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RESEARCH

Direct-to-consumer genetic testing in the news: a descriptive analysis

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Abstract

Direct-to-consumer genetic testing (DTC GT) diagnostic tools do not entail referral through a healthcare provider and are used by consumers to screen for genetic health risk, pharmacogenomics, and predisposition to certain diseases and to learn more about ancestry. The purpose of this study was to describe the content of DTC DNA online news articles – specifically to characterize how rising concerns related to consumer privacy, medical advancements, and bioethics are covered in online news as access to these testing kits continues to grow. One hundred news articles identified on Google News using the search term "direct to consumer DNA testing" were coded for pre-determined content categories. Only 34.0% of news articles were created by healthcare professionals. Only 10.0% of online news articles mentioned testing confidentiality and privacy protection. Articles that mentioned > 5 commercial DTC DNA products more often discussed how DTC DNA testing provides personalized information about health and link to family disease risk and other traits (85.7% vs. 61.1%, $p = 0.02$), can lead to the location of family members or ancestors (78.6% vs. 55.63%, $p = 0.03$), and that the testing results housed in DNA databases can be utilized by law enforcement to track suspects or their relatives (32.1% vs. 9.7%, $p = 0.01$). Articles that mentioned ≤ 5 commercial DTC DNA products failed to mention that there exists a potential for data breaches (75.0% vs. 53.6%, $p = 0.04$). Online news articles should adequately inform consumers regarding the benefits and risks of DTC GT tests to facilitate informed decision-making.

Keywords Google News · Direct-to-consumer genetic testing · Online news · Public awareness · Information seeking

Introduction

Direct-to-consumer (DTC) genetic testing (GT) is defined as "in vitro diagnostics that are marketed directly to consumers without the involvement of a healthcare provider" (United States Food and Drug Administration 2019). Though the first DTC GT premiered in 1996, mainstream adoption did not begin until the late 2010s (McLeod 2021; Regalado 2018). Prior to this transition, genetic testing was carried out at the behest of a physician after an in-person meeting detailing a patient's risk factors and family history. The results of physician-ordered tests were also interpreted by genetic counselors with an assurance of clarity and confidentiality (Amendola et al. 2021). Recent years have witnessed an increased availability of DTC GT without the need for a referral by a healthcare provider (McLeod 2021; Roberts and Ostergren 2013).

The DTC GT market in the USA generated more than $465 million in 2020 and has further invested in ancestry and relationship testing (Businesswire 2021). These genetic tests have found a niche among consumers desiring to learn more about how their genetic make-up may affect their health. Different types of DTC GT include carrier screening (indication of a genetic variant that can be inherited by potential progeny), genetic health risk (information on an individual's genetic propensity for certain medical diseases), pharmacogenomic (information on an individual's genetic disposition to react to specific therapeutic drugs), cancer

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predisposition (indication of one's individual risk of acquiring specific cancers), and ancestry (United States Food and Drug Administration 2019; Sanghavi et al. 2022). A variety of companies offer one or more of the above types of testing (Roberts 2022; Phillips 2016). DTC GT kits can be purchased in a store, ordered online, or via telephone. In fact, DTC GT has been marketed heavily as a holiday gift and often occurs as a featured sale item (Molteni 2018). Experts suggest that recipients of such gifts are often unprepared for unexpected results and repercussions, causing the risks to potentially outweigh the benefits of participating in such testing (Raven 2018; Mackley 2019).

Once a consumer's DNA is collected, typically through a saliva sample, and sent back to the company for analysis, the consumer's sample is run through massively parallel sequencing (MPS) technology which generates genomic panels as an estimate (Amendola et al. 2021). By comparing the similarities and variations in a consumer's genome to that of other customers in the company database, companies are able to determine ancestry origins and disease risk (Royal et al. 2010). However, disparities in data pools result in a sample highly representative of consumers of European descent. This calls the accuracy and utility of DTC GT into question (Desai et al. 2021). Without adequate context or professional genetic counseling, consumers may undergo testing that is not optimal for them and misinterpret their results (Majumder et al. 2021).

