Controversy goes online: Schizophrenia genetics on *Wikipedia*

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Abstract

Scientific controversy is increasingly played out via the internet, a technology that is simultaneously content, medium and research infrastructure. Here we analyse material from *Wikipedia*, focusing on schizophrenia genetics. We find that citation and curation of scientific resources follow a negotiated, ad hoc adherence to *Wikipedia* rules, are based on limited access to scientific literature, and thus lead to a partially constructed 'review' of the science that excludes non-professionals. Given its policies and systems for developing neutral, evidence-based articles, one would not expect to find controversy on *Wikipedia*, yet we find traces. Scientific ambiguity about schizophrenia genetics lends itself to multiple ways of curating resources, and the infrastructure of online spaces enables the practices behind curation work to become visible in new ways. We argue that not only does *Wikipedia* make scientific controversy visible to a wider range of people, it is also involved in the production of knowledge.

Keywords: controversy; research infrastructure; *Wikipedia*

Introduction

Controversies have long been of interest to social scientists engaged with the social, cultural, moral and political aspects of medicine, science and technology. Controversies are considered interesting because they offer insight into the processes by which facts become stable, before science becomes 'normal' (Latour, 1987). Decades of scholarship, particularly in science and technology studies (STS), have empirically shown that a vast array of actors are involved in controversies. Sometimes these are between scientific peers (Collins, 1975, 2004; Shapin & Schaffer, 1985; MacKenzie, 1990) but controversies can also involve others, such as patients and

their advocates (Epstein, 2008), sheep farmers (Wynne, 1992), and bee keepers (Suryanarayanan & Kleinman, 2013). In these (and other) accounts, actors draw on various forms of experience and expertise to position themselves within their particular area of contestation, shaping how the controversies unfold and what becomes established as fact.

Technological infrastructures of communication also play a role in how controversies take shape.[1] Historical examples can be found in the information infrastructure of postal systems in the 17th and 18th centuries, enabling the exchange of public and private correspondence between scientific 'men of letters' (Bowker et al., 2010: 104) or the mass circulation of peer-reviewed journals in the mid-19th century (Lightman, 2011). As the distribution patterns of scientific knowledge exchange widened with the development of these communication technologies, alongside developments in transportation, communication within the scientific community became, as Bowker and colleagues (2010: 104) write, 'no longer two-way, but n-way', implying a multiplicity of possible directions, a move that would be strengthened by open access to scientific publications.

We start from the assumption that new technologies of communication support forms of knowledge exchange while also creating new sites for scientific controversy. In particular, we examine how the internet provides an infrastructure for the representation and production of scientific knowledge (Bowker et al., 2010; Niederer & van Dijck, 2010; Wouters et al., 2013). The 'internet' is far from monolithic, comprising a multitude of pages, links, media and platforms, each with their own meanings, practices and possibilities. We focus on a specific scientific topic, schizophrenia genetics, and how it is discussed on a particular platform, namely *Wikipedia*. As we discuss later, schizophrenia genetics research itself is a particularly controversial area of medical science that has already captured the attention of STS scholars (Hedgecoe, 2001; Rabeharisoa & Bourret, 2009; Arribas-Allyon & Bartlett, 2010). Recent directions in schizophrenia research call for 'polyevidence' studies or mega-analyses (e.g. Schizophrenia Psychiatric Genome-Wide Association Study [GWAS] Consortium, 2011), which draw together singular studies and meta-analyses, pulling into alignment evidence from research conducted using similar or different methodologies, some including cross-species databases.

While social scientists have examined various contexts in which scientific knowledge is played out, few have focused specifically on the ways in which scientific knowledge is represented and produced online. There has been a recent focus in STS on the role of the internet in database management and knowledge production (Bowker, 2000; Hine, 2006; Leonelli, 2012). Such work examines data-based exchanges between scientists and others involved in scientific work. We complement this by looking at exchanges occurring outside the 'core-set' (Collins & Evans, 2002) of schizophrenia genetic science, namely by examining *Wikipedia*, a public internet platform accessed and constructed by users with a wide range of both professional and experiential expertise. As a prominent, almost paradigm exemplar of user-generated content, *Wikipedia* offers useful insights into the ways in which web material is constructed from scientific resources by a range of actors with diverse sets of expertise.

Spaces of contestation, controversy and debate regarding psychiatric illness have largely been restricted to physical locations such as clinical meeting rooms (Spandler, 2009), classification manuals (George et al., 2011; Kawa & Giordano, 2012), and in the field of schizophrenia genetics more specifically, the clinic, the clinic-laboratory interface (Rabeharisoa & Bourret, 2009) and journal publications (Arribas-Allyon & Bartlett, 2010; Hedgecoe, 2001). Researchers have queried whether the internet will allow room for new forms of 'psychiatric contention' to develop (Spandler, 2009: 678), and we address this by looking at what happens when knowledge about schizophrenia genetics is produced for *Wikipedia*.

We focus on how the technical architecture of *Wikipedia* shapes the utilisation of knowledge resources, rather than on the content of the research studies. In this way our work is distinguished from that of other researchers who, in the context of psychiatric genetics, have examined how scientific resources are taken up in the clinic (Rabeharisoa & Bourret, 2009), or cited in review

articles (Hedgecoe, 2006). We focus on the schizophrenia entry in *Wikipedia*.

