Autobiologies on YouTube: narratives of direct-to-consumer genetic testing

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Despite a growing personal genomics market, little is known about how people engage with the possibilities offered by direct-to-consumer (DTC) genetic testing. In order to help address this gap, this study deploys narrative analysis of YouTube videos posted by individuals who have purchased DTC genetic testing for disease. Genetic testing is said to be contributing to new states of illness, where individuals may become “patients-in-waiting.” In the videos analyzed, we found a new form of storytelling about this ambiguous state of illness, which we refer to as autobiology. Autobiology – the study of, and story about, one’s own biology – concerns narratives of sense-making through forms of biological practice, as well as wayfaring narratives which interweave genetic markers and family histories of disease. These autobiologies – part of a broader shift toward public stories about genetics and other healthcare technologies – exhibit playfulness, as well as being bound with consumerist practices.

Keywords: direct-to-consumer; genetic testing; narrative analysis; new media

Introduction

During New York Fashion Week 2008, an internet start-up company called 23andMe hosted the world’s first “spit party.” Mother Jones magazine dubbed the glamorous salivaters who attended this event the “spitterati” (Darnovsky 2008). The spitterati were some of the early adopters of a new genetic testing service, offered by 23andMe. 23andMe provides personal genetic information to individuals, for a fee, from a sample of their saliva. While not the first company to offer genetic testing directly to the public, with the launch of this and several other genetic testing companies in the same week, a new phase in direct-to-consumer (DTC) genetic
testing began, with the internet becoming the primary medium through which the tests are advertised, sold, shared and discussed.

These genetic testing services emerge in a post-Human Genome Project environment, where the costs of genetic analysis are plummeting. The services are offered to consumers who are becoming increasingly exposed to, and knowledgeable about, new kinds of genetic technologies (Petersen 2006). Genetic research breakthroughs, cheek swabbing forensic pathologists and celebrities discovering their ancestral roots are littered throughout the North American, European and Australasian media landscapes. Genetic testing is capturing the attention, and imagination, of people who can not only buy genetic tests via the internet, but can also go online to find relatives, share their results with strangers and take part in research. It is no longer only the spitterati, the elite early adopters, being tested and photographed, but hundreds of thousands of individuals are being tested, some of whom are documenting their own stories, and even throwing their own spit parties.

Despite the growing number of users of genetic testing services, it is often stated that little is known about the “publics of genomics” (O’Riordan 2010, 12), their experiences of being tested, and the ways in which they are interpreting results. With some exceptions (McGowan, Fishman, and Lambrix 2010), users have been difficult for researchers to identify and recruit, largely because their details are “owned” by the genetic testing companies, but also, as Goldsmith and colleagues (2012, 815) point out, for privacy reasons. Because of these difficulties, many researchers have studied potential users of DTC genetic tests (Cherkas et al. 2010; Goddard et al. 2009; Kolor et al. 2009). While these studies can be revealing, authors often conclude that more research is needed on “actual users” (Goldsmith et al. 2012, 815, emphasis in original). A series of papers published in 2010 and 2011 about DTC GT users, based on online surveys, has attempted to address this gap (Bloss, Schork, and Topol 2011; MacArthur, Morley, and Jostins 2010; Maher 2011). In order to achieve the analytical power that comes with large sample sizes though, the details and richness of individual accounts are often lost.

We suggest, however, that there is much to be learned from individual accounts of genetic testing, in regard to who is being tested, the experience of undergoing testing, the setting in which testing occurs and the ways in which individuals interpret results. The most visible personal accounts of undertaking DTC genetic testing to date are written by celebrity-scientists, journalists and other public figures (Nisker and Daar 2006; O’Riordan 2011, 120). There is, however, a growing body of non-elite users. These users are documenting their stories across a range of web-based media. Others have examined individual testimonies about DTC genetic testing on blogs and on company websites (Nordgren and Juengst 2009; Su, Howard, and Borry 2011), whereas we focus on YouTube videos.

We examine videos posted by users of DTC genetic testing services in order to understand more about how people are engaging with this technology. Comparing the YouTube narratives to illness narratives traditionally examined by social scientists, we argue that the videos narrate an emerging ambiguous state of illness
tied up with genetic technologies. We refer to these narratives as “autobiologies.” Autobiology – the study of, and story about, one’s own organism – is a term we use to capture narratives told at the molecular level, stories which concern genetic markers, alleles and ribonucleic acids, interweaving family histories of illness into wayfaring (Ingold 2007) narratives. They are also autobiological narratives in the ways in which they document a sense of self-making through forms of biological practice and scientific experimentation, practices which exhibit a form of playfulness, while simultaneously being bound up with consumerist concerns.

Methodology
In February 2012, we queried the YouTube database for English-language videos uploaded by users of genetic testing services in a list of companies compiled by The Genetics and Public Policy Center (2010), including only those which concerned genetic testing for illness and traits. We found 20 videos in total, all uploaded by users of the American company 23andMe, a company which actively engages with web 2.0 platforms as an important aspect of their business profile. In selecting videos, we excluded explicitly promotional videos such as those posted by companies themselves. As we discuss later however, the delineation between promotional and non-promotional videos is not clear.

