

# Online Expert Mediators: The Rise of a New 'Bipolar' Stakeholder or Going Beyond Interactional Expertise in the Blogosphere

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## **Abstract:**

Using Collins and Evans' (2002) concept of interactional expertise, this article examines the online activities of three bloggers diagnosed with bipolar disorder. It argues that by combining medical knowledge with their situated experiences, and by utilizing the affordances of blogs, these bloggers have become a new type of stakeholder, the online expert mediator. Collins and Evans' concept is extended by taking into consideration the role of the medium through which interactional expertise is displayed and by showing that its bi-directional character is more substantial than they had envisaged. The rise of this new stakeholder category denotes a possible turn from community activism to exceptional entrepreneurial selves. Despite views that the internet would have broad democratizing effects, the findings show that the high standing of online expert mediators is not the result of a subversive use of this medium, but of a dynamic alliance with 'traditional' experts and of a strong media presence.

**Keywords:** interactional expertise, illness blogs, entrepreneurial selves

## **Introduction**

Relations between important stakeholders in the field of mental health have been significantly transformed by the internet (Barak and Grohol, 2011). This medium has affected the identity and the type of interactions between knowledge producers and users (Wyatt et al., 2013), contributing to the diversification of sources of medical knowledge away from clinical environments (Nettleton, 2004), closer to the everyday settings of people diagnosed (Lucivero and Prainsack, 2015), and leading to the re-appreciation of other types of knowledge (Schaffer et al., 2008). Such changes have taken place in a context where pronounced

neoliberal tendencies have introduced a market logic in the provision of healthcare and have encouraged individuals to assume responsibility for their health (Rose, 2007; Novas, 2006). Web 2.0 technologies, such as blogs and social networking platforms, enable users not only to consume information but also to engage in its production (Lupton, 2014). As people have become increasingly involved in their health, these technologies have contributed to the development of new entrepreneurial subjectivities (Tutton and Prainsack, 2011). In this article I study the online activities of three bloggers diagnosed with bipolar disorder (BP)

using Collins and Evans' (2002) concept of interactional expertise. I show that through their skillful use of the internet, some individual patients have become highly influential, and argue that this medium has thus helped facilitate the emergence of a new type of stakeholder- the online expert mediator.

First, I consider how the role of patients in mental health has changed over the last decades, focusing on the internet's influence in these transformations. The analysis of the online activities of three bloggers indicates that they hold interactional expertise. I then show that the bi-directional character of interactional expertise is more substantial than Collins and Evans (2002) considered and expand their concept by considering the effects of the medium through which it is articulated. As Kivits (2013) argues, the current dominant imperatives to stay or become healthy by seeking and sharing health-related information have contributed to the development of a space where new forms of agency can develop. The findings indicate that through the knowledge they display and the alliances they forge, these bloggers have successfully positioned themselves within this new space, and have expanded their influence beyond that of most authors of illness blogs. In so doing, they have become online expert mediators, a new stakeholder category whose attributes I describe and discuss from a critical perspective in the conclusion.

## **Greater mental health patient engagement and the internet**

### ***Patient engagement***

As many medical sociologists have indicated, since the last decades of the 20th century patient engagement has been promoted in different areas and for different goals (Barello et al., 2014; Turner, 1995), through top-down processes (Hogg, 2009; Godfrey et al., 2003) or as the result of grassroots activities (Rabeharisoa et al., 2013; Landzelius, 2006; Novas, 2006; Kushner, 2004; Taussig et al., 2003; Barbot and Dodier, 2002). The meaning and consequences of patient engagement vary (Rowland et al., 2017; Hickey and Kipping, 1998), however, putting it simply, it is clear that by becoming more involved in their health, people have also

come to grasp the conditions of complexity and uncertainty under which medical professionals operate, leading to a growing awareness of the limits of medical expertise. These realizations have had a profound resonance in mental health, where the authority of medical professionals has been challenged since the late 1960s (Pickersgill, 2012). Most medical insights in this field have thus been criticized in many ways, including arbitrary diagnosis (McPherson and Armstrong, 2006; Wright and Cummings, 2005), the pathologizing of normal human emotions (Horwitz and Wakefield, 2007; Scott, 2006), the rationale and effectiveness of medical treatments (Whitaker, 2011; Kirsch, 2010), and the skewed power relations between medical professionals and people diagnosed, exemplified in rare(r) but still ongoing practices, such as forced hospitalization or treatment (Brodwin and Velpry, 2014). Combined with official restructuring initiatives and considerable openness among people diagnosed towards new approaches and types of knowledge, such challenges have contributed to the proliferation and diversification of mental health professionals (Grob, 2005; Brown, 1988). The relations between existing stakeholders have thus been modified, and new stakeholders, such as life coaches, homeopaths, online platform owners, and citizen scientists, have entered the field of mental health. The role of patients has also changed from passive recipients of care (Barnes and Shardlow, 1997) to consumers entitled to choose the type of care they receive (McLean, 2000). While some patients consider themselves survivors and actively militate against medical conceptualizations and interventions (Whitley, 2012; Speed, 2006; Crossley and Crossley, 2001), many others have engaged in processes of knowledge production (Gillard et al., 2012; Kemp, 2010), evaluation (Director, 2005), and implementation (Davidson, 2005), thereby acquiring a greater role in mental healthcare.

### ***The internet in mental health***

Used in mental health since its early days, the internet has importantly shaped the participation of people diagnosed in knowledge production. Already in 1999, Barak (1999: 231) noted that "the rapid developments in computers and information technology over the past decade have had an

impact on psychology, which has moved (...) from local computer applications to network applications that take advantage of the Internet." Health policy makers hoped the internet would empower patients by facilitating their access to information and the development of virtual communities (Haker et al., 2005; Eysenbach et al., 2004). It was further expected that online technologies would facilitate the development of mental health interventions at lower costs and would reach people in remote areas (Oravec, 2000). By now, numerous studies have indicated the potential (Smith et al., 2011; Barak et al., 2008; Carlbring and Andersson, 2006; Proudfoot, 2004) and variety of online interventions for mental health (Barak and Grohol, 2011; Kraus et al., 2010; Marks et al., 2007; Ybarra and Eaton, 2005). BP is among the mental health conditions affected by such approaches, as more and more people with this diagnosis use the internet (Lamberg, 2003), and various online therapies and different types of mobile phone applications have been developed (Nicholas et al., 2015).

Initially, the internet was considered "the site of a new struggle over expertise in health that will transform the relationship between the health professionals and their clients" (Hardey, 1999: 820). Since then, it has contributed to "a new way of 'doing health'" (Kivits, 2013: 220), leading to the emergence of new mediators between information producers and seekers (Wathen et al., 2008), and changing the relations between knowledge producers and users (Wyatt et al., 2013). Some patients have used their newly acquired knowledge to question and/or challenge the expertise of medical professionals in various ways (Gowen et al., 2012; Orsini and Smith, 2010; Mulveen and Hepworth, 2006; Fox et al., 2005). Others have engaged in various scientific activities, ranging from monitoring themselves using various self-tracking devices and sharing their data with others, to using collaborative platforms, such as PatientsLikeMe, to test medical hypotheses (Kallinikos and Tempini, 2014). By using the internet, such 'citizen scientists' or 'health hackers' have gone beyond the mere provision and exchange of medically interesting information, connecting with other people with the same diagnosis to 'conduct clinical trials on their own diseases' (Bottles, 2013: 88), enacting

thereby particular values and ideals of patienthood (Sharon, 2017). Such online opportunities have been all the more important in the field of mental health, where study participation has traditionally been difficult, as the symptoms of people diagnosed often rendered their adherence to specific interventions problematic, while the desire to avoid stigmatization made them reluctant to attend face-to-face meetings (Naslund et al., 2015).

There are important differences in approach, motivation, and goals among patient organizations focusing on the same condition (Barbot, 2006) and even among members of the same group (Epstein, 1996). The internet has helped render more visible the heterogeneity of bipolar patients, as various online platforms testify to their different needs and preferences. It has also contributed to the emergence of new types of involvement for people diagnosed with BP, by diversifying the range of stances at their disposal. By using the internet, they have been able to develop new skills and to acquire various resources. This has not only rendered bipolar patients more salient stakeholders, but it has also contributed to a diversification of the type of stakeholderhood they could take up. It is important to note that other factors and stakeholders play an important role in shaping the field of mental health, such as governmental agencies, the biopharmaceutical industry, insurance companies, manufacturers of medical technologies, and education curricula. Even though bipolar patients and medical professionals are not the only stakeholders whose roles have undergone important transformations, this article focuses on them given the centrality of their position in a field characterized by dynamism and versatility.