We suggest that *Wikipedia* exhibits a particular kind of 'curatorial work', a term we use to describe the management of information. The word 'curator' is derived from the Latin word that means 'to take care of', and is applied to guardianship roles as varied as priests, spiritual leaders and royal functionaries (Cash Cash, 2001: 139; quoted in Kreps, 2003: 315). In the late 19th century, the position of curator was established in museums, as they expanded their collections and professionalised their operations. At that time, curators were considered 'keepers of collections' and the term curator continues to be most associated with museum work, although it is increasingly being applied in many other contexts. Over time the work of a curator in a museum broadened beyond caring for, managing and preserving collections, to researching, interpreting and presenting collections to a range of different audiences (Kreps, 2003). One prominent role for museum curators has been the selection of works from their collections for exhibition (Harris, 2010). But, as Harris (2010) points out, the public are increasingly taking on curatorial tasks in a 'participatory' move in museums, as visitors become involved in the selection of works for display, questioning traditional roles of curatorial authority and expertise.

Leonelli (2012) also uses the notion of curation in her analysis of cross-species databases. She identifies four technical problems arising from the epistemic differences between those contributing to the databases, including '(1) what counts as reliable evidence, (2) the selection of meta-data, (3) the standardization and description of research materials, and (4) the choice of nomenclature for classifying data' (Leonelli, 2012: 216–217). The first of these is most relevant for us, and we also use the notion of curation, derived from museum studies, to discuss how resources are selected and rendered credible, by a broadening set of actors. In *Wikipedia*, we observe conflicts about authority, and particularly about what counts as reliable evidence.

In the next section we locate our approach within STS studies of the internet and healthcare, and explain how we selected and analysed the empirical material on which this article is based. We then provide an explanation of the complex and controversial area of schizophrenia genetics in order to help the reader to understand the subsequent analysis of the material we found on *Wikipedia*. In the final section, we reflect on what our analysis means for future studies of controversy and a research infrastructure such as the internet. Central to our analysis is the recognition that platforms, infrastructures and infrastructural relations (Star & Ruhleder, 1996) are not neutral, and that they sometimes serve to reinforce established social positions, even if not always intending to do so. Unlike Star and Ruhleder (1996), however, we suggest that the social and technical relationships underlying *Wikipedia* are not always invisible, and that its workings are visible not only to STS researchers but also to those who engage with *Wikipedia* in whatever capacity.

Science, medicine and the internet

Since its inception in the early 1970s (the exact date is itself subject to dispute), the internet has been embedded in many kinds of scientific endeavour. It continues to play an important role in scientific research practice, including the ways in which research groups collaborate, the sharing and analysis of large quantities of data, the dissemination of findings, and the social division of research labour (Thomas & Wyatt, 1999; Abbate, 2000; Agar, 2006; Hine, 2006; Leonelli, 2012). The internet has affected the nature of scientific questions asked, the interdisciplinary nature of scientific teams, the data sets used and shared, the relationship between those who create and generate data and those who use them, the types of expertise relevant to knowledge production, and the distance between researchers and participants. The internet also changes the temporal dimensions of research, with pressure upon scientists to conduct and publish quickly, for media to report findings speedily and for industry to respond to emerging markets (Nowotny et al., 2001; Pels, 2003).

The role of the internet in healthcare practice is also becoming increasingly visible (Adams, 2010; Wyatt et al., 2008). So-called 'web-2.0' platforms such as blogs, fora and social networking sites

are transforming relationships between healthcare professionals, patients, consumers, funding agencies, healthcare systems and industry (Dedding et al., 2011). Notions of 'the clinic' have expanded so that therapy sessions by psychologists, social workers, psychiatrists and genetic counsellors now more frequently occur via the internet (Christensen & Hickie, 2010; Harris et al., 2013; Meropol et al., 2011; Mort et al., 2003; Oudshoorn, 2012) using technologies such as webcams (Pols, 2011). Patient and user group internet fora demonstrate that the internet can be a space to share experiences and resources, discuss research developments and act as a platform for (mediated) exchange between users, for example through Listservs or bulletin boards (Kaplan et al., 2011; Prainsack, 2013). Patient-experience websites such as *HealthTalkOnline* and *PatientsLikeMe* (Tempini, 2015) demonstrate other ways in which patients, carers and others, can engage with each other, and potentially conduct their own research (Allison, 2009). The internet has a role to play in many (mental) health-related practices from making local support groups more visible, to providing contact details for hospitals and clinics and other informational sites. Ensuring quality of health information online has long been a concern (Adams & Bal, 2009), and this issue also emerges in relation to the health pages of *Wikipedia*.

