Application of evidence- or theory-based retention strategies in health-related research involving "hard-to-reach" or "vulnerable" populations: A systematic review

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ABSTRACT

Background

Strategies that increase participant retention are critical to success in health research to ensure the validity and generalizability of study findings. However, reports of strategies to increase retention within the published literature are typically brief, descriptive and inconsistent if they are mentioned at all. Researchers can and should be applying evidence-based and theoretically-informed approaches to developing comprehensive retention plans early on in the research design phase. The reporting of "retention protocols" presents an opportunity to enhance the field of retention methodology by increasing transparency around effective retention practices through systematic reporting. The BC Healthy Connections Project (BCHCP) is a large-scale, long-term trial examining the effectiveness of the Nurse-Family Partnership (NFP) compared to existing services (usual care) in improving child and maternal health within the province of British Columbia. The BCHCP's Scientific Team is developing and implementing a detailed retention protocol. This process requires a literature review to support the implementation of a comprehensive, evidence-based, theoretical framework for retention.

Objectives

This systematic review is intended to determine whether evidence exists of the application of evidence-based, theoretical approaches to retaining "hard-to-reach", "vulnerable" populations within the published health literature. If they do, they will then be evaluated to determine their applicability to the BCHCP research context and whether they can be incorporated into the BCHCP retention protocol.

Methods

Seven electronic databases were searched systemically using a detailed search term strategy that included retention, attrition, and population terms in addition to any relevant compact vocabulary terms. Selection criteria for objective one included the following retention-specific conditions: had to be retention within a research context specifically, could not involve post-hoc strategies only, had to be applied to at least one follow-up point beyond enrolment or randomization, and selection of strategies had to involve some rationale. Studies also had to refer to the involvement of "hard-to-reach", "vulnerable" populations as described for the purposes of this review. Publication limits were set for health-related research involving humans, published in English between January 1, 1980 and May 1, 2016. Objective two restricted eligibility further to studies that more closely matched the BCHCP study context in terms of study design and population as well as their approach to retention. Data items were collected in Microsoft Excel and were grouped under three main categories that included general study characteristics, retention

characteristics, and follow-up characteristics. They were then presented in three summary tables (one for each category of characteristics) by full-text article according to assigned study ID. Counts for individual data items from each table were used to assist in interpretation of results.

Results

Of 1,337 original articles, 49 articles met objective one eligibility criteria. Of those 49, two met the original eligibility two criteria. Restrictions for criteria two were retrospectively lowered so that articles meeting three of the four original criteria were included. Eight articles qualified with adjusted criteria and were assessed for comparison to the BCHCP. The articles presented a diversity of study contexts with disparate lengths of follow-up, number of follow-up points, numbers and types of strategies used, level of description provided, and analyses of retention. The ways in which strategies were reported and assessed also differed substantially. However, few made mention of cost, and less than half made an effort to garner feedback, either from participants or research staff, on the research (and retention) process. While the majority of the articles reported some form of evidence to rationalize which retention strategies were selected for a given study, there was a wide variety in type and quality of evidence provided. Furthermore, only five articles reported studies that were explicitly informed by a theoretical approach to retention. While the majority did iterate the importance of planning for retention from the outset, only seven employed the term protocol in the description of their retention approach.

Conclusions

While retention strategies may be appearing more frequently within the health-related scientific literature, efforts to adopt the practice of developing comprehensive approaches to retention during the research design phase and to include plans to systematically evaluate and report on their outcomes are still missing. Moreover, examples of the practice of employing evidence-based, theoretically-informed, comprehensive retention approaches remain lacking. Certain organizations have taken the approach of encouraging researchers to conduct methodological research within the trial process – terms trials within a trial – in order to enhance the trial methodology evidence-base. The BCHCP retention protocol, on the other hand, presents a more comprehensive and systematic means for researchers to share an entire approach to trial retention. The adoption of retention protocols should therefore be encouraged as a necessary part of the trial publication process, similar to the implementation of systematic review protocols and trial study protocols.

INTRODUCTION

Participant retention in health research

The recruitment and retention of research participants is critical to the success of the research process and should therefore be a key component of any research design (Gross, 2006; Gul & Ali, 2010). Increased attention is being paid to the process of retention as evidenced by a growing body of literature documenting the various barriers and challenges researchers face in engaging and retaining different study populations (Gul & Ali, 2010). Additionally, several systematic reviews on retention strategies have been published recently and they document a shift in the frequency with which approaches to retention are being mentioned in the published literature (Bonevski et al., 2014; Robinson et al., 2015). Despite this documented interest, the field of retention methodology remains an underdeveloped and underreported area of clinical research design (Gross, 2006; Gul & Ali, 2010). Evidence of planning and implementing strategies that specifically address the well-documented barriers faced by research participants remains notably absent in the published literature (Robinson et al., 2015). Furthermore, the potential benefits of implementing an evidence- and theory-based approach to retention within the research design phase appear to be unaccounted for.

While robust retention strategies often involve significant investments of time and money, the threats posed by participant attrition, coupled with the benefits of successful participant engagement in research, provide a strong case for prioritizing their use (Bonevski et al., 2014; Tansey, Matté, Needham, & Herridge, 2007). Failure to retain participants in randomized controlled trials (RCTs) and longitudinal studies can present serious threats to both the internal and external validity of research results (Bower et al., 2014; Gul & Ali, 2010; Page & Persch, 2013). The introduction of bias as a result of differential attrition across intervention groups, as well as a reduction in statistical power due to an overall decreased sample size are two key methodological concerns (Page & Persch, 2013; Robinson et al., 2015). A large body of research has been devoted to developing post-hoc statistical methods and techniques to account for the inevitability of some participant attrition (Gross, 2006; Hughes, Harris, Flack, & Cuffe, 2012). However, less attention has been devoted to documenting the science of actively planning for retention through the implementation of coordinated retention strategies (Gross, 2006; Gul & Ali, 2010; Robinson et al., 2015).

To date, systematic reviews examining retention strategies have focused primarily on determining how many and what kinds of strategies are used by researchers for a given study, or on cataloguing the various documented barriers and challenges to retention (Bonevski et al., 2014; Booker, Harding, & Benzeval, 2011; Bower et al., 2014; Brueton et al., 2013; Gul & Ali, 2010). The most recent of these review was conducted by Robinson et al. (2015) as an update to a previous review they published in 2007. It therefore provides a unique opportunity to track how the research environment around retention strategies continues

to change. Their search was intended to identify and assess strategies for retention involving in-person follow-up in health care studies. Their search published in 2007 identified no studies that incorporated comparative trials and only 21 that included a descriptive assessment of individual strategies. Their updated review produced an additional 67 studies meeting the same criteria, six of which were actually designed to compare different retention strategies. This search also documented a telling trend in retention reporting. It yielded only one study on retention strategies published between 1985 and 1990, whereas for the five years from 2008 and 2013, this number jumped to 47. These results suggest that researchers are becoming more invested in the reporting and sharing of retention approaches and outcomes.

While this trend in reporting of retention is promising, it still reveals substantial lost opportunity for generating evidence on effective and efficient implementation of robust retention approaches across different research contexts. The number of studies identified by existing reviews is not remotely reflective of the number of studies published during the same time period that would have employed, or would have benefited from employing retention strategies. Furthermore, the trend hides continuing limitations inherent in current retention reporting practices. Some of the most frequently cited limitations include: heterogeneity in reporting style and content; reliance on descriptive or narrative analyses of retention outcomes; absence of reporting on costs or budgetary investments; lack of transferability across study contexts; and a reliance on "business as usual" or purely practical rationale for strategy selection (Bonevski et al., 2014; Booker et al., 2011; Bruteon et al., 2013; Robinson et al., 2015; Tansey et al., 2007). The lack of consideration for strategy selection is also reflected by an absence of reporting on the planning and design of retention approaches. Each of these limitations presents an opportunity for implementing effective and appropriate solutions, specifically the implementation of systematic reporting of retention approaches that includes details on planning, budgeting, and evaluation of outcomes. Yet previous reviews have failed to identify these types of approaches to retention (Bonevski et al., 2014; Booker et al., 2011; Bruteon et al., 2013; Robinson et al., 2015; Tansey et al., 2007). They focus on analyzing relative effectiveness of individual strategies and tend to ignore the rationale researchers apply in determining which strategies to use. They also fail to provide potential solutions to the issue of study context, and therefore ignore the potential for theoretically-informed approaches, with the capacity for adapting to various contexts. They therefore offer little critical insight regarding the role of theoretically-informed and evidence-based planning for retention early in the research design phase.

Use of the terms "vulnerable" and "hard-to-reach" within health literature

Both the challenges of attrition as well as the benefits of effective retention are magnified for studies involving communities and subpopulations that have been historically absent from health-related research (Bonevski et al., 2014). These populations include groups that are frequently identified within health research literature using the terms "hard-to-reach" and "vulnerable". The definition of "vulnerable" refers

to groups of individuals who are said to share some perceived measure of identity that has exposed them to discriminatory practices, behaviours and attitudes (Bonevski et al., 2014; Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006). This identity may be rooted in historical experiences of bias and prejudice, or it may be the result of more transient measures of vulnerability such as those tied to social status (Kilbourne et al., 2006). These group identities therefore extend beyond constructs of race and ethnicity to include identities such as membership within a traditionally underserved group, living with a permanent disability, living in unstable or under non-traditional conditions, and others (Kilbourne et al., 2006). Examples often used in clinical research include women and children, ethnic minorities, immigrants, non-heterosexual individuals such as gay men and lesbians, those suffering from mental illness, the homeless, and the elderly (Kilbourne et al., 2006). These populations are identified as being at increased risk of poor physical, mental, and social health status, and therefore tend to experience a disproportionate burden of illness and disease as compared to the general population (Rukmana, 2014; Kilbourne et al., 2006). Population's labeled "hard-to-reach" within research represent groups of individuals that are perceived as being difficult to reach, to involve, or to engage in health research, health services, or preventative programs (Shaghaghi, Bhopal, & Sheikh, 2011).

These use of these terms, and other synonymous ones, to label populations within health research is controversial within the research community (Abbot et al., 2008; Hurst, 2008; Flanagan & Hancock, 2010; Levine et al., 2004). Both "hard-to-reach" and "vulnerable" are effectively blanket terms that can hide an extreme diversity of populations and individuals (Levine et al., 2004; Shaghaghi et al., 2011). Moreover, these types of population labels have been criticized for placing the burden of identity on the labeled groups or individuals and therefore failing to accurately represent the fact that challenges faced by these groups are often socially constructed and imposed on the individual (Edwards & Di Ruggiero, 2011; Froelich & Potvin, 2008). Their blanket application to cover substantial complexity and diversity, the persistent lack of consensus over their definition and application, as well as the ethical implications of labeling various groups "vulnerable" or "hard to reach" all contribute to the ongoing debate amongst researchers regarding the practicality and appropriateness of such terms. This review recognizes the importance of this debate, and the concerns associated with the application of the terms. However, reviews must also work within the constraints of the existing literature by applying commonly used terms to identify relevant evidence. The terms "vulnerable" and "hard-to-reach" are commonly used in health research publications and have also been used as subject headings in many electronic databases. For these reasons, both terms were applied in to this review.

Recent calls to increase the presence and representation of "hard-to-reach", "vulnerable" groups within health research have escalated efforts to understand and mitigate the challenges and barriers these groups face in engaging with both health services as well as health research studies (Bonevski et al., 2014). While *recruitment* of these populations has dominated much of the conversation around increasing their

engagement, *retaining* these groups across long-term RCTs or longitudinal studies is an equally important challenge. This is especially true given the fact that poor retention has traditionally been cited as one reason for deliberately excluding these groups from longitudinal research (Bonevski et al., 2014).

The case of the BC Healthy Connections Project

Young mothers who experience socioeconomic disadvantages, and their children, are one often-cited example of a "hard-to-reach", "vulnerable" group. Documented challenges to accessing and engaging individuals from this population for health-related research include factors such as unemployment and transient living conditions, inconsistent forms of contact, limited or unreliable transportation and other competing demands on families challenged by limited resources, as well as risks associated with the use of substances, experiences of intimate-partner violence, and previous negative experiences with service providers or researchers (Graziotti et al., 2012; Katz et al., 2001). Researchers' challenges in accessing and engaging this population are particularly concerning given that they are also a population that stands to reap disproportionate benefit from preventive public health interventions. The links between both young maternal age and low socioeconomic status and poor maternal and child health outcomes are well established in the scientific literature and present a considerable public health challenge and concern (Boden, Fergusson, & Horwood, 2008; Bradley, Cupples, & Irvine, 2002; Elfenbein & Felice, 2003; Jaffe et al., 2001; Jutte et al., 2010; Meade, Kershaw, & Ickovics, 2008).

Nurse-Family Partnership (NFP) is one example of a comprehensive, evidence-based, prevention intervention designed specifically to target both the unique health challenges and barriers to care faced by young, first-time mothers and their children coping with socioeconomic disadvantage (e.g., low income, low education, lone parenting or pregnancy at a young age) (Olds, Hill, O'Brien, Racine, & Moritz, 2003; Olds, 2010). The program was developed in the United States (US) nearly 40 years ago by Olds and colleagues with the specific purpose of improving the health outcomes of children, as well as the health outcomes and economic self-sufficiency of the first time mothers (Olds, 2006). This program employs nurses to conduct home visits with first-time mothers from early pregnancy through to the time the child reaches two years of age. The frequency and duration of the home visits changes over the course of the program and can be adapted to the needs and wishes of the mother (Olds et al., 2003). Nurses receive extensive training, support and supervision and follow a detailed, visit-specific guide that still allows for individualization of program delivery (Olds et al., 2003). Goals of the program include improving: child health and development; pregnancy outcomes; and maternal life course development (Olds, 2006). Recently, efforts have been made to adopt the program for implementation within Canada. International agencies are required to adapt, pilot then evaluate the effectiveness of NFP within their local context prior to full implementation (Jack et al., 2012; Olds et al., 2003). A pilot study was conducted in Hamilton, Ontario, in 2008 through McMaster University to determine the feasibility and acceptability of the program

for service providers and families and to determine any necessary adaptations (Jack et al., 2012). The success of this pilot has laid the foundations for a RCT to be conducted in British Columbia (BC).