## Illness blogs

Since the emergence of surveillance medicine in the twentieth century (Armstrong, 1995), and particularly after the adoption of a consumerist culture in healthcare (Lupton, 1995), individuals have been encouraged to engage in self-surveillance practices and to actively manage their health by staying informed. The development of digital technologies has contributed to the diversi-

fication and intensification of these tendencies (Kopelson, 2009), but has also “promoted the individual expression of a personal experience of health” (Kivits, 2013: 222), as people have been increasingly exhorted not only to seek information but also to share personal insights. Thus, the internet has enabled not only patient groups, but also individuals to become influential by achieving high levels of visibility and by acquiring numerous readers. While most researchers have studied the changing identity and growing influence of patients as the result of collective actions, several academic works have highlighted the importance of particular individuals in shaping the character of patient organizations and of their interactions with medical professionals (Lerner, 2001; Klawiter, 1999). This study contributes to the literature by showing that some individual patients have become highly influential in mental health by taking advantage of some of the opportunities generated by the development of web 2.0 platforms in the context of growing tendencies to responsabilize individuals for their health (Nettleton, 2004).

Among the multiple forms of self-expression the internet has enabled, illness blogs represent a highly popular genre (De Boer and Slatman, 2014). According to Tremayne (2007 :vii), “[b]logs are distinguished from other websites in their dynamism, reverse chronological presentation and dominant use of the first person.” Given their popularity, malleable architecture, and primarily individual character, blogs represent an excellent site to study the activities, knowledge practices, and alliances through which individuals achieve an influential position. Illness blogs are a specific type, as they “are used to express the experience of illness and to connect with readers via the Internet” (Heilferty, 2009: 1542). They differ based on their design, accessibility, and interactive character, and it is the more or less skillful combination of affordances related to these aspects that largely determines a blog’s standing.

### Three bloggers on BP

On December 3, 2016, an online search using the keywords “bipolar blog” generated 12,600,000 results in Google, and 6,870,000 on Yahoo. Regardless of search engine used, the blogs of

Natasha Tracy, Julie A. Fast, and Charlotte Walker are listed on the first page of results, either directly or mentioned under rubrics such as ‘the best bipolar blogs of the year’ on several health platforms. They are thus likely to come to the attention of many internet users. All three blogs can be accessed freely by readers.

Each of these three bloggers has been diagnosed with BP for about two decades. Tracy is a self-styled “social media strategist” and a writer on topics such as BP, depression, pharmacology, and other mental-health related issues. She has authored three blogs: *Breaking Bipolar*, *Bipolar Burble*, and *Bipolar Bites*. Her blogs attract large numbers of visitors, and many of her posts receive hundreds of comments. Fast introduces herself as “a world leading mental health expert on the topics of BP, depression, seasonal affective disorder, personality disorders and mood management”. She claims that her site and blog together have been visited by one million visitors. Unlike Tracy, her personal blog, *Bipolar Happens!*, only gathers a very modest number of comments (< 10), but there is significantly more interaction on her blog on the bp Hope magazine website, *Fast Talk*. Fast also works as a “bipolar disorder management specialist” at Share.com, the website created by Oprah and Dr. Oz. Walker is the author of the blog entitled *purplepersuasion*, which on February 11, 2017 counted as many as 1,010, 281 hits. She has also been a guest blogger for online magazines and health platforms.

While internet users have been studied as health-related information seekers and/or producers, less attention has been paid to their potential as information mediators. Illness blogs are important mediation sites, as experiential knowledge is combined with medical, pharmaceutical, and socio-economic information. Through their activities, these three bloggers function as mediators in the Latourian sense. In explaining the main differences between the ways in which sociologists of the social and sociologists of association define the social and the means by which it is achieved, Latour (2005) distinguished between intermediaries and mediators. While intermediaries transport information without bringing any modification to it, mediators “transform, translate, distort, and modify” (Latour, 2005: 39) it. They do

so to adapt it to the opportunities and limitations of the medium and to the requirements of different audiences (Wathen et al., 2008). Importantly, the development of this new stakeholder category occurs in a context where patient experiences have come to be valued, elicited in various ways online, and, subsequently, commodified (Lupton, 2014; Adams, 2013; Mazanderani et al., 2012). I argue that through their practices and collaborations with different stakeholders, these bloggers move beyond the role bipolar patients generally have in the field of mental health, and turn themselves into a new type of stakeholder - the online expert mediator.

### Theoretical framework

Several concepts have been developed by medical sociologists and anthropologists that could be applied to study the knowledge of these bloggers. Borkman (1976) put forward the influential notion of experiential knowledge, denoting individual, concrete and situated insights acquired through one's personal experience with disease. Importantly, experiential knowledge can underpin one's claims to authority, while its cathetic dimension is conducive to trusting exchanges. Arksey (1994: 445) developed the notion of lay expertise, showing that people diagnosed can become knowledgeable enough "to reverse the usual doctor-patient relationship and instead stimulate a two-way learning process". Building upon this notion, Epstein (1995) argued that patients can develop sufficient scientific knowledge to shape medical research and to modify study design and methodology. As some scholars argued that specialized knowledge cannot be held by non-specialists (Prior, 2003), and finding experiential knowledge too vague for analytical purposes, Pols (2014) put forward the concept of patient knowledge. Defined as "practical knowledge that patients use to translate medical and technical knowledge into something useful to their daily life with disease" (Pols, 2014: 73), it can be made "useful and transportable to others" (Pols, 2014: 78). Patient knowledge focuses thus on the development and transmission of techniques for living with disease in good ways, but not on the patients' substantial engagement in medical

research. While important, these notions are insufficient to analyze the diverse resources of these bloggers and the broad activities they engage in.

The online activities of the bloggers are analyzed instead using the concept of interactional expertise (Collins and Evans, 2002), which bridges the divide between practical, experiential and scientific knowledge. This notion is particularly useful, because it allows me to identify people endowed with substantial knowledge but missing official credentials, and provides an appropriate explanatory framework when studying phenomena "involving different expert communities" (Collins et al., 2017: 782). While contributory expertise denotes one's ability to contribute productively to a field (Collins and Evans, 2007), interactional expertise has been recently refined into "fluency in the spoken language associated with a practice" (Collins et al., 2017: 765). Importantly, "what distinguishes interactional expertise is the claim that, under the right social circumstances, fluency in a spoken language and a conceptual understanding of the domain to which it refers, can be acquired without experiencing the practice." (Collins et al., 2017: 765) Thus, people may acquire interactional expertise through immersion in a field, while following a different trajectory than contributory experts (Collins et al., 2006). Even though they lack accreditations, interactional experts hold specialist tacit knowledge and can reach such high levels of knowledge that contributory experts welcome conversations with them. Interactional expertise is also very specific: just like contributory experts in a field can contribute successfully only in some areas, interactional experts can be more competent about particular subdomains of a field. Furthermore, the acquisition of interactional expertise enables people to function as mediators between contributory experts in a field and the group(s) they represent.

While Collins & Evans (2015) have preferred to study interactional expertise through the Imitation Game and have, thus, resisted calls to expand their initial definition of this concept, in this study I follow the lead of scholars who have argued for a broadening of the way in which interactional expertise is understood (Goddiksen, 2014). I thus take up Plaisance and Kennedy's (2014) recom-

mendation to study interactional expertise by considering the 'fruitful' contributions people endowed with it can bring to a field due to "the various profiles that interactional experts can have as a result of who they are, why they've sought to acquire IE [interactional expertise], and how they make use of it" (Plaisance and Kennedy, 2014: 65). In so doing, I extend interactional expertise by considering the effects of taking seriously the medium through which it is displayed and I build upon several recommendations Collins and Evans made to show that its bi-directional character is more substantial and dynamic than they had envisaged.

Interactional expertise can play an important role in the relations between medical professionals and patients. Considering chronic illnesses, for instance, Collins and colleagues (2017) suggested that it would be worthwhile to study the level of expertise medical professionals have regarding their patients' lived experiences with particular conditions. While this is not the object of this study, their suggestion reveals that the experiential knowledge of patients is an area in which medical professionals might be interested to become competent and for which they require the assistance of their patients. This also means that while medical professionals are contributory and interactional experts in regard to (specific areas of) medical knowledge, they generally lack expertise regarding the lived experience of a condition. Unlike them, people diagnosed have contributory and interactional expertise regarding the latter aspect, but developing interactional expertise in the medical field is an accomplishment in which only some of them succeed. Thus, in this article I show that people endowed with interactional expertise can successfully influence the audience of bipolar patients and their families to whom they translate medical knowledge, and they can also collaborate with medical professionals. I argue that there are important differences between the activities people can engage in and the repertoire of tactics that they can choose from in order to display interactional expertise, depending on the medium they use.

