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Optimizing follow-up and study retention in the 21st century: Advances from the front line in alcohol and tobacco research

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ABSTRACT

Aims: Longitudinal studies are integral in addiction research but retention of participants over time can be challenging. While statistical algorithms for missing data have advanced, they remain less desirable than collecting actual data with high retention rates. An update to methodological primers with consideration of evolving technology and privacy concerns is needed for 21st century researchers.

Methods: Comprehensive follow-up methodological strategies were conducted in four concurrent laboratory- and intervention-based studies across N = 697 drinker and smokers enrolled in studies at the Clinical Addictions Research Laboratory at the University of Chicago. The methods of three key longitudinal research themes and their outcomes are outlined, including: a) *mindset* of the research team starting at study enrollment, b) *modalities* with a particular focus on advances in technological strategies in follow-up, and c) *mitigating* difficult to reach and challenging participants.

Results: The techniques described herein produced follow-up rates of 95% and 99% in two laboratory-based studies with follow-ups of 1- and 6-years, respectively and 94% and 97% in two intervention studies with follow-ups of 6- and 12- months. Adapting incentive strategies more than tripled on-time follow-up, from 18% to 68% of the sample, switching to more advanced technologies decreased participant burden and time by 30% from traditional telephone interviews, and difficult-to-reach participants averaged 47 contact attempts.

Conclusions: The methods presented produced exceptional follow-up retention across four studies. The principles and methodologies discussed may be modified across a range of studies to target various sub-populations in the addiction field.

1. Introduction

Alcohol and tobacco use remain two of the top three leading causes of preventable disease worldwide (Bauer et al., 2014; World Health Organization, 2010). The preponderance of studies examining these and other addictions has historically been cross-sectional [e.g., National Epidemiologic Survey on Alcohol and Related Conditions (Hasin and Grant, 2015), Monitoring the Future (Johnston et al., 2016), National Youth Tobacco Survey (Centers for Disease Control and Prevention, 2015)], but more longitudinal studies and/or subsequent analysis of existing datasets are needed to elucidate cause-and-effect factors (Maslowsky et al., 2015), developmental course over time (Resnick et al., 1997), cohort effects (Bacharach et al., 2007), and treatment and disease-related outcomes (Buccheri et al., 1996). Clinical researchers, particularly those in the addiction field, are often reluctant to embark on long-term studies given concerns about retention rates, restricted funding cycles, and project staff attrition (Robinson et al., 2005; Streissguth and Guinta, 1992). At the same time, there are examples of successful community cohort studies (Vaillant, 2003), outpatient follow-up studies (Scott, 2004), and laboratory studies with longitudinal follow-up (Schuckit and Smith, 1996).

In the aforementioned studies and in biomedical and psychosocial research in general, participant retention can be a challenge. Follow-up rates reported in published studies are often in the low-to-moderate range, from under half up to three-quarters of the original sample (Booker et al., 2011; Hansen et al., 1990). Overall follow-up rates are considered good at 70% (Mangione, 1995; Scott, 2004) when utilizing traditional methods such as mail-in surveys, telephone interviews, and in-person assessments. Careful attention to these follow-up rates are important as decreased sample size may lead to distorted accuracy of results and study bias as the sample may no longer be representative. More specifically, if the study's accuracy is compromised, conclusions made by the researcher may be erroneous and may negatively impact the internal and external validity (Barry, 2005). To account for missing

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data, investigators may employ advanced statistical techniques (Cotter et al., 2002; Wood et al., 2004). However, such statistical imputation techniques only provide a "best guess" as they require assumption of missing mechanisms (missing completely at random or missing at random; Gray, 2016). Unforeseen difficulties may arise when such algorithms are used in datasets with high proportions of missing data, large numbers of variables, small sample sizes, and data not missing at random (Sterne et al., 2009). Thus, establishing and maintaining the highest possible retention in longitudinal studies is crucial for data accuracy and to avoid pitfalls of imputation that may lead to statistical bias and affect data interpretation.

A meta-analysis of 85 longitudinally followed cohorts published in 1990 (Hansen et al., 1990) pointed to the need for more papers on retention and tracking methods specifically in addictions research. Shortly thereafter, Schuckit and colleagues (Twitchell et al., 1992) described the follow-up methodology of their San Diego Prospective Study, a laboratory and follow-up study of primarily young Caucasian male college drinkers with an impressive 99% follow-up rate (450 out of 453) during the first follow-up, 8–12 years after enrollment (Schuckit and Smith, 1996). While this 1992 primer described the architecture of excellent follow-up retention, it is now over two decades old. More recently, in 2004, the Engagement, Verification, Maintenance and Confirmation (EVMC) model was reported for follow-up in outpatient addiction treatment samples from established programs (Scott, 2004). Follow-up rates of at least 90% were cited and methodology was described for repeated contact attempts. Retention strategies have also been outlined in other work published in the 1990s and 2000s (Booker et al., 2011; BootsMiller et al., 1998; Desmond et al., 1995; Wutzke et al., 2000), but these pertain to retention methods used before the recent technological epoch that has largely changed the way that people communicate.

