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## Keeping data alive: talking DTC genetic testing

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### ABSTRACT

Direct-to-consumer (DTC) genetic testing has been discussed and critiqued from perspectives that include biomedical, commercial, ethical, legal, regulatory, and participatory stances. This study adds a perspective that emphasizes the 'liveliness of data' and treats *23andMe* genetic tests as part of an expanding self-tracking market that shapes communication, social life, and identities. In demonstrating how 'gene talk' aids and speeds the circulation of findings based on personal data, the discussion cast light on how personal data gain value in people's lives, thereby enhancing their readiness to position themselves as data subjects. Users are offered a data-enhanced existence, a 'lifeworld inc.', in which new kinds of ontological horizons are promoted by technical developments that produce numbers and calculable coordinates for descriptive regimes. Arguing that debates on DTC genetic testing and uses of personal data benefit from a more thorough analysis both of translations of genetic knowledge and emerging data practices, the aim is to critically address the active work by users that keeps genetic data alive, including the emotional longings and practical capabilities that people have in terms of genetic knowledge. Through a more comprehensive framework, recognizing the lively nature of genetic data, we can reveal how genetic testing services promote knowledge formation that mixes intimate and larger scale social and economic contexts.



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As the costs of genetic analysis decrease, purchasing genetic tests online is becoming more common. Tens of companies offer direct-to-consumer (DTC) testing, covering areas such as 'deep ancestry', 'ethnicity', 'health', and 'relationships'.<sup>1</sup> The tests have been discussed and critiqued from perspectives that include biomedical, commercial, ethical, legal, regulatory, and participatory stances (e.g., Ducournau, Gourraud, Rial-Sebbag, Cambon-Thomsen, & Bulle, 2013; Nordgren, 2014; Prainsack, 2013; Saukko, Reed, Britten, & Hogarth, 2010). Moreover, solid empirical research into people's engagements with genetic testing demonstrates that genetic knowledge contributes to individual and social lived experience and is an arena of active translation and moral and practical engagement (e.g., Harris, Kelly, & Wyatt, 2014; Nelson, 2008; Rapp, 1999; Sharon, 2014). This paper adds to

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scholarly work that treats DTC genetic testing as part of an expanding market of commercial products and services promoting self-tracking and uses of personal data which, in turn, shape communication, social life, and identities (Harris, Wyatt, & Kelly, 2013, 2014; Lomborg & Frandsen, 2016; O'Riordan, 2011, 2013; Ruckenstein & Pantzar, 2015). By proposing a comprehensive approach to DTC genetic testing, the aim is to explore wider opportunities for action and agency in terms of genetic knowledge than is suggested by mainstream research which focuses, for instance, on motivations for being tested, the clinical utility and validity of the test results, or their value in terms of personal risk assessment and behavior change (e.g., McGowan, Fishman, & Lambrix, 2010; Su, Howard, & Borry, 2011). Consequently, the emphasis in the approach implemented in this paper is placed on how knowledge from various sources is coordinated and translated, delivered to people, accepted, refuted, shared, explored, and played with.

A foundation for investigating everyday entanglements with DTC genetic testing can be found in ethnographically informed research that examines people's active relationships to personal data in formats as diverse as reports on heart-rate variability, genetic scans, CT scans, and food diaries. Findings in this field underline that data generated by digital modes of measuring and uncovering behaviors, physiologies, and biologies are characterized by diffuse processes of knowledge formation and power that spread across many kinds of networks (e.g., Cohn, 2010; Ruckenstein, 2014, 2015). In line with this kind of inquiry are recent discussions that emphasize the 'liveliness' of digital data (Lupton, 2015; Savage, 2013) which allows the data to be presented, interpreted, circulated, and repurposed by diverse actors and with very different consequences. For instance, passively stored genetic data might gain, or regain, liveliness by becoming incorporated into a dataset put together by a company or an organization at some later point, with a different purpose from that originally envisaged.

The lively data approach calls for research practices that capture ways in which data are actively kept alive, and that also seek insights into why data get 'stuck' in the sense of having no purpose or meaning (Nafus, 2014). The methodological stance developed here builds on a discourse-centered approach to culture that has proven useful for exploring the knowledge claims associated with self-tracking (Ruckenstein & Pantzar, 2015). The focus is on how talk about a topic – in this case gene talk about personal data – encapsulates and valorizes potential uses and meanings for the object being discussed, thereby making it attractive and worth engaging with (Sharon & Zandbergen, 2016). The goal is to uncover gene talk patterns that permit the presentation and interpretation of test results in a manner that supports everyday knowledge formation. In the case of DTC genetic testing, the data have already been pre-packaged into consumable reports when it reaches the consumer. Therefore, it is also important to focus on the cultural framings of genetic data by commercial agents that provide 'data materializations' (Lupton, 2015), that is, graphs, including lists of numbers, and visualizations that are designed to keep data alive so people may interact with it, or 'consume' it.

