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Return of results is important to heterogeneous research participants: A single-site survey

Sheila M. O'Byrne[1], Ismael Castaneda[1], Rayheann-NaDeja Collins[1], Dora Ventura[1], Siddiq Mohamed[1], Alejandra N. Aguirre[1], Mary Beth Terry[2], Elizabeth Cohn[3], Jiying Han[1], Cheng-Shiun Leu[1], Shing M. Lee[1], Soumitra Sengupta[1], Rhonda G. Kost[4], Karen Marder[1], Paul S. Appelbaum[1] and Nancy S. Green[1]

[1]Irving Institute for Clinical Translational Science, Columbia University Irving Medical Center, USA; [2]Herbert Irving Comprehensive Cancer Center, Columbia University Irving Medical Center, USA; [3]City University of New York School of Medicine, USA and [4]Center for Clinical Translational Science, The Rockefeller University, USA

Research Article

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Corresponding author:
N.S. Green; Email: nsg11@cumc.columbia.edu

Abstract

Background: Clinical researchers at U.S. academic health centers are becoming more attuned to the perspectives and values of research participants, seeking to partner with them to enhance their satisfaction and improve recruitment strategies. *Methodology:* We surveyed current or recent participants on their perspectives about the return of study results. Through a multi-site consortium of academic medical centers assessing the experiences of research participants using an online satisfaction survey, we added three questions to our institution's version of the survey to assess the value placed on return of research results (RoR) to current or recent adult participants. Survey participants were offered anonymous participation using four different recruitment mechanisms ("sites") hosted by our institution. Most recruitment was disease-agnostic. *Results:* A total of 506 heterogeneous respondents completed the survey. Although differences were found across recruitment sites, 73% of all participants desired and 49% expected to receive their own RoR, while 61% expected to receive the study's aggregate results. The importance of receiving their own results was especially salient for respondents from historically underserved communities, identifying as non-white, Latino/Hispanic, primarily Spanish-speaking, older or less educated. Respondents' sex was not a significant factor in preferences for return of results. *Conclusions:* Our results indicated our research participants' expectations and perceived value of receiving the results from studies in which they participated, especially their individual results. This study provides direct evidence of the desires of our research participant community and suggests that institutional support for the return of study results would better serve participants' interests and expectations in future research.

Introduction

Over the last decade or so, a growing focus on the return of research results (RoR) has led to an evolving consensus that study results should be offered for return to research participants [1]. Results obtained from individual participants may be returned to them – deemed individual return of results – or all participants may receive a study's aggregate research results. Study results that have implications for participants' medical care are often referred to as "actionable" findings, although it is widely accepted that some results may be personally actionable (e.g., leading to the purchase of long-term care insurance) even if they do not directly affect medical care [2].

The ethical arguments for individual RoR to participants were summarized in a 2018 report by the National Academies of Science, Engineering and Medicine [1]. Offering to return results, the report noted, was consistent with the key ethical principles of respect for persons and their autonomy, by not treating participants merely as means to an end; of beneficence/non-maleficence, insofar as participants can benefit from the knowledge of their results and avoid medical harm; and of justice, which calls for a fair distribution of the benefits and burdens of research. Some circumstances could preclude the offer of results from a study, e.g., use of experimental measures of uncertain validity, excessive burden of returning and interpreting results to participants, lack of clinical expertise on the research team regarding the implications of particular findings [1,3]. In addition, special considerations may apply for vulnerable populations, who may otherwise be unable to obtain comparable medical testing [4]. Collectively, these arguments have been recognized as constituting a strong basis for research studies to consider offering results to participants.

Most extant studies of RoR address the return of genetic/genomic results, perhaps because of their predictive value, preventive implications, and impact on reproductive and other decisions [5]. Outside the genetic/genomic realm, the literature on return of RoR is much smaller. Most of the prior studies have focused on receipt of data on disease-associated biomarkers that are used for disease screening, diagnosis, and/or prognosis [6]. In most cases, research participants have indicated their strong desire for individual RoR, whether results were for disease biomarkers, tests of environmental exposures or more general health measures [7]. However, not every participant desires access to their research results. For example, the return of genetic results to young adults may not be welcome if such data are uncertain, not actionable or pertain to health problems only likely to arise late in life [8,9]. These examples underscore the importance of encouraging participants to choose whether to receive their results and, if so, which types of information to receive [10]. Opportunities for participants to decide whether and which of their study results to receive (within general categories) are already being offered to participants in some studies as part of the consent process for study enrollment [1,11].

