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ARTICLE

Family secrets: Experiences and outcomes of participating in direct-to-consumer genetic relative-finder services

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Summary

In recent decades, genetic genealogy has become popular as a result of direct-to-consumer (DTC) genetic testing. Some DTC genetic testing companies offer genetic relative-finder (GRF) services that compare the DNA of consenting participants to identify genetic relatives among them and provide each participant a list of their relative matches. We surveyed a convenience sample of GRF service participants to understand the prevalence of discoveries and associated experiences. Almost half (46%) of the 23,196 respondents had participated in GRF services only for non-specific reasons that included interest in building family trees and general curiosity. However, most (82%) also learned the identity of at least one genetic relative. Separately, most respondents (61%) reported learning something new about themselves or their relatives, including potentially disruptive information such as that a person they believed to be their biological parent is in fact not or that they have a sibling they had not known about. Respondents generally reported that discovering this new information had a neutral or positive impact on their lives, and most had low regret regarding their decision to participate in GRF services. Yet some reported making life changes as a result of their discoveries. Compared to respondents making other types of discoveries, those who learned that they were donor conceived reported the highest decisional regret and represented the largest proportion reporting net-negative consequences for themselves. Our findings indicate that discoveries from GRF services may be common and that the consequences for individuals, while generally positive, can be far-reaching and complex.

Introduction

According to one popular account, genealogy is the second most popular hobby in the United States, after gardening, and the second most visited kind of website, after pornography.[1] In recent decades, genealogy has expanded beyond records research to encompass genetic genealogy, which has itself become popular as a result of direct-to-consumer (DTC) genetic testing.[2] The information that DTC genetic testing companies return to customers generally falls into three categories: (1) trait, wellness, and health information; (2) ancestry information; and (3) identification of genetic relatives.

The third category of information is generated by what are called genetic relative-finder (GRF) services. These services compare customers' DNA profiles to identify genetic relatives among them. The policies of the major DTC genetic testing companies require customers to provide consent to participate in their GRF service.[3–6] Specifically, customers agree to contribute their DNA to the company's genetic genealogy database and allow the company to search their DNA to identify genetic relative matches among other consenting customers. When a match is made between customers, they are provided each other's name (or pseudonym if one was used when creating their account) and a way to contact one another (by email or by using an internal messaging service), as well as information about their shared DNA and, often, the likely nature of their familial relationship as inferred from this genetic information, such as half sibling or third cousin.[7] Customers can then follow up directly with their matches to confirm or contextualize their genetic relationship.

In 2000, FamilyTreeDNA offered for sale the first DTC genetic test in the United States for genealogical purposes,[8] and in 2009, 23andMe launched the first GRF service using autosomal DNA.[9] Currently, the largest autosomal database is maintained by Ancestry.com,[10,11] although the autosomal database maintained by the latest industry competitor, MyHeritage, is rapidly expanding. The total number of profiles in the major DTC genetic databases has grown exponentially over the years, from approximately 5.5 million in early 2017[12] to an estimated 38 million in 2021.[10] However, the overall number of participants is somewhat lower due to the deposit of duplicate profiles—or cross-participation—in databases. In some cases, duplicate profiles occur when a customer downloads their DNA profile generated by one company and then uploads the profile to a genetic genealogy database maintained by another company that accepts such

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uploads. GEDmatch is an example of a GRF service that processes only uploaded DNA profiles; it does not offer testing.

In marketing campaigns, companies typically portray the information learned from participating in GRF services—for example, that one is descended from royalty—as generally harmless, potentially interesting, and sometimes delightful. However, as genetic genealogy databases expand and, in turn, are able to match customers to more genetic relatives, the odds are increasing that they will learn surprising and potentially distressing or destabilizing information about their families. In a recent Pew Research Center survey, 27% of DTC genetic testing customers reported learning about previously unknown close relatives.[13] For some, this "genetic reckoning"[14] has included learning that they were adopted or conceived using donor eggs or sperm; discovering a child, sibling, or other close relative whose existence was previously unknown to them; or uncovering instances of abandonment, adultery, or rape in their family tree.[7,15] Especially when what is learned involves an intentionally buried family secret, exposing those secrets via DTC genetic testing can have life-changing consequences for GRF service participants and their families.[2,14,16–20]

Whereas some participate in GRF services out of general curiosity and might be unprepared to uncover family secrets, others participate as part of their search for genetic relatives who they know exist, but whose specific identity is unknown to them for various reasons.[21] One study of U.S. domestic and intercountry adult adoptees, for example, found that 83% of the survey respondents who had participated in DTC genetic testing did so primarily to search for biological relatives.[22] But relatives who are found might have mixed feelings about being contacted, and the person searching for them might also experience a range of emotions and consequences as a result of those contacts.[23,24]

A number of studies have considered psychosocial and behavioral impacts of learning health-related[25–33] and ancestry[34–37] information from DTC genetic testing and concerns associated with participating in DTC genetic testing for those purposes. Divulging and learning about misattributed parenthood in clinical settings is also discussed in the literature.[38,39] To date, however, few empirical investigations have examined the discovery-related experiences of GRF service participants.

