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ORIGINAL RESEARCH

Public's Views toward Return of Secondary Results in Genomic Sequencing: It's (Almost) All about the Choice

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Abstract The therapeutic use of genomic sequencing creates novel and unresolved questions about cost, clinical efficacy, access, and the disclosure of sequencing results. The disclosure of the secondary results of sequencing poses a particularly challenging ethical problem. Experts disagree about which results should be shared and public input – especially important for the creation of disclosure policies – is complicated by the complex nature of genetics. Recognizing the value of deliberative democratic methods for soliciting *informed* public opinion on matters like these, we recruited participants from a clinical research site for an all-day deliberative democracy (DD) session. Participants were introduced to the clinical and ethical issues associated with genomic sequencing, after which they discussed the tradeoffs and offered their opinions about policies for the return of secondary results. Participants (n = 66; mean age = 57 (SD = 15); 70% female; 76% white) were divided into 10 small groups (5 to 8 participants each) allowing interactive deliberation on policy options for the return of three categories of secondary results: 1) medically actionable results; 2) risks for adult-onset disorders identified in children; and 3) carrier status for autosomal recessive disorders. In our qualitative analysis of the session transcripts, we found that while participants favored choice and had a preference for making information available, they also acknowledged the risks (and benefits) of learning such information. Our research reveals the nuanced reasoning used by members of the public when weighing the pros and cons of receiving genomic information, enriching our understanding of the findings of surveys of attitudes regarding access to secondary results.

Keywords Ethics · Deliberative democracy · Qualitative analysis · Participant preferences · Return of genomic results · Public policy · Secondary results · Incidental findings · Disclosure of results

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Introduction

Genomic sequencing is increasingly being used as a diagnostic tool to efficiently provide a wide-breadth of molecular data on genetic conditions and other health related information. However, because this technology generates so much data, it may also uncover information about health risks for conditions *beyond* the original, intended purpose of the clinical testing. These 'secondary results' pose an ethical dilemma for health care providers: how much of this information – spanning multiple types of diseases and conditions, with different levels of uncertainty, risk, severity, and actionability – should be shared with patients? (Berg et al. 2011; Bernhardt et al. 2015; Helm et al. 2015; Roche and Berg 2015) Further, because sequencing results can have medical, psychological,

and social implications (e.g. privacy, insurance) for patients and their families, they also present a dilemma for public policy (Downing et al. 2013; Helm et al. 2015; Klitzman 2010; Lohn et al. 2013). When developing policies, how do we find an ethically appropriate balance that provides patients and families with important health information while, at the same time, avoiding potential negative individual and societal consequences, such as increased healthcare costs, loss of privacy, and discrimination? (Christenhusz et al. 2013; Helm et al. 2015; Klitzman 2010; Wauters and Van Hoyweghen 2016).

Despite efforts to develop policy guidelines, there is no agreement on how best to approach the disclosure of secondary results. Experts including genetics researchers (Appelbaum et al. 2015; Kleiderman et al. 2015; Middleton et al. 2016; Rahimzadeh et al. 2015; Ramoni et al. 2013), genetics health professionals (Brandt et al. 2013; Grove et al. 2014; Lemke et al. 2013; Lohn et al. 2013; Middleton et al. 2016; Scheuner et al. 2015; Yu et al. 2014), healthcare providers (Reiff et al. 2014; Strong et al. 2014), and advisory bodies (Fabsitz et al. 2010; Green et al. 2013; Weiner 2014) have all weighed in with preferences and policy recommendations. These recommendations are varied and have generated much discussion, especially the American College of Medical Genetics and Genomics (ACMG) 2013 recommendation that a minimum list of 56 genetic results deemed medically actionable should always be returned, regardless of patient preference, age (including children), or age of onset (Green et al. 2013). The bioethical critiques of the 2013 ACMG guidelines have primarily centered around patient autonomy and the protection of vulnerable populations (Burke et al. 2013; Clayton et al. 2014; Holtzman 2013; Klitzman et al. 2013; McGuire et al. 2013; Vayena and Tasioulas 2013; Wolf et al. 2013). Several experts have argued that patients should have the option of declining such information and that decisions regarding genetic testing of children should be deferred until adulthood if results would not lead to clear medical benefits in childhood (McGuire et al. 2013; Wolf et al. 2013). These guidelines have since been revised after much controversy and critical debate (ACMG Board of Directors 2015; American College of Medical Genetics and Genomics 2013; Burke et al. 2013; Clayton et al. 2014; Holtzman 2013; Klitzman et al. 2013; McGuire et al. 2013; Vayena and Tasioulas 2013; Wolf et al. 2013).

In addition to expert input, several studies have suggested that patients, parents, and members of the public want more or less unrestricted access to secondary genetic results (Bollinger et al. 2012; Daack-Hirsch et al. 2013; Facio et al. 2013; Fernandez et al. 2014; Meric-Bernstam et al. 2016; Middleton et al. 2016; Sanderson et al. 2016; Sapp et al. 2014; Townsend et al. 2012). However, a few studies have found that preferences shifted toward wanting less information when participants had more extensive knowledge, including that gained as a result of genetic counseling (Bradbury et al. 2015; Middleton et al. 2016). However, there are no in-depth studies of the views of the public after receiving balanced scientific and ethical information relevant to secondary genomic results.

In order to better inform public policy on secondary genomic results, we used democratic deliberation (DD) methods to investigate the views of the public regarding potential policies for the return of secondary results from genomic sequencing (Gornick et al. 2016). The DD approach involves soliciting the *informed* voices of the general public in policy-making through a process of in-depth education and peer deliberation (Fishkin 2006; Gastil and Keith 2005; Solomon et al. 2016; Thompson 2008). DD methodology is being used to elicit the informed and deliberative input of the general public on a variety of complex bioethical issues, including biobank research, flu pandemic resource allocation, surrogate consent for dementia research, and cancer screening (Carman et al. 2015; Kim et al. 2011; McWhirter et al. 2014; Rychetnik et al. 2013; Silva et al. 2012).