Furthermore, DTC GT companies may conduct research based on their consumer genetic database. Research is only conducted if the consumer consented; however, it is important to note that the consent forms are often at a difficult reading level and filled with jargon that a layperson would not understand (Majumder et al. 2021). DTC GT companies make it easy to click through these consent forms and continue completing their order (Roberts 2022). Even though consumer participation is voluntary and the companies attempt to de-identify the data, the process carries the potential risk of data breach and return of unexpected or possibly inaccurate results (Consumer Federation of America 2020; Whittaker 2020; Tanday-Connor et al 2018).

Additionally, law enforcement can utilize DTC GT databases to identify criminals via relatives' genetic information, which is how authorities identified the Golden State Killer in 2018 (Guerrini et al. 2018). While many companies allow consumers to opt-in to be included if law enforcement chooses to use genetic databases to find relatives of criminals, this raises a variety of legal (Brown 2019) and ethical issues (Berkman et al. 2018; Kennett 2019). DTC GT websites fall behind in articulating the risk of participating in such testing to the user (Skeva et al. 2020).

Since DTC GT can be completed without medical referral and are not approved as diagnostic tools, they are not covered by most health insurance plans, even though these tests may be informative regarding disease risk (United State Food and Drug Administration 2019). Though not required, it would benefit consumers to consult with their health care providers, especially genetic counselors, to identify appropriate DTC GT, as well as discuss results with them prior to adopting health-related changes (Hsieh et al. 2021; Harris et al. 2013). Despite these limitations, there are benefits to DTC genetic tests. They can provide personalized and relevant health information to empower health-conscious individuals. The tests are low cost, non-invasive, and provided directly to the consumer (U.S. National Library of Medicine 2020).

In the current digital era, the internet and social media are important sources of healthcare and disease management information (Abernethy et al. 2022; Mendoza-Herrera et al. 2020). This is also true for DTC GT consumers who often utilize social media to discuss ancestry, experiences with DTC GT, DNA results and surprises, marketing promotions, accuracy, and information use of health-related genetic information (Basch et al. 2021a, b). Online forums and communities have emerged as a growing means of coping with unexpected genetic revelations and connecting with estranged family members in hopes of gaining closure (Zhang 2018). While academic and medical discourse on the rapidly changing landscape of DTC GT and its projected future continues to grow, public awareness of the industry is a realm of inquiry worth interrogating. Therefore, the purpose of this study was to describe the content of DTC DNA online news articles – specifically to characterize how rising concerns related to consumer privacy, medical advancements, and bioethics are covered in online news as access to these testing kits continues to grow.

Methods

Using Google News, a news aggregator that pulls articles from various online publishers based on key terms, 100 articles were sourced from the search term "Direct to Consumer DNA Testing" during June 2022. The term was selected to distinguish the results from clinical genomic testing. The results were further sorted for relevancy and adherence to the inclusion criteria (English language, non-repeating, use of the search term, or its abbreviated form DTC DNA Testing). Based on those criteria, 100 articles were deemed to be relevant. Publication dates for the articles range from November 2012 to June 2022.

Coding categories were informed by prior studies focusing on DTC DNA content on social media, which were originally created using a fact sheet. Code categories included the following: firsthand experiences with a DTC DNA test, the purpose of the test, the limitations of DTC GT, potential ramifications of using a test, and the long-term financial and legal outlook of the DTC GT industry (Basch et al. 2021a;

Basch et al. 2021b). Codes were recorded using dichotomous coding with "1" representing a present code and "2" representing an absence. Dichotomous coding was used to indicate the presence or absence of a code within an article.

We prepared descriptive statistics that included frequency distributions, mean, and standard deviation. We conducted univariable analyses using the chi-square test for categorical variables and analysis of variance (ANOVA) for continuous variables to evaluate differences between DTC DNA website characteristics. The number of commercial DTC DNA products was dichotomized at the mean and coded as ≤ 5 products vs. > 5. All analyses were performed using IBM SPSS version 28.0. This research was considered non-human subject research and therefore exempt from institutional review.

