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Updated systematic review identifies substantial number of retention strategies: Using more strategies retains more study participants

Karen A. Robinson, PhD^{a,*}, Victor D. Dinglas, MPH^b, Vineeth Sukrithan, MBBS^b, Ramakrishna Yalamanchilli, MBBS^b, Pedro A. Mendez-Tellez, MD^c, Cheryl Dennison-Himmelfarb, RN, ANP, PhD, FAAN^d, and Dale M. Needham, FCPA, MD, PhD^b

^aDepartment of Medicine, Johns Hopkins University School of Medicine, 1830 East Baltimore St., Baltimore, MD, 21287

^bDivision of Pulmonary and Critical Care Medicine, Johns Hopkins University School of Medicine, 1830 East Baltimore St., Baltimore, MD, 21287

^cDepartment of Anesthesiology and Critical Care Medicine, Johns Hopkins University School of Medicine, 600 N. Wolfe St., Baltimore, MD 21287

^dDepartment of Acute and Chronic Care, Johns Hopkins University School of Nursing, 525 N. Wolfe St., Baltimore, MD, 21205

Abstract

Background and Objective—The retention of participants in studies is important for the validity of research. We updated our prior systematic review (2005) to assess retention strategies for in-person follow-up in healthcare studies.

Methods—We searched PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane Controlled Trials Register (CENTRAL), Cochrane Methodology Register, and Embase (August 2013) for English-language reports of studies that described retention strategies for in-person follow-up in healthcare studies. We abstracted each retention strategy and two authors independently classified each retention strategy with one of the themes developed in our prior review.

Results—We identified 88 studies (67 newly identified studies), six of which were designed to compare retention strategies while the remainder described retention strategies and retention rates. There were 985 strategies abstracted from the descriptive studies (617 from new studies), with a median (interquartile range) number of strategies per study of 10 (7 to 17) and a median (interquartile range) number of themes per study of 6 (4 to 7). Financial incentives were used in 47 (57%) of the descriptive studies. We classified 28% of the strategies under the theme of ‘Contact

*Corresponding author: Tel. + 1-410-502-9216; krobin@jhmi.edu (K.A. Robinson).

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and Scheduling Methods,' with 83% of the identified studies using at least one strategy within this theme. The number of strategies used was positively correlated with retention rate ($P=0.027$), but the number of themes was not associated with retention rate ($P=0.469$).

Conclusions—The number of studies describing retention strategies has substantially increased since our prior review. However, the lack of comparative studies and the heterogeneity in the types of strategies, participant population and study designs, prohibits synthesis to determine the types of cohort retention strategies that were most effective. However, using a larger number of retention strategies, across 5 or 6 different themes, appears to retain more study participants.

Keywords

retention strategies; follow-up studies; in-person follow-up; systematic review; methods

Retention of participants plays an important role in ensuring the validity of a study, and is particularly challenging in longitudinal research. Studies with a high loss to follow-up or attrition are generally judged to be of lower quality because of the increased risk of selection bias, particularly if those remaining in the study differ from those who left the study, or if there is differential attrition across the study groups being compared.^{1,2}

Thus, optimizing retention of participants is an important consideration in the design and conduct of studies. This systematic review updates a prior review we conducted in 2005 on strategies to retain study participants for in-person follow-up.³ At that time, we identified no comparative studies and 21 descriptive studies of retention strategies. We abstracted and classified each of the 368 strategies in these studies to one of 12 iteratively developed themes, finding that studies reported a median (interquartile range [IQR]) of 17 (IQR, 9 to 25) strategies across a median of six (IQR, 4 to 7) themes. Furthermore, we found that studies with a retention rate above the mean of 86% reported using more strategies (21 versus 12, $P=0.05$).

We identified two systematic reviews of retention strategies completed since the publication of our review. Both reviews were limited to studies comparing different retention methods and both considered a variety of types of follow-up (e.g., in-person, phone-based). Booker et al. (2011) identified 28 studies, including 11 randomized controlled trials (RCTs) comparing retention strategies.⁴ This review categorized strategies as incentives, reminders, or other methods, and found that incentives of cash or gifts increased retention rates in population-based cohort studies. However, only 3 studies included in this review considered in-person follow-up. A Cochrane review identified 38 RCTs or quasi-RCTs conducted within RCTs. The authors concluded that financial incentives increased responses to questionnaires, but were unable to draw conclusions about in-person follow-up as 34 of the 38 eligible studies evaluated response to questionnaires.^{5,6}

Hence, our objective was to update our prior systematic review of retention strategies for in-person follow-up in healthcare studies.

