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## **Epilepsy, digital technology and the black-boxed self**

In 2008 British artist Gus Cummins created a piece of video art entitled 'Invaders'. Mimicking the interface of the classic 1970s arcade video game Cummins used his alien theme to figuratively relay the experience of having epilepsy. Like the attacking space invaders, epilepsy assaults the subject's autonomy, threatening the individual's control over their own mind and body, and agency: 'rogue neurons invade my brain / seizures invade comfort zones / expectations invade lives' (Cummins, 2008). Here the recall of this old new media, with its blinking, pixelated graphics and repetitive synthesised music soundtrack, its rapid and high-stress game play reliant on hand-eye coordination, and its battle scenario, complete with laser-shooting alien enemies and multiple lives, may evoke nostalgic memories for some viewers. Simultaneously it represents an environment whose features press at the thresholds of the seizure-prone brain. Cummins further overlays this interface with aural and visual renderings of his own seizure patterns, which bombard the viewer's senses. The chaotic experience of the individual who is seizing is conflated with a visual spectacle reminiscent of the drama of witnessing a seizure. Cummins' artwork asks viewers to construct meaning from such informational excess, while undermining the valence of sensory data.

'Space Invaders' gains its effects in part by tapping into a cultural tradition in which epilepsy has been conceived in terms of electrical media, and visual technologies in particular. This analogy seems almost a given today (although in fact is only one model among many by which epilepsy has been thought about through its long history). The development of electroencephalography (EEG) technology after 1929 demonstrated that this highly-stigmatised chronic brain condition, often accompanied by spectacular symptomatology, was the result of excessive electrical discharge across the neural networks in the brain; since then, with the advent of modern computing, epilepsy has

been heavily associated with malfunctioning digital machines. In this article I trace this history of epilepsy's affinities with new media, following scholars such as Friedrich Kittler (2010), Matthew Rubery (2016) and others, who argue that the emergence of new technologies has long been intertwined with new conceptions of dis/ability.<sup>1</sup>

To trace this history, I draw on instances of epilepsy's (technological) representation in the socio-cultural imaginary across the last 100 years. In addition, I place this wider narrative in conversation with interviews conducted with people with epilepsy (PWE) about their use of social and new media.<sup>2</sup> These interviews are conceived methodologically as examples of co-produced accounts of identity representation, to be interpreted across a wider set of cultural texts, rather than as offering any kind of 'revealed' truth (Savage and Burrows, 2007; Atkinson and Silverman, 1997; Roach, 2014). In bringing them together I follow disabilities scholar Rosemarie Garland Thomson (1997), who famously argued that 'representation attaches meaning to bodies' and that disability is a 'representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions, ... the attribution of corporeal deviance' (pp. 5, 6). Coining the helpful term of 'normate' to describe the 'social figure through which people can represent themselves as definitive human beings', Garland Thomson indicates that the normate and the

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<sup>1</sup> While schizophrenia has received the bulk of attention from media scholars, thanks in part to Victor Tausk's classic 1919 article 'On the Origin of the 'Influencing Machine' in Schizophrenia' (English trans, 1933), epilepsy's neurological origin and ambiguous position between physical disability and stigmatized mental illness makes it a compelling study for media theorists.

<sup>2</sup> I draw on 15 semi-structured interviews conducted with members of the Epilepsy Action e-mail list between May 2014 and December 2015. Participants were asked about their usage of social media and networked-digital devices generally and for epilepsy-management. Within this context, they were asked to reflect on their identity and self-representation online. The research was conducted in collaboration with Leone Ridsdale at the Institute of Psychiatry, Psychology & Neuroscience, King's College London [Research Ethics Committee no. PNM/13/14-18]. My thanks to the participants, to Epilepsy Action for facilitating contact, and to Leone Ridsdale for her support and guidance.

disabled are mutually-constituted figures (1997: 8). While epilepsy has an uneasy relationship to physical disability (Wendell, 2013) and is often mistakenly conceived as a mental illness, the epileptic body is frequently encoded as deviant and non-normate, becoming, like Garland Thomson's extraordinary bodies 'a repository for social anxieties about such troubling concerns as vulnerability, control, and identity' (1997: 6). As David T. Mitchell and Sharon L. Snyder have argued, historically disability has functioned as a 'narrative prosthesis', a 'crutch upon which literary narratives lean for their representational power, disruptive potential and analytical insight', (2000: 49), or what Ato Quayson describes as an excessive sign that invites, yet resists interpretation (2007; 14). In this article I demonstrate the ways in which epilepsy has been heavily technologized in the second half of the twentieth century and outline the implications of this for representations of the PWE today. Tracking this connection across the emergence of the 'societies of control' (Deleuze, 1992) reveals suggestive parallels between the stigmatised PWE and the data-driven subject (the 'dividual') of today's digital environment. As Amit Pinchevski and John Durham Peters note, 'Pathology not only reveals normality, as the doctors have always said, but it also reveals technology' (2016: 2508).

