

## Comment

### KNOW YOUR GENES. THE MARKETING OF DIRECT-TO-CONSUMER GENETIC TESTING

# Of deterritorialization, healthism and biosocialities: the companies' marketing and users' experiences of online genetics\*

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*ABSTRACT: Since the early 2000s, anybody can buy genetic tests, directly sold on the Internet. These tests provide information about susceptibilities to some diseases and/or about ancestry. Thus, this article deals with a new e-market, whose scientific basis (validity of the tests) and status (as medical devices or consumer goods) are currently controversial. On one hand, we describe the tests and the advertisement and marketing strategies used by the companies (we made an inventory of about 40); on the other hand, we discuss several aspects on the basis of interviews conducted with users: first, the entanglement of these strategies with the global context of healthism and the emphasis put on individuals' empowerment regarding health decisions — “individualized biopolitics”. In addition, this article broaches the new kind of biosocial networks appearing in these tests' wake: some users indeed gather on the basis of a genetic proximity, as is it put forward by their results.*

## Context

Direct-to-consumer genetic tests (DTCGT) are available online for some years. These devices aim at screening one's DNA for susceptibilities to common conditions (cancers, diabetes, cardio-vascular disorders), for behavioural traits (impulsiveness, attention deficit, intelligence, etc.). They may also provide the users with additional information about “ethnic origins” — called “ancestry” by tests purveyors.

The development of this market started with the 2000s in the United Kingdom<sup>1</sup> where Sciona, owner of Body Shop, tried for a while to sell cosmetics-related genetic tests. The activity rapidly expanded on the Internet from the end of 2006, when 23andMe — current leader of DTCGT — was created and partly funded by Google.<sup>2</sup> During the following months, two more companies appeared: Navigenics, partly funded by Microsoft, and deCODEme, a product of the Icelandic joint-venture deCODE.<sup>3</sup> More and more companies have blossomed since then; we have listed 42 of them, based on an inventory of their websites.<sup>4</sup> The number of DTCGT users is increasing, according to some companies' employees (an interviewee, employed by one of the biggest companies, asserted having registered more than 10 000 customers in 2009), but also to the growing activity of related blogs and forums. In summer 2010, 23andMe claimed a database of 50 000 customers, and recently made public a total samples count of 75 000.

The recent appearance of these tests is disrupting national bioethical frames and is involved in their deterritorialization. Until recently, in France as in many other countries, genetic tests for susceptibilities were legalized within the sole frame of medical consultations and prescriptions. In this context, they were almost exclusively used for early detection of genetic disorders such as cystic fibrosis or Huntington's disease.

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The online sale of genetic tests calls into question these restrictions and is the subject of intense medical, ethical and scientific debates within the geneticists' and public health experts' communities. Besides, this novel market can appear as a symbol of the newest aspects of contemporary globalization.

National and regional regulations of genetic tests delivery are far from homogeneous. No matter that, in some countries' law, this delivery is conditioned by a medical prescription and requires a medical follow-up: it is however possible to purchase tests online, without any medical supervision. Specialized websites offering DTCGT<sup>5</sup> are hosted in regions where legal frameworks are fuzzier or more permissive. The core of this market is located in the United States, where companies seem to put to good use, in some states, specificities of the local regulations<sup>6</sup> — even if federal bodies, such as the Food and Drug Administration, are currently attempting to increase their control. Other countries host these companies though, including European or its neighbouring States — Iceland, Ireland, Slovenia, Switzerland.

Restrictive regulations are bypassed by the appearance of this globalized e-market: genetic tests are currently beyond many national and regional regulatory frameworks.<sup>7</sup> The controversy about this development is partly focused on the question of direct access (i.e. without medical advice)<sup>8</sup>, questioned by part of the concerned health professionals: some probably consider that this development is endangering their sphere of activity;<sup>9</sup> others worry about the consequences of this e-market for their patients, especially regarding their ability to relevantly deal with the delivered information.<sup>10</sup> The debate also tackles the scientific quality of the tests, since the tests results are often based on the sole interpretation of statistical co-occurrences of specific genotype and phenotype.<sup>11 12</sup> These critical views are also expressed by public bodies, such as the European Society for Human Genetics,<sup>13</sup> the French National Consultative Committee for Ethics (CCNE) or the Government Accountability Office in the United States.<sup>14</sup>

## Objectives

In this social, scientific, regulatory and political context, how can we explain such a commercial expansion, when strong controversies occur about genetic tests, their results and their delivery modalities?

