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Consumer Health Informatics Aspects of Direct-to-Consumer Personal Genomic Testing

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Abstract

This paper uses consumer health informatics as a framework to explore whether and how direct-to-consumer personal genomic testing can be regarded as a form of information which assists consumers to manage their health. It presents findings from qualitative content analysis of web sites that offer testing services, and of transcripts from focus groups conducted as part a study of the Australian public's expectations of personal genomics. Content analysis showed that service offerings have some features of consumer health information but lack consistency. Focus group participants were mostly unfamiliar with the specifics of test reports and related information services. Some of their ideas about aids to knowledge were in line with the benefits described on provider web sites, but some expectations were inflated. People were ambivalent about whether these services would address consumers' health needs, interests and contexts and whether they would support consumers' health self-management decisions and outcomes. There is scope for consumer health informatics approaches to refine the usage and the utility of direct-to-consumer personal genomic testing. Further research may focus on how uptake is affected by consumers' health literacy or by services' engagement with consumers about what they really want.

Keywords:

Access to Information; Consumer Health Information; Genomics

Introduction

Advances in healthcare have created a need for informed consumers. To meet this need, the Internet has provided a way for consumers to access information; including access to medical literature, connection with patient social networks and the creation of open health data. Notoriously, the Internet is also a massive source of misinformation about health. Consumer health informatics (CHI) is concerned with the health information structures and processes that enable people who are not clinically trained (so-called "consumers") to be informed for the purpose of managing their own health. Some consumer health information resources are purpose-built, such as health information literacy aids and personal health records, while others show technological appropriation, for instance using Facebook, Youtube or Twitter for health self-management.

From a synthesis of findings reported in recent reviews [1, 2], the focus of CHI is on the types of tools or methods that can make valid health data, information and/or knowledge resources available to consumers, and the aim of CHI is to understand and improve the ways that these tools or methods: enable access, materially and intellectually, by consumers; address the health needs, interests and contexts of consumers; allow direct interaction by consumers without the presence of a healthcare professional; personalise and / or socialise consumers' interactions about their health needs and interests; aid consumers' health self-management and/or self-reported outcomes; facilitate consumers' engagement in clinical diagnosis and/or treatment. This paper uses these CHI considerations to explore one relatively new health-related phenomenon on the Internet.

Health-related personal genomic testing services have been available directly to consumers over the Internet for about ten years. Consumers register with a service, create a user account and make a payment online, then use a postal or courier service to ship some saliva or other body tissue to a laboratory, and generally receive their test results and interpretive information by email. These services are increasing in number and reach [3]. Currently over 130 service providers advertise to consumers in the English language; many of them do not require a clinical referral and are priced cheaply by comparison with clinically mediated testing [4]. Popular uptake is rising. One service, Mapmygenome (www.mapmygenome.in), according to its publicity materials, aims to touch 100 million lives and save a million lives by 2030.

However, there are mixed views as to the benefits and risks of direct-to-consumer personal genomic testing (DTC-PGT) – for example, whether empowerment or overdiagnosis is more likely to be its net result [5]. In Australia the direct sale by company of a direct-to-consumer personal genome test for health information is prohibited. However, many companies in Australia have adopted a model where they offer a personal genome test such that the sample is processed overseas. Further, Australian regulations do not stop consumers from arranging online for tests to be done outside their country of residence. Health authorities can only caution consumers about their use [6].

The function of DTC-PGT as a form of consumer health information is acknowledged by the US National Library of Medicine [7] and its use as such has been investigated in controlled settings [8]. An opportunity to use a CHI lens to form a clearer view of the information structures and processes that typify DTC-PGT using real-world data has arisen through research in a multi-disciplinary, multi-stage study to explore broadly Australians' expectations of personalised genomics. The Genioz (Genomics: National Insights of Australians) project (www.genioz.net.au) which began in 2015 involves focus groups, a quantitative survey, semi-structured interviews and ethical critique.

This paper specifically reports research into DTC-PGT services available to Australian consumers, and into public ideas about these services that have emerged in Genioz focus groups. Our aim here is to use CHI as a framework to explore whether and how DTC-PGT can be regarded as a form of information which assists consumers to manage their health.