### **Conceptualising Epilepsy**

One of the most common serious brain condition worldwide, epilepsy affects at least 50 million people worldwide, with around 80 per cent of PWE living in low-income countries with little access to medical treatment (WHO, 2016). In the UK 1% of the population are affected by epilepsy (Ridsdale, et al, 2011). Epilepsy can be overt, i.e. symptomatic (caused by to damage to the brain), cryptogenic (inferred damage to the brain) or idiopathic (no known cause). Epilepsy is characterised by the occurrence of seizures, which are caused by disruptions to the brain's electrical impulses, and excessive

discharge of energy across a group of cells. Not all seizures are due to epilepsy and the diagnosis covers a spectrum of epilepsies. Seizures can vary in type, severity and frequency and are usually distinguished as being either focal (partial) or generalised. In the former the seizure affects only part of the brain to begin with, with symptoms dependent on the area of the brain involved. These can range from temporary loss of movement or repetitive movements, the experience of strong emotions or tastes, to loss of speech and other cognitive abilities. In generalised seizures both hemispheres of the brain are affected, usually with a loss of consciousness involved (sometimes extremely brief). So-called 'tonic-clonic' seizures are historically associated with epileptic seizures that involve loss of consciousness and muscle jerks, although others involve only brief states of altered consciousness, often with the appearance of daydreaming (absence), muscle jerks (myoclonic) and other symptoms. In convulsive tonic-clonic seizures the brain can be deprived of oxygen, leading to its further injury. The medical emergency *status epilepticus* is the continuation of a seizure or cluster of seizures for more than thirty minutes and can lead to brain injury and death. Epilepsy also brings with it the risk of sudden unexpected death in epilepsy (SUDEP), the cause of which is unknown. More commonly, PWE suffer injuries (or even death) as a result of seizures, including drowning, burns, tongue-biting, head injuries, bruises and muscle strain. Photosensitivity and stress can act as triggers. There is currently no cure and treatment relies heavily on the use of anti-convulsive drugs, many of which have extensive side effects. For around a third of PWE, available treatments do not work.

Epilepsy has been heavily stigmatised across cultures and time periods, resulting in what today is understood as felt and enacted stigma (Scambler, 1989, 2009).

Throughout history epilepsy has often signified 'some sort of catastrophic upheaval in codes of propriety and the symbolic order' (Stirling, 2008: 2). Like many neurological conditions, epilepsy was poorly understood prior to the twentieth century and frequently

associated with spirit possession, religious ecstasy, mental illness and moral turpitude. While identification of epilepsy as a brain disorder has helped to assuage some stigma, even today, myths and misinformation around epilepsy are, as Sallie Baxendale and Annette O'Toole (2007) have noted, 'alive and foaming'.

In the nineteenth century confusion around the multiplicity of seizure-types slowed identification, while also opening up epilepsy to a wide range of discourses and representational economies. In this period spasms were associated with hysteria, eclampsia and orgasm, helping to position epilepsy within a discourse of feminine excess. Similarly, confusion around its relationship with catalepsy ensured that epilepsy was situated on the borderlands of scientific knowledge and entertainment (Willis, 2014). Assessing the 'aesthetics of the spasm' in nineteenth century novels, Peter Cryle (2008) argues that 'In the [epilepsy] spasm, pain, pleasure, the expression of inner forces, and an intimate foreknowledge of death were held together in one utterly compelling symptom'. Throughout its history the seizure has been conceived to be involuntary on the part of the individual experiencing it, but stimulating as a metaphorical trope within the wider culture.

Despite the spasms being on the spectrum of normal bodily function, as Jeanette Stirling (2008) has pointed out, the epileptic seizure is often conceived in modernity as a symptom of an uncontrolled body in need of Foucauldian discipline (p. 31). Interviewees recount that they are considered drunk by passersby if they seize on the street, with significant ramifications for the amount of support they receive (Participants 4, 10). The agency and (criminal) responsibility of the subject has often been an open question, something that crime writers from Robert Louis Stevenson to Agatha Christie have deployed to their advantage. Meanwhile the unconscious or mechanical actions that seemed to characterise some seizure states appeared to suggest to doctors and writers alike that the seizing subject resembled an automaton. Possessing both too much agency

and not enough, the PWE was positioned as troubling to post-Enlightenment conceptions of the subject.

