as getting the community involved in the study, including in design issues such as retention strategies, could be initiated before the start of the study. ''Study Identity'' follows ''Community Involvement'' and includes strategies such as the creation and use of a study logo on t-shirts, calendars, and all correspondence to create for the study participants a sense of identification with or belonging to a study. Although, many of the strategies could be classified across multiple themes, we classified each strategy as belonging in one theme only. We maintained the data-driven themes rather than collapse categories. For instance, ''Reminders'' were kept as a separate specific theme and not combined under ''Contact and Scheduling Methods'', a category including systematic methods for maintaining patient contact.

The largest number of strategies ($n = 123$) was classified within the theme of ''Contact and Scheduling Methods''. Eighty-six percent of studies reported using strategies from this theme, which included systematic methods for patient contact, scheduling of appointments, and monitoring of cohort retention. Specific strategies included obtaining updated contact information every 2 months [48] and making multiple attempts to contact subjects for complete data by phone and mail [41]. The theme ''Visit Characteristics'' included the next highest number of strategies ($n = 57$) and was also considered in 86% of the studies. This theme comprised strategies related to minimizing participant burden through the characteristics and procedures of the follow-up visit, such as offering to conduct the interview on the front porch or outside the home [38] and providing refreshments in the follow-up clinic [32].

Financial incentives were provided by eight studies. Eleven strategies involved payments for follow-up visits or interviews, including the provision of gift certificates. A specific dollar amount was provided for 10 of these strategies with a range of 10–50USD (median = 20USD). Two studies provided payments of 10USD or 20USD to family or friends for assistance in finding difficult to find study participants [33,37] and one reported a supplemental payment of 5USD for resistant participants [50]. Finally, one study paid 5USD for each urine sample provided [37]. The retention rate for those studies that reported using financial incentives was higher than for studies not reporting using financial incentives (mean 88% vs. 85%, $P = 0.9$).

There was a range of 3–42 strategies (median = 17) and a range of 3–10 themes (median = 6) per study (Table 3). No study reported strategies in all themes. Eight studies reported less than the mean retention rate of 86%. These studies had a mean retention rate of 76% with an average follow-up length of 22 months. The other 13 studies, with a mean retention rate of 92%, had a mean follow-up length of 35 months. The studies with retention rates below the mean reported using fewer strategies than those studies with a higher than mean retention rate (12 vs. 21, $P = 0.05$). These two groups of studies did not differ in the number of different themes (mean = 6 for both). The small number of studies and the heterogeneity of their characteristics limit our ability to further examine relationships between retention strategies or themes and retention rates.

4. Discussion

Failure to retain study participants in a research study is an important methodological concern. Given the expense of conducting health care research, the limited financial resources to support such studies and the risks patients potentially incur from participation, efforts to reduce bias from loss to follow-up are an important research priority. Large overall loss to follow-up or differential loss to follow-up threatens the internal and external validity of studies and limits the ability to draw inferences. However, there is sparse evidence concerning strategies aimed at maximizing retention of study participants. We identified only 21 studies across all health domains and no study that explicitly evaluated retention strategies. We identified 368 strategies that were classified within 12 themes. The studies used a median of 17 strategies across a median of six themes. The most commonly reported strategies dealt with themes related to systematic methods of patient contact and

Table 1
Summary of study characteristics

Study	Study type	Sample size	Condition/population	Demographics	Intervention	Number of follow-up visits[a]	Total length of follow-up (months)	Retention rate (%)
Katz, 2001	Randomized controlled trial	286	New mothers	Mothers ⩾18 years old with no psychiatric diagnoses who had <5 prenatal visits during pregnancy or had prenatal care initiated in third trimester; predominantly unmarried; mostly African American	Behavioral program	1	12	59
Catlett, 1993	Prospective cohort	145	Mothers	Mothers who gave birth to infants who weighed less than 1,500 g	No intervention	2	24	62
Pappas, 1998	Randomized controlled trial	211	Substance abuse/young urban people	Sixth-grade students at two intercity schools	Behavioral program	2	12	70
Parra-Medina, 2004	Randomized controlled trial	189	Diabetes	Overweight adults ⩾45 years old living in rural, medically underserved communities; 80% African American; 47% had less than high school education	Behavioral program	3	12	82
Hessol, 2001	Prospective cohort	2628	AIDS/women	HIV-positive women	No intervention	1	60	82
Motzer, 1997	Randomized controlled trial	217	Cancer	Families of female breast-cancer patients	Behavioral program	1	10	83
Desland, 1991	Prospective cohort	92	Substance abuse	Heroine users; included self-referred heroine users and those identified by court	Drug intervention	5	12	84
Mazzuca, 2004	Randomized controlled trial	431	Arthritis/women	Obese women 45–64 years old who had unilateral knee osteoarthritis	Drug intervention	1	30	85
Dilworth-Anderson, 2004	Prospective cohort	202	Caregivers/African American	African Americans >65 years old living	No intervention	1	60	87
BootsMiller, 1998	Randomized controlled trial	485	Substance abuse and psychiatric illness	Patients newly admitted to hospital for mental illness; 74% male, 77% African American, mean age of 33 years; 30% homeless, 47% had prior convictions	Drug intervention	5	24	88
Miller, 1999	Randomized controlled trial	187	Depression/elderly	Depressed elderly patients	Drug and behavioral intervention	1		88
Dennis, 2000	Prospective cohort	25	No specific disease/ethnic/racial minorities	Elderly African Americans living in urban areas	Drug and behavioral intervention	1	3	88

Dudley, 1995	Prospective cohort	4,954	AIDS/gay and bisexual men	Homosexual and bisexual men 18−70 years old in four urban areas	No intervention	1	114	89
Meyers, 2003	Prospective cohort	195	Substance abuse/young people	Youth (mean age = 16 years) in alcohol and drug treatment programs; 66% Caucasian, 66% male, 65% urban, 32% referred by court	No intervention	2	6	92
Bell, 1985	Randomized controlled trial	3,837	Heart disease	People who had at least one myocardial infarction	Drug intervention	3	36	92
Froelicher, 2003	Randomized controlled trial	2,481	Heart disease	Patients who experienced depression and/or low social support following myocardial infarction; 66% male, 66% white, 53% high school education or less	Behavioral program	1	54	93
Sprague, 2003	Randomized controlled trial	440	Fractures	Patients at 24 centers worldwide who had fractures of the tibial shaft	Surgery	1	12	94
Robles, 1994	Prospective cohort	829	Substance abuse and pregnancy	Women ⩾18 years old at fourth gestational month; included a group who had more than three drinks per week during the first trimester and a group who smoked two or more joints per month during first trimester; 53% nonCaucasian; average 12 years education; 73% earned less than 500USD/ month	No intervention	3	36	95
Goldberg, 2005	Randomized controlled trial	162	Weight loss	Overweight and obese adults 25−80 years old living in major metropolitan area	Behavioral program	3	18	96
Bailey, 2004	Randomized controlled trial	176	Cancer	Healthy women ⩾14 years old with cervical lesions	Drug intervention	1	48	99
Desmond, 1995	Randomized controlled trial	610	Substance abuse	Illegal opioid users treated in a methadone clinic	Behavioral program	1	12	99

[a] Number of follow-up visits with retention rate reported.