Methods

We used two data sources. First within the broad definition of DTC-PGT provided to consumers by the US National Library of Medicine [7], we selected web sites to represent a cross-section of services offering wellbeing, disease, individual and ancestral information, including some market leaders and some less well known companies. We analysed web site content that was publicly accessible in late 2015 from 10 different providers, on a total of 69 web pages: AncestrybyDNA, DNA Worldwide, EasyDNA, FamilyTreeDNA, GenetrackAustralia, GenomicsforLife, GTLDNA, Mapmygenome, PathwayGenomics, 23andMe. Data from web sites is not identified by company name, so as to avoid potential perception of bias.

Then we analysed the transcripts of seven age-category stratified GeniOz focus groups in two capital cities in 2015, involving a total of 56 members of the public. People were recruited regardless of whether they had ever undergone personal genomic testing; purposive sampling was done for gender and age. Apart from individuals' gender and age details, data are de-identified to protect confidentiality.

Since these datasets were not generated specifically to explore consumer health informatics aspects of DTC-PGT, we took a summative approach to analysis, that is, identifying certain content with the purpose of understanding it in a particular context [9]. We used a coding guide (Table 1) to identify content, a framework method [10] to chart its occurrence, and an abstract level of interpretation [11].

The coding guide supported a junior researcher to perform a systematic search for terms associated with managing data, information, and/or knowledge (manifest content); these three fundamental information science concepts align with formal models of health informatics [12, 13] but are often used interchangeably in everyday language. Then the latent content of the charted occurrences was analysed by a senior researcher with consumer health informatics expertise, in the context of the CHI concepts and concerns summarised in the Introduction section of this paper.

Table 1 – Example Terms used in Manifest Content Analysis

Data Management	Information Management	Knowledge Management
Administer	Categorize	Apply
Analyse	Classify	Decide
Capture	Filter	Learn
Integrate	Organise	Reflect
Monitor	Search	Synthesise
Store	Select	Understand

This study is preliminary to a more in-depth analysis of a larger dataset from the GeniOz project. In a larger-scale and more nuanced study, quantification of manifest content will have greater significance and other Smethods, such as sentiment analysis, also may be illuminating.

For the purpose of the present exploratory study the Results section of this paper provides selected examples only of manifest content analysis, and the Discussion singles out noteworthy results of latent content analysis.

Results

Resources and Services Offered by DTC-PGT Providers

Data is the primary resource offered to consumers of PGT services, in the form of reports of results from tissue sample testing. These reports may cover a wide spectrum of aspects of health, wellbeing, fitness and identity, based on a variety of markers, accompanied or not by raw data files. A summary of what is offered on the ten provider web sites (represented by numbers 1 to 10) is as follows:

1. Genetic information categorized four ways: carrier status, wellness, traits and ancestry. Over 100 health conditions and traits. Provides raw data.
2. Paternity, relationship, prenatal, ancestry, clinical, other tests (genetic fingerprinting, DNA profiling), health tests (skin, children's DNA, diet, nutrition, fitness, wellness, weight and lifestyle), animal tests. Based on 21 markers. Provides raw data.
3. 50 physiological and lifestyle traits, health conditions and inherited conditions. Personal, brain wellness, TB diagnostics, molecular diagnostics, forensics, merchandise. 16 markers. Provides raw data.
4. Paternity, immigration, ancestry, extended family, drug and alcohol, pets. 46 markers.
5. General health and wellness, liquid biopsy, hereditary cancer, pharmacogenomics, carrier screening. A variety of conditions including cancer risk, cardiac health, inherited diseases, nutrition and exercise response, as well as drug response for specific medications including those used in pain management and mental health. 75 markers. Provides raw data.
6. DNA origin, DNA world view, paternal and maternal. Raw data available is limited. 144 markers.
7. Disease screening, prenatal screening, paternity, immigration, > 700 inherited diseases.
8. Family finder, father's line (37, 67 or 111 markers), mother's line. Raw data provided in CSV or XML format.
9. Paternity, maternity, sibling, grandparentage, aunt/uncle, twin, ancestry test. 91 markers.
10. Paternity, prenatal, relationship, ancestry, other tests (infidelity DNA testing, DNA profile, surrogacy DNA testing, additional services, semen detection DNA testing service, genetic reconstruction testing, non-invasive prenatal test for Down syndrome). 21 markers.

