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Qualitative study of participants' perceptions and preferences regarding research dissemination

Rachel S. Purvis^a, Traci H. Abraham^b, Christopher R. Long^c, M. Kathryn Stewart^d, T. Scott Warmack^e, and Pearl Anna McElfish^f

^aOffice of Community Health and Research, University of Arkansas for Medical Sciences Northwest, Fayetteville, Arkansas, USA

^bCentral Arkansas Veterans Healthcare System, Eugene J. Towbin Healthcare Center, North Little Rock, Arkansas, USA

^cCollege of Medicine, Department of Psychiatry, Division of Health Services Research, University of Arkansas for Medical Sciences Northwest, Fayetteville, Arkansas, USA

^dDepartment of Health Policy and Management, University of Arkansas for Medical Sciences, Little Rock, Arkansas, USA

^eCollege of Pharmacy, University of Arkansas for Medical Sciences Northwest, Fayetteville, Arkansas, USA

^fCollege of Medicine, Department of Internal Medicine, Office of Community Health and Research, Center for Pacific Islander Health, University of Arkansas for Medical Sciences Northwest, Fayetteville, Arkansas, USA

Abstract

Background—The study identifies the experiences, preferences, and perceptions of research participants regarding dissemination of research findings at the participant level and community level.

Methods—The qualitative study utilized focus-group methodology to explore research participants' experiences and preferences for the dissemination of research findings. Five focus groups were held with 53 participants who were recruited through existing community advisory boards in Arkansas.

Results—Participants stated that researchers should always offer to share research findings. Participants explained that disseminating findings is appropriate because of their sense of

Contact: Pearl Anna McElfish, pamcelfish@uams.edu, University of Arkansas for Medical Sciences Northwest 1125 N. College Ave., Fayetteville, AR 72703, USA.

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ownership of results, it encourages participation facilitating higher quality research, and it may foster greater trust between researchers and participants. Participants also provided insights on how research findings should be shared, including recommendations for appropriate mode, timing, and context, as well as ways to share sensitive findings and the role of community partners in dissemination.

Conclusions—This study is consistent with other studies that document participants' desire to receive research findings and expands our knowledge by documenting participants' rationale for why they think it is important and their recommendations for how to share results. Further research is needed to understand why researchers are not disseminating study findings to participants and to test the best ways to share results.

Keywords

biomedical research; human subjects research; professional ethics; research ethics; public health

There is increased discussion about returning research findings to the participants and communities involved in research (Brownson et al. 2013; Chen et al. 2010; Rigby and Fernandez 2005; Shalowitz and Miller 2008). Return of research findings has been encouraged in part by research funders, such as the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and the Patient-Centered Outcomes Research Institute (PCORI), which have called for increased dissemination of research findings to participants and communities (Glasgow et al. 2012). Furthermore, institutional review boards (IRBs) and research ethics boards (REBs) often ask researchers to include participant- and community-level dissemination plans in study protocols (Fernandez et al. 2003; Fernandez, Skedgel, and Weijer 2004; Markman 2006). Although there is a broad call for the dissemination of research findings to participants, researchers rarely do so (Chen et al. 2010; Partridge et al. 2004; Rigby and Fernandez 2005).

Most previous studies of participants' experiences, preferences, and perceptions with respect to the dissemination of research findings show that participants have a high desire to receive findings; however, these studies focused on specific diseases (Dixon-Woods et al. 2006; Partridge et al. 2005; Fernandez et al. 2009; Baylor et al. 2013; Trinidad et al. 2015). Therefore, it has been difficult to determine participants' general beliefs and preferences for the dissemination of research findings. Some researchers have voiced concerns that sharing negative or stigmatizing study findings can do more harm than good (Lorimer et al. 2011; Murphy et al. 2008; Partridge et al. 2005; Shalowitz and Miller 2008). While researchers may be hesitant to return findings in these instances, participants have overwhelmingly stated they want findings even when these are negative or may have a negative emotional impact (Shalowitz and Miller 2008; Snowden, Garcia, and Elbourne 1998).