The tonic-clonic seizure has particularly marked the individual with epilepsy: representative of the uncontrollable body in an increasingly rationalising society. The advent of what James Beniger (1986) called the ‘Control Revolution’ of the late nineteenth century and the concomitant emphasis on classification, standardization and efficiency would begin to position the seizing body as resistant. Much has been written on the implications of this revolution, and on associated classificatory systems such as those of Alphonse Bertillon and Francis Galton, for conceptions of the citizen-subject in this era (Sekula, 1986; Seltzer, 1992). Such a capitalist framework, with its requirement for the factory worker’s body to be managed, standardised, and efficient, rendered the individual with epilepsy as threatening this order. Whether considered contagious, ‘defective’, malingering, or with increasing sympathy, the high number of PWE categorised as paupers in this period would not only render them doubly-stigmatised, (a trend that continues today (Stone 1985)), but tied representations of the ‘epileptic’ to contemporary anxieties around racial degeneration. The development of colonies in this era was partly a response to the question of how to render the lives of ‘idiots’ and ‘epileptics’ useful and protected, just as their rural setting seemed to offer a means of rendering the patient invisible to the wider social body while simultaneously opening their bodies up to the gaze of the medical establishment.<sup>3</sup>

Analogy with visual technologies and surveillance would aid understanding of epilepsy in the so-called ‘golden age of neurophysiology’ (Brazier, 1957; 212). The ‘father of epilepsy’, neurologist John Hughlings Jackson (1835-1911) was to describe focal seizures as examples of ‘double consciousness’ and a ‘dreamy state’, underlining the

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<sup>3</sup> Although, such establishments did inadvertently encourage solidarity amongst inmates and the eventual emergence of institutions such as the International League Against Epilepsy.

transformative effect epilepsy could have on the subject's viewpoint (Friedlander, 2001; 212-13). Continuing in this vein and thanks to its earlier associations with possession and prophesy, cultural links between epilepsy and creativity have been retained across the twentieth century. Cesare Lombroso (1835–1909) first wrote of the 'epileptoid nature of genius' when noting the number of famous men with the condition, although it was his association between epilepsy and the criminal personality that has unfortunately gained the most cultural traction (qtd. in Temkin, 1971: 368). Today epilepsy charities often emphasize creative associations in attempts to assuage negative stereotypes and to promote the experiences of those writers and artists living with epilepsy and their representations of the condition.

However, it is the viewpoint of the observer that has dominated cultural representations of epilepsy. Lisa Cartwright (1995) has persuasively argued that today's visual surveillance of the body has an etiology in the 'neurological gaze' of the late nineteenth century (see also Norden, 1994). While the epistemological primacy of visual knowledge in neurology had been upset by the realization of the systemic structure of the body (rather than as observable static organs) on the one hand and psychoanalysis's denial of surface reading on the other, the fin-de-siècle was also a period in which neurologists turned to new visual technologies to study patients. Pointing to the use of photographic series and motion studies of patients by neurologist Jean-Martin Charcot and others, Cartwright argues that such films and images pose questions around 'scientific spectatorship, visual pleasure, and cinematic surveillance.' (p. 48) She discusses the so-called 'Epilepsy Biographs', filmed at the Craig Colony for Epileptics (NY) in 1905 by neurologist Walter Greenough Chase at the request of medical superintendent William Spratling. These films, a 'metaphor for Spratling's own anxiety about neurology's inability to control epilepsy', surveil the inmates' seizures in minute detail, while failing to establish the condition's source (p. 63). In so doing, they outlined the 'broader paradox



of modern neurology: the need to calculate vectors of pathology that are not best characterized by visibility or fixed locale, through the discipline's traditional techniques of observation, recording, and classification' (p. 64). While medicine today utilizes a number of technologies to 'objectively' envision the internal systems of the body in a bid to manage and cure illness, as Joseph Dumit (2004) and Catherine Waldy (2000) have argued such imaging and its interpretation is strongly encoded by our own technological, medical and cultural assumptions.

### **Electrical Epilepsy**

Today, one of the most common tropes regarding epilepsy is that of epilepsy as an electrical event. The theory of the electrical basis of epilepsy first gained attention with Hughling Jackson's 1873 definition that 'Epilepsy is the name for occasional, sudden, excessive, rapid, and local discharges of grey matter.' (Jackson, 1873) The theory had in fact been proposed and tested over twenty years earlier by the clinical neurologist Robert Bentley Todd in 1849, as E. H. Reynolds (2001) has demonstrated, who concluded that 'The periodic evolutions of the nervous force which give rise to the complete epileptic paroxysm may be compared to the electrical phenomenon described by Faraday under the name of disruptive discharge.' (Todd, 2005; 1004) However, Todd's experiments were overlooked and subsequent research was hampered by confusion surrounding vascular theories, the plurality of epilepsies and neuronal function and discharge (Reynolds and Trimble, 2009). It was only in 1929 that Hans Berger would prove Jackson's theory via EEG (Friedlander, 2001; 99). In the decade following, experiments with EEG helped pioneers such as William Lennox, Frederic and Erna Gibbs, Hallowell Davis and Herbert Jasper in America and W. Grey Walters and Frederick Golla at the Maudsley Hospital in London to establish that seizures were the result of abnormal electrical impulses in the brain's neural network and that EEG in turn could be used as a

diagnostic test for the condition (Bladin, 2006).