Methods

To conduct this update, we used the same methods as in our prior review.³ Briefly, we searched PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane Controlled Trials Register (CENTRAL), Cochrane Methodology Register, and Embase (all August 2013) for English-language reports of studies that described retention strategies for in-person follow-up in healthcare studies. We also hand searched the reference list in all eligible studies and in the two existing systematic reviews.^{4–6} All retrieved citations were screened independently by two reviewers to determine eligibility. Disagreements regarding eligibility were resolved through consensus or adjudicated by a third reviewer.

Two reviewers abstracted information from each eligible study, such as target population and health condition, into a project-specific database (Microsoft Access, Redmond, WA). We also abstracted, verbatim, each retention strategy as well as the retention rates at all follow-up time points that were reported.

In our original systematic review we completed a data-driven thematic analysis of the retention strategies in a multi-step iterative process (Table 1). In this update, two authors independently classified each retention strategy with one of the themes developed in our prior review. A third person adjudicated discrepancies in the theme assigned.

We used STATA (StataCorp LP, College Station, TX.) for analysis. We calculated Pearson's correlation (r) to separately assess the linear association between retention rate and the number of strategies and the number of themes.

Results

We identified 67 studies (reported in 64 articles) since our last review conducted 8 years ago. Combined with the 21 studies from our prior review, we identified a total of 88 studies of retention strategies (Figure 1). As shown in Figure 2, the number of strategies and number of themes per study have remained relatively constant, but the number of studies assessing retention strategies has increased substantially. Between 1985 and 1990 only one study of retention strategies was published while in the 5 years between 2008 and 2013 47 studies were published. Six (7%) of these 88 studies were designed to compare retention strategies while the remaining studies described retention strategies and retention rates.

Comparative Studies

Four RCTs, one quasi-RCT and one uncontrolled trial empirically compared retention strategies (Table 2). Different types of interventions, in different study populations, were evaluated over 6 to 36 months of follow-up. Bowen et al. (2000) randomized visit days so that participants in a lung cancer prevention randomized controlled trial received one of two types of non-financial incentives or no incentive.⁷ High retention rates were achieved for all groups with no differences between groups at one and two year follow-up visits.

Using patient identification numbers, Ford et al. (2006) allocated participants in one arm from a cancer screening randomized controlled trial to case management versus a usual-care

control group.⁸ The case managers provided resources and referrals for participants, as needed, and also contacted participants by phone at least monthly. The control group received yearly reminder calls. Analysis was reported separately for 4 different screening tests stratified by participant income level. As hypothesized, among participants with low income, those within the case manager versus control group had higher retention rates. Across all participants, however, no differences were found between the two groups.

Etcheverry et al. (2013) reported that, compared to usual practice, an ‘enhanced retention’ intervention improved retention in cohort study regarding willingness to participate in an HIV vaccine trial at 6 months (76% vs 16%), 12 months (69% vs 13%), and 24 months (41% vs 5%) (test for trend, $P < 0.001$).⁹ The enhanced retention intervention comprised several strategies, including reminders (phone calls and text messages), and financial incentives at the 6 and 12 month visit. While apparently showing success of the ‘enhanced retention’ intervention, participants were not randomly allocated but were allocated based on prior visits to the healthcare facility which created groups that may have differed in health seeking behavior, comfort with the facility staff and knowledge about the resources available at the facility.

Three studies examined retention strategies for studies with substance abuse participants. Festinger and colleagues conducted two studies focusing on the potential ethical implications of offering financial incentives to substance abuse treatment clients. In the first study, participants in an observational study were randomly assigned to receive different levels of incentive in either cash or gift certificates.¹⁰ Overall retention, across groups, was 43% at the 6 month visit. Those offered the least amount (\$10) (20% retention rate) were less likely to be retained than those given \$40 (60%, odds ratio=0.36) or \$70 (59%, OR=0.34) (main effect for magnitude of payment $P = 0.001$). No differences were observed between those offered \$40 versus \$70 (60% vs. 59%). Cash incentives were more effective than gift certificates (48% versus 37% retention, OR=1.97, $P = 0.02$).

In the second RCT, Festinger et al. (2008) assessed the effect of higher value financial incentives on retention in an observational study.¹¹ As in the prior study, compared to those receiving \$70 (54%), participants receiving higher amounts were more likely to be retained at the 6 month visit (72%, OR=1.89 for \$100; 69%, OR=2.47 for \$130; 71%, 2.27 for \$160; main effect for magnitude of payment $P = 0.008$). No differences in retention were reported comparing those receiving \$100, \$130 or \$160. Also as in prior study, those receiving payments in cash were more likely to attend the follow-up visit (66% versus 57%, OR=1.53, $P = 0.04$).