Initial analysis of survey data from our DD study demonstrated broad support for a policy of returning secondary results and giving patients a choice to receive or not receive results related to medically actionable conditions. Conversely, there was an overall rejection of policies of *not* returning secondary results and *not* providing a choice regarding patients' carrier status and adult-onset disorders found in children. However, after participating in the DD session, participants became considerably more willing to endorse policies restricting access to secondary results (Gornick et al. 2016). In order to understand *how* and *why* participants arrived at these policy preferences, in this article, we explore the major themes that emerged in the deliberation among our participants as they discussed and debated public policies for the return of secondary results generated through clinical genomic sequencing.

Methods

Detailed study design and methodological procedures for this study are described elsewhere (Gornick et al. 2016). The study was reviewed by the University of Michigan's Institutional Review Board and deemed exempt from federal regulations.

Participants

Sixty-six members of the public, recruited via the University of Michigan Clinical Studies website [http://UMClinicalStudies.org](Dwyer-White et al. 2011), attended an all-day deliberative session. Because our volunteer pool tended to be older, whiter, and more female, we oversampled for age (younger), race/-ethnicity (African American), and gender (male). In order to

ensure a sufficient number of participants with medical encounters relevant to the clinical use of sequencing, we also oversampled for those with a personal history of cancer (Gornick et al. 2016). The demographic characteristics of the participants are provided in Table 1.

Procedures

Members of the public participated in a day-long DD session, which included educational presentations by experts and small group deliberations facilitated by trained staff (Table 2). The participants were assigned into 10 small groups of up to 8 persons per table (range: 5–8) based on reported personal history of cancer (3 groups with, 3 groups without, and 4 groups mixed). Each small group was led by a trained facilitator with a background in either health education or genetic counseling (Gornick et al. 2016). Experts and study team members were accessible throughout the day to answer questions that arose during the small group deliberation. Participants also completed surveys 1 month before the session, immediately after the session, and 1 month after the session.

Table 1 DD participant characteristics (n = 66)

	n (%)[a]
Gender	
Female	46 (69.7)
Male	20 (30.3)
Age, Mean (SD)	57.2 (15)
Ethnicity ("mark all that apply")	
White	50 (75.8)
Black	11 (16.7)
American Indian or Alaskan Native	4 (6.1)
Asian	3 (4.5)
Hispanic	2 (3.0)
Middle Eastern/Arab	1 (1.5)
Other	1 (1.5)
Education	
Less than BA	20 (30.3)
BA	17 (25.8)
More than BA	27 (40.9)
Annual household income	
Below $40,000	16 (24.2)
$40,000–$79,999	29 (43.9)
More than $80,000	18 (27.3)
Health status	
Poor	1 (1.5)
Fair	7 (10.6)
Good	20 (30.3)
Very good	20 (30.3)
Excellent	12 (18.2)
Has children	44 (66.7)
Had genetic testing ordered by a doctor	9 (13.6)
Has personal history of cancer	37 (56.1)
Has family history of …	
Cancer	45 (68.2)
Heart disease	38 (57.6)
Neurological disorder	12 (18.2)

[a] Some percentages do not add to 100 because not all participants answered the question

The DD day involved presentations by experts in genetics and bioethics and five small group deliberative sessions. Both plenary speakers were clinical geneticists with extensive expertise in genetic testing issues and the second speaker was also a bioethicist. The presentations were developed iteratively between members of the study team, an expert advisory panel, and the presenters. The first of the five small group sessions included an "icebreaker" exercise and discussion of an informational video on genome sequencing and the second involved a general discussion of the two expert presentations. The final three small group sessions on policies (see Table 2 for policy descriptions) are the focus of this analysis.

Small Group Voting

We asked our participants to evaluate and vote on policies for the return of three different types of secondary results: 1) medically actionable results; 2) childhood disclosure of adult-onset disorders to parents; and 3) carrier status for autosomal recessive disorders. In each case the policy included: 1) a *default* disclosure procedure (secondary results were either returned or not returned by default) and 2) if the default was *flexible* (whether or not there was a choice to receive the secondary results). For each of the three policies participants were asked to vote yes or no on this question: "Should this be the genome sequencing policy regarding [medically actionable conditions/adult-onset conditions/carrier status] results?" In order to explore the impact of small group deliberation, votes were taken twice: once after fifteen minutes of discussion and again near the end of the session. The intent of requiring participants to vote on the proposed policy was to encourage dialogue within the groups. Groups were not required to come to a consensus, but participants were asked to provide rationales for their positions.

Analyses

All 30 small group policy deliberation audio-recordings (10 tables discussing 3 policies each) were transcribed verbatim. One member of the study team (KAR) read

Table 2 Overview of DD session

Introduction	Overview of the agenda for the day
Small Group Session 1	Ice breaker exercises
	Video, "Whole Genome Sequencing and You"[a]
	Discussion focusing on reactions to the video
Plenary Session 1: Expert Presentations	Each presentation lasted 50 min, including a 15 min question and answer session.
	Presentation 1: "*What can we learn from sequencing our genes*" described the science and technology related to genetics and genomic sequencing.
	Presentation 2: "*Ethical issues in sequencing our genes*" introduced the bioethical implications of advances in genomic medicine.
Small Group Session 2	Participants were given a chance to reflect upon and discuss the 2 presentations and general thoughts on genomic sequencing. (30 min)
Plenary Session 2: Policy Presentation	Explanation of proposed policies regarding return of secondary findings in 3 situations – medically actionable results, adult-onset conditions, and carrier status. For each policy, participants were asked to consider "Should this be the genomic sequencing policy?"
Small Group Session 3	Discuss & vote on proposed policy: "Patients are given medically actionable results that are not related to the reason for the sequencing. Patients have a choice: They can ask to not be given these results." (30 min)
Small Group Session 4	Discuss & vote on proposed policy:"Children and their parents are not given results for adult-onset conditions that are not related to the reason for the sequencing. Children and their parents have no choice: They will not be given these results even if they want them." (30 min)
Small Group Session 5	Discuss & vote on proposed policy: "Patients are not given carrier status results that are not related to the reason for the sequencing. Patients have no choice: They will not be given these results even if they want them." (30 min)

[a] © 2015 Icahn School of Medicine at Mount Sinai

through all 30 transcripts and other team members read a subset of the transcripts. In order to examine the content of group discussions, we developed a coding scheme using an iterative method, drawing on codes used in a previous DD study (De Vries et al. 2013), codes derived from questions provided to facilitators to generate discussion, as well as the identification and refining of new codes based on careful reading of the transcripts and study team discussion. Two study team members coded six small group sessions to ensure accuracy of coding, as well as to ensure the clarity and completeness of the coding scheme. Coding was then conducted by one team member (KAR) using Dedoose qualitative software. After coding was completed, each transcript was systematically reviewed for the most commonly occurring themes and representative quotes were identified. In order to identify any shifts in attitudes, we also tracked policy preferences at multiple time points at the small group level (Table 3). For this paper, we paid particular attention to any group-level shifts in voting preferences (as compared to the pre-DD survey). These groups were further analyzed to better understand group processes and the reasoning used in making these shifts.