We of course acknowledge some very visible explanations: the specificity of the location of this e-market (the Internet and its blurred, or absent, boundaries); the lobbies supporting DTCGT market; the companies' close ties with the ICT industry; their sustained policy of hiring well-known geneticists in their scientific boards...

However, we aim in this article at casting light on other explanatory aspects, beyond these factors: the way marketing strategies echo common contemporary concerns about health; the current public debates about the role of non-expert discourses when it comes to interact with medical and scientific institutions; the issue of social and biological identities and categorizations.

DTCGT companies' marketing strategies aim at fulfilling certain social expectations that we describe in this article, through a quantitative description of the tests offer (inventory of the tested disorders and traits, and evaluation of the frequency of precise tests in the market) and an analysis of the graphical and discursive marketing elements displayed on the websites. In addition, this contribution shows, through interviews extracts, the significant congruence of companies' strategies and users' expectations. The users' words give access to the impact of these tests on individual experience and to the wide range of the uses of DTCGT.

## Methods

We have made an inventory of companies (see annex 1) and tests offer through targeted Internet searches and compilation of anterior lists. Regarding users' perceptions: we conducted our exploratory investigation through ethnographic method. Data have been collected on one hand through interviews (N=20) with users from different regions of the world, and on the other hand through analysis of relevant websites, blogs, social networks and forums. Interviewees have been recruited through general (Facebook, Twitter) and specialized (DNA-forums) social networks and forums, using snowballing method.<sup>15</sup> The interviews have been conducted by video-conferences.

The study aimed at investigating users' motives for purchasing such devices online, as well as details of their personal experience and modalities of their "adherence" to the economic and scientific patterns conveyed by DTCGT.

## Results

### *The core of the tests offer*

Our investigation of the purveyors' websites showed a significantly varied offer: more than 700 different genetic tests. The most frequent tests deal with common multifactorial disorders — often called "lifestyle diseases" —, such as cardio-vascular conditions (60% of the websites), cancers (about 40% of the websites offer breast cancer trait screening and 30% for lung cancer), obesity and diabetes (25%), etc. DTCGT companies thus appear in line with the public health concerns about degenerative and man-made diseases.<sup>16</sup> Hence their most probable future expansion, echoing the social visibility of the tested disorders.

In addition to these common diseases, a significant part of the tests offer targets "the commonest of the rare" affections such as cystic fibrosis, hemochromatosis and Tay-Sachs disease. These very serious disorders are presented by marketing strategies as quite common: for instance, the web slogan of GeneDX, displayed on the homepage of the company, is "Where rare is common". This type of communication scheme is likely to raise potential users' anxiety and to induce a purchase decision.

Besides susceptibilities tests, one can find other types of devices among the most frequently marketed tests: on one hand, tests related to metabolism, such as pharmacogenomic tests aiming at characterizing individuals' ability to metabolize specific medical drugs, or nutrigenomic tests, studying one's absorption of particular nutriment; on the other hand, users can purchase tests labelled as evaluating physical performance. DTC pharmacogenomic tests constitute a new use for tests that are already prescribed in medical settings for some years, for example to personalize cancer chemotherapies. As of nutrigenomic and performance tests, they are more original, first since they represent a quite novel geneticization<sup>17</sup> of certain social fields — nutrition and performance — and second because they seem to continue the social medicalization trend.<sup>18</sup> In this context, nutrigenomics echoes the commercial success of nutraceuticals — i.e. usual food items (tea, yogurt, oil...) that have been enhanced to become preventive or therapeutic food, through added molecules (antioxidants, isoflavonoids, etc.).