A recent study utilized the ResearchMatch participant registry to gauge preferences of a relatively large group of respondents ($n = \sim 3000$) in an effort to determine preferences for dissemination from a larger sample of respondents not directly connected to a disease specific study (Long et al. 2016). The ResearchMatch registry is a large database of $\sim 105,000$ past, present, and potential health research participants. While 95.6% reported a

desire to receive research findings, only 33% of participants reported receiving research findings, and more than half reported they were not given an opportunity to request findings (Long et al. 2016). Respondents indicated a preference for relatively low-cost dissemination methods, such as e-mails or study website postings (Long et al. 2016). Those who did receive results reported high satisfaction with the method of dissemination. While this study added much to the literature, the survey was limited in its ability to explain how and why participants wanted results returned.

Community-based participatory research (CBPR) approaches have shown promise in harmonizing participants' desires to receive findings and researchers' attempts to share findings at the participant and community level (Chen et al. 2010; Minkler and Salvatore 2012). The study described in this article was conducted in collaboration with four ongoing CBPR partnerships of community stakeholders and researchers from the University of Arkansas for Medical Sciences (UAMS). These CBPR partnerships allowed us to recruit racially and ethnically diverse participants with varying socioeconomic levels, thus capturing a broad range of experiences and preferences. The study was intended to expand knowledge about dissemination through inclusion of a broad, diverse sample of participants, thereby shifting the discussion concerning the sharing of findings back to the participants and communities involved.

Methods

Participants and recruitment

Focus-group methodology was utilized to explore participants' experiences with the sharing of findings from studies in which they had participated, and to understand participants' preferences for dissemination of research findings in general in order to improve participant- and community-level dissemination. Fifty-three participants were recruited by partnering with established community advisory boards in three geographic regions of Arkansas (Central Arkansas/Little Rock, the Delta Region, and Northwest Arkansas). Each community advisory board is a part of UAMS's Translational Research Institute's CBPR partnerships with the Hispanic and Marshallese communities of Northwest Arkansas and the African American communities of Central Arkansas and the Mississippi River Delta region. To recruit participants, we used a purposive sampling method and asked community advisory board members and UAMS staff working with the community advisory board to invite persons who had been involved in research projects in some capacity. These community members have been involved in a variety of roles; some were members on community advisory boards, others had been community co-investigators, and many had been research participants in a range of studies that included clinical trials, behavioral interventions, and longitudinal studies.

Five focus groups were held in community rooms in each of the regions: two in Central Arkansas ($n = 5$; $n = 8$), one in the Delta ($n = 12$), and two in Northwest Arkansas ($n = 12$; $n = 16$). Participants were given a study information sheet and provided verbal consent. A brief demographic survey was completed by 52 of the 53 participants prior to the start of the focus-group discussions. An interview guide with open-ended questions was utilized to elicit experiences, perceptions, and preferences regarding dissemination in participants' own

words. Focus groups were recorded and transcribed verbatim. There was a recording failure with one focus group; however, detailed notes were taken by the facilitator and a research associate.

Analytic strategy

A coding template was identified as the most appropriate strategy to analyze the focus groups data (King, Cassell, and Symon 2004; Nadin and Cassell 2004). Two experienced qualitative researchers developed a preliminary coding template with deductive domains reflecting the goals of the study, including (1) prior experiences with research dissemination, (2) attitudes toward dissemination, (3) motives for wanting research findings, (4) the effect of dissemination strategies on respondents, and (5) recommendations for dissemination. Researchers coded the data and then extracted data from the transcripts to conduct further analysis. Emergent subcategory themes were identified and incorporated into the coding template. Illustrative excerpts from the interviews were included for each domain included in the template. The research team critically reviewed each analysis product, ensuring analytic rigor and reliability by confirming that the data and illustrative excerpts were extracted to the correct domain. Discrepancies in data interpretation were discussed and resolved via consensus.

Results

Respondent characteristics

Demographic characteristics of respondents are presented in Table 1. The majority of respondents were female (73.1%). The mean age of respondents was 44.6 years (range = 18–83). More than one-third (38.5%) of the respondents identified as black, just less than one-third (30.8%) as Hispanic/Latino, and almost one-quarter (23.1%) as Native Hawaiian/Pacific Islander. Only 7.6% of the respondents self-identified as white. Of those respondents with previous research experience as study participants (62.7% of the total), 31.3% reported having received research findings, while 62.5% stated that they either were not given the opportunity to request findings or had requested findings without receiving them. A majority of respondents (89.4%) reported on the brief survey that researchers should always offer research findings to participants (see Table 1).