The most studied DTC genetic testing company (see Prainsack, 2013), *23andMe*, which has offered testing since 2007, is used as an example of how the consumption of genetic information, including pre-packaged reports focusing on what makes the tested individual molecularly particular, shapes understanding of personal genetic data. *23andMe* has mirrored and negotiated regulatory positions by presenting genetic tests as information

products rather than medical devices. Despite such precautions, the tests, and particularly the health information provided, have remained controversial (e.g., Annas & Elias, 2014). Customers provide a saliva sample that is partially SNP<sup>2</sup>-genotyped and results are made available to them online. In addition, uninterpreted ‘raw genetic data’ may be downloaded by customers from the website and they can export it to any other public or private initiative, or personal computer (Regalado, 2014).

Taking the user perspective, the goal is to explore framings of genetic knowledge and what they tell us about the commodification of personal data. The test takers had access to data materializations used by *23andMe* such as ancestry maps and charts listing elevated and decreased health risks including conditions such as atrial fibrillation, psoriasis, or age-related macular degeneration. Lists of ‘traits’ estimated the odds for certain hair, eye color, or ear wax type. The following account does not aim at a comprehensive account of the communicative affordances of the *23andMe* service, or a universal profile of the test takers.<sup>3</sup> With a small number of informants and a qualitative method, mainly focusing on gene talk, a more fruitful approach has been to trace discursive engagements with test results, examining how such engagements thematically and topically organize genetic knowledge.

### The inhabitable map of genetic testing

The merging of genetic material and digital participation has been described as a new form of self-discovery and social belonging (Harris et al., 2014; O’Riordan, 2013). Techno-cultural elites promote the position that people need data and algorithms in order to engage in self-discovery, supplementing the body as a site of knowledge and authority by a notion of the body as knowable only through numerical and computational practices (O’Riordan, 2011, p. 300; Ruckenstein & Pantzar, 2015). Meanwhile, a less public agenda on the part of *23andMe* is to get consumers involved in the production of a database that may be used in service development and corporate partnerships, finally resulting in ‘a loyal re-contactable cohort’ (Harris et al., 2013, p. 250) that would aid the company in its research endeavors.

In an article titled *Lifeworld Inc.*, Thrift (2011) offers valuable guidance for thinking about how *23andMe* involves users by means of numerical and calculative techniques for defining life. These techniques become visible to users as charts that shape communication and opportunities for self-reflection. As the *23andMe* website explains:

Ancestry Composition tells you what percent of your DNA comes from each of 31 populations worldwide. This analysis includes DNA you received from all of your recent ancestors, on both sides of your family. The results reflect where your ancestors lived before the widespread migrations of the past few hundred years.

Thrift suggests that what is being offered by digital services is a data-enhanced existence, which he labels ‘lifeworld inc.’, in which technologies are used for locating the individual within digitized networks and economies. The term, lifeworld inc. is borrowed, along with the meanings supplied by Thrift, for the purposes of the following discussion. In lifeworld inc., new kinds of ontological horizons for human societies are promoted by technical developments that produce numbers and calculable coordinates for descriptive regimes. Thrift calls these regimes ‘inhabitable maps’ that engineer locations ‘in order to produce

defined experiences which can be commoditized and validated as commodities by their thereness' (2011, p. 9). As he reminds us, maps have always had dynamic qualities as visual engines rather than mere representations. In the world that he is sketching, however, maps are even more tightly intertwined with the production of the everyday; they are 'a means for defining the defining features of the world' (2011, p. 9). For instance, genetic genealogy, offered by *23andMe*, is a technique for locating the person in relation to others and the world (Finkler, 2005; Kramer, 2015). Moreover, DTC genetic tests are marketed as optimistically neoliberal in their approach; they are said to aid in the production of people capable of governing their own health risks and increasing 'vital capital' by promoting optimal wellness specific to their genetic constitution (Harvey, 2009, 2010). In line with the notion of the inhabitable map, *23andMe* consistently highlights what is of interest and value in terms of genetic markers, while emphasizing genetic inheritance and aligning health risks with current notions of the 'risk society' (Hacking, 2006, p. 90). The service attaches genetically derived evidence to online profiles, thereby advancing practices, including communication and participation, linking to notions of kinship and ancestry, recognized health risks, and the future of biomedical research.