The 20 videos in our sample broadly fit into three categories or genres: unboxing/spitting videos, logging into results, and retrospective descriptive accounts. In the “unboxing/spitting” videos, individuals film themselves opening the 23andMe spit kit package and filling the tube with saliva. In the “logging into results” videos, users share their results, and their interpretation of them. In the “descriptive” videos, users describe either the process of taking the test, or the experience of reading their results. Because we were interested in the performance of biological practice and the narrative interpretation of results, we focused predominantly on the unboxing/spitting videos and the logging in videos.

Our unit of analysis is the posted video (visuals, speech and other sounds), including surrounding online content, such as other YouTube videos, hyperlinks and comments. We treated the videos as texts. This has theoretical, methodological and ethical implications. For instance, we did not contact the YouTubers about analyzing their videos. We made this decision by considering the size of the online community, the accessibility of the videos and the ethos of the site which is to “Broadcast Yourself.” Thus, we treated the videos as public textual resources, similar to a television program (Berry 2004, 327). There are many ethical and methodological reasons for contacting the YouTubers, especially in order to understand more about their engagement with DTC genetic testing (and indeed this could be another study). However, after careful consideration, we chose not to make personal contact because, for the purposes of this research, we were interested in the texts themselves, and the context of these texts, as video narratives shared with a public audience.
The YouTube material was thus analyzed using thematic narrative analysis. As a
guiding framework, we draw upon the work of Gubrium and Holstein (2009) who
emphasize the context of a story’s production. Gubrium and Holstein (1998, 163)
are interested in the conditions of storytelling, and its effects, considering the story
process within the circumstances in which it unfolds, rather than viewing storytell-
ing as an unmediated account of experience. They emphasize the social organi-
sation and interactional dynamics of narratives. In this vein, we analyzed the
context for these stories, also keeping in mind the ways in which scholars in
science and technology studies have problematized the notion of context, consider-
ing it not as something “out there,” “to be found and explicated” (Asdal and Moser
2012, 300), but rather as a process, imbued with materiality, by which a text, and its
content and subject matter, is made (Asdal and Moser 2012, 301). We consider the
material conditions of storytelling (bedrooms, computer hardware, spit kits, bed-
spreads, posters), texts (speech, computer software, the video image, hyperlinks)
and issues (genetic testing available to the public, ambiguous states of illness),
and the ways in which these are woven together in the story. We look at editing,
both of the story being told and of the video, and performativity, examining how
the storytellers position themselves in relation to the audience and other narratives.
We explore the embodied aspects of storytelling (facial expression, gestures, sali-
vating, typing), intertextual components such as different mediums and platforms
used and referred to, as well as how words, ideas and plots were drawn from
other narratives. We consider these aspects in the context of the emerging market
for DTC genetic testing, drawing upon our broader research in this area (Harris,
Wyatt, and Kelly 2013; Harris, Kelly, and Wyatt 2013; Wyatt et al. 2013).

Illness and pre-illness narratives
Public engagement with medicine has been researched extensively from the view-
point of illness narratives, which arguably contest dominant frameworks of expert-
tise about health and illness (Bury 2001). These stories include those collected and
analyzed by researchers, as well as autopathographies (Couser 1997). A significant
proportion of empirical work on illness narratives draws on frameworks proposed
by Arthur Frank (1995). Frank’s (1995, 75) work has been influential in under-
standing narrative types, which he describes as the general storyline that underlies
the plot and tensions of a particular story; he highlights quest, restitution and chaos
narratives. Michael Bury (2001) considers alternative narrative types such as con-
tingent narratives, moral narratives and core narratives. Gubrium and Holstein
(1995) move beyond Bury’s notion of “biographical disruption,” developed in
his earlier illness narrative work, to develop their own concept of “biographical
work,” which arguably offers a nonlinear understanding of experience, which is
more episodic and embedded in shifting settings, and thus does not consider
illness as part of “core identity” (Felde 2011).
These writers all emphasize the sociality of storytelling, not only regarding the social telling of stories but also the social shaping of the stories, where individuals use and adapt stories that cultures “make available” (Frank 1995, 75). As previously discussed, Gubrium and Holstein (1998, 163) in particular are as much interested in the ways that storytellers and the conditions of storytelling shape the stories, as they are about the content of the stories. While we draw on the illness narrative literature in order to think about the sociality of telling stories about health and illness, the context of storytelling in the case of DTC genetic testing differs from illness narrative in that the storytellers are not patients; they are not unwell. Instead, we found something different in the context of DTC genetic testing narration. While there may be aspects of the narrative genres identified by illness narrative theorists in these YouTube stories, these are quite different storytelling contexts.