The BC Healthy Connections project (BCHCP) is a large-scale RCT involving four of BC's five regional health authorities. It commenced recruitment in late 2013, aiming to compare NFP's effectiveness with that of existing health and social services (usual care) in support of child and maternal health and development in the province (Catherine et al., 2016). The overarching goal is to demonstrate improved children's mental health and development and improved life circumstances of enrolled mothers. The main outcomes of interest include measures of: childhood injuries; children's mental health and cognitive development; prenatal substance use and smoking; and subsequent pregnancies as a proxy measure for maternal economic self-sufficiency (Catherine et al., 2016). Eligible participants are young pregnant women (aged 24 or younger) who will be first-time mothers. At the time of enrollment, they must be less than 28 weeks gestation, able to provide informed consent in English, and meet certain indicators for socioeconomic disadvantage (i.e., 19 years of age or younger, low income, low education or lone parenting) (Catherine et al., 2016). The trial aims to enrol over 1000 women (n = 1040) to be randomly assigned to either the control arm consisting of existing services or the intervention arm, consisting of NFP plus existing services. Research data are being collected on all enrolled participants through in-person and telephone interviews at six distinct time points – until children turn two years of age (Catherine et al., 2016). The success of this lengthy and costly research endeavour in generating valid and generalizable results requires that all participants complete each stage of data collection throughout the follow-up process. The trial follows an intention-to-treat model, where all participants are included in the analyses according to the group they are allocated, regardless of the level of intervention received, or regardless of attrition.

The demands of long-term follow-up along with the additional challenge of tracking and engaging a population that is traditionally seen as "hard-to-reach" represents a unique and substantial challenge for BCHCP participant retention. Evidence from previous longitudinal research involving similar study populations would suggest that participant retention should be made a priority from the outset of the trial (Katz et al., 2001). The BCHCP Scientific Team is therefore investigating the development of a detailed, planned retention approach – detailed in a "retention protocol" document – prior to trial implementation. They will then continue to refine this approach throughout the trial. The Scientific Team is prioritizing the use of an evidence- and theory-based approach to ensure comprehensive, systematic and sustained retention efforts that employ the most relevant and appropriate strategies for this particular study population.

Why this review is important

Previous reviews have focused on assessing the quantity and quality of individual retention strategies employed within a study process (Bonevski et al. 2014; Booker et al., 2011; Brueton et al., 2013 Robinson

et al., 2015). Little attention has been paid to interpreting the rationale authors employ in making choices around strategies and approaches used. As a result, little consideration has been given to the use of planned, evidence- and theory-informed retention practices. Previous non-systematic searches by the BCHCP Scientific Team to obtain evidence to support the development of the retention protocol have reflected this. Furthermore, absence of a systematic approach to reporting retention within the literature has made it difficult to produce a targeted search that yields sufficient, relevant evidence particularly regarding the effectiveness of planned retention strategies. Therefore, accessing available literature pertaining to both research retention and the involvement of vulnerable or hard-to-reach populations requires a more comprehensive and systematic approach. A systematic review of all health-related research involving "vulnerable" or "hard-to-reach" populations (in their broadest definition) that requires the follow-up of study participants beyond the point of enrollment is required. This type of review would serve to reveal the quantity and quality of research-related retention methodology that might then be applied to a study population such as that involved in the BCHCP. It would also satisfy the question of whether or not evidence has been overlooked in the retention protocol for the BCHCP and whether further evidence-based retention efforts for the study population might be incorporated going forward.

OBJECTIVES

1. To determine whether examples exist where health-related studies involving "hard-to-reach", "vulnerable" populations have reported on the implementation and evaluation of planned, evidence- and/or theory-based retention strategies; AND
2. If examples exist, to determine whether any of identified literature represents new, relevant evidence to the BCHCP that could then be incorporated into the BCHCP's RCT retention protocol to enhance the trial's approach to participant retention.

METHODS

Criteria for considering studies

Literature for this review was limited to health-related research involving humans. It was also restricted by language and publication date to information published in English (originally or as a translation) and released between January 1980 and May 2016. The publication date was set in response to evidence gathered by previous literature reviews on published retention strategies, which have demonstrated limited available critical evidence on retention approaches up until the past three decades. Moreover, this publication limit was set to reflect the intention of the first objective of this review, which is to determine current research practices in terms of implementation and reporting on approaches to participant retention.

To be considered for objective one, literature had to refer to the use of retention strategies being applied specifically for research purposes, to retain research participants. Reports discussing the retention of patients in care, or clients in treatment were not deemed relevant to the definition of experimental retention as set forth for this review. This meant that "research" describing a retention intervention where the primary outcome was increased client or patient retention to a health service, program or treatment was excluded. This was done in order to ensure retention reflected the BCHCP scientific Team's context of working towards a retention approach for all enrolled participants across treatment allocation groups and therefore regardless of treatment context. "Planned" retention efforts were considered to be any retention efforts that were designed and implemented either prior to or during the data collection process. Literature that reported efforts to address issues of retention either at the analysis phase (i.e., statistical approaches to missing data) or which interpreted the success of retention strategies in a purely post-hoc manner were excluded. To be considered, strategies had to explicitly address efforts to encourage participant retention across all points of data collection. Articles were therefore excluded if they described efforts to ensure successful maintenance of participants during recruitment, enrolment or randomization processes alone but neglected retention during the follow-up period. The data collection process had to involve one or more data collection points beyond the point of participant enrolment. Researchers also had to offer some form of rationale for their choice of retention strategies. Finally, reports had to describe studies involving populations termed "hard-to-reach" and "vulnerable" according to the use of the terms as described earlier in this review.

The original objective two criteria limited literature further to peer-reviewed, primary, published scientific research that employed RCT or quasi-RCT (qRCT) study designs. Authors also needed to report some form of evaluative assessment of the retention strategies employed in the course of the research (this could be quantitative or qualitative in nature, no distinctions were made). The rationale provided for the use of the strategies needed to be explicitly evidence and/or theory-based (though the types of evidence that would be considered were not specified and therefore quite broad). Finally, the primary study population had to be women, girls, or young children (aged two years or under) who were socioeconomically disadvantaged (e.g., low income, low education, housing instability, single mothers). A copy of the detailed eligibility criteria forms for both objective one and objective two are included in Appendix B.

Search methods

A search strategy was developed to identify any literature from electronic databases that mentioned the topic of retention or attrition for studies involving "vulnerable" or "hard-to-reach" populations. Preliminary database-specific searches were conducted to identify any relevant contact vocabulary terms, or "subject headings" similar to the search terms of interest. Language and publication restrictions were last in every search to determine the amount of literature that could potentially be lost as a result of these additional

restrictions. The final search attempt for all included databases was conducted on July 21, 2016 at which point all search results were added to a personal Mendeley reference manager software account. Searches were conducted for each of the following electronic databases, and detailed search strategies for each can be seen in Appendix A:

- Medline, via Ovid
- Cochrane Central Register of Controlled Trials (CENTRAL), via Ovid
- Cochrane Methodology Register (CMR), via Ovid
- Cumulative Index of Nursing and Allied Health Literature (CINAHL), via EBSCO
- PsycINFO, via EBSCO
- Social Sciences Index, via Web of Science
- Science Citation Index Expanded, via Web of Science

DATA COLLECTION AND ANALYSIS

Selection of studies

The initial search yielded 1,337 citations. Search results from the various electronic databases were merged using Mendeley reference manager software to identify potential duplicates, which were then reviewed individually and 264 duplicate records were subsequently removed. Three rounds of screening were conducted. First, titles and abstracts of articles for the remaining 1,073 citations were examined. The review was over-inclusive during this round of screening, which ultimately yielded 445 relevant articles. Each of these articles was given a study ID and an attempt was made to obtain a full-text version for each of them. A total of 19 articles were excluded because full-texts could not be obtained. These excluded documents included articles from databases without University-approved access, or articles that were actually reported conference proceedings or presentations for which supplemental literature was not available. At this point, a predesigned eligibility criteria form for objective one was trialed on 10 full-text articles and small adjustments were made to refine criteria one, two, and four (see Appendix B, Form B1 for details on criteria). These adjustments introduced more detailed descriptions of retention criteria for better transparency in the selection process. The second round of screening excluded any articles that discussed attrition and retention factors but not strategies, as well as any obviously irrelevant articles that had been missed when just titles and abstracts were screened. A third round of screening was conducted for the remaining 173 full-text articles, which were compared carefully to the detailed eligibility criteria form for objective one (see Appendix B, Form B1).

There were 49 articles that met the eligibility criteria for objective one. Of these, only two met the original criteria for objective two (see Appendix B, Form B2). For a visual representation of the full review process,

see the flow diagram presented in Appendix C. The lack of eligible literature for objective two, though not entirely unexpected, was insufficient to warrant an independent analysis of objective two data as outlined in the methods. Instead, the 49 articles from objective one were retrospectively assessed for their relevance to the BCHCP using the list of eligibility criteria for objective two as a measure. Articles had to meet a new criterion, which focused the study population of interest to be more comparable to that of the BCHCP RCT, in addition to three of the original four objective two criteria (see Appendix B for list of criteria). The eight articles that met these terms were then highlighted for more rigorous evaluation in the results and analysis sections of the review. These articles are bolded within the data summary study tables for easy identification (see Appendix D for summary study tables).

Data extraction and management

Data collection forms for both objectives were designed in Microsoft Excel and included all data items outlined in the original review protocol. However, because of alteration to objective two criteria, the two forms were merged to ensure that measures of quality of evidence were collected on all 49 objective one articles. The merged form was then piloted on five of the 49 eligible articles and legends with numbered codes and symbols were created for some of the qualitative measures to facilitate interpretation. Full data extraction was then conducted for all 49 articles. For the few secondary research articles that reported information from more than one study, information from each study was grouped under a single data item entry for that article. Data from the eight objective two articles were subsequently reviewed to validate quality of data entry.

Data items were separated into three main categories. Study characteristics included publication and research details (e.g., research field and topic, and whether or not it discussed retention within the context of an actual research study) as well as study details (e.g., study design, study aim, source of funding, start and end date, number of trial groups, number of study centers, geographic location of study and setting for study enrollment, population type, and overall sample size). Follow-up characteristics included details of follow-up procedures and protocols (e.g., whether they were identical across treatment allocation groups, the dominant data types collected, number of follow-up points, time between points and overall length of follow-up, whether it was in-person and whether it required a site visit, and whether other tasks were required of participants outside of scheduled follow-up appointments). Retention characteristics included details of the reporting and outcomes from retention strategies (e.g., whether the study was a “host” trial or a comparative retention trial, whether strategies were described in detail or in brief, whether strategies were identical across trial groups, types and number of strategies employed, and brief description of rationale provided for their use).

Certain measures to determine the quality of the evidence reported for follow-up procedures and retention were also collected under both follow-up characteristics (e.g., whether reasons for lost follow-up were reported, what types of resources were invested and how they were reported, whether a cost-benefit analysis was conducted, whether feedback regarding follow-up procedures were collected, and whether an assessment of attrition bias was included) and retention characteristics (e.g. whether strategies were planned prior to commencing the study, whether the term "protocol" was explicitly used in reference to retention, and whether overall retention rate was reported). Finally, any "lessons learned" or retrospective insights shared by the authors were also recorded.

Assessment of risk of bias

The original review protocol outlined a plan to assess risk of bias for all RCTs and qRCTs included in objective two using the Cochrane 'Risk of bias' assessment tool, outlined in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins & Green, 2011). Due to the paucity of articles that actually met the eligibility criteria outlined for objective two, this portion of the analysis has been removed. This tool was designed specifically for comparing quality of evidence across RCTs and would therefore not be appropriate for assessing evidence quality and then drawing comparisons across the diverse study designs and settings represented within the literature included in this review.

Analysis

Due to the diverse nature of both the studies included in this review as well as the level of reporting, analysis was limited to qualitative assessments. Summary tables were constructed to present a descriptive assessment of the evidence regarding the current state of published methods research for retention strategies in studies involving populations described as "vulnerable" or "hard-to-reach". The intended analysis for objective two included an assessment of the effectiveness of the reported retention strategies within each study context, comparing the time and cost required versus overall retention rates and reduced risk of any associated types of bias achieved. However, this type of information remains largely unreported in the literature, particularly in terms of presenting actual quantitative measures for these types of outcomes. In general, any evaluative measures still appear to be largely descriptive or hypothetical in nature. For this reason, the analysis for objective two has also remained largely qualitative.

RESULTS

Objective 1

Study Characteristics: (Please see Appendix D, Table D1 for summary of characteristics). The 49 articles included in objective one represented research publications that ranged from nursing (e.g. applied, HIV/AIDS, public health), to substance use and HIV/AIDS prevention interventions, to child and family studies and maternal and child health, to evaluation and research methods, to ethics. Articles constituted both secondary (e.g., Buscemi et al., 2015; Resnicow et al., 2001; Striley, Callahan, & Cottler, 2008) and primary (e.g., Hwang et al., 2011; Rosser et al., 2010) research literature. Most of the studies reported in these articles were conducted in the US; however, other contexts included Peru, Ireland, Spain and Australia (Etcheverry et al., 2013; O'Keeffe, Kearney, & Greene, 2015; Silva, Smith, & Bammer, 2002; Villacorta et al., 2007). The scale of the reported studies ranged significantly, from a qualitative evaluation of barriers to research retention in clinical trials for high-risk geriatric patients that involved interviews with 50 patients, to a national longitudinal survey cohort that explored survey response patterns in over 5000 participants (Marcantonio et al., 2008; Woodruff, Edwards, & Conway, 1998) (See Appendix A, Table A1).