Based on our own successful retention over four recent and concurrent studies in drinker and smoker samples, herein we provide an updated framework for researchers to consider in conducting longitudinal research in the 21st century. Our work spans from laboratory-based to pharmacological and behavioral treatment studies across four datasets in 697 total participants. Across these studies conducted at the Clinical Addictions Research Laboratory at the University of Chicago, the samples ranged from small (n = 30) to large (n = 290), the number of follow-up assessments after enrollment ranged from 1 to 11, and the published follow-up intervals ranged from 1 month to 6 years (and continuing). Up to this juncture, we have not been able to fully describe the follow-up techniques due to publishing constraints on methodological detail in main outcome papers.

2. Methods

The four concurrent longitudinal studies using the methodology described in this paper include two laboratory-based cohort studies, the Chicago Social Drinking Project (CSDP; King et al., 2011; King et al., 2014; King, 2016) and the Emerging Adult Smoker Study (EASS; Conrad et al., 2013), and two intervention trials, the Chicago STOP Smoking Research Project (CSTOP; King et al., 2012) and the Chicago Young Adult Health Study (CYAHS; Fridberg et al., 2015). Each study's design and purpose, sample characteristics, and follow-up procedures are included in Table 1. Follow-up for each study was based on the study's purpose, including, but not limited to: drinking, smoking, drug use quantity and frequency, timeline follow-back calendars of past month daily use estimates, diagnostic symptoms, consequences, life transitions, affective status, adverse events, and other health outcomes. Retention methods are summarized in three main areas including: a) *mindset*, starting at enrollment and including all members of the research team, b) *modalities*, with particular consideration of technological advances, and c) *mitigating* difficult to reach and challenging participants.

2.1. Mindset

Early in a study, fostering a mindset of regular communications, positive alliance, and study identity have all been described as important elements to increase participant retention (BootsMiller et al., 1998; Desmond et al., 1995; Twitchell et al., 1992; Wutzke et al., 2000). We implemented these elements across our studies, so that during screening, participants are well informed of the frequency, modality, and expectations for follow-up, including the importance of retention for the scientific rigor of the study. Study candidates were not enrolled if they were unable or unwilling to provide contact information for themselves, or for collateral persons in the event that they could not be reached (see Table 2 for more details). Of note, disadvantaged subgroups, such as those who are severely addicted, medically compromised, or homeless have also been shown to be able to provide some contact information (Bonevski et al., 2014). Specific elements of our mindset are described in this section and include building a positive alliance, fostering study identification, creating and maintaining a participant-centered study website, and adopting an overall team mindset, with all members of the research group involved in follow-up.

2.1.1. Alliance

Formation of a positive alliance is a cost-effective, crucial element in longitudinal studies (DeWitt and Brady, 2003). Our group applied this principle across all of our studies by carefully training research staff to form a mutually beneficial and positive relationship with participants (Bruning, 2002). In staff trainings, we employed a series of certification requirements for conducting study interviews with videotape review to assure both standardized communications and friendly/engaging interactions. In addition, our study staff regularly recorded participant's occupation, hobbies, and interests in the participant's confidential file in order to foster re-contact attempts over time and to create a personalized staff-participant relationship.

2.1.2. Study identification

Fostering study identification is often advised in follow-up procedures (Hunt and White, 1998; Nicholson et al., 2011), with the goal for participants to gain a sense of familiarity and "ownership" of their role within the research project. In our work, identification began with creation of a branded name and logo for each study (see examples in Fig. 1). These were included in recruitment notices, letterheads, cards, newsletters, and websites. The only exception to this procedure related to communications with collateral persons, which were provided by the participant. In such contacts with collaterals, only the phrase, "the study at the University of Chicago" was utilized in order to ensure participant confidentiality.

Study identification was also facilitated by academic detailing with gift items given to participants at various stages of participation and customized to the socio-demographic characteristics of each sample. These items were able to facilitate retention by including contact study information on each gift item, which ranged in cost depending on each study's budget and scope. For example, inexpensive matchbooks with the study logo were disbursed at bars and local social events during recruitment efforts for the EASS, which had a modest budget. In CSTOP, stress balls were given as a coping tool on the quit date as well as glow-in-the-dark magnets with tabs as reminders of follow-up dates. Finally, for the CSDP, which has included more extensive and longer-term follow-up of light and heavy drinkers over time, participants were given gift items that may be regularly stored around one's home, i.e., bottle openers, pens, flashlights, and reusable shopping bags.

2.1.3. Participant-Centered study website

For each study, new websites or links within the main laboratory website were created as a point of contact for interested candidates as well as for enrolled participants. In contrast to many laboratory websites that are framed for academic colleagues and the research