In a focus group study, 114 family history practitioners interested in genetic genealogy, most of whom were members of and recruited with the help of family history societies, shared their own and others' experiences with GRF services.[2] Although some "had entered the process with known close genealogical lacunae, hoping for discoveries" to help fill them, others reported "unexpected revelations" from participating in GRF services, sometimes with "profound effects" on their relationships and conception of their families.[2] The researchers noted that these revelations had the potential to be especially disruptive given the "immediacy and unsentimentality" of DNA matches made by GRF services.[2]

More recently, in an interview study with 16 individuals based primarily in New Zealand who were recruited using social media, several learned from GRF services that a person they thought was their biological parent or grandparent was in fact not a genetic relative.[40] These interviewees described wide-ranging emotions related to their discoveries and subsequent interactions with family and newly identified relatives, including anger, emptiness, gratitude, and loss. Whereas some focused their subsequent realignment of identity on "autobiographical completeness," others also reassessed and reconstructed their family identities and relationships.[40]

Considered together, these data suggest that discoveries from GRF services might be common, and the consequences of discoveries for individuals and their families can be complex. It is not yet known, however, whether these findings are generalizable to a broader population of GRF service participants representing a range of motivations, expectations, and genealogical skill and experience. In 2020, we conducted a survey with 23,196 GRF service participants, recruited with the help of a DTC genetic testing company, to understand their experiences and outcomes of participation. Here, we report respondents' motivations for participating in GRF services, the information that they learned about themselves and their families from these services, and their responses and reflections on the personal impacts of these discoveries.

Material and methods

Survey development and fielding

In May 2020, we developed a preliminary survey, programmed it in Qualtrics, and pretested it with a convenience sample of six individuals. Pretesters were identified based on their professional work in genetic genealogy or known personal experiences with GRF services and were recruited by phone or email. After completing the preliminary survey, pretesters provided comments and suggestions by email, telephone, or both. These comments and suggestions were unstructured and focused on definitions of terms, wording of items, missing items, order of items, survey length, and their experience of participation. Based on this feedback, the preliminary survey was revised.

The final survey is reproduced in the supplemental information. The first page explained the nature of the survey and the potential risks of participation. Respondents indicated consent to participate by clicking on the forward arrow on the bottom of the first page. The requirement for written documentation of informed consent was waived consistent with U.S. federal regulations. All study materials were approved by the Baylor College of Medicine Institutional Review Board.

The survey began with definitions (and, when relevant, examples) of key terms used in the survey, including DTC genetic testing, genetic genealogy databases, and GRF services. Because the objective of the survey was to understand the experiences of genetic genealogy database participants with these services, branching logic was used to end the survey if respondents stated they had never participated in DTC genetic testing or had never participated in a GRF service. The remaining survey items were grouped as follows: reasons for participating in GRF services, discovery of

and contacts with genetic relatives identified by GRF services, discovery of new information about themselves and relatives from GRF services and outcomes of learning the information, a validated scale measuring decisional regret,[41] and demographic questions. Responses to most items were required to proceed; the exceptions were items following up on select responses and some demographic questions. The decisional regret scale was anchored to respondents' decision to participate in one or more GRF services. Possible scores range from 0 to 100; higher scores indicate greater levels of regret.

The final survey was programmed in Qualtrics and administered in October 2020. The survey remained open and active to recruitment for 8 days. Respondents were recruited via an email sent by FamilyTreeDNA to approximately 1.0 million of its DTC genetic testing customers, genetic genealogy database participants, and others who had consented to receiving such communications from the company (C. Conder, personal communication). The email included a brief description of and a direct link to the survey. To participate, respondents were required to be 18 years of age or older and able to complete the English-language online survey. The survey was programmed to deter multiple submissions by placing a cookie on the browser of those who completed it and blocking any attempted subsequent submissions.

Data analysis

We calculated descriptive statistics that included frequencies, means, medians, and modes for respondents' survey responses and demographic information. The denominator for each item depended on whether a response was required or optional. Crosstabs of counts of items inviting multiple selections (i.e., "select all that apply") were used to assess how often each selection was endorsed, alone and in combination, and to create mutually exclusive categories for race and ethnicity.

To probe the impact of discoveries, we analyzed responses to the decisional regret scale as well as the following items:

(1) "[H]ave the consequences been generally positive or negative for you?" Options were labeled from 1 to 5 with descriptions only for end points: 1 was "very positive" and 5 was "very negative"; a sixth option, "There haven't been any consequences for me," was dropped from analysis given our focus on those who experienced consequences.
(2) "What has been the effect of learning this information, if any, on your sense of self?" Response options were "select all that apply": "I feel better about myself," "I feel worse about myself," "I no longer feel like myself," "my feelings about myself finally make sense," "my feelings about myself haven't changed," and "other."

To examine potential factors associated with impacts (decisional regret and consequences) for testing in a multivariable model, we conducted bivariate analyses of identification of a new genetic relative ("yes" versus "no"), belief in the accuracy of the information learned ("yes" versus "no" and "not sure"), total number of motivations selected (from a list of 13 options, including "other"), and participant characteristics including age (continuous), gender identity ("female" versus "male"), racial and ethnic identity (due to sample size, categories were dichotomized to combine those selecting "American Indian or Alaska Native," "Asian," "Black or African American," "Native Hawaiian or other Pacific Islander," "Hispanic or Latino," "other," multiple categories, and "I prefer not to answer" [20% of respondents] versus "White" [80% of respondents]), importance of spirituality (continuous scale, options labeled from 1 to 5 with descriptions only for end points: 1 was "not at all important" and 5 was "very important"), annual household income ($99,999 or less versus $100,000 or more), and education level (less than an associate's degree versus associate's degree or higher). Only significant variables were included in the models. Linear regression was used for the continuous outcome variable decisional regret (scores from 0 to 100). Multinomial regression was used to examine the outcome variable consequences for self with three outcome categories: net-positive consequences (reference category), net-neutral consequences, and net-negative consequences.