In addition to conforming to participant desires, RoR may have advantages for the research enterprise. The offer of individual RoR may facilitate recruitment and retention and increase trust at both the individual and community levels [12]. It may also enhance research transparency and promote the engagement of participants in studies as partners rather than merely as objects of study. In that sense, it highlights the bidirectional nature of the researcher-participant relationship [1].

In biomedical studies beyond genetic-genomic research, the strength of participant interest and expectation for receipt of their study results has not yet been widely studied. Few non-genetic studies have looked at the question of RoR from the perspective of research participants themselves, especially among heterogeneous study participants. Moreover, preferences may vary by age and race/ethnicity and not be transferrable across populations [13]. Although several recommendations have been made for how results should be returned, input from research participants has been sparse and based on small samples [1].

We joined a study consortium of six other academic institutions that was performing an ongoing online research participant survey aimed at gauging the satisfaction of research participants in recent or current studies. We added questions to our version of the survey to ask specifically about participants' expectations and the importance of return of RoR, either their own individual results or aggregate study findings. The overall consortium survey architecture and results have recently been reported [14,15]. We hypothesized that research participants at our site, across heterogeneous demographic features and generally disease-agnostic studies, would desire receipt of individual and aggregate study results, and that return of their individual results would be an important motivator for their participation.

Methods

The full multi-site participant study was reviewed by each of the consortium's respective Institutional Review Boards (IRB) and approved or deemed exempt and was approved by the Columbia University IRB specifically for this sub-study.

Through a 2020 collaboration with Rockefeller University, we piloted a participant satisfaction survey in our clinical research unit and our nearby community-based research facility [16,17]. Based on our preliminary findings, Columbia University's Irving Medical Center (CUIMC) Clinical and Translational Science Award (CTSA) program was invited to join a previously constituted consortium of six academic research organizations with CTSA programs that had collaborated to administer a validated Research Participant Perception Survey to active or recent research participants [18]. The aim of the consortium survey was to determine the degree of participant satisfaction regarding various aspects of research participation. Survey data were collected and added to a consortium database via REDCap [14,15].

Prior to our survey launch at CUIMC, we revised the consortium's version of the survey to reduce the literacy level to grade 7-8 using the Flesch-Kincaid Readability measure. This revised version was translated into Spanish (back-translated to confirm accuracy) for a fully bilingual online survey [19]. The online consent language immediately followed the two eligibility questions: a) current or recent (within the prior two years) study participation; and b) age 18 years or older. If both criteria were met, a click indicated consent and led directly to the survey questions.

The overall survey was aimed at participants over a wide range of studies conducted at a large urban medical center and with varied participant demographics. The survey included questions pertaining to the respondent's demographic data including sex, age range, race, Latino/Hispanic ethnicity, and educational attainment. Our study team saw an opportunity to go beyond the participant satisfaction questions to collect additional data on the participants' range of expectations for and experiences with the return of aggregate and individual study results. Hence, in addition to contributing data to the overall study, we added three questions used only in CUIMC's survey version that pertained to RoR. These questions were: a) "Did you expect to receive your own results from the study?" with response options of: yes, no, I don't know; b) "Did you expect to receive the main study results from everyone who had joined?" with the same response options; and c) "How important is it to you to get your own study results?" with response options using a modified Likert scale of: very important, somewhat important, not important. All three questions were piloted with a broad range of research participants from our recruitment sites to ensure clarity of content and language.