Follow-up Characteristics: (Please see Appendix D, Table D2 for summary of characteristics). Length of follow-up described for studies also varied widely across the different articles. One prevention intervention trial lasted only seven days, while at the other extreme a longitudinal cohort study followed participants for 15 years (Graziotti et al., 2012; Sharpe et al., 2011). Less than half of the articles included studies that reported reasons for lost follow-up (e.g., unable to contact, moved away from study region, unwilling to continue participation), however the majority of reported studies did mention having conducted some type of sub-group analysis. The minority of these were conducted to assess risk of attrition bias, while the majority were used to determine factors associated with participant retention or attrition (e.g. Anastasi, Capili, Kim, & Chung, 2005; Brown-Peterside et al., 2001; Buscemi et al., 2015; Froelicher et al., 2003). These analyses compared characteristics of participants retained versus those who dropped out or were lost to follow-up. These comparisons were made both within treatment allocation groups as well as across groups. While most of these subgroup analyses were focused on associations with overall retention rate, a few studies explored these associations in more detail either across study phases or across individual follow-up points (e.g. Buscemi et al., 2015; Froelicher et al., 2003; Katz et al., 2001; Vincent, McEwen, Hepworth, & Stump, 2013). This allowed them to determine whether those individuals who were lost early on in the study differed significantly from those who were retained for longer periods of follow-up as well as allowing them to explore how both of these groups might differ from those who made it to study completion.

Attempts made by researchers to collect feedback as a means of evaluating follow-up approaches were also examined. Twenty articles described studies that included some attempt to collect and report on feedback as a quality measure. For a few studies, this took the form of a formal exit survey or structured interview (Geromanos et al., 2004; Haack, Gerdes, & Lawton, 2014; Whittemore, Rosenberg, Gilmore, Withey, &

Breault, 2014). For others, more informal means of acquiring feedback were described, such as through casual conversations with research staff, or information volunteered by participants during in-person follow-up assessments (Froelicher et al., 2003; Goncy, Roley, & van Dulmen, 2010; Meneses, Benz, Hassey, Yang, & McNees, 2013; Striley et al., 2008). Feedback collected by researchers included: barriers to research, reasons for lost follow-up, reasons for continued engagement, or an assessment of specifics strategies (Cepeda & Valdez, 2010; Geromanos et al., 2004; Logan, Walker, Shannon, & Cole, 2008; Marcantonio et al., 2008; Morse, Simon, Besch, & Walker, 1995).

Most articles reported descriptive assessments of either the financial or human resources that studies invested in retention. Only one article reported an estimated quantity of total research budget invested into retention for a specific study (as a percentage of the overall study budget) (Buscemi et al., 2015). Five articles showed some attempt to represent study investments in quantifiable terms, whether it was as the number of staff that were required to implement the retention strategies effectively, or the diminishing returns on investment in pursuing extremely "hard-to-reach" participants (Buscemi et al., 2015; Pottick & Lerman, 1991; Teitler, Reichman, & Sprachman, 2003; Tobler & Komro, 2011; Woodruff et al., 1998). Of these five, only four incorporated a cost-benefit analysis for individual strategies or "stepped" outreach approaches (Pottick & Lerman, 1991; Teitler et al., 2003; Tobler & Komro, 2011; Woodruff et al., 1998) and three of these were for studies involved response rates to mailed surveys, not in-person follow-up.

Retention Characteristics: (Please see Appendix D, Table D3 for summary of characteristics). Some articles described retention approaches with a high level of detail, while others were simply mentioned in brief as part of a larger methods section. The rationales researchers used to justify the selection of their strategies was not all evidence- or theory-based and the level of detail provided in describing rationales varied greatly. Thirty-six articles included some reference to evidence in support of strategy selection but the type and quality of this evidence varied significantly. Examples of evidence sources included study-specific sources such as conducting a pilot study or "run-in period" to test retention for a formal trial (e.g., Anastasi et al., 2005; Kapungu, et al., 2012; Logan et al., 2008; O'Keeffe et al., 2015) or lessons learned from previous research experiences that involved similar study populations and study designs (e.g., Buscemi et al., 2005; Katz et al., 2001; Striley et al., 2008). Other examples involved qualitative approaches to evidence-gathering, such as focus groups with individuals drawn from populations similar to those that would be involved in the study or from representative advocacy groups (Clough et al., 2011; Kapungu et al., 2012; Katz et al., 2001; Logan et al., 2008). Some community-based researchers took the approach of forming a community advisory board whose responsibilities included assisting with the selection and design of retention approaches (Tanjasiri et al., 2015; Vincent et al., 2013). One clinical trial also employed a professional panel composed of researchers and clinicians alongside community advocates (Falcon et al., 2011). In several cases, authors relied solely on published scientific literature by conducting literature reviews of their own or referencing pre-existing reviews on retention strategies (Cotter, Burke,

Loeber, & Navratil, 2002; Crowley, Roff, & Lynch, 2007; Froelicher et al., 2003; Goncy et al., 2010; Woodruff et al., 1998). However, in many of these situations the authors also explicitly documented the challenges of relying on published literature on retention including its limitation to largely descriptive assessments of effectiveness (Parra-Medina et al., 2004) and a lack of evidence on strategies specific to their study population of interest (Graziotti et al., 2012; Meneses et al., 2013). Only five articles cited the use of theoretical approaches alongside other sources of evidence to inform their retention approach (Fouad et al., 2014; Haack et al., 2014; Haley et al., 2014; Kavanaugh, Moro, Savage, & Mehendale, 2006; Meneses et al., 2013).

Regarding research that considered the importance of specifically employing planned retention protocols, in only seven articles did authors actually employ the term "protocol" when referring to a planned retention approach (Clough et al., 2011; Fouad, Johnson, Nagy, Person, & Partridge, 2014; Logan et al. 2008; Meneses et al., 2013; Rosser et al., 2010; Striley et al., 2008; Tobler & Komro, 2011). Of these seven articles, all reported some form of evidence to support the development of their approaches, while only two explicitly described using theory in addition to evidence to inform their approach (Fouad et al., 2014; Meneses et al., 2013). A total of 39 articles did include explicit mention of the importance of adopting a proactive or "planned" approach to retention that begins during the study design phase. That said, several of these same articles also included mention of the need for researchers to be adaptive to respond to fluctuations in study context as well as to changes in participant circumstances and needs. The combination of having a plan, while also being open to changing circumstances, was a common theme in those articles that reported their retention approaches in more detail.

Objective 2

The eight articles that met the adjusted criteria for objective two of this review all involved populations that consisted of women and/or children under the age of two who were experiencing some form of socioeconomic disadvantage. However, study populations still represented very diverse including populations of female commercial sex-workers, women at high-risk for HIV-acquisition, women who had experienced intimate-partner violence and unstable housing conditions, low-income women, infants born with prenatal substance exposure, and infants and children born to mothers infected with HIV. Three articles described studies using a longitudinal cohorts (Geromanos et al., 2004; Haley et al., 2014; Logan et al., 2008), one described a study using a case-control design (Graziotti et al., 2012) and the remaining four reported studies of either RCT or qRCT designs (Etcheverry et al., 2013; Fouad et al., 2014; Katz et al., 2001; Sharpe et al., 2011). Reported study sizes ranged from 85 (Sharpe et al., 2011) to over 2000 participants (Haley et al., 2014), while follow-up periods ranged from one week (Sharpe et al., 2011) to fifteen years (Graziotti et al., 2012). All eight articles described studies that employed retention strategies which were either evidence-, or evidence- and theory-based, and all but one (Sharpe et al., 2011) provided a

fairly high level of detail including descriptions of development and implementation and reflections or evaluation of their retention approaches. One article in particular was presented as a comprehensive resource regarding ethical considerations in the recruitment and retention of vulnerable populations of women (Logan, et al., 2008). The authors' aim was to collate evidence regarding research ethics involving vulnerable populations with evidence regarding recruitment and retention strategies. They did this using five different methods of evidence collection that included key informant interviews, focus groups, literature reviews, a pilot study testing study implementation, and their own case study of a longitudinal cohort involving 757 women who had experienced or were experiencing intimate-partner violence.

Six of the eight articles described studies which were host trials within which retention strategies were being applied, while two of them discussed studies that incorporated a RCT or qRCt design specifically to evaluate approaches to research retention. One of these was a randomized trial that sought to determine whether strategies employed by community health advisors improved retention of rural, low-income, predominantly African-American women in clinical trials as compared to usual research retention approaches used by research staff (Fouad et al., 2014). The other described an HIV vaccine-preparedness trial that aimed to determine the feasibility of enrolling and retaining female commercial sex-workers in a clinical vaccine trial. It compared the success of an enhanced retention strategy to a control retention strategy (Etcheverry et al., 2013).

None of the articles reported a cost-benefit analysis of the strategies employed for a given study context, none commented on the resource allocation devoted to retention within the context of the overall study budget, and all limited their evaluations of human or financial resources invested in retention to descriptive terms. Only four explicitly reported an effort to address attrition bias within the context of their retention efforts (Etcheverry et al., 2013; Graziotti et al., 2012; Haley et al., 2014; Katz et al., 2001) and only five mentioned incorporating participant feedback (Etcheverry et al., 2013; Geromanos et al., 2004; Haley et al., 2014; Logan et al., 2008; Sharpe et al., 2011). Finally, while seven of the eight articles emphasized the importance of planning for retention from the outset, only two (Fouad et al., 2014; Logan et al., 2008) employed the term "protocol" when referring to their implemented retention approach.

DISCUSSION

The primary objective of this systematic review was to determine whether examples exist where health-related studies involving "hard-to-reach", "vulnerable" populations have reported on the implementation and evaluation of pre-planned retention strategies. This review yielded 49 articles that meet these criteria. The results from the 49 articles demonstrate that, despite the trend of increased reporting of retention strategies in published health literature, there is still little evidence of a systematic method for reporting planned retention protocols for research involving "hard-to-reach", "vulnerable" populations (Robinson et

al., 2015). Moreover, reports including quantitative, empirical assessments of the effectiveness of different strategies across different contexts or incorporating cost-benefit analyses for a given strategy or set of strategies are rare. And while there is anecdotal support for the importance of considering a planned approach to retention, there is similarly little empirical evidence of researchers investing in the process of developing and implementing an evidence- or theory-based retention protocol as part of the research design process. Researchers are given little indication for what might be the most efficient and effective approach to retention for their given context with respect to key factors such as study design, population type, study size, and budget.

For the case of the BCHCP specifically, the objective two criteria proved too restrictive for evidence gathering. This demonstrates the futility of attempting to obtain reports of high-quality, evidence-based retention approaches specific to both a given study design and study population. Some studies demonstrated similarities to the BCHCP RCT in terms of length of follow-up, target population, population size, and follow-up protocol. However, these articles generally described retention within the context of longitudinal cohort or case-control studies (Geromanos et al., 2004; Graziotti et al., 2012; Katz et al., 2001). Those articles that did discuss retention within an RCT or qRCT study design appeared to not prioritize the reporting of retention strategies in that they committed minimal space within the article to discussion retention and provided very little detail. This was particularly regarding descriptions of the rationale or evidence that informed their decision-making process for strategy selection, as well as regarding the reporting of evaluative measures depicting the relative success of their approaches (Etcheverry et al., 2013; Sharpe et al., 2011; Webb et al., 2010).

This systematic review therefore confirms that the current state of the literature on retention requires researchers to conduct their own, resource-intensive review processes to obtain information relevant for their studies and contexts. It also helps elucidate whether researchers can and should be prioritizing study-specific factors within evidence searchers on retention. Initially, study population appeared to be a more critical factor than study design for determining whether a study's retention approach was applicable to your own. This was evidence by the greater yield of studies obtained for objective two after the eligibility criteria were adjusted. Despite the increased quantity of studies, their relevancy to the BCHCP was not significantly enhanced by the introduction of a study population criterion at the expense of the study design criterion. Therefore, restricting searches by a specific study population cannot be the sole approach. Furthermore, researchers have repeatedly emphasized the need to be adaptive and responsive with any retention approach due to the changing nature of study conditions and the shifts in context that can occur across a long-term study. The implications of this are that factors that speak to the quality of reporting for a retention approach – such as degree of detail in description, quantity and quality of evidence base, application of theory, and degree of planning in design – should be prioritized over study-specific

characterises such as study design or population when seeking evidence in others' studies to guide new retention planning.

One article that was rejected regarding objective two criteria on the basis of its study population represents a prime example of an informative piece of literature that might have been missed if the population description had been narrowed to match that of the BCHCP from the outset of the review. The work, by Meneses et al. (2013), presents a clear and comprehensive conceptual model through which to explore retention within a research context. The authors' used the work of Goodman et al. (1996) to develop their model, which presents retention and attrition as conditions influenced by three key factors within research: the researcher, the participant, and the research context. They also incorporated the work of Shumaker et al. (2000), which identified three levels at which retention and attrition can be acted on to influence the success of a study: primary prevention (i.e. efforts to increase screening, enrolment and randomization of participants), secondary prevention (i.e., efforts to maintain engagement during throughout the follow-up period); and tertiary prevention (i.e., efforts to re-engage dropouts or those lost to follow-up). The authors combined both models in a visual framework that then informed their decisions around both the types and timing of various retention strategies employed over the course of the research process. The visual framework as well as the matrix they used to present their retention plan can be seen in Appendix E. While their approach does not offer a formula for picking and choosing individual strategies, it does provide a robust model through which to conceptualize study retention with broad applicability across even the most disparate study contexts.