What follows are reports on key themes present in the data.

Prior experience with research dissemination

Overall, respondents who had prior experience with research and who received research findings from studies they had participated in were satisfied with the way they received the results. However, those who did not receive results from the study they participated in expressed negative emotions. For example, one respondent described a lack of closure after having participated in a clinical trial without receiving findings, despite this person's request to researchers to receive the study findings. This left the respondent dissatisfied because “for me to have participated and think that it was a beneficial thing” but never receiving results made her feel “kind of like I was hanging in the wind with that particular process [of dissemination]” (Focus Group [FG] 3). Another respondent shared his experience with

receiving findings concerning the prevalence of sexually transmitted infections in his community. For this particular person, and for others with similar experiences, the sharing of these findings was important and had an influence on their future health behavior. In his words, “Seeing those results and those numbers brought it home and made it real and [that is] extremely important” (FG 4).

Respondents' attitudes toward dissemination, motives for wanting findings returned, and the effect of receiving findings

Respondents overwhelmingly stated that researchers should always offer to share findings at the participant and community levels. Respondents explained that disseminating findings is appropriate because they have a sense of ownership of the findings. In addition, they shared their belief that dissemination encourages participation in research, which can facilitate the production of high-quality research, as well as fostering trust between researchers and participants.

Individual ownership of results

Respondents expressed an attitude of ownership of the findings from research studies in which they had participated. Participants described that while they agreed to participate in the research and provided requested samples and information, they still “owned” that information. They explained that disseminating the results back to participants and communities was an important part of acknowledging participants' retained ownership of the information. For example, a respondent explained, “You took my blood [during the research], so really those results are mine” (FG 1). Another respondent said, “You should never come to take my information, be it my health, be it my ideas or thoughts or anything from me and not let me know how you are using it” (FG 5). Ownership of their findings from research in which they had participated was mentioned by respondents across all five focus groups. The concept of ownership was connected to the idea that sharing findings encouraged participation. As one respondent hypothesized, the sharing of results “also gives a sense of more ownership in the study, so that [participants] are more likely to follow the program because they ... feel they are a part of something” (FG 4). Ultimately, respondents explained that they want to receive research findings to fulfill the implicit contract between researcher and participant and to validate that their participation mattered and was counted. “It's publicly funded and government funded and we have all this information so why don't we give it back to participants of that study?” (FG 4).

Community ownership

This sense of ownership extended to communities that participated in research, as well. This theme was present in all five focus groups. “I just think that anything that has to do with the community, whether you are a participant or not, everyone in that community should get the information,” one respondent stated (FG 5). Another respondent expressed, “When there is a community as a whole that is participating in research ... there may be something that researchers may learn that could be shared in a way that could impact the community or impact some change” (FG 3).

Encourages participation and facilitates higher quality research

The sharing of findings encourages participation, according to some respondents, because it demonstrates to research participants that their participation may potentially offer both personal and collective health benefits. One respondent expressed that receiving findings encouraged her to participate in another phase of a study because the research had the potential to benefit the broader community. Receiving findings “could actually be very impactful,” the respondent explained, because “the light bulb came on ... that it could potentially benefit a whole community ... and that was helpful to me and motivating for me” to agree to participate in the next phase of the study (FG 3). Respondents also explained that receiving findings demonstrated that their participation mattered and was valued by researchers. A respondent explained, “Don't just ask me my opinion and then throw it to the side. And that's how it makes it seem when ... I don't get results back. I think that's a lot of time how people feel when they don't hear anything back from it” (FG 5). Respondents also asserted that dissemination can produce better study results in the future because participants are more invested in the study outcomes. One respondent explained, “People will be more honest with you when answering questions” because when “you show me that you really do care about what I say, then I may take a little bit more time and answer [survey questions] correctly” (FG 5).

Encourages greater trust between researchers and participants

Respondents across all focus groups also stated findings dissemination could foster trust among participants for researchers, thus encouraging them to join future studies. A respondent explained that building trust with researchers takes time, and establishing long-term relationships with communities and sharing study findings showed participants “that [researchers] care and [they are] not ... trying to build their career off this community” (FG 3). Respondents also directly tied a lack of dissemination to distrust of researchers conducting the study. As a respondent expressed, not sharing findings is distressing and causes participants to feel their involvement in research is unimportant “because [participants] don't know what [researchers are] doing with the information” (FG 3).

