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TITLE: Using Facebook as a Tool to Reconnect with Study Participants

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ABSTRACT *must not exceed 450 words

Background:

Retaining and tracking cohort participants is essential to ensure the validity and generalizability of the data in longitudinal research. Even when numerous recommended strategies to minimize loss to follow-up are used, maintaining contact with participants is time consuming and resource intensive.

Facebook, a popular social media site, allows users to communicate and exchange information. Social media sites can be used as a database to search and find individuals, including study participants. Use of such technology may be a feasible method of contacting participants who have been lost to follow-up ultimately, reducing attrition.

Objective:

The aim of this study was to determine if Facebook was a feasible method for identifying and contacting participants of a longitudinal pregnancy cohort who had consented to follow up, but could not be reached, described as 'lost to follow-up'.

Methods:

This study used data from the All Our Families (AOF) cohort. Women were recruited during pregnancy (between 2008 and 2011) and were followed-up at 7 time points during the perinatal and early childhood period. Of 2827 mother-child dyads, 237 participants were lost to follow-up. Participants were considered lost to follow-up if they had agreed to participate in additional research and completed at least one of the perinatal questionnaires, did not complete the 5-year postpartum questionnaire, and could not be contacted after numerous attempts via phone, email or mail. Participants were considered to be matched to a Facebook profile if two or more socio-demographic characteristics matched...
Participants were sent both a friend request and a personal message, and were invited to verify their enrolment in the AOF study. If the participant responded with self-identifying information or accepted our friend request, then a personalized message was sent. Participants were considered re-connected if they accepted our friend request or responded to any messages. Participants were considered re-engaged if they provided up-to-date contact information.

Results:

Compared to the overall cohort, participants who were lost-to-follow-up (n=237) were younger (P = .003), non-married (P = .023), had lower household income (P < .001), less education (P < .001) and identified as non-Caucasian (P = .015). Of the 237 AOF participants considered lost to follow-up, 113 (47.7%) participant profiles were identified using Facebook. Among the 113 participant profiles that were identified, 87 participants were contacted (77.0%), 37 were re-connected (32.7%) and 20 were re-engaged (17.7%). No significant differences were found between those identified on Facebook (n=113) and those who were not able to be identified (n=237-113).

Conclusions:

Facebook is an effective tool at reconnecting with participants previously identified as lost to follow-up. The results from this study demonstrate that social networking sites, such as Facebook should be included in the development of retention practices, and can be implemented at any point in cohort follow-up.

KEYWORDS: Social Media, participant retention, Facebook, cohort, response rates, attrition, loss-to-follow-up

INTRODUCTION
The prospective cohort is a methodologically rigorous design to understand long-term trajectories and to identify risk and protective factors for healthy outcomes [1]. Longitudinal cohorts are susceptible to loss of participants over time as people move or lose interest in participating [2]. Birth cohorts may be particularly susceptible to participant attrition due to high mobility during this life stage, and busy schedules of families with small children. Loss of participants reduces statistical power, can threaten the accuracy of measures of association (such as odds ratios and risk ratios), and diminish the generalizability of a cohort. [2,3]. Therefore maximum follow-up rates should be attempted.

There are many methods to improve response rates in longitudinal cohorts and minimize loss-to-follow-up. These include: collection of detailed and appropriate recruitment information, implementing standardized participant tracking procedures, contacting alternative contacts, identifying 3 or more alternate contacts, increased frequency of participant contact, and offering monetary or other incentives for study participation [2,4–7]. However, even when all recommended strategies are implemented a participant may not be retained in a mobile population [2]. Addresses, telephone numbers, and even emails are becoming less predictable ways of tracking participants [8]. Recommendations to obtain personal identifying information to track participants on major databases (i.e. driver’s license numbers for use with the department of motor vehicles) [8] are not feasible in every country or region as privacy laws may prohibit researchers from accessing this information without explicit prior participant consent.

The development and now widespread use of social networking sites, such as Facebook, can provide new opportunities for locating participants who are difficult to track. Facebook has
been used to recruit research participants and may be a strategy to identify and engage participants with rare conditions, those who are hard to reach or vulnerable [9–11]. Recruitment through Facebook can be more cost effective than traditional methods, which is appealing to researchers [12–15]. Several studies have successfully used Facebook to locate participants including a longitudinal follow-up of an intervention programme for at-risk families [16], a longitudinal study of adults who use methamphetamine [4], and members of a graduating class [17]. These studies demonstrate the potential for identifying participants for whom follow up was unplanned or who were high-risk or highly mobile.

