Improving dissemination of study results: perspectives of individuals with cystic fibrosis

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Abstract
The practice of communicating research findings to participants has been identified as important in the research ethics literature, but little research has examined empirically how this occurs and what research participants’ views are in this regard. We interviewed 21 adults with cystic fibrosis who had previously participated in research and 2 research coordinators at a cystic fibrosis clinic. We aimed to better understand research participants’ views on receiving research results, types of findings they are interested in, how they would like to receive this information, and the impact this might have on future participation. Participants reported that they do not generally recall receiving study findings, though many reported that they would like to receive them. While some participants were not interested

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in receiving results, all participants felt that these results should be provided when desired by participants and believed that receiving study findings would support future participation. Participants felt that an accessible format, such as a lay summary, would be most helpful. This study supports calls to make study findings available to participants, though the format in which they are provided requires consideration. Participants rarely recalled receiving findings despite the clinic in which this study was conducted returning them regularly. Therefore, questions pertaining to the provision of study findings must focus less on whether to share the findings and more on how to share them with participants most effectively. The logistics of providing study findings may be challenging in some cases, but participant support for the practice highlights its importance.

Keywords
Cystic fibrosis, aggregate results, return of results, research participation, research findings

Introduction
In the research ethics community, providing participants with study findings is sometimes discussed in the context of returning individual-level results, which is controversial and requires consideration of complex factors (e.g. Evans and Rothschild, 2012; Knoppers and Dam, 2011). We highlight the nature of the debate about returning individual-level results but argue that informing research participants of study findings, sometimes called aggregate results, has none of the ethical complexities of returning individual results. The communication of study findings to participants should therefore not be conflated with returning individual findings. This is particularly true in light of the fact that researchers have found that participants want to receive information about the studies in which they participated (Murphy et al., 2008; Shalowitz and Miller, 2008) and that doing so has many benefits (Beskow et al., 2012; Kerasidou, 2015).

The nature of the debate
A key question that has received considerable attention is under what conditions it is necessary and appropriate to return results to participants. For example, it has been widely argued that participants should only be provided with research results with clinical validity (i.e. participants can be confident the results are correct) and utility (i.e. they are actionable—participants can do something to improve their future health based on the information (Evans and Rothschild, 2012), with some jurisdictions requiring researchers to do so (McGuire et al., 2014)). There are also conceptual differences between findings that are expected based on the research questions and those that are incidental to the purpose of the study, which may impact the consequences of providing such information (Knoppers and Dam,
2011). Risks and consequences of providing participants with research results may differ based on research area, and therefore recommendations for returning results may differ accordingly (e.g. Fabsitz et al., 2010; Jarvik et al., 2014). In the context of gene sequencing, for example, many studies are exploratory or have clinical validity without clinical utility (Evans and Rothschild, 2012) and it has therefore been argued that returning individual results could provide information that cannot be used while also straining the research system. Some have taken a strong stand against returning even results that have been aggregated across participants, arguing that in the case of large-scale biobanks with samples derived from within the health-care system or from altruistic tissue donations, all efforts should be focused exclusively on research toward collective health benefits (Forsberg et al., 2009). In general, though, debates have focused on the challenges associated with returning individual results, since providing study findings does not come with the same ethical challenges and is sometimes considered a minimum standard (Parker, 2012).

**Participant wishes for receiving results**

Research on the interests of participants in receiving study findings shows that they overwhelmingly want both individual and aggregate results (i.e. study findings; Murphy et al., 2008; Shalowitz and Miller; 2008) regardless of whether they can act on them (Bollinger et al., 2012; Burke et al., 2014), providing a potential problem for researchers and institutional review boards (IRBs) in balancing the protection of participants with acceding their wishes. In one study investigating participants’ perspectives on receiving study results for themselves and for their children, researchers conducted a deliberative discussion, during which participants were informed about the potential risks and challenges of receiving individual results (Halverson and Ross, 2012). In particular, it was explained to participants why individual results might not be provided, but this had little impact—participants still wanted these results. Others have found that while participants prefer receiving more complete results and feel researchers have a duty to provide them, they may accept more limited information (Bollinger et al., 2012).

