



## Researchers' experiences with and perceptions of returning results to participants: Study protocol



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### ABSTRACT

**Background:** Health research participants want to receive the results from research studies in which they have participated, and health research funding agencies encourage the returning of results to research participants. However, researchers rarely return results to research participants. This study protocol aims to fill the significant gap in knowledge that exists regarding experiences, perceptions, and challenges health researchers have with returning results to research participants.

**Design:** The study will use a mixed-methods concurrent triangulation design that will collect qualitative and quantitative data in one simultaneous phase to allow researchers to utilize each type of data to corroborate the findings from the other. The research team developed a mixed-methods survey to assess the experiences, perceptions, and challenges health researchers have with returning results to research participants.

**Method:** The survey includes both quantitative and qualitative (open-ended) questions and will be implemented online and will take approximately 10–15 min for respondents to complete. The survey is divided into four topics areas, which include respondents': 1) general opinion of returning results to participants in health research studies, 2) experiences with a specific study in which they did not return results to participants, 3) perceptions of specific challenges they face in returning results to participants, and 4) demographic characteristics and professional background information.

**Summary:** The study to be conducted will address knowledge gaps related to researchers' experiences, perceptions, and challenges with returning research results. The study is an important step toward pragmatic solutions that can improve researchers' ability to return results to participants.

### 1. Introduction

Health research participants report that they want to know the results of the studies in which they have participated [1–6]. Some institutional review boards (IRBs) and research ethics boards require researchers to provide plans for returning study results to participants in their study protocols [7–9]. Additionally, health research funding agencies, such as the Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI), acknowledge the need to increase the returning of research results to nonacademic audiences [10,11].

Despite these factors encouraging dissemination of results to research participants, results are rarely returned to people who have participated in the research [12,13]. Long et al. found that only

approximately 33% of 3381 participants from a wide range of studies received results [13]. Even among community-based participatory research (CBPR) studies, which has been highlighted as an effective way to engage participants, a systematic review of 101 journal articles found that only 48% of CBPR studies reported returning the results of their research to participants beyond traditional peer-reviewed publications [14]. Health researchers state that they are supportive of returning research results to participants [7,14–18]. However, researchers acknowledge that they often fail to return research results to participants [13,14,16,17].

Prior research suggests that returning results to participants may be impeded by researchers' uncertainty on how to best implement the dissemination of results to participants [19]. However, very little is known about what impediments researchers face in returning results to

**Abbreviations:** IRBs, Institutional review boards; AHRQ, Agency for Healthcare Research and Quality; PCORI, Patient-Centered Outcomes Research Institute; CBPR, Community-based participatory research; CTSA, Clinical and Translational Science Award

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participants. Few studies have examined researchers' experiences and perceptions in returning results to study participants. The limited studies available focus on documenting the perspectives of specific types of researchers, such as oncologists. For example, a 2004 study that surveyed 796 health care oncology providers found the three most reported challenges to sharing results were concerns about: the potential negative emotional effect on participants (60%), participants' difficulty understanding results (54%), and consumption of resources, including money and clinician time to complete dissemination (39%) [16]. Beyond that one article, little is known about the reasons why researchers are not returning study findings to participants, and this lack of knowledge has been cited as a significant gap in knowledge.

In 2013, after reviewing research on dissemination strategies, AHRQ documented significant gaps in knowledge exists regarding returning of research results and called for additional research [20]. Despite research funders increased emphasis on returning results to participants, much remains unknown regarding researchers' experiences, perceptions, and challenges with participant-level dissemination. It is important to address these knowledge gaps because returning results to participants is a crucial component in advancing translational science. The study to be conducted responds to AHRQ's report and will characterize researchers' experiences, perceptions, and challenges with participant-level dissemination. This paper describes the protocol of a mixed-methods study designed to understand researchers' experiences with and perceptions of participant-level dissemination.

## 2. Methods

The study is approved by the University of Arkansas for Medical Sciences (UAMS) Institutional Review Board (#205983).

### 2.1. Study aims

The primary aim of the study is to understand and document researchers' previous experiences with and perceptions of returning results to participants. A secondary aim of the study is to understand and document the challenges that researchers encounter when attempting to return research results to participants.

### 2.2. Study design

The study will use a mixed-methods concurrent triangulation design. A mixed-method concurrent triangulation design collects qualitative and quantitative data in one simultaneous phase and allows researchers to use each type of data to corroborate findings from the other [21–27]. In a mixed-method concurrent triangulation design, study data is analyzed separately and then combined during the interpretation phase. This method will allow us to cross-validate and confirm

study findings to provide a more complete illumination of the research question. The mixed-method concurrent triangulation design will allow us to overcome the inherent weaknesses of using qualitative or quantitative methods separately [21–27].

Using the mixed-method concurrent triangulation design, the research team developed a mixed-methods survey to assess the experiences, perceptions, and challenges health researchers have with participant dissemination. After the survey was initially drafted, the research team reviewed the content questions and discussed revisions. The survey went through four rounds of revision and refinement before a final draft was approved by consensus of the researchers.

The survey will be implemented online using Research Electronic Data Capture (REDCap) [28]. The survey takes approximately 10–15 min for respondents to complete. The survey is divided into four topic areas that will measure respondents': 1) general opinion of returning results to participants in health research studies, 2) experiences with a specific study in which they did not return results to participants, 3) perceptions of specific challenges they face in returning results to participants, and 4) demographic characteristics and professional background. Among the specific challenges that will be evaluated by survey respondents are: 1) financial challenges, 2) ethical concerns, 3) logistical/methodological/skill-related challenges, and 4) systemic challenges (e.g., lack of career-related incentives to disseminate results to participants).

Surveys will collect quantitative and categorical data from respondents for each of the four topic areas. Closed-ended single- and multiple-response items, yes/no items, and percentage slider items are used for respondents to report their experiences and perceptions of returning study results.

In addition, eight open-ended survey items will collect qualitative data. The open-ended items will allow researchers to provide in-depth responses about their perceptions and experience regarding returning results to participants and to describe specific challenges that they encountered with participant-level dissemination. The open-ended items will ask respondents to: 1) explain why they believe results should always be returned to participants, 2) explain why they are not sure whether or not results should always be returned to participants, 3) describe reasons why they believe results should not always be returned to participants, 4) describe the reason(s) they did not return a study's aggregated results to the participants, 5) describe any financial challenges that have discouraged them from returning results to research participants, 6) describe any ethical concerns that have discouraged them from returning results to research participants, 7) describe any logistical/methodological/skill-related challenges that have discouraged them from returning results to research participants, and 8) describe any systemic challenges that have discouraged them from returning results to research participants (see Table 1).

**Table 1**  
Open-ended survey questions.

Themes	Open-ended survey questions
Why results should be returned	● Please take a few sentences to explain why you believe results should always be shared with participants.
Why results should not be returned	● Please take a few sentences to explain why you are not sure whether or not results should always be shared with participants.
Challenges to returning results to research participants	● Please take a few sentences to describe reasons why you believe results should NOT always be shared with participants.
	● Please briefly describe the reason(s) why you did not share the study's aggregated results with the participants. For example, please describe any actual (or anticipated) barriers you encountered.
	● Please take 1–2 sentences to describe any financial barriers that have discouraged you from disseminating results to research participants.
	● Please take 1–2 sentences to describe any ethical concerns that have discouraged you from disseminating results to research participants.
	● Please take 1–2 sentences to describe any logistical/methodological/skill-related barriers that have discouraged you from disseminating results to research participants.
	● Please take 1–2 sentences to describe any systemic barriers that have discouraged you from disseminating results to research participants.

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