## Methodology

In analyzing how the bloggers display interactional expertise, I take a mediated perspective, whereby I consider the content they produce not only as the result of their particular skills and intentions, but also as importantly shaped by the technology of blogs, which facilitates particular behaviors and practices, but constrains others (Kivits, 2009). I aimed to mimic the approach of regular users, and selected these bloggers using the Google index as a relevance indicator. Data were collected between July 2014 and February 2017 and initially consisted of: bloggers' posts about the treatment of BP and information provided under the "about" rubric of every blog. The blog references used in this article can be found in Appendix 1. The direct mentions and hyperlinks on their blogs allowed me to become aware of the medical professionals and public officials Tracy, Fast, Walker knew and of the institutions they had ties with. In order to acquire a better understanding of their standing, information on their other public activities and on the signs of recognition they had received was needed. Additional online queries were therefore subsequently conducted, using the bloggers' names as search terms in the search engine Google. The search 'Natasha Tracy' generated 19,600,000 results, while 'Julie A. Fast' 349 million. Since the query using 'Charlotte Walker' was confounded by hits concerning other public people, I refined the search terms to 'Charlotte Walker bipolar'. This query generated 979,000 results. Another search using 'Charlotte Walker purple persuasion' generated 668,000 results. The biographical and social data were collected from the first ten pages of results.

I performed thematic analysis of all the texts collected, including hyperlinks and images, by identifying important themes through repeated readings (Lupton, 1997). Given the bloggers' online standing, the initial coding process focused on (1) the type of information they made available about BP on their blogs, with the themes identified including: treatment, management of the condition, lived experiences of people diagnosed broadly understood, and (2) on their interactions with readers, which were roughly thematized into provision of (emotional) support, provision of additional information, reactions to

challenges, and reactions to positive feedback by the bloggers. Based on these preliminary findings and in consultation with the literature, the coding of the data was subsequently refined in line with the notion of interactional expertise. I operationalized interactional expertise based on Collins and colleagues (2006) into three main dimensions: linguistic fluency in the field of medical knowledge about BP; ability to evaluate and distinguish between medical professionals; ability to provide practical advice about relevant matters in the field. Given the aim of expanding the notion of interactional expertise by focusing on its bi-directional character and by considering the effects of the medium through which it is articulated, the following aspects were additionally focused upon using also the biographic data collected: how and when bloggers invoked and displayed medical knowledge; the bloggers' relations with medical professionals; the alliances they forged; elements conveying the bloggers' standing; the bloggers' use of online affordances. In the following sections, I show that these bloggers hold interactional expertise and that they have turned themselves into online expert mediators through a substantial use of its bi-directional character and by expanding their mediation work online and offline.

## Analysis

### *Linguistic prowess*

The display of linguistic fluency in a field is the main mark of people endowed with interactional expertise (Collins and Evans, 2002). While Tracy, Fast, and Walker are not medical professionals, nor did they study medicine, the many years since they have been diagnosed with BP, the multitude of treatments they have tried and the great variety of professionals they have consulted have provided them with ample opportunity to observe the practices of the medical community. Furthermore, their own pro-active attitudes have enabled them to deepen their medical knowledge about BP. These three bloggers display their linguistic prowess throughout their posts and interactions with commentators, as they explain medical phenomena using a more accessible vocabulary and providing examples, they give advice about

the most appropriate therapeutic approaches depending on one's symptoms and/or life circumstances, and are aware of the latest developments in the field. The excerpt below is illustrative of such activities:

Drug tolerance is also known to occur upon drug-discontinuation. In other words, someone who has previously responded well to lithium discontinues the drug, symptoms reemerge, the person goes back on lithium but does not find it effective. Again, we don't know why this occurs but it does appear to in a small percentage of patients. In one study, it occurred in 13.6 percent of people taking lithium. (...)

Warning, this is a preclinical study and as such the implications from it may not be fully understood. Please make sure to make any medication changes only with doctor oversight. For more information please see the study *Tolerance to the Prophylactic Effects of Carbamazepine and Related Mood Stabilizers in the Treatment of Bipolar Disorders* [hyperlink provided]. (Tracy, *Bipolar Bites*, May 30, 2012)

This quote indicates Tracy's position as mediator between medical professionals and bipolar patients, position which I argue that is characteristic for this new type of stakeholder. While it may be that it refers to the level of knowledge available to the whole of humanity, the use of 'we' in a context where study results are discussed suggests that Tracy sees herself more as a member of the medical community. At the end of the post, however, she reclaims her subordinate position to medical professionals, while by sharing the source she used, Tracy reveals her awareness of the need to legitimize her claims.

Mediators importantly transform the meaning of the information they transmit and this is obvious in the posts authored by all three bloggers. While they convincingly use medical vocabulary, they do so in particular ways. For instance, Tracy puts forward her own reading of personalized medicine, as on numerous occasions she seems to believe that each person displays an individual mix of symptoms and reacts differently to treatment, as the quote below illustrates:

And if 99 people say the med is bad, but 1 says it's good, what benefit is that? Should the patient not try it? Should the patient assume the med won't work or will have too many side effects? The 99:1 ration essentially means nothing because we're all different. (Tracy, *Breaking Bipolar*, June 30, 2011)

Furthermore, Tracy often uses statistics and results obtained through randomized controlled trials to support her claims. This shows that she makes strategic choices about the ways in which she refers to medical information, a tactic previously identified among patient organizations (Treichler, 1999). This rather complicated balancing act is necessary as it allows her not to alienate readers with experiences different from the ones she describes, while maintaining her authority. At the same time, it enables her not to stray too far from the prevailing medical consensus, thereby retaining her ties with the medical community.

The bloggers display their linguistic prowess also by distinguishing between different medical professionals in the field of BP, and they often criticize the prescription habits of general practitioners. As such views are expressed in posts where they provide the latest insights into a particular treatment, it would appear that these bloggers position themselves as more up-to-date than some medical professionals. Since Collins and Evans' (2002) conceptualization of expertise is based upon the idea that no contributory expert is equally competent in all areas pertaining to a particular domain, it remains open for debate whether such online contributions are meant to be understood as epistemic gaps which the bloggers seek to fill or whether they represent interventions through which they challenge the authority and standing of medical professionals who are lower positioned than specialists and scientists, for instance. This ambiguity is further exacerbated by the fact that such online comments are balanced by entries where Tracy, Fast, and Walker warn readers about their lack of medical credentials and take up a complementary function to medical professionals. They try, for instance, to prevent people from quitting their medication when scandals related to pharmaceutical companies emerge. Fast even depicts herself (and people diagnosed) as useful allies, helping doctors identify dishonest claims made by phar-

maceutical companies through their experiential knowledge of the effects and side effects of medications (Fast, *Bipolar Happens!*, October 16, 2016). Furthermore, multiple entries (Tracy, *Breaking Bipolar*, July 5, 2012) show that through their immersion in the community of medical professionals, these bloggers have also become familiar with the political economy of the pharmaceutical industry.

Tracy, Fast, and Walker display their fluency in medical knowledge also by evaluating the merits of various studies and by distinguishing between medical information based on its source. Walker goes beyond the evaluation of statements and specialists in the field, and calls upon her online followers in order to verify results obtained by reputed researchers. Having read in the highly authoritative *The Lancet Psychiatry* a critical article about the quality of care provided by Home Treatment Teams (HTTs) in the U.K., she starts an online survey to find out if her readers, to whom she promises anonymity, confirm these findings:

I threw the issue of HTTs/CRTs open to my Twitter feed. I'm not pretending this is in any way "research"; I simply asked people to share their experiences. (...) A sizeable minority found their HTT invaluable and were full of praise; others found parts of the system helpful .... (Walker, June 23, 2014).

Her decision to replicate the study online illustrates the major role the internet has played in expanding the repertoire of activities bipolar patients could take up, and how it has changed their position in relation to medical professionals. By sharing her findings, Walker presents her blog post and inquiry as replicates or alternatives to the processes undertaken by the team of medical professionals who authored the article.

Through their online posts, Tracy, Fast, and Walker show that they are endowed with sufficient medical knowledge (both substantive and methodological) to be able to distinguish between professionals based on their training and prescription habits, that they can correctly interpret the results of scientific studies, and can even seek to replicate them. Furthermore, they provide ample advice about the treatment and management of BP. These bloggers thus show that they have

become fluent in the language of medical professionals and have therefore successfully developed interactional expertise.

### **Bi-directionality**

Bi-directionality is an important aspect of interactional expertise, yet Collins and Evans do not sufficiently theorize this ability of people endowed with interactional expertise to function as mediators between others with the same kind of contributory expertise as they and with individuals who have contributory expertise in the field where they hold interactional expertise. For Collins and Evans (2002), interactional experts translate the scientific practices of contributory experts in one field for people with contributory expertise in another field, and shape the knowledge contributory experts produce by questioning some of their practices or by making them aware of other perspectives on an issue of interest. Thus, Collins and Evans see interactional experts as providing contributory experts with sources of inspiration. I argue, however, that people with interactional expertise can engage in more substantial exchanges, and that more attention should be paid to the type and quality of their interactions with contributory experts in different fields. The exchanges of the bloggers studied here are revelatory in this sense.