Less frequent tests (offered by 2 of the 42 DTCGT websites) follow simultaneously the geneticization and the medicalization trends mentioned above: intelligence and hyperactivity tests constitute a "come-back" of biological explanatory models applied to human behaviour.

### *The healthism niche: a clever positioning*

Additionally to this medicalization dynamics, the tests offer echoes a major cultural, political and ideological evolution of contemporary societies: personal health is more and more considered as a core value and concern, and those who follow specific hygienist principles are supposed to benefit from physical and intellectual longevity. Some scientists describe this tendency as a form of religion, such as Sfez,<sup>19</sup> who writes about the implementation of the "Big Health" (*la Grande Santé*) as a contemporary religious utopia. This social movement, called healthism in North America,<sup>20</sup> led to a significant change of social representations of health, which is visible in manifold behaviours, such as increased attention to new symptoms, growing interest for preventive products and techniques, or rising legitimacy of medical expertise in new social fields.

Using the "healthism niche", DTCGT companies tend to strengthen health concerns among potential users, partly by echoing and reinforcing fears. Some of the websites' slogans, making use of the life expectancy lever, clearly exemplify the tone of this communication strategies: "*Confront risk early, prolong your health*"; "*Genetic testing for a healthier future*", "*Improving your future through personalised genetics*", or "*Prevention is an investment for the future*".<sup>21</sup> Other websites tend to focus on stressful genetic related situations, with slogans such as: "*Knowing Your DNA Could Save Your Life!*", or "*It runs in the family*" (website specialized in brain nutrigenomics), or — about Alzheimer

disease — *“It gradually destroys brain cells, making it increasingly difficult for people to work, participate in hobbies and even care for themselves. It is not a natural part of aging”*.

The information about genetic risk that is offered with the test results also follows the healthism path: it mainly draws attention on the difference of prevalence between the user’s genotype groups and the general population. Users thus get a relative evaluation of risk, through percentages (for instance “25 % of risk increase to be affected by [...]”) or frequency adverbs (“elevated/standard/decreased risk of being affected by [...]”).<sup>22</sup> Within such a categorization, a very rare disease (i.e. with a low prevalence rate) can be listed among elevated risk items, and thus focus disproportionate attention. This shows the importance of the problematic question of personal estimation of relative risk. It is noteworthy that most of the companies do not precise the confidence intervals they use (even though this could enable users to better tackle the scope of their own relative risk values), nor the prevalence of the tested traits in general population (although it is capital information when it comes to multifactorial common disorders), nor their interpretation of statistical sensitivity (that allows to determinate the percentage of affected individuals who are carriers of a specific trait).

Moreover, our study showed that the representation of risks is generally based on a high estimation of prevalence, that can reinforce users’ anxiety — one of the implicit pillars of DTCGT companies’ strategy. In this context, the construction of the normal and the pathological is more and more performed through systematic comparison of one’s personal risk values with average (i.e. general population’s) values — the potential harmfulness of such a process has been known since Canguilhem’s work<sup>23</sup>, which emphasized the importance to appreciate the normality of a living being through its biological singularity. The use of the deviation from the mean is problematic, since it produces abnormality, and hence risk, while obliterating the potential apprehension of other risks that could be more relevant to a particular individual and his/r biological, social and environmental particularities.

We have collected narratives of the expectation and discovery of the results, from users who were mostly interested in health matters. Many of these accounts are highly emotional, mixing curiosity and anxiety. Simone<sup>24</sup>, a 56-year old French journalist, told us how she discovered — with a “click” — the electronic file containing her results, while sitting next to her husband and how she suddenly felt the same emotional tension she had experienced some years before, when reading the results of an HIV-test:

*“I was curious about the results, of course, and a little bit apprehensive of what I will supposedly discover. I actually think there are people who discover unpleasant things. [...] I clicked on the results for breast cancer after having read a bit quickly. I remember that my husband was next to me and I hold his hand because I didn’t know. [Finally] I didn’t have the mutations they test for; these ones I didn’t have. It doesn’t mean that I don’t have fifty others, but at least, I didn’t have these ones. But I clicked a bit too fast.”*