Four CUIMC resources were used to invite current or recent (within the prior two years) research participants to take the survey: 1) the CTSA's outpatient Clinical Research Resource (CRR), a site for conducting clinical studies, and 2) the Community Engagement Core Resource (CECR), a community-based research resource located nearby in the Washington Heights community, both of which recruited participants in person or sent them a QR code enabling them to take the survey on their mobile phones; 3) the Herbert Irving Comprehensive Cancer Center (HICCC), which sent an email invitation to approximately 3,000 former patients who had enrolled in research studies and had subsequently consented to be contacted for future research studies; and 4) the CUIMC version of a research recruitment website, RecruitMe (https://recruit.cumc.columbia.edu/home), a publicly accessible, national online tool used to connect research teams to people interested in participating in specific research projects, which posted the study.

The CTSA's Biostatistics, Epidemiology, and Research Design resource conducted descriptive analyses of demographic data by recruitment site and for the overall study and provided descriptive analyses of the three questions pertaining to RoR, with logistic regression to assess the effect of categorical independent variables.

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Table 1. Sample demographics overall and by survey recruitment site

	Total *N* (%) sample *N* = 506	CRR *N* (%) sample *N* = 155	HICCC *N* (%) sample *N* = 157	RecruitMe *N* (%) sample *N* = 157	CECR *N* (%) sample *N* = 37
Location					
Washington heights/Harlem/Bronx	162 (31.8)	59 (38.3)	30 (19.2)	39 (24.8)	31 (86.1)
Other Borough	216 (42.4)	68 (44.2)	54 (34.6)	88 (56.1)	5 (13.9)
Outside NY	131 (25.7)	27 (17.5)	72 (46.2)	30 (19.1)	0 (0.0)
Age					
18–44	175 (34.4)	35 (22.6)	15 (9.6)	115 (73.7)	7 (19.4)
45–64	113 (22.2)	38 (24.5)	38 (24.2)	27 (17.3)	10 (27.8)
>65	221 (43.2)	82 (52.9)	103 (66)	14 (9.0)	19 (52.8)
Gender					
Female	320 (65.3)	98 (67.6)	93 (60.4)	95 (62.1)	30 (90.9)
Male	170 (34.7)	47 (32.4)	61 (39.6)	58 (37.9)	3 (9.1)
Race					
White	302 (65.4)	87 (64.9)	116 (80.6)	85 (55.9)	12 (42.9)
Non-White	160 (25.6)	47 (35.1)	28 (19.4)	67 (44.1)	16 (57.2)
Ethnicity					
Non-Hispanic/Latino	345 (67.4)	86 (56.2)	128 (83.7)	122 (78.2)	7 (19.4)
Hispanic/Latino	159 (31.1)	67 (43.8)	25 (16.3)	34 (21.8)	29 (80.6)
Language					
English	446 (87.1)	116 (74.8)	151 (96.2)	157 (100.0)	17 (45.9)
Spanish	66 (12.9)	39 (25.2)	6 (3.8)	0 (0.0)	116 (74.8)
Education					
8th grade & high school GED	74 (14.6)	41 (26.5)	9 (5.8)	12 (7.6)	10 (27.8)
Some college & 4-year college	222 (43.7)	61 (39.4)	53 (34.4)	91 (58.0)	16 (44.4)
>4-year college	212 (41.7)	53 (34.2)	92 (59.7)	54 (34.4)	10 (27.8)

CRR = Clinical Research Resource; HICCC = Herbert Irving Comprehensive Cancer Center; RecruitMe = an online Columbia University recruitment site; CECR = Community Engagement Core Resource.

Results

The survey was open for data collection for a seven-month period in 2023–24. Of 971 people who began the screening questions of the CUIMC survey, 512 met both eligibility criteria and continued to complete the online survey. A total of 506 (99.8%) completed the survey, which we defined as having answered at least 75% of the questions, including those on demographics placed at the end. Completed responses from each of our four recruitment sites ranged from *N* = 37 to 158 (Table 1). Overall, 31.8% of participants resided in the highly heterogeneous neighborhoods closest to CUIMC in Northern Manhattan/Bronx/Harlem, with the remainder from other New York City boroughs or outside of New York City.