Wilcox et al. (2012) conducted an uncontrolled study embedded in a study in which opioid-dependent youth were randomized to different treatments, each with weekly visits.¹² Participants were paid \$75 per visit for weeks 4, 8 and 12 and \$5 for weeks 3, 5, 7, 9 and 11. The lowest retention occurred at 11 weeks (68%). During the weeks with lower compensation, the average retention rate was 27% and 67% in the two treatment groups, compared to 54% and 72% in the higher compensation weeks. However, even with the higher compensation, the retention was only 60% at the end of the study.

Descriptive Studies

The remaining studies (n=82) described retention strategies and retention rates (Appendix). There were 985 strategies with a median number of strategies per study of 10 (IQR, 7 to 17) and a median number of themes per study of 6 (IQR, 4 to 7). We classified 28% of the 985 strategies under the theme of 'Contact and Scheduling Methods,' with 83% of studies having at least one strategy in this theme (Table 1 and Appendix Table 2). The theme 'Community Involvement' had the fewest strategies (2%) and was used in 15% of the studies.

The reported retention rates varied from 41% to 99% (median [IQR] 84.5% [IQR, 79 to 92]). The number of strategies used was positively correlated with retention rate, with the number of strategies used explaining about 6% of the variation in retention rate (Figure 2; $r=0.24$, $P=0.027$), but the number of themes was not associated with retention rate ($r=0.08$, $P=0.469$).

Financial incentives, examined in 4 of the 6 comparative studies of retention strategies, were used in 47 (57%) of the descriptive studies. In 33 of these descriptive studies, financial incentive was one strategy, in 9 studies two different financial incentive strategies were employed, and 3 or more financial incentive strategies were used in 5 studies. Financial incentives ranged from \$5 for provision of a urine sample to \$275 for completing questionnaires and clinical assessments. In some studies, different amounts were offered for different visits or types of visits or study activities. This variability limited our ability to draw conclusions about specific incentive amount.

Discussion

Since our prior systematic review in 2005 there has been a more than 4 fold increase in the number of studies of strategies to retain participants in healthcare research. In this updated review, we identified a total of 88 studies of retention strategies, with six of these studies explicitly comparing the effectiveness of different retention strategies for in-person follow-up. Differences in the study designs, participant populations and interventions limited our ability to synthesize these comparative studies. However, the 4 studies assessing financial incentives suggest that financial incentives, and specifically higher incentive amounts and cash incentives, result in higher retention rates.

We abstracted 985 strategies from the 82 studies that described retention strategies and retention rates, identifying a median of 10 strategies per study. As in our prior systematic review, the themes of "contact and scheduling methods" and "visit characteristics" represented the largest number of strategies and were used most frequently in the studies. In this markedly larger update, we also confirmed the finding from our prior review that studies with more retention strategies have higher retention rates.

Our review is unique in terms of its focus. First, prior reviews have included response to surveys or questionnaires, either by post or electronic means.^{4-6,13,14} Regardless, similar to these prior reviews, we found that financial incentives improved the retention of participants for in-person follow-up. Second, considering different study designs made our review more

comprehensive than prior reviews. However, even among the RCTs in our review there was methodological variability, and the vast majority of the identified studies were descriptive in nature. More research is needed to determine the most effective ways to retain participants in follow-up studies. In particular, the best way to assess different methods of cohort retention is to embed research within studies as described in the “Study Within A Trial” program.¹⁵

In conclusion, loss to follow-up is a significant threat to the validity and thus usefulness of a study. The recognition of the need to conduct valid studies in an efficient manner is reflected in the very large increase in the number of studies assessing strategies to retain study participants. However, the existing research has been limited, primarily to descriptive studies with few randomized evaluations of cohort retention strategies, with varied design and population characteristics. This means that we cannot determine which particular strategies are most effective. However, the existing research demonstrates that to improve participant retention studies should use many different strategies, across at least 5 to 6 different themes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Flow diagram of searching and screening results

Figure 2.

Number of studies, themes and strategies, by publication year from 1984 to 2013 in 2-year periods

Figure 3.
Retention rate by number of strategies

Table 1

Retention strategy themes

Theme	Description	Examples	Number (%) of Strategies Abstracted
Contact and scheduling methods	Use systematic method for patient contact, appointment scheduling, and cohort retention monitoring	Obtain multiple contacts for each participant, including two contacts not residing with the participant. Enlist cooperation of family and friends through phone calls and letters. Use of social networking sites to contact participants via private messages.	280 (28%)
Visit characteristics	Minimize participant burden through characteristics and procedures of follow-up study clinic	Offer flexible clinic appointments (early morning, evenings, and weekends). Avoid a hurried atmosphere by having adequate spacing between appointments. Offer convenient locations.	146 (15%)
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. Hire culturally competent and culturally sensitive staff with strong interpersonal skills.	95 (10%)
Non-financial incentives	Provide nonfinancial incentives or tokens of appreciation	Provide an inexpensive token of appreciation with study logo (e.g., coffee mug, pen) at each visit. Host holiday parties for study participants. Provides letters of appreciation or certificates for participation.	80 (9%)
Financial incentives	Provide financial incentives or payment	Provide payment to participants in control group. Provide pharmacy gift certificate at first follow-up visit. Provide cash incentive at time of data collection.	69 (7%)
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. Remind participants of follow-up appointments during field visits.	62 (6%)
Special tracking methods	Methods of tracking hard-to-find or difficult participants	Conduct clinic and street outreach for lost to follow-up participants. Identify and address obstacles hindering participation for challenging participants. Use or subscribe to search engines to	54 (5%)