As a result of these medical advances, it is now extremely common for epilepsy to be depicted in terms of electrical systems: *'I am an electrical impulse. I discharge at random across a synapse, at the threshold of a seizure.'* (Hawthorne, 1992; 1) Ray Robinson's 2006 novel *Electricity* plays extensively with the parallel, as protagonist Lily O'Connor works first in an arcade complete with synthesized sounds and flashing lights, before dating electrical contractor Dave. As we later discover, Dave has been photographing Lily's naked, seizing body and likely selling on the images to others. The 'flash. White light' of the camera is indistinguishable from her ictal state and the analogy between tech and seizure that renders Lily vulnerable to such abuse (p. 320). Her attempt to 'make him invisible' following this discovery highlights the overburdened association between knowledge and vision, between knowledge and electrical light in our culture and the vexed implications of this for people living on its threshold (p. 321).

The development of EEG technologies offered clinicians and neurologists a means of envisioning brain activity and anatomy. The electrical pattern of a seizure (its course if not its cause) has become visible to medicine as an electrical system functioning imperfectly. During diagnosis PWE are often stimulated with flashing lights to provoke an EEG response. Over the last half century, new technologies such as videotelemetry, Positron emission tomography, Magnetic Resonance Imaging and Single-photon Emission Computer Tomography have further underscored parallels between vision, technology and abnormal brain activity. Such visibility has improved diagnosis – and rendered certain surgical procedures possible – even though a cure for epilepsy remains elusive. If anything, medical emphasis on seeing the seizure has, as Stirling argues, privileged the 'technologies of epilepsy' over PWEs' in the twentieth century experiences of symptomatology (2008; 182). In this respect, computational medicine has done little to

advance the situation facing nineteenth-century PWEs, who were regularly subjected to the spectacular gaze of clinicians and neurologists.

### **Cybernetic Epilepsy**

Over the last eighty years, the parallel between epilepsy and technology has been underscored thanks to the development and widespread use of electronic digital computing. Since midcentury computers have dominated all aspects of society, including medicine; we no longer live in the world of Krapp's analogue tapes, but an environment dominated by the 'either-or logic' of binary computing, what Manuel Castells (2009-2010) titled the 'Information Age'. For the PWE, for the cultural representation of the condition, this wider realignment has had a number of local results.

Many of the early advances in digital computing were underpinned by the new field of cybernetics. Drawing on the pioneering work of Alan Turing and John von Neumann, and spearheaded by mathematicians Claude Shannon, Norbert Wiener and colleagues such as neurophysiologist Warren S. McCulloch, this new science of information concerned the 'control and communication in the animal and the machine' (Wiener, 1961). Emphasising the study of systems, whether organic or mechanical, cybernetics offered biologists, neurologists and psychiatrists new approaches to thinking about the design and function of anatomical and neurological systems, just as much as it stimulated those working in electrical engineering, artificial intelligence and computer design. Encouraging parallels between human and technological systems, cybernetics would do much to promote the point that 'the brain and the computing machine have much in common' in the years after the Second World War (Wiener, 1961; 144; Von Neumann, 1963). As part of a broader popularization of this now pervasive metaphor, epilepsy would increasingly be conceived in terms of this computational systems: the seizing body as a sign of the catastrophic failure of operability within an overloaded

electrical network. Like Arnie's damaged Terminator, visibly sparking and malfunctioning, the seizing body was now the spectacular indicator of a machine on the verge of failure.

The huge importance of cybernetics encourages us to conceive of the conceptual movement between cybernetics and epilepsy as unidirectional and originating with the former. However, if we attend more closely to the intellectual history of cybernetics, a very different picture emerges – one in which thinking about epilepsy informs cybernetics and not the other way around. We can, in other words, feasibly talk of an epileptiform cybernetics. For Norbert Wiener, epilepsy was a key indicator of the brain's computational structure in his field-defining *Cybernetics* (1948) and many of the cybernetician pioneers had in fact trained as neurologists and physiologists in the 1930s and 1940s. Most tangibly, it was the twelve years that McCulloch spent studying seizure patterns and trauma-related epilepsy as part of a general interest in brain localisation that led him to the theories advanced in one of cybernetics seminal papers, co-written with Walter Pitts (1943), on the function of neural networks (Abraham, 2016). Drawing on McCulloch's knowledge of brain physiology gleaned through his years working on epilepsy, the paper made an analogy between the "all-or-none" law from physiology (effectively that a nerve has a finite threshold that excitation must exceed for it to fire) and Boolean logic (Abraham, 2002). At the same time that he was advancing the field of cybernetics, McCulloch continued to follow clinical advances in epileptology both as part of his role as Head of the Neurophysiology Laboratory at the University of Illinois, luring Frederic and Erna Gibbs there from Harvard to continue their work on epilepsy and EEG (Hughes, Penney and Stone, 1994), and later when he moved to MIT. Meanwhile over in Britain a number of early members of the Ratio Club, including Jack Cowan and W. Grey Walter, would combine their interest in the new field of cybernetics with research into epileptiform brain wave patterns and seizure thresholds (Husbands

and Holland, 2012; Pickering, 2010). Placing the ‘neurological gaze’ at the heart of technological advances at mid century, in a very real sense cybernetics originated and developed within a broader context of epilepsy research and not the other way around.