Table 2
Retention strategy themes

Theme	Description	Examples
Community involvement	Involve community in study design, recruitment, and retention	Present pilot project idea to church leadership and congregation
		Create community advisor panel and consult with panel for recommendations regarding protocol and participation
Study identity	Create study identity for participants	Create a project identity by using similar colors and fonts on all study materials
		Give participants a t-shirt printed with study logo
Study personnel	Characteristics, training, and management of study personnel	Assign one primary clinician to each participant
		Encourage study personnel to show empathy toward subject's personal situation in scheduling appointments/cancellations
Study description	Explain study requirements and details, including potential benefits and risks, to participants	Inform subjects that they will be followed over time and specify the timetable and the methods that will be used to locate them
		Offer a copy of a newspaper article or study brochure to each participant
Contact and scheduling methods	Use systematic method for patient contact, appointment scheduling, and cohort retention monitoring	Mail a newsletter to participants that includes a message from PI, photos of project staff, and preliminary findings
		Obtain multiple contacts for each participant, including two contacts not residing with the participant
Reminders	Provide reminders about appointments and study participation	Mail reminder postcards to participants one week before appointment
		Visit in-patients before discharge to remind them of out-patient follow-up plan
Visit characteristics	Minimize participant burden through characteristics and procedures of follow-up study clinic	Offer flexible clinic appointments (early morning, evenings, and weekends)
		Provide background music for restful atmosphere in clinic
Benefits of study	Provide benefits to participants and families that are directly related to the nature of study	Provide free annual physical examination
		Form educational and support groups for families and patients
Financial incentives	Provide financial incentives or payment	Provide payment to families in control group (20USD/visit/four visits)
		Provide pharmacy gift certificate to participant at first follow-up visit ($25)
Reimbursement	Provide reimbursement for research-related expenses or tangible support to facilitate participation	Provide taxi fare or have staff member pick up study participants
		Provide child care during visit
Nonfinancial incentives	Provide nonfinancial incentives or tokens of appreciation	Provide an inexpensive token of appreciation (e.g., coffee mug, pen, refrigerator magnet) to participant at each visit
		Host holiday parties for study participants
Special tracking methods	Methods of tracking or dealing with hard-to-find or difficult participants	Conduct clinic and street outreach for lost to follow-up participants
		Identify and address obstacles hindering participation for problem patients

scheduling procedures and minimizing patient burden through modification of characteristics of the study visit or clinic.

Studies with lower retention rates (less than the mean rate of 86%) reported the use of fewer strategies than those studies with higher retention rates despite having a lower mean overall follow-up duration. The relatively small number of studies and their heterogeneity limited our ability to further quantitatively synthesize the results. Consequently, our best advice to investigators who are designing cohort retention protocols for studies with in-person follow-up is to use multiple strategies across multiple themes. A list of strategies abstracted from the 21 studies is available (see Appendix B on the journal's web site at www.elsevier.com).

We are not the first to develop a list of strategies and themes. Davis et al., in review of 21 community-based trials, identified nine themes and noted that those studies with the highest retention rate appeared to use a combination of strategies [6]. Hunt and White chose to review four longitudinal studies to develop a list of general strategies to maximize retention [15]. Their four categories included some but not all of the same themes we identified: enrollment, consent, and baseline activities; bonding; frequency of contact; staff characteristics; and incentives. Coday et al. used principles of Social Cognitive Theory to identify eight retention categories from the 61 strategies elicited from study staff [5]. Some of the retention themes are very similar to those identified in our review. However, we identified additional different sorts of themes, such as ''Community involvement'' and also had narrower themes in some cases. For instance, our theme ''Visit Characteristics'' is very similar to the category ''Be flexible'' as well as the category ''Give instrumental or tangible support'' identified in the Coday study, as both categories included offering more convenient visits, such as home visits. As another example, the data guided us to separate the strategies encompassing reimbursement, financial incentives, and nonfinancial incentives which were combined by Coday et al. We identified similar strategies but we built on the findings of these earlier studies by systematically reviewing the literature across all health domains, incorporating all relevant

Table 3
Number of strategies by theme

Study	Community involvement	Study identity	Study personnel	Study description	Contact and scheduling	Reminders	Visit characteristics	Benefits of study	Financial incentives	Reimbursement	Nonfinancial incentives	Special tracking methods	Total number of strategies per study	Total number of themes per study	Retention rate (%)
Katz, 2001					2	1	1			1	2	1	8	6	59
Catlett, 1993			1					1		1			3	3	62
Pappas, 1998					3	2	1				1		7	4	70
Hessol, 2001	1		1		9	2	4	3	2	2	4	1	29	10	82
Parra-Medina, 2004		2	3		3	2	1		5	1	1		18	8	82
Motzer, 1997		1	3		6		2		1		4		17	6	83
Desland, 1991				1	5		1						7	3	84
Mazzuca, 2004				1	5			1	1		1		9	5	85
Dilworth-Anderson, 2004		1	7	9	6	2	9					1	35	7	87
BootsMiller, 1998			3		13	2	3		3		1		25	6	88
Dennis, 2000	4						1	1			3		9	4	88
Miller, 1999			3	1				3		1			8	4	88
Dudley, 1995	1				13	2	3	4			1	1	25	7	89
Bell, 1985			3		6	2	7	7		4			29	6	92
Meyers, 2003					13	3	2		1	2	1	1	23	7	92
Froelicher, 2003			7	3	13	1	5	2		4	2	5	42	9	93
Sprague, 2003				3	8		5					2	18	4	94
Robles, 1994			2	1	5		2	1	2	2	1		16	8	95
Goldberg, 2005		1	2	1	3		3						10	5	96
Bailey, 2004			2	1	2		3	1	1	2	1		13	8	99
Desmond, 1995			1	1	8		4		3				17	5	99
Number (%) of studies with theme	3 (14%)	4 (19%)	13 (62%)	10 (48%)	18 (86%)	10 (48%)	18 (86%)	10 (48%)	9 (43%)	10 (48%)	13 (62%)	7 (33%)			
Total number of strategies per theme	6	5	38	22	123	19	57	24	19	20	23	12	368		

study designs, to identify a larger and more comprehensive list of strategies and themes.

More research is needed in this field including explicit evaluation of the effectiveness of different cohort retention strategies. Given the need for all studies to retain participants, it may be more feasible and appropriate to focus on testing those retention strategies with higher costs, in terms of expense and research staff time. This research could include a comparison of the costs and benefits of different strategies. Finally, more papers on actual experiences with retention of participants in research studies should be published and study investigators should be encouraged to more explicitly report their retention strategies and retention rates. Adoption of standards for reporting retention strategies and rates would be helpful to improve the disclosure and consistency of these data.

Methods of recruiting participants may also be relevant for retaining participants. Consequently, research on recruitment strategies may be consulted. For instance, a recent Cochrane review of 15 controlled trials of strategies to improve the recruitment of study participants, categorized recruitment strategies into five types: (1) provision of information before invitation to join the study (prewarning), (2) provision of extra information about study benefits and risks, (3) changes to the study design to account for patient preference, including not having a placebo study arm, (4) changes to the consent process, and (5) incentives [52]. The authors noted that the results of a few studies suggest that financial incentives and provision of extra information are of some benefit. Similar to our review, the authors noted that the heterogeneity of the studies limited their ability to quantitatively synthesize the effect of specific strategies.

We acknowledge that our study has limitations. First, our efforts to classify retention strategies may have misclassified some strategies. Second, given the significant heterogeneity of the studies we were not able to provide detailed quantitative analyses. This includes an inability to identify associations between the types of strategies, retention rate, and the type of study population. Finally, we were able to abstract only the retention strategies as described in the reports of the studies and were unable to determine, for instance, the frequency or intensity of application of the strategies. Because of these limitations, we are unable to provide specific guidance on what works for whom or under what circumstances. Nevertheless, we have identified important relationships between the number of strategies used and retention rates.

Our study has some notable strengths. We built on earlier anecdotal examinations of retention strategies by systematically seeking and synthesizing studies addressing retention strategies. In addition, by classifying retention efforts into strategies and themes, and in identifying an association between number of strategies and retention rates, we can provide researchers with a guideline to plan cohort retention efforts in health care research studies.

Loss of study participants may threaten the power of a study and lead to bias. This common and important threat to validity has received very limited attention in the research literature. Use of a greater number of retention strategies from a wide variety of themes may improve study participant retention. However, further research is needed, including the explicit evaluation of the effectiveness of different strategies.

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References

[1] Szklo M, Nieto FJ. Epidemiology—Beyond the basics. Boston, MA: Jones and Bartlett Publishers; 2004.

[2] Friedman LM, Furberg CD, DeMets DL. Fundamentals of clinical trials. St. Louis, MO: Mosby; 1995.

[3] Cassidy EL, Baird E, Sheikh JI. Recruitment and retention of elderly patients in clinical trials: issues and strategies. Am J Geriatr Psychiatry 2001;9(2):136–40.

[4] Shumaker SA, Dugan E, Bowen DJ. Enhancing adherence in randomized controlled clinical trials. Control Clin Trials 2000;21(5 Suppl):226S–32S.

[5] Coday M, Boutin-Foster C, Goldman Sher T, Tennant J, Greaney ML, Saunders SD, et al. Strategies for retaining study participants in behavioral intervention trials: retention experiences of the NIH behavior change consortium. Ann Behav Med 2005;29(2 Suppl): 55–65.

