

# Health research participants' preferences for receiving research results

*Clinical Trials*

1–10

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## Abstract

**Background:** Participants in health research studies typically express interest in receiving the results from the studies in which they participate. However, participants' preferences and experiences related to receiving the results are not well understood. In general, the existing studies have had relatively small sample sizes and typically address specific and often sensitive issues within targeted populations.

**Methods:** This study used an online survey to explore attitudes and experiences of registrants in ResearchMatch, a large database of past, present, and potential health research participants. Survey respondents provided information related to whether or not they received research results from studies in which they participated, the methods used to communicate the results, their satisfaction with the results, and when and how they would like to receive research results from future studies. In all, 70,699 ResearchMatch registrants were notified of the study's topic. Of the 5207 registrants who requested full information about the study, 3381 respondents completed the survey.

**Results:** Approximately 33% of respondents with previous health research participation reported receiving the results. Approximately half of respondents with previous research participation reported no opportunity to request the results. However, almost all respondents said researchers should always or sometimes offer the results to participants. Respondents expressed particular interest in the results related to their (or a loved one's) health, as well as information about studies' purposes and any medical advances based on the results. In general, respondents' most preferred dissemination methods for the results were email and website postings. The least desirable dissemination methods for the results included Twitter, conference calls, and text messages. Across all the results, we compare the responses of respondents with and without previous research participation experience and those who have worked in research organizations versus those who have not. Compared to respondents who have previous participation experience, a greater proportion of respondents with no participation experience indicated that the results should always be shared with participants. Likewise, respondents with no participation experience placed higher importance on the receipt of each type of results' information included in the survey.

**Conclusion:** We present findings from a survey assessing attitudes and experiences of a broad sample of respondents that addresses gaps in knowledge related to participants' preferences for receiving the results. The study's findings highlight the potential for inconsistency between respondents' expressed preferences to receive specific types of results via specific methods and researchers' unwillingness or inability to provide them. We present specific recommendations to shift the approach of new studies to investigate participants' preferences for receiving research results.

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## Keywords

Results' dissemination, results' communication, disseminating results, participant preferences, research results, dissemination, social media dissemination, dissemination survey, ResearchMatch, participant registry

Members of the research community often express support for communicating research results to research participants and to the general public.<sup>1–7</sup> To this end, institutional review boards (IRBs) and research ethics boards often require researchers to address plans for the dissemination of study results in their study protocols.<sup>3,8,9</sup> Likewise, research funders—including the United States National Institutes of Health (NIH), Patient-Centered Outcomes Research Institute, and Agency for Healthcare Research and Quality—have emphasized the importance of dissemination of the results to nonacademic audiences.<sup>10–12</sup>

Despite the recommendations to disseminate the results to participants and communities, participant- and community-level dissemination may be rarely implemented by researchers. One survey of oncology physicians and nurses found that 72.4% of respondents believed most participants wanted to know the results of clinical trials, yet 62.4% of respondents shared trial results with participants less than 20% of the time.<sup>4</sup> Likewise, among 158 researchers presenting at an American Society of Hematology Annual Meeting, 69% supported returning research results to participants, but only 30% of the researchers had a plan to offer the results to participants.<sup>5</sup> Similarly, it is rarely clear from the published research articles whether or not the results have been communicated to participants or the general public. A review of 101 journal articles reporting on community-based participatory research studies found that only 48% indicated further dissemination beyond publication of the articles.<sup>2</sup>

While many in the research community express support for communication of the results, some researchers have raised ethical concerns related to the consequences of communicating the results to participants.<sup>9,13,14</sup> Researchers have expressed concern about participants receiving research results that they find difficult to understand or emotionally troubling.<sup>1,15–17</sup> A 2008 review of research on participants' responses to receiving research results found participants report a range of positive and negative reactions, ranging from anxiety, anger, or guilt to relief or pleasure.<sup>18</sup> In addition, unintended consequences can result from participants' uncertainty with what to do with the results or from researchers' uncertainty with how best to present the results or which results to share with participants.<sup>13</sup>

Nevertheless, the 2008 review examined nine studies reporting percentages of participants who indicated preferences for receiving the results; it found a median of 90% of participants reported wanting to receive the results.<sup>18</sup> Prominent among participants' reported

motives to receive the results are that the results carry potential clinical implications for themselves or their loved ones and that participants have a general right or need to know the results of studies in which they participated.<sup>15,18–21</sup>

Taken together, the existing studies about communicating research results to participants suggest the following pattern: participants and research team members typically express support for communicating research results; the results are seldom communicated to participants; when the results are communicated, participants' responses may include positive or negative emotions (or both).<sup>18</sup>