Results

In small group sessions 3–5, participants were asked to evaluate three specific policies for return of secondary results. There was a distinct and striking pattern to the voting on the three proposed policies (Table 3). Small groups strongly agreed with the policy on disclosure of medically actionable results (in which patients are given results, but have a choice). At the second vote, 6 out of 10 groups agreed by consensus and 1 group by majority with the policy for medically actionable results. However, small groups tended to disagree with the policies on childhood disclosure of adult-onset conditions and carrier status results (in which parents/patients are *not* given results nor have a choice). At the second vote, only 1 out of 10 groups agreed by consensus and 2 groups by majority with the policy for adult-onset conditions; and only 1 group agreed by majority (all other groups were consensus "disagree") with the policy for carrier status results.

In our previous quantitative analysis of participants' survey responses, we found that participants did not significantly change their views regarding the policy for the return of medically actionable results across surveys (Gornick et al. 2016). However, while the majority still disagreed with the policies

Table 3 Agreement with policy by survey and small group voting

	Small group 1 (n = 8) n (%)	Small group 2 (n = 8) n (%)	Small group 3 (n = 6) n (%)	Small group 4 (n = 8) n (%)	Small group 5 (n = 7) n (%)	Small group 6 (n = 5) n (%)	Small group 7 (n = 6) n (%)	Small group 8 (n = 6) n (%)	Small group 9 (n = 5) n (%)	Small group 10 (n = 7) n (%)
Medically Actionable										
Pre-DD Survey	6 (85.7)	8 (100.0)	6 (100.0)	7 (87.5)	7 (100.0)	4 (80.0)	6 (100.0)	6 (100.0)	4 (80.0)	5 (71.4)
Vote 1	2 (25.0)	8 (100.0)	6 (100.0)	6 (75.0)	7 (100.0)	0 (0.0)	6 (100.0)	6 (100.0)	5 (100.0)	7 (100.0)
Vote 2	1 (12.5)	8 (100.0)	6 (100.0)	2 (25.0)	7 (100.0)	0 (0.0)	5 (83.3)	6 (100.0)	5 (100.0)	7 (100.0)
Post-DD Survey	3 (37.5)	7 (87.5)	6 (100.0)	5 (62.5)	7 (100.0)	5 (100.0)	6 (100.0)	6 (100.0)	4 (100.0)	7 (100.0)
Follow-up Survey	6 (85.7)	7 (100.0)	4 (66.7)	8 (100.0)	6 (85.7)	5 (100.0)	6 (100.0)	6 (100.0)	5 (100.0)	7 (100.0)
Adult Onset Conditions										
Pre-DD Survey	0 (0.0)	1 (12.5)	0 (0.0)	1 (12.5)	0 (0.0)	1 (20.0)	0 (0.0)	0 (0.0)	1 (20.0)	2 (28.6)
Vote 1	1 (12.5)	2 (25.0)	5 (83.3)	3 (37.5)	1 (14.3)	4 (80.0)	2 (33.3)	3 (50.0)	2 (40.0)	6 (85.7)
Vote 2	1 (12.5)	2 (25.0)	6 (100.0)	3 (37.5)	0 (0.0)	4 (80.0)	1 (16.7)	3 (50.0)	2 (40.0)	6 (85.7)
Post-DD Survey	2 (28.6)	2 (25.0)	6 (100.0)	4 (50.0)	0 (0.0)	3 (60.0)	1 (16.7)	2 (33.3)	2 (40.0)	6 (85.7)
Follow-up Survey	1 (14.3)	3 (42.9)	0 (0.0)	1 (12.5)	2 (28.6)	1 (25.0)	1 (16.7)	2 (33.3)	2 (40.0)	2 (33.3)
Carrier Status										
Pre-DD Survey	1 (12.5)	0 (0.0)	0 (0.0)	1 (12.5)	1 (14.3)	1 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Vote 1	0 (0.0)	1 (12.5)	1 (16.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	5 (83.3)
Vote 2	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	5 (83.3)
Post-DD	2 (25.0)	0 (0.0)	3 (50.0)	4 (50.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (25.0)	5 (71.4)
Follow-up Survey	0 (0.0)	1 (14.3)	1 (16.7)	1 (12.5)	0 (0.0)	1 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)

Valid percent as not all participants responded to every question. See Table 2 for descriptions of each of the three proposed policies

for adult-onset and carrier status, participants' views did change between the pre- and post-DD surveys, becoming increasingly supportive of policies in which parents/patients are *not* given results and do *not* have a choice. For the policy on the return of adult-onset results, participants remained significantly more supportive at 1-month follow-up.

Looking at attitudes toward the disclosure policies for adult-onset disorders and carrier status results by small group at the pre-DD survey, we find that majorities in all groups disapproved of both (Table 3). However, we also see a shift toward becoming more supportive of the policy for adult-onset results during the voting (as compared to the pre-DD survey) with a few small groups agreeing with the policy by majority (small groups 3, 6, and 10), which is reflected in their responses to the post-DD survey. For carrier status, one small group (10) shifted toward agreement with the policy by majority both during voting and at the post-DD survey. For medically actionable results, while seven of ten small groups voted to support the policy, three small groups (1, 4, and 6) disagreed with the policy by majority during voting. However, this view was reflected in only one small group (1) by majority at the post-DD survey.

To better understand the views of participants, we looked at the content of their small group discussions. We wanted to learn: 1) why participants tended to approve of the policy for medically actionable results (in which patients are given results, but have a choice), but disapprove of the adult-onset and carrier status policies (in which parents/patients are not given results nor have a choice); 2) why some small groups shifted their views, especially with regard to adult-onset (and in 1 small group, carrier status) results; and 3) participant concerns and reservations about the policies and how they wished these concerns to be addressed.