[6] Davis LL, Broome ME, Cox RP. Maximizing retention in community-based clinical trials. J Nurs Scholarsh 2002;34:47–53.

[7] Anderson RT, Ory M, Cohen S, McBride JS. Issues of aging and adherence to health interventions. Control Clin Trials 2000;21(5 Suppl): 171S–83S.

[8] Andreasson S, Parmander M, Allebeck P. A trial that failed, and the reasons why: comparing the Minnesota model with outpatient treatment and non-treatment for alcohol disorders. Scand J Soc Med 1990;18:221–4.

[9] Brown DR, Fouad MN, Basen-Engquist K, Tortolero-Luna G. Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. Ann Epidemiol 2000;10(8 Suppl): S13–21.

[10] Colby SM, Lee CS, Lewis-Esquerre J, Esposito-Smythers C, Monti PM. Adolescent alcohol misuse: methodological issues for enhancing treatment research. Addiction 2004;99(Suppl 2):47–62.

[11] Farrington DP. Longitudinal research strategies: advantages, problems, and prospects. J Am Acad Child Adolesc Psychiatry 1991;30: 369–74.

[12] Good M, Schuler L. Subject retention in a controlled clinical trial. J Adv Nurs 1997;26:351–5.

[13] Hough RL, Tarke H, Renker V, Shields P, Glatstein J. Recruitment and retention of homeless mentally ill participants in research. J Consult Clin Psychol 1996;64:881–91.
[14] Hudson P, Aranda S, McMurray N. Randomized controlled trials in palliative care: overcoming the obstacles. Int J Palliat Nurs 2001;7: 427–34.
[15] Hunt JR, White E. Retaining and tracking cohort study members. Epidemiol Rev 1998;20:57–70.
[16] Ickovics JR, Meisler AW. Adherence in AIDS clinical trials: a framework for clinical research and clinical care. J Clin Epidemiol 1997; 50:385–91.
[17] Leach MJ. Barriers to conducting randomised controlled trials: lessons learnt from the Horsechestnut & Venous Leg Ulcer Trial (HAVLUT). Contemp Nurse 2003;15(1–2):37–47.
[18] Lilley K. Motivating patients to participate in clinical trials. Good Clin Pract J 1999;6(5):21–5.
[19] Marcellus L. Are we missing anything? Pursuing research on attrition. Can J Nurs Res 2004;36(3):82–98.
[20] McKenzie M, Tulsky JP, Long HL, Chesney M, Moss A. Tracking and follow-up of marginalized populations: a review. J Health Care Poor Underserved 1999;10:409–29.
[21] Bonfill X, Marzo M, Pladevall M, Marti J, Emparanza JI. Strategies for increasing women participation in community breast cancer screening. Cochrane Database Syst Rev 2001;(1). CD002943.
[22] Prinz RJ, Smith EP, Dumas JE, Laughlin JE, White DW, Barron R. Recruitment and retention of participants in prevention trials involving family-based interventions. Am J Prev Med 2001;20(1 Suppl):31–7.
[23] Pruitt RH, Privette AB. Planning strategies for the avoidance of pitfalls in intervention research. J Adv Nurs 2001;35:514–20.
[24] Sand EA. Longitudinal studies: social and psychological factors. Rev Epidemiol Sante Publique 1989;37(5–6):485–97.
[25] Shih WJ, Quan H. Testing for treatment differences with dropouts present in clinical trials–a composite approach. Stat Med 1997;16: 1225–39.
[26] Trottier D, Kochar MS. Overcoming obstacles to recruitment and retention of subjects in clinical studies. J Clin Res Drug Dev 1994;8:49–54.
[27] van Mechelen W, Mellenbergh GJ. Problems and solutions in longitudinal research: from theory to practice. Int J Sports Med 1997;18(Suppl 3):S238–45.
[28] Wilson K, Rose K. Patient recruitment and retention strategies in randomised controlled trials. Nurs Res 1998;6:35–46.
[29] Woolard RH, Carty K, Wirtz P, Longabaugh R, Nirenberg TD, Minugh PA, et al. Research fundamentals: follow-up of subjects in clinical trials: addressing subject attrition. Acad Emerg Med 2004;11: 859–66.
[30] Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. J Health Serv Res Policy 2005;10:45–53.
[31] Bailey JM, Bieniasz ME, Kmak D, Brenner DE, Ruffin MT. Recruitment and retention of economically underserved women to a cervical cancer prevention trial. Appl Nurs Res 2004;17:55–60.
[32] Bell RL, Curb JD, Friedman LM, McIntyre KM, Payton-Ross C. Enhancement of visit adherence in the national beta-blocker heart attack trial. Control Clin Trials 1985;6:89–101.
[33] BootsMiller BJ, Ribisl KM, Mowbray CT, Davidson WS, Walton MA, Herman SE. Methods of ensuring high follow-up rates: lessons from a longitudinal study of dual diagnosed participants. Subst Use Misuse 1998;33:2665–85.
[34] Catlett AT, Thompson RJ Jr, Johndrow DA, Boshkoff MR. Risk status for dropping out of developmental followup for very low birth weight infants. Public Health Rep 1993;108:589–94.
[35] Dennis BP, Neese JB. Recruitment and retention of African American elders into community-based research: lessons learned. Arch Psychiatr Nurs 2000;14:3–11.
[36] Desland M, Batey R. High retention rates within a prospective study of heroin users. Br J Addict 1991;86:859–65.
[37] Desmond DP, Maddux JF, Johnson TH, Confer BA. Obtaining follow-up interviews for treatment evaluation. J Subst Abuse Treat 1995;12(2):95–102.
[38] Dilworth-Anderson P, Williams SW. Recruitment and retention strategies for longitudinal African American caregiving research: the Family Caregiving Project. J Aging Health 2004;16(5 Suppl): 137S–56S.
[39] Dudley J, Jin S, Hoover D, Metz S, Thackeray R, Chmiel J. The Multicenter AIDS Cohort Study: retention after 91/2 years. Am J Epidemiol 1995;142:323–30.
[40] Froelicher ES, Miller NH, Buzaitis A, Pfenninger P, Misuraco A, Jordan S, et al. The Enhancing Recovery in Coronary Heart Disease Trial (ENRICHD): strategies and techniques for enhancing retention of patients with acute myocardial infarction and depression or social isolation. J Cardiopulm Rehabil 2003;23(4): 269–80.
[41] Goldberg JH, Kiernan M. Innovative techniques to address retention in a behavioral weight-loss trial. Health Educ Res 2005;20: 439–47.
[42] Hessol NA, Schneider M, Greenblatt RM, Bacon M, Barranday Y, Holman S, et al. Retention of women enrolled in a prospective study of human immunodeficiency virus infection: impact of race, unstable housing, and use of human immunodeficiency virus therapy. Am J Epidemiol 2001;154:563–73.
[43] Katz KS, El-Mohandes PA, Johnson DM, Jarrett PM, Rose A, Cober M. Retention of low income mothers in a parenting intervention study. J Community Health 2001;26:203–18.
[44] Mazzuca SA, Brandt KD, Katz BP, Lane KA, Bradley JD, Heck LW, et al. Subject retention and adherence in a randomized placebo-controlled trial of a disease-modifying osteoarthritis drug. Arthritis Rheum 2004;51:933–40.
[45] Meyers K, Webb A, Frantz J, Randall M. What does it take to retain substance-abusing adolescents in research protocols? Delineation of effort required, strategies undertaken, costs incurred, and 6-month post-treatment differences by retention difficulty. Drug Alcohol Depend 2003;69:73–85.
[46] Miller MD, Frank E, Reynolds CF. The art of clinical management in pharmacologic trials with depressed elderly patients: lessons from the Pittsburgh Study of Maintenance Therapies in Late-Life Depression. Am J Geriatr Psychiatry 1999;7:228–34.
[47] Motzer SA, Moseley JR, Lewis FM. Recruitment and retention of families in clinical trials with longitudinal designs. West J Nurs Res 1997;19:314–33.
[48] Pappas DM, Werch CE, Carlson JM. Recruitment and retention in an alcohol prevention program at two inner-city middle schools. J Sch Health 1998;68:231–6.
[49] Parra-Medina D, D'antonio A, Smith SM, Levin S, Kirkner G, Mayer-Davis E. Successful recruitment and retention strategies for a randomized weight management trial for people with diabetes living in rural, medically underserved counties of South Carolina: the POWER study. J Am Diet Assoc 2004;104:70–5.
[50] Robles N, Flaherty DG, Day NL. Retention of resistant subjects in longitudinal studies: description and procedures. Am J Drug Alcohol Abuse 1994;20:87–100.
[51] Sprague S, Leece P, Bhandari M, Tornetta P 3rd, Schemitsch E, Swiontkowski MF. Limiting loss to follow-up in a multicenter randomized trial in orthopedic surgery. Control Clin Trials 2003;24: 719–25.
[52] Mapstone J, Elbourne D, Roberts I. Strategies to improve recruitment to research studies. In: The Cochrane Database of Methodology Reviews: Reviews 2002, Issue 3. Chichester, UK: John Wiley & Sons, Ltd.; 200210.1002/14651858.MR000013.Pub2. (3).