Numbers, typically offered as percentages, are thus instrumental in the transformation of 'raw genetic data' into consumable information: figures make risk estimates appear reliable and pin down the descriptive regime of genetic tests results. Moreover, the numerical information assists users in the navigation of heterogeneous findings. Thrift argues (2011, p. 10) that 'the inhabitable map produces both a knowing, empowered imperial audience and its subjects'. In a similar vein, he refers to Google Earth as a pleasurable way of wandering in the world that is simultaneously a poignant reminder of how we become observed: inhabitable maps colonize and take over. *23andMe* inscribes each participant with a genetic identity based on numbers, calculations, graphs, and charts. Users have no access to how data about them are analyzed in order to evaluate its validity; they are merely empowered by a non-transparent logic of numbers to assist their quest for self-knowledge in the realm of lifeworld inc.

### **Methodological considerations**

The notion of lifeworld inc. offers important insights into the capitalist logic of genetic testing, including the commercialization of health data and participatory research initiatives (Harris et al., 2014). Earlier research demonstrates how the rhetoric of participation suggested by platforms such as *23andMe* contrasts with the lack of transparency regarding company outputs and uses of personal information; the economic value of health data, for example, is never shared with the test takers whose samples make up the database. From the everyday perspective, however, the critique exaggerates the role of commercial endeavors in defining actions and identities. Genetic testing not only prescribes and constrains people's commodified genetic lives, but also opens a route to genetic knowledge that explains why the tests, or their users, do not always work the way *23andMe* proposes. It is, therefore, also important to attend to how people work 'off the inhabitable map' – how they doubt and refute the framings offered by *23andMe* – and to trace how alternative frameworks of interpretation are applied to the test results, contributing to perceptions of what is accorded significance in terms of genetic knowledge and people's lifeworlds. In terms of research methodology, it is thus important to take into account how the

communicative affordances and capabilities mobilized in and through the testing service aid people in intertwining their past and future connections, and in evaluating and narrating actual and potential relations and belongings.

The empirical material consists of discussions, taking place between September 2014 and May 2015, with 20 Finnish<sup>4</sup> people who had purchased a *23andMe* test from the United States since 2012.<sup>5</sup> Because I was interested in the defining features of the online service as well as user perspectives, I first needed to create an account with it. Joining the service meant that I became part of the social network of ‘genetic relatives’ defined by *23andMe*. Indeed, the ‘relative finder’ tool, through which people share their results and link up with their ‘genetic cousins’, is a popular feature of the service. I contemplated whether it would be ethically acceptable to contact ‘genetic relatives’ through the service and, following the general ethical principle outlined by the Association of Internet Researchers to the effect that even people operating in public spaces may maintain strong perceptions or expectations of privacy, (see <http://aoir.org/ethics/>), I decided to approach only those users who had posted profiles that typically included their names, photographs, years of birth, family surnames, or places of origin; many had also shown an interest in sharing personal information by issuing invitations to compare test results. I sent short message to a small group of genetically related users, explaining the research and asking whether they would share their views about *23andMe*. I also provided my email address to make sure that possible future conversations would take place outside the service because, as Harris et al. (2013, p. 251) argue, we need to be cautious about the data provided by participants online, particularly if we want to engage in a critical analysis of uses of personal data by genetic testing companies.

People responded quickly and within a day, ten people had agreed to answer an initial survey.<sup>6</sup> Additional research participants were identified through these informants, an approach that led to snowballing. The participants, aged between 22 and 55, were professionals and entrepreneurs from various fields. Many had a longer history with DTC genetic tests, making them ‘lay experts’ (Jauho, 2016) on retail genetics. As in a study of early adopters of genetic testing (McGowan et al., 2010), the people who most contributed to this study served as informants (with whom dialogue has been ongoing), rather than as mere interviewees. I encouraged such dialogue by facilitating participatory research; for instance, by circulating my main research findings concerning gene talk patterns among the participants. Ultimately, the conversations suggested that as users of genetic tests gradually learn more about genetic knowledge production, their opinions and perceptions of genetic testing develop and transform in dissonant ways. For instance, while endorsing and promoting testing in general, they denigrate the actual information packages offered by testing services.

Testing might have been suggested by family members, friends, or work colleagues.<sup>7</sup> The motivations for, and expectations of, testing concurred with earlier research (Su et al., 2011), in that participants were curious about the technical and visual qualities of the test. For younger Finns, particularly those working in the fields of social media and information technology, genetic tests are attractive as part of a larger trend of self-tracking and biohacking; tests are discussed in a favorable light, for instance, in the Facebook group ‘Quantified Self and Biohacking in Finland’ that has more than 3100 subscribers (December 2015). An interest in the future of genomics, and the possibility of learning about genealogy and health risks were widespread motivations to take a test. Some participants had



actively sought information about genetic testing, or seen mention of it in the media, while others were fascinated by stories of high-profile test takers, such as Google founder Sergey Brin's search for a cure for Parkinson's disease.

