A virtual ethnography of the *madosphere* - exploring a disrupted relationship between users and providers of mental health services

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

My thesis seeks to answer the question: **'to what extent is the relationship between users and providers of mental health services being disrupted in the *madosphere*?'** It arises from curiosity about the extent to which online interactions have the potential to interrupt and complicate boundaries between providers and receivers of care. I consider the interplay between mediations of mental health in mainstream media and a space and set of practices I refer to as the *madosphere*. Through my research I endeavour to answer questions about the intersection of two discourses that are not obviously connected – the treatment of people with mental health problems by institutions and the existence of social networking sites as spaces to share information and develop common cultures.

My research endeavours to understand ways in which people accessing and providing mental health services are interacting in particular online spaces; how participants in those spaces are engaging with current social and political issues relating to mental health; how they are encountering and resisting representations of mental ill-health in mainstream media, with a particular focus on stigma and discrimination. I elucidate themes relating to social practices, cultural norms, identity, power formation and impacts on mental health and wellbeing. My research comprises four sub-questions, which are set out below:

1. Disrupted relationships - who is participating in the madosphere, how do participants experience and understand their engagement, and what meanings does it carry for them?

2. An account of the *madosphere* - what are the behaviours, practices and social norms in the *madosphere*?
3. Re-mediation of representation - how do participants engage with and resist mainstream media reporting of mental health issues?
4. Fractured power and expertise - how do participants engage in themes of identity, power, stigma and discrimination? How are participants resisting and subverting institutional paradigms and discourses relating to mental health?

I conclude with a series of recommendations for mental health professionals and institutions in relation to their engagement with social networking sites.

Table of Contents

Chapter 1

Introduction

1.0 #SamaritansRadar

On 29 October 2014, the Samaritans, a suicide prevention charity, launched a Twitter application called Samaritans Radar. Its purpose was to monitor the tweets of everyone an individual follows on Twitter and send an alert if keywords were detected that indicate someone may be struggling to cope. Despite the positive intent of the charity, there was an instant outcry from many people who use Twitter to discuss mental health in general and their personal experiences more specifically.

Through the ensuing debate on Twitter, and numerous blog posts written on the topic, it became apparent that the mobile application had inadvertently encroached upon an unrevealed ecosystem of people discussing mental health in this space. Firstly, concerns were raised about use of data and the legality of a surveillance application which does not have the consent of people it monitors; secondly, the potential unintended consequence of providing 'trolls' an opportunity to more easily seek out and cause distress to vulnerable people was identified; lastly, and most pertinent to my research, many people articulated concerns that the charity had failed to understand how they used Twitter in regard to their mental health.

Using the hashtag #SamaritansRadar, people elucidated how they use Twitter to have conversations about mental health with people who are like them and who can relate to their mental distress and suicidal feelings; they shared how their conversations feel

safe because they are separate to friends, family and agencies who may not understand them; they described how they feel in control and able to self-mediate their identity. Samaritans Radar was an unwelcome intrusion into an existing ecosystem of cultural norms and mediating practices - it compromised people's sense of agency; increased emotional distress; changed how people talked about mental health; and some people even removed their accounts or made them private.

The Samaritans compounded the dismay of the mental health community on Twitter by at first attempting to defend the mobile application and then ceasing to engage with any conversation about it at all (Samaritans, 2014). When they did finally suspend the application after a two week period, they did so with an apology, the apparently reluctant tone of which only increased the ire of its detractors:

> We apologise to anyone who has been inadvertently caused distress by the range of information and opinion circulating about #SamaritansRadar

Despite the fact that the Samaritans followed with a more heart-felt apology, the damage appeared to have been done and the above tweet itself became a much debated topic of conversation (Judah, S. 2014). Through their apparent lack of awareness and understanding of the delicate ecosystem created by the mental health community on Twitter, and underlying theme of agency and control, an established and well regarded charity appeared to lose the confidence of a section of its users and potential users.

A consistent theme underpinning the dialogue between people with mental health problems about Samaritans Radar was one of agency versus control. Many people

articulated a shared view that the Samaritans were attempting to determine what was good for them without asking for their consent. An age old tension between institutional power and individual agency was re-ignited and revealed. What was novel in this instance, was the affordance of blogs and micro-blogs to render this rupture visible, enabling people to share their opinions both to the Samaritans, to each other, and to the wider public. The momentum of this stream of public dialogue seemed unstoppable and it was only a matter of time before the charity was compelled to withdraw the mobile application. My research relates to this story in an original way: it seeks to understand a space and set of practices that have previously been hidden from view and which are easily misunderstood and underestimated by mental health professionals and institutions, as illustrated by Samaritan's Radar.

2.0 Research Thesis

Whilst the Samaritans Radar incident happened towards the end of my research, it sheds light on the very foundations of my fascination with online social networking sites and mental health. It pivots on the heart of my research question, which explores the extent to which relationships between people accessing and providing mental health services and the mainstream media are being re-shaped and disrupted on social networking sites.

My thesis seeks to answer the question: **'to what extent is the relationship between users and providers of mental health services being disrupted in the *madosphere*?'**. It arises from curiosity about the extent to which online interactions have the potential to interrupt and complicate boundaries between providers and receivers of care. I am similarly intrigued by the related interplay between mediations of

mental health in mainstream media and a space and set of practices I refer to as the *madosphere*. Through my research I endeavour to answer questions about the intersection of two discourses that are not obviously connected – the treatment of people with mental health problems by institutions and the existence of social networking sites as spaces to share information and develop common cultures.

My research endeavours to understand ways in which people accessing and providing mental health services are interacting in particular online spaces; how participants in those spaces are engaging with current social and political issues relating to mental health; how they are encountering and resisting representations of mental ill-health in mainstream media, with a particular focus on stigma and discrimination. I elucidate themes relating to social practices, cultural norms, identity, power formation and impacts on mental health and wellbeing. My research comprises four sub-questions, which are set out below:

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I conclude with a series of recommendations for mental health professionals and institutions in relation to their engagement with social networking sites.

3.0 The *Madosphere* Introduced

The *madosphere* is a term coined by a loose affiliation of people conversing about mental health on a blog entitled The World of Mentalists (TWOM), which forms the main site of my research. TWOM is a longstanding UK blog in which people using and working within mental health services routinely interact. It is co-edited by a mental health professional and an individual user of mental health services. It has a separate blog roll for people with mental health problems - 'mentalists' - and people working in mental health services ' T3h Pr0fessi0nalz'. TWOM is an e-zine of news, commentary and blog digests in the arena of mental health. Weekly blog digests, known as This Week in Mentalists (TWIM), are a regular feature of the blog and comprise selected writings from blogs across the *madosphere*. They are routinely produced by guest editors. This configuration of the blog means that it has a wider natural ecosystem comprised of contributors, featured blogs and people commenting on the blog itself.

Participants in the *madosphere* are not typical Internet users in so far as their engagement with online social networking sites is significantly deeper than that of the general population (Dutton & Black 2013). My interviewees can be characterised as deeply engaged with online social networking through producing, sharing and engaging with content on the theme of mental health and mental distress. Whilst I interviewed a small number of people in their early twenties, the majority of my interviewees were aged 30 and 50 years old and all reported regularly posting original content and sharing

content from others. Most had their own blog and used multiple social media platforms such as Twitter and Facebook as well as engaging with TWOM.

Whilst the blog itself came to an end during the course of my research, I have continued to use the term as a way of describing social media practices which disrupt and problematize the relationships under study. As is the case with the Internet more widely, the *madosphere* is both a space and a set of mediating practices which are both shaped by and shape the affordances of the technology. This dialectic is at the heart of much research on social networking sites – that mediating practices are enabled by the space but which also shape the space themselves. Technologies are both derived from a social context and often emerge in ways unimagined by the people who created them. Baym describes this process as social shaping in which she argues: 'people, technologies, and institutions all have power to influence the development and subsequent use of technology' (Baym, 2010, p.45). A constant theme in my research is the ways in which individuals and institutions engage in contested territory in their use of social networking sites; with institutions increasingly attempting to boundary and contain the activities of individuals, and individuals using the affordances of social networking sites to challenge the authority of institutions.