Appendix A

Search strategies

PubMed

((attrition[tiab] OR retention[tiab] OR patient dropouts[mh] OR ''loss to follow-up''[tiab]) AND (minimize[tiab] OR strateg*[tiab] OR procedure*[tiab] OR technique*[tiab] OR method[tiab]) AND (longitudinal [tiab] OR follow-up[tiab] OR cohort studies[mh] or trial*[tiab]) AND eng[la] NOT review[pt] NOT (animals[mh] NOT humans[mh]))

CINAHL

[(AB (attrition OR retention OR ''loss to follow-up'') Or TI (attrition OR retention OR ''loss to follow-up'') OR MH patient dropouts) AND (TI (strateg* OR minimize OR procedure* OR technique* OR method) Or AB (strateg* OR minimize OR procedure* OR technique* OR method)) AND (TI (longitudinal OR follow-up OR trial*) Or AB (longitudinal OR follow-up OR trial*) OR MH prospective studies)]

The Cochrane Library (CENTRAL, Cochrane Methodology Database)

#1 attrition OR retention OR ''loss to follow-up'' in Record Title or attrition OR retention OR ''loss to follow-up'' in Abstract or patient dropouts in Keywords in CENTRAL and CMR
#2 minimize OR strateg* OR procedure* OR technique* OR method in Record Title or minimize OR strateg* OR procedure* OR technique* OR method in Abstract in CENTRAL and CMR
#3 longitudinal OR follow-up OR trial* in Record Title or longitudinal OR follow-up OR trial* in Abstract or cohort studies in Keywords in CENTRAL and CMR
#4 #1 AND #2 AND #3

EMBASE

#1 attrition:ti,ab OR retention:ti,ab AND [english]/lim AND [humans]/lim
#2 (minimize:ti,ab OR strateg*:ti,ab OR procedure*:ti,ab OR technique*:ti,ab OR method:ti,ab) AND [english]/lim AND [humans]/lim
#3 (longitudinal:ti,ab OR ''follow-up'':ti,ab OR ''cohort analysis''/exp OR trial*:ti,ab) AND [english]/lim AND [humans]/lim
#4 #1 AND #2 AND #3

Appendix B

Study	Theme	Retention strategy
Bailey, 2004	Study personnel	Have nurse practitioners make initial contact, deliver study drugs, make reminder phone calls, and attend follow-up appointments
Bailey, 2004	Study personnel	Develop strong professional relationships between study nurses and participants
Bailey, 2004	Study description	Spend a significant amount of time answering participants' questions during enrollment
Bailey, 2004	Contact and scheduling methods	Contact patients via telephone on evenings and weekends
Bailey, 2004	Contact and scheduling methods	Develop a confidential phone contact list with all possible means of contact, including pagers and cellular phones
Bailey, 2004	Visit characteristics	Strive for rapid clinic visits
Bailey, 2004	Visit characteristics	Arrange for clinic visits on off-hours, weekends, and holidays
Bailey, 2004	Visit characteristics	Allow patients to be seen in their usual health care clinics or more convenient clinics
Bailey, 2004	Benefits of study	Send participants back to the referring provider with complete documentation of their disease status and recommendations for further treatment or follow-up
Bailey, 2004	Financial incentives	Provide honorariums
Bailey, 2004	Reimbursement	Offer child care
Bailey, 2004	Reimbursement	Provide taxi rides to the clinic
Bailey, 2004	Nonfinancial incentives	Offer phone cards to patients
Bell, 1985	Study personnel	Have the same staff members see patients at each visit to establish continuity of care and rapport
Bell, 1985	Study personnel	Maintain close and personal professional relationships with patients
Bell, 1985	Study personnel	Establish trust with patients
Bell, 1985	Contact and scheduling methods	Send newsletters once or twice annually

(*Continued*)

Appendix B
Continued

Study	Theme	Retention strategy
Bell, 1985	Contact and scheduling methods	Send mailings to patients to encourage continued participation and inform them of new and relevant issues
Bell, 1985	Contact and scheduling methods	Send letters and conduct phone calls in the patient's language
Bell, 1985	Contact and scheduling methods	Send birthday, holiday, and condolence cards
Bell, 1985	Contact and scheduling methods	Call no-shows on same day as planned appointment for rescheduling
Bell, 1985	Contact and scheduling methods	Have principal investigator (PI) send letters to consistent no-shows; have coordinator send letter for subsequent no-show visits
Bell, 1985	Reminders	Send reminder postcards 1 week before appointments
Bell, 1985	Reminders	Make reminder phone call 2–3 days before appointment; stress the importance of the visit
Bell, 1985	Visit characteristics	Create a friendly but professional clinic environment
Bell, 1985	Visit characteristics	Ensure adequate spacing of patient appointments to avoid a hurried atmosphere
Bell, 1985	Visit characteristics	Make sure patients are seen promptly with minimal wait time in clinic and in radiology
Bell, 1985	Visit characteristics	Incorporate background music for restful atmosphere in clinic
Bell, 1985	Visit characteristics	Provide refreshments, such as coffee or juice, in clinic
Bell, 1985	Visit characteristics	Dispense drugs in clinic to avoid waits at pharmacy
Bell, 1985	Visit characteristics	Schedule home visits for data collection
Bell, 1985	Benefits of study	Make available educational booklets and pamphlets in the clinic
Bell, 1985	Benefits of study	Inform patients of their lab results by phone or letter
Bell, 1985	Benefits of study	Emphasize that clinic visits are beneficial to the patient for reasons beyond the study requirements
Bell, 1985	Benefits of study	Form educational and support groups for families and patients
Bell, 1985	Benefits of study	Send letters to patients' private physicians regarding their status and lab results
Bell, 1985	Benefits of study	Circulate relevant books among patients and families
Bell, 1985	Benefits of study	Encourage family members to attend clinic to have their questions answered
Bell, 1985	Reimbursement	Refer patients to appropriate agencies for financial or psychosocial problems
Bell, 1985	Reimbursement	Pay hotel expenses if overnight stays are necessary
Bell, 1985	Reimbursement	Pay air fare for patient who live far away
Bell, 1985	Reimbursement	Offer taxi transportation
BootsMiller, 1998	Study personnel	Pay interviewers using a piece-rate system
BootsMiller, 1998	Study personnel	Interviewer selection, training, and supervision
BootsMiller, 1998	Study personnel	Create interviewer incentive system for timely completion of interviews
BootsMiller, 1998	Contact and scheduling methods	Complete phone calls on different days of the week and at different times of the day
BootsMiller, 1998	Contact and scheduling methods	Create project business cards with interview reminder dates, study logo, and phone number
BootsMiller, 1998	Contact and scheduling methods	Use and maintain written tracking logs for calling back previously disconnected phone number
BootsMiller, 1998	Contact and scheduling methods	Send birthday, Christmas, and get-well cards
BootsMiller, 1998	Contact and scheduling methods	Get a toll-free phone number with memorable study acronym and use a 24-hour answering machine
BootsMiller, 1998	Contact and scheduling methods	Hold weekly meetings regarding patient retention; include brainstorming with field worker who are at a dead end
BootsMiller, 1998	Contact and scheduling methods	Create informal agency relationships with homeless shelters, county morgues, prisons, and jails and have them forward messages to participants
BootsMiller, 1998	Contact and scheduling methods	Complete tracking forms at baseline and each follow-up and include patient's home address, work address, names and addresses of family/friends/apartment manager/case worker/parole officer/physician, as well as dates of incarceration
BootsMiller, 1998	Contact and scheduling methods	Use formal agency relationships with mental health departments, local psychiatric hospitals, and county community mental health boards
BootsMiller, 1998	Contact and scheduling methods	Use computerized database to maintain contact information and track patients
BootsMiller, 1998	Contact and scheduling methods	Gain cooperation of family and friends through phone calls and letters
BootsMiller, 1998	Contact and scheduling methods	Print ''address correction requested'' on each envelope