This idea of using a comprehensive, theoretically-based model to inform the adaptation of various retention strategies within a planned framework shares many similarities with the approach currently being considered for use in developing the BCHCP retention protocol. This approach would involve the participant-centered model developed by Marcellus (2004), grounded in ecological theory, in combination with a protocol framework developed by Scott (2004) that targets four main procedures for retention: engagement, verification, maintenance and confirmation (EVCM). The model informs the types of strategies selected, while the theory informs the various "nested" levels at which these strategies might operate. Both the approach under consideration for the BCHCP protocol and that taken by Meneses' et al. adopt a multi-factoral and multi-level approach to understanding retention that also allows for a consideration of the influences of both space and time on retention within the research context and show strong theoretical and conceptual similarities. This evidence supports the approach taken by the BCHCP in adopting a theoretically-informed, evidence-based model for retention. Comparing the strategies employed by Meneses et al. (2013) (Appendix E, Figure E2.) to those selected for the BCHCP retention protocol could help corroborate the BCHCP strategies as well as illustrate any potential gaps or additional strategies that might be applied. As well, Schumaker et al.'s (2000) model for prevention of attrition through the triaging of primary, secondary, and tertiary retention approaches should be considered. It can be compared

with Scott's (2004) EVCM model to determine whether the two models complement each other in terms of their interpretation of how both time and participant position impact retention.

The five articles that mentioned the use of theory, in addition to evidence, to inform the development of their retention approach once again reflect the heterogeneity in the literature; in this case by virtue of their diversity in types of theories described and reasons given for their use. It is important to note though, that unlike the study conducted by Meneses et al. (2013), none of these studies were clinically-based research studies that employed nurses or primary care practitioners as research staff. Fouad et al. (2014) described the use of an adaptation of the "empowerment model", a model that emerged from educational theory, which promotes the idea of personal and social change. This model matched the researchers' investment in taking a participant-centered, community-based approach by asking community-members to identify their critical issues and to work with the research team to design and implement strategies to address them. Haley et al. (2014) focused more directly on their study population through the application of the Gelberg-Anderson behavioural model for vulnerable populations. They describe this model as recognizing the unique challenges faced by populations with experiences of specific vulnerabilities in accessing health services, and therefore health research. The model explores the relationship between three sets of factors – predisposing, enabling, and need – specific to these populations and has been used successfully in other studies of health service utilization (Haley et al., 2014). Meanwhile, Kavanaugh et al. (2006) took a unique and labour-intensive approach to their qualitative research involving socially sensitive subjects. They employed Swanson's "middle-range theory of caring" to ensure that strategies were guided first by caring behaviours that conveyed researchers' empathy and warmth. This approach focuses intensely on the needs and well-being of participants and requires significant investment into developing researcher-participant relations. Haack et al. (2014) prioritized the need for culturally appropriate approaches to research in their work involving Latino families. They opted for the use of Bronfenbrenner's socioecological model, which looks at the impact of three spheres of influence (family, community, and culture) on participant retention. These four articles, in addition to that by Meneses et al. (2013), demonstrate that despite the rarity of theory-based approaches to retention, there is in fact ample opportunity for adopting and adapting theoretically-informed models in retention methodology. They also provide examples of the effective use of theoretically informed conceptual frameworks or models in informing comprehensive, planned designs for participant retention. What is needed now is further evidence of the use of theory-based approaches in retention methodology and measures of their effectiveness.

In their recent systematic review, Robinson et al. (2015) emphasize a need for further research, particularly comparative studies, to determine the most effective methods for retaining participants in longitudinal health research. This review argues that there is a greater potential benefit in going one step further – beyond a consideration of evidence indicating individual strategies relative to one another – to an evaluation that assesses a complete, comprehensive plan for retention developed within a theoretical and

evidence-based framework and implemented from the outset of the study process. Robinson et al. (2015) suggest that the best way to address the evidence gap around retention methods is by embedding methodology research within a larger study context, as promoted by the "Study Within a Trial", or SWAT program. SWAT is a program being developed by the Northern Ireland Network for Trials Methodology Research in collaboration with the Medical Research Council's Network of Hubs for Trials Methodology Research in the United Kingdom (UK) (HTMR Network), the Health Research Board's Trials Methodology Research Network in Ireland (HRB-TMRN), and others (Northern Ireland Network for Trials Methodology Research, 2010). This national program seeks to encourage the routine adoption of nested studies, presented as short protocols within larger clinical trials, to evaluate methods employed within clinical trials or systematic reviews to support evidence-based decision making around study design and conduct. The program was presented at the 22nd Cochrane Colloquium in 2014, with the aim of educating researchers about the program as well as encouraging them to consider the idea of nested method studies within their own research (Clarke et al., 2014).

"Trial Forge" represents another example of an institutionally-based organization that has similarly recognized the gap in evidence base for clinical trial methodology and is seeking to enhance it. Based in the Health Services Research Unit at the University of Aberdeen in the UK, their primary aim is to increase the evidence base for decision-making regarding available methods and infrastructure for conducting randomized trials to improve trial efficiency (Treweek et al., 2015). The Global Health Network is yet another example of an organization taking strides to inspire increased investment in methodology research and the SWAT approach, this time by providing online resources and supports for practitioners in global health (Global Health Trials, 2016). Similar to the focus of previous systematic reviews such as that of Robinson et al. (2015), these efforts place considerable emphasis on the value of individual, comparative trials in exploring the relative efficiency of individual techniques (or strategies) – while failing to grasp the potential for evaluating an entire approach to retention as part of the research design process. The comparative trial approach is inefficient and therefore unlikely to appeal to many in the research community, particularly when considering time and resource limitations.

These organizations have failed to generate a significant response across the international research community, as evidenced by an absence of trial registration through their online platforms. They have also failed to drive reporting of the development, implementation, and evaluation of retention strategies specifically. This is evidenced in the results of this and the other systematic reviews, which reveal continued inconsistent and inadequate reporting on retention methodology (Bonevski et al., 2014; Booker et al., 2011; Brueton et al., 2013; Robinson et al., 2015). This scenario might represent a case of good intentions gone wrong. The Global Health Network, SWAT, and Trial Forge represent three separate organizations that are attempting to implement their own systematic approach to tackling the need for methodology research within the health research community. (These three are by no means an exhaustive

list; it is possible that other organizations are making similar attempts.) However, for a systematic reporting system to be successful within the health research community, a single dominant form must emerge. The benefits to be gained from systematic reporting stem from the idea that there is a single tested and accepted way of presenting information that all researchers can readily recognize and use to interpret and adopt evidence. Shared information becomes interpretable, comparable, and applicable in this way.

This process has been demonstrated by the success of organizations such as the Cochrane Collaboration, which has proven successful in making planned protocols for systematic reviews an essential pre-requisite to the production of a quality review. Their approach involved mandating the publication of review protocols as a pre-requisite for publication within their review database registry. In doing so, the research community has effectively shifted the methodological standards for clinical systematic reviews. Their success appears to stem from Cochrane's well-established position within the research community. Perhaps what is required for advancing retention methodology through the adoption of protocol reporting is for a well established and internationally-recognized research organization to take leadership in designing and marketing a systematic approach to protocol reporting, rather than relying on well-intentioned but nonetheless individual, institutionally- or practice-based organizations acting in isolation.

CONSORT is a working group established by the research community that sets "Consolidated Standards of Reporting Trials" to address the issue of inadequate reporting of RCTs. The group has had a massive impact on influencing quality and consistency of reporting of RCTs by developing an evidence-based, minimum set of recommendations for reporting randomized trials referred to as the "CONSORT Statement". According to their website, the CONSORT statement "promotes a standard way for authors to prepare reports of trial findings, facilitating their complete and transparent reporting, and aiding their critical appraisal and interpretation" (http://www.consort-statement.org/). Researchers are asked to registry their trials through CONSORT by publishing a trial protocol that meets the group's standards for reporting. In terms of establishing minimum requirements for retention reporting however, it has only gone so far as to include attrition (listed as "participant flow") on its checklist of recommended items to report (Schulz, Altman, & Moher, 2010). This is clearly not comparable to the idea of a retention protocol. However, CONSORT could provide the appropriate platform from which to promote this type of approach.

The research community shares responsibility – collectively – for the quality of research methods that are employed universally across study designs. Retention, as a critical component of the research process, is demanding of its own field of methods research. The retention of study participants presents not only a shared challenge for researchers in ensuring valid, powerful, and generalizable results, but also an ethical consideration in conducting research. Striley et al. (2008) outline the important ethical implications for researchers who fail to maintain the engagement of enrolled participants. They emphasize that the lack of an intentional, systematic and comprehensive approach to subject retention violates the principles of justice

by failing to provide study subjects the benefits of research participation as outlined in the informed consent process. Ethical implications for participants and actual statistical implications for the quality, validity and generalizability of study results are further compounded by logistical concerns regarding the human and financial costs of conducting rigorous, long-term trials (Bonevski et al., 2014). These costs suggest a further ethical responsibility to research staff as well as funders in ensuring effective participant engagement and successful completion of study protocols. These responsibilities all validate the need for evidence to support "best practice" approaches to retention. While the implementation of systematic reporting of retention protocols is a necessary eventuality, it should not dissuade individual research teams from championing this work in the meantime – by developing, implementing, and reporting on their own retention protocols, as the BCHCP has done.

LIMITATIONS

There are several limitations to this review. First, the searches were limited to electronic databases only. The grey literature was not searched and no hand searches were conducted of either available trial registries or reference lists for included articles. Given more time, this addition to the review may have revealed new evidence to support a more thorough analysis of the current state of the retention literature. Second, while the review's population-focus was intentional, the results from this review suggest that population type may not be an effective factor by which to gage the relevancy of retention research. There may be valuable evidence of evidence-informed, theoretically-based, planned retention protocols designed for study populations that may not be labeled as "vulnerable". Similarly, due to inconsistencies in reporting and the potential for both delays and human errors in cataloguing curated online databases employing compact vocabulary terms, it is possible that some relevant literature involving "vulnerable" populations may not have been captured. Until reporting of retention protocols becomes standardised and commonplace, a more effective approach may be to restrict initial searches to only retention and attrition terms. Third, it may also be beneficial to expand eligibility criteria to include retention within a program, service or treatment context versus limiting it to retention within a research study specifically. It is likely that this type of evidence would by highly context-specific (e.g., report the influence of factors specific to a prescribed intervention), which is why such research was excluded from this review. However, it is possible that some aspects could be transferrable to differing research contexts. These three limitations could have compounded the issue of obtaining minimal results for objective two for comparison to the BCHCP context. However, they also illustrate the reality of working within the context of a clinical research timeline. While evidence-informed decision-making is a crucial part of any public health undertaking, there is an inevitable limit on the amount of time, energy, and resources that are available to a given trial or research study. This makes the need for a readily identifiable, comprehensive and consistent reporting platform for retention methodology even more apparent.

CONCLUSIONS

Strategies that increase participant retention are critical to the success of health research by ensuring the validity and generalizability of study findings. While strategies to increase retention are becoming more frequently mentioned within the scientific literature, their reporting remains largely descriptive and inconsistent, with little effort invested in rationalizing which strategies to use and why. Efforts to adopt the practice of developing comprehensive approaches to retention during the research design phase and to include plans to systematically evaluate and report on their outcomes are still rare. More needs to be done to encourage the practice of employing evidence-informed, theoretically-influenced, comprehensive retention approaches and of prioritizing their development during the research design phase. Several organizations have begun to encourage researchers to conduct methodological research within the trial process to enhance the trial methods evidence base. This may prove useful for the evaluation of individual retention strategies. The BCHCP retention protocol, on the other hand, presents a more comprehensive and systematic means for researchers to share an entire approach to trial retention. The adoption of retention protocols should therefore be encouraged as a necessary part of the trial publication process, similar to the implementation of systematic review protocols (Cochrane Collaboration) or study trial protocols for RCT's (CONSORT).

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CRITICAL REFLECTION

This process has been an extremely rich learning experience. I have gained new skills in evidence gathering that will be essential to conducting evidence-informed decision-making within public health practice. I have also gained a new appreciation for what a systematic review of the literature entails, and have learned what features distinguish it from other forms of evidence gathering. This experience has been a successful marriage of past professional experience in clinical research with new skill development. It has also expanded my understanding of important health research concepts, methods, tools, and processes. More importantly, it has afforded me a unique opportunity to see how concepts, theories and skills that were discussed in the classroom component of the program emerge in a real-world practice setting.

The content of this capstone paper reflects critical issues that were also emphasized within various courses. The essential role of longitudinal studies in epidemiological research, the challenges researchers face in conducting follow-up, the issue of attrition (both differential and within-group) and threat of bias to research validity and generalizability were all key concepts in epidemiology and statistics. The socioecological framework, along with several other frameworks, and their application for the interrogation of health disparities and evaluating health interventions, were explored as part of a course covering the social and behavioural determinants of health and disease. This review has demonstrated its application to retention methodology as well. The importance of systematic evidence gathering was emphasized throughout program as a core skill for evidence-informed decision-making within a professional public health setting. Similarly, the significance of the knowledge to action cycle was also emphasized. It is embodied in this paper's practice-based purpose of informing the BCHCP protocol development and, hopefully, the BCHCP protocol can provide evidence to feed back into the research production cycle through the actions of other researchers interested in applying and enhancing retention methodology.