In order to better situate these narratives, we turn to a body of literature where concepts such as “partial patients,” “proto-disease” and “patients-in-waiting” have been introduced. “Partial patients” refers to people who do not feel ill, most or all of the time, but who have been informed that because of certain characteristics they may have a disease, or be at risk of getting the disease (Greaves 2000). “Proto-disease” has been described in reference to asymptomatic conditions such as hypertension and hypercholesterolemia (Rosenberg 2009). Timmermans and Buchbinder (2010) use the umbrella term “patients-in-waiting” to capture both of these concepts, as well as individuals on a spectrum of disease, such as autism. In a similar vein, Novas and Rose (2000) have discussed the “genetically at risk.” These are all emerging states between risk factor and manifest illness, a hovering between sickness and health characterized by uncertainty. Timmermans and Buchbinder (2010, 409, 417) argue that “in-waiting” will be a persistent form of liminality in contemporary health care, one that can be seen to have emerged with technologies of medical surveillance (Adams 2013; Armstrong 1995). While their description of patients-in-waiting being on “a rollercoaster ride between alarm and hope” (Timmermans and Buchbinder 2010, 418), at the mercy of health policies and medical gatekeeping, does not apply directly to the YouTubers engaging with genetic testing (for, as will become apparent, they were very casual about their results), the kinds of narratives we discuss in this paper could be broadly categorized into these emerging states of illness liminality.

The convergence of the internet and genetics in DTC genetic testing means that it is pertinent to consider the digital nature of storytelling about these issues. The autobiologies we examine are digital narratives, told, uploaded, shared and discussed through the internet, via webcams (Miller and Sinanan 2013) and other devices. The internet and related technologies allow for new kinds of self-expression, through the use of written and spoken words, images (moving or still), hyperlinks, avatars and other online features.

The study of digital illness narratives is still in its infancy. Researchers who have examined how individuals are engaging with YouTube for health and illness issues
have looked at, for example, obesity (Yoo and Kim 2011), organ donation (Tian 2010) and cancer survivorship (Chou 2011). Rather than examine narratives however, these studies focus on the role of these videos in health promotion and raising public awareness, how they provide information and support and potentially change behavior. Further qualitative research has been conducted on the video narratives posted on the HealthTalkOnline website (Newman, Ziebland, and Barker 2009). These are interviews about particular health conditions, videos made by researchers or videographers. We are interested in individuals’ self-made narratives about the experience of genetic testing. Our work relates more closely to O’Riordan’s (2011, 127) work on biodigital lives, emerging from “a new field of biographical and autobiographical tales from the genome” which is crossing multiple media forms.

We thus build upon and contribute new insights to a body of literature about illness narratives, digital narratives and patients-in-waiting in our study of narratives about DTC genetic testing found on YouTube. In The Wounded Storyteller, Frank (1995, 76) writes that there are more narratives to be found about illness than the three that he identifies and which are most commonly drawn upon by social scientists in illness narrative analysis. We take Frank up on this provocation and consider what other kinds of stories there are to be found in relation to genetic testing. We consider these stories in context, that is, the content of the stories, the way they are being told and the circumstances of the telling, including their performativity. We do not claim to “capture” context but rather provide insights into aspects of this context. In the following section, we examine some of the common features of these videos, before exploring in more detail the autobiographical nature of the stories.

**You and Me: a brief introduction to YouTube narratives from 23andMe users**

YouTube was launched in 2005 as a user-friendly video-sharing site, and bought by Google in 2006 (Shifman 2012, 189). It has been described as enabling a new visual genre of individual expression, with some scholars also referring to a YouTube community (Shifman 2012; Wesch 2008). YouTube is a particularly good place in which to examine stories about genetic testing for a number of reasons. First, it is used by many DTC genetic testing companies, and presumably by a number of their customers as well. Second, it provides access to users’ stories in the public domain, with qualitatively rich details about the process of undergoing testing and interpreting results, results which are their own rather than the hypothetical scenarios used in many of the survey studies mentioned previously. And finally, it is a website, just like the genetic testing websites, where the individual meets the collective, where individual stories/genetic data are shared and discussed and the private is rendered public. Considering a collection of narratives about testing “me,” as in 23andMe, as autobiologies captured in, and on a “you” tube,
thus seems particularly apt. As McGowan and colleagues (2010, 276) point out, it is important to consider how users of DTC genetic testing not only use the internet as a tool to purchase the product but also to comment on it.

The YouTube videos we analyzed shared a range of features, some shared with YouTube videos more broadly such as amateur videography and focus on an “ordinary person” (Shifman 2012). Irrespective of whether the videos were filmed with a stationary webcam or by someone with a handheld camera, they mostly focus on one person, except for one video of a spit party in which multiple users are visible. This collection of videos is posted by 17 predominantly young North Americans. We meet PandyFackleresque, or Pandy for short. Pandy has a new Mohawk, multiple piercings, tattoos and posts one “spitting” video and one “logging in” video. Another YouTuber who has posted two videos is Jen McCabe, a health 2.0 activist championing the 23andMe Research Revolution. There is also Zyloga, a psychology major who provides a more cynical critique of the company’s activities; and Eric, who was somewhat surprised when he received his spit kit in the mail as a gift from friends. While we can describe some characteristics of the storytellers of the autobiologies we examine, we know less about the audience for these videos, other than what can be gleaned by reading the comments. We do know that the audiences for some videos were relatively large. At the time of analysis, Zyloga’s video had been visited 45,000 times, and Zyloga herself is a kind of “micro-celebrity” (Marwick and boyd 2011, 121), whereas other videos only had a little over a hundred views.