**Returning study findings has many benefits**

Given the relative ubiquity of participant interest in receiving research results, some have argued that researchers should err on the side of communicating findings to participants (Shalowitz and Miller, 2005). However, for the reasons described in the preceding text, providing individual results can be problematic; in contrast, returning study findings provides relatively few ethical challenges. In addition, possible benefits of providing study findings include affirming that participation is
helpful, providing additional information about the study, educating participants about the incremental nature of research, and building trust (Beskow et al., 2012). Providing study results has further been identified as potentially helpful because doing so informs participants about the nature of the research and the fact that participants’ data were not used in diagnosis, serving to better inform them about the differences between research and clinical care (Kerasidou, 2015).

The practice of sharing study findings is also seen as a core aspect of community-based participatory research in that it builds knowledge and empowers people to improve their health (Israel et al., 2017). Indeed, community-based participatory research holds the dissemination of findings and knowledge as one of its core tenets. While not all research can or should be participatory in the sense that it may not involve the community (in this case the patients) in all aspects of the research process, the principles of community-engaged scholarship are nonetheless important. In particular, the idea of community-engaged research as being motivated by the needs of the community seems self-evident in the case of research that is designed to improve health. While many instances of medical research may not involve the community in research design (as principles of community-engaged research would demand), it can nonetheless be community engaged by sharing the knowledge that is gained from that research with the community that contributed to the research and stands to gain from that knowledge (Hodgetts and O’Doherty, 2019).

It is unknown how often investigators provide study results to participants and less is known about the wishes of participants who typically participate more extensively in research. Participants with cystic fibrosis (CF) regularly take part in research, have often done so since childhood, and may even view research participation as part of their hospital experience (Dobson et al., 2015). As a result, they have important contextual knowledge about the research process, would potentially receive information about numerous studies, and therefore may have important insights about receiving study results.

**The current study**

There are two types of research studies directly involving patients that are conducted in the clinic in which this study was conducted: those that have relatively minimal participant involvement (e.g. taking a blood or sputum sample to correlate with clinical data) and more labor-intensive clinical trials where patients are randomly assigned to therapies and are subsequently seen on multiple occasions to capture outcome measures. These clinical trials tend to be of long duration (often more than 6 months) to be able to detect differences in outcomes, such as rates of pulmonary exacerbations. The recruitment phase of the study may also extend over years if the study’s test treatments for events that do not occur frequently
(e.g. pulmonary exacerbations). Dissemination of results can only occur once the study is complete (including data collection and analysis). Some clinical trials are industry-sponsored studies of new therapies where treatment allocation, study outcomes, adverse events, and safety data are collected electronically and stored and analyzed by the sponsor.

The results of industry-sponsored trials are generally reported at the international CF meetings (held twice a year). Confidentiality agreements mean that even the aggregate results of the studies cannot be disseminated until they are in the public domain, which may take 6-12 months from study end. Within the clinic, these results are communicated through both informal and formal means. For studies that have outcomes of immediate interest to participants, such as the findings from clinical trials, the principal investigator communicates the results personally when the patient is next seen. For all studies, the general results are made available on the clinic website (they were formerly delivered by newsletter), through discussions with the research coordinators, and also by providing the publication upon request, once it is available. The provision of individual results is more complex and depends on the final publication of the results. In the case of industry-sponsored clinical trials, the research team at the clinic would only have access to information such as whether the patient received the drug or the placebo once the study has been published.

Given this context of established practices for communicating study findings but limitations around the timing of such communication, we aimed to learn more about participant perspectives on receiving research findings. We interviewed participants with CF to determine their recollections of what kinds of information they receive currently, how they feel about receiving study findings, and how this information might impact their future participation.