The effectiveness of using social media to re-contact participants in a longitudinal pregnancy cohort has not previously been examined. Among social networking sites, Facebook has emerged as one of the dominant platforms reporting 1.4 billion daily active users as of December 2017 [18]. Facebook was initially targeted to young adults, however in 2010 users over the age of 34 became the fastest growing demographic group [19]. Unlike traditional communication platforms, Facebook URLs are associated with longer periods of use compared to email addresses [4]. This study investigated the efficacy of one social networking site, Facebook, for both identifying and re-contacting participants of a contemporary longitudinal pregnancy cohort, situated in Calgary, Alberta, Canada.

METHODS

The All Our Families Study
The All Our Families cohort (AOF, formerly the All Our Babies Study) is a contemporary ongoing prospective community-based pregnancy cohort situated in Calgary, Alberta, Canada. A detailed overview of the study design, recruitment, eligibility and data collection is described elsewhere (Gracie et al, 2010; McDonald et al, 2013; Tough et al, 2017). In brief, AOF aims to investigate the influence of early events on long-term health and development of both mothers and children by examining factors across the life course. To do so, detailed information was collected on demographics, lifestyle, mental, psychosocial and physical health, pregnancy history, health service utilization, quality of life, and breastfeeding practices.

Since recruitment between 2008-2011 participants have completed seven questionnaires; three questionnaires in the perinatal period (22-24 and 32-36 weeks gestation, and 4 months post-partum) and four questionnaires in the early childhood period (1, 2, 3 and 5 years post-partum). Questionnaires were mailed to participants along with a pre-paid return envelope. If questionnaire data was missing or the questionnaire was not returned within three weeks, trained research assistants contacted participants via telephone and/or email to provide a reminder message to complete the questionnaire. Multiple telephone and/or email attempts were made until the participants was contacted and either provided the opportunity for a new questionnaire to be mailed or the participant completed the questionnaire over the telephone. To ensure participants remain informed about the study, semi-annual newsletters containing information on project progress and findings (e.g., most popular baby names), preliminary results (e.g., influence of child care on language development) and research team member profiles were mailed to participants.

Of the 2827 mother-baby dyads who were eligible to complete the 5 year questionnaire, 237 participants were considered lost to follow-up (Figure 1). Participants were considered lost to follow-up if they had agreed to participate in additional research and completed at least one of the perinatal
questionnaires, did not complete the 5-year postpartum questionnaire, and could not be contacted after numerous attempts (n=237). Participants were excluded from the reengagement study if they had previously withdrawn or discontinued from the study, or had indicated a lack of interest in this data wave.

**Figure 1:** Eligibility criteria of lost to follow-up participants
In order to contact participants, an All Our Families Study Facebook profile ([www.facebook.com/AllOurBabiesCohort/](http://www.facebook.com/AllOurBabiesCohort/)) was created. Throughout the course of the reengagement study, the AOF Facebook profile included the study logo, a brief paragraph describing the study, the study's contact information, and frequent updates regarding the study.

To reengage participants, those lost to follow-up were first identified by searching the first and last name on Facebook. To verify the participants' identity, profiles were browsed for known identifiers including birthdate, home address, email address, child's name, spouse's name, phone number and if the alternate contact on file was included in the participant's friends list. If a Facebook profile contained at least two identifiers that matched data previously collected by the study the participant was considered found on Facebook. Profiles with matching identifiers were then sent friend requests and a personalized message via Facebook's direct messaging service asking the profile owner to confirm their identity and their participation in the All Our Families study. If participants responded to the initial message, unique follow-up messages were sent asking participants if they would be willing to update their contact information so they could be reached by telephone, email and/or mail. Any participant questions were also addressed in follow-up messages and they were subsequently encouraged to contact our team via email or telephone for any additional information.

If participants did not respond to the initial message for two weeks, a follow-up message was sent informing participants who were unable to be contacted for the 5-year questionnaire and whose contact information was out of date. A second and final follow-up message was sent to participants if they did not respond for a total of one month following the initial message.