This capstone has both mirrored and enhanced my experiences in the classroom by demonstrating the importance of both hard as well as soft-skill development. I have had to apply self-directed learning in order to obtain the necessary resources and information to conduct a successful review. I have had to critically assess the quality of these resources and, in the process, acquired access to new online, evidence-based tools and methods registries and resources that will prove very useful in a wide range of public health practice settings. This project has been an amazing opportunity to develop evidence-gathering skills, specifically in terms of learning the methodology of a systematic review. I have learned a substantial amount about search techniques, I have become familiar with a variety of different online database platforms, I have learned criteria for several different systematic review publishing platforms and have constructed a detailed review protocol, I have also learned how to quality assess evidence, and how to document in detail the methods used to perform a review. Finally I have had ample opportunity to work on a variety of communication skills, from formal report writing and oral presentation, to professional interpersonal and email communication.

In addition to this experience as a knowledge and skill building exercise, it has also been a unique opportunity for self-reflection and self-learning. From searching down potential project leads, to having to ask for help in securing a project topic, to picking the project, developing it, and bringing it to fruition, I have had significant opportunity to stop, pause and reflect across the various stages. It has been extremely important for me to be clear with myself about what I ultimately hope to achieve from this experience and part of this has meant constantly reiterating to myself the role of this project as a learning experience first and foremost. It is also important to me that I know what and how my work might be used, to know that it has a tangible and practical purpose and that any knowledge generated from it's production will prove of value to someone in some way. If I could do anything differently, it would simply be to start the process earlier and to invest greater consideration into the planning and development stages. Given different timelines, it might also have been beneficial to be present and had access to the BCHCP Scientific Team

during their conversations around retention and the development of the retention protocol. Nicole Catherine was instrumental in providing me with the necessary resources, background information, and inspiration for this study. However, I think being present during some of the formative stages of the protocol development and having access to other members of the team involved in its development would have helped enforce and strengthen my own understanding of how this review might best serve the project.

Critical to the success of this project and this program has been the mentorship I have received. I was lucky enough to have worked with several people throughout the course of the program who value mentorship and who see the worth in investing the role of a mentor. My preceptor at my practicum was one such individual and her influence has extended well beyond the realm of a four-month student practicum position. However, none has been so critical as that of my supervisor, Dr. Nicole Catherine. She has been instrumental in ensuring the success of this process as a learning experience and has encouraged self-directed learning while also providing support, focus, and direction when needed. Working with these mentors has reiterated for me the power and importance of relationship-building within professional practice and the significant returns that come from investing in the success and achievements of others, whether colleagues, peers, or pupils. I hope to carry this appreciation and attitude forward in my practice, and to always remember the importance of investing in the success of others in my field.

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APPENDICES

Appendix A – Search strategies

Search A1. Used for Medline and Cochrane Central Register of Controlled Trials (CENTRAL) – via Ovid

1. ((increas* or encourag* or maximi* or promot* or improv*) adj2 (retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")).ti,ab.
2. (difficult* adj2 (retain* or retention)).ti,ab.
3. ((strateg* or method* or technique* or protocol*) adj2 (retain* or retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")).ti,ab.
4. ((minimi* or prevent* or lessen* or decreas* or reduc*) adj2 ((loss* or lost) adj2 (follow-up* or "follow up*"))).ti,ab.
5. ((minimi* or prevent* or lessen* or decreas* or reduc*) adj2 (attrition or dropout* or "drop out*" or "attrition rate*" or nonresponse* or non-response*)).ti,ab.
6. ((strateg* or method* or technique* or protocol*) adj2 (attrition or "attrition rate*" or dropout* or "drop out*" or nonresponse* or non-response*)).ti,ab.
7. (("hard to reach" or hard-to-reach) adj2 (population* or group* or patient* or communit*)).ti,ab.
8. ((disadvantaged or marginalized or stigmatized or discriminated or sensitive or underserved or "under served") adj2 (population* or group* or patient* or communit*)).ti,ab.
9. (("at risk" or at-risk) adj2 (population* or group* or patient* or communit*)).ti,ab.
10. Lost to Follow-Up/
11. Patient Dropouts/
12. Vulnerable Populations/
13. 1 or 2 or 3 or 4 or 5 or 6 or 10 or 11
14. 7 or 8 or 9 or 12
15. 13 and 14
16. limit 15 to (english language and humans and yr="1980 -Current")

Table Legend: * = truncation term; adj2 = adjacency term (within two words of each other); ti. = located within title; ab. = located within abstract; limit = publication limits.

Search A2. Used for Cochrane Methodology Register (CMR) – via Ovid

1. ((increas* or encourag* or maximi* or promot* or improv*) adj2 (retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")).ti,ab.
2. (difficult* adj2 (retain* or retention)).ti,ab.
3. ((strateg* or method* or technique* or protocol*) adj2 (retain* or retention or "retention rate*" or

"response* rate*" or follow-up* or "follow up*")).ti,ab.
4. ((minimi* or prevent* or lessen* or decreas* or reduc*) adj2 ((loss* or lost) adj2 (follow-up* or "follow up*"))).ti,ab.
5. ((minimi* or prevent* or lessen* or decreas* or reduc*) adj2 (attrition or dropout* or "drop out*" or "attrition rate*" or nonresponse* or non-response*)).ti,ab.
6. ((strateg* or method* or technique* or protocol*) adj2 (attrition or "attrition rate*" or dropout* or "drop out*" or nonresponse* or non-response*)).ti,ab.
7. (("hard to reach" or hard-to-reach) adj2 (population* or group* or patient* or communit*)).ti,ab.
8. ((disadvantaged or marginalized or stigmatized or discriminated or sensitive or underserved or "under served") adj2 (population* or group* or patient* or communit*)).ti,ab.
9. (("at risk" or at-risk) adj2 (population* or group* or patient* or communit*)).ti,ab.
10. 1 or 2 or 3 or 4 or 5 or 6
11. 7 or 8 or 9
12. 10 and 11

Table Legend: * = truncation term; adj2 = adjacency term (within two words of each other); ti. = located within title; ab. = located within abstract; limit = publication limits.

Search A3. Cumulative Index of Nursing and Allied Health Literature (CINAHL) - via EBSCO

S17	S14 AND S15	Limiters - Published Date: 19800101-20160631; English Language; Human; Language: English Search modes - Boolean/Phrase
S16	S14 AND S15	Search modes - Boolean/Phrase
S15	S7 OR S8 OR S9 OR S12 OR S13	Search modes - Boolean/Phrase
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S10 OR S11	Search modes - Boolean/Phrase
S13	SU medically underserved	Search modes - Boolean/Phrase
S12	SU special populations	Search modes - Boolean/Phrase
S11	SU research dropouts	Search modes - Boolean/Phrase
S10	SU research subject retention	Search modes - Boolean/Phrase
S9	("at risk" or at-risk) N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase

S8	(disadvantaged or marginalized or stigmatized or discriminated or sensitive or underserved or "under served") N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase
S7	("hard to reach" or hard-to-reach) N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase
S6	(strateg* or method* or technique* or protocol*) N2 (attrition or "attrition rate*" or dropout* or "drop out*" or non-response* or nonresponse*)	Search modes - Boolean/Phrase
S5	(minimi* or prevent* or lessen* or decreas* or reduc*) N2 (attrition or dropout* or "drop out*" or "attrition rate*" or non-response* or nonresponse*)	Search modes - Boolean/Phrase
S4	(minimi* or prevent* or lessen* or decreas* or reduc*) N2 ((loss* or lost) N2 (follow-up* or "follow up*"))	Search modes - Boolean/Phrase
S3	(strateg* or method* or technique* or protocol*) N2 (retain* or retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")	Search modes - Boolean/Phrase
S2	difficult* N2 (retain* or retention)	Search modes - Boolean/Phrase
S1	(increas* or encourag* or maximi* or promot* or improv*) N2 (retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")	Search modes - Boolean/Phrase

Table Legend: * = truncation term; N2 = adjacency term (within two words of each other).

Search A4. PsycINFO - via EBSCO

S17	S14 AND S15	Search modes - Boolean/Phrase
S16	S14 AND S15	Limiters - Published Date: 19800101-

		20160631; English; Language: English; Population Group: Human Search modes - Boolean/Phrase
S15	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S12 OR S13	Search modes - Boolean/Phrase
S13	SU treatment dropouts	Search modes - Boolean/Phrase
S12	SU experimental attrition	Search modes - Boolean/Phrase
S11	SU at risk populations	Search modes - Boolean/Phrase
S10	SU disadvantaged	Search modes - Boolean/Phrase
S9	("at risk" or at-risk) N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase
S8	(disadvantaged or marginalized or stigmatized or discriminated or sensitive or underserved or "under served") N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase
S7	("hard to reach" or hard-to-reach) N2 (population* or group* or patient* or communit*)	Search modes - Boolean/Phrase
S6	(strateg* or method* or technique* or protocol*) N2 (attrition or "attrition rate*" or dropout* or "drop out*" or non-response* or nonresponse*)	Search modes - Boolean/Phrase
S5	(minimi* or prevent* or lessen* or decreas* or reduc*) N2 (attrition or dropout* or "drop out*" or "attrition rate*" or nonresponse* or non-response*)	Search modes - Boolean/Phrase
S4	(minimi* or prevent* or lessen* or decreas* or reduc*) N2 ((loss* or lost) N2 (follow-up* or "follow up*"))	Search modes - Boolean/Phrase

S3	(strateg* or method* or technique* or protocol*) N2 (retain* or retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")	Search modes - Boolean/Phrase
S2	difficult* N2 (retain* or retention)	Search modes - Boolean/Phrase
S1	(increas* or encourag* or maximi* or promot* or improv*) N2 (retention or "retention rate*" or "response* rate*" or follow-up* or "follow up*")	Search modes - Boolean/Phrase

Table Legend: * = truncation term; N2 = adjacency term (within two words of each other).

Search A5. Social Sciences Index and Science Citation Index Expanded - via Web of Science

#12	(#9 AND #8) *AND* **LANGUAGE:** (English)
#11	(#9 AND #8) *AND* **LANGUAGE:** (English)
#10	#9 AND #8
#9	#7 OR #6 OR #5
#8	#4 OR #3 OR #2 OR #1
#7	TS=((“at risk” or at-risk) near/2 (population* or group* or patient* or communit*))
#6	TS=((disadvantaged or marginalized or stigmatized or discriminated or sensitive or underserved) near/2 (population* or group* or communit*))
#5	TS=(hard-to-reach near/2 (population* or group* or patient* or communit*))
#4	TS=((strat* or method* or technique* or protocol*) near/2 (attrition or “drop out*” or dropout* or “attrition rate*”))
#3	TS=((minimi* or prevent* or lessen* or decreas* or reduc*) near/2 ((attrition or "attrition rate*" or drop-out* or dropout*) or ((loss* or lost) near/2 (follow-up* or followup*))))

#2	TS=((increas* or encourag* or maximi* or promot* or improv*) near/2 ("retention rate*" or "response rate*" or follow-up* or followup* or participation))
#1	TS=((strat* or method* or technique* or protocol*) near/2 ("retention rate*" or "response* rate*" or follow-up* or followup* or participation))

Table Legend: * = truncation term; near/2 = adjacency term (within two words of each other).

Appendix B – Eligibility criteria forms

Form B1. Objective 1, full-text review

Criteria:		**Code:**	**Met:**
Retention	Does the publication refer to retention strategies that are being applied for RESEARCH purposes? (Aka retention of STUDY PARTICIPANTS and not simply client retention to available program/intervention/health services)*.	1	
	Does the publication describe the implementation of retention strategies before and/or during a research study? (Aka NOT solely a post-hoc analysis/discussion of retention).	2	
	Are the strategies employed specifically to impact retention over the course of follow-up? (Aka NOT simply rates of recruitment, enrolment, and/or randomization).	3	
	Does the follow-up process involve data collection at one or more time points beyond the point of study enrolment and/or randomization? (Aka not just a single data collection point).	4	
	Is some explanation or rationale offered for why these specific strategies were selected?	5	
Population	Does the study population fit the description of a hard-to-reach or vulnerable population as defined for the purposes of this study?	6	
Limits	Is the publication in English?	7	
	Was it published after 1979?	8	
	Does the publication discuss a health-related research context?	9	

**Note – this excludes "research" where the intervention is the retention strategy and the outcome of interest is increased recruitment and/or retention to a health service or treatment (in this case PARTICIPANTS are simply the client population). Aka "retention in treatment" vs. "retention in study" (i.e. medication adherence, treatment retention, follow-up care, program retention, etc.)*

Form B2. Objective 2, full-text review

Criteria:		**Code:**	**Met:**
Study design	Does the publication constitute peer-reviewed scientific literature?	1	
	Is the study design a RCT or qRCT?	2	
Retention strategy	Does the study involve an evaluative assessment of a retention strategy (or strategies)?	3	
	Is the rationale provided for the use of the specific strategy (or strategies) either theory or evidence based?	4	
Population **Added after initial objective 2 screening*	Primary description must include both: Socioeonomically disadvantaged (low income, low education, housing instability, single mothers); AND **Error! Not a valid link.**	5	

* This eligibility form was adjusted after the initial screening for objective 2, which yielded only two articles. The population criterion was added as a requirement for inclusion, along with any three of the four original criteria (this approach yielded eight articles in comparison to just the two original articles).