There are limitations to generalizing across the results of the existing studies of participants' reactions and preferences related to receiving research results: In general, the existing studies have had relatively small sample sizes and typically address specific and often sensitive issues within targeted populations. Representative examples include studies of 20 participants in a UK trial of prenatal antibiotics;<sup>19</sup> 24 potential participants (or parents of potential participants) in a study testing children for neurodevelopmental deficits;<sup>22</sup> 44 participants in a UK dementia study;<sup>23</sup> 135 US participants in a phase II trial of breast excision as breast cancer treatment;<sup>24</sup> 409 Canadian and US parents of children with cancer and 86 adolescents with cancer;<sup>20</sup> 540 Ugandan participants in observational research on living with HIV;<sup>25</sup> and 121 potential participants in genetic research, including 60 Seattle members of a health maintenance organization and 61 Yup'ik Alaska Native people.<sup>21</sup> These studies document sample-specific concerns and preferences; broadly, their results converge most conclusively upon the basic finding that study participants would like to receive research results.

Rather than focusing on a particular subgroup, this study assessed attitudes and experiences of a broad sample of participants who have signed up to be part of a research registry. Investigating participants' preferences related to the communication of research results, this study used online survey methodology to explore attitudes and experiences of registrants in a large database of past, present, and potential health research participants. Survey respondents provided information across a range of topics, including whether or not they received research results from studies in which they participated, their satisfaction with those results, and when and how they would like to receive research results from future studies.

In addition, the study is intended to increase understanding of similarities and differences between

respondents from specific groups who have been examined separately across previous studies related to the communication of the results. For example, the analytic strategy compares preferences of respondents who have worked for research-focused organizations and those who have not. Likewise, the number of survey respondents was large enough to allow comparison between preferences of respondents with previous research participation experience and respondents who have registered as potential participants but had not yet participated in research.

## Method

### *Participants and recruitment*

Supported by the NIH as part of the Clinical Translational Science Award program, ResearchMatch<sup>26</sup> is a registry of volunteers from the United States who have indicated interest in being contacted to participate in research studies.<sup>27</sup> Intended to connect researchers and people interested in participating in health research, ResearchMatch<sup>28</sup> was developed by academic institutions, who have used online and face-to-face methods to register volunteers for the database. Although ResearchMatch<sup>29</sup> registrants represent all 50 US states, they are approximately 70% female and 80% White and 90% non-Hispanic/Latino. Approximately 40% of ResearchMatch<sup>29</sup> registrants report no health conditions, and 40% report no medications. Typical projects that recruit participants from ResearchMatch<sup>27</sup> range in scope from brief surveys to clinical trials.

To recruit respondents, an email notification was sent to all ResearchMatch registrants who were aged 18 years or older. This notification gave registrants the option to indicate whether they were interested in participating in a study about the dissemination of research results. ResearchMatch then displayed the email addresses of interested registrants to the researchers. The researchers contacted potential participants via email to explain the study and provide the opportunity to consent electronically and participate. The email included a link to an online survey. Respondents were not compensated for completing the survey. Of the 70,699 individuals who were notified of the study's topic, 5207 expressed interest in the study and were sent a link. Of those who received a link, 3381 respondents completed the survey between 9 December 2014 and 20 March 2015. This project was determined to be exempt from human protections oversight by the IRB at the University of Arkansas for Medical Sciences (203614) on 14 October 2014.

### *Survey*

The researchers developed a survey targeting the general population of research participants, incorporating

adapted items, response options, and concepts originally assessed by Fernandez et al.,<sup>20,30</sup> Dorsey et al.,<sup>31</sup> Murphy et al.,<sup>32</sup> and Partridge et al.<sup>33</sup> The survey was administered online with a median completion time of 5.4 min. The survey used Likert-type and multiple-response items to capture perceptions and preferences regarding whether, when, what, and how research results are disseminated. To examine the possibility that working for organizations that conduct research might influence individuals' beliefs and preferences regarding the dissemination of the results, a question was included to identify those individuals who have worked or currently work for research organizations. Also, if respondents indicated they had participated in research in the past, they were asked a series of questions to determine whether and how they had received the research results and their satisfaction level with the communication of those results. All respondents (both those who had and had not participated in research) were asked to rate their perceptions about the importance of disseminating research results, the frequency and type of the results that should be shared, and the method of dissemination. In addition to traditional dissemination methods, respondents were asked in detail about their preferences for the use of social media, websites, online video, and text messages in the dissemination of research results.

### *Analytic strategy*

Due to the relatively large number of survey respondents and the large number of potential inferential analyses, the analytic strategy focused on presenting the results of descriptive analyses for each topic included in the survey. Where inferential comparisons are presented (e.g. comparisons between respondents with vs without previous research experience), indicators of effect size are included to aid interpretation of the results. Not every statistically significant inferential comparison (where  $\alpha = 0.05$  and  $p < 0.05$ ) is reported. We emphasized reporting the results for which effect sizes were non-negligible or which could be interpreted in the context of other reported results. For example, post hoc analyses of differences among respondents as a function of race/ethnicity yielded no differences large enough to report, particularly given the relatively low number of respondents from various race/ethnic groups, the relatively small effect sizes, and the inconsistent patterns among those small differences. All inferential analyses presented below were planned a priori. (Any planned analyses not reported below are presented in a supplemental document at the journal website, including unreported comparisons between respondents with vs without previous research experience or who have vs have not worked in research organizations.)