### Working off the inhabitable map

Depending on the people tested, some are content with the results provided by *23andMe*, finding therein satisfactory explanations for the ways their biologies and genealogies are ordered. As noteworthy, however, was the active translation of genetic information and discussions about 'raw data' that *23andMe* makes accessible to users. From the perspective of people's readiness to position themselves as data subjects, the service offered by digital technologies of handling personal data and delivering it back in a packaged form is of utmost significance. Gene talk, as suggested by the empirical material, clustered around the dual topics of ancestry and health risks, which is not surprising because these are the topics promoted by the company's numerical formats. The ways that talk on these subjects was framed, however, took some surprising turns. The test results were generally considered reliable, or somewhat reliable, but typically, they were not read as predictions, prognoses, or generators of further action. Similarly, earlier research suggests that people might be casual about DTC genetic testing: for instance, genetic risk information appears to have little effect on health behavior (McBride, Koehly, Sanderson, & Kaphingst, 2010). The content of tests is ignored and doubted, or treated as of little importance (Harris et al., 2014). These findings led to a more consistent focus on how users critique and bypass genetic test results. I heard stories of people, usually spouses or family members of those I talked with, who had no interest in their test results; they might not even have logged into the service to see their information packages, and their *23andMe* accounts were being managed by others, typically those who had convinced them to take the test in the first place.

The refusal to engage with test results is an important topic in its own right (see Wyatt, 2005), opening a vista onto how people ignore or reject genetic knowledge. Reasons given for this ranged from the perceived irrelevance of DTC genetic tests, through not wanting to know the results, to poor English language skills. In the context of this study, the refusal to engage with the tests actually led to a more consistent focus on how tests are made meaningful, an approach that emphasizes the active work of translation and contextualization conducted by test takers. Indeed, the latter is of utmost importance for the success of testing services and reminiscent of the labor of users in the digital world more broadly (Terranova, 2000; see also Nafus, 2014). Thus, in terms of methodology, it was important to focus on the communicative efforts of people to keep the genetic data alive, to create a context for test results, and to maintain and strengthen various kinds of relational ties, including familial, ethnic, or professional. In tracking talk patterns that make DTC testing meaningful for users, in addition to the topical clustering, two areas emerged as particularly noteworthy: people used alternative or interchangeable maps for interpreting genetic testing results, and they praised the value of raw data. In the following, the active translation of genetic information is explored with the more general aim of better understanding how services based on personalized delivery of genetic data intertwine with the lifeworld inc. project and shape everyday uses of genetic knowledge.

## Engagements with the Neanderthal

The topical clustering of talk about ancestry is enabled by the way *23andMe* advocates different orders of belonging and connection, with the test results tracing lines of male descent, and identifying ‘populations’, distant ‘maternal ancestors’, and ‘genetic cousins’. For the more experienced ancestry explorers who had taken other tests, for instance, through the FamilyTreeDNA<sup>8</sup> and the National Geographic’s ancestry project,<sup>9</sup> *23andMe* offered limited information. For others, the service provided the first glimpses of genealogical belonging: they recalled the interest and enthusiasm with which they studied the ancestry composition map. By clicking on the various options for reading the results, one can dwell on the inhabitable map and get a sense of the geographical composition of biology. From the Finnish perspective, however, rather than opening a plethora of interesting kinship options, *23andMe* results typically present a somewhat dull version of local ethnicity which is reflected in the comments of participants:

Too much Finnishness in the results, and my co-worker said the same, quite boring. Nothing of interest was found. When I was waiting for the results I was hoping that something exciting would come up, but then there was just so much Finnishness. (Female, 34 years)  
I was anxiously waiting for my results, so that I could find out all the different nationalities in me. It ended up being a great disappointment because I am almost one hundred percent Finnish. (Male, 53 years)

When circulating the finding of ‘too much Finnishness’ among the participants, one of them – who, unlike others, was proud of testing almost 100% ethnically Finnish – stated that people are after the foreign: ‘They would like to discover a Swedish king or queen in their ancestry.’ One of the great promises of consumer culture is the individuality and difference secured by acts of consumption: in the case of tests purchased by Finns, however, the desire for exotic difference might remain unfulfilled: ‘The only aspect worth mentioning is that I am 0.2 percent Romanian’, as one concluded. After getting his results, a man in his thirties wondered whether they were based on his genes, or his address and credit card information. The inhabitable map of *23andMe* failed to communicate ancestral connection in a stimulating or convincing manner. A woman in her early thirties questioned whether an algorithm, used by *23andMe*, could calculate one’s Finnishness: a reminder of the company’s lack of transparency regarding the analysis of personal data.