(*Continued*)

Appendix B
Continued

Study	Theme	Retention strategy
BootsMiller, 1998	Contact and scheduling methods	Create two release forms: one lists names of persons who could be contacted during tracking phase and the second is an agency release form to gather information from community agencies such as jails and community health boards
BootsMiller, 1998	Reminders	Send reminder letters regarding appointments 4–6 weeks before interviews
BootsMiller, 1998	Reminders	Have office staff and field interviewers make phone calls before interview dates
BootsMiller, 1998	Visit characteristics	Schedule meetings at convenient locations, including participant's home, restaurant, park, hospital, interviewer's car, or prison
BootsMiller, 1998	Visit characteristics	Use in-person interview if patient is within a 100-mile radius
BootsMiller, 1998	Visit characteristics	Use phone interviews if in-person interviews are not feasible
BootsMiller, 1998	Financial incentives	Offer monetary incentive/reimbursement to relatives or friends for assistance in finding difficult-to-locate participants
BootsMiller, 1998	Financial incentives	Provide participant incentives
BootsMiller, 1998	Financial incentives	Offer gift certificate for fast food restaurant for responding to phone calls or letters
BootsMiller, 1998	Nonfinancial incentives	Send thank-you letters for responses to letters or phone calls
Catlett, 1993	Study personnel	Foster staff-participant bonding by extending invitation to participate in the study during infant's neonatal intensive care unit stay
Catlett, 1993	Benefits of study	Provide parents with findings from the developmental, medical, and speech/language assessments
Catlett, 1993	Reimbursement	Provide transportation to and from the clinic for participants if it has prevented patients from keeping appointments
Dennis, 2000	Community involvement	Publish study announcements in church bulletins
Dennis, 2000	Community involvement	Publish recruitment requests in church bulletins
Dennis, 2000	Community involvement	Engage church leadership
Dennis, 2000	Community involvement	Present pilot project ideas to church leadership groups and congregations
Dennis, 2000	Visit characteristics	Schedule weekly intervention group meetings at church before bible-study classes
Dennis, 2000	Benefits of study	Give folders with physical exams and test results to participant
Dennis, 2000	Nonfinancial incentives	Provide small tokens of appreciation for those who complete the study
Dennis, 2000	Nonfinancial incentives	Offer recognition at church services for those who complete the study
Dennis, 2000	Nonfinancial incentives	Send thank-you letters to those who complete the study
Desland, 1991	Study description	Obtain informed consent
Desland, 1991	Contact and scheduling methods	Send letters to contact persons
Desland, 1991	Contact and scheduling methods	Contact persons names and contact info
Desland, 1991	Contact and scheduling methods	Use treatment and legal systems to find participants
Desland, 1991	Contact and scheduling methods	Use research data, including social networks, treatments, and legal and employment history, for subsequent tracking
Desland, 1991	Contact and scheduling methods	Use hospital records to obtain current addresses and contact information
Desland, 1991	Visit characteristics	Offer flexible, convenient interview times and locations
Desmond, 1995	Study personnel	Choose follow-up staff that are assertive, tactful, competitive, and ingenuous
Desmond, 1995	Study description	Inform subjects that they will be followed and specify the timetable and the efforts to locate them
Desmond, 1995	Contact and scheduling methods	Document follow-up activities in detail in notes that include time and date that each attempt was made
Desmond, 1995	Contact and scheduling methods	Use locator forms that include full names, nicknames, Social Security numbers, driver's license or other ID numbers, current residences, mailing addresses, addresses of closest female relative, phone numbers, parole/probation status, and names of friends
Desmond, 1995	Contact and scheduling methods	Make a telephone call for appointments if letters fail
Desmond, 1995	Contact and scheduling methods	Find correct phone numbers by using phone directories, city directories, and treatment records
Desmond, 1995	Contact and scheduling methods	Develop and exploit institutional information sources, such as criminal justice systems, health care providers, and public assistance programs
Desmond, 1995	Contact and scheduling methods	Check county and state prison systems, parole and probation offices, local courts, and Federal Prison Bureau for patients
Desmond, 1995	Contact and scheduling methods	Identify the caller and purpose during phone calls
Desmond, 1995	Contact and scheduling methods	Mail request letters for appointments using addresses on locator forms

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Appendix B
Continued

Study	Theme	Retention strategy
Desmond, 1995	Visit characteristics	Use repeated home visits with prolonged wait at houses if patient cannot be contacted
Desmond, 1995	Visit characteristics	Make follow-up interviews brief; 30 minutes is optimal for drug using patient population
Desmond, 1995	Visit characteristics	Schedule field visits if patient cannot be contacted
Desmond, 1995	Visit characteristics	Conduct interviews where subjects are found and willing to be interviewed
Desmond, 1995	Financial incentives	Offer a fee for providing urine samples
Desmond, 1995	Financial incentives	Offer a fee for one follow-up interview
Desmond, 1995	Financial incentives	Send a finders fee to relatives of elusive subjects
Dilworth-Anderson, 2004	Study identity	Mail scenic calendars and magnets with study logos and toll-free phone numbers to participants
Dilworth-Anderson, 2004	Study personnel	Recruit interviewers who have previous experience conducting interviews and who understand cultures and traditions of study population; recruit interviewers who have an interest in the areas of research
Dilworth-Anderson, 2004	Study personnel	Emphasize that each contact with each caregiver is important to the outcome of the study
Dilworth-Anderson, 2004	Study personnel	Require an interviewer certification interview as quality-control measure
Dilworth-Anderson, 2004	Study personnel	Train interviewers in the importance of intercommunication skills, affect, familiarity with the environment, and the ability to observe while interviewing
Dilworth-Anderson, 2004	Study personnel	Train interviewers about measures and instruments, informed consent and confidentiality, quality-control procedures, and refusal conversion; encourage interviewers to contact study PI to answer ongoing interviewing questions
Dilworth-Anderson, 2004	Study personnel	Train interviewers in building trust in participants, gaining knowledge about cultural norms and values, and understanding social issues that participants may face; emphasize that the study population is not a homogenous group
Dilworth-Anderson, 2004	Study personnel	Require interviewers to have reliable transportation
Dilworth-Anderson, 2004	Study description	Offer patients a copy of the newspaper article or study brochure
Dilworth-Anderson, 2004	Study description	Read the consent forms aloud and stop to answer any questions to contend with low literacy
Dilworth-Anderson, 2004	Study description	Explain the contents of the interview and the types of questions that will be asked
Dilworth-Anderson, 2004	Study description	Ensure caregiver that all information is confidential and no identifying details will be connected to his/her answers
Dilworth-Anderson, 2004	Study description	Emphasize that it is important to interview several members of the caregiving network to get a clear picture
Dilworth-Anderson, 2004	Study description	Refer caregivers to other study participants who already have completed the interviews
Dilworth-Anderson, 2004	Study description	Assure caregivers that nobody other than study staff will have access to the data
Dilworth-Anderson, 2004	Study description	Contact supervisors to get permission for paid caregivers to participate and provide study overview and consent forms to supervisors for approval
Dilworth-Anderson, 2004	Study description	Allow participants not to answer questions that make them uncomfortable
Dilworth-Anderson, 2004	Contact and scheduling methods	Build relationships with participants through the use of telephone and field tracking by designated trackers
Dilworth-Anderson, 2004	Contact and scheduling methods	Mail appointment reminder cards to participants after appointments are made
Dilworth-Anderson, 2004	Contact and scheduling methods	Provide caregiver with toll-free phone number for reaching interviewer or project staff
Dilworth-Anderson, 2004	Contact and scheduling methods	Mail newsletter to participants that includes message from PI, photos of project staff, and preliminary findings from data collection
Dilworth-Anderson, 2004	Contact and scheduling methods	Be persistent in phone calling
Dilworth-Anderson, 2004	Contact and scheduling methods	Use directory assistance and SelectPhone database software to find new phone numbers if originals are disconnected
Dilworth-Anderson, 2004	Reminders	Make preappointment phone reminders 24 hours in advance
Dilworth-Anderson, 2004	Reminders	Mail letters to participants before each upcoming data collection period
Dilworth-Anderson, 2004	Visit characteristics	Assure participants that you will help them in every way possible to complete the interviews
Dilworth-Anderson, 2004	Visit characteristics	Schedule the interview time and location at the convenience of the caregivers