The videos are set in bedrooms, home studies, workplaces, a dining room, a university common room and a sun deck, all places becoming in some ways at-home biological “laboratories.” In the bedrooms, it is possible to see messy, unmade beds, posters on the walls and wine bottles. A cat climbs the stairs in the background of one video and runs back down. Other backgrounds are littered with computer hardware.

All videos are edited on a number of levels. The footage itself is edited, mostly concerning the “spitting” moments either being deleted or “sped up.” The videos are also edited regarding which aspects of the genetic results the individuals choose to share, attempts at maintaining privacy by covering up names or birth dates and other editing of storylines. Some videos are enhanced with soundtracks and hyperlinks (to 23andMe, blogs, Wikipedia pages and Twitter accounts). As well as linking across internet platforms, the videos are interlaced with technological hardware such as other computers and printers. The computers may be visible in the background, a computer screen the focus of the video, or the camera capturing the view from the computer, the presence of the screen just a blue glow on someone’s face. Other technologies make an appearance such as iPhones and iPods – Zyloga has uploaded her genetic results onto her iPod so that she can carry it around with her, while Florian times his spitting on his iPhone (it takes eight minutes) taking a call mid-way through the video, “hey Tracey, what’s up? [pause] I am spitting into a cup.” The YouTubers are constantly moving between
a range of other texts: the 23andMe website text (read out, scrolled through, hyper-
links clicked) and the leaflet that arrives with the spit kit explaining how to collect
the saliva sample. Our focus on materiality extended to the objects commonly
found in many of the videos, such as 23andMe boxes and the spittoon, objects
which featured most prominently in the unboxing/spitting videos; this is explored
in more detail in the following section.

“This is pretty disgusting but I would like to share it with you”: sense-
making through biological practices

Jen sits at her office desk in a bright pink t-shirt, city lights sparkling beyond a large
window behind her, also reflecting someone holding a video camera. She is being
filmed excitedly rubbing her cheeks and spitting into a tube. In his home study, Eric
opens a FedEx box. He continues to glance simultaneously at a YouTube music
video on his computer screen (a YouTube within a YouTube), “The Final Count-
down” building cinematic climax as he reaches to find the spit kit (a tube within
a box). Nick is also opening a box, laying out its contents on a table in neat parallel
and perpendicular lines, then registering his details on a computer framed by a hap-
hazard assemblage of Post-It notes. In a busy common room, a group of university
students are having a spit contest to see who can fill the “crazy looking tubes” the
fastest. Florian describes what everyone is doing:

I received this [spittoon] from 23andMe. This is the thing you have to spit in. You are
not allowed to smoke, chew gum or eat 30 minutes before putting your saliva in this
thing. This thing here [spittoon lid] is filled with liquid, so don’t close that, as soon as
you close it the liquid goes in the tube [Reads out from instructions, gets comfortable
on the chair] Relax, and rub your cheeks gently for 30 seconds to create saliva. [Rubs
his cheeks with his hands. Leans forward to spit, video skips to him showing the tube
half full] … OK next step, spit, until the amount of saliva, not bubbles … close the
lid, snap, unscrew the tube from the roof … pretty full huh, so don’t fill too much
above the line. Pick up the small cap, and screw it on. Close tightly huh. Now shake
for five seconds. Discard or recycle the blue funnel. We will discard. Put the sample
tube in a plastic bag … There you go, it is closed, now this bag you put in this envel-
lope which comes in your package, the rest you need is this [holds up form], and three
copies of this [holds up another form], you put in this see-through thing and send.

Florian and many of the other YouTubers are filming themselves doing the work of
DTC genetic testing. For many, this is “disgusting.” “Oh that’s gross, I don’t like
spit,” Pandy exclaims, then later, laughing, “this is probably the grossest video I
have ever made.” Some, like Florian, feel uncomfortable spitting on camera,
others continually showing the spittoon as it “fills up.” Many of them go about
the process of testing diligently. They read the written instructions and rub their
cheeks. Seen as a collection of videos the cheek rubbing and massaging almost
become a form of ritualistic behavior (Pace 2008), as does “unboxing” the
package, all of these practices integrated into the testing experience.
YouTubers often take great care in filling up the tubes appropriately, sealing bags properly, finding barcodes and registering online. And like any “good” patient about to have a clinical test, most make sure not to eat or drink half an hour before spitting. They post the package, despite grumbles about FedEx; as Zyloga says, “I’m mailing my spit to California.”