Ancestry tests are material for autobiologies and narratives that include molecular information in processes of identity and self-making (Harris et al., 2014). The communicative affordances of *23andMe* invite people to connect through genealogical charts, lines, and comparisons that tie people between geographies and generations all the way back to the Neanderthals with their heavy eyebrow ridges and truncated skulls. Indeed, the fact that the Neanderthal DNA percentage is meant for consumption purposes is underlined by the option to order a tee shirt with one’s Neanderthal percentage printed on it through the website. For some, the Neanderthal figure is a particularly engaging feature of the service. One of the men reported comparison and competition among an all-male group: the higher the percentage, the better. The Neanderthal genetic input, reaching as high as 3.4% among my group of informants, is interpreted as part of ‘a caveman identity’, of one’s belonging to an ancient lineage.

In terms of the communicative affordances of *23andMe*, engagements with ancestry findings exhibit emotional gravity, as in the case of finding close relatives, or more



light-hearted playfulness that becomes tangible, for instance, in relation to the figure of the Neanderthal that is used in a performative manner for pointing out gender difference: as one of the men said, ‘The test tells my wife the underlying cause for my being so lousy at vacuuming.’ While the ancestry test is accompanied by claims that it tells people ‘who they really are’ (Kramer, 2015, p. 83), test takers actively select information of which they approve to circulate to others. In light of communicative efforts to keep genetic test results alive, the engagements with ancestry results generate talk that is thematically arranged around pursuing difference, recognition, and social belonging. The ancestry talk underlines the fact that the genetic knowledge is used for reflecting on, and displaying to others, who people think they are and want to team up with. Even though the *23andMe* inhabitable map is criticized for being partial, or incorrect, it becomes meaningful as a trigger that can help in performing the act of situating oneself in the map of shared ancestry.

### Enacting health histories

Gene talk patterns on the subject of health are enabled by the fact that the inhabitable map of *23andMe* is designed to offer the experience of difference and variation in terms of the specific strengths and weaknesses of ‘the molecular self’. The personalized health overview presents risks in three categories: elevated, decreased, and typical. In each category, the user is offered comparative percentages. For instance, the first lines of the elevated risks category contain the following: ‘Atrial fibrillation, your risk 20.5%, average risk 15.9%, compared to average 1.29x.’ The results do not reveal the numbers behind the average as the presentation of risks simply focuses on possible deviations. Before receiving the results, people might have been worried about what they learn about themselves through newly discovered risk information. Ultimately, however, the results were not very surprising or remarkable.

I think I had two elevated risks: one of them was Alzheimer’s, which we have in our family: my grandmother became senile with old age. And then the risk of cardiovascular disease – surprise, surprise: I am a Finnish man. (Male, 45 years)

I wasn’t shaken in any way: perhaps wondered why I didn’t have increased cancer or diabetes risk. That would have suited the picture. (Male, 40 years)

Since the mathematics of probability is not something most people master, health risks are poorly understood in technical terms (Su et al., 2011, p. 143). Instead, listed risks shape and promote communication concerning test results by reinforcing the idea that family health histories are important tools for identifying risks and the possibility of illness. Notions about kinship and heredity are mobilized for evaluating genetic information (Chilibeck, Lock, & Sehdev, 2011, p. 1773), as the following quote demonstrates:

Even if I don’t really believe in health risk predictions, getting the results was a relief. None of the elevated risks was unreasonable, and in a funny sort of way, even though possibly only by chance, among the most elevated risks were diseases that I know from my family. (Female, 31 years)

After getting the results, some participants interviewed their parents and other relatives about family histories and causes of death, meaning that the test results generate and become part of ‘family work’ (Geelen, Van Hoyweghen, & Horstman, 2011). Participants described how genetic testing brings one’s relatives closer, emphasizing a unity and sameness that had not been apparent before. This explains why people found taking the test

satisfactory, even if they did not learn very much from the actual results; rather, it tended to trigger talks within the family, among past, existing, and newly found relatives.

I made my mother take the test: we were comparing our health histories and illnesses and causes of the death in our family. I don't remember when I had a bond like that with my mother: we phoned back and forth and talked about taking other tests as well, like the Family Tree DNA. (Female, 48 years)

As this extract suggests, the test opened a new way to belong to one's family, promoting re-enactments of family histories; health histories, the reconstruction of which is triggered by genetic testing, feature war veterans, emigrants, illegitimate children, cousin marriages and poverty, and offer an engrossing topic of conversation for family members. In terms of keeping the data alive, it is of utmost importance that people work off the map and share genetic testing knowledge in private discussions. The active work that becomes observable in people's talk maintains the liveliness of the data by translating and contextualizing test results while, without such talk, they can remain uninspiring, revealing mere curiosities which are quickly forgotten. The tests become worthy of more detailed storytelling and speculation when combined with other people's results as well as evidence that originates outside *23andMe*, features of the sense-making efforts that enliven genetic tests.