In their interactions with bipolar patients, Tracy, Fast, and Walker go beyond the mere provision and explanation of medical information, and often position themselves as complements or alternatives to medical professionals. The bloggers achieve this by combining knowledge with care, by expressing concern for the realities of their readers' lives. They try to locate for them institutions that might be of help, they explain how to apply for social provisions, and express empathy towards the difficult choices people face in relation with BP and its treatment. The bloggers also give practical advice, stemming from their experiential knowledge: "Freeze your fish oil pills! This makes them a lot easier to digest. I take mine right before bed." (Fast, September 22, 2008). Furthermore, they give suggestions on how to behave when interacting with medical professionals, on how to meditate, or prepare for stressful events, such as holidays or Christmas. Tracy, Fast, and Walker

also mediate between people diagnosed and their loved ones, shedding light upon some of the former's behaviors and advocating for particular approaches in their interactions. The bloggers show thus their substantial knowledge while remaining relatable, and readers often express gratitude for the information they provide: "It is through your blog that I have learnt such a lot about the different bipolar drugs that are available because I have no real idea apart from the meds I take" (LucyG, purplepersuasion, July 9, 2016). Thus, many readers seek the counsel of this new type of stakeholder because they are convinced of their expertise and because they trust them. While the bloggers acknowledge the authority of mental health specialists and display substantial medical knowledge to render their views credible, they try to steer away from the controversy and suspicion which regularly surround the recommendations of medical professionals who receive honoraria from pharmaceutical companies. Such tactics are in line with those observed by scholars among 'A-list' political bloggers, who sought to increase their authority by professing their independence from the establishment, i.e. 'big media', while taking up some of their activities and professional values (Park, 2009).

One of the challenges encountered by researchers interested to collaborate with patients is to enable their contributions (Hewlett et al., 2006). This is another area where online expert mediators engage in mediation work, as they succeed to enhance the cathetic dimension Borkman (1976) referred to, and develop a space where their readers can articulate their experiences and negotiate how they position themselves in relation to their condition and the medical community. The bloggers educate people diagnosed about medical terminology and perspectives, so that they are better able to engage in collaborative projects with researchers. This is important, because not all bipolar patients may have the time and health condition necessary to grapple with medical terminology and research methodology. Moreover, Tracy, Fast, and Walker may provide people diagnosed with the confidence that the insights they have are relevant and valuable, thus enabling them to interact with medical professionals with the assurance and

determination necessary to move towards more equal exchanges. They may also help those interested in research participation to develop the patience and distance needed to accept results which may contradict their personal views.

Next to bipolar patients, the bloggers have constituted themselves into valuable allies for medical professionals who lack but need their insights derived from the lived experience with this condition for various aims. Thus, online expert mediators can assist medical professionals to acquire interactional expertise regarding the embodied experience of BP, and thus help them develop a broader perspective about this condition and novel research ideas. By positioning themselves as representatives of their bipolar readers, the bloggers provide medical professionals with important information regarding the research directions bipolar patients would find relevant. In a context where medical expertise continues to be challenged, online expert mediators further serve the interests of the medical community, by bestowing additional credibility upon the scientific approaches they champion.

The bloggers have also acquired sufficient medical knowledge and other relevant resources for medical professionals to want to collaborate with them. For instance, together with Prakash Masand, M.D., Tracy wrote an article published in 2014 in the medical journal *The Primary Care Companion for CNS Disorders*. Furthermore, in July 2016 she initiated a survey about patients' experiences concerning electroconvulsive therapy (ECT) on her personal blog:

My name is Natasha Tracy and this ECT survey was my idea. I am running this survey with Dr. Prakash Masand [hyperlink provided], the psychiatrist behind the site Global Medical Education [hyperlink provided] which aims to educate others, particularly doctors, about medical issues such as those surrounding mental illness.

For my part, I have BP and have had ECT for bipolar depression. This has made me passionate about the subject as I see the extreme debate that goes on about this treatment online. (Tracy, Bipolar Burble, July 3, 2016)

This quote emphasizes Tracy's claims to expertise -experiential but also informed by knowledge acquired online- and the complementary role she ascribes to medical professionals in the practices she takes up. While she is knowledgeable enough to come up with this idea and for an authoritative medical figure to collaborate with her, Tracy needs this partnership to legitimate her endeavor, since she lacks the apparently still necessary official accreditations. Tracy's position as an influential blogger enables her to collect quickly and cheaply data from many readers, which her medical collaborator can then use in order to produce further knowledge. Furthermore, Tracy's expertise about BP has been publicly acknowledged by medical professionals. For instance, Ronald Pies, M.D., wrote about her:

As a specialist in bipolar disorders, I can say that Natasha's understanding of this illness is more accurate and sophisticated than that of many physicians I have encountered over the past 30 years. But more than that: she shows uncommon wisdom and deep compassion, when it comes to discussing psychiatrists and psychiatry. (Pies, *Psychiatric Times*, May 24, 2012).

Reputed medical professionals have also collaborated with Fast. For instance, she co-authored the books *Take Charge of Bipolar Disorder: A 4-Step Plan for You and Your Loved Ones to Manage the Illness and Create Lasting Stability* (2004), *Loving Someone With Bipolar Disorder* (2004) and *Get It Done When You're Depressed* (2008) together with Dr. John Preston. He is now professor emeritus with Alliant International University in Sacramento, the author of 21 books, and the recipient of the "President's Award" from the Mental Health Association and of "Distinguished Contributions to Psychology Award" from the California Psychological Association. Furthermore, Fast is claimed to "train pharmacists, psychiatric residents, social workers, alternative health care practitioners, general physicians, nurse practitioners, therapists and many more health care professionals on the topics of depression and bipolar disorder management" (Amazon, 2016). The bloggers represent this new type of stakeholder, since both they and medical professionals profit from forging alliances.

The power and legitimacy they acquire through collaboration with medical professionals are subsequently used by Tracy, Fast, and Walker to engage even more substantially in research practices. For instance, Fast ventured in the production of medically-relevant knowledge on her own, developing *The Health Cards Treatment System for Bipolar Disorder*, which “works with or without medications”, as she claims (Bipolar Happens!, 2016). This system is meant both for bipolar patients and family members, and Fast states it is very successful: “I know that tens of thousands of my readers use the Health Cards daily... (...) Even my health care professionals use them!” (Fast, Bipolar Happens!, May 6, 2010). Apart from legitimating her invention, such claims show that there are areas where medical professionals can learn from her. While using Fast’s cards attests to an awareness by medical professionals that bipolar patients and their families may have needs that traditional medical approaches insufficiently address, it may also be a means for them to retain monopoly over medical knowledge at a time when other professionals challenge it.

Walker was invited to work as a researcher under supervision on a study on medication use during pregnancy, as her being a woman diagnosed with BP was thought to make the interviewees feel more comfortable. Her recounting of the first meeting with the other research collaborators reveals the importance of her online resources for researchers:

I listen to other service users’ involvement in postgraduate work and wonder who I think I’m kidding. I waffle about being a mother with bipolar disorder and having a background in maternity services. Almost as an afterthought I add that I maintain a mental health blog and have a Twitter following of several thousand service users, carers, and health professionals. “Now that”, says McPin’s Research Director, Vanessa Pinfold, “could be very useful in recruitment and dissemination.” (Walker, 2015:785)

These bloggers are thus more than interesting and inspiring conversation partners for medical professionals. They are stakeholders that researchers want to collaborate with substantially, as they can facilitate the enrolment of a high number of study

participants, they can provide experiential knowledge and important insights into relevant areas for future research. The way for such partnerships has already been paved by patient organizations, but there have also been several substantial collaborations between researchers and particular individuals. Notable in this sense are the research activities of Portia Iversen (Iversen, 2007) and Sharon Terry (Terry and Boyd, 2001), who have directly contributed to the development of new therapeutic approaches for autism, and to the identification of the gene mutation causing Pseudoxanthoma Elasticum (PXE), respectively. Yet, whereas Iversen and Terry had at their disposal important resources as the leaders of two influential patient groups and were not themselves diagnosed with the conditions they studied, Tracy, Fast, and Walker are bipolar patients and have managed to acquire the resources mentioned above individually, through their skillful use of the internet.

### **Expanding mediation**

Tracy, Fast, and Walker have expanded their mediation work by developing close relations with mass media outlets, thereby further increasing their influential standing. Tracy has been often interviewed and participated in documentaries about BP. In 2008, Fast hosted a weekly radio program, *The Julie Fast Show*, on KTRO in Portland, during which she had a number of ‘special guests’, medical professionals or people diagnosed with various mental conditions, who often wrote about their experiences and participated in advocacy actions. She is regularly interviewed on diverse mental health issues, such as Britney Spears’ nervous breakdown and Carrie Fisher’s death, and writes on mental health in magazines such as *People* and *US Weekly*. Fast was also the original consultant for the character played by Claire Danes in the popular drama series *Homeland*. Walker is a close BBC collaborator, having given numerous interviews, and participated in various talk-shows and documentaries. Fast and Tracy have also published books about their experiences with BP, thereby further extending their reach. In 2016, Tracy wrote *Lost Marbles: Insights Into My Life with Depression and Bipolar*. Fast is the author of five books, which have sold over 250,000 copies, four of which are “on the Amazon.com mood

disorder bestselling book list" (Fast, Bipolar Happens!, 2016). Through such activities, the bloggers also reach broader audiences than bipolar patients and their families, thereby contributing to how BP and other related conditions are understood by the general public. As they become more familiar with other media, these bloggers can use their skills for more political purposes, as they may generate public sympathy, emphasize the urgency of particular pieces of legislation or treatment provisions, or put forward more complex images of life with BP. In so doing, Tracy, Fast, and Walker expand their mediation work beyond the more immediately responsive online medium, translating, synthesizing, bringing together, and refining different types of knowledge about BP in formats in which interaction is more difficult, takes more time, and occurs more frequently away from the public. Yet, it is precisely through their ability to use different media and to retain a coherent image across them that these bloggers retain and further increase their influence and standing.