**Table 1.** Characteristics of survey respondents.

|   | Respondents who have worked for research organizations (n = 1704) | Respondents who have not worked for research organizations (n = 1632) | Respondents with previous research experience (n = 2516) | Respondents without previous research experience (n = 857) | All respondents (n = 3381) |
|---|---|---|--|--|----------------------------|
| Gender  |   |   |  |  |                            |
| Female  | 1444 (84.9)   | 1203 (74.0)   | 2017 (80.3)  | 658 (77.1)   | 2681 (79.5)                |
| Male  | 254 (14.9)  | 421 (25.9)  | 488 (19.4)   | 195 (22.9)   | 685 (20.3)                 |
| Other   | 3 (0.2)   | 2 (0.1)   | 6 (0.2)  | 0 (0.0)  | 6 (0.2)                    |
| Age (years)   | 44.6 ± 14.9 (18–95)   | 48.3 ± 14.7 (18–92)   | 45.8 ± 15.1 (18–95)                                      | 48.0 ± 14.5 (18–92)  | 46.4 ± 15.0 (18–95)        |
| Race/ethnicity  |   |   |  |  |                            |
| White non-Hispanic  | 1484 (87.2)   | 1432 (87.9)   | 2213 (88.2)  | 733 (85.5)   | 2953 (87.5)                |
| Black/African-American  | 91 (5.3)  | 90 (5.5)  | 132 (5.3)  | 51 (6.0)   | 183 (5.4)                  |
| Hispanic/Latino(a)  | 49 (2.9)  | 49 (3.0)  | 64 (2.5)   | 34 (4.0)   | 99 (2.9)                   |
| Asian   | 41 (2.4)  | 16 (1.0)  | 43 (1.7)   | 15 (1.8)   | 58 (1.7)                   |
| American Indian/Alaskan Native  | 9 (0.5)   | 14 (0.9)  | 18 (0.7)   | 7 (0.8)  | 25 (0.7)                   |
| Native Hawaiian/Other Pacific Islander  | 3 (0.2)   | 4 (0.2)   | 6 (0.2)  | 1 (0.1)  | 7 (0.2)                    |
| Other   | 24 (1.4)  | 25 (1.5)  | 34 (1.4)   | 16 (1.9)   | 50 (1.5)                   |
| Highest level of education completed  |   |   |  |  |                            |
| Less than high school degree  | 1 (0.1)   | 11 (0.7)  | 6 (0.2)  | 6 (0.7)  | 12 (0.4)                   |
| High school degree/equivalent (e.g. GED)  | 22 (1.3)  | 91 (5.6)  | 64 (2.6)   | 51 (6.0)   | 115 (3.4)                  |
| Some college but no degree  | 151 (8.9)   | 399 (24.5)  | 348 (13.9)   | 210 (24.6)   | 558 (16.6)                 |
| Associate degree  | 92 (5.4)  | 178 (10.9)  | 174 (6.9)  | 96 (11.2)  | 271 (8.0)                  |
| Bachelor's degree   | 590 (34.7)  | 546 (33.6)  | 886 (35.3)   | 262 (30.7)   | 1151 (34.2)                |
| Graduate degree   | 845 (49.7)  | 401 (24.7)  | 1030 (41.1)  | 229 (26.8)   | 1263 (37.5)                |
| Household income  |   |   |  |  |                            |
| Less than US\$20,000  | 79 (4.8)  | 177 (11.2)  | 169 (6.9)  | 91 (11.0)  | 260 (7.9)                  |
| US\$20,000–US\$34,999   | 153 (9.2)   | 202 (12.8)  | 249 (10.2)   | 108 (13.0)   | 358 (10.9)                 |
| US\$35,000–US\$49,999   | 208 (12.5)  | 221 (14.0)  | 303 (12.4)   | 131 (15.8)   | 434 (13.2)                 |
| US\$50,000–US\$74,999   | 342 (20.6)  | 313 (19.8)  | 513 (20.9)   | 158 (19.0)   | 671 (20.4)                 |
| US\$75,000–US\$99,999   | 290 (17.4)  | 241 (15.2)  | 421 (17.2)   | 116 (14.0)   | 538 (16.4)                 |
| US\$100,000–US\$149,999   | 348 (20.9)  | 260 (16.4)  | 479 (19.6)   | 129 (15.5)   | 611 (18.6)                 |
| US\$150,000 or more   | 243 (14.6)  | 168 (10.6)  | 315 (12.9)   | 98 (11.8)  | 414 (12.6)                 |
| Ever worked for a research organization?  |   |   |  |  |                            |
| Yes   | 1704 (100.0)  | 0 (0.0)   | 1488 (59.4)  | 214 (25.0)   | 1704 (50.6)                |
| No  | 0 (0.0)   | 632 (100.0)   | 994 (39.7)   | 632 (73.9)   | 1632 (48.5)                |
| Unsure  | 0 (0.0)   | 0 (0.0)   | 23 (0.9)   | 9 (1.1)  | 32 (1.0)                   |
| Ever participated in research/been guardian of minor participating in research? |   |   |  |  |                            |
| Yes   | 1488 (87.4)   | 994 (61.1)  | 2516 (100.0)   | 0 (0.0)  | 2516 (74.6)                |
| No  | 214 (12.6)  | 632 (38.9)  | 0 (0.0)  | 857 (100.0)  | 857 (25.4)                 |