There is a script to these activities, in the sense of what is inscribed in the technology (Akrich 1992), and also in regard to the spoken narrative about testing, in the form of a set of written instructions read out loud, sometimes twice, and constantly referred to. Like all scripts however, these instructions are not followed “to the letter,” although these variations take place in a different way to what McGowan and colleagues (2010) describe as a reinterpretation and co-construction of the technology. Instead, more mundane off-script events occur, such as spilling the mixing solution in distracted moments, eating M&Ms before the test (turning one university student’s saliva green), collecting spit in New York (but posting it from Massachusetts) and not always rubbing cheeks for 30 seconds.

These kinds of scripted and non-scripted practices involved in creating a saliva sample for genetic analysis can be described as performing forms of biological practice, practices that are pseudo-clinical, in how the individual performs patient-like tasks, and also scientific, in their involvement in sample collection. The videos document and provide tutorials about how to undertake these practices, offering “handy hints” on ways to fill the tube, in the same way a YouTube tutorial on knitting may recommend stitch techniques. The videos give context to the setting of these practices in a number of ways. They concern the bodily nature of taking part in DTC genetic testing; the saliva created and users’ embodied engagement with their computers for example. The context of these narratives also concern the materiality of practices in regard to objects – boxes, tubes, the other vibrant matter (Bennett 2010) of DTC genetic testing – and places in which these practices occur.

“Oh boy” Jen exclaims, “you can see the solution mixing with the spit, very cool – it is like those oil and colored water experiments in elementary and middle school science, very cool.” There is an air of experimentation being performed here, the personal experience of undergoing genetic testing turned into a shared video experiment, the testing itself also experimental not only in relation to the symbolic association with test tubes, but also in regard to playing with a new technology. Videos have a backyard biopunk (Wohlsen 2011) feel, the YouTubers referring to themselves as “nerds” and “geeks,” amateur scientists reveling in the experimental nature of taking part in testing. Florian has posters of scientists such as Richard Feynman and Albert Einstein pinned up on his walls which he points out to the viewer. The biohazard bag for the spittoon becomes part of the experiment – “I love this biohazard icon – oh man – To think that my spit is a biohazard!” Another says “my favourite part about this sample bag is right there – biohazard – because my saliva is so dangerous – it makes me feel pretty cool, like I am in a post-apocalyptic world.” This YouTuber also comments bemusedly that he is
surprised at how small the packaging of the spit kit was, and states that he was half expecting a small laboratory to be delivered in the mail.

“This is a home movie for the grandchildren to watch”: wayfaring genetic narratives

Several months after uploading her unboxing/spitting video, Pandy uploaded a 10-minute video in which she shares her results. These two genetic testing videos are part of a collection of over 200 videos which she has uploaded about a range of topics, many of them science-related. At the time of analysis, the video in which Pandy shares her genetic testing results had been viewed over 4500 times. The video begins with Pandy on her sun deck, logging into her account one week after she has received them. She gives a commentary of her results:

The other things I have are chronic ahh lymphocytic leukaemia – not cool – high blood pressure, hypertension. That runs in my family so I kinda saw that one coming. However when I click on it to see exactly what they are talking about … [clicks on a hyperlink, reads out some web text, moves camera to the screen]. They even tell you where they found this on your genotype – I have to keep covering up my name here. These are the genes that they are talking about – GT, they found it on that specific one [camera reflected on screen, points to screen with her finger] … You can even go to which exact allele they are on … [increased glare on the screen] And of course it just got really sunny out. My decreased risks are type 2 diabetes, which is surprising since my maternal grandmother has that. But my risk is a 13.3%, the average risk is 18.2% so while it is a decreased risk, it is still not something that I don’t need to look out for, especially since it runs in the family. I also have a decreased risk of heart attack, psoriasis, melanoma, which is surprising because my father has melanoma. All kinds of stuff. They also list typical risks – so my risk for obesity is a 59.9% and the average risk is a flat 59%. I don’t think I am going to be obese any time soon … Carrier status … These are things I can actually print out for my children and be like, don’t be an asshole, you might actually have this …

In this edited section of Pandy’s autobiographical video, she weaves knowledge from the genetic testing into her own story about health and illness. Pandy often interprets her genetic test findings in light of her own family history: hypertension runs in the family, so she “sees that one coming”; she is surprised about her decreased risk of diabetes since her maternal grandmother has that; and the decreased risk of melanoma since her father has that. She follows hyperlinks to find out the alleles and markers which make up her results. She weaves in and out of describing these findings as susceptibilities and diagnoses, weaves between her grandmother’s health conditions and her potential future children’s traits, between refuting the findings and agreeing with them.

Pandy’s narrative style was not unusual in our collection of videos, in the ways she threads in and out of diagnosis/susceptibility, family history and genetic markers. In her video titled “Exploring the ‘Me-ome’,” Jen McCabe records
herself looking at her 23andMe results for the first time, two days after receiving notification that they were available. She also oscillates between describing her results as probabilities and certainties, between accepting and refuting the findings. Ataralas, who bought the test because she wanted to see if she “had the genes for celiac disease, as well as whatever else I had because, hey, it was on sale and I was curious,” thought her “heart stuff would have been higher,” since she had looked up the death certificates of relatives on her mother’s side and almost everyone had had heart attacks. In her narrative, she also talks about the things she could pass onto her (as yet non-existent) children and the diseases she knows she does and does not have.