Respondent ages were fairly well distributed: 18–44 (34.3%), 45–64 (22.2%), with the largest proportion aged ≥65 (43.2%). The majority of participants were female (65.3%) and primarily English-speaking (87.1%). Many identified as people of color (25.6%) and 31.1% as Latino/Hispanic. In all, 14.6% of our participants reported education levels of high school or equivalent (GED); 43.7% reported having at least some college or finished a 4-year college; and 41.7% had more than a 4-year college education. Survey recruitment sites varied by these demographics, resulting in greater total diversity among respondents.

We analyzed the overall responses to each of the three questions posed about RoR. To the question, "Did you expect to receive your own results from the study," 49% of respondents responded affirmatively (Table 2, Figure 1), 34% negatively, and 16% did not know. To the question, "Did you expect to receive the main study results from everyone who had joined?," only 20% agreed, while 61% did not expect to receive results and 18.8% did not know. To the question, "How important is it to you to get your own study results?," 73% felt that it was important (39% very important and 34% somewhat important), while 27% felt it was not important.

Results differed by recruitment site (Table 2), but despite those differences, the largest proportion of respondents at each of the four sites indicated their expectations of receiving their own results (question 1) but not aggregate results (question 2). Similarly, the largest group at three of the sites said return of individual results was very important, while completed surveys from the CUIMC online study recruitment site, RecruitMe, reflected a more tepid perception of the importance of receiving their own results.

Using logistic regression, responses by demographics were often in the same direction across at least 2 of the 3 questions (Table 3). These relationships were most consistently strong in response to the question about the importance of receiving individual study results.

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Table 2. Perspectives about return of research results for each of the 3 survey questions

Survey questions	Totals *N* (%) sample *N* = 506	CRR *N* (%) sample *N* = 155	HICCC *N* (%) sample *N* = 157	RecruitMe *N* (%) sample *N* = 157	CECR *N* (%) sample *N* = 37
Did you expect to receive your own results from the study?					
Yes	249 (49.2)	88 (57.5)	65 (41.9)	70 (44.6)	22 (62.9)
No	176 (34.8)	39 (25.5)	60 (38.7)	66 (42.0)	10 (28.6)
I don't know	81 (16.0)	26 (17.0)	30 (19.4)	21 (13.4)	3 (8.6)
Did you expect to receive the main study results from everyone who had joined?					
Yes	103 (20.4)	34 (22.1)	42 (27.1)	22 (14.2)	4 (11.4)
No	307 (60.8)	84 (54.5)	75 (48.4)	116 (74.8)	28 (80.0)
I don't know	95 (18.8)	36 (23.4)	38 (24.5)	17 (11.0)	3 (8.6)
How important is it to you to get your own study results?					
Very Important	198 (39.1)	81 (52.6)	59 (38.3)	30 (19.1)	23 (63.9)
Somewhat important	173 (34.1)	54 (35.1)	45 (29.2)	64 (40.8)	10 (27.8)
Not important/not very important	136 (26.8)	19 (12.3)	50 (32.5)	63 (40.1)	3 (8.3)

CRR = Clinical Research Resource; HICCC = Herbert Irving Comprehensive Cancer Center; RecruitMe = an online Columbia. University recruitment site; CECR = Community Engagement Core Resource.