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Appendix B
Continued

Study	Theme	Retention strategy
Dilworth-Anderson, 2004	Visit characteristics	Offer to meet caregiver in public place
Dilworth-Anderson, 2004	Visit characteristics	Use the same interviewers for each caregiver throughout the study period
Dilworth-Anderson, 2004	Visit characteristics	Promise to complete the interview in a specified amount of time
Dilworth-Anderson, 2004	Visit characteristics	Let caregiver know that chatting will prolong interview
Dilworth-Anderson, 2004	Visit characteristics	Use a chart book by pointing to the number instead of the words to deal with low literacy
Dilworth-Anderson, 2004	Visit characteristics	Offer to conduct the interviews on front porches or outside of homes
Dilworth-Anderson, 2004	Visit characteristics	Offer to do interview in sections due to respect time constraints
Dilworth-Anderson, 2004	Special tracking methods	Organize field tracing by using nationwide credit bureau databases, CD-ROM directories, and hands-on investigation, such as talking with neighbors and checking with police and local businesses
Dudley, 1995	Community involvement	Ask community advisory panel to make recommendations regarding protocol and participation
Dudley, 1995	Contact and scheduling methods	Arrange for phone follow-ups for nonresponders to mailings
Dudley, 1995	Contact and scheduling methods	Obtain multiple contacts, including two contacts who do not reside with the subject
Dudley, 1995	Contact and scheduling methods	Request address correction service with mailings
Dudley, 1995	Contact and scheduling methods	Arrange for quarterly phone contact for those who cannot visit in person
Dudley, 1995	Contact and scheduling methods	Use registered mail
Dudley, 1995	Contact and scheduling methods	Send newsletters
Dudley, 1995	Contact and scheduling methods	Obtained Social Security numbers
Dudley, 1995	Contact and scheduling methods	Obtain driver's license numbers
Dudley, 1995	Contact and scheduling methods	Have subjects schedule next appointment before leaving current appointment
Dudley, 1995	Contact and scheduling methods	Use the postal service's forwarding service
Dudley, 1995	Contact and scheduling methods	Obtain the names of subjects' physicians and arrange for the release of medical records
Dudley, 1995	Contact and scheduling methods	Define search procedures for nonresponders to mail, phone, or appointment contacts
Dudley, 1995	Contact and scheduling methods	Send birthday and holiday greetings
Dudley, 1995	Reminders	Make appointment reminder phone calls 0–2 weeks before appointments
Dudley, 1995	Reminders	Send reminder letters 2–4 weeks before appointments
Dudley, 1995	Visit characteristics	Offer phone interviews when in-person visits are not possible
Dudley, 1995	Visit characteristics	Offer home visits when in-person visits are not possible
Dudley, 1995	Visit characteristics	Use abbreviated survey by mail for those who cannot fully participate for in-person follow-up
Dudley, 1995	Benefits of study	Provide forums for subjects to meet investigators
Dudley, 1995	Benefits of study	Offer free annual physical examinations
Dudley, 1995	Benefits of study	Provide no-fee lab results to subjects
Dudley, 1995	Benefits of study	Offer up-to-date information about HIV
Dudley, 1995	Nonfinancial incentives	Provide small gifts, such as candy, pencils, condoms, or pads of paper
Dudley, 1995	Special tracking methods	Search for missing participants by using county and state death certificates, obituaries, AIDS registries, national death indexes, department of motor vehicles, consumer information services, and tax and voter rolls
Froelicher, 2003	Study personnel	Assign compassionate, flexible, and persistent staff with the responsibility of calling and tracking patients
Froelicher, 2003	Study personnel	Ensure consistency by using the same staff members
Froelicher, 2003	Study personnel	Listen to and be understanding of problematic patients
Froelicher, 2003	Study personnel	Train staff members in motivational interviewing and specific cultural-sensitivity training
Froelicher, 2003	Study personnel	Ask about and record personal information that is important to patients
Froelicher, 2003	Study personnel	Use Spanish-speaking interviewers and psychologists for patients who speak Spanish
Froelicher, 2003	Study personnel	Be positive when you see problematic patients and encourage their continued participation
Froelicher, 2003	Study description	Translate all study materials into Spanish for patients
Froelicher, 2003	Study description	Review the schedule of calls and visits at the time of the final baseline visits
Froelicher, 2003	Study description	Let patients know the importance of the visits
Froelicher, 2003	Contact and scheduling methods	Send holiday cards to participants
Froelicher, 2003	Contact and scheduling methods	Call at least a month before the due date to schedule appointments

(*Continued*)

Appendix B
Continued

Study	Theme	Retention strategy
Froelicher, 2003	Contact and scheduling methods	Have staff carry pagers and cell phones
Froelicher, 2003	Contact and scheduling methods	Send birthday cards to participants
Froelicher, 2003	Contact and scheduling methods	Call at every scheduled contact with problematic patients to see how they are and try to obtain information; if a patient does not respond to calls or letters, the PI should send a letter telling them of importance of the research project and asking them to participate
Froelicher, 2003	Contact and scheduling methods	Send multisite newsletters to participants
Froelicher, 2003	Contact and scheduling methods	Confirm the contact person's name and number at each contact
Froelicher, 2003	Contact and scheduling methods	Have the counselor promptly contact patients randomized to the intervention group, in person if possible
Froelicher, 2003	Contact and scheduling methods	Request forwarding address service from the U.S. Postal Service with each mailing
Froelicher, 2003	Contact and scheduling methods	At the end of the call, let patient know what and when the next scheduled contact will be
Froelicher, 2003	Contact and scheduling methods	Document the time of day that patients prefer to be called
Froelicher, 2003	Contact and scheduling methods	Give a welcome packet with personnel names and contact phone numbers
Froelicher, 2003	Contact and scheduling methods	Send humorous postcards to patients who are hospitalized
Froelicher, 2003	Reminders	Confirm clinical appointments the day before
Froelicher, 2003	Visit characteristics	Offer home visits for those that are very ill, disabled, or refuse a clinic visit
Froelicher, 2003	Visit characteristics	Request completion of the questionnaires over the phone
Froelicher, 2003	Visit characteristics	Use satellite offices to cover large recruitment areas
Froelicher, 2003	Visit characteristics	Offer to break up questionnaire into several brief calls at participants' convenience
Froelicher, 2003	Visit characteristics	Provide flexible clinic appointments that include early mornings, evenings, and weekends
Froelicher, 2003	Benefits of study	Complete the education at baseline visits after the patients leave the hospital
Froelicher, 2003	Benefits of study	Send letters to primary physicians informing them of the randomization assignments
Froelicher, 2003	Reimbursement	Offer mileage reimbursement
Froelicher, 2003	Reimbursement	Provide transportation via Medi-Car, bus pass/transit tokens, taxi fare, or limousine service
Froelicher, 2003	Reimbursement	Pay for parking passes at the facility
Froelicher, 2003	Reimbursement	Offer remuneration for childcare
Froelicher, 2003	Nonfinancial incentives	Offer incentives for attending a relevant events
Froelicher, 2003	Nonfinancial incentives	Thank patients for their participation in the research project
Froelicher, 2003	Special tracking methods	Continue calling problematic patients; do not give up
Froelicher, 2003	Special tracking methods	Encourage problematic patients to commit to visit dates and times
Froelicher, 2003	Special tracking methods	Send letters and retention videos to problematic patients
Froelicher, 2003	Special tracking methods	Respect the wishes of problematic patients who no longer want to be involved in attending assessments and receiving phone calls, but avoid severing all ties; ask permission to access the medical records at their physician's office or hospital
Froelicher, 2003	Special tracking methods	Identify and address obstacles that are hindering problematic patients from participating
Goldberg, 2005	Study identity	Create project identities that incorporate consistent colors and fonts on all study materials
Goldberg, 2005	Study personnel	Decrease participant ambivalence through the use of emotivational interviewing techniques
Goldberg, 2005	Study personnel	Provide support to participants
Goldberg, 2005	Study description	Write protocols to address common participant questions
Goldberg, 2005	Contact and scheduling methods	Get two secondary contacts by asking subjects to sign a letter notifying contacts of study participation and giving permission to provide forwarding information
Goldberg, 2005	Contact and scheduling methods	Make multiple attempts to contact subjects for complete data by phone and mail
Goldberg, 2005	Contact and scheduling methods	Send birthday cards
Goldberg, 2005	Visit characteristics	Attempt to be on time for clinic appointments
Goldberg, 2005	Visit characteristics	Get subjects who move from the area to complete surveys and have clinical data collected and verified by another clinician
Goldberg, 2005	Visit characteristics	Offer flexible scheduling