The marketing strategies, combined with previous individual experiences, tend to assimilate DTCGT results discovery to biological diagnosis. Even if these tests (in Simone’s case, for mutations associated with certain types of breast cancer) only provide information about the risk of the appearance of a specific disorder, they can represent an undoubted diagnosis for some users. Consequences of this aspect of course vary from one individual to another, but a common one is modification of lifestyle (diet, hygiene, physical activity) that echoes the healthism philosophy carried out by DTCGT. For instance, Cynthia (a 56-year old American attorney), states:

*“— Well it said that I had a little bit of an increased risk for heart attack, and I’ve tried to be a little more conscious about what I eat and how I exercise, but I’m not fanatical about it [laughs].*

*[...]*

*— Ok, and could you give me an example of this change, please?*

*— Yes, I had been a person who has been a meat eater for a long time – I don’t really like meat but it’s convenient, quick and convenient, but then when I got the tests I really questioned why I was still eating meat when I don’t like it that much, and that has helped me reduce my intake of red meat. Just thinking about it made me more conscious about it.”*

*Making use of the curiosity for genomics and "individualized biopolitics"*

Besides healthism, DTCGT companies draw on another societal trend: the contemporary claims of healthcare systems users for empowerment and autonomy within the medical decision process. To this end, the marketing emphasizes the innovative characteristics of the tests, based on the most recent biotechnological advances. One can for instance read on a website's homepage: "*Do you have the CCR5 delta 32 ( $\Delta$ 32) mutation?*" (that protects against certain aspects of HIV infection). Other websites openly promote alternatives to the usual doctor/patient relationship (right to know, empowerment, shared medical knowledge, etc.): one company asserts "*Your health, Your right to know*", another promises "*Personal control over private genetic information*", some offer to "*Empowe[r] individuals with the predictive power of DNA*". Some other stress on the novelty of the personalized biotechnology they offer to their customers: "*Genome sequencing for individuals*", "*Genetics just got personal*".

Interviewees are receptive to this type of sale arguments. Genomic advances arouse curiosity, since this scientific domain is considered as the potential path to the physical and chemical understanding of numerous disorders, diseases and behaviours. In order to attract this curiosity, some DTCGT websites rely on conventional knowledge about genetics, and offer, for example, to screen their customers' genome for the "warrior gene". This type of discourse scores with some users, such as Bruno, a 30-year old French student:

- "*What was your interest in purchasing these tests?*"
- "*I don't know how I could say that... Good question [laughs] I was interested in determinism, because I know schizophrenia has been proven to be genetic, that there are other diseases such as diabetes, cancer... I was in the medical milieu, I knew it was genetic. I thought: "oh, with violence now, we can even know...". There is this warrior gene, one can know there are people who are more capable of being violent than others. And this is something true, actually... That's curiosity about biological determinism, that's it."*

DTCGT are presented as serving the individual's interests and his/r autonomy regarding health decisions. Companies' slogans affirm that by purchasing a test, the user is enabled to adapt his/r behaviour to his/r body and health, according to the risks values disclosed in the test results: "*Make better lifestyle choices*", "*Be on the lookout for common conditions*", or "*Prepare for serious diseases*". On the companies' websites, customers can access examples of advices given after test results, for instance incentives to lifestyle modifications (diet, exercise, medical check-ups frequency) or to family health discussions. DTCGT companies offer to the public a novel approach to certain traits and diseases — genetics, sometimes even genetic reductionism —, and also stress on innovation and self-determination abilities that users can build up from their DTCGT experience. Their communication policy skilfully replaces biological determinism and fate by non-determinism and individual empowerment regarding health. One website even mixes warning and invitation, when claiming: "*There's DNA. And then there's what you do with it. [Our] genetic test gives you insight into your personal health.*". The communication packaging of DTCGT is thus using, as a sale argument, an observation<sup>25</sup> made about the transfer of genetic knowledge within the frame of usual genetic counselling: genetic tests can be experienced as liberating technologies of the self that deliver one — among others — type of information that individuals can use to lead and orientate his/r own life.