Values represent number of respondents with percentage of survey respondents in parentheses or mean ± standard deviation with range in parentheses. Percentages are based on the number of valid responses for each item.

## Results

### Participant characteristics

Demographic characteristics of the respondents are presented in Table 1. The majority of respondents were females (79.5%) and White non-Hispanic/Latino (87.5%), similar to the overall ResearchMatch<sup>29</sup> population (70% female, 80% White, and 90% non-Hispanic/Latino). Over two-thirds of respondents have household incomes of at least US\$50,000 (67.9%) and have completed at least a Bachelor's degree (71.7%). Approximately half of the respondents have worked or currently work at research organizations (50.6%).

### Comparison of respondent demographics

Comparing the demographics of respondents who work or have worked at research organizations (50.6%) with respondents who have never worked at research organizations (48.5%) yielded several statistically significant differences. Relative to those who have never worked at research organizations, respondents who have worked at research organizations were more likely to be female than male (85.0% vs 74.1%;  $\chi^2(1) = 61.64, p < 0.01, \phi = 0.14$ ), to be younger ( $M = 44.58$  vs  $M = 48.34$ ;  $t(3289) = 7.30, p < 0.01, d = 0.24$ ), to have completed a higher level of education (Mann–Whitney  $U = 898,543.50, p < 0.01, r = 0.31$ ), and to have a higher income (Mann–Whitney  $U = 1,110,240.50$ ,



$p < 0.01$ ,  $r = 0.14$ ). Those who have worked at research organizations were also more likely to have participated previously in research either as participants or as guardians of participants, than were those who have never worked at research organizations, 87.4% versus 61.1%,  $\chi^2(1) = 303.27$ ,  $p < 0.01$ ,  $\phi = 0.30$ .

Likewise, comparing demographics of respondents who previously participated in research (74.6%), either as participants or as guardians of participants, with those who have never previously participated (25.4%) yielded statistically significant differences similar to those reported above. Relative to those who have never participated, respondents who have participated in research were more likely to be female than male (80.5% vs 77.1%;  $\chi^2(1) = 4.49$ ,  $p = 0.03$ ,  $\phi = 0.04$ ), to be younger ( $M = 45.84$  vs  $M = 48.00$ ;  $t(3325) = 3.64$ ,  $p < 0.01$ ,  $d = 0.15$ ), to have completed a higher level of education (Mann–Whitney  $U = 829,243.00$ ,  $p < 0.01$ ,  $r = 0.32$ ), and to have a higher income (Mann–Whitney  $U = 904,956.50$ ,  $p < 0.01$ ,  $r = 0.14$ ). For the results reported below, we noted where patterns of responses differ between respondents who have and have not worked at research organizations and between respondents who have participated in research and those who have not been research participants or guardians of participants.

### Past experiences

Respondents who had previously been participants or guardians of participants were asked to report on their experiences associated with any one of the previous studies in which they participated. Of these respondents, 51.8% indicated they were given no opportunity to request the study's results, 9.0% chose not to receive the study's results, and 6.2% indicated they never received the results they had requested. Only 33.0% reported receiving the study's results.

Among respondents who reported receiving the results, satisfaction with both the method by which the results were provided and with the information provided was high,  $M = 6.26$  (standard deviation ( $SD$ ) = 1.08) and  $M = 6.15$  ( $SD = 1.00$ ), respectively, on a 7-point scale anchored from 1 = *completely dissatisfied* to 7 = *completely satisfied*.

Table 2 shows the respondents who reported receiving the results through each of a series of different methods. The most commonly reported methods were letters or fliers distributed via email or postal mail. Among the 548 respondents who reported receiving the results through only a single method, the highest level of satisfaction with the communication method was associated with receiving the results via a meeting with a researcher whereas the least satisfaction was associated with receiving the results via a website posting,  $M = 6.66$  ( $SD = 0.56$ ) and  $M = 5.79$  ( $SD = 1.41$ ), respectively.