All of these various forms of internet-mediated healthcare raise issues concerning privacy, expertise, rapport, access, exclusion and anxiety. Often celebrated as a tool of empowerment (Jenkins, 2006; Surowiecki, 2004; Tapscott & Williams, 2006), particularly in the scientific and medical fields, others have shown that engagement with web technologies is more complex, involving the replication of dominant hierarchies, differences in access and new kinds of 'free labour' (Goldberg, 2011; Proulx et al., 2011; Terranova, 2000). Our analysis builds upon these critical studies of the internet, which recognise the contradictory aspects of web engagement, where internet infrastructure both enables and constrains engagement with scientific research. The example of schizophrenia genetics provides insight into the role that *Wikipedia* plays in the production of knowledge about a particular medical condition, that is itself controversial, both in its definition and in the understanding of its causes.

Methodology

Our analysis focuses on how research into the genetic basis for schizophrenia is presented and contested in *Wikipedia*. We began collecting *Wikipedia* data in October 2011 by collating all material related to schizophrenia genetics.

Figure 1: 'Causes of Schizophrenia' Talk pages, accessed 10 October 2011

Relevant material was sourced from the English-language 'Schizophrenia' article and from its 'daughter' article, 'Causes of schizophrenia' (see Figure 1). All material on these pages was read systematically for relevance to schizophrenia genetics. We looked not only at text and images in the articles but also at the 'talk pages' for these topics, which are archived conversations between editors accessed via the background tab on most *Wikipedia* articles.

In the 'talk pages' users are encouraged to articulate the reasons for their edits, and bot edits (automated edits made by software) are also made visible. The talk pages are sites for exchange of controversial views as editors justify their actions, and participants negotiate whose expertise is trusted and which resources are to be used. The talk pages thus offer rich material for social scientists wanting to study how the representation of controversial scientific knowledge is discussed, debated and revised by internet users. Given the multiple purposes of these talk pages however, much of the material was irrelevant to our study, such as discussions about duplicated references and tagging, or other biological causes of schizophrenia. In order to identify relevant sections, the complete material was screened a second time to find entries related to genetics. The *Wikipedia* material we collected dated from August 2006 to October 2011, and included 20,000 words of talk text and 13,000 words of article text.[2] This material is available for consultation with the authors.

Our methodological approach to the internet aligns with those who consider the infrastructural details of internet technology as important and worthy of analysis (Beaulieu & Simakova, 2006; Bowker et al., 2010; Hine, 2006; Wouters et al., 2013). For this reason we examined infrastructural details such as hyperlinks, which provide insight into how online spaces share and circulate scientific resources (Beaulieu, 2005), as well as examining where decisions concerning the controversy are made more visible, such as in *Wikipedia* talk pages (König, 2013).

We performed thematic analysis of all collected material including words, images and hyperlinks. Analysis involved detailed and repeated readings of the material, looking for themes (Lupton, 1997). When examining this material, we focused on how scientific resources were utilised. For example, we examined text on the *Wikipedia* talk pages where editors negotiated the inclusion of resources.[3]

Schizophrenia genetics

Schizophrenia is a mental illness characterised by severe psychosis, with clinical symptoms of hallucinations, delusions and interference with thought processes. The disorder is chronic and can be marked by apathy and social isolation. Schizophrenia has a prevalence of 1% in the general population. Since the early 20th century, when schizophrenia was first labelled, a familial aspect has been suspected. While schizophrenia is known to be highly heritable, with an estimate between 80% and 90%, scientists have struggled to reach consensus about the genetic basis for the condition (Lewontin, 1991; Hedgecoe, 2001).

As technologies of genetic analysis have evolved, the methods of searching for genetic associations with schizophrenia have changed from the early focus on twin and adoption studies. More prevalent in the early 21st century are reports of genome-wide association studies (GWAS) which can detect genes with small effects by scanning the whole genome in large study populations; the results of research studying gene and environment interactions; and rare and de novo mutations (Burmeister et al., 2008; Maiti et al., 2011; Tienari et al., 2004; Walsh et al., 2008). In a move from 'meta-analysis' (see Jukola, 2015) to 'mega-analysis', research is being conducted by well-funded large consortia which amalgamate databases across multiple research institutions in the hope of finding rare genetic associations for schizophrenia. A study from The Schizophrenia Psychiatric Genome-Wide Association Study Consortium (2011) combined GWAS data from 17 separate studies conducted in 11 countries, involving almost 10,000 cases and over 12,000 controls. A study published in *Molecular Psychiatry* in 2012 brought together data from these GWAS, as well as results concerning linkages, copy number variants, gene expression (from human post-mortem samples, cell lines, or blood samples), and animal model studies of schizophrenia (GenomeWeb staff reporter, 2012).

Controversies have plagued this continually evolving field, including its association with eugenics, the role of twin and adoption studies in understanding the genetic basis of the mental illnesses (Hedgecoe, 2001), and the failure of genetic linkage studies to find 'genes for' schizophrenia (Arribas-Allyon & Bartlett, 2010). Despite a series of 'landmark' research papers mentioned above, there remains no consensus on identifying an exact genetic cause of schizophrenia (Duncan & Keller, 2011). Concern is raised in academic journals, in newspapers, and in blogs, about the lack of replication of research findings and whether each new study ever reveals anything really novel. Some believe that the difficulties lie in an unclear definition of the schizophrenia phenotype (Frazzetto, 2009), which is based on clinical examination and diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders* or the *International Classification of Disorders* (Burmeister et al., 2008: 529). These diagnostic criteria are themselves controversial, in the clinic and in research (Hedgecoe, 2001).[4] Considering this diagnostic uncertainty, some researchers advocate for research into endophenotypes, a somewhat vague concept used in psychiatric genetics from the 1970s to mean a heritable trait or characteristic of a condition, such as anxiety, that recognises that genetic variants do not map neatly onto current diagnostic categories (Insel & Wang, 2010). Endophenotype research, adopted by one of the DTC GT companies discussed below, is argued however to be just another framework for the same project of attempting to understand the genetic basis of schizophrenia (Arribas-Allyon & Bartlett, 2010).