Some data management features are explicit on some web sites, such as these examples of access, security, and visualization:

"choose to authorise [the provider] to share their data with specific individuals" (1)

"access an interactive version of your report anytime, anywhere" (5)

"once the testing is completed and the results provided to the client, all raw data is purged from our system" (6)

"browser allows you to see where on your chromosomes a match shares DNA with you" (8)

Information services that contextualise results reporting may be available. Selected examples are:

"reports in four categories: carrier, ancestry, wellness and traits" (1)

"interesting facts about your own haplogroup…. access to information about your extended genetic cousins" (2)

"an expert review of your case looking at possible reasons for the results" (4)

"a detailed manual that explains your results" (6)

"an in-depth guide to understanding and interpreting your results" (8)

Information filtering also appears, in the form of messages advising on appropriate use of the data. For example, seven providers' web sites included content that recommended against using their genetic tests for clinical or diagnostic purposes.

Some providers socialise the sharing of information by hosting user comments. For example,

"very interesting, but I'm a little unhappy that the information provided for conditions genetic genealogy and interspecies genealogy is so poor despite a fantastic database, genbank and published tables for much of this stuff" (1, user comment)

Knowledge management facilitation for users is promoted prominently. Providers' web site content uses the language of insight into self and others, actionable information, decision-support. For example:

"knowing your level of genetic predisposition toward developing particular conditions can help both you and your children live healthier and longer lives" (2)

"help you understand what your genetic variations mean and how it may affect you. … learn about inherited and acquired genetic health risks"(3)

"reports provide actionable information and recommendations that provide individuals with a roadmap to achieve optimal heart health" (5)

"discover your geogenetic links by seeing your match with studied populations and anthropological groups around the world" (10)

Several providers offer access to online genetic counselling or other clinical services, as a way for consumers to leverage test results and information. Knowledge management may also include suggestions on engaging expertise, for example:

"empowers the physician to help patients make informed decisions regarding diet and exercise, while also providing information about medication response" (5).

Communicating with other service users or other communities of interest is sometimes an option, for example:

"enhance your experience with relatives" (1)

"names and emails of your matches … are provided to you in order to collaborate" (8).

Ideas about DTC-PGT Held by Members of the Public

Examples of considerations that members of the public (Participant ID number / Gender / Age) voiced about managing data, information and knowledge are provided here. Key data management concepts were access and governance.

- The right to data (restricting citizens' access to information was the way one person interpreted one DTC-PGT provider's legal issue over non-compliance with laboratory testing regulations):

  "the authority in the [United] States said 'no you can't do that', they didn't feel it appropriate that people should know this information because they may misunderstand it which is rather strange, there is a big battle going on at the moment and it looks like they are going to get the okay to release that information" (P40/M/72)

- Direct and timely access to the data:

  "go online and find this stuff and just put an order in, pay for it and get it delivered to our door" (P5-6/F/36)

  "you get massive bottlenecks … now you've got the thousand dollar human genome and the twenty dollar bacterial genome … why they don't just sequence things in the hospital more often" (P23/M/22)

- Management and governance of the data:

  "I'm only interested in looking at myself, I don't like it to be publicly accessible or set up as a database" (P12/M/32)

  "they [test providers] might keep a database of all the genetic information about you, for future reference" (P13/F/25)

  "the legitimacy of the company that is handling it, what might they do with it" (P14/F/20)

  "who are you going to offer these tests, how are you going to dictate what information is given out on the test, how are you going to ensure the validity of these tests" (P23/M/22)

People expressed attitudes about information management issues, particularly usefulness and shared use:

- Information usefulness limited in scope:

  "this genetic testing gives you a window into what the possibilities are, but it doesn't define you" (P20/M/23)

  'if I paid my hundred dollars today I don't know that it's actually better than what it might be if I survive another ten years, if I'm getting imperfect information how useful is the information" (P23/M/22)

- Information usefulness contingent on external validation:

  "find other people who have done the test … a while ago and then see if the things that came back from their test … what good are they, the test[s], a certain number of years down the track" (P7-6/M/22)

  "if the website looked really legit … if the government was recommending it … if other people say this genetic testing has really helped me … it depends on the person [delivering the message] and how they interpret it for you" (P25/M/21)

- Information usefulness linked to clinical consultation:

  "if having an understanding of genetic make-up is providing information that shows patterns in or information about it will help health conditions and that can then inform medical practitioners to come up with preventative measures" (P5-1/M/41)

  "if my doctor said I would gain a lot from this I would do it" (P25/M/21)

- Information uses shared with other parties, not necessarily aligned with the consumer's values:

  "people who want to try and genetically dictate what their children's genes are going to be" (P14/F/20)

  "that information would be really useful for me … but for my health insurer, that's an extra risk for them" (P53/M/42)

Knowledge management attitudes of members of the public were mixed.