All statistical analyses were performed using SPSS 27 (IBM Corp., Armonk, NY, USA). All p values were two-sided, and statistical significance was set at $p < 0.05$.

Results

Responses for a total of 36,649 surveys were recorded over the survey period. We excluded responses from participants reporting that they were under 18 years old (n = 7), had never participated in DTC genetic testing (n = 5,907), or had never participated in at least one GRF service (n = 4,607). In addition, we excluded participants who did not complete at least 80% of the survey (n = 2,372) or made selections that were inconsistent or otherwise suggested completion by a bot (n = 560), which were identified from the appearance of nonsense characters or phrases in open-ended responses, the use of identical open-ended responses for different items, and selection of every response for all "select all that apply" items. The final sample for analysis consisted of 23,196 completed or substantially completed surveys.

Characteristics

Respondent characteristics for the final sample are presented in Table 1. The mean age of respondents was 63 years old (range: 18–99 years old). Slightly more than half (n = 12,014, 52%) identified as female, and most (n = 18,478, 80%) self-described as White. Respondents had generally completed higher education: 36% (n = 8,326) had received an associate's or bachelor's degree, and 38% (n = 8,762) had received a graduate degree. Although we did not collect data on country of residence, given FamilyTreeDNA's customer base (C. Conder, personal communication), an estimated 60% of respondents were located in the United States. A minority of respondents reported that they were adopted (n = 1,606, 7%) or conceived by donor eggs or sperm (n = 131, 1%).

Genetic genealogy participation

Most respondents (n = 12,942, 56%) had been tested by more than one DTC genetic testing company. Among respondents, the most popular DTC genetic testing providers were FamilyTreeDNA (n = 15,072, 65%) and Ancestry (n = 15,071, 65%) (Figure S1). Three-quarters of respondents (n = 17,490, 75%) had participated in FamilyTreeDNA's GRF service, called Family Finder (Figure S2),

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Table 1. Respondent characteristics

Characteristic	n (%), unless noted
Age, in years,[a] N = 23,155	
Mean (SD)	63 (12.7)
Min–max	18–99
Prefer not to answer	1,460 (6)
Gender,[a] N = 23,179	
Female	12,014 (52)
Fale	10,837 (47)
Identify as neither female nor male	45 (0.2)
Prefer not to answer	283 (1)
Race/ethnicity,[a,b] N = 23,179	
American Indian or Alaskan Native	46 (0.2)
Asian	73 (0.3)
Black or African American	237 (1)
Hispanic or Latino	274 (1)
Native Hawaiian or other Pacific Islander	8 (0.03)
White	18,478 (80)
Multiple categories selected	1,892 (8)
Other	1,635 (7)
Prefer not to answer	536 (2)
Education,[a] N = 23,133	
High school grad or less	1,393 (6)
Some college	3,765 (16)
Associate's or bachelor's degree	8,326 (36)
Master's, doctoral, or professional degree	8,762 (38)
Prefer not to answer	887 (4)
Annual household income,[a] N = 23,118	
$49,999 or less	4,087 (18)
$50,000–$99,999	5,738 (25)
$100,000 or more	6,593 (29)
Prefer not to answer	6,700 (29)
Importance of religion or spirituality,[a] N = 23,163	
Mean (SD)	3 (1.6)
Mode	5
Prefer not to answer	1,037 (4)
Adopted, N = 23,196	
Yes	1,606 (7)
Learned from GRF service, N = 1,606	244 (15)
Donor conceived, N = 23,196	
Yes	131 (1)
Learned from GRF service, N = 131	59 (45)

[a]Responses to these items were not required, so N item < N final sample. Sum of percentages may not equal 100 due to rounding.
[b]Respondents were asked to select "all that apply." Categories were subsequently transformed and are presented as mutually exclusive.

and almost half (n = 10,897, 47%) had participated in at least three GRF services.

Motivations

Motivations for using GRF services are presented in Table 2. The most common reasons why respondents chose to participate were interest in building their family trees (n = 17,516, 76%) and general curiosity (n = 16,703, 72%). Some selected specific reasons for participation, such as to search for a biological parent (n = 2,054, 9%), child (n = 142, 1%), or other relative (n = 4,409, 19%) or to investigate a suspicion that they might not be genetically related to family members (felt out of place in family: n = 656, 3%; suspected their biological parent was not who they had been told: n = 563, 2%). Nine percent (n = 2,085) of respondents participated in GRF services to share health information with relatives.

Most respondents, however, selected multiple motivations. From the 13 options provided to respondents (including "other"), 28% (n = 6,440) of respondents selected one motivation, 35% (n = 8,065) selected two motivations, and the remaining 37% (n = 8,691) selected 3 or more motivations. Among those endorsing only one motivation, either general curiosity or family tree building was selected by 77% (n = 4,982) of respondents. Among those endorsing two motivations, general curiosity and family tree building were most frequently selected and together constituted the pair selected by 72% (n = 5,797) of this subpopulation.

Discoveries

We designated the discoveries that resulted from participating in GRF services as falling into two nonexclusive categories: learning the identities of genetic relatives and learning new information about themselves or their relatives. Although selections for these categories often overlapped—90% (n = 12,710) of individuals who discovered new self or relative information also had learned the identity of at least one genetic relative—the categories are distinct. For example, an adoptee might learn the identity of a biological parent from a GRF service, but the fact of their adoption might already have been known to them and they might not have learned anything new about themselves, their biological parent, or that parent's family if they did not make contact or conduct further research.