Schizophrenia genetics remains a controversial area of research (Brzustowicz & Freedman, 2011; Burmeister et al., 2008; Mitchell et al., 2010). Following all of the controversies in this scientific field is beyond the scope of this article, however it is important to locate our argument within this contentious area of scientific research related to schizophrenia genetics as well as within the controversial nature of internet-mediated healthcare and scientific practice, as outlined above.

Wikipedia: Talk below the surface

> The causes of schizophrenia have been the subject of much debate, with various factors proposed and discounted or modified […] Some scientists criticize the methodology of the twin studies, and have argued that the genetic basis of schizophrenia is still largely unknown or open to different interpretations [hyperlink to resource] (Causes of schizophrenia article, *Wikipedia*, accessed 10 October 2011).

So begins the *Wikipedia* 'Causes of schizophrenia' article, a daughter article of the 'Schizophrenia' page, sub-divided in order to cope with the sheer volume of information on the aetiology of the disease. This quote explicitly recognises the contested nature of scientific research in the area. How are such statements constructed, or in other words, what is the work which goes into making these claims? What resources are used as evidence? In this section, we address these questions, focusing on how the technologies and norms of *Wikipedia* shape and produce scientific knowledge.

Building a wiki

Wikipedia began in 2001 under the name of *Nupedia*. At that time, academic experts were invited to write articles in an encyclopaedic format. This approach was abandoned due to the slowness of editing. A wiki format was then adopted where scholars and interested lay people could contribute content (Niederer & van Dijck, 2010; König, 2013). While the early wiki adopters were mainly an elite group, from 2006 the number of novice users steadily increased (Niederer & van Dijck, 2010), forming a larger *Wikipedia* 'community' (Pentzold, 2011).

Wikipedia has received significant criticism regarding the contested ability of anonymous amateurs to produce accurate information. Nonetheless a study by *Nature* found that it was not significantly any more inaccurate than the *Encyclopædia Britannica* (Giles, 2005), even though the range of topics covered varies dramatically.[5] Britannica responded by challenging the methods used in the *Nature* study, whereas *Wikipedia* responded by correcting the mistakes.[6] In any event, *Wikipedia* pages are some of the most

commonly visited on the internet. Scholars have both celebrated its democratic potential (e.g. Surowiecki, 2004) and critiqued it for retaining hierarchies and reinforcing dominant viewpoints (König, 2013). Niederer and van Dijck (2010) suggest that many discussions of *Wikipedia* have been misguided in that they focus on human resources, neglecting the technological tools and managerial dynamics that structure and maintain content. We follow Niederer and van Dijck (2010) by focusing on how the infrastructural arrangements of *Wikipedia* not only shape the representation of scientific knowledge, particularly evident in the talk pages, but also contribute to the production of knowledge.

Rules for participation

Some of the most important infrastructural arrangements shaping *Wikipedia* content are the rules for participation, upon which editing decisions are based. The existence of these rules would, at first glance, rule out the appearance of controversy on the pages of *Wikipedia*. The NOR (No Original Research) rule states that all material must be attributable to a reliable, published source. The NPOV (Neutral Point of View) rule states that representation needs to be given proportionally, without bias, of published information by reliable resources. A related sub-rule is SYNTH (Synthesis of published material that advances a position) that disallows the combination of material from multiple sources to reach or imply a conclusion not explicitly stated in those sources. If one 'reliable source' says A and another 'reliable source' says B, these cannot be joined to make conclusion C, as that would be considered to be original research (see NOR rule above). Contributors who deviate from these rules have their edits blocked, but rather than being a form of social control, Niederer and van Dijck (2010) argue that this is *protological* control, both social and technological. They argue that protological adherence to rules, through a combination of technical infrastructure and the collective wisdom of contributors underlies the success of *Wikipedia*.