Results

Most of the online news articles were created in 2022 (44.0%), and only 34.0% were created by healthcare professionals (Table 1). Information related to the DTC DNA testing process was minimal with only 41.0% of online news articles mentioning that testing does not require approval from a healthcare provider or insurance company. Only 10.0% of online news articles mentioned testing confidentiality and privacy protection. Most online news articles (84.0%) mentioned at least one specific DTC DNA product. The mean number of products mentioned per article was 4.4 [SD 6.9] with a range of 1 to 54. In all, 127 specific commercial DTC DNA products were mentioned 443 times in our sample of 100 articles. The most commonly named product was 23andMe ($n = 77$), followed by Ancestry.com ($n = 53$). Compared to websites that mentioned ≤ 5 commercial DTC DNA products, websites that mentioned > 5 products more often discussed the sample collection process (60.7% vs. 33.3%, $p = 0.01$) and more frequently mentioned 23andMe (96.4% vs. 69.4%, $p = 0.003$) and Ancestry.com (85.7% vs. 40.3%, $p < 0.001$).

Three-quarters of DTC DNA online news articles mentioned using testing to connect with family or understanding heredity, 77.0% stated that DTC DNA testing promotes genetic disease awareness, 60.0% asserted that DTC DNA results can make one more proactive about their health, but only 15.0% mentioned that DTC DNA results can reveal information that is directly relevant to family members who may not want to learn that information and the ethical dilemmas that could arise, especially for cancer-related risks. Furthermore, only 12.0% of articles stated that DTC DNA testing results could impact the ability to obtain life, disability, health, or long-term care insurance (Table 2). The most mentioned limitation of testing was that DTC DNA testing may or may not pinpoint any health conditions or traits that are of interest to the individual (59.0%). Articles that mentioned > 5 commercial DTC DNA products more often discussed how DTC DNA testing provides personalized information about health and link to family disease risk and other traits (85.7% vs. 61.1%, $p = 0.02$), can lead to the location of family members or ancestors (78.6% vs. 55.63%, $p = 0.03$), and that the testing results housed in DNA databases can be utilized by law enforcement to track suspects or their relatives (32.1% vs. 9.7%, $p = 0.01$) compared to articles mentioning ≤ 5 commercial DTC DNA products. More often, articles that mentioned ≤ 5 commercial DTC DNA products failed to mention that there exists a potential for data breaches or unauthorized use of personal genetic data, compromising patient privacy (75.0% vs. 53.6%, $p = 0.04$).

Discussion

The findings of our study are noteworthy for several reasons. The mean number of products mentioned per online article was 4.4 [SD 6.9] with a range of 1 to 54. Given the proliferation in the availability of DTC GT, consumers are faced with many options and services, and they are consistently portrayed in the news in this fashion. In concert, fewer than 40% of the DTC GT Google News articles state that testing is more accessible through DTC avenues than via one's healthcare provider. This highlights the fact that although most Americans have a primary care provider (Levine et al. 2019), they may be driven toward convenience, despite the scarcity of genetic counselors and geneticists working in the USA for follow-up (United States Government Accountability Office 2020). Furthermore, it is unclear where consumers turn for follow-up information, given the lack of transparency in company guidelines (Laestadius et al. 2017).

It is quite important for consumers to understand that their results may impact others or raise concerns they had not considered. The findings indicate that a mere 15.0% of online news articles mentioned that DTC DNA results can reveal information that is directly relevant to family members who may not want to learn genetic-based personal and familial information and the ethical dilemmas that could arise. This is especially true for cancer-related risks. For example, those who consent to the "genetic relative finder" feature may reveal unknown relatives (Majumder et al. 2021), potentially affecting one's own identity (Copeland 2020; Vinopal 2020; Shapiro 2020).

Furthermore, only 12.0% of websites stated that DTC DNA testing results could impact the ability to obtain life, disability, health, or long-term care insurance. Although the Genetic Information Nondiscrimination Act (GINA) prohibits genetic discrimination when it comes to health insurance (Sanghavi et al. 2022; Soo-Jin Lee and Borgelt 2014), there are no current legal ramifications for using genetic information to affect life, disability, and long-term care insurance. DTC GT could alter participant premiums, and DTC GT

Table 1 Differences in website and DTC DNA testing characteristics among 100 DTC DNA websites by the number of DTC DNA products mentioned dichotomized at the mean: 0–4 vs. > 4