Either way, across the last fifty years parallels between overloaded (or threateningly out of control) computers and the epilepsy brain have pervaded cultural representations of the disease. Artist and author Richard F. Davis presents the experience of epilepsy as something out of a science-fiction future. In the acrylic painting ‘Virtual Memory Gone’ (n.d) a brain is being attacked – fried – by crackling charges of electricity emitted from computer chips. Writing in his memoir *Seized Again*, Davis emphasizes the failure of the analogy between brain and computer: **‘Our brain wires cannot be replaced... If you lose your wires, you can’t throw out your internal computer out and get a new one... Complete memory gone’** (2011; 169, bold in original).

Computational metaphors also feature centrally in explanatory settings; PWEs commonly describe their condition via analogy with the failure of digital technology: ‘I switch off. Reboot my computer and then all of a sudden ... where I stopped I’ll start talking again... it’s almost like somebody switched a flick on me.’ (Participant 6)<sup>4</sup> Figuring the seizure as one of (social) system failure helps to position the condition as one of bodily rather than mental limitation and in doing so potentially reduce associated stigma. Concretising the problem in this way offers a means by which a line can be drawn between an essential and transcendental selfhood and the physical limitations of faulty wiring or corrupted discs.

In an era dominated by digital networked technologies, these parallels have become, if anything more pervasive. Conceiving of epilepsy in terms of cybernetics can

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<sup>4</sup> I leave the spoonerism in for its lovely echo of N. Katherine Hayles’s (1993) concept of both the ‘flickering signifier’, and its concomitant reminder that we deal here in the bringing together of ‘language with a psychodynamics based on the symbolic moment when the human confronts the posthuman’ (n.pag).

also draw attention to other examples of what Eugene Thacker (2003) calls ‘biomedia’, or ‘an instance in which biological components and processes are informatically recontextualized for purposes that may be either biological or nonbiological’ and the uses to which they have been put culturally (p. 52). Deployed neutrally – ‘epilepsy is not unlike a computer virus—bad code that hijacks the system’s circuitry to run its malicious program’ (Gay, 2015: 82) – biomedia can help to neutralize older stigmatic associations, between epilepsy and moral failings, for example. However, they can also be deployed to affirm cultural discrimination in our digitally oriented world. The analogy between brain and computer can be used to erode these individuals’ statuses – already precarious – as subjects. Historically, subjectivity has been entangled with claims about higher level consciousness, with these ‘modes of awareness’ (Hayles, 2017) equated to greater agency and in turn used to police borders between human and machine. The altered consciousness that is characteristic of many epilepsy seizures can unfortunately be deployed to underline parallels between the PWE and the automaton, denying subjectivity. It is therefore alarming to see ‘seizure’ deployed on Twitter, for example, in a derogatory sense a full 41% of the time, as McNeil et al’s (2010) study demonstrated. Elsewhere examination of popular epilepsy-related videos on YouTube resulted in similar findings, with ‘persistent stigma and misinformation towards epilepsy’ demonstrated in comments (Lo, Esser and Gordon, 2010; 545). More worryingly, responses to hacker group 4Chan’s 2008 attack on epilepsy online forums (by posting flashing gifs in the hope of producing seizures in those with photosensitive epilepsy, a depressingly common occurrence) spoke of such efforts as ‘hacking peoples [sic] unpatched brains’ (Weev qtd. in Schwartz, 2008). Characterising the epileptic brain as faulty software in need of an urgent update in this context evokes the eugenics-driven programmes to sterilize PWE that existed in many American states and countries as late

as the 1970s. Presenting epilepsy within the context of biomedicine can have real-world implications for people's sociopolitical statuses.

### **Black Box/Black Bag**

While brain-computer analogies proliferate in our culture, it is a more precise metaphor that fuels one of the most practically significant analogies made between epilepsy and new media: the cybernetic black box. Black-boxing was an approach developed during the Second World War in which rather than opening up an entity to discover its operations (which in the case of a missile might risk detonating it), focus was placed entirely on inputs and outputs. By examining how the observed system interacted with its environment, the researcher could perhaps deduce what went on inside the black box, or more radically, ignore the innards of the container entirely. A 'new epistemic object', the black box offered what Philipp von Hilgers described as 'the chance to continuously and operatively determine anew the relation between knowing and not-knowing' (2011; 46, 52). This approach was central to first-order cyberneticists.