Scholars of *Wikipedia* have shown that there are embedded hierarchies within this platform, and amongst users. Contributing administrators, registered users, anonymous users and software bots are ranked in an ordered system (König, 2013; Niederer & van Dijck, 2010) which determines and shapes their editing capabilities. Due to significant vandalism of the schizophrenia article, with the genetics section being completely removed on repeated occasions by one anonymous editor, regular editors applied for 'protected editing status' of the article, meaning that anonymous contributors would not be allowed to edit. All editors, regardless of their position in the hierarchy, must adhere to the rules for participation. In a *Nature* article on *Wikipedia* specifically addressing the schizophrenia page, a Wikipedian and neuro-psychiatrist Dr Bell claims that "disputes are settled through the discussion page linked to the entry, often by citing academic articles. 'It's about the quality of what you do, not who you are,' " (Giles, 2005: 901). Contrary to what Bell declares, we found that 'who you are' is important when it comes to editing the schizophrenia article. As König (2013) points out, legitimacy for editing is constantly debated amongst Wikipedians, in our case a group of people self-identifying as living with schizophrenia, doctors (including the neuropsychiatrist, Dr Bell), and other users. The negotiation of legitimacy became particularly evident when it concerned patient expertise. While some editors suggested their own experiences of living with schizophrenia reinforced the importance of their edits, others argued that such additions are anecdotal and biased, and not based on objective evidence. Protological use of rules comes into effect, as when one editor says to another "it's important that we not let your self-observations as a patient become SYNTH or OR". Later, in an exchange between the same editors:

> As much as I feel very sympathetic to what you have gone through, I think we need to be careful about what kind of a role we take on. It is worth reading WP:NOTGUIDE [wikilink – a hyperlink leading to a page within the wiki], which is very relevant to all of this discussion. (Tryptofish, 16:04, 27 July 2009 [UTC])

Not only is anecdote and personal experience discouraged from inclusion in the published articles, it is also discouraged from the talk pages, the purposes of which are defined as legitimating resource selection, not sharing stories. Editors are

directed towards talk page guidelines if they bring too many anecdotes into their comments. The talk page is itself edited, with some editors removing personal stories, comments and discussion not related to building the article itself.

The *Wikipedia* article on schizophrenia, in particular schizophrenia genetics, is thus shaped by rules for participation and the protological following of these rules by editors, as well as by embedded hierarchies and the expertise of contributors. Priority is always given to the published scientific literature. As we demonstrate below however, consensus about this published evidence is not always easily achieved.

What is evidence?

> Evidence suggests that genetic vulnerability and environmental factors can act in combination to result in diagnosis of schizophrenia. Research suggests that genetic vulnerability to schizophrenia is multifactorial [wikilink], caused by interactions of several genes [wikilink]. (Schizophrenia article, *Wikipedia,* accessed 10 October 2011)

As outlined earlier, numerous articles have been published in leading scientific journals that claim to provide 'evidence' of genetic associations with schizophrenia. Despite this body of work, there is no consensus on the genetic basis of the disease, making it difficult for Wikipedians to provide an encyclopaedic overview of this area of controversial science. Single studies of associations, while fitting the OR rule, do not provide encyclopaedic-level evidence based on overview studies for a genetic association for schizophrenia. 'Curating' a list of publications runs the risk of drawing conclusions that are not in the original papers, and thus violating the SYNTH rule. These difficulties of curation are discussed and debated in the

I tagged this article as 'confusing.' I did so even though I appreciate the amount of content it has. My concern is that there are so many hypotheses and anecdotes that it becomes difficult for the general public reader to navigate. Perhaps it would be better to decrease the large number of primary references and their often-anecdotal accompanying text, and limit the page to ideas that have been reviewed by secondary sources (Tryptofish, 22:04, 21 July 2009 [UTC]).

I agree in part. There is no use in an article that is unreadable. But I think the state of the article reflects the state of science in this area and perhaps this should be made more clear in the introduction - that there are various hypotheses. It would be good to retain the comprehensiveness of the article though […] One thing we want to avoid is pretending that we are speaking authoritatively on an agreed upon and proven cause - which would be misleading (Notpayingthepsychiatrist, 08:13, 22 July 2009 [UTC]).

I think we clearly agree more than we disagree. Just to clarify my point, though, I feel that, for the very reason that we, indeed, do not want to speak authoritatively on a single proven cause, this is more than just saying explicitly up front that there are multiple theories. Whether our audience includes those touched by the affliction, or also those from the general public who want to learn more, we owe it to them not to give undue weight [wikilink] to observations that exist as isolated anecdotes in the literature, even the academically peer-reviewed literature (Tryptofish, 17:02, 22 July 2009 [UTC]).

I am with you wholeheartedly on the 'undue weight' issue... It is an article for general reading and an introduction to the subject and should parse in those terms, rather than have the look and style of a research paper. Of course, you do want it to be even-handed and not have the appearance of an introduction to the subject, and yet be an advocate of a certain position under the surface, as is, for instance, NIMH's position paper on schizophrenia, a different example of how it ought not to be done (Uniquerman, 19:25, 23 July 2009 [UTC]).

Box 1: Discussing the nature of evidence suitable for *Wikipedia*

talk pages. The problem of the nature of evidence is highlighted in this excerpt from the causes of schizophrenia talk page:

> The professional literature contains a lot of primary publications that are anecdotal case studies; these are useful because they provide a database for subsequent analysis. But when a site like ours presents these cases as encyclopedic, we risk misleading the public by implying that they are significant evidence, when in fact subsequent scientific analysis may (or may not!) demonstrate that an isolated observation was a false lead. Thus the value of subsequent (secondary) scientific review. (Tryptofish, 14:46, 23 July 2009 [UTC])

The way in which the nature of evidence is constantly negotiated, whether experiential evidence or secondary reviews, with ongoing consideration of audience and the need to uphold neutrality, is also visible in Box 1, which gives sections of dialogue between editors conducted over 48 hours in July 2009.