**Table 2.** Satisfaction with disseminated results among respondents who had received results from previous participation experiences.

|  | All respondents who indicated having received study results from previous participation ( $n = 826$ ) |
|--|---|
| <b>Method(s) researchers used to provide study results</b> |   |
| Group information session                                  | 43 (5.2)  |
| Phone call with researcher                                 | 95 (11.5)   |
| Meeting with researcher                                    | 150 (18.2)  |
| Letter or flier via mail                                   | 273 (33.1)  |
| Letter or flier via email                                  | 306 (37.0)  |
| Information posted on website                              | 179 (21.7)  |
| Other  | 106 (12.8)  |
| <b>Satisfaction with method used to provide results</b>    |   |
| Completely satisfied                                       | 439 (54.9)  |
| Mostly satisfied   | 226 (28.2)  |
| Somewhat satisfied   | 74 (9.3)  |
| Neither satisfied nor dissatisfied                         | 37 (4.6)  |
| Somewhat dissatisfied                                      | 14 (1.8)  |
| Mostly dissatisfied  | 6 (0.8)   |
| Completely dissatisfied                                    | 4 (0.5)   |
| <b>Satisfaction with information provided</b>              |   |
| Completely satisfied                                       | 353 (44.2)  |
| Mostly satisfied   | 294 (36.8)  |
| Somewhat satisfied   | 92 (11.5)   |
| Neither satisfied nor dissatisfied                         | 41 (5.1)  |
| Somewhat dissatisfied                                      | 16 (2.0)  |
| Mostly dissatisfied  | 2 (0.3)   |
| Completely dissatisfied                                    | 1 (0.1)   |

Values represent number of respondents with percentage of survey respondents in parentheses. For the methods items, participants could endorse more than one response option, so percentages are based on the number of respondents who indicated having received study results from previous participation. For the satisfaction items, percentages are based on the number of valid responses for each item.

### Perceptions related to the communication of research results

**Desirability of receiving study results.** Only eight respondents indicated that researchers should never offer research results to participants (0.2%). As shown in Table 3, 63.2% reported that researchers should always offer the results to participants, and 32.4% reported that researchers should sometimes offer the results to participants. Among respondents who had experience as participants or as guardians of participants, there was a smaller proportion of respondents who indicated that researchers should always share the results than among those who did not have such experience; 61.3% versus 68.5%,  $\chi^2(1) = 13.33$ ,  $p < 0.01$ ,  $\phi = 0.06$ .

**General preferences for methods of receiving results.** Respondents were asked to consider a hypothetical situation in which they or a loved one had participated in a research study and to then indicate the

**Table 3.** Perceived desirability of researchers' offering research results.

|   | Respondents who have worked for research organizations (n = 1704) | Respondents who have not worked for research organizations (n = 1632) | Respondents with previous research experience (n = 2516) | Respondents without previous research experience (n = 857) | All respondents (n = 3381) |
|---|---|---|--|--|----------------------------|
| Should researchers offer to give study results to the participants? |   |   |  |  |                            |
| Yes, always   | 1024 (62.1)   | 1010 (64.2)   | 1495 (61.3)  | 562 (68.5)   | 2062 (63.2)                |
| Yes, sometimes  | 561 (34.0)  | 485 (30.8)  | 835 (34.3)   | 223 (27.2)   | 1059 (32.4)                |
| No, never   | 3 (0.2)   | 5 (0.3)   | 5 (0.2)  | 3 (0.4)  | 8 (0.2)                    |
| Not sure/undecided  | 60 (3.6)  | 73 (4.6)  | 102 (4.2)  | 33 (4.0)   | 136 (4.2)                  |

Values represent number of respondents with percentage of survey respondents in parentheses. Percentages are based on the number of valid responses for each item.

desirability of receiving the study's results through each of a series of different methods (i.e. informational sessions at universities or community gathering places, letters/fliers mailed or emailed, Facebook, Twitter, postings or videos on a website, text messages, and phone or conference calls). On a 5-point scale anchored from 1 = *very undesirable* to 5 = *very desirable*, respondents rated letters or fliers distributed via email ( $M = 4.06$ ;  $SD = 0.95$ ) and postings on study websites ( $M = 3.83$ ;  $SD = 1.01$ ) as the most desirable methods, and Twitter ( $M = 2.00$ ;  $SD = 1.05$ ), text messages ( $M = 2.35$ ;  $SD = 1.23$ ), and conference calls ( $M = 2.35$ ;  $SD = 1.17$ ) as the least desirable methods. Informational meetings—whether at universities ( $M = 3.20$ ;  $SD = 1.16$ ) or community gathering places ( $M = 3.12$ ;  $SD = 1.12$ )—were not rated as particularly desirable or undesirable.