Overall Attitudes toward Policies

Certain key themes emerged in our analysis to explain the differences in participants' attitudes toward the three policies: a general preference for choice, a preference for information, and a concern over the risks (and benefits) of having or not having choice and/or information.

Preference for Choice

Participants emphasized the importance of flexibility and choice throughout all three policy sessions–medically actionable (MA), adult-onset (AO), and carrier status (CS) results:

ID-13: If I'm responsible for my own life, I should be making the choices about what I hear and when I hear it, not somebody else. (MA)

ID-39: I think the parents should have, you know, that option. I think that they should have the flexibility of asking for that information if they want it . . .that they should be able to get it if they want it. (AO)

ID-52: The whole point is that the patient should have the choice. ID-67:Exactly. That's what it boils down to for me. Choice. (CS)

As seen in Table 2, the policy for return of medically actionable results, included flexibility, i.e. patients could choose to receive or not receive these results. Small groups emphasized the importance of having this choice in their agreement with this policy.

ID-68: I think it's a very reasonable policy, giving the patient the option . . . The doc might say, "Hey, we found other things in your genomic sequencing that you might want to know that has an effect on your future healthcare." You're giving the patient the option to decline that or . . . I think it's a very reasonable policy. I think it would be a fair and reasonable policy. (MA)

On the other hand, the policies for return of adult-onset and carrier status results did *not* include flexibility, i.e. parents and children (for adult-onset) and patients (for carrier status) were not given the choice to receive the results. Small groups tended to react negatively to this lack of choice:

ID-06: Once that word "choice" comes up and you tell people, "we're taking it away from you," they get up in arms over it. (AO)

ID-29: I just believe that, again, it's my genome and I should have the choice on whether or not I want that information. So, I would say, "no." I vote "no" on this policy because I think that I should have a choice. (CS)

Choice Respects Personal/Cultural Differences

Participants gave a number of reasons for preferring policies (regardless of type of result) that included choice. They recognized that people are diverse in their informational needs, their ability to handle information, and their personal and cultural values, and felt that these differences should be respected. For example, participants acknowledged that others may wish to have more or *less* information: "*Just because I would want the information, it doesn't mean somebody else should be forced to hear it.*" *(ID-14, MA)*

Participants asserted the need for flexibility due to concerns that some individuals may not be able to handle this information:

ID-50: Ultimately you'd want to do what's in the best interest of the patient. So, they're not wanting to know the information because they're afraid that they'll be too anxious, then you can work with that. I think that counselling ahead of time would be really helpful. And I do think patients have the right to know or not to know. (MA)

Participants also acknowledged that diverse personal and cultural beliefs may play a role in people's different choices about information:

ID-34: I think because we are a democracy, we respect other peoples' ethics and religious and all those things, I think you want to be as inclusive as possible in the broad sense so that everybody has access, and that person then gets a choice to either opt-in or opt-out and say, "No. I'm not interested." (CS)

An individual's right to choose also was recognized as an important shared cultural value: *ID-51: This is America, and so why aren't we allowed to have the choice? ID-53: Exactly. ID-50: It's my body. (MA)*

Choosing Not to Know

Others stressed that an individual's right *not* to know was also an important value:

ID-39: I don't think that you can force people to take the information and be expected to act on it if they don't want the information. I do think that there are people who don't want to know, you know? I mean we all know a family who's had a child and they had the option of knowing in prenatal testing and said, "I don't want to know." And they had a baby, and that baby has maybe significant problems, but you can't make people, you know . . . FACILITATOR: Choose to find out. ID-39: …choose to find out if they don't want to. I mean they have a right to not know. I think that's as much of a choice, you know? (CS)

In fact, for some participants, this 'right not to know' superseded societal benefit even in the context of results that are medically actionable:

ID-11: The individual's right to choose trumps whatever societal benefit. And the other part of it is, what really scares me, is that somebody in Congress might get an idea to pass legislation that says that you don't get medical care anymore because you ignored the risk of this condition and developed it. You didn't get the reasonable precautions. ID-16: That would be like leaving the guys without their helmets on the side of the road when they get in an accident. (MA)

Choosing for Children

The issue of choice in the context of the adult-onset conditions was complicated by the question: "Whose choice is it, anyway?" Does the choice belong to the parent(s) or the child? One participant sets out the conundrum: "*See, that's the problem. You know, someone making a decision for an individual early on versus having that individual make it for himself later.*" *(ID-70, AO)* However, most small groups emphasized that parents should have a choice to know (or not) in the case of adult-onset conditions: "*My point is that that's my kid, and if they have that information and I want it, I should be able to get it.*" *(ID-29, AO)*

Participants presented several reasons why parents' right to choose takes precedence over their children's rights. One participant pointed out that children are not yet able to make fully-informed decisions on their own: "*As a parent, there's a maturity level that you have to consider. Although I have a 17-year-old that's intelligent and well-rounded, she's still immature. So, I just…I think parents should have a choice.*" *(ID-30, AO)* Another pointed out that children's right to choose should not equal that of adults: "*Children should not have the same level of choice as adults.*" *(ID-16, AO)* Another participant pointed out that parents make decisions for their children all the time: "*How many choices do we make as parents then? We make choices every day for our children that are going to affect them into adulthood.*" *(ID-67, AO)* In fact, parents have this right to make decisions for their children even if they may make mistakes: "*Parents make choices that are bad for their kids all their lives. So, they have a right to know this.*" *(ID-47, AO)* And policies that take away parental rights to make choices for their children are suspect: "*Now to me, that strikes of big brother looking out for you.*" *(ID-67, AO)*

However, other participants pointed out that parents' having the right to choose to know this information takes away children's future autonomy and their right to choose for themselves later.