### Alternative maps for translating genetic knowledge

The empirical material suggests, time and again, that in light of communicative aims, the genetic test is part of a more all-encompassing quest for knowledge. Moreover, results are accepted, refuted, and made to resonate with concerns and objectives that have to do with personal beliefs, notions of health, or the future of health research. In light of gene talk patterns, the talk is organized thematically, but it also has a spatial dimension. Genetic test results are interpreted by using alternative or interchangeable maps, in addition to the one offered by the inhabitable map of *23andMe*, that reflect people's more encompassing aims. For instance, one of the participants explained that since he is a Jehovah's Witness, he is interested in genetic tests that prove that 'we are all related to one another and we all originate from the nuclear family that the Bible talks about'. For him, the important map was the biblical genealogical chart. A social media professional described how genetic health risks gave her clues in much the same way as an astrological map: it is her task to decide how she evaluates their weight and interprets them in relation to the various determinants of health including diet, mood, stress, sleep, and sexuality.

The alternative maps used for interpreting test results might also be based on more holistic and comprehensive notions of health, arguing against the 'clinical gaze': the dominant medical mode of knowing that focuses on diagnosing and localizing pathologies and abnormalities (Foucault, 2012). The interviewees emphasized the problematic aspects of the clinical gaze by highlighting how the person needs to be seen as a whole: the individual disease map consists of interrelations between symptoms. For instance, a woman who self-diagnosed her celiac disease talked of the long journey of 'biohacking' her stomach problems.

People like us, who have ended up self-tracking, have felt firsthand how doctors are not the ones who know better. Fine and good doctors certainly exist, but many of them cannot help when you have complaints and discomforts. They are not trained to look at the bigger picture. (Female, 22 years)

Translations of test results suggest that rather than dwelling on the inhabitable map of *23andMe* in its given form, people use the test results for seeking evidence from alternative maps that aid them in terms of health and identity. Test results become incorporated into a self-tracking journey, as in the case of the young woman with celiac disease, or add details and certainty to a larger framework envisioning future directions for health. A food industry professional treated personal testing as a step toward nutrigenomics, a fact-based tool for creating food effects maps and improving health through dietary modification. ‘We could finally learn how to feed children right’, he envisioned. In common with experts in the field, he believed that nutrigenomics could guide people in the optimization of their health by adjusting the nutritional environment in which one’s genome operates (Harvey, 2009). In light of the notion of lively data, the active work of mapping is part of the effort to make the test results resonate with aims and value projects that people have and seek to share with others. The communicative affordances of the genetic test promote interpretations of, and interactions with, the test results that support alternative maps that not only maintain the liveliness of data, but also validate people’s notions of genetic information as a building block for various kinds of causes, including the personal, religious, or professional.

### **The value of ‘raw data’**

The final area of discussions meriting attention in terms of gene talk patterns is made possible by the fact that *23andMe* makes the ‘raw data’ accessible to users. A participant with expertise in data analytics and signal processing clarified that he has little interest in individual test results as they are not based on sufficiently broad evidence to define health risks accurately. Rather, genetic information becomes important in the future by being a part of larger datasets that include environmental and lifestyle-related information. He saw himself as a data contributor, an active part of the movement to stock databases that can then be subjected to analysis in order to uncover the systematic bases of health and well-being. His ideas echoed the so-called option value of data (Mayer-Schönberger & Cukier, 2013), suggesting that data can be used in the future in ways not identified at the time of collection.

Valuing access to ‘raw data’ was discursively linked to the idea that in the future genetic data, particularly when combined with other datasets, will generate better health care. Participants who valued access to ‘raw data’ praised it as groundbreaking, as something that should develop into standard practice in medical research (see Prainsack, 2013). A couple of participants had ‘donated’ their data to professionals with the idea that perhaps the experts could uncover something of interest, while one of the men expressed frustration about the limited possibilities to participate in genetic research. Despite DIY initiatives and citizen science efforts, the fields of genetics and genomics are still the realms of experts and professionals. The role of amateurs is mainly that of supplying biological samples and taking part in platforms such as *23andMe* with predefined aims, audiences, and modes of participation (Prainsack, 2013). By getting access to raw data, people imagined that they could become more active agents in research efforts: they could own and control their data, and give it away for whatever purpose they wanted to promote.