Neurophysiologists were also amenable to this 'new epistemic object'. Before the advent of medical imaging enabled scientists and doctors to 'see' inside the brain, the black-boxed approach was de facto the only means of acquiring knowledge of its inner workings. Invasive localization techniques had not proved as useful as hoped, nor had early attempts at brain surgery; by contrast, EEG offered a new way of recording brain function and a new output that could be measured and quantified. For early cyberneticists like McCulloch, who had trained as a neurophysiologist and was interested in neural networks, the black box was an appealing concept. As psychiatrist and cyberneticist W. Ross Ashby made explicit: 'Though the problem [of the black box] arose in purely electrical form, its range of application is far wider. The clinician studying a

patient with brain damage and aphasia may be trying, by means of tests given and speech observed, to deduce some of the mechanisms that are involved.’ (1956; 86)

Such black boxing privileges the perspective of the observer; in the case of epilepsy the perspective of the diagnosing clinician is privileged and over the last thirty years, the PWE has been heavily black-boxed by medicine. Even as brain imaging has improved, in the absence of a cure the medical focus in epilepsy has been on tracking inputs and outputs, monitoring seizures and managing symptoms and pharmacological side effects. The ideal is to obtain perfect ‘control’, defined clinically by a lack of seizures and culturally by the invisibility of their epilepsy identity to observers – one interviewee offered the suggestive anecdote that she wore an epilepsy bracelet as a kind of cipher: a sign that, while visible and therefore protecting her from accusations of hiding her condition, could only be decoded with the right knowledge key (Participant 1). For PWE today the result of this black-boxing is often the demand that they record all symptoms via a seizure diary. Such self-observation is not only burdensome in terms of time and attention but for many well-nigh impossible given that the individual is often not aware if they have had a partial seizure. What is termed ‘self-management’ is often enacted as a form of surveillance by a family member.

This movement toward seizure monitoring is part of a more general trend in medicine. The medical sociologist David Armstrong has proclaimed that we live in an era of ‘Surveillance Medicine’. In describing an emergent (Foucauldian) mode of medicine based on the surveillance of normal populations, Armstrong identified several features that characterize this mode: the dissolution of categories of ill and healthy via the problematization of ‘normal’; a new predictive orientation in the relationship established between sign, symptom and illness; and the relocation of illness outside the space of the corporeal body. Armstrong persuasively argued that Surveillance Medicine inaugurated a new conception of illness, wherein ‘health no longer exists in a strict binary relationship



to illness', but as a network of risk factors and a 'point of perpetual becoming'. In turn, these practices delineate a new 'temporalised risk identity', with 'patients' given responsibility to monitor their own data points (1995; 400, 402, 403). For the increasing number of individuals living with incurable chronic diseases, such as epilepsy, migraine, arthritis or diabetes, under this regime such an identity is not only perpetually present, but also rendered in terms of personal responsibility: risk can be managed only through better data analysis and control. As sociologists of illness have noted, any deterioration in condition or relapse is often conceived by others as a personal failing (Wendell, 2013; 170); not only do subjects experience profound suffering, what Michael Bury (1982) described as 'biographical disruption' and Kathy Charmaz (1983) 'loss of self', but they are also held accountable for such social discrediting (Goffman, 1963).

Although Armstrong's essay was retrospective in its focus, identifying a mode with its origins earlier in the twentieth century, the patterns he discussed have been only magnified by digital health technologies and practices in the years since his article was published. Since the mid 1990s, the development of the Internet, Web 2.0 and digital health technologies, have supposedly opened the 'black bag' of medicine and healthcare that epilepsy treatment exemplifies (Webster, 2006; 1). Amplifying the trend toward patient-centred care, use of the Internet and digital technologies has flourished in the realm of healthcare. Summarising the potential import of connective media for health and illness, Sue Ziebland and Sally Wyke (2012) identified seven domains: finding information, feeling supported, maintaining relationships with others, affecting behaviour, experiencing health services, learning to tell the story and visualizing disease. Others have emphasized the potential for patient groups to use such media to direct research agendas, transform doctor-patient relations and 'empower' themselves through new modes of biosociality (Banner, 2014).

In the realm of chronic illness, studies have noted the therapeutic benefits of using social media platforms, in particular, to improve outcomes: ‘social ties forged in online spaces can perform self-management work that can improve an individual’s illness experience and can reach areas that are particularly difficult to navigate offline.’ (Allen et al, 2016; 61; Patel et al, 2015). In the case of epilepsy, regular contact with a healthcare professional has been demonstrated to improve self-management and reduce hospital admissions and recent studies seem to suggest that web-based interventions offer similar functionality, with Wicks et al. (2012) noting that online communication between PWEs appeared to improve outcomes (see also Walker et al., 2012).

In my own interviews, participants expressed enthusiasm for the possibilities the Internet and social media afforded them. This included the ease with which they could find information on drugs and their side effects, but also the opportunity to connect and communicate with other PWE. For those unable to access support groups in the offline world – often reliant on evening public transport, many reported difficulty in attending such groups – online communities oriented around epilepsy, whether those run by epilepsy organizations or less formally arranged around Facebook groups, offered important social support. The more digitally literate interviewees I spoke to, the majority of whom had had the condition for a number of years, expressed their sense of the efficacy of sharing their experiences online and satisfaction in being able to offer advice to those newly-diagnosed with the condition.