- Self-knowledge for its own sake, sometimes with unrealistic expectations:

  "sometimes just knowing can make things a lot easier and having more time to understand it and understand what's going to happen and … knowing a timeline, it's almost like knowing this is what I have before this is going to start setting in" (P7-1/F/24)

  "for a company to say, we can decode it and tell you with any certainty … psychologically, it could be wish fulfilling" (P6-2/F/63)

  "if I did find out that I'm going to have an issue with my health in the future, I wouldn't want them to tell me when it was going to be, I wouldn't want to put a timer on myself" (P7-6/M/22)

"somehow that would give you some idea of how long you're going to live for" (P49/M/77)

- Knowledge for the sake of significant others:

  "for the benefit of my next generation, yeah, and I can afford it, I will definitely go for that. To find out if there's anything which can be mended before [conception / birth]" (P5-4/F/45)

  "whilst I don't want my information, I really don't want to know where my life's going to go to, I sort of feel that for my child or a grandchild or another person, I would do that and find out because it's something that can be prevented" (P46/F/63)

  "we've got a social responsibility … to find out whether we've got [conditions that could be passed on to children]" (P47/F/75)

- Knowledge as a prompt to action; or a deterrent:

  "if I knew I had a predisposition to melanoma, I wouldn't be going out in the sun. It would change how I do stuff in my life, some genetic testing could change your behaviour" (P24/F/23)

  "I considered whether or not I got tested to see if my body type was one that would gain muscle quicker than someone else … I considered it but then … if I did find out that ultimately I'm a really fat body … I'd give up on life … like 'well there's no point' … and then … the course of your life changes" (P25/M/21)

  "if you knew there was a tendency to diabetes in your inherited characteristics you might pay a bit more attention to your diet as you age" (P28/F/72)

- Managing uncertainty or bad news:

  "if you think you could get a report that you could get breast cancer, then you spend the next x number of years with sleepless nights thinking 'oh am I going to get breast cancer or not, is today the day?' … that sort of uncertainty is a little bit of a drawback" (P20/M/23)

  "anybody can get their genome sequenced for a thousand dollars, and it means nothing …we have no idea what the mutations mean, we have nothing to compare them to overall, we have no baseline and no comparator, so that's cool, you may have really good genetics, you may not" (P23/M/22)

  "what that might allow me to learn about myself that I might or might not like ... you'd measure your own genome with a view to find out something as I say that you might or might not like" (P58/M/57)

Discussion

Within the overall focus group dataset, comments that could be related to management of DTC-PGT data, information and knowledge occurred infrequently. This is not so surprising since the general aim of the data collection was to explore broader public attitudes and understandings regarding personal genomics. The variety of ideas that was put forward suggests that there is scope for more specific investigation on this topic.

People appeared to be unfamiliar with the specifics of DTC-PGT data reports and additional information services. Major concerns about privacy did not emerge from these groups. People had more to say about the aids to knowledge that they thought DTC-PGT could provide, and some of what they said was similar to the benefits described on provider web sites. Some expectations were inflated, for example, the idea that you can learn how long your life will be (though indeed some companies suggest that this is possible).

Turning to the broader question of how DTC-PGT can function as consumer health information, the findings here provide evidence that it has some of the features that would be advocated by CHI, and that it offers some scope for the kinds of improvements that could be guided by CHI.