Secondary analyses, or reviews, are constantly referred to as appropriate evidence. The very nature of 'review' is unclear in this context however. For example, one editor suggested including a recent study published in *Nature Genetics*:

> It's called *Exome sequencing supports a de novo mutational paradigm for schizophrenia* by Bin Xu, Maria Karayiorgou and several others. It costs $18. Can anybody who is actively working on this article afford to buy it? There are high level summaries in WebMD [hyperlink], Ars Technica [hyperlink] and elsewhere. Thanks. (SusanLesch, 9 August 2011 [UTC])

Another editor replies by referring SusanLesch to the MEDRS rule (Identifying reliable sources [medicine]), stating that: "we try to base all references on review articles especially for a topic with as much research as this one". The first editor writes back "That means that nobody can include this study [hyperlink], until somebody decides to write a review? I apologize for being impatient but the findings seemed rather important". The second editor replies:

> Not necessarily a review, but some sort of evaluative discussion in a top-level source, for example a 'perspective' piece in Nature or Science. Let me note that although this seems to me as well to be very interesting, the fact that it appeared in Nature Genetics rather than Nature suggests that there may be a few issues with it. The number of subjects, for example, does not seem huge given the statistical levels of difference being reported. We should really allow some sort of expert evaluation to take place before we try to include the study here. (Looie496, 17:18, 9 August 2011 [UTC])

These sections of talk show that editors are constrained in their edits not only by physical and financial access to the article but also by needing to wait for 'expert' evaluations of the literature, before such research can be included as evidence. As the talk demonstrates however, this kind of evidence is defined rather vaguely as "some sort of evaluative discussion in a top-level source". Attention to the reference list in the schizophrenia article at the time of our study revealed numerous citations that were not reviews, as well as one reference to another *Wikipedia* article (against rules) and also a schizophrenia forum discussion. Rather than a neat protological following of rules, what we find instead is a rather ad hoc assemblage of resources.

Closer examination of the structuring of the genetics section in the 'Causes of schizophrenia' article reveals how these additions accumulate in sequential order, rather than being coherently edited as a whole. An early paragraph in the genetics section details a 2003 review with seven genetic associations, and two 'recent' (2005 and 2006) reviews with evidence for another handful of genes. The text states that a number of other genes showed 'promising results' (with wikilinks given to genetic associations). A later paragraph in the same section states that the 'largest', most 'comprehensive' study of schizophrenia genetics actually disputed many of the findings mentioned in the previous paragraph, and that it was unlikely that the variations accounted for genetic risk. The next paragraph mentions the schizophrenia consortium we discussed earlier, with a meta-analysis (wikilink provided) showing nominal effects while subsequent text concerns copy number

variants, endophenotypes and epigenetics. The article becomes a chronological patchwork of studies that nonetheless does have the effect of synthesising knowledge.

Controversy in action

Citation and curation of contentious knowledge online

Schizophrenia genetic science can be represented in multiple ways across different media. *Wikipedia* provides an ad hoc citation and curation of scientific resources, the selection of which is shaped by embedded hierarchies, protocols, expertise and access to literature. The discussions and negotiations amongst Wikipedians are visible for all potentially see. The internet is clearly an important medium for the exchange of scientific information amongst scientists, and also between science, industry, government and the public. But of course the infrastructural relations of the internet more broadly and of *Wikipedia* specifically are not neutral. Looking at the ways in which controversy appears across platforms helps to open the black box of the internet itself. Our analysis revealed citations-in-the-making, and the curatorial practices of actors who draw on resources in ad hoc and contradictory ways. The infrastructure of the internet enables these processes to be made more visible, and in this way provides an interesting counterpoint to the usual suggestion (Star & Ruhleder, 1994; Edwards et al., 2009) that infrastructure is only visible when it does not work. We found evidence in the *Wikipedia* talk pages of new kinds of interactions between patients, scientists, medical professionals and others, negotiating expertise and evidence, in ways which have not been previously possible in hospitals, clinics, laboratories, and other places where the classification, diagnosis and treatment of disease have been discussed. The visibility of the infrastructure and of the content makes these relations and interactions possible.

When sociologists of science began studying controversies in the 1970s, they studied them as experiments that opened up the formal hard shell of science to expose the "soft social inside filled with seeds of everyday thought" (Collins & Evans, 2002: 248). Controversies have always been enabled and enacted through communication media, although we argue that the internet facilitates this process, by making those 'everyday thoughts' visible in ways which were not previously possible. *Wikipedia* thus offers a more public viewing of 'controversy in action', of the ways in which actors select and use resources, that differs from the more closed-shop controversial work that goes into discussing the clinical relevance of genetic findings behind the closed doors of expert group meetings (Rabeharisoa & Bourret, 2009).