**Preferences for types of results to be disseminated.** Table 4 shows respondents' relative preferences for receiving the results for particular kinds of research. On a 4-point scale anchored from 1 = *not important* to 4 = *very important*, respondents indicated the highest importance for receiving the results directly related to their health or the health of a loved one, followed by the results from research in which the respondents have participated,  $M = 3.61$  ( $SD = 0.63$ ) and  $M = 3.34$  ( $SD = 0.82$ ), respectively. The results not directly relevant to one's health or to the health of loved ones was rated as relatively unimportant,  $M = 2.22$ ;  $SD = 0.84$ .

With respect to rating the importance for receiving the results for particular kinds of research, there were no notable differences between respondents who have worked at research organizations compared to those who have not. However, for each kind of research, respondents who have previous participation experience—either as participants or as guardians of participants—rated receipt of results' information as less important than did those who have no previous experience, all  $t$ s  $\geq 3.44$ , all  $p$ s  $\leq 0.01$ , all  $d$ s from 0.14 to 0.38.

Respondents were also asked to indicate specific types of information participants should receive when receiving the results in general. Their responses are summarized in Table 5. The most commonly endorsed type of information was the purpose of the study (90.2%), followed by medical treatment advances based on the study's results (85.2%). Although at least 70% of participants endorsed each type of information, the least commonly endorsed types were neutral results of the study (70.3%) and respondents' own personal results (70.6%).

The greatest percentage difference between the responses of those who have worked at research organizations versus those who have not were that relatively more of those who have worked at research organizations indicated that participants should receive information about neutral results of the study (74.5% vs 65.7%). There were no percentage differences of this magnitude found when comparing responses from respondents with previous participation experience—either as participants or as the guardians of participants—and those without such experience.

### Preferred frequency and milestones for sending results to participants

With respect to respondents' desired frequencies and milestones for sending the results to study participants, no option was endorsed by a majority of respondents. As Table 6 indicates, the modal responses indicated that study participants should receive the results after the final results have been reviewed for accuracy by other researchers (46.9%) or after the study has been published (45.6%).

The greatest percentage difference between the responses of those who have worked at research organizations and those who have not was that a greater percentage of those who have worked at research organizations selected post-publication as a milestone at which researchers should send the results to participants (52.6% vs 38.6%). Compared to respondents

**Table 4.** Perceived importance of receiving different types of research results.

| Importance of receiving results ...                        | Respondents with previous research experience (n = 2516) | Respondents without previous research experience (n = 857) | All respondents (n = 3381) |
|--|--|--|----------------------------|
| For studies conducted in my community                      |  |  |                            |
| Very important   | 616 (25.1)   | 249 (30.1)   | 868 (26.4)                 |
| Important  | 945 (38.5)   | 345 (41.8)   | 1293 (39.3)                |
| Somewhat important   | 679 (27.7)   | 177 (21.4)   | 857 (26.1)                 |
| Not important  | 215 (8.8)  | 55 (6.7)   | 271 (8.2)                  |
| For studies addressing topics that interest me             |  |  |                            |
| Very important   | 950 (38.8)   | 417 (50.4)   | 1368 (41.7)                |
| Important  | 1071 (43.8)  | 336 (40.6)   | 1411 (43.0)                |
| Somewhat important   | 366 (15.0)   | 68 (8.2)   | 435 (13.3)                 |
| Not important  | 59 (2.4)   | 7 (0.8)  | 67 (2.0)                   |
| For a study I participated in                              |  |  |                            |
| Very important   | 1202 (49.0)  | 548 (66.3)   | 1752 (53.3)                |
| Important  | 776 (31.6)   | 208 (25.2)   | 988 (30.0)                 |
| Somewhat important   | 390 (15.9)   | 59 (7.1)   | 450 (13.7)                 |
| Not important  | 85 (3.5)   | 12 (1.5)   | 98 (3.0)                   |
| For a study a family member or loved one participated in   |  |  |                            |
| Very important   | 951 (39.1)   | 445 (54.1)   | 1397 (42.8)                |
| Important  | 783 (32.2)   | 238 (29.0)   | 1025 (31.4)                |
| Somewhat important   | 514 (21.1)   | 102 (12.4)   | 617 (18.9)                 |
| Not important  | 185 (7.6)  | 37 (4.5)   | 224 (6.9)                  |
| Directly relevant to my health or a loved one's health     |  |  |                            |
| Very important   | 1615 (65.9)  | 592 (72.1)   | 2212 (67.5)                |
| Important  | 653 (26.7)   | 195 (23.8)   | 850 (25.9)                 |
| Somewhat important   | 156 (6.4)  | 32 (3.9)   | 188 (5.7)                  |
| Not important  | 26 (1.1)   | 2 (0.2)  | 29 (0.9)                   |
| NOT directly relevant to my health or a loved one's health |  |  |                            |
| Very important   | 149 (6.1)  | 70 (8.4)   | 220 (6.7)                  |
| Important  | 663 (27.2)   | 257 (30.9)   | 921 (28.1)                 |
| Somewhat important   | 1117 (45.8)  | 362 (43.6)   | 1483 (45.2)                |
| Not important  | 512 (21.0)   | 142 (17.1)   | 656 (20.0)                 |

Values represent number of respondents with percentage of survey respondents in parentheses. Percentages are based on the number of valid responses for each item.