**Ethical considerations**

Social media platforms such as Facebook provide an innovative means for recruitment and retention, however, the use of social media may increase risks to participant privacy and confidentiality.
This study recognized that ethical principles for ensuring privacy and confidentiality of study participant’s personal information may be affected with the use of Facebook. To protect participants’ privacy on our Facebook page the study’s Facebook privacy settings were set to “Disable posts by other people on the Page”. Recognizing that confidentiality cannot be guaranteed if a participant “shares” or “likes” our page, however by preforming these actions the participant, who has agreed to the terms and conditions of the social media site, has the ability to disclose this information as they wish according to their own privacy settings. Non-participants also have equal opportunity to utilize these social media functions which further protects confidentiality as the communication is not exclusive to participants. In addition to the above safeguards, Facebook’s privacy settings were regularly monitored.

The All Our Families Study was approved by the Child Health Research Office, Alberta Health Services, and the Conjoint Health Research Ethics Board of the University of Calgary. Written informed consent was obtained from the study participants at the time of recruitment, who were also provided copies for their records. Additional ethical approval for this participant re-engagement was obtained, taking into account the specific privacy and confidentiality concerns regarding the use of social media.

Data Analysis

For the purpose of this analysis, participants were considered to be identified on Facebook if their identity could be confirmed on their profile. Participants were considered contacted if a friend request and a personal message could be sent. If a participant accepted our friend request and/or replied to any of our messages, they were considered as being re-connected with our study. Finally, if a participant responded to our messages and provided their up-to-date contact information, they were considered as being reengaged with our study.

Bivariate analyses were used to compare demographic variables of active study participants and participants considered lost-to-follow-up, using chi-square or Fisher’s exact tests. Bivariate analyses were
also used to compare those whose Facebook profiles were identified compared to those who could not be identified. A p-value of <0.05 was considered statistically significant. Statistical analyses were performed using SPSS version 23.

RESULTS

Data collection was initiated June 2016 and was completed August 2016. Of the 237 AOF participants considered lost to follow-up, 113 (47.7%) participant profiles were identified using Facebook. Among the 113 participant profiles that were identified, 87 participants were sent messages through the messenger application (77.0%). 37 participants (32.7%) responded to the sent messages, and 20 of these participants (17.7%) were re-engaged in the study’s follow-up.

To understand the differences between active participants (n=2590) and participants considered lost-to-follow-up (n=237), baseline data was compared on the following variables: maternal age, marital status, born in Canada, household income, education status, ethnicity and language spoken at home (Table 2). Participants considered lost-to-follow-up when compared to continuing participants were younger (P=.003), single (P=.023), had a lesser household income (P<.001), lower education (P<.001), and were more likely to identify as ethnic (P=.015).

No significant differences were found between those whose Facebook profiles were identified (n=113) and those who could not be identified (n=124; Table 3).

Table 2: Characteristics of continuing and lost to follow-up participants

<table>
<thead>
<tr>
<th>Demographic characteristic (at recruitment)</th>
<th>Was this participant identified as Lost to Follow Up?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No n (% column) n= 2590</td>
</tr>
</tbody>
</table>

10
<table>
<thead>
<tr>
<th>Demographic characteristic (at recruitment)</th>
<th>Was this participant identified on Facebook</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No n (% column)</td>
<td>Yes n (% column)</td>
</tr>
<tr>
<td></td>
<td>n= 124&lt;sup&gt;a&lt;/sup&gt;</td>
<td>n=113&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Maternal Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 35 years</td>
<td>104 (88.1)</td>
<td>97 (88.2)</td>
</tr>
<tr>
<td>35 years or older</td>
<td>14 (11.9)</td>
<td>13 (11.8)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Common Law</td>
<td>111 (92.5)</td>
<td>102 (91.1)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (7.5)</td>
<td>10 (8.9)</td>
</tr>
<tr>
<td>Born in Canada?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>89 (73.6)</td>
<td>86 (76.8)</td>
</tr>
<tr>
<td>No</td>
<td>32 (26.4)</td>
<td>26 (23.2)</td>
</tr>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$60,000</td>
<td>31 (26.5)</td>
<td>31 (29.4)</td>
</tr>
<tr>
<td>$60,000 or greater</td>
<td>86 (73.5)</td>
<td>78 (71.6)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>33 (27.0)</td>
<td>26 (23.2)</td>
</tr>
<tr>
<td>Some or completed post-secondary</td>
<td>89 (73.0)</td>
<td>86 (76.8)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>34 (28.1)</td>
<td>27 (24.1)</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>87 (71.9)</td>
<td>85 (75.9)</td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>103 (85.1)</td>
<td>101 (90.2)</td>
</tr>
<tr>
<td>Other</td>
<td>18 (14.9)</td>
<td>11 (9.8)</td>
</tr>
</tbody>
</table>