Appendix C – Literature review flow diagram

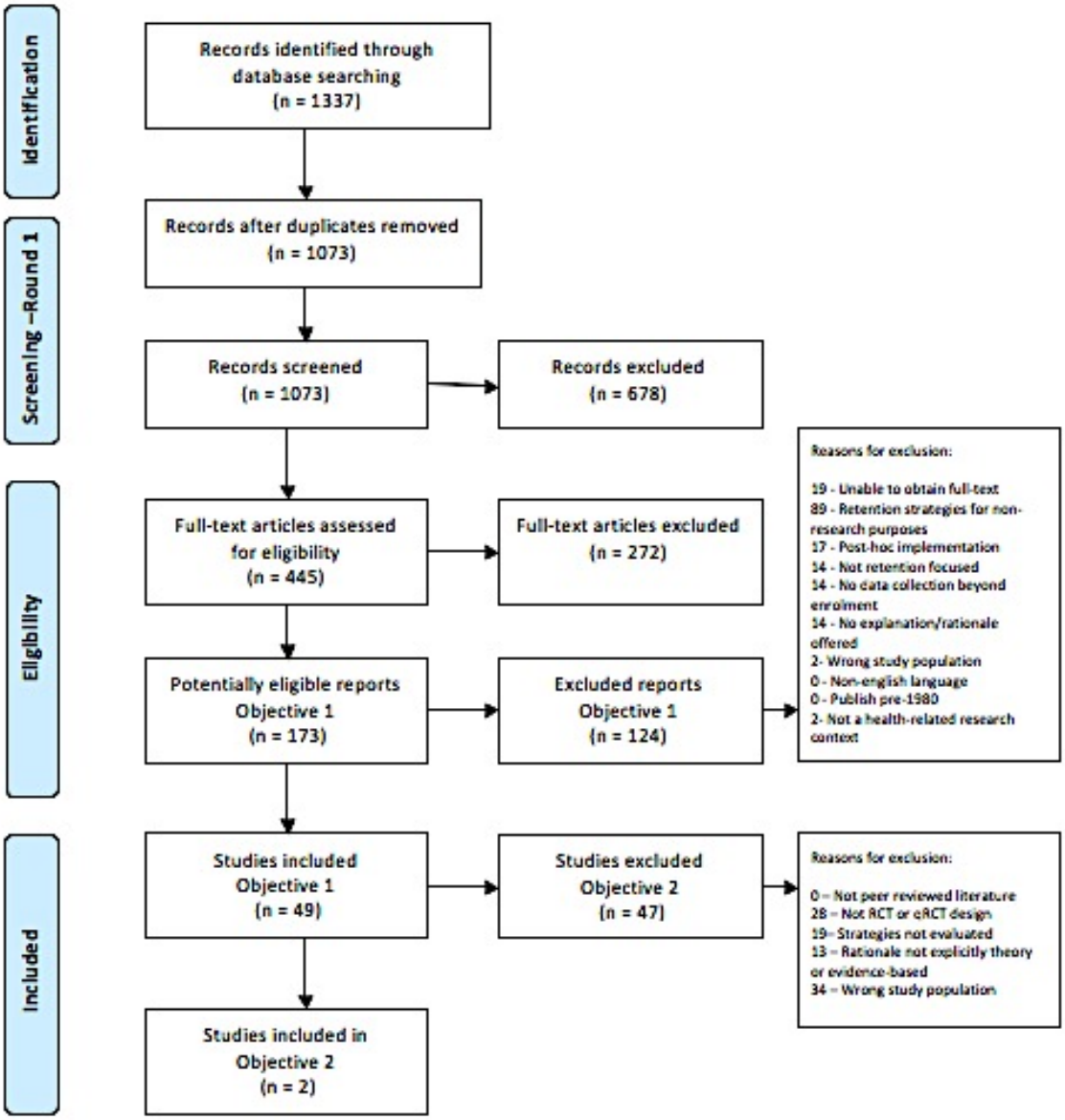

***Figure adopted from**:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med 6*(7): e1000097. doi:10.1371/journal.pmed1000097

Appendix D – Study tables

Table D1. Summary of study characteristics for included studies (by study ID #)

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
13	Anastasi, 2005	Nursing	(Adult) patients with HIV (and chronic diarrhea)	75	Host	RCT	Nutritional intervention	2	Y	Mixed
16	Armistead, 2004	Child & Family Studies	African American families	770	Host	qRCT	Sexual educational intervention	3	N	Mixed
19	Bailey, 2004	Nursing	Women, 14+ (with cervical intraepithelial neoplasia II or III who were willing to post- pone standard ablative therapy and receive topical retinoic acid treatment)	176	Host	RCT	Prevention intervention (delay surgery)	3	Y	Quantitative
36	Brown-Peterside, 2001	HIV intervention	HIV-negative at-risk women (18-60)	164	Retention	Long. Cohort	Retention intervention	1	Y	Quantitative
38	Busecmi, 2015	Child &Family Studies	Pre-school aged children (and parents)	197-325	Host	RCT, Long. Cohort	Obesity prevention intervention	2	Y	Quantitative
44	Cepeda, 2010	Substance Use	Adult Mexicana American substance-users	300	Host	Long. Cohort	No intervention	1	Y	Qualitative
50	Choudhury,	Primary Health	Adults living in Tower Hamlets	350 (x2)	Retention	Cross-	Retention	2	N	Survey

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
	2012	care	borough (low-income, low-education, high % minority community)	+ 78		sectional survey	intervention			
52	Clough, 2011	IPV	Women experiencing both intimate partner violence and housing instability	278	Host	Long. Cohort	Housing intervention	2	NR	Qualitative
62	Cotter, 2002	Child & Family Studies	Clinic-referred boys with disruptive behaviour disorders	177	Host	Long. Cohort	No intervention	1	Y	Qualitative
67	Crowley, 2007		Clients of HIV community-based organization services	1516	Retention	Long. Cohort	Retention intervention	2	N	Survey
92	Marcantonio, 2008	Geriatrics	High health-risk elderly people (aged 70+)	50	Retention	Long. Cohort	Retention intervention	2	N	Qualitative
93	Froelicher, 2003	Rehabilitation	Adults with depression, low social support, or both after a myocardial infarction	2481	Host	RCT	Behavioural/Mental health intervention	2	Y	Mixed
95	**Etcheverry, 2013**	**HIV intervention**	**Female commercial sex-workers**	**130**	**Retention**	**qRCT**	Retention intervention	**2**	**N**	**Quantitative**
96	Morse, 1995	Nursing	CPCRA staff/client information	NR	Retention	Qualitatitveinterview	Retention intervention	1	Y	Qualitative
98	Falcon, 2011	HIV	ARV-experienced women and men	429	Retention	Long.	Retention	2	N	Quantitative

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
		intervention				Cohort	intervention			
102	**Fouad, 2014**	**Cancer**	**Women residing in Jefferson County, Alabama**	**632**	**Retention**	**CT**	Retention intervention	**2**	**N**	**Quantitative**
106	Fredrickson, 2005	Primary Health care	Medicaid consumers	3685	Retention	Cross-sectional survey	Retention intervention	3	N	Mixed (Survey)
113	**Geromanos, 2004**	**Nursing**	**Infants and children born to mothers infected with HIV**	**298**	**Host**	**Long. Cohort**	No intervention	**1**	**Y**	**Mixed**
118	Goncy, 2010	Research Methods	Adolescents (aged 10-14 years)	106	Host	Long. Cohort	No intervention	1	Y	Survey
124	**Graziotti, 2012**	**Nursing**	**Infants born with prenatal substance exposure**	**1388**	**Host**	**Case-control**	No intervention	**1**	**Y**	**Mixed**
136	Haack, 2014	Child & Family Studies	Latino families (parents who self-identified as Latino and had at least one child between age 1-5)	74	Retention	Long. Cohort	Retention intervention	1	Y	Mixed
138	**Haley, 2014**	**AIDS/HIV intervention**	**Low income women at increased risk of HIV acquisition**	**2099**	**Host**	**Long. Cohort**	HIV prevention intervention	**1**	**Y**	**Quantitative**
146	Hindmarch, 2015	Research Methods	Families with pre-school aged children attending children's centres in disadvantaged areas in England	1112	Host	RCT	Injury prevention intervention	3	N	Survey

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
155	Hughes, 2012	AIDS/HIV intervention	HIV clinical trial (adult) participants	2290	Retention	Clinical trials	Retention intervention	1	Y	Mixed
159	Hwang, 2011	Public Health	Homeless and vulnerably housed adults (majority male)	1192	Host	Long. Cohort	Housing intervention	1	Y	Qualitative
183	Kapungu, 2012	Child & Family Studies	Adolescents receiving psychiatric care and their caretakers (slight majority female)	305	Host	qRCT	HIV prevention intervention	3	N	Mixed
185	**Katz, 2001**	**Health Promotion**	**Low-income mothers**	**286**	**Host**	**qRCT**	Prenatal care intervention	**2**	**N**	**Mixed**
186	Kavanaugh, 2006	Nursing	Parents who had either experienced the death of their infant or were involved in life support decisions because of potentially giving birth to an extremely premature infant	NR	Host	Long. Cohort	No intervention	1	N	Qualitative
189	Kelley-Baker, 2007	Evaluation Methods	Women (aged 16-23 years) who cross the border into Mexico at San Ysidro, California, to visit the bars and clubs in neighbouring Tijuana	1018	Host	Long. Cohort	No intervention	1	Y	Survey
266	Meneses, 2013	Nursing	Rural women, breast-cancer survivors (hard-to-reach, underserved)	432	Retention	RCT	Retention intervention	2	N	Mixed
275	Montanaro,	Substance Use	Youth (ages 14-18 years), school	244	Retention	Case-	Retention	2	Y	Mixed

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
	2015		based and juvenile justice centers			control	intervention			
280	Silva, 2002	Research Methods	Adult, working women (NOT necessarily socioeconomically disadvantaged)	292	Retention	Cross-sectional	Retention intervention	2	N	Survey
288	O'Keeffe, 2015	Maternal & Child Health	Mother-infant pairs at time of birth	1185	Retention	Long. Cohort	Retention intervention	1	Y	Survey
296	Parra-Medina, 2004	Diabetes management/ prevention	Adults with diabetes, living in rural, medically underserved communities (majority African American, low-income, females)	143	Host	qRCT	Obesity intervention	3	N	Mixed
309	Pottick, 1991	Research Methods	Parents of inner-city youths and the human service workers who serve them	219	Retention	Cross-sectional survey	Retention intervention	2	N	Qualitative
322	Resnicow, 2001	Substance Use	HRY (high risk youth)	NR	NR	Long. Cohort/ qRCT	Substance use prevention intervention	NR	NR	NR
328	Rosser, 2010	AIDS/HIV intervention	Men who use the Internet to seek sex with men (MISM)	650	Host	RCT	Sexual education/ HIV prevention intervention	2	N	Survey
339	Schubert, 2005	IPV	People with mental illness who are repeatedly involved in violent encounters (gender unclear)	132	Host	Long. Cohort		1	N	Qualitative

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
344	**Sharpe, 2011**	**Physical Activity & Health**	**Overweight women from economically disadvantaged neighbourhoods**	**85**	**Host**	**RCT**	Obesity intervention	**2**	**N**	**Mixed**
364	Striley, 2008	Research Ethics	Street-recruited out-of-treatment drug users	NR	Host	qRCT	No intervention	1	Y	Mixed
372	Tanjasiri, 2015	Health Promotion	Pacific Islander women (ages 21- 65 years) who are married or in a long-term (>5year) relationship	473 (women)	Host	qRCT	Cervical cancer prevention intervention	2	N	Survey
375	Teitler, 2003	Research Methods	Fathers enroled in the Fragile Families and Child Wellbeing Study, a national longitudinal survey of new parent	1713	Retention	Long. Cohort	Retention intervention	3	N	Survey
380	**Logan, 2008**	**Violence Against Women**	**Women with partner violence victimization experience**	**757**	**Host**	**Long. Cohort**	No intervention	**1**	**Y**	**Qualitative**
383	Tobler, 2011	Evaluation Methods	Racial/ethnic minority, urban, early-adolescents	4259	Host	qRCT	Alcohol prevention intervention	2	N	Survey
398	Villacorta, 2007	AIDS/HIV intervention	Men who have sex with men, street-youth/men, and "women who spend time on the streets socializing with men"	NR	Host	RCT	HIV prevention intervention	2	N	Mixed

ID	Study	Research Field	Population Demographics	Sample Size	Host or Retention trial	Study design	Intervention	# of groups	Identical FU	Dominant data type
400	Vincent, 2013	Diabetes management/ prevention	Spanish-speaking adults of Mexican origin	58	Host	qRCT	Diabetes prevention intervention	2	N	Mixed
412	Webb, 2010	Research Methods	Women who previously delivered premature (< 35 weeks gestation) infants (predominantly urban population with substantial proportion of low income and minority residents)	1126	Host	qRCT	Prenatal care intervention	2	N	Mixed
425	Whittemore, 2014	Nursing	Adults at-risk for type II diabetes living in public housing communities	67	Host	qRCT	Diabetes prevention intervention	2	N	Mixed
434	Woodruff, 2998	Evaluation Methods	Newly enlisted women in the U.S. Navy	5503	Retention	Long. Cohort	No intervention	1	Y	Survey

Table Legend: N = No; Y = Yes

Table D2. Summary of retention characteristics for included studies (by study ID #)

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
13	Anastasi, 2005	Brief	Y	7	Pilot-informed, client-based feedback (client requests), literature	E	N	N	68% (51)	Pay close attention to needs (barriers) of community from which participants will be drawn when designing strategies; funding agents should

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										be receptive to providing budgets for R&R.
16	Armistead, 2004	Detailed	N	15	Literature	E	N	Y	80% (618)	Get community input on design and implementation of study; be responsive to participant needs; consider interpersonal characteristics of staff; cater strategies to each research phase; & PLAN AHEAD.
19	Bailey, 2004	Brief	Y	5	NR	NR	N	Y	99.3% (175)	Consider participant characteristics; incorporate research into regular patient care; patients from certain populations feel disenfranchised with medical system, need to build trust/invest in relationships; retention was facilitated through multi-faceted, participant-specific problem solving; importance of professional relationship between the study nurse and the participant.
36	Brown-Peterside, 2001	Detailed	Y	8	NR	NR	N	Y	92%	Make retention a priority from the beginning, retention support required at least 1 full time staff member as well as financial support for home visits and computerized tracking system.
38	Busecmi, 2015	Detailed	Y	8	Previous research experience (15years), literature	E	N	Y	73-89%	Adjust and respond to context; plan prior to recruitment; requires significant staff time and resources (apprx. 20% of overall budget); buy-in from community partners; recommend tailoring specific strategies to the specific study

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										setting, population, and study design; suggest future studies report retention data at all time points and provide description of retention strategies used to help inform future work.
44	Cepeda, 2010	Detailed	Y	8	NR	NR	N	Y	98%	Developed six principles of special importance in reducing the attrition rate in follow-up studies of heroin drug users.
50	Choudhury, 2012	Detailed	N	4	Literature, pilot test	E	N	N	Varied	Range of methods of questionnaire administration may be required when conducting a survey with a hard to reach group in a deprived and ethnically diverse population.
52	Clough, 2011	Detailed	Y	14	Literature, domestic violence advocates	E	Y	Y	94%	Protocol was developed in consultation with domestic violence advocates; consider ethical and personal as well as research goals.
62	Cotter, 2002	Detailed	Y	7	Literature	E	N	Y	92.6%	Success due in large measure to persistence of project staff and diversity of methods used. Develop strategies early, and incorporate new techniques whenever possible. Don't give up on difficult to schedule or hard to locate participants. Experiences led to several hypotheses regarding participation in longitudinal research, unfortunately unable to test.