(*Continued*)

Appendix B
Continued

Study	Theme	Retention strategy
Hessol, 2001	Community involvement	Consult with national and local community advisory boards on strategies for recruitment and retention, protocol design, study-visit satisfaction, and participant compliance with study protocols
Hessol, 2001	Study personnel	Incorporate respectful, nonjudgmental, bilingual study staff that are the same sex as participants
Hessol, 2001	Contact and scheduling methods	Keep contact with primary care providers
Hessol, 2001	Contact and scheduling methods	Use contacts to reach patients not available at their homes
Hessol, 2001	Contact and scheduling methods	Search the National Death Index and local death registries for missing subjects
Hessol, 2001	Contact and scheduling methods	Update locating form for contact persons at each contact
Hessol, 2001	Contact and scheduling methods	Send birthday and holiday cards
Hessol, 2001	Contact and scheduling methods	Monitor admission records for patient status and contact information
Hessol, 2001	Contact and scheduling methods	Checked with jails and prisons to track down missing participants
Hessol, 2001	Contact and scheduling methods	Create local site newsletters with information about HIV, study protocol and results, and staff changes
Hessol, 2001	Contact and scheduling methods	Conduct computer searches of medical databases to get updated location information on participants
Hessol, 2001	Reminders	Make reminder phone calls for appointments
Hessol, 2001	Reminders	Send reminder letters for appointments
Hessol, 2001	Visit characteristics	Perform study visits at jail or conduct phone interviews
Hessol, 2001	Visit characteristics	Create abbreviated interview options for illnesses or detentions
Hessol, 2001	Visit characteristics	Allow for flexibility in rescheduling missed or canceled appointments
Hessol, 2001	Visit characteristics	Create safe, comfortable environments at study sites
Hessol, 2001	Benefits of study	Send study test results to primary care givers after obtaining patient consent
Hessol, 2001	Benefits of study	Conduct educational forums
Hessol, 2001	Benefits of study	Provide personalized attention at visits by referring patients to social and medical services and counseling for abnormal lab or exam findings and high-risk behaviors
Hessol, 2001	Financial incentives	Offer grocery coupons
Hessol, 2001	Financial incentives	Provide monetary compensation in cash for study visits; some sites should increase cash amount for later visits
Hessol, 2001	Reimbursement	Provide transportation assistance in the form of bus tokens, train tickets, money for gas, or cab vouchers
Hessol, 2001	Reimbursement	Provide child care during visit and offer gifts to children
Hessol, 2001	Nonfinancial incentives	Host holiday parties
Hessol, 2001	Nonfinancial incentives	Pass out movie or museum passes
Hessol, 2001	Nonfinancial incentives	Give away gift incentives, such as dental kits, cosmetics, male and female condoms, or food coupons
Hessol, 2001	Nonfinancial incentives	Provide meals and/or snacks
Hessol, 2001	Special tracking methods	Incorporate clinic and street outreach for participants who are lost to follow-up
Katz, 2001	Contact and scheduling methods	Collect multiple contacts' phone numbers and addresses at time of enrollment
Katz, 2001	Contact and scheduling methods	Hold monthly meetings that include people applying intervention to identify participants for whom data are missing
Katz, 2001	Reminders	Send telephone and mail reminders before visits
Katz, 2001	Visit characteristics	Allow participants to bring siblings to the parent groups
Katz, 2001	Reimbursement	Provide transportation to and from study events
Katz, 2001	Nonfinancial incentives	Give gifts to intervention mothers as part of the curriculum
Katz, 2001	Nonfinancial incentives	Provide incentive gifts for completing successive phases of the project
Katz, 2001	Special tracking methods	Visit participants' last known residences if contact is lost and no telephone information is useable
Mazzuca, 2004	Study description	Have study coordinators emphasize that subjects will be expected to undergo exams at 16 and 30 months, even if study medication is discontinued
Mazzuca, 2004	Contact and scheduling methods	Have coordinators monitor safety and reinforce participation through monthly telephone calls between visits
Mazzuca, 2004	Contact and scheduling methods	Send birthday cards
Mazzuca, 2004	Contact and scheduling methods	Have coordinating center continuously monitor overall and center-specific rates of subject retention for exams

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Study	Theme	Retention strategy
Mazzuca, 2004	Contact and scheduling methods	Send summaries of subject retention—including anonymous normative comparisons among centers, as well as retention promoting strategies used by the most successful centers—to study coordinators and investigators at regular intervals
Mazzuca, 2004	Contact and scheduling methods	Send holiday greeting cards to participants
Mazzuca, 2004	Benefits of study	Dispense sunscreen and miconazole cream free of charge to minimize side effects of the treatment
Mazzuca, 2004	Financial incentives	Offer monetary compensation for each appointment kept
Mazzuca, 2004	Nonfinancial incentives	Offer inexpensive tokens of appreciation—such as coffee mugs, pens, and refrigerator magnets—that feature the study logo
Meyers, 2003	Contact and scheduling methods	Obtain multiple contacts
Meyers, 2003	Contact and scheduling methods	Use institutional services such as social services and community services for finding subjects
Meyers, 2003	Contact and scheduling methods	Call from multiple phones to avoid caller ID
Meyers, 2003	Contact and scheduling methods	Use a log to track progress with follow-up for the cohort
Meyers, 2003	Contact and scheduling methods	Make phone calls to subjects to make appointments
Meyers, 2003	Contact and scheduling methods	Obtain personal information about the subject, including hang-outs, tattoos
Meyers, 2003	Contact and scheduling methods	Tracking in the field
Meyers, 2003	Contact and scheduling methods	Hold weekly research meetings regarding status of follow-up
Meyers, 2003	Contact and scheduling methods	Use directory assistance and Internet directory services for phone numbers or addresses
Meyers, 2003	Contact and scheduling methods	Request forward or return-service mailings
Meyers, 2003	Contact and scheduling methods	Make phone calls to contacts to find subject
Meyers, 2003	Contact and scheduling methods	Track follow-up efforts in a quantitative way, such as number of phone calls made
Meyers, 2003	Contact and scheduling methods	Send letters to subjects to make appointments
Meyers, 2003	Reminders	Send reminder mailings for appointments
Meyers, 2003	Reminders	Make reminder phone calls for appointments
Meyers, 2003	Reminders	Tell in-patients about follow-up visits before they are discharged
Meyers, 2003	Visit characteristics	Arrange study visits that piggyback on other pre-existing appointments, such as visits to the doctor or probation officer
Meyers, 2003	Visit characteristics	Allow for flexible scheduling
Meyers, 2003	Financial incentives	Reimburse patients for their time
Meyers, 2003	Reimbursement	Reimburse the contact accompanying the subject to appointment
Meyers, 2003	Reimbursement	Reimburse transportation expenses
Meyers, 2003	Nonfinancial incentives	Send thank-you letters after appointments
Meyers, 2003	Special tracking methods	Apply tracking techniques
Miller, 1999	Study personnel	Give psychosocial information about the study participants to all protocol team members
Miller, 1999	Study personnel	Assign one primary clinician to each participant
Miller, 1999	Study personnel	Use different approaches for patients from varying ethnic backgrounds, if necessary
Miller, 1999	Study description	Review study consent forms and study protocol frequently and provide broad education for participants and families
Miller, 1999	Benefits of study	Tailor psychosocial interventions to the specific phase of the study by, for example, assuring patients who are in remission that they need to remain on treatment
Miller, 1999	Benefits of study	Manage side effects of the medications aggressively; this includes warning patients, offering countermeasures early, and carefully evaluating each complaint
Miller, 1999	Benefits of study	Involve participants' family members in study activities.
Miller, 1999	Reimbursement	Provide social support—such as help with managing finances or finding housing—to participants who are in need of it
Motzer, 1997	Study identity	Establish bonds between personnel and participants through the use of logos on all correspondence, business cards, questionnaires, poster and newspaper advertisements, and certificates
Motzer, 1997	Study personnel	Ensure that study staff receive extensive training in, and are engaged in weekly discussions about, interacting with distressed families within the study protocol; this will foster bonds between team members and the study staff