Different versions of schizophrenia genetics are enacted on *Wikipedia* through partial curation of resources. We have seen that contributors can utilise varied and often creative understandings of 'citation'. The citation is attempted to be used protologically on the *Wikipedia* pages, our analysis revealing a somewhat patchwork application of the *Wikipedia* rules. This ad hoc approach is partly a result of the sheer number of unreplicated studies being published in peer-reviewed journals, the ever-changing review articles in this area of science in top journals, and the constant stream of 'breakthroughs'. It is also shaped by the infrastructural specificities of the platform, being both enabled and constrained by them. In the talk pages for instance, it is clear that editors have difficulties not only in determining what is evidence, but also in finding resources. Many of the genetic research papers that are hyperlinked require subscriptions in order to access them. While subscriptions are shared between some Wikipedians, structural barriers exist for those who do not have access to these resources.[7] In many ways however, the resource at the end of the hyperlink is not always important. The hyperlink functions not only in directing the user to the resource, but also as a way of creating legitimacy by creating alliances which may not necessarily be two, or even n-way, but often one-way. This becomes important as we have seen that *Wikipedia* editors may only be linking to abstracts as evidence, within which the complexities of a scientific paper are not always evident.

Different versions of schizophrenia genetics are being represented on *Wikipedia*. In many ways, this could be considered as not surprising, because the definition, causes, diagnosis and treatment of schizophrenia have always been and

continue to be deeply controversial. But in other ways, it is very surprising because in its rules of engagement *Wikipedia* tries to prevent controversy erupting on its pages. Below the surface of main articles, we observe debate and dissent. But we want to go further, and consider these not only as places where knowledge is distributed and knowledge claims are debated but also as places where knowledge is produced. *Wikipedia* is not just a collation of resources but a significant resource that has been curated, and in the process contributes to the production of knowledge.

Controversial knowledge production

The internet is an important source of information for individuals about health and illness, including schizophrenia. Informational websites such as *Wikipedia* have become popular sources of health information. In a 2008 article in *Social Science and Medicine* about schizophrenia websites (Read, 2008), the *Wikipedia* page was ranked third in Google, and second on their list of relevant websites (a Wikipedian recently informed his fellow editors that this ranking had, since the publication of the article, jumped to first place).[8] Scholars have argued that websites discussing schizophrenia aetiology offer an important service to the public, in presenting accurate, complex information (Read, 2008) on which people base potentially life-changing decisions. The prominence of *Wikipedia* as a source of information on schizophrenia leads us to consider its role not only in the representation of knowledge, but also in knowledge production.

The Wikipedians who contributed to the schizophrenia article were certainly aware of their audience, and the effect that their article may have on illness perceptions. For example, one editor promoted a more positive outlook about the disease, and argued for the use of neutral words such as 'condition' and 'diagnosis' rather than 'illness' and 'disorder', in order to help 'recovery'. *Wikipedia* is considered by one of its editors to have an important role to play in educating doctors about schizophrenia, particularly regarding its classification, while another sees it as making a major contribution to understanding schizophrenia and research. While the NPOV page declares that *Wikipedia* '*describes* disputes' but does not '*engage* in disputes', our analysis reveals a more active engagement in the debates. The nature of *Wikipedia*'s involvement in controversy however, is partially determined by the scientific literature itself. While the speed of knowledge production on *Wikipedia* is often celebrated (Giles, 2005), our analysis showed that the publication of review articles in the major scientific journals remains a limiting factor when editing. Wikipedians thus continue to rely on more traditional forms of knowledge production, find it difficult to agree on what counts as reliable evidence when curating data, research findings and publications, and in this they are not dissimilar to professional scientists (Leonelli, 2012). Similar to the scientific review article (Hedgecoe, 2001), *Wikipedia* is a textual space in which knowledge is constructed.

Conclusion

In this article, we have shown how experts and non-experts come together on *Wikipedia* in order to produce knowledge that will be widely available. But this is not a free-for-all in which all utterances are treated equally. We have also shown that platforms, infrastructures and infrastructural relations are not neutral, but can reinforce established social positions. *Wikipedia* has clear rules which serve to structure and mediate what kinds of knowledge are (re)produced. We have demonstrated how knowledge from elsewhere is curated to create an easy-to-read entry. On *Wikipedia*, 'reviews' of the science are negotiated by Wikipedians who have varying degrees of access to the scientific literature. These curated spaces exist outside the core set of schizophrenia genetics research, yet rather than producing what Hedgecoe (2006) describes as an 'alien science' (an inaccurate view of the science by outsiders, based on the literature), we suggest that these actors negotiate, produce and circulate new forms of knowledge that is potentially global in its distribution.

The multitude of theories, methods, and research studies in the field of schizophrenia genetics means that each online representation of the science is not 'inaccurate' as such, but rather a partial 'curation' of resources in which material is selected, evaluated and presented. This results

not only in the circulation of existing knowledge but also in the production of new knowledge.[9] We argue that the internet and the *Wikipedia* platform enable social action around the curation of these resources in ways which were not possible with earlier forms of communication technology, and features such as journal subscription fees and editing rights work to constrain engagement with the science. The infrastructural arrangements of sites such as *Wikipedia* also make these social actions more visible than they have been before, not only to STS researchers but also to the broader public.