That their standing goes beyond that of the average blogger is indicated by the numerous awards Tracy, Fast, and Walker have received. Tracy received the Beatrice Stern Media Award and the #ErasingtheStigma Leadership Award, and has been listed as the fourth HealthMaker in the top ten online influencers in the area of mental health by Sharecare.com. She was also a speaker at the National Council on Mental Health and Addictions Conference and is hailed as one of the 'heroic' figures of people diagnosed with BP. Another indicator that her reach goes beyond the small circle of family and friends is the fact that she has been a contributor on health platforms and a subject matter expert on BP at Answers.com, all of which have millions of visitors. Fast received the Mental Health American Journalism award for the Best Mental Health Column in the U.S., while Walker's blog was selected by the UK *Mail on Sunday* as a top health blog. The blogs they authored have been voted many times among the best bipolar blogs.

### ***Interactional expertise and the internet***

In their conceptualizations of interactional expertise, Collins and Evans do not consider the effects of the medium through which interactional

expertise is displayed. I expand this notion by showing that the internet has importantly shaped how Tracy, Fast, and Walker have displayed their interactional expertise. This is all the more relevant, since "in the context of the digital shift, the demarcation between certified experts and lay people is blurring" (Dickel and Franzen, 2016 :3) An important step in this direction was taken by Shanahan (2010), who studied how scientific and personal expertise about health were expressed and discussed in the online comment section of a newspaper. Unlike Shanahan, I focus on specific individuals with a well-established public persona, who have to further demonstrate the interactional expertise displayed in their posts by (not) engaging with their readers' comments. While their audience may include contributory and interactional experts, an important difference from Shanahan is that such exchanges already take place in conditions of inequality, since as authors and owners, the bloggers speak to their readers. Her findings are nevertheless relevant, showing that online scientific expertise is not determined based on the invocation of credentials, but on one's ability to take up scientific practices, such as the provision of evidence and the citation of relevant sources, thereby revealing one's familiarity with the scientific norms and culture.

Such tactics were also adopted by Tracy, Fast, and Walker as means to articulate and reinforce their online standing. For instance, comments from readers are used as opportunities to display their expertise by giving additional medical information and by correctly identifying specific interventions. Since people with experiential expertise display growing tendencies towards scientisation in their contributions (Shanahan, 2010), these bloggers do not merely invoke scientific claims, but carefully select, apply, and interpret them. This is how Tracy reacts to a vague comment about a new test meant to determine the effectiveness of medical treatments for BP: "I believe you're talking about the cytochrome P450 (CYP450) tests which I know are offered at the Mayo Clinic. (Also used in cancer treatment)". (Tracy, Breaking Bipolar, November 5, 2012) Thus, apart from having sufficient knowledge to understand what the contributor is referring to, Tracy also contextualizes the test, linking it to other medical disciplines. The

bloggers further use their readers' comments as indicative of their informational needs and as sources of inspiration for some of their posts. From this perspective, comments help bloggers retain their popularity and influence by addressing topical issues.

Yet, the internet also poses challenges to the display of interactional expertise, as the information they provide is open to the scrutiny of people with different levels of education, different views, and at different moments in time. To become and remain credible mediators, Tracy, Fast, and Walker therefore need to show that the knowledge they share is authoritative while staying open to different perspectives. One way in which they manage such contradictory expectations is by using the internet's multiplicity, giving different nuances to their messages on different platforms. They further use the asynchronous and selective character of comment exchanges to respond advantageously to their readers' unexpected questions or reactions. Since Tracy, Fast, and Walker are at liberty to choose when they react to comments, they can take the time to acquire more information or to work on a reply until it has a satisfactory shape. In the meantime, other readers may come to their 'help', by sharing their knowledge and experiences. Their successful display of interactional expertise is also informed by the wise selection of instances when they interact with their readers. Thus, while they choose to intervene in situations where their knowledge, empathy, and relatability are emphasized, they remain silent in front of provocations which may alienate their audiences. Comments rules are another important instrument through which the bloggers may contain their readers' challenges and avoid controversy. For instance, initially Tracy did not allow commentators to provide the exact names and dosage combination of medicines. While this approach was meant to prevent readers from trying medicines without medical approval, it also weakened the epistemic claims and challenges they could bring against her.

The technology of blogs also enables Tracy, Fast, and Walker to display their interactional expertise using images and hyperlinks. Their blog entries are often accompanied by images which either illustrate the main message of the post or

bring an additional dimension to the information provided in writing. Depending on the topic, the bloggers choose for different ratios between written material and images. For instance, when discussing alternative ways of ensuring mood stability, Fast only writes a few lines but provides numerous images depicting relaxing activities. When the effects of particular medications are discussed, however, the written text dominates. Hyperlinks reveal important alliances as well as power relations. All three bloggers use them in order to show that the information they provide is based on reliable sources. They refer mainly to articles available in medical databases such as PubMed and Medscape or to posts by medical professionals on platforms where they collaborate. Tracy, Fast, and Walker thus position themselves as trustworthy mediators between reliable sources of medical knowledge and interested audiences. Hyperlinks are also used by bloggers to emphasize their vast body of work. For instance, Tracy uses them to direct readers to her older posts. Interestingly, the bloggers generally refrain from using these affordances to share knowledge produced by other people lacking accreditations or to introduce their readers to projects initiated by 'citizen scientists'. This indicates that the high standing these bloggers enjoy is not due to a subversive use of the internet, but rather to their alliances with powerful stakeholders.

In general, all three bloggers adapt the combination of medical and experiential knowledge, so that it is in line with the type of platform they contribute on, they react to comments strategically, and are very careful in their use of hyperlinks. Thus, their display of interactional expertise is importantly shaped by their use of blog affordances.

## Discussion

The bloggers discussed here can be seen as a particular and highly successful form of entrepreneurial selves (Petersen and Lupton, 1996). This new type of stakeholder- online expert mediators- represents a move away from social movements, and a focus upon exceptional patient figures, who have been able to use various resources and the opportunities and limitations the internet has

made available to become highly influential. This stakeholder category emerges thus at the intersection between a (mental) health condition, the acquisition of particular types of knowledge, and the use of a specific medium. By combining personal experiences with medical knowledge, Tracy, Fast, and Walker have gone beyond the average illness blog, where one's personal experiences are conveyed in an intimate, diary-like fashion, and have come closer to issue-based blogs, where different types of information considered relevant about a particular topic are provided and discussed using arguments and multiple perspectives (O'Neil, 2005). The interactional expertise that they develop and articulate to various degrees has a strong bi-directionality, as they need to be fluent in the language of medical knowledge of BP as well as to retain their experiential knowledge in a format which allows them to relate to readers diagnosed with BP and their families. Thus, in their acquisition and articulation of interactional expertise, online expert mediators are reminiscent of journalists, who "develop different degrees of bipolar 'interactional expertise', specializing in interactions with their sources on the one hand and audiences on the other" (Reich, 2012: 339).

The rise of these stakeholders takes place in a context in which the informational and health imperatives require people to assume responsibility about their health (Kivits, 2013), yet the difficulties of living with a particular condition may prompt them to prefer to follow someone else's lead (Lemire et al., 2008). Since the expertise of medical professionals has been challenged over the last decades, many people diagnosed may seek to resolve this tension by following the advice of this new stakeholder type, by using such expert bloggers as arbiters. At the same time, the rise of this new stakeholder is also due to patients and their families requiring, apart from medical information, also encouragement and guidance. Nevertheless, these new stakeholders are also confronted with suspicion given the varying quality of the health information available online and the growing awareness that many public speakers and opinion-setters represent particular groups of interest. To be successful, online expert mediators therefore need to convince their

readers to develop different types of trust: they must trust the bloggers; they must trust certain online spaces or platforms; they must trust (at least) the branches of science the bloggers themselves rely upon (Harris et al., 2011).