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
67	Crowley, 2007	Detailed	N	4	Literature	E	N	Y	79.2% (1200)	Community staff relationship may impede research.
92	Marcantonio, 2008	Detailed	Y	10	Pilot study, patient feedback	E	N	Y	NR	Barriers and incentives for elderly patients reported.
93	Froelicher, 2003	Detailed	Y	14	Literature	E	N	Y	93.02%	Retention efforts began the day the patient was recruited.
95	**Etcheverry, 2013**	**Detailed**	**N**	**6**	**Pilot study**	**E**	**N**	**Y**	**69%**	**To ensure broad participation in clinical trials and cohort studies including women at high risk for HIV infection, modifications of the retention strategies, such as building in more study visits to maintain sufficient participant contact and full identification details may be required. Furthermore, financial compensations and outreach activities might increase the engagement to participate in future vaccine trials.**
96	Morse, 1995	Detailed	N	6	Staff feedback	E	N	Y	NR	Nurses key to success, able to identify barriers and recognize specific needs of patient populations. However, community-based health care units have to learn to culturally acclimate health care and administrative staff to rigorous and sometimes seemingly antithetical demands of research.

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
98	Falcon, 2011	Detailed	N	9	Partnered with clinicians, researchers, and community advisors	E	N	Y	67.2% (women)	Successes due to pre-trial preparation, engagement of community advisors, mandated enrolment quotas, choice of study sites, and providing study sites with the resources and flexibility to adapt practices as necessary to support patients. Place more emphasis on study retention during study start-up.
102	**Fouad, 2014**	**Detailed**	**N**	**6**	**Using the CHA model and the empowerment theory**	**T, E**	**Y**	**Y**	**80%**	**Study outcomes indicated that CHAs can take on roles of research staff and perform such tasks with increased effectiveness.**
106	Fredrickson, 2005	Detailed	N	3	Existing literature on surveys for low-income/education populations, pilot results	E	N	Y	64%	Using consumer-based preferences significantly increased response rates to satisfaction survey.
113	**Geromanos, 2004**	**Detailed**	**Y**	**9**	**Existing evidence on the role of nurse coordinators in research**	**E**	**N**	**Y**	**80%**	**Retention was a priority from the out-set. Key to retaining patients and families appears to have been the nurse coordinators' persistence, flexibility, creativity, and emotional commitment to the patients.**
118	Goncy, 2010	Detailed	Y	9	Literature on strategies used in longitudinal research	E	N	N	77%	Participants described use of reminder letters, cards, newsletters, and personal phone calls as thoughtful and useful and positive relations with research team. Consider your study population,

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										develop and maintain trust, consider creating community advisory boards, provide diversity training. Recommendations: hire a good project coordinator and build rapport with participants.
124	**Graziotti, 2012**	**Detailed**	**Y**	**12**	**Existing literature on long. Retention strategies (found little to support their specific study population)**	**E**	**N**	**N**	**76%**	**Staff changes over course of long-term study can have significant impact on participant retention; persistence and incentives were important; important for families to understand in a meaningful way why they were participating in the study and what they were contributing. Use of multiple tracking techniques is essential.**
136	Haack, 2014	Brief	Y	7	Socioecological model	T, E	N	Y	95% (70)	NR
138	**Haley, 2014**	**Detailed**	**Y**	**14**	**Informed by the Gelberg-Andersen Behavioral Model for Vulnerable Populations; and by available literature, HPTN and study site best practices, and ethnographic assessments**	**T, E**	**N**	**Y**	**94%**	**Engage community in all stages of study development and implementation; invest extensive face time to develop trusting relationships with participants early on; collect detailed locator information which includes permission to contact participants through multiple modalities and update frequently; be as flexible as possible regarding study visits; develop community partnerships and provide referrals for other services outside scope of the**

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										study; use multiple retention approaches and modify retention strategies throughout based on site experience; follow incarcerated participants if protocol allows; continue tracing efforts throughout study implementation; provide staff with training and resources needed to implement retention strategies; develop systems to assess the relative cost-effectiveness of different retention strategies.
146	Hindmarch, 2015	Brief	N	4	Cochrane review (note: not much available evidence on their population group, used what they could find); also previous research they had conducted	E	N	Y	68% (751)	Provide incentives for collaborating centers/organizations.
155	Hughes, 2012	Brief	Y	8	Pooled analysis of previous HIV trial results (factors associated with attrition)	E	N	Y	NR	NR
159	Hwang, 2011	Brief	Y	4	Informed by previous study: methods shown to be effective at tracking and retaining homeless and vulnerably housed participants (McKenzie et al.	E	N	Y	NR	NR

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
					1999)					
183	Kapungu, 2012	Detailed	N	9	Focus groups, pilot trials, literature	E	N	Y	72%	Diverse reasons for non-attendance imply need for strategies or design changes to counteract participant barriers. Cannot evaluate the relative importance of each approach. Future research should evaluate differential effects of specific strategies. Future research may benefit from considering financial cost and time investment required to achieve high retention among difficult to reach families.
185	**Katz, 2001**	**Detailed**	**N**	**6**	**Previous studies with similar populations, focus groups**	**E**	**N**	**Y**	**59% (168)**	**Community-based research studies and service models targeting women with poor prenatal care need to incorporate a variety of strategies to enhance program participation. There is a continued need to explore strategies that support participation of study populations at high psychosocial risk.**
186	Kavanaugh, 2006	Detailed	Y	NR	"Swanson's middle-range theory of caring"	T	N	Y	NR	NR
189	Kelley-Baker, 2007	Brief	Y	2	Developed new study method (portal surveys)	NR	N	N	45.6% (308)	
266	Meneses,	Detailed	Y	10	Conceptual model of	E, T	Y	Y	77%	Highly recommend the need for prospective

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
	2013				retention based on 3 factors: researcher, participant, context. Supported by existing literature (though little on this particular study population)				(332)	evaluation of the effectiveness of differential retention strategies, specifically for those studies that are associated with higher costs in retaining participants.
275	Montanaro, 2015	Detailed	Y	8	Report few studies have empirically evaluated which approaches facilitate retention and/or disseminated those methodological details to other teams in the field – used what little evidence they could find	NR	N	Y	84.6% (203)	Further investigations needed into the individual differences that facilitate or impede retention, determining the expected cost and effort needed to retain participants, and helping research staff to flag those participants who might require extra effort.
280	Silva, 2002	Detailed	N	2	Hypothesis testing: authorization or response rates might be reduced if permission to access health care records was requested at the same time as completion of a detailed health survey	NR	N	Y	53% (155)	Delay: found that authorization rates were not affected, but survey response rates were reduced by around 15%, which was statistically significant.
288	O'Keeffe, 2015	Brief	Y	3	Informed by pilot study, and US version of PRAMS	E	N	Y	718 (61%)	Additional efforts such as stratification and over-sampling are required to increase

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										representativeness among hard to reach groups such as younger, single and multiparous women before expanding the project to an ongoing, national surveillance system in Ireland.
296	Parra-Medina, 2004	Brief	Y	7	Pre-existing literature on strategies used (however, explicitly state none of these are empirically evaluated)	E	N	Y	81.50 %	Study population required substantial human and monetary resources to recruit and retain. Did not quantify relative effectiveness of individual strategies, however most successful and important strategies seemed to be establishing partnerships with the health centers and using a subcontract to establish the program clearly within the clinical setting familiar to the participants and their providers.
309	Pottick, 1991	Brief	N	4	NR	NR	N	Y	73-78%	
322	Resnicow, 2001	Detailed	NR	7	Previous professional experiences, the scientific literature, and a panel of evaluation experts convened by CSAP	E	N	Y		
328	Rosser, 2010	Brief	Y	2	Prior research on factors associated with MISM dropout	E	Y	Y	76-99%	Reach (getting people to the site) and retention (keeping people on site) have been identified as 2 major challenges for internet-delivered interventions for adolescents [26–28]. Believe may

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										be the same for MISM, recommend researchers measure and report these in their evaluations.
339	Schubert, 2005	Detailed	Y	7	NR	NR	N	Y	92%	Most important approaches for retention came from thinking about what study involvement felt like for the participants; strong impression is that the skills and commitment of staff are far more important to retention than monetary incentives.
344	**Sharpe, 2011**	**Brief**	**Y**	**5**	**One particular study (Trost et al.) recommended including a combination of investigator-based and participant-based strategies to promote adherence with protocols**	**E**	**N**	**Y**	**95% (57)**	**In addition to employing general adherence strategies, considering the specific needs and challenges of the study population is also important. Future studies should include adherence rates and reports of adherence enhancing strategies (successful and unsuccessful) as a part of standard reporting of measurement methods to facilitate the development of a set of best practice procedures.**
364	Striley, 2008	Detailed	N	8	Their previous 20 years of research experience working on community-based epidemiology studies among hard-to-reach vulnerable populations	E	Y	Y	90%+	Retention requires a plan. Receiving feedback from study participants on what they would like to gain from study participation and on what they appreciated from past study participation allows tailoring of particular study benefits to a specific population.

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
372	Tanjasiri, 2015	Brief	N	5	CBPR theoretical approach as a "strategy"; individual strategies not explicitly linked to theory	NR	N	N	63.5% (242)	PI-specific organizational recruitment and individual retention is influenced by different study issues and cultural factors in each community.
375	Teitler, 2003	Brief	N	1	Building on existing evidence base	E	N	N	80%	Found that sample representativeness increased as response rates increased, but returns appear to have diminished at very high levels of effort.
380	**Logan, 2008**	**Detailed**	**Y**	**8**	**Multiple methods of evidence collection: literature reviews, key informant interviews, focus groups, pilot study and case-study for a longitudinal study**	**E**	**Y**	**Y**	**94% (710)**	**9 key themes emerged from data collection methods: community collaboration; participant benefits; transportation and child care; partner issues; participant comfort; participant understanding; challenges of home visits, interviewer flexibility; participant safety & data quality monitoring.**
383	Tobler, 2011	Brief	Y	3	Compared to similar strategies employed in other trials	E	Y	Y	61%	
398	Villacorta, 2007	Detailed	Y	9	Many "novel" approaches due to research context, but some from previous published literature	E	N	Y	84%	Required: detailed preliminary ethnographic research to identify the behaviours of key target groups, approaches to develop strong informal bonds between project staff and participants outside of study settings, and methods to enhance positive participant attitudes towards the study.