Certain DTCGT websites consider their users as actors of human genetics research, and not only as consumers. With these companies, customers can benefit from special offers: sending a saliva sample and answering questionnaires entitles them to join one of the company's research projects — and to access the entire range of the website's services. Besides the price advantage, the marketing mainly stresses on a new type of medical research ("*Get involved in a new way of doing research*"), which is depicted as closely matching the users' concerns ("*Direct research by participating in studies of conditions and traits you care about*") and directly useful to them ("*Learn new things about yourself—and what your genes may have to do with them*"). Once again, the marketing discourses emphasize the novelty of the approach, and its core specificity: the co-production<sup>26</sup> of research, i.e. the direct involvement of users within research projects, far beyond the sole usual role of research participants as data providers.

The keystone of DTCGT companies marketing is thus the valorisation of the individual, his/r autonomy, and his/r emancipation from various burdens and controls (ignorance, medical paternalism, technocracy). Following this policy, the companies try to capture and prolong a societal movement that is going towards a management of life by delegation to individuals (individualized biopolitics), more and

more distant from States' and experts' controls.<sup>27</sup> This trend has a particularity within the frame of personalized genomics and DTCGT: it is not related to the medical and public institutions and is displaced towards the expression of a new type of biopolitics that is disconnected from state control and deprofessionalized. Individualized biopolitics is involved with the dynamics of globalization and weakening of national, regional and professional regulations. As mentioned above, the appearance of this e-market for genetics, based of direct access without prescription or medical follow-up, is jeopardizing numerous bioethical regulation systems built by State or professional communities.

Users are highly motivated and interested by this type of cooperation about genetics, such as Simone (56 year-old French journalist):

*“There is also, these investigations, for example: skin aging, physical activity, one about depression... And then they [owners of the websites] use this, because they have some dozen thousands people in their database who participate; they have already published an article about one of the results. People are so motivated that they answer honestly. It's not like with other investigations. Here, I feel there is a real will to know what are the links between the things; people thus may tend to be more honest than usually. And it's really a website where people do not have anything to hide and which is not visible by everyone. To be admitted, you need to have made your test. So, it's sort of select, actually. We know we are between people who all gave the same thing.”*

#### *Marketing (bio-)social links and medical democracy*

The websites we analyzed generally develop parallel blogs and forums and/or provide links to other websites. User-friendly pictograms symbolizing sharing signpost these browsing paths. These parallel virtual spaces perform a triple function: they allow users to directly discuss with websites administrators and other users, within a kind of online medical and scientific democracy about genomics, but they are also designed for networking purposes. Some of these forums indeed represent social networks, where users share personal genetic information: one of the websites displays a “*Search for and invite friends*” thumbnail that points at a search page allowing to find out one's genotypic similarities with other users, and to communicate with them via Facebook. Another site does not even use a third party social network, but directly allows contacts between users on the basis of genetic resemblance: each user is provided with a private inbox — administered by the website —, through which s/he can be invited to join online genome sharing activities. Some users post on companies' blogs, in order to get in touch with others. One of them, for example, writes: “*I'm looking for other people who are H1d1, so please post if your Y chromosome has these mutations*”.

Some interviewees, like Simone, so much embraced these new communication tools that they even abandon more general social networks:

*“I have to say that my own social network is [name of the website], it's not Facebook. I'm also on Facebook and I go on my account once in a while, but the place I go on the most regular basis is [name of the website]. I want to see if someone is looking for someone from haplogroup Y, thus paternal I2, and I find few people. But H7, for example, which is my maternal haplogroup, there is a thread, a forum that started with the question “are you H7?” and thus, there, I entered directly.”*