**Methods**

Recruitment was conducted through an adult CF clinic in Toronto, Canada. Potential participants were identified by clinic staff (research coordinators) who described the study to patients who had previously participated in biomedical research. If these potential participants agreed, contact information was given to DET who called or e-mailed to arrange an interview. Twenty-one patients aged 21–59 years old ($M = 35$, SD = 10.9) participated (11 female, 10 male) and interviews were conducted primarily by phone ($n = 10$), at the participant’s home ($n = 7$), the clinic ($n = 2$), or their workplace ($n = 2$). Interviews were generally conducted individually except for two brothers who chose to be interviewed together. We also interviewed two clinic research coordinators to better understand the process of research participation and provide additional details about participation experiences.
Participants were interviewed by EC and KS. Consent was obtained at the time of the interview and interviews were audio recorded. Participants chose or were assigned a nickname to maintain confidentiality. A preliminary question guide based on previous research (Christofides et al., 2016; Dobson et al., 2015) was used and follow-up questions evolved with subsequent interviews. Sample questions included “What does being in a research study mean to you?” and “What kinds of questions did you have for the researcher?” Questions about the communication of results primarily occurred as a follow-up to comments made by the participants. We used the same question guide as a basis for interviews with the research coordinators, with some modification based on their different role in the research process. Specifically, research coordinators were able to provide context on practices of returning results in research conducted in the clinic where they did the recruiting and about the perspectives both of participants who chose to participate in studies and those who did not. Our study received ethical clearance from the University of Guelph and from St Michael’s Hospital research ethics board, where the CF clinic is located.

Transcription and analysis occurred as the interviews progressed so that we could amend questions to explore emerging themes in subsequent interviews. EC and KS coded sections of the interviews that referred to the return of results as a concept, searching for overarching themes and organizing the information into descriptive categories. With the aid of qualitative analysis software (NVIVO-10), codes and themes were continually refined and once the codebook was finalized, we went back to the existing interviews and ensured that the codes were applied consistently.

Results

Many participants initiated discussion about receiving study results without our prompting them, primarily focusing on receiving the overall findings of the study. While some participants also described the return of individual and personal results or information about the progress of CF research more generally, our analysis focuses specifically on our participants’ views on study findings. We first describe what, if any, results participants recall having received, whether they are interested in seeing study results, how seeing the results would impact them and their future research participation, and how they wanted to receive this information.

Do participants recall receiving study results?

Participants generally did not recall receiving results of studies they had participated in. Dee (female, 43 years) reported, “I’ve participated in so much research that I’ve never heard anything come out of.” The research coordinators explained
that whether participants would be informed about the outcome of the study depends on the researchers and there is therefore no single approach across all studies. When we told Sean (male, 27 years) that following our research we would provide a summary of the findings, he responded, “Yeah that’s not common practice.” While many participants did not believe they were told anything about the results of studies they had participated in, others thought perhaps they had, but were unsure. For example, Sarah (female, 34 years) explained, “I’m sure people have told me but I never have followed up, I think once or twice somebody sent me follow up information but yeah no not really.” With only a few exceptions, participants reported that they never learned the outcome of the studies in which they participated.

Would participants like to see study results?

Though some participants were indifferent, most were enthusiastic about receiving findings from the studies in which they participated. For example, Marie (female, 32 years) was interested in receiving study results. She explained,

Yeah, I’m always curious. Like I always ask, like I want the study results. I want to know what’s going on, like, I’m doing all of this stuff, what’s coming of it? . . . I participate in all these studies and you never really find out, what the result was, what the clinical implications were.

Other participants were similarly enthusiastic, though they varied on whether they thought they would be able to understand the information provided. Some felt it would likely be written in complex and technical language. Regardless of their personal interest in receiving study findings, participants generally felt it should be the participant’s decision as to whether or not to receive this information. As Adam (male, 43 years) summarized, “I think they should be given the choice.”

In addition, there were some differences in the type of findings participants wanted to receive. For example, while Claire (female, 20 years) said that she did not usually think about the outcome of the research she participated in, she had an important caveat: “I don’t really need to know. . . . Unless it’s like good for me then, yeah I want to know.” That is, Claire did not feel that she generally wanted to hear about the results of the studies she was involved in unless they uncovered something that might impact CF treatment or care. Finally, a few participants indicated that they would really only be interested in hearing about research breakthroughs. For example, while Sarah (female, 34 years) thought that she would be likely to hear about major findings in the news, she would like to be informed about this through the research she participated in as well. She explained that she would want to be informed, “If it was something really promising for a treatment or if it was something like, ‘Oh this will cure you,’ yes. . . . If it was a major breakthrough.” In sum, while there was variation in participants’ preferences for receiving study findings,
regardless of their own preferences, they and the research coordinators believed it was important to have the choice of receiving the findings from studies.