Importantly, this study has indicated that the medium plays an important role in how interactional expertise is displayed, thereby extending Collins and Evans conceptualization of this notion. In so doing, it has also brought into relief some problematic aspects concerning the development of this new stakeholder category. While interactional expertise is necessary for this new type of stakeholdership, a strong medium is also needed. Developing interactional expertise has enabled Tracy, Fast, and Walker to gain access and to develop close contacts with medical professionals, yet it is their online popularity which has provided them with the resources necessary to engage in substantial exchanges with the latter. The internet has therefore allowed them to convincingly position themselves in their relations with medical scientists as representatives of people with BP in a way which is reminiscent of the tactics of American AIDS activists described by Epstein (1996). Epstein problematized the position 'lay experts' occupy in relation to the 'lay lay', highlighting that the acquisition of competence into a new type of knowledge impacts on how one understands and relates to the other types of knowledge with which one is endowed as well as on one's relations to others. Thus, he argued that by "learning the language and culture of medical science" (Epstein, 1995: 417) people diagnosed risk distancing themselves from other people diagnosed with the same condition, from their views and interests. From this perspective, the close collaborations the bloggers develop with medical professionals may lead to a further obfuscation of the differences in experience as well as in interests, needs, and values existing between people diagnosed with BP (Rowland et al., 2012), who follow these bloggers online.

While blogs have been acknowledged as technologies with a democratizing potential (Huovila and Saikkonen, 2016), the findings presented here show that online expert mediators acquire such high standing by developing close ties with 'traditional' experts. Thus, rather than contributing to

opening the field of scientific knowledge production to more people who lack official credentials, online expert mediators might inadvertently contribute to the refinement of existing hierarchies in the relations between medical professionals and patients. From this perspective, it is regrettable that the interactions between these bloggers and medical professionals occur most of the time offline or through private communication, so that it is not possible to observe how they negotiate participation in various projects and support for various initiatives. Since the bloggers' interactional expertise is limited to particular areas of medical knowledge on BP and does not exclude personal preferences, online expert mediators also risk presenting their readers a skewed perspective on the use and effectiveness of the currently available forms of treatment. Another danger stems from the mediation work online expert mediators engage in between family members, as they may end up certifying particular symptoms and behaviors, with which they are acquainted, while casting doubt upon the authenticity of those they are not familiar with.

The online expert mediators studied here creatively combined their personal insights about BP with medical knowledge in their online contributions. In so doing, they not only selected and adapted the medical knowledge they were familiar with to best serve their purposes, but they also translated it into a more accessible vocabulary for people less familiar with medical terminology. By doing so, they may help bridge the digital divide when it comes to medical literacy by sharing medical knowledge in an accessible manner, by making people diagnosed and their families aware of the options at their disposal, and by helping them get in touch with support groups and other organizations. While some people diagnosed with other mental conditions, such as autism and schizophrenia, have used the internet to legitimate their claims by arguing that their personal experiences should be understood as different ways of being in the world rather than as pathological behaviors (Ringer and Holen, 2016; Crossley, 2006), the online expert mediators discussed here legitimated their claims

using medical knowledge. Having achieved a highly influential position, in the future they might harness their creativity and various skills to contribute in novel ways to the proliferation and diversification of collaborations between people diagnosed and medical professionals.

The analysis of these bloggers' activities has also provided important insights regarding some of the conditions necessary to become such stakeholders. Thus, next to an official diagnosis, people's health needs to be stable enough for them to engage in various activities requiring a lot of time and energy. They also need to be able to communicate in ways which can capture and retain the interest of different stakeholders. Furthermore, those interested need either to financially afford giving up their jobs to dedicate themselves to the development of blogs or to be willing to accept sponsorship or another form of payment, thereby running the risk of losing their social benefits. More research is needed to understand the ways in which other kinds of knowledge and online skills shape the acquisition and articulation of interactional expertise, and into the differences and similarities concerning the mediation work undertaken by this new stakeholder category across different conditions. Fortunately, the internet waits to delight<sup>1</sup> in further interactions and new questions...

## Acknowledgements

The research on which this article is based was supported by the Netherlands Organization for Scientific Research (grant number PGW-14-07/2014). I am very grateful to Sally Wyatt and Tamar Sharon for their support and constructive feedback through multiple readings and discussions of the materials presented here. I would also like to thank Johanna Höffken and Gili Yaron, who gave feedback on an earlier version of this paper at a PhD Writeshop organized by the Netherlands Graduate School of Science, Technology and Modern Culture (WTMC). I am grateful to the anonymous reviewers, whose constructive comments and suggestions helped improve the paper greatly.

## References:

- Adams S (2013) Maintaining the Collision of Accounts: Crowdsourcing Sites in Health Care As Brokers in the Co-Production of Pharmaceutical Knowledge. *Information, Communication & Society* 17(6): 657-669.
- Amazon (2016) Julie A Fast – Amazon webpage. Available at: <https://www.amazon.com/Julie-A.-Fast/e/B001IGUPAA> (accessed 3.12.2016)
- Arksey H (1994) Expert and Lay Participation in the Construction of Medical Knowledge. *Sociology of Health & Illness* 16(4): 448-468.
- Armstrong D (1995) The Rise of Surveillance Medicine. *Sociology of Health & Illness* 17 (3): 393-404.
- Barbot J and Dodier N (2002) Multiplicity in Scientific Medicine: The Experience of HIV-positive Patients. *Science, Technology & Human Values* 27: 404-440.
- Barbot J (2006) How To Build An “Active” Patient? The Work of AIDS Associations in France. *Social Science & Medicine* 62: 538-551.
- Barak A (1999) Psychological Applications on the Internet: A Discipline on the Threshold of a New Millennium. *Applied & Preventive Psychology* 8: 231-246.
- Barak A and Grohol J (2011) Current and Future Trends in Internet-Supported Mental Health Interventions. *Journal of Technology in Human Services* 29(3): 155-196.
- Barak A, Hen L, Boniel-Nissim M and Shapira N (2008) A Comprehensive Review and a Meta-Analysis of the Effectiveness of Internet-Based Psychotherapeutic Interventions. *Journal of Technology in Human Services* 26(2/4): 109-160.
- Barello S, Graffigna G, Vegni E and Bosio A (2014) The Challenges of Conceptualizing Patient Engagement in Health Care: A Lexicographic Literature Review. *Journal of Participatory Medicine* 6(11): 1-15.
- Barnes M and Shardlow P (1997) From Passive Recipient to Active Citizen: Participation in Mental Health User Groups. *Journal of Mental Health* 6(3): 289-300.
- Borkman T (1976) Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups. *Social Service Review* 50(3): 445-456.
- Bottles K (2013) Health Hackers and Citizen Scientists Shake Up Medical Research. *Physician Executive Journal*: 88-90.
- Brodwin P and Velpry L (2014) The Practice of Constraint in Psychiatry: Emergent Forms of Care and Control. *Culture, Medicine, and Psychiatry* 38(4): 524-526.
- Brown P (1988) *The Transfer of Care: Psychiatric Deinstitutionalization and Its Aftermath*. London: Routledge Kegan & Paul.
- Carlbring P and Andersson G (2006) Internet and Psychological Treatment. How Well Can They Be Combined? *Computers in Human Behavior* 22: 545-553.
- Collins H and Evans R (2002) The Third Wave of Science Studies. Studies of Expertise and Experience. *Social Studies of Science* 32(2): 235-296.
- Collins H, Evans R, Ribeiro R and Hall M (2006) Experiments with Interactional Expertise. *Studies in History and Philosophy of Science* 37: 656-674.
- Collins H and Evans R (2007) *Re-thinking Expertise*. Chicago: The University of Chicago Press.
- Collins H and Evans R (2015) Expertise Revisited, Part I - Interactional Expertise. *Studies in History and Philosophy of Science* 54: 113-123.
- Collins H, Evans R and Weinel M (2017) Interactional Expertise. In Felt U, Fouché R, Miller C and Smith-Doerr L (eds) *The Handbook of Science and Technology Studies* (4th ed). Cambridge, MA: The MIT Press, pp. 765-792.