These YouTube narratives reveal what anthropologist Ingold (2007) refers to as “wayfaring,” the term he uses to describe a line that wanders about. In his book Lines, he considers many kinds of lines including the genealogical line, which he theorizes quite differently from his anthropological predecessors, as a connection amongst and between generations, which rather than occurring in a sequence, is a line where ancestors weave and lean over each other, touching at different points. Generations become entangled through a series of interlaced trails, where grandchildren learn stories from and about grandparents that they carry forward in life and so forth, the result being a braid of lines that continually extends as lives proceed. Ingold compares his wayfaring line to the traditional genealogical model adopted in anthropology, whereby attributes such as make-up, character and identity are bestowed via genetic and cultural means, as a form of transmission down which pass, from point to point, person to person, the information for how to live life. This more traditional genealogical line is similar to the linear lines that Finkler (2005, 1065) discusses in her work on genetics and kin work, for Finkler argues that genetics reinforces the linearity of genealogy and kinship, joining individuals together and disallowing memory lapses and the forgetting of the past.

The YouTube videos on the other hand are filled with lapses and skips, with wayfaring lines of biological inheritance. The YouTubers weave between possible futures, the present and the past, and the results about disease outcomes are read simultaneously as probabilities, certainties, susceptibilities and nothing of much importance. The YouTube narratives reflect, to quote Ingold (2007), the “narrative interweaving of present and past lives [where] retracing the lines of past lives is the way we proceed along our own.” This is a trans-generational flow in which people and knowledge undergo perpetual formation, made evident in autobiologies through the way in which most people make sense of their world; by telling stories. Autobiologies about DTC genetic testing are, to follow Ingold, a narrative interweaving of past and future states of actual and potential illness, where biologies of the past and imagined future biologies touch, and intermingle with biological practices in the present. Telling such stories involves threading in materials, technologies, information, people and gestures, to name a few.

Thrift (2011, 7) argues that the world in which Ingold’s wandering wayfaring line exists is being rebuilt out of a field of numbers and calculable coordinates.
We also found numbers threaded into the wayfaring line, where biological numbers in the form of genetic markers and alleles (Navon 2011), as well as comparative percentages and hyperlinks, became part of the autobiology, along with other multifactorial risk factors which are far from genetically deterministic (Hacking 2006, 91; McGowan, Fishman, and Lambrix 2010, 284). The YouTubers work both on and off “script” – their genetic results are created within a 23andMe risk assessment framework (Saukko et al. 2012), yet they contribute their own interpretations following wayfaring lines, accepting and refuting findings according to their own understandings of illness, often using the results to explain what they already know.

Our findings resonate with those other anthropological and sociological studies of how individuals knit genetics into their own pre-existing stories of relatedness and perceptions of risk. Lock and colleagues (2006) have argued that genetic knowledge rarely usurps other forms of understanding, but rather is woven into previously held ideas, discussing notions of blended inheritance, where diseases “run” in the family. Cox and colleagues (1999, 628) found that the relevance of genetic risk to individuals is fluid and contingent, with information given higher relevance at certain critical junctures and at other times being much less important. These frameworks of understanding are consistent also with Gubrium and Holstein’s (1995) notion of “biographical work,” and how individuals bring medical regimes into their own lives (Felde 2011). The wayfaring line contributes to this literature by describing how individuals weave intergenerationally, where the threads are braided, allowing room for spaces and other fragments of information to be integrated into one’s autobiology and understandings of potential and existing illness, whether these may be genetic markers, percentages, websites or environmental effects.

Stories of playful experimentation and consumption

In the previous sections, we documented autobiologies in the form of storytelling about biological practices and narratives which weave biological understandings of illness into family histories and other understandings of disease. As we have stated, these are very different stories from illness narratives. The YouTubers exhibited a sense of indifference toward the results of their genetic testing, an indifference that was possible because they were not patients. Often in their interpretation of results, they might list the names of diseases, displaying no attachment to them, often not being able to pronounce them or know what they are. The engagements with disease and disease risk seem fleeting and “playful,” the moral responsibility that Frank (1995, 137) describes in the stories of illness seemingly absent and the kinds of biosocial virtual communities of “at risk” individuals that Novas and Rose (2000, 508) describe and predict, also missing. These YouTubers also get easily distracted, by data visualizations, hyperlinks and the multiple tabs they have open. In using the term “playful” here, we draw on the work of Horlick-Jones, Walls, and Kitzinger (2007) who describes the playful way in
which individuals respond to the interpretive possibilities regarding issues of genetic modification. The videos we studied exhibited different kinds of playfulness, from the laboratory experimentation with spit and biohazard bags to the way-faring stories which are told when interpreting results, which show a playfulness in the ways in which individuals project forward to imagined futures.