Respondents' recommendations for how and when to share findings

Respondents explained the best way to share findings depended on the type of study being conducted. Dissemination methods, they insisted, must also take into consideration the specifics of the participant population, such as gender, age, educational level, and cultural backgrounds, when assembling dissemination plans. Respondents provided insights into how findings should be shared, including recommendations for appropriate mode, timing, and context. Respondents also provided recommendations for how sensitive results should be shared and the role of community partners for dissemination.

Appropriate mode

The question about the preferred mode for sharing findings produced the widest variety of responses. Younger respondents expressed openness to receiving findings via e-mail, via text, or through other social media, while older respondents generally preferred standard mail or face-to-face communication and, less often, telephone. In this respect, one

respondent stated how findings are shared “depends largely on your [study] population” because older participants “may not even have an e-mail address or use Facebook or Twitter or YouTube” as modes of communication (FG 4). Certain modes of dissemination, like phone calls, texts, and academic publications or presentations, were the least preferred ways of receiving findings. Despite the variance of responses, respondents agreed that findings should be presented in a variety of ways (e.g., in writing, using graphs) and in language free of academic or medical jargon to ensure understanding among participants of varying educational levels. As one respondent explained, “If [findings are] not shared in a way that is layman’s terms or something that they understand, then it also puts up a barrier to participate again” (FG 3). Some respondents also noted that researchers should use interpreters to present findings when there are language differences. Respondents overwhelmingly stated that researchers should offer findings in multiple ways and participants should be allowed to select from a list of preferred methods of dissemination, which they suggested be offered at the time of consent.

Timing

When discussing the timing of dissemination, respondents overwhelmingly reported they would like to receive updates about a study’s progress throughout the duration of the research project. Some thought periodic check-ins might encourage greater engagement in the research by study participants. They recommended that recruitment and study progress updates be given at intervals during the course of the study, in addition to research findings at its conclusion. “I think there still needs to be some base touching,” one respondent stated, “whether you give them any information other than to say: ‘Hey, we’re still working on this’” (FG 4).

Context

Respondents across all five focus groups said findings should be contextualized to help recipients of the information understand the generalizability of findings. As a respondent explained, researchers should remind participants “this is a small study... you might have different results [with a larger study population] and that needs to be made clear” (FG 4). Another respondent emphasized researchers “have to make it clear that it’s the results of the whole study” to help participants understand the difference between their individual results and aggregate study findings (FG 4).

Sharing sensitive findings

While an overwhelming majority of respondents said researchers should always share findings, they also debated when and how to share findings with the potential to harm or stigmatize an individual or community. Focus group participants were asked: 1) Is there any reason, in your opinion, why participants should not be given research results?; and 2) For example, should researchers not share findings that may stigmatize either a participant or a community, such as findings about the prevalence of an infectious disease like tuberculosis? One respondent stated while she was not entirely comfortable sharing potentially stigmatizing findings, withholding such information “would also feel unethical...even if it might be difficult information to hear” (FG 3). Although almost all were in favor of disseminating sensitive findings, respondents repeatedly stated researchers must consider the

proper way to communicate sensitive findings. A few encouraged avoiding stigmatization by engaging public health organizations, such as the health department, in providing context that would “help community members cope with difficult health information” (FG 5).

Involving community partners

Many respondents stressed the importance of collaborating with trusted community leaders for dissemination at the community level. Respondents suggested that working with trusted community partners would allow researchers to communicate properly important findings in a culturally and contextually appropriate way. Collaborating with community leaders would also allow researchers to help communities understand the potential impact of study outcomes. As one respondent explained, “If you bring some information about our community to ... leaders, people that we believe and trust, we will hear them, but you have got to be sure that they understand [the results] and are willing to share [them]” (FG 5).