The irreverent tone implicit within the notion of the *madosphere* alludes to the rupturing of customary relationships that I have been curious to explore and understand. The word *mad* is both pejorative and often used as a term of abuse in everyday life. However, TWOM not only reclaims the word but also employs it to satirise the very people who use it. *Madosphere* is a play on the word blogosphere which denotes a network of blogs converging around the theme of mental health. The *madosphere* is

considered in more detail within an account of the space and related set of practices in Chapter 5.

The locus of my ethnographic research is practices on the TWOM blog and its surrounding ecosystem of blogs, and on the micro-blogging site Twitter. The term 'social networking sites' requires clarity for the purposes of this research. Social networking sites are characterised by primarily interpersonal interactions, founded on patterns of everyday relations and which are adapted to online settings. They enable people to create a profile, follow or 'friend' others and view other members' connections. They allow people to produce as well as consume content as well as enabling multiple overlapping connections between different social spheres (Paracharissi, 2011, p.305). Boyd (2014, p.11) defines four affordances offered by social networking sites that have different characteristics to traditional physical public spaces, and which provide both opportunities and challenges:

- persistence: the durability of online expressions and content;
- visibility: the potential audience who can bear witness;
- spreadability: the ease with which content can be shared; and
- searchability: the ability to find content.

In my research I consider how these affordances are experienced and actualised by people engaging in the *madosphere*. The affordance of a persistent voice for people who have been marginalised by society and misrepresented by mainstream media is a theme threaded throughout my research; the ability to produce one's own content, share one's story and self-mediate one's experience can be profound. The affordance offered by social networking sites for people to seek out others with similar

experiences, to connect with and reduce the isolation that can exist with a stigmatised identity, is similarly significant. At the same time, such affordances create substantial challenges for professionals and institutions, whose orientation is towards specialist expertise alongside mediation of knowledge and information. The primarily interpersonal nature of social networking sites, founded on interaction, can jar with the formality of institutional practices. Practices in the *madosphere* create opportunities and hazards for people who wish to have conversations that are outside of institutional boundaries. These are all themes I will return to throughout my thesis.

My thesis has two overarching themes threaded throughout which I return to in each chapter. Firstly, I am concerned with identity, self-presentation and how stigmatised identities are experienced, resisted and challenged in the *madosphere*. I explore how social networking sites offer possibilities for people with stigmatised identities to engage in practices which build a positive sense of self-identity and subvert negative stereotypes. Secondly, I am concerned with themes of power and resistance between individuals and institutions and how these are engaged with in the *madosphere*. I explore how individuals employ social networking sites in a variety of ways to engage in collective action in opposition to both mental health institutions and mainstream media. Both themes are considered in relation to the affordances of social networking sites as I investigate how people are negotiating these thematic areas as participants in networked publics.

Throughout my research I draw extensively on the seminal writing of the sociologist and ethnographer, Erving Goffman. Goffman's work on stigma (1963) underpins virtually all contemporary theorising on the subject and is particularly relevant as mental health stigma is a core theme within his writing. I elucidate how mental health stigma is

experienced, reproduced and contested in the *madosphere*. In particular, I apply empirical research about what works in challenging mental health stigma to the *madosphere* with the purpose of assessing what particular affordances social networking sites offer to those who wish to interrupt and challenge stigma.

Goffman's Asylums (1961) is an empirical ethnographic work on the characteristics of institutions that was written on the basis of a year spent on a hospital ward where he observed the social world of the 'hospital inmate'. I employ his detailed delineation of the characteristics of institutions as a reference point for exploring the extent to which the qualities of the institutions are replicated or contested in the *madosphere*. In Chapter 4 I give a detailed account of the *madosphere* in which Goffman's asylum is the locus against which it positions itself and against which it is in constant tension. The institution is a constant theme and reference point throughout my research – the extent to which it is disrupted and the extent to which it reasserts itself when practices emerge which challenge its authority.

Finally, I draw on Goffman's work on self-presentation (1959) in which he employs a drama based metaphor to shed light on how one endeavours to control how one presents oneself to others. In the digital age, social networking sites provide the stage for self-presentation and identity negotiation where our public selves and our private selves are performed (Paparacharissi, 2011, p.304). For those with stigmatised identities, whose self-presentation may be ruptured by social anxieties or the visible effects of medication, I consider the affordances and limitations of social networking sites for self-presentation. My interviews illuminate the ways in which some people with lived experience exploit the technological affordances of social networking sites to present themselves in ways which are meaningful to them, and how they can turn

something which is often experienced as a deficit in everyday life into an asset in the *madosphere*.

A review of the existing literature relevant to my research question is presented in Chapter 2. I begin with an appraisal of popular conceptualisations of mental distress which range from medically and biologically orientated approaches through to socio-constructionist approaches. This provides the context for my research in which I explore how people participating in the madosphere make sense of and conceptualise mental distress. I go on to appraise literature relating to theories of power, stigma and discrimination alongside empirical research about the effects of stigma experienced by people with lived experience and how it is resisted. This provides the context for an application of stigma and discrimination theory to conversations about mental distress in the *madosphere*; throughout the chapters I assess the extent to which they confirm or disconfirm existing research. Lastly, I consider existing literature about social networking sites and the small body of studies which relate specifically to social networking and mental health. In further chapters I explore the extent to which practices in the *madosphere* are the same or different to those described in the new media literature.

In Chapter 3 I set out a rationale for employing an online ethnographic methodology for my research, which is based on my intention to develop a rich and deep qualitative understanding of practices within my field of study. Ethnography is defined by Gobo (2008, p.12) as 'a methodology which privileges the (cognitive mode of) observation as its primary source of information' and includes other sources of information such as 'informal conversations, individual or group interviews and documentary materials'. I explain how I have utilised a number of ethnographic techniques to illuminate my

research question. Firstly, online participant observation has enabled me to discern behaviours, social practices, rules and rituals operating within the *madosphere*. Secondly, in-depth qualitative interviews with key actors within the *madosphere* have enabled insights into personal experience, motivations and interpretations of those practices. Detailed field notes from TWOM have provided a rich account of design, content and practices at the heart of the *madosphere*. Lastly, I present a number of case studies in order to explore my research question holistically through specific events that occurred during the course of my research.

In Chapter 4 I employ an historical lens to chronicle key actors and events where dominant institutional paradigms of mental distress have been challenged. Records of people objecting to mental health institutions go back to the early asylums and workhouses (Morrison, 2005; Porter; 2002; ; Nolan, 1993; Scull, 1993). Secondly, I draw on Speed's (2006) theoretical framework of mental health discourse to illuminate a spectrum of behaviours which range from acceptance and assimilation through to challenge and rupture of received relationships. Goffman's (1961) analysis of patient and professional roles and interactions within institutions provides a reference point for examining present-day practices within the *madosphere*. His dramaturgical metaphor is employed to consider the affordances of social networking to manage self-presentation and negotiate social identities they may have varying degrees of agency to control (1959). I argue that social networking sites afford unprecedented opportunities for people to self-mediate their social identities on their own terms, with potential for reach beyond the parameters of in-person public networks. I make the case that conversations within the *madosphere* are characterised by a dynamic combination of talking to and about, talking with and talking back to professionals and institutions.

In Chapter 5 I give a detailed account of the *madosphere* and describe how it metamorphosed during the period of my research as practices evolved and conversations moved from TWOM towards Twitter. I consider the language and conventions of the *madosphere* which draw on a combination of civil rights history and contemporary popular culture. I explore who is participating in the *madosphere*, how they experience and understand their engagement, and what meanings it carries for them. I describe the behaviours, practices and social norms in the *madosphere*. I endeavour to paint a rich picture with texture and depth for others to see, understand and appreciate. My intention is to illuminate the *madosphere* in ways which value this diminutive corner of the Internet that is dynamically created and recreated from the ingenuity and effort of its participants. In my delineation of the *madosphere* I use Goffman's Asylums (1961) as a point of reference as to how the institution is both reproduced and contested, and finally how it encroaches and replicates itself on social networking sites.

In Chapter 6 I consider the ways in which mainstream print media frame mental distress and how this is contested in the *madosphere*. I examine mainstream media constructs of mental distress and how this is both resisted and alternative constructs are represented in the *madosphere*. I argue that each offer competing public discourses about mental health and mental distress with the madosphere as a site of defiance. I argue that practices in the *madosphere* are orientated towards self-mediated first person accounts which provide an alternative discourse to the objectifying accounts which still dominate mainstream media. I also explore how this is shifting and emergent media practices of sourcing content directly from social networking sites, thus amplifying the voices of people with lived experience to the consumers of mainstream

media. I give detailed accounts of two events - The Sun newspaper's '1,200 Killed by Mental Patients' story and the Asda 'Mental Patient' story, to illuminate my arguments.