Horlick-Jones, Walls, and Kitzinger (2007, 84–85) incorporate this sense of playfulness, as part of a bricolage of sense-making – a term they take from Irwin (who takes it from Levi-Strauss) – whereby people use, inventively and playfully, whatever comes to hand. This bricolage is evident in a number of ways in the videos we studied. Videos posted about genetic testing are often one or two of many posted by a single individual. Video collections may concern unboxing other products (a plasma television, a router, a speaker stand), political rallies, music concerts, restaurant reviews or wigs. Self-expression involves not only undergoing genetic testing and consuming/interpreting/critiquing/playing with the results, but also other choices made about the body (hairstyles, tattoos), carefully placed objects in rooms (webcams, posters on bedroom walls) as well as a vast repertoire of other aspects of self-making that define each YouTuber as both an individual and as part of a broad set of social groups, telling a story to an “imagined audience” (Marwick and Boyd 2011). The videos can be read as just another online extension of the genetic testing experience, stories to be shared in a participatory environment (John 2013), and to encourage further participation – “I wanted to try it and spark the conversation” Melissa says, “OK, converse.”

What are the broader conditions of this playful experimentation? The YouTubers are telling stories for themselves and sharing them with their imagined audiences. But they are also doing work for the company, on a number of levels. First their video becomes a form of promotion of the company, a free form of advertising in the same way wearing a branded t-shirt advertises a label. The genetic testers are consumers of a product, their narratives also those of consumption. Zyloga received her spit kit as a “Materialism Day gift” from her parents, as she says, “one of the coolest gifts I have ever gotten, way cooler than the bike I was going to ask for instead.” YouTube has been described as offering a new space for consumers to engage creatively with products and brands and other aspects of consumerism (Pace 2008, 217). The unboxing videos are most obvious in this aspect, as they document a YouTube practice whereby individuals film themselves opening a box containing a piece of technology, in order to share this experience with others online (Walker 2009) as well as – semi-didactically – sharing information. The unboxing video genre emerged around the same time as 23andMe (Wikipedia 2012). The way in which many of the YouTubers discuss product placement of other products in their narratives suggests that they do not consider their videos about 23andMe as explicit advertisements for the company.

It would be naïve, however, to ignore the consumerist nature of these practices, and the ways in which participatory engagement online, especially concerning genetic testing, is tied into larger economic concerns (Harris, Wyatt, and Kelly...
First, the work of spitting and submitting a saliva sample serves an economic purpose, which is to help to create a valuable database of biological samples for the genetic testing company. Individuals’ clinical labor, and the access they give the company to their in vitro biology, becomes a biological resource which produces economic value (Mitchell and Waldby 2010, 339). There is extensive interplay between genetic testing practices and the production of genomic goods, just as there is interplay between online participation more broadly and the creation of economic value (Goldberg 2011; O’Riordan 2010; Proulx et al. 2011). Posting videos online becomes another form of free labor, disguised by altruistic notions such as “sharing” (John 2013). Others have also observed and commented on the commodification of illness narratives, including those shared via social media, and the biographical value of these accounts (Mazanderani, Locock, and Powell 2013). The material practices we examine in this paper, documented in the form of autobiology, are thus not only about sense-making and wayfaring, but also about branding and economics.

Conclusion

Public engagement with genetic testing is broadening beyond the elite early adopters. In this paper, we turned to individual accounts of DTC genetic testing by non-elite users, to understand more about those engaging in genetic testing, the settings in which this is occurring, the practices of testing and the ways in which people are interpreting their results. In doing so, we found narratives on YouTube which we described as autobiologies. Autobiologies differ from illness narratives in that they are not stories about states of sickness and suffering, but are rather narratives of playfulness, possible to those “in-waiting” who can afford a more casual engagement with the technologies. It may be that the media by which these stories are told, YouTube video, invites a more casual performance, an indifference toward illness that may differ from other forms of storytelling, highlighting the importance of context in analysis of these narratives.

YouTube is also a platform for stories of consumption, the narratives of DTC genetic testing we have argued, being tied into consumerism and larger economic concerns. YouTube is a rich although to date largely understudied resource for understanding more about emerging states of illness, such as “patients-in-waiting,” and how the public is engaging with, science, genetics, biology and bodies. Autobiologies are narratives which form part of a broader shift toward public stories about genetics and other healthcare technologies and experiences, which concern people’s exploration and sharing of their own biology (Abadie 2010; Duncan 2009; Frank 2011).

Our narrative analysis of videos about DTC genetic testing builds upon and contributes novel insights into the literature about illness narratives, digital narratives and patients-in-waiting. We have highlighted the advantage of using the term “autobiology” to consider these narratives about emerging states of illness.
ambiguity. Autobiologies draw from and contribute to the world of DTC genetic testing – they become part of the online texts about genetic testing, and the companies themselves are increasingly playing with this format with video competitions and other YouTube-related activities, no doubt aware of the conversations their customers are having on this platform. As Ingold (2007, 116) writes, “making their ways through the tangle of the world, wayfarers grow into its fabric and contribute through their movements to its ever-evolving weave.” The YouTube videos we studied originate from moments of biological experimentation and consumerism in bedrooms and offices, but as the wayfaring stories which emerge from the interpretation of results show, the stories stretch back into past lives and reach out into imagined biological futures.