The internet is well on the way to becoming black boxed, as the inner workings of computers and the means for connecting them are increasingly taken for granted. This only makes it more crucial to pay attention to how different platforms affect how patients, carers, scientists and medical professionals understand, interpret and engage with science. Our contention is that the internet is opening up new c/sites of scientific controversy shaped not only by consumers, patients, scientists, citizens, companies and doctors but also by technological infrastructure, which allows new interactions and makes actors' engagements with these controversies visible in previously unseen ways. By recognising that platforms such as *Wikipedia* can and may be used differently by actors, providing different kinds of information about an important topic, such an analysis aims to keep the black box open. Numerous STS researchers have broadened the spaces for examining the production of scientific knowledge beyond the laboratory, and in this article, we have contributed an analysis of another set of spaces in which controversies unfold.

This article relates to STS work concerning controversy, and the infrastructure of communication technologies, specifically connecting to previous work about schizophrenia genetics. By taking the online infrastructure as our starting point, we are able to follow how knowledge is curated and produced by those outside the 'core set' of scientific knowledge production. Unlike in the clinic, where categories of illness are attempted to be stabilised, or in journal articles, where coherent narratives are constructed, on the internet we see deliberate playing with the instability induced by controversy. The internet allows new spaces for analysis of controversy, each version, representation and argument shaped by actors and the infrastructure of the platforms. While we recognise that the internet, especially web 2.0 platforms such as *Wikipedia*, allows for new forms of engagement with science, we are cautious in celebrating what many regard as the emancipatory, democratic potential of this participatory engagement with genetic science. Instead we have examined how the internet affects and structures the ways in which controversies play out, and how that process sometimes stabilises and sometimes undermines existing knowledge, and sometimes generates new knowledge.

Notes

1 In their otherwise still excellent overview of different ways of studying controversy, Martin and Richards (1995) did not pay any attention to the medium of communication. They identified four approaches: positivist, group politics, constructivist and social structural; and compare them across six dimensions: epistemology, focus of analysis, conceptual tools, closure mechanisms, partisanship of analyst, and decision-making procedures. They recognise that no single study of controversy will fit neatly into one of these ideal types. Our analysis fits somewhere between constructivist and social structural, especially as our focus of analysis is the content and medium of communication in which both those inside and outside the scientific community take part.

2 The material has been stored offline by the authors, and can be consulted by appointment.

3 Our analysis leaves open questions and areas for further research. We still know little about *Wikipedia* editors. There are many other internet spaces which need further research regarding their role in controversy, such as the websites of companies selling genetic tests, mental health blogs, Listservs, fora and video sharing sites. In the case of schizophrenia genetics for example, user fora in particular could potentially provide an important resource for understanding how patients and consumers share resources, as well as genetic data, phenotypic information and illness experience, these forms of knowledge engaging with, contradicting and replicating biomedical understandings and scientific research. Ethical questions arise when considering contacting, quoting from and engaging with fora in research, highlighting the controversial nature of conducting internet-based research, especially about sensitive topics such as mental health.

4 In the DSM-5, published in May 2013, the diagnostic criteria for schizophrenia were adjusted in order to try to increase the reliability of diagnosis. Sub-types have been eliminated, instead clinicians are advised to focus on the severity of individual core symptoms, including hallucinations, delusions and disorganised speech. Available at: http://pro.psychcentral.com/dsm-5-changes-schizophrenia-psychotic-disorders/004336.html (accessed 4.9.2015).

5 For example, Suchecki and his colleagues (2012) have visualised the bottom-up categories generated by Wikipedians with the top-down determined categories used by the Universal Decimal Classification used in many libraries. The latter devotes over 70% to science-related topics while in *Wikipedia*, topics related to arts, entertainment and sport are much more highly represented. See the visualisation at: http://www.scimaps.org/detailMap/index/design_vs_emergence__127 (accessed 10.9.2015).

6 This was stated by Jimmy Wales, one of the founders of *Wikipedia*, during a public meeting held on 15 January 2015 at the Royal Netherlands Academy of Arts and Sciences, Amsterdam.

7 One of the much-touted advantages of open access publication is precisely to make scholarly publications available to everyone with an internet connection (see Meyer, 2013).

8 The results provided by *Google* and other search engines are subject to enormous variability, depending on the search history of the user, the machine on which the search is conducted, the filters installed by administrators, and many other factors. Nonetheless, when searching using different search engines on 6 August 2013 and again on 25 April 2015, two of the authors also consistently received *Wikipedia* amongst the top three results.

9 As Lynch et al. (2008) point out, the US legal system seems to encourage scientific dissent in the ways in which new scientific techniques are admitted as evidence. The internet has certainly magnified the possibilities for 'ersatz scientific dissent' as well as for junk controversy.

Acknowledgements

The research on which this article is based was supported by the Netherlands Organization for Scientific Research (grant number 463-09-033) and the UK Economic and Social Research Council (grant number ES/H0250330/1 (Kelly)/RES-000-22-3864), under their Bilateral Agreement Scheme. The project was called, 'Selling genetic tests online', and was funded for two years from 2010-12. We are grateful to Ties van der

Werff and Bart van Oost who provided useful feedback during the STS 'summer harvest' at Maastricht University in September 2013. We have also learned a great deal from the insightful comments provided by anonymous reviewers and the editors of this special issue.

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