In Chapter 7 I give an account and analysis of disrupted relationships, power, identity and expertise in the *madosphere*. Drawing on my own experiences of participating in the *madosphere*, as well as field notes and interview data, I consider the extent to which identities and conversations in social media sites are similar or different to those in everyday life. I argue that practices in the *madosphere* are orientated towards increased empathy between people accessing and providing mental health services, but that suspicions and barriers in everyday life are also experienced in this space. I explore the affordance of social networking sites to enable people with lived experience to engage in peer support beyond the boundaries of mental health services. Drawing on literature related to social capital, I explore the benefits people derive, both personally and professionally, from their practices in the *madosphere*. Lastly, I explore the extent to which power and expertise is fragmented or reinforced in the *madosphere*.

Chapter 8, my final chapter summarises my thesis and offers a series of recommendations for mental health professionals and related institutions with regard to use of social networking sites. The recommendations are intended to offer an application of insights gleaned through my research in an everyday practice context.

4.0 Stigma and Discrimination

My ethnographic research captures an extended period during which I have endeavoured to learn from and participate in the *madosphere*. I have been motivated by a long standing awareness of inequality experienced by people with mental health problems who are often marginalised by mainstream society (Link & Phelan, 2006). I am particularly concerned by mental health stigma and discrimination which has been theorised extensively in academic literature (Thornicroft, 2006; Corrigan, 2004; Dinos et al, 2004; Wahl, 1999; Goffman, 1963). Its origins, manifestations and social solutions have been vehemently debated and contested since mental distress began to be clearly conceptualised from the 19th Century onwards. Mental health issues affect one in four people in any one year and are therefore widespread with profound implications for society (Health and Social Care Information Centre, 2007). Beliefs, for example, that people with mental health problems are violent, are pervasive and have a significant detrimental effect on people with lived experience. As well as the damaging effect of public attitudes, the negative attitudes of health professionals have also been found to be resistant to change (Cockcroft et al, 2013). Mental health and related distress is not just an issue of public prejudice, it is one in which discrimination is endemic within the very health and social care services established to offer care and support.

Mental health services are caught within a dialectic - they are shaped by societal stigma but also create it, as does the mainstream media. Thus, where care is largely based on institutions and coercion, people will assume that that is because people with mental health problems are dangerous, irresponsible and need to be segregated. How services can shift from contributing to disempowerment towards empowerment is a central challenge. It can be enthralling to see such inherent tensions and divergent perspectives on the future of mental health care debated in full public gaze within the *madosphere*.

5.0 Use of Language

Throughout my thesis I use the phrase *mental health services* to refer to the range of statutory organisations and the professional groups working within them in the United Kingdom. These include, but are not limited to psychiatrists, psychologists, social workers, nurses and occupational therapists. I am particularly interested in statutory organisations as they have specific powers to detain and contain people deemed a danger to themselves or others. However, it is recognised that mental health services are also provided by third sector and community organisations. I use the term mainstream media to refer to broadcast, print and internet technologies intended to communicate to large audiences and which are regulated by professional codes. I specifically focus on mainstream print media within my research as a point of comparison to blogs and micro-blogs on social networking sites. Social networking sites are websites where individuals create profiles to which they can upload diverse media and then connect with others through following or 'friending'. Blogs are websites where individuals can upload 'posts' in which the most recent post is shown at the top of the page. Twitter is a micro-blogging site where individuals can create 140 character posts. Social networking sites are characterised by user generated content and an interplay between consumption and production of information (Baym, 2010, p.16). During the course of my research there has been an exponential growth of new social networking sites such as Instagram and Snapchat whilst others, such as MySpace, have declined in popularity. My thesis focuses on the sites most strongly connected to The World of Mentalists (TWOM) ecosystem.

Whilst tensions and disagreements abound, it is unsurprising that language is contentious in any discussion of mental health. I therefore explain the language I have chosen to use in my research. Expressions such as ‘patient’ and ‘service user’ are commonly used to describe people accessing mental health services. The terms ‘expert by experience’ and ‘patient leader’ have become fashionable as a means of attempting to recognise the knowledge that arises from personal experience. Some find the term ‘patient’ too medically orientated and others are repelled at the notion of ‘service user’ with its drug using inference. My preference is to refer to the person first and, where necessary, the label second. Throughout my research I refer to people with ‘lived experience’ or people ‘accessing services’. I draw distance between a diagnosis and an individual in order to place a question mark about the essential validity of that diagnosis. For example, I may refer to someone ‘living with a diagnosis of bipolar disorder’ rather than someone ‘with bipolar disorder’. Similarly I may describe someone ‘living with a diagnosis of depression’ as opposed to ‘suffering from depression’ in order to avoid a discourse of pity and sorrow. Some may regard these subtle language choices as petty or irrelevant but I contend that language is important because it reflects how we conceptualise distress and more importantly frames it in certain ways when we converse with others. Care and delicacy in my use of language reflects a care and concern for people affected by social injustice, stigma and discrimination. Furthermore, in my research I have been less concerned with diagnosis and more concerned with the effects of that diagnosis on identity and stigma.

6.0 Personal Reflections

The question I explore in my research has been of increasing interest to me since my gradual immersion in social networking, which began with an introduction to Twitter by a colleague in 2010. Employed as a senior manager in an NHS Trust, I soon began connecting with a diverse variety of people both accessing and working in mental health services. I observed that parameters and barriers routinely established between these groups of people appeared to be different on social networking sites. I became curious about whether blogging and micro-blogging sites created spaces where people could participate in practices which may have a disruptive and even liberating quality to them. By disruptive I mean a destabilising of institutional order and received roles and identities; and by liberating I refer to the sense of emancipation and freedom experienced by people disrupting institutional hegemony.

On a personal level, I certainly experienced a sense of liberation in the ability to have conversations about the contested nature of mental distress with a diverse range of people with varied views and experiences. Previously the potential to engage in those conversations was constrained both temporally and spatially. Before my introduction to social networking sites, the chances of engaging in conversations that actively challenge the hegemony of the institution were limited by lack of opportunity and access. My participation in the *madosphere* has enabled me to participate in dialogue outside of hierarchical and medicalised parameters of the institution. Online social networking sites have afforded new possibilities for me to converse with people interested in discussing similar issues who I never otherwise have come into contact with. During the course of my research I have had the privilege of meeting many of them in person.

7.0 Conclusion

In conclusion, my research aims to offer insights into how struggles of identity, power and resistance are negotiated within the *madosphere* and how the affordances of social networking sites are engaged with by people with lived experience, professionals and institutions. Whilst those affordances create valuable opportunities for self-mediation and challenge to dominant narratives of mental distress, it is also the case that professional and institutional practices are increasingly encroaching and mollifying the *madosphere*. I argue that over the four year course of my research, practices on social networking sites have been characterised by a continuous tension between institutional practices and those outside of institutional boundaries in the *madosphere*. During that time the institution and institutional practices have emerged into social media spaces and attempted to reinstate institutional order with varying success. Negotiation of power and expertise between those with lived experience of mental health difficulties, professionals and institutions remains a constant and unresolvable site of contest in the *madosphere*, as it is in everyday life.

Chapter 2

A Review of the Literature

1.0 Introduction

The dissonance between often stereotypical mass mediated constructs of mental distress and individual subjective experiences, affects increasing numbers of people (NHS Confederation 2014). The pernicious consequences of negative mediations of mental health for individual identity and experience of discrimination have been widely researched and are closely bound to power and labelling (Wahl, 1999; Dinos et al, 2004). In this chapter I examine two separate and not obviously connected strands of literature that relate to mental health and online social networking respectively. Brought together, they provide the context for my thesis which explores the extent to which the relationships between users and providers or mental health services are being disrupted through self-mediating practices in the *madosphere*.