These online communities, based on genome sharing activities, can be considered as biosociality phenomena. As Gibbon & Novas<sup>28</sup> emphasize, the concept of biosociality that has initially been coined by Rabinow<sup>29</sup> in the 1990s has been very relevant for anthropologists and sociologists who reflected on the novel shaping of identities and communities by contemporary advances in genetics. This concept aims at going past the nature/culture opposition, on two ways: it is first related to the growing artificiality of nature, through genomic discoveries and applications; secondly, it allows to describe the appearance of new social entities (such as patients groups, sharing a same genetic specificity) based on the latter. Groups and even institutionalized associations have been formed to promote medical and scientific democracy on the basis of a common biological and/or pathological particularity. Members of these groups managed here and there to stand up for their rights, raise funds, focus research interests and sometimes invent new knowledge-building modalities. Petryna's work<sup>30</sup> about the biological citizenship claimed by groups of irradiated individuals from Chernobyl is one example of the practical consequences of biosocialities.

Nevertheless, these newly appearing biosocialities on the DTCGT websites seem to differ from this type of phenomena. It is noteworthy that they are partly used for commercial purposes; genetic information sharing among users, possibilities to meet people with similar genotypes, opportunity to create marker-specific interest groups: these aspects are services, somehow part of customer service.

The existence of these biosocialities also questions several social, ethical and even political stakes. One can for example observe differentiation/grouping processes based on haplogroups; a forum participant comments: "it is a matter of who has the most original haplogroup that s/he will only share with few people". This kind of atmosphere can lead some users to distance themselves from the online platforms:

*"It goes very far. Because, I mean, the last time it was a mess. We go from genetic genealogy with amateurs, specialists, theories, and then we find ourselves with... so, people do not put this in the forums, but it's sure that one can... err... for me, it's sure that I can think, well, I will go along with this person because this person has got the very same marker. It can lead to a sort of... not racism, but genetic discrimination. It's not entirely racism, it's genetic discrimination, because it would be even between White people. So, this is even more subtle racism."*  
(Bruno, 30-year old French student).

These new biosocialities seem to open up wide and varied horizons, from complex and multiple social forms to interactions based on the sole — reductionist — sharing of a genetic marker. This perspective inevitably leads to question the anthropological stakes of these new practices: they might potentially lead to an impoverishment of the concept of human identity, which is rich of the entanglement of multiple cultural, social and biological significations.<sup>31</sup>

## Conclusions

This article showed that we can differentiate three main commercial strategies used by DTCGT purveyors. These marketing policies are related to manifold stakes and risks we can anticipate, on the basis of our first analyses:

- 1 riding on the healthism wave: this can be extremely lucrative, but is potentially stressful for users;
- 2 exploiting contemporary claims linked to individualized biopolitics and curiosity for advances in genomics: this strategy indeed creates a social field for the expression of these claims, but it can also bypass the usual forms of scientific and clinical validation, to the detriment of the service quality;
- 3 offering biosocial networks: this third strategy can lead to the simplistic assimilation of identity to genetics, and carries the specific risk of forming users' groups deprived of the usual democratic debate tools that could enable them to work on enhancing the service quality.

Blogs and forums in which users can take part appear monitored by DTCGT purveyors, notably through netiquette, flag-posting and community managers' supervision. It is thus relevant to wonder whether these companies would allow — moreover in pages hosted on their own servers — the appearance of a public and informed debate about scientific and clinical validity of DTCGT. These online communities are so entangled with the commercial strategies of the purveyors' websites that one can question the very possibility of scientific and medical democracy in these virtual spaces.

In addition to these political and economical stakes, DTCGT also raise the question of genetic risk, and more precisely of its construction and perception outside of a healthcare relationship. Scientific bases of the validity of the tests are presented in brief and incomplete ways. Many users thus consider the statistically proven association of a precise phenotype with a precise genotype as the certainty of a pathology. If established in their own test results, the presence of a fateful genetic trait is considered in isolation: in such cases, the hybridity of the statistical value that also includes environmental factors, is ignored by the customer. Users may even endow their results with a diagnosis value. This process is double-sided: on one hand, it implies the assimilation of co-occurrence and causality (by brushing aside environmental factors); on the other hand, it is part of a global geneticization phenomenon that impacts more and more social fields. This lay process of causal imputation is partly due to the way results are presented, but it is also linked to specific fertile social grounds, that Giddens has described as the "risk society", where "traditional certainties and securities can no longer be assumed [and where] increases in

scientific knowledge lead to a more contingent society where the risks of anticipated events influence today's decisions.<sup>32</sup>

Despite — or because of — the publication of a recent article<sup>33</sup> asserting the psychological incoherence of DTCGT, we consider the ethnographical investigation of the reception of these tests and of their lay interpretation a necessity.