Characteristics	Total	No. of commercial DTC DNA products mentioned		*P* value
		0–5	> 5	
Website related				
Year uploaded				0.96
2012–2019	24 (24.0)	18 (25.0)	6 (21.4)	
2020	9 (9.0)	6 (8.3)	3 (10.7)	
2021	23 (23.0)	17 (23.6)	6 (21.4)	
2022	44 (44.0)	31 (43.1)	13 (46.4)	
Author with professional credentials				0.48
Yes	34 (34.0)	26 (36.1)	8 (28.6)	
No	66 (66.0)	46 (63.9)	20 (71.4)	
DTC DNA testing related				
No need for approval from healthcare provider or insurance				0.01
Yes	41 (41.0)	24 (33.3)	17 (60.7)	
No	59 (59.0)	48 (66.7)	11 (39.3)	
Describes the DTC DNA sample collection process				0.001
Yes	36 (36.0)	19 (26.4)	17 (60.7)	
No	64 (64.0)	53 (73.6)	11 (39.3)	
Features a person taking a DTC DNA test or talking about their experience taking the test				0.76
Yes	16 (16.0)	11 (15.3)	5 (18.5)	
No	83 (83.0)	61 (84.7)	22 (81.5)	
DTC DNA testing may be less expensive than if obtained through a healthcare provider				0.40
Yes	7 (7.0)	4 (5.6)	3 (10.7)	
No	93 (93.0)	68 (94.4)	25 (89.3)	
DTC DNA testing may be more accessible than if obtained through a healthcare provider				0.30
Yes	35 (35.0)	23 (31.9)	12 (42.9)	
No	65 (65.0)	49 (68.1)	16 (57.1)	
DTC DNA testing confidentiality and privacy				0.28
Yes	10 (10.0)	9 (12.5)	1 (3.6)	
No	90 (90.0)	63 (87.5)	27 (96.4)	
Number of DTC DNA products mentioned	443	125	318	
Mean [SD]	4.4 [6.9]	1.7 [1.4]	11.4 [10.0]	< 0.001
Range	1–54	0–4	5–54	
23andMe	77 (17.4)	50 (69.4)	27 (96.4)	0.003
Ancestry.com	53 (12.0)	29 (40.3)	24 (85.7)	< 0.001
Others	313 (70.6)	27 (37.5)	28 (100.0)	< 0.001

companies should note this so that consumers can be fully informed prior to their decision to participate in testing. This is especially true since research indicates that the legal outlook related to DTC GT is largely unknown to the public (Greely 2020; Prince et al. 2021).

Finally, more often, websites that mentioned ≤ 5 commercial DTC DNA products failed to mention that there exists a potential for data breaches or unauthorized use of personal genetic data, compromising patient privacy. While privacy and confidentiality continue to remain among the top concerns of consumers (Ruhl et al. 2019), history indicates that there have been multiple failures of DTC GT companies to maintain user privacy and confidentiality (Whittaker 2020). User privacy risks continue to be present in DTC GT (Wallace-Brewster 2021), yet they were rarely mentioned in the sample of online news reviewed in this study. The inclusion of such information on privacy issues would behoove consumers who are concerned about unauthorized access to this personal information.

There are some limitations to this study that should be noted. The first of which is that all articles were sourced from Google News. Google News is a singular news aggregator and may not be representative of all news related to direct-to-consumer genetic testing. Additionally, Google News results are affected by one's previous search history as well

Table 2 Differences in topics related to DNA testing and benefits and limitations of DTC DNA testing among 100 DTC DNA websites related by the number of DTC DNA products mentioned dichotomized at the mean: 0–5 vs. > 5