ID-36: As far as I understand the reasoning behind it, this will not affect a child until they're an adult, and they should make their own decisions at that time. (AO)

ID-66: I mean you're not getting consent from the patient. My concern is that you're . . . this is protecting the patient which is the child, and so when the parents are not given the choice and not given the information, you're allowing that child to consent to whatever . . . eventually to consent. So it's protecting the rights of the actual patient who is the child. (AO)

This perspective was clearly reflected in the three small groups (3, 6, and 10) who shifted toward *agreement* with the adult-onset policy of non-disclosure/no choice during voting. Participants in these small groups argued that a policy of non-disclosure of adult-onset conditions protects a child's right to choose later when they become an adult:

ID-46: One of the pros is that because the child is not of age to consent and/or decide if they themselves want the results, that this gives no option that their . . . choice would be compromised because it doesn't offer that choice. So technically, that is a pro for that potential child. (AO)

ID-70: I think that at some point it's this child's decision. So I think, you know, if they want to know at 18 or whatever their sequencing information, then they should have the ability to do that if the sequencing has been done as a child or whatever and has been sitting there. I think they should have the right then to find out for themselves. (AO)

One participant illustrated this point using the example of "two sons":

ID-19: Let's say I did have two sons, right, and both of them . . . You know some test was done and both of them had a gene that they were going to get Alzheimer's in their fifties. One of them might want to know that based on his personality. He would want to know. "Alright, I'm gonna get Alzheimer's in my fifties unless maybe I can do this, this, this and reduce my risk." The other one would be like, "No, don't tell me. I want to live my full life." Kind of like . . . more like ID-18's view on these things. But because those two kids might treat it differently and the onset would be so late in their lives, maybe when they were 18 or 20 or 25, they could decide for themselves. One kid would be like, "Yeah, I want to get tested to see if I have the Alzheimer's thing." The other one would be like, "No, don't tell me." So part of me is wondering, do I have the right to make that decision for my sons or daughters when they might have wanted the other alternative if they were older? (AO)

When Choice Not to Know Harms

In the context of medically actionable results, a majority of participants and small groups supported the policy, which included flexibility. However, in a few groups participants argued that there should *not* be a choice to refuse secondary results because *not* knowing this medical information could be harmful. Small group 4, for example, moved from a majority in support of the policy at first vote to majority *not* supporting the policy at the second vote because they felt individuals should be *required* to receive secondary results that are medically actionable:

> *ID-29: If it's something that's preventable and, you know, treatable, screenable, preventable, whatever, they should know. That's something they should know, not only for the . . .* "*Well, I'm going to sue the doctor later,*" *but also because . . . for the same reason they tell you about high blood pressure or high cholesterol or whatever . . . so that you can do something about it. (MA)*

Individuals in other small groups also expressed concern about flexibility, noting that finding out about medically actionable conditions may benefit the individual, their family, and society:

> *ID-01: Absolutely I would want to know. And it's fairness to the people . . . to my family . . . in fairness to society . . . You know, what if I have nobody to take care of me and I end up, you know, wherever because I haven't been able to plan financially and emotionally and socially? (MA)*

> *ID-11: I basically agree with this philosophy, but I have one serious concern. All of these results that would normally be disclosed are medically actionable, meaning that they can either be reduced or prevented. Don't we have an obligation to know these things and act on them, because otherwise we're using up medical resources? It's the same concept as having to wear a helmet when you ride a motorcycle and wear a seatbelt, in that if you don't do those things, you may incur huge costs to society for your own adventuresome self, and why should we permit that to happen? (MA, emphasis added)*

Preference for Information

In their policy discussions, many participants expressed their preference for receiving information about secondary results (regardless of type): "*Knowledge is power. You know how to plan for your life or whatever that's going to come along if you know. I want to know. Don't sugarcoat anything for me.*" *(ID-25, MA)*

Benefits of Knowing/Risks of Not Knowing

In the context of medically actionable results, participants stressed the potential harms to the patient of *not* knowing this type of information:

> *ID-01: I'm just wondering that it's an ethical issue that you should be told. If you know that there's something wrong with you on down . . . that is a medically actionable situation, that you have an ethical . . . You have to ethically tell that person. It's like,* "*What you don't know won't hurt you.*"*But in this case, what you don't know will hurt you. (MA)*

Participants also emphasized that receiving medically actionable information would allow patients to take positive action, to possibly improve or save their lives:

> *ID-66: I do think there are a lot of good sides to this policy because it does allow access to information that could give…you know, I would have the responsibility of taking care of, but it also lets me . . . I can invest in that condition or in that situation. I can make changes to hopefully have a better outcome for myself. So it gives me that option of getting information that could be beneficial for me. (MA)*

This preference for information was also frequently discussed in the context of adult-onset and carrier status policies (both of which provided no access to this information). Participants stressed the benefits of knowing information for parents or patients in decision-making, planning, and the welfare of children (or potential children).

> *ID-37: If there's something that they can prevent or alleviate that might occur as a result of it, why not test for it and give that information? That doesn't seem very unreasonable to me if we're practicing preventative medicine. If we can find that now to enhance that child's lifestyle or life 20 or 30 or 40 or 50 years, why not give that information? (AO)*

One participant discussed protective measures they could take with their own children:

> *ID-15: As I think about it, both my mother and my father were type II diabetes, and I would want to know if my kids, you know, were at risk depending on who I was married to and what her DNA was all about, and then I*

guess I would be careful with those kids that they don't overeat, that I don't urge seconds on them. (AO)

Another participant pointed out that this information could help patients make decisions about their future child-bearing, given individuals' varying abilities to cope with the challenges of children with serious conditions:

ID-22: I do think it is a tool and, you know, as much as all of us love our children, we're fortunate enough that we can be in a place where no matter what, we had the wherewithal emotionally, financially, spiritually to take care of those kids and not all people are equipped to do those things, and they need to make decisions. Not everybody can take care of a special needs child. (CS)

In the context of adult-onset policy, some participants worried that if parents fail to find out information now, the child might *not* find out later when they were an adult or when the information is most needed/becomes relevant.