For other participants it was the assistive possibilities digitally-enabled devices offered that was most significant. When one interviewee stated that ‘My phone is my brain’, ‘That is my brain it tells me what I’m doing, what has happened... My brain has no chance with the epilepsy’, she used the analogy between the memory capabilities of an internet-enabled telecommunications device and the brain to highlight the manner in which the phone had become a technological prosthesis in her life (Participant 4). For

others such technology is assistive in providing virtual contact with persons outside the house. Networked videoconferencing technology offered one woman a way to ‘open up’ what had been a ‘very closed’ existence: ‘it’s like somebody has given a basket full of chocolates to a chocoholic. It was fabulous. I still can’t drive, but it’s opened up, I keep in touch, I Facetime with my sister. I just, I have more contact’ (Participant 6). For others such technology can be used as a means for relatives to visually ‘check in’ on them.

Despite dominating treatment, such technologizing and black-boxing of the PWE is clearly not without its problems. Although, as Andrew Pickering (2010) points out, ‘[e]ven in its most asymmetric early moments, cybernetics never imagined that the classical model of control was in fact possible’, black-boxing can curtail the agency of the patient-subject in troublesome ways (p. 383). It privileges the expert-observer’s interpretation of inputs and outputs over the subject’s experiences. In the case of the PWE, this approach parallels stigmatizing features of the condition: the tonic-clonic seizure itself effectively black-boxes the subject who has no conscious access to the event that identifies them to the observer as possessing what Erving Goffman (1963) called a ‘spoiled identity’. This has been exacerbated by what Webster describes as the ‘reconfiguring of patient information and symptomatology as digital data’ (2006; 4). For PWE, increased self-tracking doesn’t necessarily equate to better management of their disease, nor increased agency or control over interpretation or the data itself. As Deborah Lupton has persuasively argued, we would do well to promote a ‘critical digital health studies’ (2014; 1347).

Over the last thirty years scholars such as Arthur Frank (2013), Arthur Kleinman (1988), Rita Charon (2006) and Kathryn Montgomery (1991) have developed the field of so-called ‘illness narratives’. Itself part of a response to the cybernetic, behaviourist understanding of the self so dominant in medicine at mid century, illness narratives

attend to the ways in which individuals experience, understand and claim agency over the representation of their illnesses. This scholarship has had a significant impact not only on scholars interested in thinking about relations between literature and medicine, but also with medicine itself and the generalized move towards patient-centred care. Attempting to respond to and resist the conceptualization of the subject as a series of symptoms or outputs, the behaviourist black box is (theoretically at least) repudiated in favour of narrative-sensitive medicine that is conscious of the individual experience (Vaccarella, 2011; Vickers 2016).

Yet in the increasingly technologized world of medicine, within the burgeoning field of e-health and even what Anna Munster (2011) has described as the ‘neurological turn’ in and against networked media, how precisely such illness narratives might operate in an online setting, and the existential issues this union might provoke, becomes a complex question. The prominent inclusion of patient stories (text-, audio- and video-based) on websites such as NHS Choices, Patientstories.org.uk, Patientvoices.org.uk, Patientopinion.org.uk and Healthtalkonline.org indicates a certain perceived value or utility of such narratives in an online setting, and the relation of individual and ongoing stories of PWE on blogs and other social media platforms has exploded since the late 1990s. While illness narratives themselves have become ‘of increasing importance precisely because they have provided a rich source of sociological data about the way in which people manage illness in practice’ (Webster 2007: 96), the value of sharing such narratives for those with stigmatized identities in an increasingly networked digital environment in which context collapse is commonplace, is somewhat uncertain.

### **Digital Black Boxed Selves**

Dominant in conception of epilepsy representation and treatment, this ‘heuristic’ of the black box is ‘pervading the digital age’ (Berry, 2012) notes. Indeed, the black box is

‘widely taken as read both in terms of empirical descriptions of technology, the state, the market, everyday life today, and so forth, but also in terms of the possibility of a methodology to understand and explore it’ (n.pag). In one such example, media theorist Alexander Galloway argues that:

It is thus today no longer a question simply of the enemy’s black box, but the black boxing of the self, of any node contained in a network of interaction. The enemy’s machine is not simply a device in a German airplane, it is ourselves: a call center employee, a card reader at a security checkpoint, a piece of software, a genetic sequence, a hospital patient. (2011: 243)

Here, far from being restricted to programming, the black box is utilized as a concept and metaphor across a host of phenomena and processes, from the postfordian worker to political actions. In particular, the black box is utilized as an analogy for the human brain, bringing about as we have seen, what N. Katherine Hayles (1999) famously termed the ‘posthuman’, or cybernetics’ de-materialization of both information and the subject.