I begin by evaluating the literature on contemporary dominant paradigms of mental distress and related debates about the role of individual agency versus professional and institutional control. I go on to evaluate the literature in relation to mental health stigma and discrimination both within mental health services and within the wider public, and its implications for people affected by mental distress. I review literature which interrogates mainstream media's role in perpetuating negative public attitudes towards mental health difficulties. I then consider existing empirical research on the effects of stigma and effective strategies to reduce it within healthcare, mainstream

media and the general public. An evaluation of mental health literature in this field provides a context for my thesis by setting out existing research on the relationship between users and providers of mental health services. It is apparent from a review of the literature that there is currently a scarcity of research that considers the impact of online social networking for relationships between users and providers of mental health services. As such a paucity of research exists in the field of online social networking and mental health, I go on to evaluate a separate strand of new media literature which considers the affordance of online social networking for self-mediation and disruption of mainstream media and institutions. I consider related literature on online personal identity and social capital as well as citizen journalism. I set out the implications of the digital divide and the implications of social exclusion. I conclude this section by evaluating the diminutive but growing body of literature that connects mental health and online social networking.

Throughout the chapter, I draw heavily on the work of Erving Goffman as I evaluate these two separate strands of literature. Goffman is notable in that his extensive body of sociological research addresses the apparently divergent core themes of my research in a number of his books and essays. In *Asylums: Essays on the Social Situation of Mental Patients and other Inmates* (1961) and *Stigma: Notes on the Management of Spoiled Identity* (1963) Goffman creates the foundations of ensuing research and theorising on mental health, institutions and stigma. In his earlier work *The Presentation of Self in Everyday Life* (1959) Goffman employs a dramaturgical metaphor to theorise the importance of everyday social interactions. As the first researcher to treat face-to-face interactions as the subject of sociological research, Goffman's work on human interaction is the foundation for subsequent theorising of offline and online intercommunication.

I conclude the chapter by bringing these two separate traditions of literature together to consider the implications of one for the other. I argue that a research gap exists in assessing the implications of how people with mental health difficulties and professionals are engaging in practices which interrupt and problematise established institutional hierarchies. This analysis creates new knowledge which diverges from the main trend towards appraising the implications of online social networking for professional boundaries, ethical concerns, and clinical practice. I explore what online social networking means for the subjective identities of people producing and consuming content. I also consider how this might accelerate or ameliorate cracks in the edifices of mental health services and mainstream media.

2.0 Mental Distress - Identity, Power, Stigma and Discrimination

In this section I appraise literature which explores relationships between people accessing and providing mental health services. I identify the limitations of this research and set out how my thesis contributes to original knowledge which builds on existing literature by considering relationships in defined online spaces and mediating practices.

2.1 Understanding Mental Distress

Origins, causes, experience and interventions for mental distress are highly contested both between people with mental health difficulties, mental health professions and the general public (Herron & Mortimer; 1999). My thesis considers how these contested concepts inform conversations about mental health in the *madosphere* and my

research interviews explore individual understandings of mental health. The tension between disruptive practices and institutional encroachment is an underpinning theme throughout my research, and this is reflected both in the notion of recovery and the notion of the *madosphere*. It is therefore pertinent to summarise competing contemporary discourses which conceptualise mental health and mental distress.

Sociological theorising of mental distress considers the relationship between internal experience and social identity, social rules and conformity. Goffman conceptualises mental distress less in terms of physical or emotional attributes and more in terms of social relationships between those affected and not affected by them (Goffman, 1961, p.119). Goffman's locus problematises what might otherwise be seen as common-sense or natural internal experiences and social relations. His theorising of identity, knowledge and power is echoed in the work of Foucault (1963), a contemporaneous philosopher who in *The Birth of the Clinic* identifies a fundamental shift in the organisation of medical knowledge during the development of medicine in the late eighteenth century. He argues that this epistemological shift is bound up in the power interests of the medical profession; in particular, he contends that an emerging medical discourse separates the mind of the patient from the body of the patient. This de-humanising 'medical gaze' reduces the patient to their biology and gives primacy to the visible. He challenges the notion that developments in medicine are a common sense progression towards empirical 'truth', but rather a new discourse and way of organising knowledge that is located in power.

Sociological and philosophical critiques of the aetiology of mental illness by Goffman and Foucault continue to be the subject of contemporary theorising, as exemplified by campaigns such as the Critical Psychiatry movement, which reject the dominance of

perceived biomedical reductionism. Rogers and Pilgrim (2001, p.105) summarise a critical analysis of a medically orientated conceptualisation of mental distress when they contend that:

> Medicine and professions close to it have had a central role … with their interests in diagnosis, testing, assessment and observation and the treatment, management and surveillance of sick and healthy bodies in society.

The position that adherence to primacy of the biomedical model in mental health care is concerned with the status and power of existing professional groups, remains salient (Slade, 2009, p.13). The challenge to the dominant medicalised model arises from the fact that, unlike most conditions of the body, a physical test does not exist to diagnose a 'mental illness'. Diagnostic manuals are based on descriptors, with medics relying on patients to describe their experiences so they can categorise them and assign a label. This carries inherent risks of standardising what it is to be normal or abnormal using subjective culturally specific bias (Slade, 2009 p.8).

Critics argue for a more rounded approach to conceptualising mental distress that converges the social, psychological and biological. They argue that primacy should be given to helping people find meaning in their experiences and achieve their potential. Slade (2009) argues that mental health services tend to give primacy to nomothetic (generalised) knowledge over the idiographic (specific), and contends that neither is satisfactory in isolation. He promotes a constructivist epistemology in understanding the causes and effects of mental distress, which holds that: 'all knowledge is constructed, and does not necessarily reflect external reality, but rather depends on a combination of convention, individual perception and social experience' (Slade, 2009,

p.54). My research is grounded in a position that identity is emergent and embedded in social context and formed through relationships. This conceptual position offers a map for an analysis of the meanings of interaction on social networking sites for people with mental health difficulties, both with each other and with mental health professionals.

A dominant contemporary paradigm which has shaped recent and current mental health policy is the notion of 'recovery' (Braslow, 2013, p.781). The recovery movement emerged in the 1980s from activist and consumer movements which had their origins in the sixties, and defined itself in resistance to the paternalism of mental health institutions as delineated by Erving Goffman (1963) in his seminal ethnographic study of the asylum. The most commonly contemporary cited definition of 'recovery' is articulated by Bill Anthony:

> Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life event within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993, cited in Slade, 2009, p.38).

The concept of recovery is both highly contested and carries many meanings - it is variously regarded as being an idea, a movement, a philosophy, a set of values, a paradigm, policy and a doctrine for change; it can be both considered simplistic from one perspective and revolutionary from another (Bonney & Stickley, 2008, p.140). The term 'recovery' itself is contested as some argue it is constrained by the paradox that it employs the language of illness whilst attempting to create an alternative to a

predominantly medicalised model (Slade, 2009). Biomedical approaches tend to define recovery in terms of absence of symptoms whereas others argue that medication suppresses symptoms and hinders recovery. Recovery has been conceptualised and defined both at a personal level, a clinical level and a service level (Le Boutillier et al, 2015). The contemporary drive for outcome measures and targets can lead to a uniformity of provision that contradicts the notion of personal recovery and transforms it into a model of service provision (Slade & Perkins, 2012).

Proponents of the concept of recovery argue for mental health services which transform dependent patients in to independent citizens, fuelled by hope, optimism and greater individual control. However, Braslow argues that the discourse of recovery is closely aligned to neoliberal policies on welfare reform which promote individualism over collective social responsibility, with the underpinning aim of reducing dependency on publically funded services: 'recovery provided a crucial therapeutic rationale for linking service reduction to the best interests of patients' (Braslow, 2013, p.799). It has been argued that successive governments have appropriated the work of activist advocates of recovery to articulate an individualised conceptualisation of mental health recovery and to justify reduction in service provision (Bonney & Stickley, 2008, p.148). The radical origins and potential of recovery principles have become subsumed within and appropriated by mental health institutions. This has echoes of the *madosphere*, which as I argue has also been gradually encroached upon by the institution during the course of my research, in the guise of a plethora of policies, guidelines and professional practices. The very origins and meanings of mental health and mental distress are the subject of contention both within the mental health system and also aligned to particular professional and political interests. This context is salient to an

exploration of the *madosphere* as it shows that whilst the online context may be new, the conversations have a long established provenance.