ID-52: If you're at the place right then and there to obtain that information as opposed to waiting until your child is 18 or 21 or something like that, where it may become more difficult to get that information, I would kind of like there to be the option . . .at least the option. (AO)

One participant used her own experience of early breast cancer and her daughter's risk as an example: "*If you know something, you can act on it. And if you don't know about it… She may end up getting breast cancer in her twenties like I did.*" *(ID-48, AO)*

In the context of carrier status, participants placed an emphasis not only on the potential negative impact of withholding such information from individuals and families, but also the potential impact it might have on society:

ID-69: I'm not wanting to open it wide to a fishing expedition, but I'm thinking if there are life-threatening and expensive . . . That's not just an individual good. That's a societal good if we can prevent it, and sickle cell is the only example that I know of . . . I don't know, there may be others, but . .. That one troubles me. (CS)

ID-50: For society, I think the testing would be cost effective because when you think about the cost of a medical care for a disabled child, it's astronomical. And so to pay out $1,000 to get testing would be nothing. (CS)

Interestingly, the only small group (10) who voted to *support* the policy on carrier status (which includes non-disclosure and no choice) did so, despite expressing a strong preference for receiving this type of information.

ID-72: *What harm could [this information] do?* ID-75: *More risk to not being given it.* ID-70: *More risk not to be. Again, power is knowledge. It's just a piece of information.* ID-72: *The benefit outweighs the risk. (CS)*

Their decision to *accept* the policy was the result of their understanding that retrieving secondary carrier status results would require additional cost, effort and analysis by the genetics laboratory to generate and interpret this type of secondary information. As pointed out by one participant: "*But if the information is not there, they cannot force the analysis to be done because they want it to be done.*" *(ID-70, CS)* This reasoning was unique. Some groups did not focus on the cost and effort of the additional analysis required to obtain this information. Other groups believed the information was, or could be, readily available: "*…we're probably talking about microseconds or seconds anyway of additional computer time by which you could develop information…*" *(ID-11, CS)* or felt the benefits of knowing (or having a choice to know) outweighed the cost of additional analysis. The concern of group 10 appears to have originated in an earlier session (AO) when, in response to a question by a group member, an expert pointed out that the clinician does not actually have the information in hand. This response altered their thinking about the AO policy (in addition to their concerns regarding children's rights) and the CS policy.

Benefits of Not Knowing/Risks of Knowing

While participants communicated a strong preference for choice *and* information, they also expressed reservations. Many small groups and individuals discussed the potential risks of finding out these different types of information, or put another way, the benefits of *not* knowing and *not* having a choice. These reservations were expressed across all result types, but most often during the MA policy discussion—as this policy provided both information *and* choice.

Information Overload

Several participants were concerned that patients may experience information overload.

ID-17: I think some people maybe just couldn't or wouldn't want to handle a bunch of extra information. You know, they just might have enough on their plate already, so to speak. So to find out, "*Oh, when you're this age you're going to get this,* ". . . *It's like,* "*Don't tell me. I . . . You know, life's hard enough.*" *(MA)*

Participants were also concerned about parents being overloaded with their children's adult-onset information: "*... it's a disservice to the parents. You run the risk of giving them TMI. Let's not overload them.*" *(ID-69, AO)*

Information Requires Interpretation

Participants pointed out that patients may not only experience information overload, but they might not have the ability (for a variety of reasons) to fully understand this complex genetic information:

> *ID-42: I kind of have a caution. I guess the concern would be for misinterpretation if you give full disclosure to the patient . . . them accepting that and getting that, and interpreting that, which could be a wrong interpretation in some instances about the disease, the severity of it. (MA)*

One participant also noted the potential educational barriers to informed consent:

> *ID-66: I've had 16 years of education, and so I'm not coming in with a third grade education. I'm not coming in with a low literacy level. And so I guess my concern would be that if someone is giving consent, how informed is it?"(MA)*

Information Leads to Anxiety

Participants also expressed concern that patients may experience anxiety and fear if they found out this type of information: "*It can cause a lot of people to behave differently, for good and for worse. It can cause undue anxiety, depression, suicide.*" *(ID-12, MA)*

One participant pointed out that this information might end up causing additional health harms:

> *ID-50:. . . to play the devil's advocate . . . what if patients become so anxious that their blood pressure goes up and everything goes up, so their risk factor for cardiac disease go up because they're so afraid. Or they may become fatalistic. They'll say,* "*Well, I'm going to get it anyway . . . might as well eat this ice cream.*" *(MA)*

In the context of adult-onset policy, participants also worried that parents' knowledge about their children's risk for adult-onset disorders may cause distress:

> *ID-26: So it's everybody's choice, you know. When my husband first got [the condition], I felt like I needed to rush my kids in right away and get them all MRIs and everything, but as I thought about that and thought about that, it was like, you know,* "*No, I can't do that.*" *It would be like. . . It would just be too terrifying, all the time being worried . . . (AO)*

Information Interferes with Relationships

Participants were also concerned that this information may result in parents overprotecting and restricting children who get 'labelled' with a risk for an adult-onset condition. They worried that parents may overprotect their children and that these children may not get the opportunity to lead a normal childhood:

> *ID-51: You know, when a child comes to elementary school and the parents have taken them to the doctor since they were 4 and they have ADD and ADHD . . . They have a label, and that child is treated differently, and I feel like . . . not necessarily in the education realm . . . they'll be treated differently, but if a parent knows that their child has a potential for breast cancer, well then they're going to sit there and they're going to go out of their way for things because that's typically what parents do, and I feel like that . . . some of these things could hinder a child. You know, like . . . most people think that Alzheimer's is when things start to go wrong in the head. Well, you can't play football because you'll get a concussion. You could get maybe an earlier onset. You can't do this . . . ID-50: What's wrong with that? ID-51: I'm not saying that football is the safest sport, but I'm just . . . You know, the child might become hindered in just growing up because at one point in time they could potentially have this and, you know, they're held back from their potential to even just enjoy themselves. ID-47: Overprotected and sheltered . . . (AO)*

Information and Stigma

Across all policies, participants expressed concerns that individuals who learn secondary results may be at greater risk for loss of privacy, discrimination and stigma. One participant worried about the consequences of medically actionable information being entered into their medical record:

> *ID-58: For me, the revelation was if you decide to take the choice and be given the results, you're opening it up to your doctor and to your healthcare company as well. It will be on your medical record, and then it might be held against you at some point if you don't get the treatment for something, so . . . And I didn't think*

it would bother me as much . . . but it's starting to bother me. (MA)

Another participant discussed the possible implications of having access to adult-onset information in a society which already struggles with issues of inequality and discrimination:

ID-19: So I guess the main thing I was thinking is that right now in our society, we struggle with things like racism, sexism and other forms of discrimination. If in the future there's a case where the majority of people . . . their genomes are tested and known, that can become a really big source of stigma and discrimination as well, and there might be situations where, you know, a guy is 30 years old and applying for a job and his employers find out that he's going to develop Huntington's because it's an autosomal dominant disease and there's nothing you can do about it. He's going to develop it in his forties or fifties. They might not hire that person, you know. There's not just Huntington's, but there's many examples of diseases where you're going to get it if you have that gene. So this might be another source of discrimination just like our other social identities that we struggle with now. (AO)

In small group 3, it was concerns like these – about stigma and discrimination – (along with support for children's rights) that prompted a shift to support for the AO policy, in which parents are *not* given results and do *not* have a choice to receive them.