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Table 2. Motivations to participate in GRF services endorsed by respondents

		Selection given total number of motivations selected[b]		
	Selection all that apply,[a] N = 23,196	1, N = 6,440	2, N = 8,065	3+, N = 8,691
Motivations	**n (%)**	**n (%)**	**n (%)**	**n (%)**
To build family tree	17,516 (76)	2,846 (44)	6,818 (85)	7,852 (90)
General curiosity	16,703 (72)	2,136 (33)	6,681 (83)	7,886 (91)
Searching for relative (not parent/child)	4,409 (19)	233 (4)	621 (8)	3,555 (41)
To help relative build family tree	3,922 (17)	86 (1)	402 (5)	3,434 (40)
Other[c]	2,849 (12)	602 (9)	586 (7)	1,661 (19)
To share health info with relatives	2,085 (9)	19 (0.3)	131 (2)	1,935 (22)
Searching for biological parent	2,054 (9)	313 (5)	337 (4)	1,404 (16)
Ancestry results not what expected	1,690 (7)	69 (1)	226 (3)	1,395 (16)
Investigating something about relative	1,632 (7)	63 (1)	154 (2)	1,415 (16)
To help in criminal investigations	758 (3)	4 (0.1)	35 (0.4)	719 (8)
Generally felt out of place in family	656 (3)	7 (0.1)	48 (1)	601 (7)
Suspected parent isn't biological parent	563 (2)	47 (1)	73 (1)	443 (5)
Searching for child	142 (1)	15 (0.2)	18 (0.2)	109 (1)

[a]Respondents were asked to select "all that apply."
[b]Columns should be interpreted as follows: of the total number of respondents who selected 1 motivation, n (%) selected a specific motivation as that 1 motivation; of the total number of respondents who selected 2 motivations, n (%) selected a specific motivation as one of the 2 motivations; of the total number of respondents who selected 3+ motivations, n (%) selected a specific motivation as one of the 3+ motivations.
[c]Examples of "other" included "helping other people who are adopted or are otherwise trying to find their roots"; "I used to be a sperm donor, and wanted anyone conceived using my donations to be able to find me"; "I wanted to validate many years of genealogy research"; "brain exercise, stimulating more than anything I had ever done"; and "applying for DAR [Daughters of the American Revolution]."

Learning the identities of genetic relatives

As shown in Table 3, regardless of their reasons for participating in GRF services, most respondents (n = 19,095, 82%) reported that they learned the identity of at least one genetic relative as a result of doing so. Among this subpopulation, 10% (n = 1,883; 8% of total sample) identified a biological grandparent, 10% (n = 1,851; 8% of total sample) identified a full or half sibling, and 7% (n = 1,296; 6% of total sample) identified a biological father. Notably, most of those who learned the identity of one or more genetic relatives attempted to contact at least one of them. When the newly identified relative was a biological parent, child, or sibling, the relative usually responded to efforts to contact them. Indeed, newly identified siblings (n = 1,393, 92% of those contacted) and children (n = 67, 94% of those contacted) almost always responded to such outreach.

Learning new information about self or relatives

Separately, most respondents (n = 14,134, 61%) reported learning something new about themselves or their relatives using GRF services. For 12% of respondents who provided information regarding timing, these discoveries had been made in the previous 6 months and so were still relatively new (Figure S3). On the other end of the spectrum, 14% made their discoveries over 5 years ago.

Table 4 shows the specific information that respondents reported learning from GRF services, as well as the overall consequences for themselves, the effect on respondents' sense of self, and respondents' feelings of regret associated with their decision to participate in GRF services. Among this subpopulation, a minority of respondents learned new information about their first-degree or second-degree relatives, such as that a person they believed to be their biological parent is not their biological parent (n = 646; 3% of total sample) or that they had a full or half sibling they had not known about (n = 1,171; 5% of total sample). Data reported in Tables 1 and 4 indicate that most adoptee respondents (n = 1,362, 85%) knew about their adoption before participating in a GRF service, whereas almost half of donor-conceived respondents (n = 59, 45%) learned about their conception from a GRF service.

Those who reported learning new information about themselves or their relatives were asked about the personal impacts of these discoveries. As shown in Table 4, the majority of this subpopulation reported the consequences for themselves as net positive or neutral (n = 10,425, 74%) (almost a quarter reported no consequences) and their feelings about themselves as unchanged (n = 8,230, 58%), and almost a third reported feeling better about themselves (n = 4,329, 31%). Decisional regret was also low. From a possible score of 0 to 100, the mean score on the decisional regret scale was 10 (SD 14.0).