2.2 The Power of Labels

An exploration of identity in relation to mental health has to consider the role of diagnostic labels in so far as they are key to defining and classifying sets of experiences. Modified labelling theory provides a conceptual foundation from which to understand the impact of mental ill-health labels on both individuals who receive them, those who confer them, and the general public (Link et al, 2004). According to modified labelling theory, when a person receives a mental health diagnosis the negative cultural conception of mental illness becomes personally relevant, and is transformed into an internal expectation of devaluation and discrimination. These expectations lead to behaviours associated with preventing negative responses, such as withdrawal from social situations, concealing a diagnosis, and masking one's mental health history. These actions lead to increased vulnerability and exacerbated mental ill-health. As well as shaping the behaviour of people with a mental health diagnosis, they also shape the behaviour that others direct towards them, creating a circular negative effect (Link et al, 2004). My research considers whether social networks offer different opportunities for self-presentation that might ameliorate the potential negative effects of self-mediating a mental health diagnosis in face-to-face communication.

Link and Phelan (2001, p.386) argue that the use of the term 'label' is significant in that it leaves: 'the validity of the designation an open question' and alerts us to the fact that characteristics that become subject to stigmatisation vary between cultures and at different times. Similarly, Morrison (2005, p.164) proposes that a mental patient identity

is one which is achieved, that is, it is: ‘officially assigned to a person by an expert other’ and then: ‘confirmed by a societal response’. As the person is labelled and medicalised, they experience the consequences of this process, which may be beneficial or harmful, or both. Morrison (2005, p.165) identifies a range of possible responses to a diagnostic label:

> Rejection of the expertise of those who label, reject the treatments associated with that label and promote alternatives, claim the identity (madness) and celebrate it, accept the label and fight stigma and welcome the treatments that approximate one’s normalisation.

Researchers have identified both positive and negative consequences of diagnostic labelling of mental distress. Positive effects include giving a distressing experience a name as well as removing the stress of keeping that experience a secret. Labels can help people identify and connect with others whose experiences have been similarly categorised. Telling one’s story can be experienced as liberating, empowering and can reduce social isolation and loneliness (Thornicroft, 2006, p.207). A label can be a starting point to identify commonality and connectedness and can be perceived to bring benefits such as access to treatment and services (Kroska & Harkness, 2006, p.325). However, many people avoid sharing a psychiatric label because of the associated stigma and fear of discrimination (Corrigan, 2004; Thornicroft, 2006, p.89). A negative consequence of diagnosis can be a resulting perception of an individual as ‘defective’ and ‘flawed’. There is an additional risk that people accessing mental health services, and those around them, experience their diagnostic status as their core identity rather than one feature of their lives (Slade, 2007, p.23; Sayce, 2000, p.70). Psychiatric labelling carries the peril of people experiencing prejudice and discrimination when they

disclose that label to others (Thornicroft, 2006; Corrigan, 2005). It is argued that a clinical assessment process that focuses primarily on deficits, dysfunction and disorder in order to diagnose an illness creates stigma and potential dependency on mental health services (Slade, 2009, p.23). Participants in the madosphere routinely discuss the problematic nature of diagnosis and medication. The Twitter hashtag #pillshaming is just one example of a conversation about the role of diagnosis and associated medication in the sphere of mental health. The literature on labelling illustrates how this topic has a long provenance in the academic arena and my research illuminates how individuals are conversing on the same themes as part of online social networks.

2.3 Patient and Professional Relationships - Boundary Violation, Discourse and Power

Slade (2009, p.73) argues that without a critique of power relations, the current social policy agenda of recovery orientated mental health services: 'simply becomes the next thing to do to people with mental illness.' The function of discourse, that is use of language as a means of mediating power relations, is key to an exploration of how identities are constructed by people accessing and providing mental health services. It is particularly pertinent to researching social networking sites, which create new and relatively un-researched affordances for online dialogue between groups and people with different interests in the public sphere.

Both Goffman (1963) and Foucault (1973) interrogate social relationships constructed between professionals and patients as represented through discourse. They are interested in forms of knowledge, and the systems and practices associated with that

knowledge. Hardey (2001, p.389) argues that ‘carefully guarded’ information is the basis for what he describes as: ‘professional monopolies such as medicine’. I am curious about what happens to dominant professional discourses in the *madosphere* where access to knowledge, and tools for communicating knowledge, are shaped in different ways and with different implications for influencing dynamics of power and identity formation. Social networks afford the opportunity for anyone to produce their own content, self-mediate their identity, and share their views and ideas, irrespective of societal role or institutional position. Morrison argues that the ‘movement’ to challenge the dominant psychiatric model is on a par with any other rights movement. She describes the key features as:

> A common identity of having been psychiatrised, and this identity has a group awareness and common grievances. There is a shared grievance of loss of power, stigmatisation and injustice in the achieved master status of mental patient. There is a shared experience of discrediting and betrayal of trust in the relationship defined by that status (revealed in the survivor narrative) and a common goal of claiming the same rights as others in spite of the label of psychiatric diagnosis (Morrison, 2005, p.160).

Goffman (1963, p.367) argues that the relationship between the psychiatrist and patient are defined according to certain unspoken rules that bolster their separate identities and respective power relationship. The psychiatrist is the ‘medical server’, an expert providing treatment. The patient is required to respond with ‘a contrite admission of illness stated in modestly un-technical terms and a sincerely expressed desire to undergo a change of self’. Where this compliant role is not understood or willingly assumed by the patient they unwittingly pull the relationship out of the ‘service schema’

and the psychiatrist responds by treating this non-compliance, not as usable information, but as signs of the illness itself. Whilst mental health services in the United Kingdom are no longer delivered in asylums, contemporary research suggests that issues of power and control continue to have salience in relationships between people accessing and providing services (Slade, 2009). My research takes the notion of unspoken rules between people accessing and providing mental health services and considers how these are expressed, resisted and subverted in the *madosphere*. I make the case that the practise of blending of personal and professional identities in the *madosphere*, alongside conversations which open up to question and debate these core issues, allow for different types of knowledge to be shared and different types of relationships to be formed.

Slade (2009) argues that because identity involves relationships, both with ourselves (personal identity) and other people (social identity), social interaction has salience in relationships between mental health professionals and people accessing mental health services. Slade describes a spectrum of professional/user relationships from detached through to partnership focused; whereby a detached relationship tends towards a paternalistic approach locating power and expertise with the professional; whilst a partnership approach tends towards collaboration and sharing of power. The tension between the professional and the personal is a boundary for both parties to negotiate, either implicitly or explicitly, in day-to-day working relationships. He argues that recovery is positively influenced by professionals who are:

> willing to break the boundary that traditionally lies between them and their clients, for example by receiving gifts from them or meeting them when off-duty,

> they make their most important contributions to client recovery (Slade, 2011, p.9).

Slade names this willingness to engage in relationships outside of institutional boundaries a 'boundary violation' from institutional norms and advocates that professionals make such behaviours more acceptable in their work. Practices in the *madosphere* that violate boundaries between people accessing services and professionals is a key focus of my research and one which has not yet been addressed in the academic literature. I argue that people within the *madosphere* are consciously exploiting the affordances of social networking sites to form relationships and connections and engage in dialogue that violate traditional boundaries. Participants perceive this to be a positive effect of engaging in online social networks.

The notion of boundaries and how they are maintained or violated in social interactions aligns with Goffman's (1959) conceptualisation of social interaction, in which a performative metaphor is employed to illuminate how social roles are enacted. According to Goffman, social interaction is underpinned by an unconscious desire to maintain a coherent self-presentation. The actor attempts to present a controlled 'front stage' performance whilst keeping the 'back stage hidden' in order to avoid embarrassment. Slade's call to professionals to violate boundaries has echoes of Goffman's notion of a back-stage performance. He is invoking professionals to interrupt their professional front stage performance and allow aspects of their back stage selves to be visible in order to build authentic relationships for the benefit of people they care for. This requires taking professional risks and, in Goffman's terms, opening oneself to potential vulnerability or embarrassment. In Slade's analysis this is a transformative process from paternal institutional relations to authentic and meaningful connections.

My research takes both Slade's conceptualisation of boundary violation and Goffman's conceptualisation of self-presentation as a performance and explores their application to self-mediating practices in the *madosphere*. In Chapter 7 I explore the blurring of personal and professional identities. I consider the extent to which practices in the *madosphere* may be accelerating a growing schism in professional knowledge and power through content produced by people with lived experience of mental distress. To what extent do practices in the *madosphere* enable people with experience of mental distress to define their own identities on their own terms, to self-advocate and engage with mental health professionals on more equal terms or opt out of the system altogether?