Characteristics	Total	No. of commercial DTC DNA products mentioned		*P* value
		0–5	> 5	
Mentions uses or considerations for DTC DNA testing				
Family or heredity				0.20
Yes	75 (75.0)	51 (70.8)	24 (85.7)	
No	25 (25.0)	21 (29.2)	4 (14.3)	
Age				0.50
Yes	11 (11.0)	7 (9.7)	4 914.3)	
No	89 (89.0)	65 (90.3)	24 (85.7)	
Race				0.80
Yes	25 (25.0)	19 (26.4)	6 (21.4)	
No	75 (75.0)	53 (3.6)	22 (78.6)	
Gender				0.50
Yes	12 (12.0)	10 913.9)	2 (7.1)	
No	88 (88.0)	62 (86.1)	26 (92.9)	
Mentions of the benefits of DTC DNA testing				
Promotes awareness of genetic disease				0.20
Yes	77 (77.0)	53 (73.6)	24 (85.7)	
No	23 (23.0)	19 (26.4)	4 (14.3)	
Can result in being more proactive about one's health				0.59
Yes	60 (60.0)	42 (58.3)	18 (64.3)	
No	40 (40.0)	30 (41.7)	10 (35.7)	
Provides personalized info about health and links to family disease risk and other traits				0.02
Yes	68 (68.0)	44 (61.1)	24 (85.7)	
No	32 (32.0)	28 (38.9)	4 (14.3)	
Can lead to the location of family members or ancestors				0.03
Yes	62 (62.0)	40 (55.6)	22 (78.6)	
No	38 (38.0)	32 (44.4)	6 (21.4)	
DTC DNA databases have been utilized by law enforcement to track suspects or relatives of suspects				0.01
Yes	16 (16.0)	7 (9.7)	9 (32.1)	
No	84 (84.0)	65 (90.3)	19 (67.9)	
Mentions the limitations of DTC DNA testing				
May or may not pinpoint any health conditions/traits that are of interest to the individual				0.81
Yes	59 (59.0)	43 (59.7)	16 (57.1)	
No	41 (41.0)	29 (40.3)	12 (42.9)	
Cannot definitively tell the probability of developing a specific disease				0.84
Yes	48 (48.0)	35 (48.6)	13 (46.4)	
No	52 (52.0)	37 (51.4)	15 (53.6)	
May provide unexpected information about health, family relationships, or ancestry				0.94
Yes	47 (47.0)	34 (47.2)	13 (46.4)	
No	53 (53.0)	38 (62.8)	15 (53.6)	
Results may be stressful or life changing				0.19
Yes	35 (35.0)	28 (38.9)	7 (25.0)	
No	65 (65.0)	44 (61.1)	21 (75.0)	
May lead to decision-making based on inaccurate, incomplete, or misunderstood information				0.45
Yes	38 (38.0)	29(40.3)	9 (32.1)	
No	62 (62.0)	43 (59.7)	19 (67.9)	

Table 2 (continued)

Characteristics	Total	No. of commercial DTC DNA products mentioned		*P* value
		0–5	> 5	
Results can be misleading or not have enough scientific evidence to link a particular genetic variation to a disease/trait				0.24
Yes	45 (45.0)	35 (48.6)	10 (35.7)	
No	55 (55.0)	37 (51.4)	18 (64.3)	
DTC DNA results can reveal information that is directly relevant to family members who may not want to learn that information. Ethical dilemmas may arise, especially in cancer-related risks				0.55
Yes	15 (15.0)	12 (16.7)	3 (10.7)	
No	85 (85.0)	60 (83.3)	25 (89.3)	
Genetic information privacy may be compromised due to data breach or unauthorized use				0.04
Yes	31 (31.0)	18 (25.0)	13 (46.4)	
No	69 (69.0)	54 (75.0)	15 (53.6)	
DTC DNA results may impact the ability to obtain life, disability, health, or long-term care insurance				0.74
Yes	12 (12.0)	8 (11.1)	4 (14.3)	
No	88 (88.0)	64 (88.9)	24 (85.7)	

as location. While all history on the searched browser was cleared, the algorithm used may result in slightly different outcomes by the user. Furthermore, the articles sourced were restricted to English, and the exclusion criteria were minimal. Regardless of these limitations, this study provides insight into the current perspective of direct-to-consumer genetic testing coverage in online news, its benefits, potential consequences, and long-term viability. Online news articles related to DTC GT testing are not adequately covering important areas of risk and concern related to the process, thus exposing consumers to a one-sided perspective. It is most beneficial to consumers' informed decision-making process if the news is written in a way that adequately presents both the benefits and the risks.

Author contribution CHB, LS, and BC conceptualized the study. GCH completed the data analysis, while ED completed the data collection. All authors contributed to writing and revising the manuscript.

Declarations

Competing interests The authors declare no competing interests.

Ethics approval This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of interest Corey Basch, Grace Hillyer, Lalitha Samuel, Erela Datuowei, and Betty Cohn declare no competing interests.

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