## Acknowledgements

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## Notes and references

- <sup>1</sup> L. Hennen, A. Sauter and E. Cruyce (2008), *Direct to consumer Genetic Testing, final report*, European Technology Assessment Group.
- <sup>2</sup> Co-founded by Anne Wojcicki, who is married to Sergey Brin, one of Google's founders.
- <sup>3</sup> DeCODE had previously built a bio-bank with the DNA of part of the Icelandic population, this leading to an intense social and parliamentary debate in the country. For an anthropological study of these events, see for instance: M. Fortun (2008), *Promising genomics. Iceland and deCODE Genetics in a world of speculation*, Berkeley, University of California Press.
- <sup>4</sup> See list of the companies in the annex 1.
- <sup>5</sup> It is noteworthy that extraction and shipping of DNA are performed in similar ways by all purveyors of tests: for a price varying between 60 and 2 000 euros, users have to send back to the company a saliva sample kit.
- <sup>6</sup> A. Pollack, *California Licenses 2 Companies to Offer Gene Services*, *New York Times*, (19/08/2008), <http://www.nytimes.com/2008/08/20/business/20gene.html> (accessed on 23/08/2011).
- <sup>7</sup> K. Sénéchal, P. Borry, H.C. Howard and D. Avard (2009), *Les tests génétiques offerts directement aux consommateurs: vue d'ensemble des normes et politiques applicables*, *GenEdit* 7(1):1-14.
- <sup>8</sup> H.C. Howard and P. Borry (2008), *Direct-to-consumer genetic testing: more questions than benefits?*, *Personalized Medicine* 5(4):317-320;
- J.-C. Kaplan (2011), *Le point de vue du "dinosauré". Génomique et médecine: du bon usage du génome humain*, *Cahiers de Myologie* 4:46-47.
- <sup>9</sup> See for instance the *American Medical Association* press releases: <http://www.ama-assn.org/ama/pub/news/genetic-testing-qualified-professionals.page>.
- <sup>10</sup> D.J. Hunter, M.J. Khoury and J.M. Drazen (2008), *Letting the Genome out of the Bottle - Will We Get Our Wish?*, *New England Journal of Medicine* 358:105-107.
- <sup>11</sup> Some scientific studies presenting such co-occurrence results have been publicized as “discoveries”, even though they referred to limited populations. See: T.M. Morgan, H.M. Krumholz, R.P. Lifton and J.A. Spertu (2007), *Non-validation of reported genetic risk factors for acute coronary syndrome in a large-scale replication study*, *JAMA* 297:1551-1561.
- <sup>12</sup> Besides the statistical validity of association (of genotypes and phenotypes) studies, the very definition of phenotype criteria is problematic. It is all the more difficult when it comes to “behavioural genetics”. DTCGT purveyors seem to ignore two aspects: the above mentioned phenotype criteria are defined — constructed — within precise social and cultural systems. In addition, these labelling processes convey a significant risk of essentialization (T. Duster (1992), *Retour à l'eugénisme*. Paris, Editions Kimé).
- <sup>13</sup> See the view of the European Society for Human Genetics on the document about DTCGT issued by the UK-based Human Genetics Commission (PPPC-EHSG responds to the consultation on A Common Framework of Principles for direct-to-consumer genetic testing services, <https://www.eshg.org/fileadmin/www.eshg.org/documents/PPPC-ESHG-DTC-06122009.pdf>).
- <sup>14</sup> See the GAO report, written by G. Kurtz, that is based on a comparison of different DTCGT companies' results when analyzing identical DNA kits and shows significant variation of these very results. (“*Direct-to-consumer genetic tests: misleading test results are further complicated by deceptive marketing and other questionable practices*”, GAO-10-847T July 22, 2010, [www.gao.gov/new.items/d10847t.pdf](http://www.gao.gov/new.items/d10847t.pdf))
- <sup>15</sup> Interviewees' locations: USA (5), UK (2), France (4), Germany (3), Portugal (1), Belarus (1), Canada (1), Netherlands (1), Italy (1), Algeria (1), Females: 7; Males: 13. Age range is 26-63.
- <sup>16</sup> A.R. Omran (1971), *The Epidemiologic Transition: A Theory of the Epidemiology of Population Change*, *Milbank Memorial Fund Quarterly* 49(4):509-538.
- <sup>17</sup> A. Lippman (1991), *Prenatal genetic testing and screening: constructing needs and reinforcing inequities*, *American Journal of Law and Medicine* 17:15-50.
- <sup>18</sup> This trend has for instance been studied by Aïach in P. Aïach (1994), *La prévention, une idéologie de progrès?*, *Agora. Ethique, médecine, société* 30:11-15 and in P. Aïach (1998), *Les voies de la médicalisation*, in *L'ère de la médicalisation. Ecce homo sanitas.*, edited by P. Aïach and D. Delanoë. Paris: Éditions Economica.
- <sup>19</sup> L. Sfez (1997), *La Santé parfaite. Critique d'une nouvelle utopie*, Paris: Seuil.
- <sup>20</sup> R. Crawford (1980), *Healthism and the medicalisation of everyday life*, *International Journal of Health Services* 10:365-388.
- <sup>21</sup> In passing, it is noteworthy that preservation of health is discussed and presented through management and economics vocabulary.