2.4 Stigma and its Consequences

The term stigma originates from the Greeks, who used it to refer to markings cut or burnt in to the skin of undesirable people, as a signifier of their defective moral status. In a contemporary context stigma has come to refer to the undesirable attributes of an individual which do not correspond with accepted social norms (Goffman, 1963, 13). Mental health stigma arises from perceptions of mental distress in the public consciousness based on assumptions and stereotypes. For example, despite the pervasive belief that people with mental health difficulties are violent, they are in fact more likely to be the recipients of violence than the general population (Thornicroft, 2006, p.74). Goffman's (1963) seminal work on stigma examines how interactions between stigmatised and non-stigmatised individuals disrupt received social roles. (Hayward & Bright, 1997) This frame is pertinent to my research as I argue that the heart of the *madosphere* can be found in interactions amongst and between people who are the subjects of stigma, and interactions between people who are the subjects

of stigma and those who are not. In Goffman's conceptualisation of stigma, the 'normals' avoid interacting with the stigmatised because it creates unease and discomfort, brought about by internal anxieties and fear of social rule transgression; whereas the 'wise' are those people who understand and ally themselves with the stigmatised. Employing Goffman's idiom, the *madosphere* can be conceptualised as interplay between the stigmatised, the normal and the wise. It is in these interactions that possibilities for reimagining and reshaping understandings of and attitudes towards mental health are located.

Goffman (1963, p.132) differentiates between personal and social aspects of identity that are connected and contingent on each other. Personal aspects of identity relate to subjective experience; whereas social identity is the result of one's various social experiences which are mediated from social norms and expectations. A stigmatised individual acquires expectations about what is an acceptable identity alongside an awareness that they are unable to conform to that identity - this inner conflict results in a sense of ambivalence about one's own self, resulting in shame and self-alienation. Corrigan (2004) similarly distinguishes between public stigma and self-stigma whereby social norms and expectations are internalised by an individual causing emotional conflict (Corrigan & Watson, 2002). Issues of stigma are routinely conversed upon within the *madosphere* and a review of the literature illustrates that these are well established debates, but taking place in a new context and self-mediated by individuals in the online public sphere.

My research extends the current literature on stigma by considering how personal and social aspects of stigma are negotiated and resisted through self-mediating practices in the *madosphere*. Empirical research demonstrates that issues of stigma are a

significant concern for people living with mental health difficulties. Qualitative studies with people experiencing mental distress indicate that the experience of stigma can be more damaging and limiting than the experience of the condition itself. In an in-depth qualitative study, Dinos et al (2004, p.178) found that the most common consequences of feelings of stigma were: 'anger, depression, fear, anxiety, feelings of isolation, guilt, embarrassment and prevention from recovery or avoidance and prevention from recovery or avoidance of help-seeking'. Wahl (1999) similarly found that stigma has a variety of lasting personal effects including lowered self-esteem and self-confidence, avoidance of social contact, reduction in trust of others, and increased sensitivity to slights. Stigma is therefore an important consideration in relation to research which endeavours to understand self-mediation of identity both by people with mental health difficulties and by institutions such as health services and the mainstream media – I consider the extent to which social networks offer affordances for people to self-mediate a stigmatised identity in different ways and what meanings this may carry for them.

A number of typologies of stigma endeavour to pinpoint the distinguishing features ascribed to the subjects of stigmatising attitudes (Jones et al, 1984; Hayward & Bright, 1997; Angermeyer & Matschinger, 2005; Penn & Martin, 1998). Characteristics associated with mental distress likely to invoke stigmatising attitudes relate to social skills and physical appearance such as the unwanted visible effects of medication (Dunn 1999). Prejudice arising from identification of such characteristics fall into three categories: a perception of dangerousness; a perception that people are childlike; or a perception that people are rebellious, free spirits (Corrigan, 2000). These prejudices influence discriminatory behaviours which in turn decrease opportunities in all aspects of public life, such as employment and housing as well as increased coercive

responses and treatment (Corrigan, 2000). Corrigan (2000) applies attribution theory to an analysis of stigma, which assumes that individuals search for causal understandings of everyday events with associated emotional and behavioural responses. Two relevant constructs are 'stability of causality and controllability'. Firstly, a belief that a mental health condition is permanent and rarely improving leads to increased stigma, despite the research evidence that shows that this is not the case for most people. Secondly, a belief that an individual is responsible for their mental health condition increases a blame response or conversely a belief that is it a biomedical condition leads to pitying and helping behaviours. In Chapter 6 I consider the extent to which self-mediated online identities that present the day to day complexities of living with a mental health difficulty, disrupt stereotyped perceptions that lead to stigma.

Goffman (1963) differentiates between those stigmas which are easily identified and those which are hidden, a mental health 'condition' being one that may often be hidden. Hidden stigmas require a decision to be made about whether or not to disclose this information. According to Goffman, there are two important phases in the learning process of a stigmatised person - firstly, an individual learns 'the normal point of view'; what is socially acceptable and what is not. In becoming aware of this, they come to an understanding that they are 'disqualified' from it. Secondly, the individual learns to cope with the way that others treat the kind of person they can be shown to be – finding out what other people think of people like him or her. This accords with qualitative research findings that the most commonly reported experience of stigma is witnessing negative comments or depictions of mental ill-health (Wahl, 1999; Link et al, 2004). This leads to a third stage which is learning to 'pass' as 'normal' to avoid the stigma. This is only available to those for whom aspects of identity that are stigmatised can be hidden or partially hidden. An option for those who are not able to 'pass' is to 'cover',

that is to reduce the obtrusiveness of the stigmatisation by reducing the extent to which it is apparent in a social situation. In a mental health context, this might mean a person avoiding making visible this aspect of their identity and experience in conversation, hiding self-harm scars, or avoiding taking medication that results in slurring of speech. Wahl (1999) found that people often or very often avoided telling people outside immediate family about their mental health problems. Research to date largely relates specifically to face-to-face interactions, whereas my study explores the particular affordances of social networking sites which provide different opportunities for self-presentation and identity control. Do online social networks afford the possibility to self-mediate one's identity without the trappings of physical characteristics likely to induce stigmatising attitudes, or conversely, can a stigmatised identity become an asset in an online social networking context?

As set out above, in everyday life an individual with mental health difficulties may have a sense of self-identity imbued with prejudiced and stereotyped public attitudes which are internalised as self-stigma. An individual's sense of self can be circumscribed and limited by these beliefs which in turn affect day to day performance of social roles. Whilst there has been extensive research on the effects on many aspects of public life, such as employment and access to services (Griffiths et al, 2014; Dinos et al, 2004; Corrigan & Watson, 2002), the implications of practices on social networking sites remains largely un-researched in the mental health literature. My research contributes to this relatively unexplored aspect of online social networking, by examining how people with mental health difficulties and professionals self-mediate identity and engage with stigma online. I consider what this means both for individuals with mental health difficulties and public attitudes towards mental health.

2.5 Discrimination, Exclusion and Power

What is the relationship between individually experienced stigma and systemic discrimination that disadvantages people living with mental health difficulties? Yang et al (2007, p.1526) build on theories of stigma to argue for 'an expanded conceptual lens' that goes beyond stigma and incorporates experience of discrimination. They contend that typologies of stigma are often reductive in that they largely localise its effects within the perpetrator and target of stigma. Stigma research needs to take into account the 'apparatus of the state, whose agents and agencies can stigmatise entire groups' and subject them to discrimination. Corrigan (2004) defines discrimination as a behavioural reaction to the cognitive and affective response of prejudice. It manifests itself as a negative action against an 'out group' or positive action for the 'in group'. According to Sayce (2001,p.8) discrimination, or unfair treatment, is a useful concept in mental health because it is an established 'common sense' term that resonates with existing movements that challenge unfairness with other groups, such as disabled people and black people. 'Discrimination' and 'social exclusion' are powerful terms because they enable people with mental health difficulties to benefit from notions that have already been established - that discrimination is unfair and that everyone should have a chance to contribute and be involved.