**Why do participants want study findings?**

For some participants, hearing about the results of research studies was important because research was associated with improvements to treatment and care. Learning about the results enabled them to see the progress of research. For example, Martin (male, 48 years) described taking part in a study that tested a method of administering medication more quickly. This study investigated something he perceived to be beneficial, so he not only wanted to take part but also wanted to hear about the outcome.

Other participants were interested in learning about the results of studies because they had an interest in science and the medical aspects of CF. For some, taking part in and learning about the outcome of the research they participated in was positive and interesting. For others, it also gave them the opportunity to be well informed about what changes to CF care might be forthcoming. As Marcus (male, 38 years) described,

> I was getting almost like, free knowledge by doing them, in a way. I was knowing before anybody else what was coming. . . . And it’s good psychologically too. Because you like, already know like, this is what they’re doing, this is where they’re headed. Okay. Good. Or bad, you know what I mean?

**How might receiving study results influence future participation?**

While our participants indicated that they consented to research regardless of whether they were provided the results of the study, some felt that learning about research outcomes would encourage them and others to participate in future studies. For example, Paul (male, 30 years) and Sean (male, 27 years) wondered why they did not receive more information and felt that learning about the outcomes of the research would encourage them to keep participating. They explained,

P1 (Participant 1): That would be great. . . . They could send us a letter saying, “Hey this worked this didn’t work.” . . . I’m sure they publish the scientific paper about it, I would love to get that paper. Even if it’s all over my head. I’d love to, you know, read the ex-extract and understand what the study really was about. What results they found or what conclusions they made.

P2 (Participant 2): Yeah that would be great I’m surprised that we’ve never [P1: Yeah I’m really surprised] been given anything.
Both Paul and Sean were committed to participating in research despite not recalling having received the results of studies in which they had participated in the past. However, they felt that receiving study results would serve to reinforce that their participation was making a difference. As Marie (female, 32 years) explained, “I think it makes it even more worthwhile that you find out what the outcomes are. . . . You might want to participate even more.”

Other participants recalled repeatedly participating but did not recall learning of the impact of their participation. The research coordinators were also concerned that some people might become fatigued by research participation if they did not learn of study results. Despite identifying potential logistical challenges to returning results, they felt that doing so was important so that participants did not become jaded and therefore less inclined to participate. While we spoke with people who do participate in research, the people who do not typically participate in research also did not participate in our study; in contrast, the research coordinators speak with all patients when recruiting for research studies. As a result, they had a unique perspective on participation decisions as well as people’s reasons for choosing not to participate. As one research coordinator explained,

I have heard from a few patients like, “The reason why I’m not interested is because—” or “I’m not interested, like I have research fatigue because I never see anything that, that changes.” “I don’t get the results back” and that’s a huge problem in my opinion.

**How do participants want to receive study results?**

Participants had several suggestions as to how they wanted to find out about the results of studies they participated in. While some participants were comfortable reading scientific papers, others preferred a summary or “Coles Notes” version (Tom, male, 55 years); participants generally indicated that an accessible format would be easier to understand. They also offered their suggestions as to how to access that information, with ideas such as the clinic website and the CF foundation website. Research coordinators also referred to the clinic website, though they noted the copyright issues involved in making academic research papers available
in this way. Some participants believed, whether correctly or not, that the researchers already have their contact information and so should be able to send the study results to them directly. Participants also referenced the time that they spend waiting in the clinic as a good opportunity to read about the findings.

**Discussion**

Our study highlights the importance of providing research participants with the opportunity to learn about findings from the research studies in which they participate. Participants in our study were not focused on the return of individual findings as has been found elsewhere (Burke et al., 2014; Halverson and Ross, 2012; Shalowitz and Miller, 2008). Rather, those who wanted results were interested in knowing that their participation was helpful and wanted to hear about promising advances in CF care and treatment. However, they recalled only rarely receiving results and shared with us that this information would often be welcome. A significant challenge in interpreting the results of this study is the fact that the clinic in which we conducted the study does communicate study findings as a matter of practice, either via the clinic’s website or individually to patients when relevant.