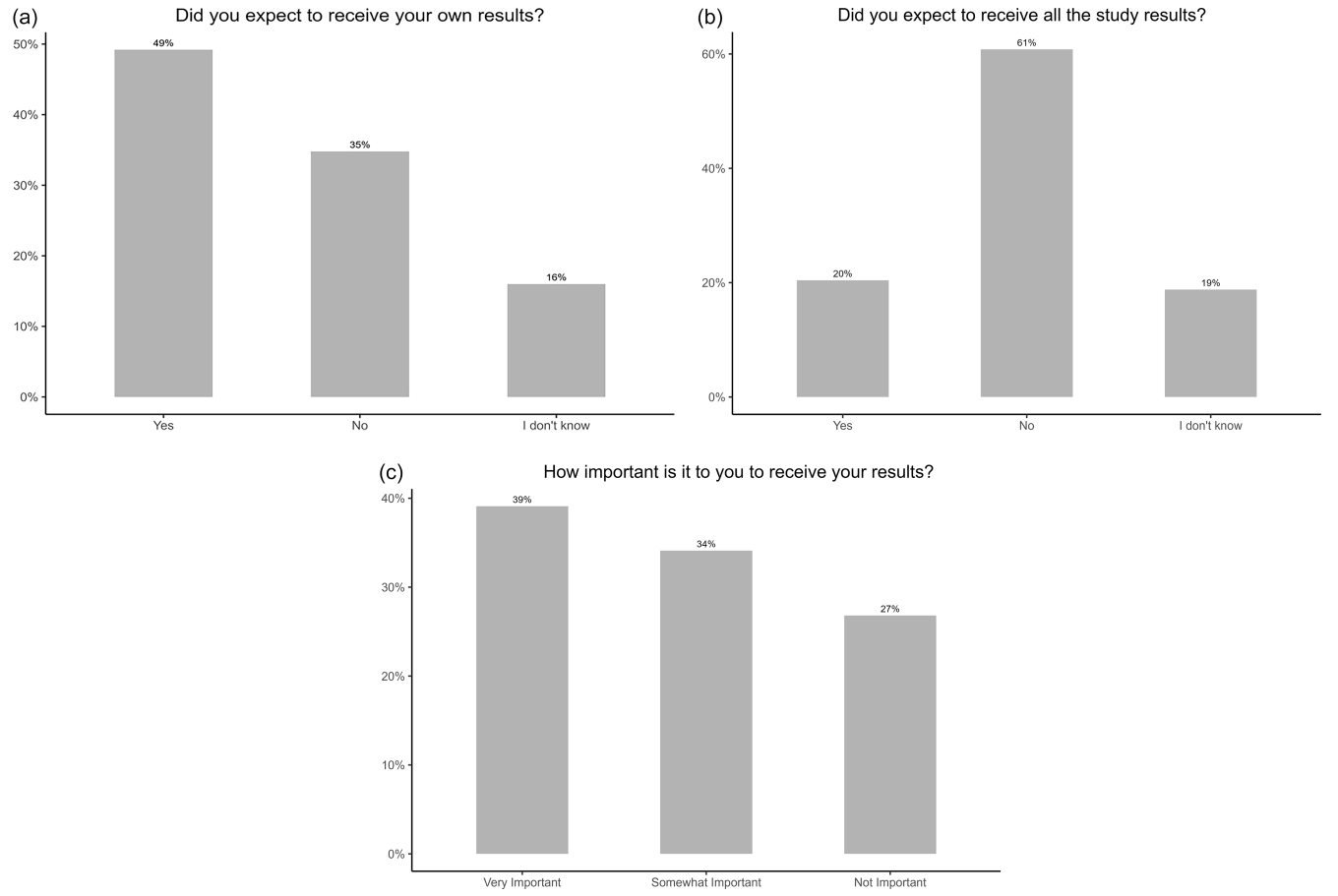

Figure 1. (a–c) Distribution of responses to each of the 3 survey questions about return of research results (*N* = 506).

Regarding geographic location, those living within the neighborhoods surrounding CUIMC were twice as likely to value receipt of their own results. Compared to white respondents, those identifying as non-white were 1.7-fold more likely to value the receipt of their own results. Similarly, those identifying as Hispanic/Latino or who used the Spanish survey version were 2 to 3 times more likely to expect their own results and to consider the receipt of their results important (Table 3). Those over 65 years of age were also more than

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Table 3. Logistic regression analysis of the value of returned results by demographic variables