The quotation above is taken from Galloway’s essay ‘Black Box, Black Bloc’ in which he characterizes contemporary society as dominated by the emergence of a ‘specific kind of invisibility, a specific kind of blackness’ (2011: 239). In defining this invisibility, Galloway points to a shift in the way that the black box entity is conceived today: ‘It is no longer a question of illuminating the black box by decoding it, but rather that of functionalizing the black box by programming it.’ (2011: 244) The goal is no longer to open, reveal, render visible and transparent; instead, the focus is on operability and functionality. Like the PWE cajoled into self-monitoring when computational medicine’s visioning of the brain fails to relieve symptomatology, the limits of the black-box-as-cipher approach are seemingly circumvented today by adopting the model of

black-box-as-function. In Galloway's list mention of the hospital patients falls at the end, a seemingly casual example among many of the black-boxing of the self in contemporary society; however, in pursuing the conceptual affinities between epilepsy and new media, I want to pause on this example in order to consider *not* what the black box might tell us about the hospital patient, but rather what the hospital patient, or in fact the individual managing the chronic condition of epilepsy, might suggest about the more widespread 'black boxing of the self' today.

The representation of the PWE over the last half-century foreshadows in significant ways the representation of the citizen-subject in our digitally networked society. The seizing body highlights cultural anxieties around the programmability, control and functionality demanded of the subject today, with responsibility for monitoring that threshold placed firmly on the 'patient'. The temporality that has often been associated with the experience of chronic illness, and the anticipatory nature of felt stigma, find a parallel in the so-called inferred 'algorithmic identity' that John Cheney-Lippold (2011) identifies as characteristic of our digital world. Writing on the 'feed-forward' operation of twenty-first century media, Mark Hansen notes that digital media have shifted from a 'past-driven recording platform to a data-driven anticipation of the future', whereby consciousness is bypassed (2015: 4). Similarly, Wendy Hui Kyong Chun describes a logic of 'Habit + Crisis = Update' as characterizing our digital environments and technologies (2016: 2). Networked time, for Chun, is structured by the twinning of habits – mechanical yet 'creative anticipations based on past repetitions' – and crisis, or punctuated time that demands real-time response (2016: 3). Although her example of the impact of networked time is that of slut-shaming, a more explicit analogy can be found in the chronically-ill person with uncontrolled epilepsy, who lives precariously between habit and crisis and for whom 'update' represents merely the prospect of yet more medication. Collectively, these scholars represent the digital user experience as mirroring

that which characterizes the experience of the chronically ill individual. Representations of digital subjectivity and the technologising of the PWE have foreshadowed the experience of the digital subject today.

It is in the arena of cognition that the PWE offers perhaps the most suggestive figure. The seizure, so problematic for a post-Enlightenment conception of subjectivity that turn to higher-level consciousness to distinguish between human and machine, is also representative of a more complex understanding of cognition in our digital era as the interpenetration of different processes. This is a schema that has received a large amount of attention from recent critics of digital media; as they note, today's millions of digitally-networked devices and infrastructures exhibit what Hayles calls 'cognitive nonconscious' and operate at what Hansen describes as 'precognitive' levels (that is faster than human modes of awareness) (Hayles, 2017; Hansen, 2015). In this new environment of 'cognitive assemblages' (Hayles, 2017), human higher-level consciousness has been decentred, and digital subjectivity necessarily conceived as more expansive. In this regard the historical non-normate PWE now models a new normate for the digital environ.

However, lest we forget, this is also a potentially black-boxed self. I make the above parallels not to universalize the experience of disability or chronic illness in our contemporary digital society, nor minimize the challenges, representational and physical, faced by people living with epilepsy today. Rather, I do so to highlight the degree to which the digital subject, like the non-normate on which he or she is modelled, holds tenuous representational agency – even in a situation in which black-boxing might be conducted by the technological nonconscious and not by a human surveilling gaze. Expanding our definition of cognition does potentially posit a similarly expansive model of subjectivity; but it leaves agency, and particularly, agency over representation, ambiguously situated.

Galloway himself suggests that the black-boxing trend might mark the 'death of

Freud and Marx and hermeneutics in general' (2011: 239). He identifies a political equivalent of the black box, the black bloc, a 'tactic of anonymization and massification' wherein the strategy is not a demand for political representation, but disruption of power networks via nonparticipation, as dominating digital society (2011: 239). Yet for those struggling under the burden of excessive representation and a lack of interpretive agency, nonparticipation and even anonymization offer little comfort. Even if we posit a third strategy, neither black boxing or hermeneutics, what Best and Marcus (2009) and Love (2010) call 'surface reading', the subject's interpretive agency remains elusive. Meanwhile, for the digital subject encouraged to 'empower' themselves by expressing their unique voice on social media, such requests now seem suspect. They mirror, in disquieting ways, the limits of the illness narrative movement for the PWE in the grip of Surveillance Medicine. Even as it offers an expanded conception of cognition, digital subjectivity mirrors the problematic control over representational agency that PWE's evince. Far from an evocative technology of yesteryear, the space invaders track and target us today.

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