An expanded conceptual model that includes the structural determinants of stigma is important in understanding how it may be re-produced in communication between people with experience of mental health difficulties, mental health professionals and mental health services. This leads to an exploration of the role of power relations that are legitimised through social structures, experienced as stigma and expressed in actions as discrimination. Link and Phelan (2001) have developed a conceptual

framework for stigma that described a four stage process for stigmatisation that exists within the context of power relations. According to this model, mental health stigma has four key components (i) people distinguish between and label personal characteristics (ii) labels are linked to undesirable characteristics which results in stereotyping (iii) labelled persons are seen as part of an out-group (iv) labelled people experience status loss and discrimination; more recently authors of this model have included the emotional reactions which may accompany each of these stages (Link et al, 2004). This model is particularly useful in conceptualising stages of the stigmatising process and how this then leads to discrimination; the focus on the structural elements of discrimination and analysis of power inform my research into the relationship between institutions which hold power and people with mental health problems who are subject to discrimination. To what extent do online social networks afford possibilities to interrupt and reshape established power based social relations, and can institutional power be disrupted through the practices of socially networked individuals? I address this question in Chapter 7 in which I consider how power relations can be fractured and complicated online.

A conceptualisation of discrimination is pertinent to considering both the mental health professions and the mainstream media as powerful institutions which have access to considerable resources through which to propagate constructs of mental distress and mediate them to the public. Empirical research, as I will set out later in this chapter, demonstrates that both are culpable of manufacturing and transmitting knowledge and ideas that result in discrimination and reduced life chances experienced by people with mental health difficulties. My research considers how issues of discrimination are negotiated in the *madosphere* and explores events in which individuals have

collectivised efforts to challenge mental health discrimination perpetuated by institutions.

2.6 Stigma and Discrimination in Mental Health Services

Stigma and discrimination not only operate within the public consciousness, they are also manifest within the fabric of professional attitudes and services designed to both care for and contain people with mental health difficulties. A qualitative study with people who have a diagnosis of schizophrenia found that nearly one quarter of subjective experience of stigma related to contact with mental health professionals (Schulze et al, 2003). Another study found that a quarter of interviewees complained of professionals' low expectations of them and discouragement from setting high goals (Wahl, 1999). Stigma and discrimination within mental health services has deep implications for relationships between people accessing and providing services both within a clinical context and within the *madosphere*. Do online social networks afford possibilities for the stigmatising attitudes of some mental health professionals to be interrupted and what happens when stigmatising attitudes are expressed in the *madosphere*?

Thornicroft (2006, p.87) argues that: 'it is a paradox that many mentally ill people do not speak highly of mental health staff, who are specifically trained to treat people with such conditions … indeed service users often rate mental health staff as one of the groups which most stigmatises 'mentally ill' people'. According to Sayce (2000), invalidation of individual views is at the heart of statutory mental health services through the use of compulsory detention and treatment enshrined in mental health

legislation. She suggests that discrimination within services is ‘virtually endemic’ with a common experience of feeling dehumanised by contact with mental health professionals and a common view that discrimination starts within services (p.65). Corrigan (2004) argues that stigma represents a public health concern because it is a major barrier to seeking help from mental health services or participating in treatment. However, he fails to explicitly note that the consequences of contact with mental health services, such as labelling and the side effects of medication, are frequently experienced as stigmatising. In their qualitative study of 34 people with mental health difficulties, Powell and Clark (2006) found that lack of information about diagnosis and medication was experienced by participants as disrespectful and unequal. They also found that mental health professionals often had negative reactions when participants found and presented their own information. In a survey of people using secondary mental health community services, Corker et al (2013) found that over a third of respondents reported they had been treated unfairly by mental health staff. The survey was undertaken in 2008 and when repeated four years later showed no significant change in reporting in this category, comparing negatively to other domains where there was reported improvements in attitudes. Townsend et al’s (2012) American study into the reasons why people choose Internet based support groups over formal mental health treatment, found the most common reasons were fear of being hospitalised and fear of being required to take medication. The authors relate this to concerns about losing autonomy and the perceived coercive nature of services.

Several studies, summarised by Schulze et al (2003), suggest that mental health professionals display a desire for social distance from people with mental health problems. A systematic review of the literature found that nearly three quarters of the relevant publications report that beliefs of mental health providers do not differ from

those of the population, and can be even more negative (Schulze, 2007, p.142). Lauber et al (2004) undertook a study on the implications of social distance - that is the willingness to engage in relationships of varying degrees of intimacy - for mental health stigma. After social status, the authors argue that social distance is the biggest aspect of stigma experienced by people with mental health difficulties. The researchers found that having a medicalised understanding of mental distress increased desire for social distance; whereas believing a mental health condition is an experience of a life crisis decreases social distance. Their results (p.270) appear to confirm other research indicating that biomedical explanations of mental ill-health reinforce stigma, and perhaps partly explains why mental health professionals, often working within a predominantly biomedical model, also desire social distance. Another explanation for the desire of professionals for social distance is articulated by Goffman (1963, p.67) who suggests this is a way in which: 'awe can be generated and sustained in the audience [who] can be held in a state of mystification.' Social distance can therefore be conceptualised as a means of defining and sustaining the role of mental health professional; it is one that requires co-operation of the audience to also act in a 'respectful fashion, in awed regard for the sacred integrity imputed to the performer'. To have social contact runs the risk of rupturing the performed identities of professional and patient. There is currently an absence of research into how this apparent desire for social distance may be manifested online. In Chapter 4 I explore the extent to which online social networking sites afford possibilities for people accessing and providing mental health services to connect and even collaborate in ways which decrease social distance and increase empathy and mutual understanding.

2.7 Stigma, Discrimination and Mainstream Media

Representations of mental distress by mainstream media contrast with the affordances of online social networking sites in which mental health stereotypes can be challenged. Research suggests that mainstream media play a significant role in influencing the background knowledge people have about mental distress and the mental health profession (Birch 2012; Schulze, 2007; Thornicroft, 2006; Pilgrim & Miller, 2001; Sayce, 2000). The way we interpret our experiences of personal contact are filtered through our background knowledge of what diagnoses mean, our attitudes about what emotional reactions are socially acceptable, and our understanding of what types of behaviour are socially acceptable (Thornicroft, 2006). Birch (2012, p.17) goes further to suggest that 'pejorative mediations work to mobilise moral panics in the audiences by giving the public set characteristics about mental health which originate in myth'. As well as influencing public opinion, Birch argues that negative mainstream mediations have a pernicious effect on people with a mental health diagnosis whose subjective experiences of stigma may lead them to already feel 'inferior and incomplete in identity'. Do online social networks afford possibilities for these pernicious effects to be interrupted and remediated in novel ways? In a review of international research on print media, Thornicroft (2006, p.113) concludes that:

> newspaper coverage of mental illness tends to be short of accurate and detailed content, emphasises violence over all other aspects of mental illness, and reinforces prejudice against people with mental illness.

A similar picture emerges with both television and film (Birch, 2012). McNair (2009, p.219) writing about changes in the global media environment more broadly, argues

that hierarchical, centralised, commercial and industrialised mainstream media, serve the interests of elite groups at the expense of those with less power and influence. Birch (2012, p.27) contextualises the rise of mental health difficulties in the context of the current global economic downturn and questions the implications for people 'whose identity and subjectivity may be susceptible to mental health pressures'. He argues a need for mainstream media to find new ways to mediate mental distress which avoid stereotypes of dangerousness. Despite a useful critique of representation of mental ill-health in the context of commercialisation and globalisation, Birch omits to consider the affordances of online social networking for alternative narratives to be self-mediated which challenge those which dominate mainstream media. However, the extent to which such self-representations permeate mainstream media is not clear.

The Glasgow Media Group identify a rationale which underpins dominant mainstream media stereotyped mediation of mental distress. They found that prevailing news values are informed by notions of 'novelty, universality, topicality, impact and controversy' in which simplistic stereotypes provide shortcuts to audience understanding (Philo et al, 2010). Research undertaken through content analysis of television and press output as well as a series of focus groups found that negative attitudes relating to mental distress can clearly be related to media accounts (Philo, 1999). Mediations of mental distress connected to violence are more likely to make headlines, whereas more sympathetic representations are more likely to feature in problem pages and health stories (p.54). The 'confessional' is a strong theme in mainstream media representations of mental distress, comprising formats such as 'problem pages' in magazines, 'agony aunts' on radio stations, phone-ins and confessional style TV programmes (Pilgrim and Miller, 2001). Birch (2012, p.85) summarises a review of historical representations of mental distress from the arts

through to the media and psychiatry, and asserts that these diverse influences have become incorporated into the ‘sediment of culture’ that bears little relationship to the realities of mental distress as subjectively experienced at an individual level. Primacy is given to communicating ideas largely associated with violence that are ill-informed and inaccurate.