Some test takers had uploaded the *23andMe* data into the *Promethease* website. *Promethease* reanalyzes tests sold by a variety of companies, including *23andMe*. Created

by Greg Lennon, a geneticist, and Mike Carias, a computer programmer, it works by comparing a person's DNA data with entries in SNPedia, a public wiki on genetics that operates with the help of volunteer editors (Regalado, 2014). The *Promethease* report offers a vast amount of detailed information in a manner that illustrates the limitations of *23andMe*. The goal of *Promethease* is not to operate as an inhabitable map: health risks are not combined into comprehensible numbers and charts; rather, users browse through contradictory evidence that scientific research suggests could raise, or lower, health risks. From the user perspective, the report is a compilation of apparently random facts rather than a coherent risk analysis framework, mirroring the current state of scientific research that offers conflicting and uncertain information about the genetic disposition of health.

When I got the results, I was confused. There was so much contradictory information. I was also left wondering what to think of *23andMe*: should I trust it or not? We urgently need interpreters who can help us with all of this information. (Female, 42 years)

In Finland, genetic counseling offered by the formal healthcare system is not accessible to people purchasing DTC genetic tests. Some participants were eager to find people with whom to discuss the validity of the test results but, without a geneticist in the family or among friends, they had no one to guide them through the results. From the perspective of genetic understanding of the self, the *Promethease* results are discouraging: the principal lesson to be learned concerns the difficulty, if not impossibility, of mastering the self on the molecular level. With all the inconsistencies and insecurities posed by the listed results, the creation of a consistent narrative of autobiography that would prioritize genetic knowledge in terms of health is problematic. On the other hand, as the test takers noted, this finding is somewhat reassuring; rather than providing a comprehensive resource for self-making, the test merely offers one possible stream of information. Through their own trials, people can revisit the communicative affordances of *23andMe* and, ultimately, revise their ideas on the truthfulness or accuracy of the tests. This fits into how people act upon genetic test results in the context of their daily lives by combining them with other knowledge streams.

### Becoming part of data movements

By taking genetic tests, people become part of the lifeworld inc., thereby promoting larger circuits of data movements. As already noted, *23andMe* has a greater investment in collecting usable genetic information for its database than aiding users to navigate the vagaries of the genetic testing market. As the tests become more readily available, a possible future scenario is that uploading and sharing biological information will become the norm: in techno-cultural work environments, for instance (O'Riordan, 2011, p. 307). Yet, with limited understanding of the ramifications and futures of genetic information, it is impossible to fully comprehend what this means in the long run. Social media and information technology professionals might communicate light-heartedly about their newly found genetic cousins without realizing that they have given away control and oversight of information that is not only personal, but extends to other people (Shabani & Borry, 2015). As O'Riordan (2011, p. 307) maintains:

To have a biodigital presence is to give something up, to take a substance from the body and put it into the circuit of production. Genome sequencing is not like making a web page, it is a

biotechnological process at some radical remove from participation [ ... ] People do not have much control or oversight about what their genome communicates, what it means, or how it is communicated to them.

Within the parameters of this study, people did not show much concern about sharing genetic information, repeatedly noting how important it was that their personal genetic information was no longer available only to the professional elite. Some of them exhibited great confidence that access to personal data will promote the possibility that genetic information can be harnessed to more citizen-centric and communally minded projects. Despite the power asymmetries that define lifeworld inc. and the genetic testing market in particular, including the sale of data to third parties, test takers willingly position themselves as data subjects. On the other hand, however, I did hear about instances of resistance to, and frustration with, genetic testing and data practices which started to appear when participants learned more about the testing market and began to realize how unaware they were of what actually happens to genetic information once it is transmitted to servers and cloud archives. Thus, the commodification of genetic information is not uncritically cherished by test takers; the participants in this project explicitly pointed out the dangers of the lack of regulation such as the absence of opportunity to review current data movements and the lack of guarantees that the testing products will deliver what was promised. One of the younger women paid a testing service that promised to provide her with advice on optimizing her sporting activities, based on data from *23andMe*, but the results contained no relevant information. Fundamentally, participants agreed with expert opinion that regulatory oversight is needed to ensure the quality and safety of DTC testing services (Nordgren, 2014).