Theme	Description	Examples	Number (%) of Strategies Abstracted
Study description	Explain study requirements and details, including potential benefits and risks, to participants	<p>obtain updated contact information.</p> <p>Inform subjects that they will be followed over time and specify the schedule of visits and the methods that will be used to locate them.</p> <p>Spend time answering participants' questions.</p> <p>Provide realistic estimates of the schedule for visits and time for each visit.</p>	51 (5%)
Benefits of study	Provide benefits to participants and families that are directly related to the nature of study	<p>Provide free annual physical examination.</p> <p>Form educational and support groups for families and patients.</p> <p>Provide relevant informational resources such as books or pamphlets.</p>	47 (5%)
Reimbursement	Provide reimbursement for research-related expenses or tangible support to facilitate participation	<p>Provide taxi or bus fare for study participants to get to visits.</p> <p>Provide child care during visit.</p> <p>Provide prepaid cell phones to enhance communication.</p>	47 (5%)
Study identity	Create study identity for participants	<p>Create a project identity by using similar colors and fonts on all study materials.</p> <p>Give participants a t-shirt printed with study logo.</p> <p>Keep participants informed of study progress and results.</p>	38 (4%)
Community involvement	Involve community in study design, recruitment, and retention	<p>Present pilot project results to church leadership and congregation.</p> <p>Create community advisor panel and consult with panel for recommendations regarding protocol and participation.</p> <p>Seek ongoing community involvement through nonprofessional, trained community interventionists recruited from the participants' neighborhoods in effort to tailor the intervention to the participants.</p>	17 (2%)

Adapted from: Robinson KA, et al. Systematic review identifies number of strategies important for retaining study participants. *Journal of Clinical Epidemiology* 60 (2007); 757–765

Table 2

Characteristics of comparative studies of retention strategies

Study Sample Size Design	Condition	Population	Total follow-up (months)	Groups (Sample Size)	Retention Rates (%)	Findings
Bowen, 2000 N=4728 RCT 2x2 factorial	Lung cancer	Mean age 58 years old, males (63%) from Carolene and Retinol Efficacy Trial (CARET)	24	Pin alone (n=1169) Certificate alone (n=1056) Pin+certificate (n=1189) None (n=1171)	95 93 93 94	No evidence for effect of interventions.
Echeverry, 2013 N=251 Quasi-RCT	HIV prevention	Women/transgender sex workers 18–40 years old	24	Enhanced retention (n=130) Control retention (n=121)	41 5	Improved retention at 6, 12, and 24 month visits.
Festinger, 2005 N=350 RCT 2X3 factorial	Substance abuse	Mean age 38 years old, males (65%), African-American (75%)	6	Cash (\$10) Cash (\$40) Cash (\$70) Gift certificate (\$10) Gift certificate (\$40) Gift certificate (\$70)	20* 60 59 30 38 40	Those offered higher amounts and those offered cash were more likely to be retained.
Festinger, 2008 N=419 RCT 2X4 factorial	Substance abuse	Mean age 37 years old, male (57%), African-American (60%)	6	Cash (\$70) Cash (\$100) Cash (\$130) Cash (\$160) Gift certificate (\$70) Gift certificate (\$100) Gift certificate (\$130) Gift certificate (\$160)	54 72 69 71 41 53 69 63	Those offered higher amounts and those offered cash were more likely to be retained.
Ford, 2006 N=703 RCT	Cancer screening	African-American men, mean age 63 years.	36	Case management (n=352) Control (n= 351)	95** 95	Higher retention rate only for case management intervention in a subgroup of low income participants.
Wilcox, 2012 N=152 Uncontrolled trial	Substance abuse	Aged 15–21 years old seeking treatment for opioid dependence	3	Low compensation (\$5) (weeks 3, 5, 7, 9, 11) High compensation (\$75) (weeks 4, 8, 12)	27 & 67 average 54 & 72 average	Higher compensation resulted in higher retention, particularly for the control group.

* abstracted from figure

** from Brueton review; N=number; RCT=randomized controlled trial; HIV=human immunodeficiency virus