Variable *reference group*		Expect aggregate results				Expect own results				Importance of own results			
		OR	*P* value	95% CI		OR	*P* value	95% CI		OR	*P* value	95% CI	
Location *North Manhattan and Harlem/Bronx*	Other Boroughs	0.87	0.61	0.52	1.47	0.68	0.09	0.43	1.07	0.53	**0.011**	0.33	0.86
	Outside New York	1.17	0.61	0.65	2.09	0.69	0.17	0.41	1.17	0.55	**0.032**	0.32	0.95
Age *18–44 years*	45–64	1.46	0.26	0.76	2.80	1.63	0.07	0.96	2.75	2.20	**0.004**	1.29	3.78
	>65	2.32	**0.002**	1.37	3.94	1.61	**0.035**	1.03	2.50	2.49	**<0.001**	1.59	3.91
Gender *Woman*	Man	1.42	0.15	0.88	2.30	1.30	0.23	0.85	1.97	1.25	0.30	0.82	1.91
Race *White*	Non-White	0.99	0.98	0.62	1.61	1.44	0.09	0.94	2.19	1.70	**0.021**	1.08	2.67
Ethnicity *Non-Hispanic/Latino*	Hispanic/Latino	1.18	0.50	0.73	1.89	1.93	**0.003**	1.26	2.97	2.01	**0.003**	1.27	3.2
Language *English*	Spanish	1.55	0.15	0.85	2.83	2.84	**0.002**	1.48	5.44	6.49	**<0.001**	2.31	18.22
Education *High school/GED or less*	Some or completed 4-year college	0.42	**0.005**	0.23	0.77	0.77	0.39	0.43	1.39	0.47	**0.044**	0.23	0.98
	>4-year college	0.45	**0.010**	0.24	0.82	0.75	0.35	0.42	1.36	0.32	**0.002**	0.15	0.65

GED = general educational development (high school equivalent diploma).
Bold font signifies *P* value <0.05.

twice as likely to expect aggregate study results and value the receipt of their own study results, while those with advanced education were less than half as likely to do so. Interestingly, no associations were seen by sex. Overall, respondents who were of traditionally minoritized communities – living near our medical center and identified as non-white, Latino/Hispanic, primarily Spanish-speaking, aged greater than 45 years and especially over 65 years, and with less education – were significantly more likely both to expect and value the receipt of their own study results.

Discussion

The U.S. 2016 mandate for patients to have access to their personal clinical electronic health record, similar to provisions in Canada and several European countries, has resulted in high levels of user satisfaction [20]. Thus, it would not be surprising for research participants to have similar expectations for access to their study results. However, despite recommendations for the return of research results to study participants, data on participants' views have been based mostly on small samples and primarily focused on RoR for individuals' genetic/genomic data [1,21,22].

Survey results from our substantial and heterogeneous participant sample demonstrate that the majority of current or recent research participants expect and value individual RoR, with lower expectations about receipt of aggregate study results. Demographic analyses indicate that people who expected their individual RoR were more likely to be living in our local geographic area of northern Manhattan, Harlem and the Bronx, a highly heterogeneous area of New York City, with high levels of social and economic disadvantage and underserved [23]. In this population, which may have difficulty accessing medical care, results from research participation may have particular value. Older adults and those with less education also placed higher value on individual RoR, perhaps for the same reason. At several meetings with our CTSA's Stakeholders in Translational Research (STAR) Ambassadors Program, echoed in meetings with leaders from a variety of communities in New York City, RoR was uniformly identified as a high priority for their participation in research studies, with expressions of frustration that participants often do not receive their individual study results from research teams. They emphasized the importance of bi-directional communication and partnership for facilitating study enrollment, retention and overall positive perspectives on participation in research.

Notwithstanding the desires of participants to be offered RoR, we recognize that practical issues frequently constitute barriers to offering results to participants and discourage researchers from doing so. Many researchers in the U.S. and elsewhere are supportive of the principle of returning results, especially for findings with implications for participants' health [24–26]. However, they worry about the burdens that such an obligation would impose on the research team and potentially on participants [27]. Returning results requires the time and expertise of the research staff, who may be diverted from other research tasks, both during a study and after it has ended [28]. Time will be required not only for the actual RoR, but also for preparing explanatory materials that participants want and will need to follow up on disclosures, e.g., by sharing the results with their physicians [29]. Cost is a related consideration for staff time and, in some cases, for confirmation of research findings in laboratories certified for clinical testing under the Clinical Laboratory Improvement Amendments [30,31]. Researchers may also lack the expertise to explain individual findings – and to respond to participants' questions – especially when they are not themselves clinicians or when the findings relate to an area of medicine outside their clinical expertise [28]. At times, results will derive from experimental analyses for which the clinical impact is unclear [27]. Other challenges for RoR may include difficulty contacting participants, who may have moved or changed phone or email addresses, or who may be unresponsive to outreach efforts, all requiring additional staff time to pursue.