Discussion

Although dissemination of research findings is not typically performed by researchers at the participant level and community level, participants have reported a strong preference for receiving them (Cox et al. 2011; Murphy et al. 2008; Partridge et al. 2003; Partridge et al. 2005; Shalowitz and Miller 2008). The literature available shows that participants particularly want to receive findings that are significant for their personal health or a family member's health, that they believe they have a right to these findings (Fernandez et al. 2007), and that they think sharing findings demonstrates researchers' respect for their participation (Shalowitz and Miller 2008). The findings of this study are consistent with prior studies and provide greater understanding of why dissemination is important, as well as insights underlying respondents' recommendations for how and when to share findings. For respondents, the sharing of study findings is an important step that fulfills the social contract between the researcher and the research participant. Sharing knowledge can promote changes that benefit society and potentially improve health outcomes, which is an important part of a health professional's contribution to the field of public health (Sinha 2011). Respondents stated that they want research findings because they have a right to the findings and expressed a sense of ownership of the findings. Respondents' statements concerning this sense of ownership went beyond individual ownership to include a collective sense of ownership of and the value of disseminating of study findings. The theme of ownership at both the individual level and community level emerged across all focus groups and was a consistent point respondents stressed when describing why findings should be shared with the individual and communities participating in the research. Sharing findings also validates respondents' participation and demonstrates that researchers value their time. Respondents also stated that dissemination encourages future participation in research and fosters trust among participants for researchers, which respondents assert will improve the quality of research. Respondents had several recommendations about when and how to share research findings. In addition to receiving findings at the completion of a study, many respondents stressed the need for updates to keep participants engaged throughout the study. Respondents also recommended that researchers provide findings in multiple formats that participants could choose from at the time of consent. Likewise, respondents highlighted the

need for researchers to provide context for the results that they provide (e.g., to explain that aggregate results do not necessarily describe the variance in outcomes experienced by individual participants).

Limitations and strengths

The study findings are based upon the preferences and experiences of people who were recruited from existing CBPR partnerships that are intended to encourage greater participation in research among minority populations in Arkansas. As a result, our findings may not be generalizable to the broader U.S. population. Despite this limitation, the study provides one of the first qualitative studies of respondents' general experiences, perceptions, and preferences related to research dissemination, and provides recommendations directly from participants that can propel knowledge and future research regarding dissemination forward.

Future research

While there is broad support for dissemination of research results to participants and communities, dissemination is hindered by pragmatic concerns about how to carry it out (Miller et al. 2008). Additional research is needed to understand why researchers do not disseminate findings to participants and communities, specifically the barriers and facilitators to dissemination. CBPR has shown promise in communication about research with communities, yet researchers have found that even CBPR studies are not better with sharing findings. A 2010 systematic review found dissemination beyond academic publications was only reported in 48% of the CBPR articles, and various challenges and barriers to timely and widespread dissemination were identified (Chen et al. 2010). Initiatives developed among researchers conducting CBPR may be a good start to gather and act on best practices regarding the dissemination of research findings.

In all focus groups, respondents said they strongly desired receiving results from studies they had participated in because of their sense of ownership of the research results. Respondents stated that better dissemination practices and policies will encourage greater participation in research and will result in better science. Additionally, respondents explained that the failure to share results leads to a lack of trust among participants for research. Respondents stated this distrust also may affect researchers' ability to recruit study participants, especially for clinical trials. Respondents offered researchers a variety of preferences for communicating research results to study participants and stressed the need to present results in different ways to ensure they are understood by participants from various educational levels. While researchers are often more focused on the barriers to participant- and community-level dissemination, respondents clearly expressed that they want to receive study results. Further research is needed in order to understand why researchers are not disseminating findings to participants.

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Table 1

Respondent demographics and experiences with research.

Response category	<i>n</i> (<i>N</i> = 52)	Percent of sample (%)
Age (years)		
18–24	6	11.5
25–34	11	21.2
35–44	9	17.3
45–54	13	25.0
55–64	7	13.5
65C	6	11.5
Gender		
Male	14	26.9
Female	38	73.1
Race		
White (non-Hispanic)	4	7.7
Black	20	38.5
Hispanic/Latino	16	30.8
Native Hawaiian/Pacific Islander	12	23.1
Have you ever participated in research?		
Yes	32	62.7
No	19	37.3
Did you receive the results of the study?		
Yes, but I did not request them	7	21.9
Yes, I requested that results be given to me	3	9.4
No, I was not given opportunity to request results	19	59.4
No, I requested results but did not receive them	1	3.1
No, I chose not to receive them	2	6.3
Should researchers offer results to participants?		
Yes, always	42	89.4
Yes, sometimes	4	8.5
No, never	1	2.1

Note. Percentages are based on the number of valid responses to relevant items. Due to rounding, percentages may not sum to 100%.