**Table 5.** Types of information that should be sent to study participants.

| Type of information that should be included in results sent to participants | Respondents who have worked for research organizations (n = 1704) | Respondents who have not worked for research organizations (n = 1632) | Respondents with previous research experience (n = 2516) | Respondents without previous research experience (n = 857) | All respondents (n = 3381) |
|---|---|---|--|--|----------------------------|
| Purpose of the study  | 1543 (90.6)   | 1463 (89.6)   | 2226 (90.1)  | 774 (90.3)   | 3048 (90.2)                |
| Medical treatment advances based on the study's results                     | 1464 (85.9)   | 1379 (84.5)   | 2148 (85.4)  | 726 (84.7)   | 2881 (85.2)                |
| Good results of the study   | 1418 (83.2)   | 1276 (78.2)   | 2049 (81.4)  | 679 (79.2)   | 2735 (80.9)                |
| General scientific advances based on the study's results                    | 1432 (84.0)   | 1244 (76.2)   | 2053 (81.6)  | 656 (76.5)   | 2715 (80.3)                |
| Bad results of the study  | 1403 (82.3)   | 1263 (77.4)   | 2030 (80.7)  | 670 (78.2)   | 2707 (80.1)                |
| How the study was conducted   | 1357 (79.6)   | 1273 (78.0)   | 1963 (78.0)  | 694 (81.0)   | 2665 (78.8)                |
| Potential new research based on the study's results                         | 1344 (78.9)   | 1244 (76.2)   | 1956 (77.7)  | 661 (77.1)   | 2625 (77.6)                |
| Potential policy changes based on the study's results                       | 1275 (74.8)   | 1092 (66.9)   | 1817 (72.2)  | 577 (67.3)   | 2400 (71.0)                |
| Results that are specific to me   | 1167 (68.5)   | 1186 (72.7)   | 1751 (69.6)  | 630 (73.5)   | 2386 (70.6)                |
| Neutral results of the study  | 1270 (74.5)   | 1073 (65.7)   | 1801 (71.6)  | 569 (66.4)   | 2377 (70.3)                |

Values represent number of respondents with percentage of survey respondents in parentheses. Participants could endorse more than one response option. Percentages are based on the total number of survey responses for each group.

**Table 6.** Milestones when study information should be sent to study participants.

|  | Respondents who have worked for research organizations (n = 1704) | Respondents who have not worked for research organizations (n = 1632) | Respondents with previous research experience (n = 2516) | Respondents without previous research experience (n = 857) | All respondents (n = 3381) |
|--|---|---|--|--|----------------------------|
| How often should information about a study be sent out?                            |   |   |  |  |                            |
| Progress updates every 6 months  | 153 (9.0)   | 283 (17.3)  | 259 (10.3)   | 182 (21.2)   | 442 (13.1)                 |
| Progress updates every 12 months   | 165 (9.7)   | 133 (8.1)   | 228 (9.1)  | 69 (8.1)   | 299 (8.8)                  |
| After the final study results have been analyzed                                   | 591 (34.7)  | 666 (40.8)  | 927 (36.8)   | 347 (40.5)   | 1278 (37.8)                |
| After the final study results have been reviewed by other researchers for accuracy | 795 (46.7)  | 765 (46.9)  | 1172 (46.6)  | 407 (47.5)   | 1584 (46.9)                |
| After the study has been published   | 896 (52.6)  | 630 (38.6)  | 1229 (48.8)  | 312 (36.4)   | 1543 (45.6)                |

Values represent number of respondents with percentage of survey respondents in parentheses. Participants could endorse more than one response option. Percentages are based on the total number of survey responses for each group.

without participation experience, a lower proportion of respondents with previous participation experience—either as a participant or as the guardian of a participant—endorsed a frequency of every 6 months as a recommendation for how often the results should be sent to participants (10.3% vs 21.2%), but a higher proportion of respondents with previous research participation indicated that the results should be sent post-publication (48.8% vs 36.4%).

## Discussion

While most prior studies of participants' preferences for receiving the results focus on small samples of specific patient populations,<sup>18–21,24,25,34</sup> this study assessed the preferences of a much larger sample of respondents selected independent of their health history. The profile of respondents' preferences in this study is in many ways consistent with prior smaller-sample studies. As in previous studies,<sup>18</sup> over 90% of survey respondents indicated that researchers should offer the results to participants at least sometimes. Respondents were particularly interested in receiving the results related to their health or the health of a loved one,<sup>15,18–21</sup> even if those results are not personalized, individual results. Respondents with research participation experience reported satisfaction with the results they have received from studies; however, consistent with prior research,<sup>18</sup> only 33.0% of participants reported receiving the results from a study in which they participated, and over half indicated being given no opportunity to request the results.