**YouTube material**

23andMe sample collection from Eric: [http://www.youtube.com/watch?v=TSRlr606kw4&feature=related](http://www.youtube.com/watch?v=TSRlr606kw4&feature=related)

23andMe.com Results of Florian Hotz: [http://www.youtube.com/watch?v=2G3l6b31vbU&feature=related](http://www.youtube.com/watch?v=2G3l6b31vbU&feature=related)

23andMe.com saliva sample instructions: [http://www.youtube.com/watch?v=LRoCvzYn9eM&feature=related](http://www.youtube.com/watch?v=LRoCvzYn9eM&feature=related)

23andMe DNA Saliva Test Kit: [http://www.youtube.com/watch?v=x3dI4O9BEPg](http://www.youtube.com/watch?v=x3dI4O9BEPg)

23andMe: [http://www.youtube.com/watch?v=8VymmmZNgzY&feature=related](http://www.youtube.com/watch?v=8VymmmZNgzY&feature=related)

Mailing my spit to California – 23andMe: [http://www.youtube.com/watch?v=juaRpGv3Bgk&feature=related](http://www.youtube.com/watch?v=juaRpGv3Bgk&feature=related)

23andMe Genetic Testing: My Experience: [http://www.youtube.com/watch?v=OV6eWmaXsgU&feature=related](http://www.youtube.com/watch?v=OV6eWmaXsgU&feature=related)

23andMe Research Revolution 2009 BEGINS! FIRST Patient-Driven Genomic Research Campaign!: [http://www.youtube.com/watch?v=D8vBy2Ua81k&feature=related](http://www.youtube.com/watch?v=D8vBy2Ua81k&feature=related)

@23andMe Unboxing and Testing – Part 1: [http://www.youtube.com/watch?v=9zoO3eBAoiY&feature=related](http://www.youtube.com/watch?v=9zoO3eBAoiY&feature=related)

In Which I Spit in a Test Tube: [http://www.youtube.com/watch?v=IbtvbywYMSoQ&feature=related](http://www.youtube.com/watch?v=IbtvbywYMSoQ&feature=related)

23andMe Results: [http://www.youtube.com/watch?v=4ttuwFDTKCo&feature=related](http://www.youtube.com/watch?v=4ttuwFDTKCo&feature=related)

@23andMe Unboxing and Testing – Part 3: [http://www.youtube.com/watch?v=Jckjzo1g010&feature=related](http://www.youtube.com/watch?v=Jckjzo1g010&feature=related)

23andMe Unboxing: [http://www.youtube.com/watch?v=t9B7drES5mw&feature=related](http://www.youtube.com/watch?v=t9B7drES5mw&feature=related)

Singularity University 23andMe Spit Party: [http://www.youtube.com/watch?v=EbcUEW0saOk&feature=related](http://www.youtube.com/watch?v=EbcUEW0saOk&feature=related)

23andMe Genetic Testing: a one-year follow-up: [http://www.youtube.com/watch?v=sT9fOLaQKl8&feature=related](http://www.youtube.com/watch?v=sT9fOLaQKl8&feature=related)
23andMe intro: http://www.youtube.com/watch?v=D_Esze1-4D4&feature=related
23andMe Package and Sample Tutorial: http://www.youtube.com/watch?v=psficiQijw
23andMe Health: http://www.youtube.com/watch?v=wef3HP17LiI&feature=channel&list=UL
23andMe Unboxing: http://www.youtube.com/watch?v=DBSm7FW1RaI
@jensmccabe – Exploring the “me-ome” 23a: http://www.youtube.com/watch?v=IIOVsNgZWWc&feature=player

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Notes

1. Since this article was written, 23andMe received a letter from the US Food and Drug Administration (FDA) requesting the company to stop selling and marketing health-related genetic tests until they received appropriate FDA approval. In December 2013, 23andMe announced that they would comply with the FDA’s directive and stop selling tests to new customers while they underwent the review process: http://blog.23andme.com/news/23andme-provides-an-update-regarding-fdas-review/
2. This figure is based on the customer base of one DTC genetic testing company, 23andMe, being over 150,000 alone, in April 2012: https://www.23andme.com/about/press/finding_your_roots/
3. See the Singularity University 23andMe Spit Party YouTube video: http://www.youtube.com/watch?v=EbcUEW0saOk&feature=related
4. There are also several academic autoethnographies in the literature as well (Corpas 2012; Pálsson 2012; Richards 2010).
5. Two of these videos also contained small sections of “spitting” footage.
6. This project was granted Ethics Approval from The University of Exeter, UK.
7. While we read the comments in order to put the videos in better context, a detailed systematic analysis of these comments was beyond the scope of our study.
8. The experimental nature of DTC genetic testing is also evident in the Nature survey (Maher 2011, 5), where 13.6% respondents reported to have engaged in forms of self-experimentation such as growing their own cells.
9. While we are critical of DTC genetic testing companies’ economic motives, we are also reflexive of our own research practices in using YouTube material.
10. Thanks to an anonymous reviewer for making this point.

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