A minority of respondents who learned new information about themselves or their relatives experienced negative outcomes, characterized as reports of net-negative consequences for themselves (n = 352, 2%), not feeling

Table 3. Genetic relative identity discoveries and subsequent contacts

Relative identity discoveries	Yes, n (%)	Contact attempted?[a] Yes, n (%)	Relative responded?[b] Yes, n (%)
Any relative, N = 23,196	19,095 (82)	15,120 (79)	–
Specific relative,[c] N = 19,095			
Mother	522 (3)	205 (39)	139 (68)
Father	1,296 (7)	436 (34)	267 (61)
Child	101 (1)	71 (70)	67 (94)
Full and/or half sibling(s)	1,851 (10)	1,511 (82)	1,393 (92)
Grandparent	1,883 (10)	295 (16)	–
Other genetic relative	17,066 (89)	13,482 (79)	–

[a]Column should be interpreted as follows: of the total number of respondents who made the relative identity discovery identified in first data column, n (%) reported that they attempted to contact that relative. Response to this item was not required.
[b]Column should be interpreted as follows: of the total number of respondents who attempted to contact the discovered relative identified in second data column, n (%) reported that the relative responded. Response to this item was not required. Response data were not collected for grandparent and other genetic relative identity discoveries.
[c]Respondents were asked to select "all that apply." Percentages of specific relative identity discoveries in first data column are based on those who reported "specific relative, N = 19,095."

like themselves (n = 179, 1%), or feeling worse about themselves (n = 112, 1%). Further, 11% of those who learned new information about themselves or their relatives (n = 1,542) reported decisional regret scores at or above the cutoff of 30, which indicates respondents agreed more or less with at least one of the scale's statements about an experience of regret,[42] and 418 (3%) scored at or above 50. Compared to respondents making other discoveries, those who reported learning that the person they thought was a biological parent is not their biological parent and those who discovered that they were donor conceived reported the highest decisional regret and represented the largest proportion reporting net-negative consequences for themselves and not feeling like themselves.

Consequences and feelings about self were found to be correlated with decisional regret. Those who reported net-negative consequences for themselves, no longer feeling like themselves, or feeling worse about themselves tended to have higher decisional regret scores (respectively, 30 [SD 24.5], 33 [SD 27.8], and 27 [SD 24.9]) than the average (10 [SD 14.0]), and those who reported their feelings about themselves finally made sense had lower decisional regret (8 [SD 13.2]) than the average.

Regression analyses were conducted to identify independent predictors of consequences and decisional regret. Respondents who had received at least an associate's degree, identified genetic relatives, and believed that information provided by GRF services is accurate were more likely to report positive consequences for themselves and less likely to report higher decisional regret (all $p < 0.05$). Female respondents were more likely than males to report negative versus positive consequences, but gender was not a significant factor when comparing neutral versus positive consequences ($p = 0.002$ and $p = 0.661$, respectively). However, male respondents were more likely than females to report higher decisional regret ($p < 0.001$). Additionally, older-age respondents were less likely to report higher decisional regret than younger-age respondents ($p = 0.002$). Finally, those who endorsed more motivations for participating in GRF services were more likely to report positive versus neutral consequences and less likely to report higher decisional regret (all $p < 0.05$), but number of motivations was not significant when comparing negative versus positive consequences ($p = 0.781$).

Finally, as shown in Table 5, more than half of respondents who learned something new about themselves or their relatives (n = 7,175, 51%) reported behavioral responses to their discoveries. Some engaged in new or different activities related to their health, such as discussing a disease or health condition with their doctor (n = 904, 6%); related to their lifestyle, such as participating in new cultural activities (n = 783, 6%) or moving (n = 64, 1%); or with legal implications, such as changing their name (n = 75, 1%). However, the most common response (n = 4,935, 35%) was recommending to someone that they participate in a GRF service. By comparison, only 1% (n = 172) of those who learned something new about themselves or their relatives reported recommending to someone that they *not* participate in a GRF service.

Discussion

To our knowledge, this exploratory survey with 23,196 GRF service participants is the first to be conducted with this specific population and one of the largest studies to date relevant to DTC genetic testing experiences and outcomes. Although a recruitment email was sent to approximately 1.0 million individuals, the scale of response over the 8-day survey period exceeded our expectations given that we were unable to compensate participants for their time and did not have an established relationship with the sampling frame. We believe the relatively enthusiastic response is evidence of a high level of interest in genetic genealogy and, as reported in the media,[43] a perhaps surprising willingness of individuals who have made discoveries from GRF services to share their experiences with others.

The majority of our respondents self-identified as White and reported relatively high education and household income. This profile is generally consistent with the demographics of DTC genetic testing customers participating in other survey studies.[28,29] Further, the proportion of female respondents (52%) in our sample is in line with those other studies (46%–60%) although noticeably less than the sample of family history practitioners who participated in recent focus groups to share their genetic

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Table 4. Self and/or relative information discoveries and outcomes