- Crossley M and Crossley N (2001) 'Patient' Voices, Social Movements and the Habitus: How Psychiatric Survivors 'Speak Out'. *Social Science & Medicine* 52:1477-1489.
- Crossley N (2006) The Field of Psychiatric Contention in the UK, 1960-2000. *Social Science & Medicine* 62: 552-563.
- Davidson L (2005) Recovery, Self Management and the Expert Patient- Changing the Culture of Mental Health from a UK Perspective. *Journal of Mental Health* 14(1): 25-35.
- De Boer M and Slatman J (2014) Blogging and Breast Cancer: Narrating One's Life, Body and Self on the Internet. *Women's Studies International Forum* 44(1): 17-25.
- Dickel S and Franzen M (2016) The "Problem of Extension" Revisited: New Modes of Digital Participation in Science. *Journal of Science Communication* 15(1): 1-15.
- Director D (2005) Using an Action Research Approach to Involving Service Users in the Assessment of Professional Competence. *European Journal of Social Work* 8(2): 165-179.
- Epstein S (1995) The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. *Science, Technology & Human Values* 20(4): 408-437.
- Epstein S (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Eysenbach G, Powell J, Englesakis M, Rizo C and Stern A (2004) Health Related Virtual Communities and Electronic Support Groups: Systematic Review of The Effects of Online Peer To Peer Interactions. *British Medical Journal* 328(7449): 1166-1170.
- Fox N, Ward K and O'Rourke A (2005) The 'Expert Patient': Empowerment or Medical Dominance? The Case of Weight Loss, Pharmaceutical Drugs and the Internet. *Social Science & Medicine* 69: 1299-1309.
- Gillard S, Simons L, Turner K, Lucock M and Edwards C (2012) Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study. *Qualitative Health Research* 22(8): 1126-1137.
- Goddiksen M (2014) Clarifying Interactional and Contributory Expertise. *Studies in History and Philosophy of Science* 47: 111-117.
- Godfrey M, Callaghan G, Johnson L and Waddington E (2003) *Supporting People: A Guide to User Involvement for Organizations Providing Housing Related Support Services*. London: Office of the Deputy Prime Minister.
- Gowen K, Deschaine M, Gruttadara D and Markey D (2012) Young Adults with Mental Health Conditions and Social Networking Websites: Seeking Tools To Build Community. *Psychiatric Rehabilitation Journal* 35(3): 245-250.
- Grob G (2005) The Transformation of Mental Health Policy in Twentieth-Century America. In: Gijswijt-Hofstra M, Oosterhuis H, Vijselaar J and Freeman H (eds) *Psychiatry and Mental Health Care in the Twentieth-Century: Comparisons and Approaches*. Amsterdam: Amsterdam University Press, pp. 141-161.
- Hardey M (1999) Doctor in the House: The Internet as A Source of Lay Health Knowledge and the Challenge to Expertise. *Sociology of Healthy & Illness* 21: 820-835.
- Haker H, Lauber C and Rössler W (2005) Internet Forums: A Self-Help Approach for Individuals with Schizophrenia? *Acta Psychiatrica Scandinavica* 112: 474-477.
- Harris A, Wyatt S and Kelly S (2011) Conceptualizing Trust in Digital Environments. Health-e skepticism: Trust in the Age of the Internet. In: *A Decade in Internet Time: Symposium on the Dynamics of the Internet and Society* (OII-ICS Symposium), Oxford, UK, 21-24 September 2011, 1-11.
- Heilferty C (2009) Toward A Theory of Online Communication in Illness: Concept Analysis of Illness Blogs. *Journal of Advanced Nursing* 65(7): 1539-1547.

- Hewlett S, Wit M, Richards P et al. (2006) Patients and Professionals as Research Partners: Challenges, Practicalities, and Benefits. *Arthritis Care & Research* 55(4): 676-680.
- Hickey G and Kipping C (1998) Exploring the Concept of User Involvement in Mental Health Through a Participation Continuum. *Journal of Clinical Nursing*, 7: 83-88.
- Hogg C (2009) *Citizens, Consumers and the NHS: Capturing Voices*. Basingstoke: Palgrave Macmillan.
- Horwitz A and Wakefield J (2007) *The Loss of Sadness. How Psychiatry Transformed Normal Sorrow into Depressive Disorder*. Oxford: Oxford University Press.
- Huovila J and Saikkonen S (2016) Establishing Credibility, Constructing Understanding: The Epistemic Struggle over Healthy Eating in the Finnish Dietetic Blogosphere. *Health* 20(4): 383-400.
- Iversen P (2007) *Strange Son: Two Mothers, Two Sons, and the Quest to Unlock the Hidden World of Autism*. New York: Riverhead Books.
- Kallinikos J and Tempini N (2014) Patient Data as Medical Facts: Social Media Practices as a Foundation for Medical Knowledge Creation. *Information Systems Research* 25(4): 817-833.
- Kemp P (2010) The Creative Involvement of Service Users in the Classroom. In Weinstein J (ed) *Mental Health, Service User Involvement and Recovery*. London: Jessica Kingsley Publishers, pp. 15-29.
- Kirsch I (2010) *The Emperor's New Drugs: Exploding the Antidepressant Myth*. New York: Basic Books.
- Kivits J (2009) Everyday Health and the Internet: A Mediated Health Perspective on Health Information Seeking. *Sociology of Health and Illness* 31(5): 673-687.
- Kivits J (2013) E-Health and Renewed Sociological Approaches to Health and Illness. In: Orton-Johnson and Prior N (eds) *Digital Sociology. Critical Perspectives*. Houndmills: Palgrave Macmillan, pp. 213-226.
- Klawiter M (1999) Racing for the Cure, Walking Women, and Toxic Touring: Mapping Cultures of Action within the Bay Area Terrain of Breast Cancer. *Social Problems* 46(1): 104-126.
- Kopelson K (2009) Writing Patients' Wrongs: The Rhetoric and Reality of Information Age Medicine. *Journal of Advanced Composition* 29: 353-404.
- Kraus R, Stricker G and Speyer C (eds) (2010). *Online Counseling: A Handbook for Mental Health Professionals* (2nd ed). San Diego, CA: Elsevier Academic Press.
- Kushner H (2004) Competing Medical Cultures, Patient Support Groups, and the Construction of Tourette's Syndrome. In: Packard R, Brown P, Berkelman R and Frumkin H (eds) *Emerging Illnesses and Society: Negotiating the Public Health*. Baltimore: John Hopkins University Press, pp. 71-101.
- Lamberg L (2003) Online Empathy for Mood Disorder. Patients Turn to Internet Support Groups. *Medical News & Perspectives* 289(23): 3073-3077.
- Landzelius K (2006) Introduction: Patient Organization Movements and New Metamorphoses in Patienthood. *Social Science & Medicine* 62(3): 529- 537.
- Latour B (2005) *Re-assembling the Social. An Introduction to Actor-Network Theory*. Oxford: Oxford University Press.
- Lemire M, Sicotte C and Paré G (2008) Internet Use and The Logics of Personal Empowerment in Health. *Health Policy* 88: 130-140.
- Lerner B (2001) No Shrinking Violet: Rose Kushner and the Rise of American Breast Cancer Activism. *Western Journal of Medicine* 174(5): 362.
- Lucivero F and Prainsack B (2015) The Lifestylization of Healthcare? Consumer Genomics' and Mobile Health as Technologies for Healthy Lifestyle. *Applied & Translational Genomics* 4: 44-49.
- Lupton D (1995) *The Imperative of Health: Public Health and the Regulated Body*. London: Sage Publications.

- Lupton D (1997) Foucault and The Medicalisation Critique. In: Petersen A and Bunton R (eds) *Foucault, Health and Medicine*. London: Routledge, pp. 94-112.
- Lupton D (2014) The Commodification of Patient Opinion: The Digital Patient Experience Economy in the Age of Big Data. *Sociology of Health & Illness* 36(6): 856-869.
- Marks I, Cavanagh K and Gega L (2007) *Hands-On Help. Computer-aided Psychotherapy*. New York: Psychology Press.
- Mazanderani F, Locock L and Powell J (2012) Being Differently The Same: The Mediation of Identity Tensions in the Sharing of Illness Experiences. *Social Science & Medicine* 74(4): 546-553.
- McLean A (2000) From Ex-Patient Alternatives to Consumer Options: Consequences of Consumerism for Psychiatric Consumers and the Ex-Patient Movement. *International Journal of Health Services* 30(4): 821-847.
- McPherson S and Armstrong D (2006) Social Determinants of Diagnostic Labels in Depression. *Social Science & Medicine* 62(11): 50-58.
- Mulveen R and Hepworth J (2006) An Interpretative Phenomenological Analysis of Participation in a Pro-Anorexia Internet Site and Its Relationship with Disordered Eating. *Journal of Health Psychology* 11(2): 283-296.
- Naslund J, Aschbrenner K, Marsch L, McHugo G and Barteks S (2015) Crowdsourcing for conducting randomized trials of internet delivered interventions in people with serious mental illness: A systematic review. *Contemporary Clinical Trials* 44: 77-88.
- Nicholas J, Larsen M, Proudfoot J and Christensen H (2015) Mobile Apps for BP: A Systematic Review of Features and Content Quality. *Journal of Medical Internet Research* 17(8): e198.
- Nettleton S (2004) "The Emergence of E-scaped Medicine?". *Sociology* 38(4): 661-679.
- Novas C (2006) The Political Economy of Hope: Patients' Organizations, Science and Biovalue. *BioSocieties* 1: 289-305.
- Park D (2009) Blogging with Authority: Strategic Positioning in Political Blogs. *International Journal of Communication* 3: 250-273.
- Pickersgill M (2012) What is Psychiatry? Co-Producing Complexity in Mental Health. *Social Theory & Health* 10: 328-347.
- Plaisance K and Kennedy E (2014) A Pluralistic Approach to Interactional Expertise. *Studies in History and Philosophy of Science* 47: 60-68.
- Pols J (2014) Knowing Patients: Turning Patient Knowledge into Science. *Science, Technology & Human Values* 39(1): 73-97.
- Prior L (2003) Belief, Knowledge and Expertise: The Emergence of the Lay Expert in Medical Sociology. *Sociology of Health & Illness* 25: 41-57.
- Proudfoot J (2004) Computer-Based Treatment for Anxiety and Depression: Is It Feasible? Is It Effective? *Neuroscience and Behavioral Reviews* 28: 353-363.
- O'Neil M (2005) Weblogs and Authority. *Selected Works*. University Paris IV Sorbonne. Available at: [https://works.bepress.com/mathieu\\_oneil/12/](https://works.bepress.com/mathieu_oneil/12/) (accessed 18.11.2014).
- Oravec J (2000) Online Counselling and the Internet: Perspectives for Mental Health Care Supervision and Education. *Journal of Mental Health* 9(2): 121-135.
- Orsini M and Smith M (2010) Social Movements, Knowledge and Public Policy: The Case of Autism Activism in Canada and the US. *Critical Policy Studies* 4(1): 38-57.