There are several possibilities for the fact that participants in our study generally did not recall receiving these findings. First, because of the potentially long time period between study participation and the release of results, results for particular studies may not have been available at the time of the interviews. Additionally, participants may not visit the website on which results are reported or may not even be aware that results are reported on the website. This scenario seems likely given that a number of participants suggested that the website be used, without seeming to realize that this is current practice. Finally, participants may have simply forgotten receiving findings for the studies in which they participated. Within the context of patient recollection of information provided during the informed consent process for proposed medical treatments, research has consistently illustrated that patients have poor recollection of such information (Cordasco, 2013). Similarly, within a research context, poor recollection of information included on industry study consent forms has been documented (Dresden and Levitt, 2001). Such findings suggest that within the context of research participation, a large amount of information is provided, which may limit the amount any one individual can retain. Therefore, it is important to communicate study findings to participants in a manner conducive to enhancing participant recollection.

An important point to consider is that in some contexts, the advancement of research depends on the participation of particular participants. CF participants seem to understand this and do participate in research to advance research on their treatment and care (Dobson et al., 2015). Still, some of the participants in our study indicated that they found it difficult to repeatedly participate without ever
Knowing how their participation impacted the state of knowledge about CF, which indicates that how results are communicated is of critical importance since patients who do not recall receiving results perceive a deficiency in communication, even if such information is available to them. The research coordinators especially were concerned with this issue as they also interact with participants who choose not to participate in research, in some cases, because of a lack of information as to the impact of their participation. Consequently, questions regarding the communication of study findings should focus not only on whether to communicate them but also on how to do so effectively.

What to return

In our study, we wrote a summary of the research findings and communicated this information directly with participants by e-mail, an effort that they appreciated. While some people were interested in receiving whatever information was available, both the research participants and research coordinators indicated that academic papers might not be as useful as a lay summary. Academic papers have the advantage of having been validated by peer review (Miller et al., 2008), but they can be difficult to understand and are often not available without a journal subscription. In addition, academic papers can take many years to reach publication, typically long after interaction with participants is concluded. This time lag is exacerbated by the fact that even general results cannot be distributed until after they have been presented publicly. These issues may necessitate a two-step process whereby participants are provided with a descriptive summary at the conclusion of data collection and a more substantive summary of the findings if requested once they have been presented, with the option of receiving the peer-reviewed publication.

Our study shows a more varied set of opinions about the types of results desired by participants than other studies have. This suggests the possibility of providing participants with options in terms of the type of information they receive. For example, if a two-step approach were implemented, some participants may choose not to receive the descriptive summaries of studies and only receive summaries of published research or only published research in a particular category (e.g. improvements to treatment, to care, to diagnosis). While these results would be at the aggregate level, they may nonetheless only be of interest to participants if they have the potential to impact their treatment or care, which has been referred to elsewhere as actionable results (Evans and Rothschild, 2012).

How to return results

Providing information directly to participants can pose logistical challenges, which, while important to consider, should not deter efforts to do so. In other studies we
have attempted to provide a lay summary to participants and have come across challenges with team approvals of such a summary, having to request distribution of the summary to research participants in cases where we do not have their contact information, and have found that such delays can sometimes make distribution difficult. Both participants and research coordinators offered some practical suggestions on how to provide this information to participants. For example, if research clinics or networks maintain a website that provides information on completed studies, as is done in this clinic, participants could be notified when relevant information has been uploaded. Similarly, other studies have found that participants would like to receive paper or e-mail newsletter updates (Mester et al., 2015). While such information is available in the clinic where this research was conducted, participants generally did not realize this, indicating that the direct communication provided by a notification, e-mail, or newsletter may be more effective than uploading study results on a website where they may not be accessed.

Conclusions

Past research into participant preferences for the return of results typically finds that participants want both individual results and study findings. Our investigation with CF participants showed that they rarely recall receiving study findings even though these are provided routinely by the clinic. This points to the need to communicate study results to participants in a way that enhances recollection. Participants believed they should have the choice to receive study findings, particularly in an easily readable format. As has been argued elsewhere (Beskow et al., 2012), doing so offers a relatively simple way of thanking participants for their participation and encouraging future participation. Given that providing study findings is fairly uncontroversial ethically, efforts should now focus on ways of overcoming the logistical challenges of providing this information to participants and work on doing so in ways that meet the patients’ needs.

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