## Conclusions

In terms of research initiatives concerning forms of self-tracking and personal data uses, combing the notion of lively data with a discourse-centered perspective on culture offers methodological support for exploring how people engage in sense-making efforts that actively translate delivered data into various kinds of interpretative frameworks. By taking advantage of the lively data approach, emphasizing how thematic clustering in transmitted talk aids and speeds the sharing and circulation of findings based on personal data, this study has offered insights into the relationship of ordinary people with personal data and data practices, paving the way for further exploration of everyday data relations. As has been suggested above, people discursively connect genetic testing with numerous topics including family health histories, religious affiliations, astrology, data analysis, and nutrigenomics; it is these kinds of linkages that should become a focus of more sustained inquiry in relation to DTC genetic testing. Professionals might find the messiness of genetic knowledge in action anomalous, but it is crucial to attend to the trend of increasing numbers of people becoming familiar with this type of information and the numerical and visual formats used for delivering it. In order to critique market developments, it is important to differentiate between services and their aims and how they approach their users, particularly as the field of testing services expands and more ways of becoming a part of data movements are offered.

Current self-tracking services tend to privilege knowledge formation that conforms to expectations aligning with neoliberal political efforts, emphasizing the significance of self-

reflection and taking responsibility for governing oneself and improving one's health and life changes. The findings of this study argue that in order to provide a critical assessment of the tendencies affecting how commoditized personal data is delivered, shared, circulated, and used, discussions among researchers, ethicists, and policy-makers should acknowledge the active work by users that keeps data alive, as well as the emotional longings and practical capabilities that people have in terms of personal knowledge. In terms of self-tracking research, it is of utmost importance not to simply replicate the logic of lifeworld inc. While lifeworld inc. promotes digital platforms such as *23andMe*, the very same platforms are also employed by their users as a resource for drawing alternative maps and routes that create their own inhabitable conditions. From this perspective, commercial services offering access to personal data are used for defining and redefining personal lifeworlds. Indeed, the desire to work on personal lifeworlds is a major part of why people actively promote DTC genetic testing, as demonstrated by those participants of this study who had recruited others to take part.

Redefinitions of personal lifeworlds by means of personal data delivery offer important clues as to why services that take advantage of personal data continue to attract people. The gene talk patterns explored, for instance, propose a range of possibilities for action in terms of retail genetics. By encouraging those who are interested to take part in knowledge work in this field, genetic testing can promote a more reflective and collective approach to genetic information rather than merely tying people to poorly defined health risks and population histories. Furthermore, this study has drawn attention to how the value of personal data itself is enhanced by its connections with issues salient in everyday knowledge production, and how this, in consequence, readies those taking part in the talk to position themselves – on one side or the other – with regard to potential future enactments as data subjects.

## Notes

1. [http://www.isogg.org/wiki/List\\_of\\_DNA\\_testing\\_companies](http://www.isogg.org/wiki/List_of_DNA_testing_companies) (accessed 20 July 2015).
2. Measurement of variations in single-nucleotide polymorphisms between members of a species.
3. The test results discussed in this article were received before a warning letter from the FDA (Food and Drug Administration) was issued in 22 November 2013. In that letter, the agency asked *23andMe* to stop selling health-related test results until it received the agency's regulatory approval. The FDA took the position that although susceptibility genes associated with complex diseases, including cardiovascular disease and Alzheimer's, can be tested for, estimating how and under what circumstances segments of DNA function – thereby placing individuals at increased risk – is difficult, if not impossible. *23andMe* complied with the demands, while deciding to maintain access to health-related reports for customers who had purchased tests before the letter (Annas & Elias, 2014; Regalado, 2014).
4. A certain marginality and distance characterize Finnish experiences in relation to *23andMe*. As is typical for social media, sharing is made easy: people can exchange both messages and test results, write posts, and participate in research (Harris et al., 2013). With its rhetoric of empowerment and participation, Finns tend to see aspects of *23andMe* as directed to an American audience and rarely participate in discussion forums.
5. When *23andMe* was launched, the high-end DNA saliva test cost \$999 and was out of reach for most. Later, *23andMe* began to advertise the test as a more mainstream lifestyle add-on. Gradually, the price of the test dropped to just \$99 in 2012. Most participants of this study purchased the test the following year. Despite shipping costs to Finland, which doubled the price, people thought that the price was very reasonable.



6. Out of fourteen people initially contacted, four declined the invitation to share their experiences, two of whom explained their non-participation: a young man wrote that he would prefer to answer an online questionnaire, as is typical for *23andMe* research endeavors, rather than taking part in a time-consuming personal encounter; the other respondent thought that he had nothing to share because he did not get much out of the genetic test.
7. I learned of group orders that were coordinated at the work place or online; indeed, this type of initiative had been arranged by two of the women I interviewed.
8. See, for instance, the 'Finland DNA' group project in the FamilyTreeDNA that has over 5000 members, <https://www.familytreedna.com/group-join.aspx?Group=Finland>.
9. See <https://genographic.nationalgeographic.com/>.

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