- <sup>22</sup> See the demo results posted on 23andMe blog, TheSpittoon : <http://spittoon.23andme.com/2010/12/01/health-at-23andme-navigating-your-health-results/>
- <sup>23</sup> G. Canguilhem (1998) [1966], *Le Normal et le pathologique*, Quadrige, Paris: PUF.
- <sup>24</sup> All interviewees' names are pseudonyms.
- <sup>25</sup> N. Rose (2007), *The politics of Life itself. Biomedicine, Power and Subjectivity in the Twenty-first century*, Princeton: Princeton University Press.
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- <sup>33</sup> C.S. Bloss, N.J. Schork and E.J. Topolo (2011), *Effect of direct-to-consumer genomewide profiling to assess disease risk*, *New England Journal of Medicine* **364**:524-534.

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## **Annex I**

### **Inventory of DTCGT companies as of end of 2010**

42 websites

23andMe	Genova Diagnostics
Agendia	Genzyme genetics
Athenadiagnostics	G-nostics
Atlas Genes	Graceful earth
BioResolve	Great Lakes Genetics
Carolyn Katzin's The DNA Diet	Hairdx
Consumer Genetics	Healthcheck
CyGene Direct	Hivgene
deCODEme	Holistic Health consultants
Dermagenetics	IMMD (Institute of medical molecular diagnostics)
DNA dimensions	Inneova
DNA direct	Interleukin Genetics
Dna Traits	Kimballgenetics
Eastern Biotech Lifesciences	Knome
Enterolab	Labgenetics
GeneDX	Mygenome
Geneessence	Myriad
Genelex	Navigenics
GeneLink Biosciences	New Hope Medical
Genetic Health	Psynomics
Genetic Technologies	Salugen (Genotrim)

N.B. this list does not include companies whose activity is only dedicated to ancestry tests (such as Igénée or Family Tree DNA).

Among these 42 websites:

- 18 do not require any preliminary counseling session;
- 10 offer DTCGT after a counselling session with a genetic counsellor (appointed by the company or whose contact details are provided by the company);
- 4 formally request a medical prescription (but do not provide contact details of medical professionals);
- 9 do not precise delivery modalities;
- 1 does not sell tests but only offers results interpretation.