<sup>a</sup> small variations in totals may exist due to missing data (less than 3%)

<sup>b</sup> indicates statistical significance (<0.005)
Our study has two key findings. Firstly, Facebook is a feasible way to identify lost to follow-up participants even without a priori collection of Facebook identifiers. Using the social networking site 48% (n=113) of lost to follow-up participants were identified, and 17% (n=20) of those identified were re-engaged in the study's follow-up. Finding and contacting lost to follow-up participants often depends upon collection of detailed information at time of recruitment [6]. Using only the participant information collected at recruitment (i.e. first and last name, email, and alternative contacts) almost half of our lost to follow-up participants were identified.

Secondly, Facebook can assist with identifying participants who are at risk of loss to follow up given that those who were re-engaged were younger, unmarried, had a lower household income, less education, and were more likely to identify as non-Caucasian compared to ongoing participants. This is consistent with other studies where more vulnerable groups are more susceptible to lost to follow-up [20,21]. Of note, among those lost to follow-up, there were no differences between those who were found through Facebook and those that were not identified.

Although this study was able to use Facebook to identify participants without a priori data collection, collection of Facebook specific identifiers at study outset is recommended if possible. Facebook's privacy settings are continually changing to keep up with the public demand for privacy and security of data, and it may become more difficult to use Facebook to connect with participants. Unlike phone or email, Facebook URLs are associated with longer periods of use [4]. Collection of Facebook ID at time of recruitment would expedite the process of connecting with participants and would increase confidence that the profile corresponds to the study participant. Researchers using any type of social media to engage participants should remain vigilant to the dynamic nature of privacy settings on social media platforms.

This method should be adapted depending on the demographic of the particular study. For this study, Facebook was the best social media platform to use as the median age of the All Our Families
cohort and the typical age of Facebook users overlapped. However, if looking at a younger cohort other social networking sites should be considered as they may be of greater benefit. The use of social media to engage participants brings in new ethical considerations and early incorporation of possible social media use in the informed consent process is recommended. Social media technology is innovative for recruitment and retention as it encourages the free sharing of information through an interactive and expanding platform. Although all of our participants agreed to participate in the follow-up studies and signed consent forms allowing us to contact them in the future, explicit consent from participants at study outset for use of social networking sites for both knowledge dissemination as well as participant communication would reduce the likelihood of participants finding this form of contact intrusive.

This study had some limitations, including a small sample size. 237 participants were identified as lost to follow-up after the 7th wave of data collection in the All Our Families pregnancy cohort. This sample size limits the statistical power when determining differences between those found and those not found. However when considering the literature surrounding finding, contacting and re-engaging lost to follow-up participants our sample size is consistent with other studies [16,21]. An additional limitation is that only one social media platform was used to re-contact participants, and these efforts were limited to a three month period. This proposed method of contacting lost to follow-up participants using Facebook was initiated in June of 2016 and completed in August of 2016, for a total data collection period of 3 months. The short time frame of our social media presence may have limited the effectiveness in contacting and re-engaging lost to follow-up participants, especially considering the summer season. Our participants are mothers of school aged children, and this same protocol at another time of year may increase the likelihood of contacting and re-engaging participants. Additionally, our Facebook profile was created specifically for this study in May of 2016. Had Facebook or other social networking sites been integrated earlier into the study protocol it may have been more successful at re-engaging lost to follow-up participants or reducing attrition over the 7 waves of follow.
The results from this study demonstrate that social networking sites, such as Facebook should be included in the development of retention practices, and can be implemented at any point in cohort follow-up.

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CONFLICTS OF INTEREST

None declared

REFERENCES