In the context of carrier status, one participant brought up the ethical challenges that may arise within society over disability rights and parents choosing not to have children with certain types of conditions:

ID-46: I think the sticky part is figuring out where that line is and who gets to determine that line because, you know, I think about the disability community and the fact that there is a community of people who do identify positively as being members of that community and that there is a culture there, and passing judgment as somebody who does not experience any physical disabilities or mental disabilities that limit me in a strong way, to be able to make that choice of whether or not that is ethically sound. Does that make sense? Okay. So, for example, thinking about people who are part of the deaf community . . . may not see themselves as having wanted to be hearing. They may positively identify with being deaf, but would their potential parents decide, "Well, I don't want to raise a deaf child"? (CS)

Uncertainty and the Value of Information

Participants were also concerned about individuals taking on these potential risks of knowing this information, when the very nature of the genetic information includes uncertainty—that these secondary results only provide information about a *risk* to potentially get (or to pass along) a condition.

ID-18: The bottom line is I don't want to go through life worrying about what I could get, do you know what I'm saying? I've got to try to keep my head on straight dealing with all this craziness out here and just, you know, live a balanced life . .. eat healthy, exercise, whatever, you know, but I don't need to know a bunch of stuff that might happen to me, you know, down the road. (MA)

ID-08: In that way, if you think about it like a physician, that makes sense because these results are not 100% sure. So they do not want parents . . . I am talking for the policy now . . . They do not want parents to be stressed out that their kid might be getting cancer [. . .] because these results are not 100%. So why do you want to tell parents that, "Oh, your child might get leukemia." "But are you sure?" "No."(AO)

A summary of the comments we heard regarding the benefits of not knowing and the risks of knowing can be found in one group's discussion (6) about the proposed MA policy (in which patients are given results, but have a choice). This was the only group that voted by consensus *against* the MA policy (Table 3), a shift generated by their conversation about the downsides of genetic information. Among the concerns mentioned were information overload, lack of medical knowledge and misunderstanding of information, not knowing what to do with the information, and the risk of too much testing with uncertain benefit. A few participants proposed that information overload could be reduced by allowing *more* choice (giving individuals the opportunity to select the types of MA results to be returned). One participant suggested the dangers posed by genetic information could be abated by allowing a clinician to decide what information to share. This shift in group 6, however, did *not* persist to the post-DD survey.

Toward Better Policies

The small groups provided several recommendations to make the policies better, safer and/or fairer. As seen in their preference for choice, the most common recommendation was to provide flexibility in the policies that did not allow choice (the adult-onset and carrier status policies), but participants had additional ideas about how to improve the proposed polices.

There was widespread concern about the quality of informed consent (particularly in case of MA policy in which

patients are given results, but have a choice). For example, small group members found it important to provide patients with sufficient time to ask questions and process information:

> ID-57: *So I think that it would be helpful to have some time . . . I don't know how much time people would need, but I know I've been in the doctor's office before and I've been smacked with something that I was not expecting, and I didn't even . . . I couldn't think . . . I just couldn't react, you know, until afterwards. (MA)*

Participants also stressed the need for support from trained specialists to help patients to process and understand complex genetic information.

> *ID-27: Is that doctor qualified to give a context for this very, very scary but new information, this new technology, and I'm thinking about is there a whole new breed of medical social workers going to be hand-in-hand with the doctors saying, "Oh, by the way, here's what this means and this is the context for this." I'm not sure doctors today are qualified to give a context for this kind of powerful information. (MA)*

> *ID-42: I'm just throwing it out there . . . but you have a professional available for the person that is being counseled on what . . . what the findings are and ways to process it. (MA)*

> *ID-50: I think that counselling ahead of time would be really helpful. And I do think patients have the right to know or not to know. (MA)*

Another concern focused on the necessity of safeguards against discrimination.

> *ID-03: Their insurance should not be influenced by whatever status they may have . . . more prone to this. What they're going to charge . . . That shouldn't enter into the picture at all. FACILITATOR: So if parents do find out the carrier status and then they elect to have the child anyway, you're saying that should not . . . Is that the situation . . . ? ID-03: It should not affect the child's insurance possibilities. (CS)*

> *ID-59: Being able to use this information, and I'm wondering if there could be some kind of preventative clause that this would be . . . If an insurance company finds out that you have the potential to get this or the potential to get that, they can't use that against you because that should fall under the . . . Let's say Americans with Disabilities Act. They can't discriminate against people with HIV for instance or any kind of physical disability from being hired. (MA)*

Some participants discussed the desirability of an "opt-in" policy model (i.e. you don't get secondary results, unless you request them): "*I think it's a lot of over-testing that doesn't need to happen, but with the flexibility that you could ask for it if you wanted.*" *(ID-39, CS)* In fact, small group 1 voted *against* the opt-out policy on medically actionable results (i.e. you automatically get secondary results, unless you refuse), because a majority preferred an *opt-in* model to better protect individuals and groups who do *not* want to know this type of information:

> *ID-07: I guess my thinking when I heard that is that I'd like to see it the other way around where you opt in to get it versus opting out as the default since it's unknown and there's certain groups that don't want that data. So maybe we should be cognizant of that. (MA)*

Finally, in the context of adult-onset results, participants made recommendations to preserve the data and to allow deferred choice to children when they became adults: "*I would mandate that the information be maintained in that child's record and offered to them when they are at the age of majority.*" *(ID-38, AO)*

Discussion

In our previous report of pre- and post-DD survey responses, we found that participants strongly agreed with policies on return of secondary genomic results that included the flexibility to choose to receive (or not receive) information and that they strongly disagreed with policies that provided no information and no flexibility. Importantly, however, support for the two policies that included non-disclosure – carrier screening and testing children for adult-onset conditions — *increased* after education by experts and deliberation amongst peers. Support for the non-disclosure policy for adult-onset results shifted from 9% to 44% and support for carrier status increased from 5% to 22% (Gornick et al. 2016).