ID	Study	Retention description	Same across groups	# used	Description of rationale	Evidence or theory	"Protocol" referenced	"Planned"	Retention rate % (n)	Lessons learned
										Approaches used, while technologically simple, were labour intensive. Involve a large number of staff conducting numerous visits to residential areas over time in order to establish and maintain trust and rapport with the study groups.
400	Vincent, 2013	Brief	N	4	Informed by community advisory board	E	N	N	57% (33)	Differences in perceived value of control and intervention services can lead to differential attrition rates. Further research needed to examine recruitment and retention strategies for this study population.
412	Webb, 2010	Detailed	Y	7	NR	NR	N	Y	43.6%	Findings from recruitment analysis presented here adds to small but growing body of literature that increasingly challenges widely held belief that low income and minority women are necessarily averse to enrolling in clinical trials or community studies.
425	Whittemore, 2014	Brief	N	10	NR	NR	N	N	57%	NR

Table legend: NR = Not reported; N = No; Y = Yes**; E = Evidence; T = Theory;**

Table D3. Summary of follow-up characteristics for included studies (by study ID #

ID	Study	# FU points	Same across groups	Total length of FU	In-person FU	Site visit FU	Reasons for lost-FU	Resources reported	Cost-benefit analysis	Participant feedback	Attrition bias evaluated
13	Anastasi, 2005	6	Y	24 weeks	Y	Y	N	D	N	N	Y
16	Armistead, 2004	3	N	36 months	Y	Y	N	D	N	N	Y
19	Bailey, 2004	6	Y	12 months	Y	N	N	D	N	N	Y
36	Brown-Peterside, 2001	3	Y	12 months	Y	B	N	D	N	N	N
38	Busecmi, 2015	5	Y	12-24 months	Y	N	N	Q	N	N	Y
44	Cepeda, 2010	3	Y	12 months	Y	N	N	D	N	Y	N
50	Choudhury, 2012	1	N	Varied	B	N	Y	D	N	N	Y
52	Clough, 2011	3	Y	18 months	Y	B	Y	D	N	Y	N
62	Cotter, 2002	NR	Y	13 years	B	B	Y	D	N	Y	N
67	Crowley, 2007	1	N	Varied	Y	Y	Y	D	N	Y	Y
92	Marcantonio, 2008	NR	Y	NR	Y	NR	N	NR	N	Y	N
93	Froelicher, 2003	11	Y	54 months	B	B	Y	D	N	N	Y
95	**Etcheverry, 2013**	**2**	**N**	**24 months**	**Y**	**B**	**Y**	**D**	**N**	**Y**	**N**

ID	Study	# FU points	Same across groups	Total length of FU	In-person FU	Site visit FU	Reasons for lost-FU	Resources reported	Cost-benefit analysis	Participant feedback	Attrition bias evaluated
96	Morse, 1995	1	N	6 months	Y	Y	Y	D	N	Y	N
98	Falcon, 2011	NR	N	48 weeks	NR	NR	Y	D	N	N	Y
102	**Fouad, 2014**	**4**	**N**	**24 months**	**Y**	**Y**	**Y**	**D**	**N**	**N**	**N**
106	Fredrickson, 2005	1	N	NR	N	N	N	D	N	Y	Y
113	**Geromanos, 2004**	**Varied (10-20)**	**Y**	**5 years**	**Y**	**Y**	**Y**	**D**	**N**	**Y**	**N**
118	Goncy, 2010	4	Y	12 months	B	B	N	D	N	Y	N
124	**Graziotti, 2012**	**NR**	**Y**	**15 years**	**Y**	**B**	**Y**	**D**	**N**	**N**	**Y**
136	Haack, 2014	NR	Y	NR	Y	Y	N	D	N	Y	N
138	**Haley, 2014**	**2**	**Y**	**Varied (6 or 12 months)**	**Y**	**Y**	**Y**	**D**	**N**	**Y**	**Y**
146	Hindmarch, 2015	NR	N	12 months	N	N	N	D	N	N	Y
155	Hughes, 2012	NR	Y	NR	NR	NR	Y	D	N	N	NR
159	Hwang, 2011	2	Y	24 months	Y	N	N	N	N	N	N
183	Kapungu, 2012	5	N	12 months	Y	Y	Y	D	N	Y	Y

ID	Study	# FU points	Same across groups	Total length of FU	In-person FU	Site visit FU	Reasons for lost-FU	Resources reported	Cost-benefit analysis	Participant feedback	Attrition bias evaluated
185	**Katz, 2001**	**Varied (apprx. 32)**	**N**	**12 months**	**Y**	**N**	**Y**	**D**	**N**	**N**	**Y**
186	Kavanaugh, 2006	NR	Y	NR	Y	N	N	D	N	Y	N
189	Kelley-Baker, 2007	2	Y	1week	N	N	Y	D	N	N	Y
266	Meneses, 2013	4	Y	12 months	N	N	N	D	N	Y	Y
275	Montanaro, 2015	2	Y	6 months	N	N	N	D	N	N	Y
280	Silva, 2002	Varied (1,2)	N	6+ months	N	N	N	NR	N	N	N
288	O'Keeffe, 2015	1	Y	Varied (up to 133 days)	N	N	N	D	N	N	Y
296	Parra-Medina, 2004	3	Y	12 months	Y	Y	Y	D	N	N	Y
309	Pottick, 1991	3	N	NR	Y	N	N	Q	Y	N	Y
322	Resnicow, 2001	NR	NR	NR							
328	Rosser, 2010	5	Y	12 months	B	B	N	D	N	N	N
339	Schubert, 2005	26	Y	6 months	Y	N	N	D	N	N	N
344	**Sharpe, 2011**	**1**	**Y**	**Varied**	**Y**	**Y**	**Y**	**D**	**N**	**Y**	**N**

ID	Study	# FU points	Same across groups	Total length of FU	In-person FU	Site visit FU	Reasons for lost-FU	Resources reported	Cost-benefit analysis	Participant feedback	Attrition bias evaluated
				(7-14 days)							
364	Striley, 2008	3	N	12 months	Y	Y	N	D	N	Y	NR
372	Tanjasiri, 2015	3	N	6 months	B	B	N	D	N	Y	NR
375	Teitler, 2003	1	N	Varied (1-256 days)	B	N	N	Q	Y	N	Y
380	**Logan, 2008**	**2**	**Y**	**12 months**	**Y**	**N**	**Y**	**D**	**N**	**Y**	**N**
383	Tobler, 2011	2	Y	3+ years	B	N	Y	Q	Y	N	Y
398	Villacorta, 2007	2	Y	24 months	Y	N	N	D	N	N	Y
400	Vincent, 2013	11	N	NR	Y	Y	N	D	N	Y	N
412	Webb, 2010	5	Y	24 months	Y	Y	N	D	N	N	Y
425	Whittemore, 2014	Varied (7 vs. 2)	N	6 months	Y	Y	N	D	N	N	Y

Table Legend: NR = Not reported; N = No; Y = Yes; B = Both; D = Descriptive; Q = Quantitative.

Appendix E – Visual frameworks from theoretical models

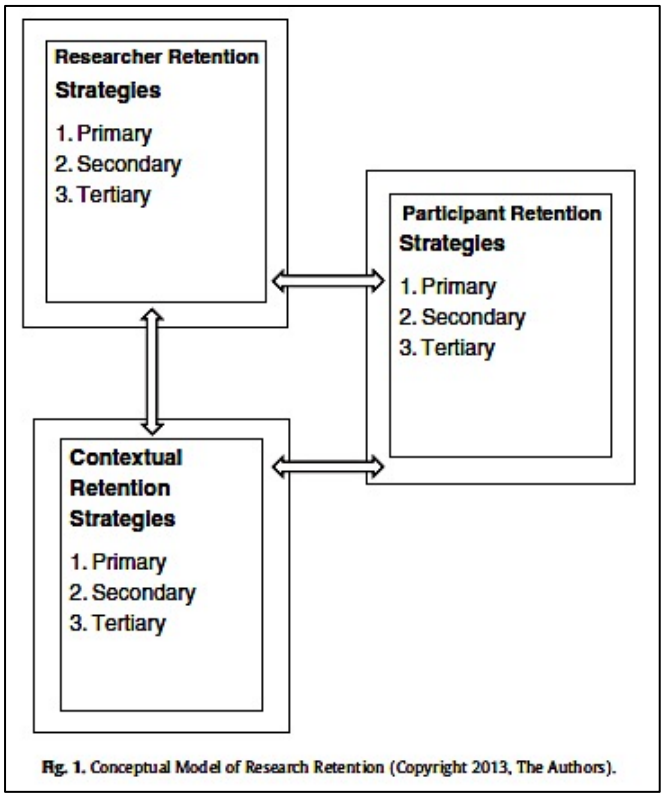

Figure taken from: *Meneses, et al. (2013).*

Figure E1. Conceptual retention prevention model by Meneses et al. (2013) incorporating three influential factors (participant, researcher, and context) at three levels of retention intervention (primary, secondary and tertiary).

Table 1
Description of RBCS retention strategies and characteristics.

Researcher Retention Strategies	*Primary prevention* 1. Develop structured retention protocol 2. Training of research staff in protocol 3. Frequent clinical and research team meetings 4. Allow for a run-in period between interest and baseline measures 5. Contact interested participants within 5 days of notification of interest 6. Schedule first call for at least 15 minutes to allow for discussion 7. Schedule second call back to allow for answering of questions and discussion 8. Send separate written informed consent 9. Provide time for questions after initial consent 10. Describe mutual expectations 11. Call promptly for scheduled visits	*Secondary prevention* 1. Call back 15 minutes after first failed attempt to contact 2. Leave voice message or email if no response to second attempt 3. Follow-up missed appointments with at least 3 telephone calls or emails at different times of day	*Tertiary prevention* 1. Send a recontact letter with study logo, signed by the research nurse after 3 failed attempts to contact by phone or email 2. Three follow-up phone calls made to the initial recontact letter 3. Send a recontact letter with an Option to Withdraw after three failed attempts to contact after first letter 4. Administrative withdrawal of participants one year after baseline completion
Participant Retention Strategies	*Primary prevention* 1. Clinicians assigned a set of participants to work with throughout the year 2. Encouraged trusting relationships between researcher and participant 3. Schedule calls at a convenient time for researcher and participant 4. Use email if participant allows 5. Frequent/monthly contact throughout the study 6. Provide reminders as requested 7. Provide a written schedule for participants in their materials 8. Offer flexible scheduling and breaks if needed during telephone calls 9. Be mindful of participant emotions during the call 10. Provide tailored education and support 11. Provide written materials to reinforce education and support 12. Provide financial incentive after completion	*Secondary prevention* 1. Provide the option for reminder calls/emails/cards for participant who is lagging 2. Reinforce the time commitment of the study 3. Reinforce the roles and responsibilities of the research participant 4. Offer flexible scheduling including breaking visits into smaller blocks of time, changing the time of the scheduled appointment 5. Send a handwritten note or card to participants experiencing unforeseen life circumstances (i.e., weddings, births, deaths, cancer recurrence)	*Tertiary prevention* 1. Use of email, telephone, and mail to reach lagging or difficult to reach participants 2. Continued tracking of the time since participant enrollment 3. Provide support and understanding even if participant is difficult to reach or not able to complete study measures
Contextual Retention Strategies	*Primary Prevention* 1. Development and use of Recruitment Tracking database 2. Development and use of Enrollment Tracking database	*Secondary Prevention* 1. Continued utilization of the Recruitment and Enrollment Tracking databases	*Tertiary Prevention* 1. Continued utilization of the Recruitment and Enrollment Tracking databases

Figure taken from: *Meneses, et al. (2013).*

Figure E2. Table of retention strategies implemented by Meneses et al. (2013) by factor (researcher, participant, context) and level of intervention (primary, secondary, tertiary).

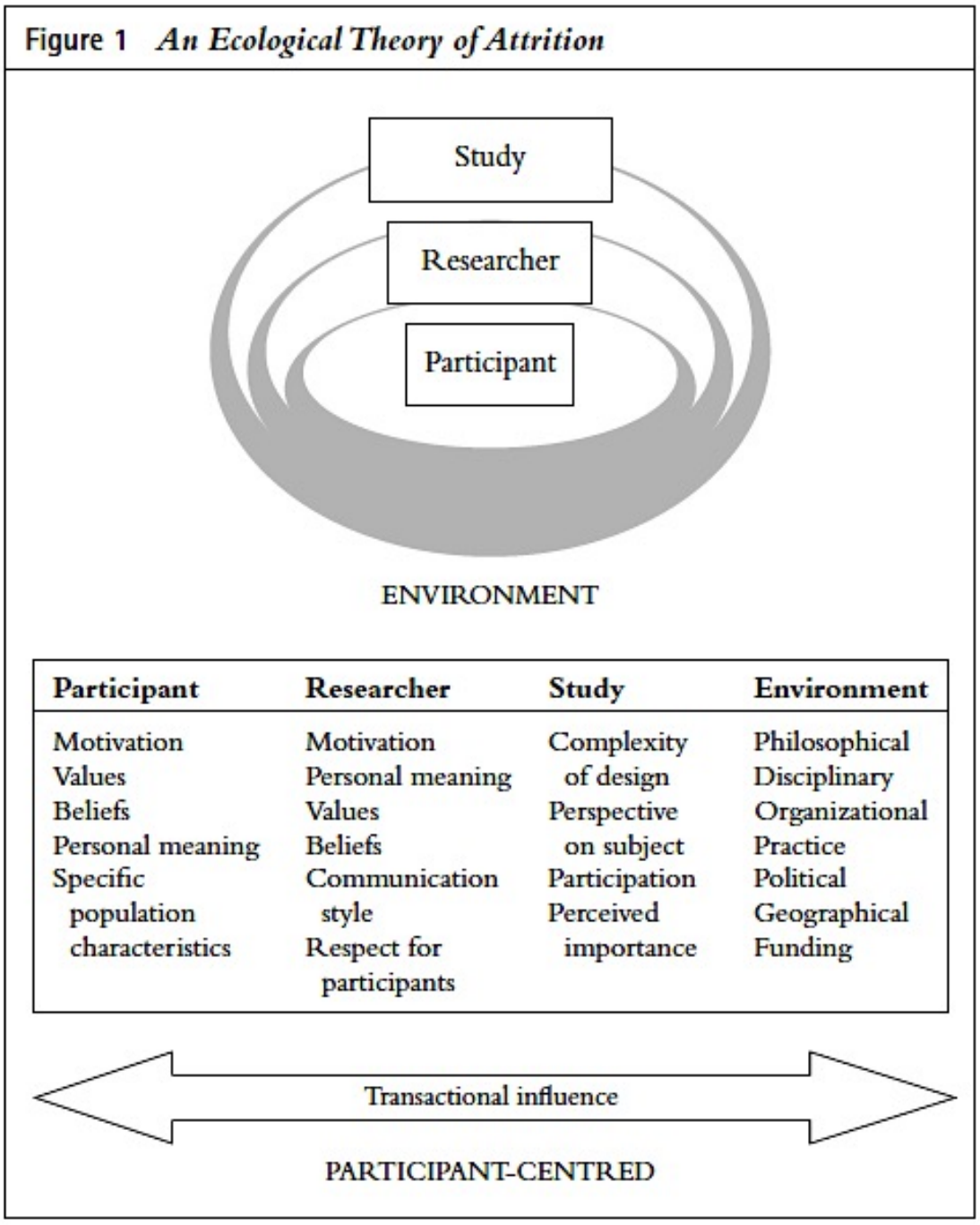

***Figure taken from**: Marcellus (2004).*

Figure E3. Visual theoretical framework of attrition from Marcellus (2004) depicting participant-centered, ecological theory based model of attrition used to develop planned retention strategy.