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Study	Theme	Retention strategy
Motzer, 1997	Study personnel	Base study team selection on professional education and experiences with families, breast cancer, home health, or public nursing
Motzer, 1997	Study personnel	Make sure study team members are comfortable with their research roles; this will help assure that families are equally comfortable as research participants
Motzer, 1997	Contact and scheduling methods	Visits to be scheduled within the next month were noted on the team meeting agenda, when visits were scheduled they added to the spreadsheet
Motzer, 1997	Contact and scheduling methods	Have team members schedule their own family visits
Motzer, 1997	Contact and scheduling methods	Create a schedule of all visits over a 10-month period for each participant family
Motzer, 1997	Contact and scheduling methods	Have the team discuss strategies to overcome scheduling difficulties
Motzer, 1997	Contact and scheduling methods	Conduct systematic monitoring of the timeliness of scheduled visits
Motzer, 1997	Contact and scheduling methods	Ensure regular monitoring of visit scheduling and completion
Motzer, 1997	Visit characteristics	Allow for a shortened, in-home visit—with pre-emailed selected questionnaires to be completed prior to the visit—to overcome scheduling difficulties
Motzer, 1997	Visit characteristics	Allow flexibility in time between visits to maximize retention
Motzer, 1997	Financial incentives	Offer payments to families in control groups
Motzer, 1997	Nonfinancial incentives	Provide gifts—such as pencils, pens, stickers, or bookmarks—for each child at each evaluation
Motzer, 1997	Nonfinancial incentives	Send handwritten thank-you notes from nurses after each evaluation visit
Motzer, 1997	Nonfinancial incentives	Distribute certificates of appreciation that include names of younger children at the end of the last evaluation
Motzer, 1997	Nonfinancial incentives	Send formal thank-you letters from PI and site coordinators after enrollment, first visit, and study completion
Pappas, 1998	Contact and scheduling methods	Use school personnel to track participants who are students
Pappas, 1998	Contact and scheduling methods	Update address information every 2 months
Pappas, 1998	Contact and scheduling methods	Call to verify addresses before each mailing
Pappas, 1998	Reminders	Send reminders of data collection 1 week before event
Pappas, 1998	Reminders	Send mailings to parents reminding them of upcoming program activities
Pappas, 1998	Visit characteristics	Allow for flexible scheduling of data collection
Pappas, 1998	Nonfinancial incentives	Provide incentives for data collection; incentives can be food and entertainment coupons, gift certificates, compact discs, sports memorabilia, t-shirts, or lottery tickets for larger incentives such as stereos, TVs, backpacks, or family vacations
Parra-Medina, 2004	Study identity	Create refrigerator magnets that include study phone numbers
Parra-Medina, 2004	Study identity	Create t-shirts for study participants
Parra-Medina, 2004	Study personnel	Foster empathy toward subjects' personal situations in scheduling appointments/cancellations
Parra-Medina, 2004	Study personnel	Emphasize the importance of the study in communication between research staff and subjects
Parra-Medina, 2004	Study personnel	Recruit research staff of similar cultural background as subjects
Parra-Medina, 2004	Contact and scheduling methods	Follow up on missed appointments by phone or in-person
Parra-Medina, 2004	Contact and scheduling methods	Use tracking software for appointments
Parra-Medina, 2004	Contact and scheduling methods	Send birthday greetings
Parra-Medina, 2004	Reminders	Make appointment phone calls
Parra-Medina, 2004	Reminders	Send appointment-reminder letters
Parra-Medina, 2004	Visit characteristics	Offer flexible appointment scheduling
Parra-Medina, 2004	Financial incentives	Provide monetary incentives after randomization
Parra-Medina, 2004	Financial incentives	Create a monetary incentive of a pharmacy gift certificate at first 3-month follow-up
Parra-Medina, 2004	Financial incentives	Provide grocery gift certificate at 6-month follow-up
Parra-Medina, 2004	Financial incentives	Provide grocery gift certificate at 12-month follow-up
Parra-Medina, 2004	Financial incentives	Provide grocery gift certificate at first visit
Parra-Medina, 2004	Reimbursement	Provide transportation for study subjects
Parra-Medina, 2004	Nonfinancial incentives	Give away cookbooks
Robles, 1994	Study personnel	Establish rapport with subjects and discuss why participation is difficult
Robles, 1994	Study personnel	Express concern for participants' other problems
Robles, 1994	Study description	Describe the voluntary nature of study and potential benefits to other children

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Study	Theme	Retention strategy
Robles, 1994	Contact and scheduling methods	Make telephone calls during the daytime and evening
Robles, 1994	Contact and scheduling methods	Stage home visit with two staff members to reintroduce the study and encourage appointment
Robles, 1994	Contact and scheduling methods	Conduct frequent and lengthy phone calls
Robles, 1994	Contact and scheduling methods	Create completely personalized handwritten notes asking patient to contact the study
Robles, 1994	Contact and scheduling methods	Send form letters along with handwritten notes asking patient to contact the study
Robles, 1994	Visit characteristics	Offer home-assessment option if participants are unwilling to come to office
Robles, 1994	Visit characteristics	Offer alternative interview locations, such as day-care centers and caregiver homes
Robles, 1994	Benefits of study	Provide results of physical examinations and developmental assessments of children to mothers for free
Robles, 1994	Financial incentives	Offer supplemental payments to resistant participants
Robles, 1994	Financial incentives	Supply regular interview payments
Robles, 1994	Reimbursement	Offer child care during interviews
Robles, 1994	Reimbursement	Provide transportation in the form of taxi fare, or have staff member pick up participants
Robles, 1994	Nonfinancial incentives	Provide holiday gifts for children
Sprague, 2003	Study description	Provide patients with information on their injuries, the risk of complications, potential treatment effects, expectations for personal benefit from study participation, and motivation for adherence with follow-up visits and research protocols
Sprague, 2003	Study description	Fully inform patients about the burden of the study prior to randomization
Sprague, 2003	Study description	Have the attending surgeon take time with patients to emphasize how the study will help future patients and to discuss the importance of returning for all follow-up visits
Sprague, 2003	Contact and scheduling methods	Continue trying to contact lost patients and all alternate contacts until you are able to reach someone to determine the patient's status, unless the telephone lines have been disconnected
Sprague, 2003	Contact and scheduling methods	Have the methods center contact the clinical center immediately if it receives an early withdrawal form
Sprague, 2003	Contact and scheduling methods	Have study staff at the methods center contact the clinical sites regularly to discuss and help locate any patients who have overdue visits
Sprague, 2003	Contact and scheduling methods	Provide patients with reminders for upcoming follow-up visits and obtain information on any planned change in residence
Sprague, 2003	Contact and scheduling methods	Have clinical staff watch for patients reappearing in their clinics for other reasons
Sprague, 2003	Contact and scheduling methods	Obtain contact information for the patients, primary care physicians, and alternate contacts
Sprague, 2003	Contact and scheduling methods	Closely monitor data for missed and overdue follow-up visits
Sprague, 2003	Contact and scheduling methods	Contact patients or alternate contacts by telephone for follow-up, even during evenings and weekends if necessary
Sprague, 2003	Visit characteristics	Schedule follow-up appointment times around patient preferences.
Sprague, 2003	Visit characteristics	Design the study's follow-up schedule to coincide with normal surgical follow-up visits
Sprague, 2003	Visit characteristics	Minimize the amount of time patients spend waiting at a follow-up visit and encourage patients to complete questionnaires while waiting
Sprague, 2003	Visit characteristics	Reduce the demands of study participation for patients who have a language barrier, cognitive impairment, or, as a last resort, for patients who do not want to complete the quality-of-life questionnaires by following for primary events only
Sprague, 2003	Visit characteristics	Have study staff negotiate with patients to encourage them to continue with the study; have staff offer to reduce the demands of study participation
Sprague, 2003	Special tracking methods	Have methods center staff develop strategies with the clinical staff to locate patients with overdue follow-up appointments.
Sprague, 2003	Special tracking methods	Have staff at the methods center help the clinical centers contact patients they are having a difficult time reaching.