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

DCGT: the individual's benefits above all

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ABSTRACT: Easy, cheap, efficient as online service often are. Direct to Consumer Genetic Testing (DCGT) represents a big evolution towards personalised medicine. If the phenomenon seems to be unstoppable, the first aim of its present and future developments should be the customers' benefits. A certified quality of the services provided, a clear communication and a well-structured support to customers should be the critical conditions that could transform those online services in something really important: for the individual's health and the society as a whole.

It seems just an online service, like many others. You know how online shopping works: push the computer start button, type in the right address and, sitting comfortably on your favourite chair, you can buy almost everything. From your computer you can get almost any object you desire, book a flight or a hotel for your vacation, send a present to your friends. You can even buy a genetic test, turn on the light on the secrets of your own DNA. What are the origins of your ancestors? Where were they from? Are there people around the world sharing the same DNA patterns and ancestors with you? Spending 99\$, thanks to *23andMe*, you can easily obtain some of this information.

23andMe is one of the many online companies offering Direct To Consumer Genetic Testing (DCGT). It was named “Invention of the year” by *TIME* magazine in 2008. Its online services can do more than «grow your family tree», actually. Looking at the “Health” section of the website, a different world opens to your eyes. You can discover your risk factor over 100 diseases: from asthma to kidney cancer, from Alzheimer’s to Parkinson’s to diabetes; you can know «your predicted response to drug, from blood thinners to caffeine»; if you are planning for a baby, you have the chance to discover your carrier status for 24 different illnesses. You simply have to order your kit, spit into the tube and send it back to the lab. In 6-8 weeks you will get the results for less than 100\$. Easy, cheap, convenient as online services often are.

However there are many issues to consider with respect to DCGT. The first is related to the respect of personal choice and will. Health is a private and intimate field where the guiding principle should be the individual's right of looking for information, freely selecting the source, in order to take the most appropriate decision. Another issue comes directly from one of the appealing claims on the *23andMe* website: «Take a more active role in managing your health». An individual who is more and more informed and responsible for his/her personal health status is often seen as a crucial achievement for future society. Internet is having a huge role in it: “Google was my doctor” entitled an article on *The Times* few years ago. This is a phenomenon that, simply, cannot be ignored even if, as Joanne Shaw stated, «many doctors regard such trends as highly threatening and react to them with outright horror or with resignation, as a necessary evil». In her *BMJ* article entitled “A reformation for our time”, she wrote about the increasing demand for online health information and its consequences, saying that it is not just unstoppable but «it should be encouraged as good for patients and doctors alike. We need people to be more prepared to take responsibility for their own health, work out what may be wrong with them, and research how best to care for themselves. Many minor ailments can be safely and cost effectively managed in this way». She ended her piece with an important statement: «People who look to the internet as a legitimate tool to help with their health may already be in the majority, and this is something for us to celebrate».

What is the role of DCGT in this context? There is no doubt that DCGT and companies offering this kind of services could represent a big evolution towards personalised medicine, contributing to create a new kind of autonomy for individuals. Some other issues arise, though. Are customers ready to properly interpret the result they get, understanding the real value of that fraction of risk? Are they competent

enough to attribute the right value to such data that, up to know, have been always filtered and interpreted by health professionals? It may be curious to discover that we have an Eskimo ancestor, that's true. But discovering a high risk for a severe disease may not be as pleasant. There is something more to consider, indeed. On the basis of the results, customers (and their relatives) could become "patients". Are they really aware of this possible switch?

A meeting organized by SISSA (Trieste, Italy) in 2010 faced those questions, gathering together 60 experts from a broad range of disciplines. The workshop, supported by the European project "bid-brains in dialogue" (www.neuromedia.eu), focused on genetic testing for neurodegenerative disorders such as Alzheimer's, Parkinson's, and Huntington's diseases. These syndromes were taken as a model in the discussion. It is well known that just few neurodegenerative diseases have a Mendelian inheritance: this is the case for Huntington's disease. Instead only a small percentage of Alzheimer's or Parkinson's cases, usually early-onset, have a strict genetic cause, while the majority of cases seems to be associated to both genetic and environmental factors making it difficult to predict the disease risk. Thus, for example, genetic testing for Alzheimer's disease is suggested only for individuals with a familiar history of early-onset or having first grade relatives with the disease even though a polymorphism in the Apolipoprotein E (APOE) has been unequivocally associated with the most common late-onset form of the disease (the APOE gene is the one investigated by 23&Me). Even if the identification of risk factors through epidemiological studies may be useful for understanding the molecular basis of the disease, it may have a really vague meaning for the individual. Despite that, online companies offer an evaluation of risks related to Alzheimer's and Parkinson's often without a counselling support service. This is, in our opinion, the most crucial point.

As the workshop's attendees underlined, DCGT raise several issues concerning different disciplines: from genetics to medicine, from ethics to economy, from law to philosophy. Here we would like to stress a very practical aspect: since the information coming from a genetic test is particularly complex and its interpretation requires a specific expertise, the customer should be given the right support and tools to deeply understand the results' meaning, the real entity of the risk and the quality of services provided, avoiding any ambiguity. That is particularly true when diseases investigated are severe, with no preventive measures or treatments, as in the case of neurodegenerative diseases. Worries that several observers have underlined in this sense should not be considered "excessive". The statement appearing on the 23andMe website, just at the end of the complete list of services offered, remarks this need. There we can read: «The tests have not been cleared or approved by the FDA but have been analytically validated according to CLIA standards. The information on this page is intended for research and educational purposes only, and is not for diagnostic use». A contradiction seems to emerge between the overall website communication and this clarification: What kind of information does the customer really get? How should he/she use it? Is the customer really aware that the service is paying for is something related to research and education rather than to diagnosis?

Marketing rules are clear and well-known: charming claims and attractive product presentations are the usual communicative strategy. In the case of DCGT, the situation appears much more serious. We are not dealing with a new high-tech device, a luxury car or a fashion product. We are testing our health and our future, or the one of our progeny, and the answer we are getting after spitting in that tube could have a strong impact on our life. If the phenomenon of DCGT seems to be unstoppable, with potentially important positive consequences, the first aim of its present and future developments should be the customers' benefits. A certified quality of the services provided, a clear communication and a well-structured support: those should be the critical conditions that could transform those online services in something really important for the individual's health and the society as a whole. The healthcare systems and regulators at national and international level should be in charge of guaranteeing that. Unfortunately, despite some attempts, a legal framework for DCGT does not exist, yet, and just few countries have already taken some regulatory measures. For those who are involved, in different ways, in this promising but complex field, this is something to urgently work on.

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