Information discoveries	Discovery	Consequences for self, n (%)[a]				Feelings about self, n (%)[b]					Mean decisional regret score (SD)[c]
		Negative	Positive	Neutral	None	Feel better	Feel worse	Not like self	Make sense	No change	
Any discovery, N = 23,196	14,134 (61)	352 (2)	9,305 (66)	1,120 (8)	3,357 (24)	4,329 (31)	112 (1)	179 (1)	1,637 (12)	8,230 (58)	10 (14.0)
Specific discovery,[d] N = 14,134											
Parent not bio parent	646 (5)	108 (17)	336 (52)	126 (20)	76 (12)	220 (34)	43 (7)	92 (14)	293 (45)	187 (29)	15 (19.9)
Bio parent had +children	1,171 (8)	63 (5)	855 (73)	123 (11)	130 (11)	519 (44)	22 (2)	41 (4)	342 (29)	503 (43)	7 (12.4)
GR parent not bio parent	1,012 (7)	55 (5)	670 (66)	104 (10)	183 (18)	315 (31)	17 (2)	31 (3)	134 (13)	563 (56)	9 (13.7)
Unexpected family health	1,745 (12)	51 (3)	1,275 (73)	142 (8)	277 (16)	743 (43)	21 (1)	40 (2)	421 (24)	788 (45)	8 (12.9)
Unexpected race/ethnicity	4,098 (29)	99 (2)	2,579 (63)	328 (8)	1,092 (27)	1,451 (35)	44 (1)	75 (2)	699 (17)	2,181 (53)	10 (14.1)
Other[e]	8,132 (58)	121 (1)	5,539 (68)	562 (7)	1,910 (23)	2,314 (28)	28 (0.3)	29 (0.4)	567 (7)	5,009 (62)	10 (13.6)
Self donor-conceived	59 (0.4)	10 (17)	28 (47)	14 (24)	7 (12)	21 (36)	5 (8)	12 (20)	30 (51)	10 (17)	18 (24.3)
Self adopted	244 (2)	22 (9)	159 (65)	34 (14)	29 (12)	131 (54)	5 (2)	10 (4)	107 (44)	74 (30)	10 (15.9)
GR donor-conceived	27 (0.2)	1 (4)	18 (67)	5 (19)	3 (11)	10 (37)	17 (63)	2 (7)	7 (26)	11 (41)	12 (18.9)
GR adopted	274 (2)	7 (3)	206 (75)	25 (9)	36 (13)	98 (36)	2 (1)	4 (1)	38 (14)	146 (53)	8 (11.5)

bio, biological; GR, genetic relative.
[a]Columns should be interpreted as follows: of the total number of respondents who made the information discovery identified in first data column, n (%) reported the assessment of consequences for self.
[b]Respondents were asked to select "all that apply." "Other" response option is not shown. Columns should be interpreted as follows: of the total number of respondents who made the information discovery identified in first data column, n (%) reported the feeling.
[c]Decisional regret scores range from 0 to 100; a higher score equals higher regret.
[d]Respondents were asked to select "all that apply." Percentages of specific information discoveries in the first data column are based on those who reported "specific discovery, N = 14,134."
[e]Examples of "other" included: "family changed its name"; "brother unknowingly fathered a child"; "my first cousin was adopted by another family"; "unexpected origin of genetic great-grandparent"; and "people I have known for many years turned out to be distant relatives."

genealogy perspectives and experiences (78%).[2] While our sample was relatively old (mean age: 63), this characteristic is consistent with the sample of family history practitioners, the "vast majority" of whom were retired or over age 60.[2]

Almost half (n = 10,779, 46%) of our sample had decided to participate in GRF services solely for non-specific purposes that included interest in building their family trees and general curiosity. Compared to those who participated also or solely for specific reasons—for example, because they were told they were adopted and were looking for genetic relatives or because they had always felt out of place in their family and sought to explore the basis for those feelings—individuals who participated solely for non-specific reasons might be described as especially unprepared to make significant discoveries about their family trees. Notably, those who endorsed more motivations for participating in GRF services and therefore likely had specific reasons for doing so were less likely to report higher decisional regret. It is possible that this group expected to learn information that might impact their self-identity and family relationships and so were better able to process this information and integrate it into their lives, even if what they learned was unexpected.

Regardless of their motivations, most of our respondents had learned the identity of a genetic relative, and in 10% of those cases (n = 1,851; 8% of total sample), the person identified was a full or half sibling. Moreover, most who learned the identity of genetic relatives attempted to contact at least one of them. When the identified relative was a biological child or sibling, contact was frequently attempted, and the relative almost always responded. Efforts to contact newly identified biological parents and grandparents were less common, but that finding might have been due to the older age of these relatives. Specifically, contact would not have been attempted with a newly identified relative who was deceased.

The high proportion of contacts attempted and successfully made with genetic relatives discovered via GRF services is significant for several reasons. First, it means that the match lists returned by these services are usually not interpreted in isolation but rather with the input of

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Table 5. Behavioral responses to self and/or relative information discoveries, N = 14,134