In addition, participants in research studies often need expert support for data interpretation and understanding the implications

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of results for their health and health behaviors. To help with these challenges for study participants, a number of genetic studies have included genetic counselors who are tasked with interpretation and communication of RoR. Of course, not every study necessarily requires or has sufficient resources to cover genetic counselors or other health professionals with specialized expertise. Nonetheless, study leaders and key participant-facing staff (e.g., coordinators) can convey study results or participants can be directed to a centralized system for self-retrieval of individual findings [32]. Regardless of the approach(es) used, some resources will be needed to convey the medical implications of the results to participants, respond to questions, and direct them to further care when indicated.

Researchers have often expressed concern that RoR might lead to harm to their participants, especially if the implications of the results fail to be correctly understood, e.g., by creating excessive anxiety or leading to unnecessary medical testing or interventions [33,34]. However, studies of the return of individual research results have demonstrated that most participants do not experience heightened anxiety or depression, and when such reactions exist, they tend to be transient [35].

Participants in our study were asked about and expressed strong interest in their individual results. Prior published surveys of research participants over a range of medical conditions reported high levels of interest in aggregate RoR from clinical trials. [36,37] Those findings suggest that aggregate RoR can help build research-engaged communities affected by chronic health conditions. In several meetings we held with community leaders and members, attendees indicated high interest in receiving aggregate RoR for studies related to the health of their community, with particular interest in studies on common chronic conditions such as diabetes, hypertension and obesity. They believed that RoR is only fair given their community's contributions to the study and that they may be able to leverage such aggregate RoR to improve the health of their community. Aggregate RoR may also be more feasible for research teams, as results can be placed on websites for the community to access, requiring initial set up and some maintenance, but less personnel time than return of individual results.

Desire for individual and/or aggregate results may also vary over a participant's course in a study. For example, a survey of parental attitudes to results from their child's cancer study revealed that initially parents were more interested in the study's aggregate results, while later in the trial they were understandably more interested in study results of their own child [38]. In addition, several studies have illustrated that some participants may not desire RoR. Instead, results should be offered to individual participants, with respect for those who prefer not to receive their results [39,40].

As recently reported by the multi-site consortium conducting the overall participant satisfaction survey, respondents were asked about study features that made them more likely to enroll in a future study [15]. Among the choices provided, return of aggregate and individual study results were chosen as the first and second most valued factors, respectively. Other, less commonly selected (<30%) options pertained more to the logistical aspects of study participation, e.g., flexible study hours, available parking and reimbursement for participation.

Limitations: Our survey containing the three questions about research RoR was based on a convenience sample, with most participants recruited from one of three specialized sites associated with CUIMC. Nonetheless, excepting the HICCC (our Comprehensive Cancer Center), survey recruitment was agnostic to medical condition, covered a wide range of study types, was offered at a modest level of health literacy, and afforded a seamless choice between English and Spanish, the two predominant languages spoken in New York City. Given our recruitment methods, we were unable to determine the number of people who reviewed the online survey invitation and chose not to complete the survey. Responses to the initial two questions, "Did you expect . . . " may have been affected by the information received at enrollment in a prior study. In this exploratory study, we did not correct for multiple comparisons when examining the impact of demographic features on the responses. We did not inquire about participants' perceptions of potential harms, although the value they placed on RoR suggests a perception that the benefits outweigh possible risks that may accrue [41,42]. Regarding the generalizability of our findings on participants' perspectives of RoR, including perceptions of relative benefits and potential harms, these may vary by types of studies and especially the types of research results, geographic location, especially globally, and cultural norms.

Our study describes the high expectations of participants in research at CUIMC to receive individual study results and the importance they attach to them. Expectations and/or value placed on the receipt of individual results were especially high in the surrounding communities of our institution, in populations of color, Latino/Hispanic participants, those who completed the survey in Spanish (presumably their primary language), and respondents middle-aged or older, or with less education. Similar findings also applied to their expectations of receiving aggregate results. These novel findings provide valuable information from our institution's research participant communities about the value of return of individual results. Moreover, these results strongly support an institutional approach to encourage and facilitate RoR to research participants.

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