Our qualitative analysis of small group deliberations provides a deeper understanding of the underlying attitudes toward these policies, helping us to better appreciate why education and deliberation increased participant willingness to support policies that restrict access to secondary results. Like others, we found a strong preference for choice and the disclosure of information (Bollinger et al. 2012; Daack-Hirsch et al. 2013; Facio et al. 2013; Fernandez et al. 2014; Meric-Bernstam et al. 2016; Middleton et al. 2016; Sanderson et al. 2016; Sapp et al. 2014; Townsend et al. 2012). However, when we listen in on the small group conversations, it is clear

that participants used the information from the education sessions, their deliberations with each other, and their own experiences, to consider the risks and conflicts that may arise from having a choice or receiving information. Participants acknowledged that personal and cultural values vary and that people have different informational needs and abilities to process information. They also noted that receiving information about secondary results could negatively impact patients' (and parents' and children's) quality of life and may result in distress, anxiety, loss of privacy, discrimination, and stigma. Participants recognized that a person has a right to choose *not* to find out information that may have important and irreversible personal, familial, and societal consequences.

After reflecting on these concerns, participants recommended safeguards to protect against the risks of choice. Among these suggested safeguards were strategies for ensuring a truly informed consent by allowing patients time to ask questions and to consider the potential consequences before consenting, as well as having trained specialists (i.e., genetic counselors) to help them process and understand complex genetic information.

Previous studies found that genetic counseling and more extensive knowledge shifted preferences toward a desire for less, rather than more genetic risk information (Bradbury et al. 2015; Middleton et al. 2016). Our study found similar shifts in the public's policy preferences for the return of secondary genomic results, suggesting that in-depth education and peer deliberation may lead to a more nuanced (and sometimes more critical) view of the value of this type of information. Our findings also speak to the strength of democratic deliberation as a method for soliciting *informed* public opinion. Educating the lay public on the ethical and scientific complexities associated with genomic sequencing and allowing them to take part in small group discussions, generated reasoned shifts in policy preferences. This is consistent with previous DD research that found changes in policy views were not only due to participants becoming more informed from the educational presentations, but also from talking with peers about the underlying issues (Kim et al. 2011).

Our qualitative analysis of participants' deliberations provides a richer understanding of the reasoning that underlies these shifts in policy preferences. Listening to participant deliberations, we discovered that concern for the child's future autonomy and appreciation of the potential harms to the child – including labeling, stigma, and discrimination – increased support for policies that restrict the disclosure of secondary results related to adult-onset conditions. It is important to keep this finding in mind as the clinical use of genomic sequencing in pediatric and adolescent populations becomes more common, making it necessary to decide whether secondary alterations associated with adult-onset conditions should be purposefully sought and returned (Mody et al. 2015). As stated by the American Academy of Pediatrics and American College of Medical Genetics and Genomics, and reinforced by the American Society of Human Genetics position statement, the decision to offer genetic testing and screening should be driven by the best interest of the child and should be made in the setting of genetic counseling (Botkin et al. 2015; Committee on Bioethics 2013; Ross et al. 2013).

While participant views on carrier status policy remained overwhelming negative, one small group, despite expressing a strong preference for carrier status information, voted *for* the policy by majority because the analysis was not already completed and would require additional steps and cost to generate this type of secondary information. Finally, while views on the policy for medically actionable policy (with disclosure and flexibility) remained overwhelmingly positive and did not significantly change across surveys, some small groups withheld approval during deliberation and voting due to concerns about the risks of knowing information, preference for an opt-in vs. opt-out model, and preference for *no* choice due to the results being medically actionable and potentially life-threatening.

Study Limitations

There are important limitations to our analysis. Our population was recruited through a clinical studies website and oversampled for a number of demographic characteristics, including a personal history of cancer. Also, because DD sessions require a considerable time commitment on behalf of the participants, there is likely some level of self-selection. Our sample was also highly educated, disproportionately female, and had very few Hispanics and, therefore, results will not be representative of the general public. To broaden the representativeness of public input, it would be useful to have any future DD sessions recruit more diverse members of the general public. It is also important to note, that despite in-depth educational presentations, some participants struggled to understand certain aspects of genomic sequencing – such as the work required to make secondary results available, who will know the information (even if patients choose not to receive that information), or the precise definitions of "adult-onset," "carrier status," and "medically actionable." In a few instances, these misunderstandings persisted, despite repeated explanation by experts. This limitation, however, may also be considered an important finding, underscoring the difficulty of explaining genetics to a lay audience. Future studies that elicit lay perspectives on genomic results must give careful consideration to what members of the public need to know and how to best convey that information. A final limitation of our research is that given sample size constraints, we could not assess whether the deliberation or the educational aspect of the DD accounted for movement in participants' views. However, we know from earlier research using DD methodology that information alone does not account for these changes (Kim et al. 2011).

Policy Implications and Research Recommendations

Our study demonstrates that while the public appears to strongly support policies that provide disclosure and flexibility with regard to return of secondary genomic sequencing results, after education and deliberation they recognize the potential barriers and risks related to these preferences. As seen in the reasoning they used, our participants developed a more nuanced and critical perspective on receiving secondary results information. This study confirms the value of a DD approach for soliciting public input on genomic medicine and for providing an in-depth understanding of the reasons given by members of the public for their policy positions. Education by content experts enhances the lay public's awareness of the intricacies of precision medicine and this, together with discussion amongst peers, is an effective way to obtain *informed* and *considered* public opinions and, therefore, should be used in developing societal policies involving complex ethical and scientific elements.

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Compliance with Ethical Standards

Conflict of Interest Kerry Ryan, Raymond De Vries, Wendy Uhlmann, J. Scott Roberts, and Michele Gornick declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures performed in studies involved human participants were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). This study was deemed exempt from federal regulations by the University of Michigan's Institutional Review Board.

Animal Studies No animal studies were carried out by the authors for this article.

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