Behavioral response[a]	n (%)	Illustrative comments[b]
No response	6,959 (49)	N/A
Any response	7,175 (51)	N/A
Health response		
Saw doctor to discuss disease/condition	904 (6)	• "Ruled out 6+ medical conditions that I didn't have." • "Stayed on my doctors for [] years on having a health condition they told me I did not have, but finally the correct test [sic] were run." • "I had a complete cardiac evaluation."
Joined support group	539 (4)	• "When I first learned via a DNA test that my daddy was not my father, I had a nervous breakdown … After the initial trauma, I determined to learn all that I can about genetics and to help other people in a similar situation." • "Questioned everything about my whole life and relationships … Learned … [t]hat needing a support group is a life saver."
Changed diet or exercise	525 (4)	• "Diet changes prompted by [medical testing] sparked from genetic genealogy testing which has positively impacted my health." • "I am going to be as healthy as I can be now. Not waiting."
Began taking new medication	162 (1)	• "Having medical history caused my doctor to change my treatment plan and helped in the diagnosis of a [medical condition]."
Changed medication	106 (1)	• "Awhile back I had hurt [myself] … Doctors had no diagnosis. After getting the data it was shared with me that I was allergic to [medication]. The data saved me from injuring myself further. I stopped taking [the medication]."
Began seeing mental health professional for treatment	118 (1)	• "Because of being rejected, after learning [the identity of certain relatives], it has caused me to seek professional counseling help to deal with the feelings that the rejection has caused."
Changed mental health treatment	71 (1)	• "It all made much more sense … My therapist agreed [with the interpretation from the discovery]. It's been healing."
Lifestyle response		
Began participating in new cultural activities	783 (6)	• "Began cooking a food that was native to the countries that my ancestors came from." • "I learned about Jewish history and began to observe certain traditions and even holidays … after learning of my Jewish roots."
Changed hobbies	311 (2)	• "I am more similar to my biological father than to either of the parents who raised me. Embracing our commonalities as well as other hobbies he and his family partake in has been such a joy."
Moved	64 (1)	• "I moved to the area my ancestors lived and several living relatives are currently living so I could research in person and meet with relatives to discuss any new findings." • "Moved after I found my biological mom and half siblings so that I could get to know them."
Changed appearance	51 (0.4)	• "I was surprised at my desire to change my appearance to look more like my biological relatives after I found them [] years ago. I've lost significant weight, now exercise regularly, and grew my hair longer."
Changed educational program	41 (0.3)	• "I undertook a diploma in family history … so that I could learn more."
Changed job	27 (0.2)	• "I was able to forensically reconstruct mom's life (while abandoning my own career) and identify causes and effects."
Legal response		
Changed name	75 (1)	• "I've changed my middle and last name to match my biological [parent]'s name."
Made a will	68 (1)	N/A[c]
Changed will	58 (0.4)	N/A[c]
Recommendation response		
Recommended GRF service	4,935 (35)	• "It's an essential part of being human to know who you are. These tools are vital, despite how painful the process may be." • "Emotionally it helped several people in my family heal from a secret that was kept." • "I am so pleased, besides being shocked to find relatives I never knew about. I have had positive contact with new people that are equally intrigued by it all."
Recommended against GRF service	172 (1)	• "I tell people that are thinking of doing a genetic test to consider the results and not to do it if they are not prepared for a surprise." • "In some ways I wish I had not done this testing. Truth is not always better."

(*Continued on next page*)

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Table 5. ***Continued***

Behavioral response[a]	n (%)	Illustrative comments[b]
Other[d]		
	2,270 (16)	• "Travelled to Europe to visit newly discovered family." • "I've developed a new appreciation for how events in world history have shaped my life." • "Changed my parenting." • "Became a vocal proponent for adoptee rights." • "Speaking to groups about DNA testing and preparing for outcomes." • "I'd have to write a book."

[a]Behavioral responses were selected in response to the question "What have you done, if anything, as a direct result of learning information from using one or more online relative-identification tools?" Respondents were asked to select "all that apply." Percentages are based on those who reported making a self- and/or relative-information discovery, N = 14,134.
[b]Except as noted in footnote d, comments were provided in response to the question "Is there anything you'd like to share about the things you did as a direct result of learning this information?" Respondents were not asked to associate these comments with specific response options that they selected. Illustrative comments were selected as representative of a specific response option, where the respondent selected at least that response option, based on the content of the comment.
[c]Illustrative comments were not selected.
[d]Comments were provided in response to the prompt to "please explain" when "other" was selected.

matches and perhaps also their kin. Second, because GRF services share contact information with matches, interpretation can happen quickly, shortening the time between learning that something is not as expected to learning exactly how that is the case. Third, even if participants do not immediately learn anything of interest from their match lists, participants in GRF services could learn something unexpected upon being contacted by a match at a much later date. In short, participation in GRF services is not a private event that is limited to one moment in time. Rather, it is a social experience that can play out over a long period of time, during which one's personal identity and family identity are continually subject to redefinition.

One question is why 18% of our respondents reported that they had not learned the identity of any genetic relatives from GRF services. After all, given the large sizes of genetic genealogy databases and their algorithms' ability to detect very small amounts of shared DNA, GRF services should be able to identify multiple genetic relatives for each participant. Although the number and distance of matches for any participant depends on a number of factors and also is restricted by some databases, that number will still likely be quite large. In 2019, for example, Ancestry announced that it provided, on average, 50,000 matches to each customer.[44] Since many of those matches were likely not previously known to them, why didn't all of our respondents affirm that they had discovered "genetic relatives [they] hadn't previously known about"?

There are several nonexclusive explanations for this outcome. Among them, although the survey defined genetic relatives in terms of biological relatedness without limitation on distance, it is possible that some respondents answering this item focused on matches that were memorable to them. A relative match might be memorable if a GRF participant perceived the match to be a close relation, learned something interesting about the match's life, or was surprised to learn they are related to the match. Alternatively, some respondents might have limited their responses to encompass only matches who had meaningfully interacted with them, which can promote notions of kinship.[45] As additional explanations, some respondents might not have explored their entire match list to the point of identifying any previously unknown genetic relatives, or they might have been confused by their results, which a previous study found was common among GEDmatch participants.[46] These hypotheses might be explored in follow-up interviews with respondents.

Separately, most respondents reported learning new information concerning, for example, the structure of their family tree. For a minority, these discoveries involved close relationships: 3% of the total sample (n = 646) learned that the person who they thought was their biological parent is not, and 5% of the total sample (n = 1,171) learned about the existence of a full or half sibling. The prevalence of such events is not known—estimates of non-paternity events, for example, vary widely[47]—and so it is not clear if the proportions we identified are elevated compared to the general population. This could be the case if individuals who know or correctly suspect they are disconnected from kin are overrepresented among GRF service participants, or if GRF service participants who discovered significant family secrets were more likely to complete our survey than those who did not make such discoveries. Future research might test these and other possibilities.

