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Disseminating Aggregate Research Findings to Participants

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Introduction

It is becoming increasingly common to return individual-level research results to participants, especially in genetic studies (1). Yet, when the study ends, it is rare for participants to learn the study's aggregate results (2). The contributors to this include limited time and funding, limited expertise in effective communication with non-medical audiences, and journal embargo policies. The ethical reasons for returning aggregate trial results include respect for participants' time, promoting trust, and sharing information with those who made the results possible. However, there is a paucity of evidence to inform effective approaches to provide aggregate study results to participants (3–5).

Methods

The purpose of this report is to detail our approach to returning the aggregate results of a recent randomized controlled trial to participants (6). Based on focus group input, we developed three communication formats, using principles of low-health literacy/numeracy: a 1-page text-based summary, a 1-page infographic, and a 2-minute video. Each format offered both English and Spanish versions. The content of each method was identical, highlighting why the research was conducted; what was done; and what was found. The messaging also emphasized our appreciation for research participants. Participants received a text message with a web-link to aggregate results. To study the acceptability of these formats and identify participant preferences, we also invited participants to complete a brief survey. Interested participants completed electronic informed consent and received a \$10 gift card. The Vanderbilt University Medical Center IRB approved this study.

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Author Contributions: All authors had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Ethical Considerations: Participants completed an electronic informed consent process, approved by the Vanderbilt University Medical Center IRB.

Conflict of Interest Disclosures: We have no conflicts of interest to report.

For each communication method, participants were asked about the ease of understanding and to rank their preferred format. Participants were also asked whether receiving these results would impact their participation in future research studies.

Results

Among the 610 participants in the original trial (90% Latino, 10% Black, non-Hispanic), we sent 551 text messages (the number of participants retained at the end of the study), 206 participants accessed the results website (a secure REDCap database), and 120 completed the survey. All three communication formats were rated as “very easy” or “somewhat easy” to understand, including 85% for the print-based method, 83% for the infographic, and 93% for the video. In addition, 97% of participants reported that each format provided sufficient information. The preferred communication format was video (63%), followed by the infographic (28%), and the print-based (9%) versions. Among participants who completed the survey, 72% indicated that they were “very willing” to participate in future research with 21% “somewhat willing,” 6% “neutral”, and <1% “somewhat unwilling.” Receiving these results increased willingness to participate in research among 73% of respondents, with 25% no change.

Discussion

Returning aggregate research results to a population of low-income predominantly Latino participants suggested that the approach was easily understood, sufficient, and increased willingness to participate in future research. The preferred method of receiving results was a video summary, but a multi-modal distribution approach may be most effective, based on participant choice.

This study has some limitations. First, the time between study completion and communication of study results was more than 2 years, an intrinsic limitation to the current paradigm of reporting results. Second, many participants had changed cell-phone numbers, limiting the reach of this process to approximately one-third of the original sample and introducing the possibility of a responder-bias.

The time is right to set new standards in research dissemination. Dissemination plans and journal policies should address the return of aggregate study findings to research participants. This represents an untapped opportunity to improve the relationship between the academic research enterprise and the public. And, it’s the right thing to do.

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Impact:

1. What is the key message of your article?

Returning aggregate research results to a population of low-income predominantly Latino participants suggested that the approach was easily understood, sufficient, and increased willingness to participate in future research. The preferred method of receiving results was a video summary, but a multi-modal distribution approach may be most effective, based on participant choice.

2. What does it add to the existing literature?

This reports an evaluation of preferred methods for returning aggregate research results to participants.

3. What is the Impact?

We are proposing a new paradigm in dissemination of aggregate research, where aggregate results are regularly returned at the end of the trial.