While replicating previous research findings, this study moves beyond those findings in important ways. For example, inasmuch as our study found that participants want the results provided back to them, our respondents also indicated that relatively low-cost

methods of dissemination such as email or website postings may be acceptable to participants.

It is important to note several potential limitations to our findings' generalizability. These findings are based on the preferences and experiences of respondents from ResearchMatch who expressed a willingness to participate. This survey's respondents are approximately 80% female and 90% White non-Hispanic/Latino and overrepresent particular demographic segments of the US population whose responses may or may not generalize to other groups' responses. However, in post hoc analyses of differences among respondents as a function of race/ethnicity, we found no differences large enough to report.

A second potential limitation is that no data were collected regarding participants' current or prior health conditions; likewise, for those 50.6% respondents who have worked in research institutions, we are uncertain of the extent to which they were directly involved in research endeavors. For these reasons, it is difficult to determine the extent to which respondents' experiences are reflective of the population of people who might participate in any particular health research study (e.g. respondents with research expertise may be biased toward sharing all the results, regardless of outcome, or toward the use of low-cost dissemination methods). Moreover, no data were collected regarding the time elapsed since respondents participated in the studies they described; the possibility exists that the passage of time has introduced biases among some survey responses (e.g. misremembering whether or not the results were received from a study).

Another potential limitation relates to questions on the survey asking participants to report whether or not they would like information about the results from a hypothetical study. Absent presentation of potential risks or costs associated with receiving the results, it is unsurprising that participants would generally report



wanting this information.<sup>35,36</sup> Participants may also overestimate the practical utility of the results of individual studies and therefore place a high value on receiving the results. Because of these ambiguities, further large-sample research is needed to specify respondents' motivations for desiring the results, both within and across specific populations.

The above limitations notwithstanding, this study assessed the attitudes and experiences of a broad sample of respondents as a step toward addressing gaps in knowledge related to participants' preferences for receiving the results, and it explored differences between participants with and without previous participation experience and those who have and have not worked at research organizations. This study's findings highlight the potential for inconsistency between respondents' expressed preferences to receive the types of the results via specific methods, and researchers' unwillingness or inability to provide them. Most respondents indicated preferences to receive the results, but only 33.0% of respondents reported receiving the results from studies in which they participated. The resolution of this inconsistency is unlikely to be simple, as would be asking participants to check online repositories of research results or of publications after the study's completion. For example, a 2010 analysis showed that fewer than half of NIH-funded trials post results within 30 months after completion, and a third of trials remained unpublished after a median of 51 months after completion.<sup>37</sup>

We suggest the following approaches to identify and address barriers to dissemination of research results to participants. Current knowledge about participants' preferences and experiences related to receiving the results is based largely on findings from studies mostly intended to document preferences and experiences of specific populations. A 2013 Agency for Healthcare Research and Quality report reviewing the existing research on health research communication and dissemination strategies noted significant gaps in knowledge, some of which were related to the homogeneity of research methodologies often employed in this domain.<sup>38</sup> To address these gaps, the report recommends reliance on "proven data collection methods that can include, but might go beyond, self-reported attitudes, levels of knowledge, and behaviors"<sup>38</sup> (p. 121). For the specific domain of disseminating results to participants, we echo this recommendation. We advocate shifting the focus away from studies that document preferences and toward approaches that investigate (a) origins of participants' expressed preferences, (b) how participants' preferences are informed by knowledge about particular studies and about the research process in general, (c) whether and how participants intend to use—and then how they actually use—the results from studies in which they participate, and (d) variations in satisfaction and impact of different dissemination approaches.

To further identify and address barriers to dissemination of research results to participants, we recommend expanding the scope of the existing research, for example,<sup>4,5,39</sup> on health researchers' intentions related to returning the results. Specifically, we advocate for investigations of how researcher intentions; characteristics of particular types of studies; and logistical, economic, and other barriers interact to contribute to the disjunction between participants' preferences to receive the results and researchers' inability or unwillingness to provide them. We also recommend involving participants and researchers in a collaborative process to address this disjunction, in order to gain understanding of how to modify participants' preferences, researchers' practices, or both. For example, there are important questions about the extent to which researchers must balance responsiveness to participants' preferences for research results against any obligations to educate participants with respect to issues of generalizability, replicability, or utility of the results.<sup>6,13</sup> This could be accomplished by convening working groups of relevant stakeholders to identify appropriate research questions and research agendas that are meaningful to researchers, community members, and patients. Collaboration between researchers, patients, and other stakeholders is a necessary step toward an ethical, practical plan for dissemination that satisfies both constituencies.

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