Most who discovered new information about themselves or their relatives reported that these discoveries had no consequences or net-neutral or -positive consequences for themselves and had low regret regarding their decision to participate in GRF services. However, there was a large spread in the timing of when respondents made discoveries from GRF services, from less than 6 months to over 5 years prior to participating in the survey. We were unable to analyze associations between timing and experiences of discoveries due to the data structure, but it is possible that respondents who had more time to process their discoveries and utilize supportive resources were more likely to frame the outcomes of participating in

GRF services in a positive light or to generally be at peace with their discoveries, compared to those for whom discoveries were still new. Regardless of their perceptions of overall consequences, many respondents who made such discoveries reported engaging in new or different activities as a result. Some of these activities, such as moving, changing their name, or adjusting health behaviors, can be characterized as major life changes, suggesting that the impacts of GRF service discoveries can be far-reaching even if not perceived as net negative.

Compared to respondents making other types of discoveries, those who reported learning that they were donor conceived reported the highest decisional regret and represented the largest proportion reporting net-negative consequences for themselves and not feeling like themselves. These findings align with reports that donor-conception discoveries can be especially difficult to process and manage because they often involve concurrent identification of many new half siblings and their extended families, which multiplies the number of new relationships that the donor-conceived person might suddenly find themselves navigating.[48] In addition, there are unique challenges with donor-conception discoveries stemming from the clinical nature of gamete donation and artificial insemination. Especially if the donor was guaranteed anonymity and never emotionally invested in their donations, they might not welcome the unmasking of their identities from GRF services and be inclined to reject or ignore any efforts by their (possibly many) donor-conceived offspring to contact them.[49]

Other surveys indicate that DTC genetic testing plays a key role for donor-conceived individuals in not only identifying genetic relatives but also learning the truth of their origins. For example, among the 481 participants in the 2020 We Are Donor Conceived survey, 78% stated that they had identified their donor, 70% had identified at least one sibling, and 34% had learned they were donor conceived from DTC genetic testing.[50] Further, 46% of respondents said they had sought professional therapy to process their emotions around being donor conceived, and an additional 17% stated they would like to do so. Although some DTC genetic testing companies provide short lists of mental health resources for those who make unexpected discoveries,[51,52] our results suggest that some customers might appreciate expanding those lists, perhaps most immediately with resources relevant to donor-conception discoveries.

This research is subject to limitations. First, the survey was conducted with a non-probability sample. FamilyTreeDNA emailed a link to the survey to individuals who consented to receiving these communications from the company, but we do not know how many emails were actually received. Further, recipients were able to forward the email or share the link with others. Because we do not know how many individuals had an opportunity to participate in the survey and declined, or intended to respond but did not do so before the survey closed, we are unable to report a response rate.

Second, there are several factors that might have contributed to selection bias. Specifically, both purchase of DTC genetic testing from more than one company and participation in multiple GRF services were common, suggesting that the genealogical interest and/or skill of the sample might have been higher than would be expected from a typical GRF participant. As noted above, however, cross-participation in GRF services is relatively easy once testing has been performed, and other research has found that it is not unusual for individuals with access to their DNA profiles to participate in multiple third-party genetic interpretation services.[46] Indeed, that a greater proportion of respondents reported participating in FamilyTreeDNA's Family Finder service than purchasing DTC genetic testing from FamilyTreeDNA can be explained by the company's policy allowing individuals tested by other companies to upload their DNA profiles to its genetic genealogy database.

In addition, those who had more impactful experiences from participating in GRF services might have been more likely to participate. Conversely, our inability to compensate individuals for participating in the survey might have discouraged participation among lower-income individuals as well as individuals with less free time on their hands, such as caregivers. Further, our respondents' experiences and outcomes might not be representative of GRF participants belonging to different sociodemographic groups. As one example, our sample reported generally high education and income, which could have helped them in accessing supportive resources and consequently influenced their perceptions of consequences and decisional regret.

Third, a cross-sectional survey is unable to capture nuances and changes in perceptions of events over time. We encourage the use of longitudinal research methods to better understand the experiences of GRF service participants and what factors contribute to improved outcomes. Among other things, it will be helpful to understand the resources that participants have found useful in navigating their discoveries; the impact of those resources on conceptions of self and family; and the unmet psychosocial needs, if any, related to making discoveries from GRF services. In addition, psychosocial assessments of participants using validated measures can help illuminate whether reported outcomes of discoveries are associated with personality traits, individual psychosocial functioning, or perceived family functioning.

Finally, we were unable to isolate the impacts of specific discoveries from GRF services on respondents because they were asked to identify and reflect on all of their discoveries, and most respondents reported making more than one. Although this design limited the specificity of our findings, it is consistent with the layered nature of the information that can be learned from GRF services.

Conclusion

This study, which examines the outcomes of participating in GRF services, is one of the largest related to DTC

genetic testing. As such, it provides valuable insight into the experiences and potential psychosocial support needs of GRF service participants. In future research, we hope to use in-depth interview and case study methods to unpack the potentially complex experiences of GRF service participants and the impacts of their discoveries on individual well-being, relationships, and notions of genetic identity, kinship, and belonging.

Data and code availability

Relevant data will be made available upon reasonable request.

Supplemental information

Supplemental information can be found online at https://doi.org/10.1016/j.ajhg.2022.01.013.

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Declaration of interests

C.J.G. and S.M.F. are members of the Investigative Genetic Genealogy Working Group of the Scientific Working Group on DNA Analysis Methods. A.L.M. was a founding member of the FamilyTreeDNA Citizen's Panel. B.K. is founder and owner of Watershed DNA, LLC. All other authors declare no competing interests.

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