- Pies R (2012) Moving Beyond Hatred of Psychiatry: A Brave Voice Speaks Out. *Psychiatric Times*, May 24, 2012. Available at: <http://www.psychiatristimes.com/bipolar-disorder/moving-beyond-hatred-psychiatry-brave-voice-speaks-out> (accessed 3.12.2016).
- Rabeharisoa V, Moreira T and Akrich M (2013) Evidence-based Activism: Patients' Organizations, Users' and Activist's Groups in Knowledge Society". *CSI Working Papers Series* 033: 1-27.
- Radin P (2006) "To Me, It's My Life": Medical Communication, Trust, and Activism in Cyberspace. *Social Science & Medicine* 62: 591-601.
- Reich Z (2012) Journalism as Bipolar Interactional Expertise. *Communication Theory* 22: 339-358.
- Ringer A and Holen M (2016) "Hell, no, they'll think you're mad as a hatter": Illness Discourses and their Implications for Patients in Mental Health Practice. *Health* 20(2): 161-175.
- Rose N (2007) *The Politics of Life Itself. Biomedicine, Power and Subjectivity in the Twenty-First Century*. Princeton: Princeton University Press
- Rowland P, McMillan S, McGillicuddy P, Richards J (2017) What Is "The Patient Perspective" in Patient Engagement Programs? Implicit Logics and Parallels to Feminist Theories. *Health* 21(1): 76-92.
- Schaffer R, Kuczynski K, Skinner D (2008) Producing Genetic Knowledge and Citizenship Through the Internet: Mothers, Pediatric Genetics, and Cybermedicine. *Sociology of Health and Illness* 30(1): 145-159.
- Shanahan M (2010) Changing the Meaning of Peer-To-Peer? Exploring Online Comment Spaces as Sites of Negotiated Expertise. *Journal of Science Communication* 9(1): 1-13.
- Sharon T (2017) Self-tracking for Health and the Quantified Self: Re-articulating Autonomy, Solidarity and Authenticity in An Age of Personalized Healthcare. *Philosophy & Technology*, 30(1): 93-121.
- Smith DJ, Griffiths E, Poole R et al. (2011) Beating Bipolar: Exploratory Trial of a Novel Internet-Based Psychoeducational Treatment for BP. *Bipolar Disorders*, 13: 571-577.
- Scott S (2006) The Medicalisation of Shyness: From Social Misfits to Social Fitness. *Sociology of Health & Illness* 28(2): 133-153.
- Speed E (2006) Patients, Consumers, and Survivors: A Case Study of Mental Health Service User Discourses. *Social Science & Medicine* 62: 28-38.
- Taussig K-S, Rapp R and Heath D (2003) Flexible Eugenics: Technologies of the Self in the Age of Genetics. In: Goodman A, Heath D and Lindee SM(eds) *Genetic Nature/Culture: Anthropology and Science Beyond the Two-Culture Divide*. Berkeley: University of California Press, pp. 58-76.
- Terry S and Boyd C (2001) Researching the Biology of PXE: Partnering in the Process. *American Journal of Medical Genetics* 106: 177-184.
- Treichler P (1999) *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press.
- Tremayne M (2007) *Blogging, Citizenship and the Future of Media*. London: Routledge.
- Turner B (1995) *Medical Power and Social Knowledge* (2nd ed). London: Sage.
- Tutton R and Prainsack B (2011) Enterprising or Altruistic Selves? Making Up Research Subjects in Genetics Research. *Sociology of Health & Illness* 33(7): 1081-1095.
- Wathen N, Wyatt S and Harris R (2008) *Mediating Health Information: The Go-Betweens in a Changing Socio-Technical Landscape*. Houndmills: Palgrave Macmillan.
- Whitaker R (2010) *Anatomy of An Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness*. New York: Crown Publishing Group.
- Whitley R (2012) The Antipsychiatry Movement: Dead, Diminishing, or Developing? *Psychiatric Services* 63(10): 1039-1041.

Wright R and Cummings A (2005) *Destructive Trends in Mental Health. The Well-Intentioned Path to Harm*. London: Routledge

Wyatt S, Harris A and Adams S (2013) Illness Online: Self-Reported Data and Questions of Trust in Medical and Social Research. *Theory, Culture & Society* 30(4): 131-150.

Ybarra M and Eaton W (2005) Internet-Based Mental Health Interventions. *Mental Health Services Research* 7(2): 75-87.

## Appendix 1

### **Blog references cited in this article:**

- Fast J (2008) Omega 3 Fish Oil Tip. *Bipolar Happens!*, September 22, 2008. Available at: <http://bipolarhappens.com/bhblog/omega-3-fish-oil-tip/> (accessed 3.12.2016)
- Fast J (2010) Don't Forget Your Health Cards. *Bipolar Happens!*, May 6, 2010. Available at: <http://bipolarhappens.com/bhblog/dont-forget-your-health-cards/#comments> (accessed 3.12.2016)
- Fast J (2015) What is the Difference between BP and Schizo-Affective Disorder? *Fast Talk*, December 31, 2015. Bp Hope. Available at: <http://www.bphope.com/blog/what-is-the-difference-bw-bipolar-disorder-and-schizo-affective-disorder/> (accessed at 3.12.2016)
- Fast J (2016) BP Medications: Kaiser sues Pfizer over Misrepresentation of Gabapentine (Neurontin). *Bipolar Happens!*, October 17, 2016. Available at: <http://bipolarhappens.com/bhblog/kaiser-sues-pfizer-over-misrepresentation-of-gabapentine-neurontin/> (accessed 22.11. 2016)
- Tracy N (2012) What to Do About Drug Tolerance. *Bipolar Bites*, May 30, 2012. Available at: <http://www.healthline.com/health-blogs/bipolar-bites/what-do-about-drug-tolerance#1> (accessed 23. 04.2016)
- Tracy N (2012) How Do You Know If It's the Therapy or the Drugs That Is Working? *Breaking Bipolar*, November 5, 2012. Available at: <http://www.healthypace.com/blogs/breakingbipolar/2012/11/how-know-therapy-or-drugs-working/> (accessed 9.09.2014)
- Tracy N (2013) New Recommendations for Antidepressant Use in BP. *Bipolar Bites*, July 10, 2013. Available at: <http://www.healthline.com/health-blogs/bipolar-bites/new-recommendations-antidepressant-use-bipolar-disorder#1> (accessed 23.04.2016)
- Tracy N (2012) GlaxoSmithKline to Pay \$3 Billion in Fines -So What? *Breaking Bipolar*, July 5, 2012. Available at <http://www.healthypace.com/blogs/breakingbipolar/2012/07/glaxosmithkline-pay-3-billion-fines-so-what/> (accessed 19.07.2016)
- Tracy N (2011) Be a Good Mental Health (or Bipolar) Patient- Participate and Choose to Get Better. *Breaking Bipolar*. Reply to comment by Joel, June 30, 2011. Available at: <http://www.healthypace.com/blogs/breakingbipolar/2011/07/be-a-good-patient-choose-to-be-get-better/> (accessed 15.09.2014)
- Tracy N (2016) Real Patient Experiences with ECT and Perspectives on ECT. *Bipolar Burble*, April 24, 2016. Available at: <http://natashatracy.com/treatment/neurostimulation-treatment/ect/real-patient-experiences-ect-perspectives-ect/> (accessed 03.07.2016)
- Walker C (2014) A bath, a brew and a benzo: is this what Home Treatment Teams have come to?. *purplepersuasion*, June 23, 2014. Available at: <https://purplepersuasion.wordpress.com/2014/06/23/a-bath-a-brew-and-a-benzo-is-this-what-home-treatment-teams-have-come-to/> (accessed 22.11.2016)
- Walker C (2015) It's my movie, and I'll watch where I want to. *purplepersuasion*, February 11, 2015. Available at: <https://purplepersuasion.wordpress.com/2015/02/11/its-my-movie-and-ill-watch-where-i-want-to/> (accessed 22.11.2016)
- Walker C (2016) Look Mum, no antipsychotics! *purplepersuasion*, July 8, 2016. Available at <https://purplepersuasion.wordpress.com/2016/07/08/look-mum-no-antipsychotics/> (accessed 22.11.2016)

## Notes

- 1 The last sentence of this article is a paraphrase of a line from Charles Bukowski's poem "The laughing heart". *Betting on the Muse: Poems and Stories* (1996). Harper Collins e-books.