In terms of features, its essential rationale is to allow consumers direct interaction with data, without the presence of a healthcare professional. It appears to enable access by consumers, both materially (people did not foreground connectivity or cost or other issues of accessibility) and intellectually, considering the information services that providers offer to explain testing and support reading of test results. Personal genomic test results by their very nature personalise consumers' interactions with information about health, to the extent that they identify the individual's inherited conditions, risk factors and potential response to therapies. Likewise, the fundamental connection between the individual's test results and their genetic family members' past, present and future socialises this form of consumer health information; further, some providers offer suggestions and facilities for a consumer to exchange data and information with family members and other consumers. A few DTC-PGT providers also encourage and support consumers to share data with a health professional, such as a genetic counsellor available through the provider, or their own treating clinician.

In terms of improvements, the validity of the data and the value of the surrounding service which DTC-PGT provides to consumers is a key unresolved aspect of whether it is fit for purpose as consumer health information. This is unresolved partly because the consumer's personal genomic data is being reported and interpreted to them as a formulaic business transaction, within a dynamic field of knowledge where there is much still to be determined about the underlying biomedical science and social science. CHI could be applied to improve tools that assist with health literacy in this area and thus create more discernment in the consumer market for DTC-PGT and the after-market for medical services (as described in [14]). This is unresolved also because web site analysis shows considerable variation in the description of services, so that it is complicated for consumers to make choices about whether a service provider will meet their health needs and difficult for them to be confident about using the ensuing information as a basis for health decisions. Within a model of self-regulation of direct-to-consumer services, there is scope for CHI to contribute to formulating and monitoring industry standards (on data management, for example [15]) and to developing aids that allow consumers to compare the services on offer.

On the question of whether DTC-PGT is actually working as a form of consumer health information, findings from the focus groups suggest that it has not yet captured widespread public attention, certainly in Australia. By comparison, other more conventional forms of consumer health information provided by public agencies (such as Better Health Channel) and private interests (e.g. BUPA Health and Wellness) are much more familiar to the Australian public. It is noteworthy that DTC-PGT has not taken off given high rates of Internet use (around 80% of Australians were using the Internet to look for health information nearly a decade ago [16] and 61% had purchased goods and services online during a three-month period surveyed in 2014-15 [17]).

This suggests that DTC-PGT as a model of consumer health information on the Internet may not be working in terms of the way it addresses two particular CHI concerns. Does it address the health needs and interests and contexts of consumers? People had no direct experience of working with DTC-PGT information to report. They had ambivalent ideas about whether it could do this – some expressed personal curiosity or a sense

of obligation to family members, but others said that they preferred not to know or that they wanted more assurance about the information quality. Does it help consumers with their health self-management decisions and outcomes? Some people hypothesized that it would be an effective tool to support healthy behaviours and constructive health actions including seeking professional help. Others were less certain, alluding to anxiety and unhappiness that could ensue.

What consumer health information works and why is often explained by consumers' health literacy, or by service providers' engagement with consumers about what they really want [18]. Both of these factors in DTC-PGT, and possibly others that were not identified in this study, deserve further research.

Conclusion

This paper presents an exploratory investigation of whether we can regard DTC-PGT as a form of consumer health information, in actuality or potentially. In actuality, it does not seem as widespread or well-known among the Australian public as one might expect from industry reports. Its potential as consumer health information is unclear overall. We found inconsistent offerings and divergent attitudes, and this situation is echoed in other places. On one hand a highly articulate consumer feels "seduced by the idea that it [information from PGT] fills a void in unanswerable questions, yet without enough knowledge to properly interpret its true ramifications" [19]. On the other hand a highly regarded physician argues that health and consumer authorities should put greater effort into working with reputable consumer genomics companies to allow them to deliver more health information [20].

DTC-PGT is an Internet phenomenon which has been the subject of considerable research, but perhaps not enough through the lens of consumer health informatics. Based on the exploratory study reported here, the question of whether DTC-PGT can be or should be taken seriously as a form of consumer health information cannot be resolved. However, the need to address this issue spiked sharply from April 2017 when, after years of deliberation, the US Food and Drug Administration finally made it legal for one DTC-PGT company (23andMe) to market genetic health risk tests for a limited number of conditions [21]. Whether and how the forms and functions of health information of this kind can be systematically made safe, effective, accessible and equitable will have a major influence on the DTC-PGT industry and on healthcare generally.

From a CHI perspective, that is, seeking to understand how the Internet may be used optimally to increase the reach and sophistication of high quality information, DTC-PGT surely warrants further research and development before its growing range of information products and services can be either dismissed or endorsed as aids to health self-management.

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