In an analysis of documentary mediations of mental health, Birch (2012, p.151) argues that in more recent times observational pieces have prevailed, which aim to illuminate experience of mental distress through first-hand accounts. However, mainstream media ‘appear reluctant’ to cover mental health issues in this way without ‘celebrity’ endorsement. Recent examples are Alastair Campbell’s documentary Cracking up (2008),Stephen Fry’s The Secret Life of the Manic Depressive (2006) and Tulisa Contostavlos’s Tulisa: My mum and me (2011). In his New Statesman article Get Me Sporty Spice, Caprani (2009) echoes this sentiment and critiques mainstream media’s reluctance to cover stories of people experiencing mental distress who are not in the public eye.

Mental health professionals, and in particular psychiatrists, are also subject to stereotyped representations in mainstream media which can have a stigmatising effect. The psychiatrist has been typified variously:

> as madman, as a powerful force for tinkering with the soul, and as a wonder worker who cures patients by uncovering a single traumatic event (Schulze, 2007, p.145).

Schulze (p.146) argues that dominant negative media portrayals of the mental health profession undermine the credibility of practitioners with a related impact on the experience of people accessing their services. Does this shared experience of stigma lead some mental health practitioners to exploit online social networking as a means of articulating their position and being understood? Perhaps there are commonalities as well as power differences between people accessing and providing services. As explored in Chapter 6, the *madosphere* appears to be a space and set of practices that bring actors together in a shared desire to disrupt public narratives of mental distress perpetuated by mainstream media.

How does negative mediation of mental distress through the mass media impact on the subjective experience of people experiencing mental health difficulties? Empirical research indicates stark similarities to the influence of mental health services in negatively impacting on personal identity. In interviews with 32 people using mental health services, Philo (1999, p.57) found that the most powerful negative affect was in self-definition. Just as the general public source their background ideas about mental distress from the mass media, so do those directly affected by the issues. These findings are replicated within qualitative research which indicated that public perceptions mattered enormously to people with mental health difficulties (Birch, 2012). These studies are significant in illuminating how people with mental health difficulties are likely to respond as consumers of mass media mediations of mental health. However, it is limited by the fact that participants are situated solely as consumers and recipients of mainstream mediations. Within the *madosphere* participants not only consume but produce content and actively engage with mainstream media content. To what extent are mainstream media representations conversed upon and resisted in the *madosphere*?

Writing before the emergence of social networking sites, a number of researchers consider how mainstream media representations of mental distress can become more accurate and less stigmatising. Henderson (1996, p.36) suggests that people who have experienced mental distress are likely to remain 'invisible' unless they become active participants in the media production process. Birch (2012, p.57) similarly argues that new mediations of mental health should 'ideally be led by people who themselves have experience of a mental health condition'. He omits to note that self-mediated identities that resist mainstream media and institutional stereotypes are increasingly commonplace on social networking sites. The question remains about the extent to which self-mediated productions of mental health identities influence mainstream media representations and I consider this further in Chapter 6.

2.8 Symbols and Assets - Effects of Stigma and Strategies to reduce it

My research explores how participants in the *madosphere* are conversing about experiences of stigma and discrimination and often actively challenging stigma through blogs and micro-blogs. Existing research regarding the effectiveness of stigma and discrimination reduction strategies are therefore relevant. Corrigan (2006) conceptualises three core strategies for challenging mental health stigma, namely protest, education, and contact. Protest operates as a reactive strategy that reduces negative attitudes but fails to promote positive ones; educative approaches provide information to the public can be effective in reducing negative stereotypes; direct contact between people with mental health problems and those without is most effective in engendering positive attitudes and greater general acceptance. Corrigan

(2001) notes that research on the impact of these three strategies is limited in so far as they assess self-reported changes rather than observed behaviour changes.

Research on the effectiveness of direct contact as a stigma reduction strategy identifies a number of required conditions, which include equal social status and common goals shared between the stigmatised and non-stigmatised person (Pettigrew & Tropp, 2006). The key challenge, however, is that direct contact is compromised through the pre-influencing factor of stigma itself which can reduce willingness to engage in social contact and self-disclosure. As a consequence, Sayce (2000, p.211) asserts that many messages to shift public attitudes developed by the mental health community are 'doomed to fail'. However, she argues that: 'the most credible presenters of new ideas about disability are generally disabled people who themselves portray non-stereotyped images.' Does the physical distance afforded by online social networking reshape contact between people with mental health and difficulties and the public in new ways not previously imagined?

Brohan et al (2010) use a consensus study approach to identify the key messages likely to have the most impact in reducing public mental health stigma. A key effective message is one which places an emphasis on seeing the person over the diagnosis and avoiding stereotypes and labels. It is significant that the biomedical messages that tend to emphasise that mental illness is similar to physical illness and is treatable by medication, were the least favoured messages in the study; they tend to reduce blame but not positively affect a desire for social distance. Do online social networks afford the possibility for people with mental health difficulties to self-mediate their identities in ways which interrupt the limitations of labels and stereotypes? Professionally led anti-stigma campaigns have been critiqued as a 'concealed attempt' at raising the profile of

psychiatry rather than enabling equality for people living with mental health difficulties. Whilst it has been established that mental health professionals can perpetuate stigma, it is also the case that they subject to stigmatising attitudes perpetuated by mainstream media (Schulze, 2007, p.145). Schulze (p.153) argues that the mental health profession should campaign to reduce stigma whilst carrying a reflexive awareness of its role in perpetuating stigma and taking steps to reduce it.

The experience of stigma can result in those affected dividing their social worlds to retain control of identity and reduce the negative impact of stigmatisation. This may be characterised by a division of social relations whereby in one group the stigmatised aspects of identity are hidden and in another everything is shared for the purposes of help and support (Goffman, 1963). An expectation of discrimination, otherwise known as anticipated stigma, can be disabling and result in self-limiting social contact to those who share this stigma, thus avoiding the unpleasantness of exposure (Goffman, 1963; Thornicroft, 2006 p.156). The consequence of suppressing aspects of one's identity has its own limiting effects in terms of emotional costs and limitation of self-expression (Birch, 2012, p.10). Goffman refers to this as a 'back place' where the individual may locate themselves either through choice or coercion. In addition to managing a stigmatised identity, people 'artfully dodge' or constructively challenge stigma and engage in a range of resistant practices which can of themselves have transformative potential (Link & Phelan, 2001; Riessman, 2000, 131). Goffman (1963) argues that a stigmatised individual may exercise control over information about their personal identity by wearing a stigma symbol that is visible to everyone. In his words, this is the 'final, mature, well adjusted' stage of the 'moral career' of a stigmatised individual. This notion accords with qualitative research which found the most common strategy for coping with stigma was participation in organised efforts to counter stigma (Wahl;

1999). Slade notes that terms such as ‘madness’ and ‘mad pride’ have been re-appropriated by people with experience of mental health difficulties, echoing the ‘black pride’ mantra of the civil rights movement. My research considers how such symbols or props may be expressed in the *madosphere*, perhaps as an avatar, personal biography or ‘liking’ a Facebook page that makes explicit reference to one’s mental health history. This raises questions about the intention of people who present their identity in relation to their mental ill-health and the reactions they experience from others.

The role of peer relationships is being increasingly emphasised in mental health policy and tends to comprise self-help groups, peer support workers and user-led services, and emphasise egalitarianism, equality and collective social action (Slade, 2007, p.103). My research explores how peer support is mediated in an online environment and considers what might be the similarities and differences to offline relationships. Burrows et al (2001, p.99) offer a summary of the medical, psychological and sociological research that they argue routinely concludes that there is a clear relationship between social support and both physical and mental health and wellbeing. People who have a high degree of social participation and good social and community relationships, tend to have better physical and mental health. With the rapid growth of the Internet, Burrows et al (p.105) argue that a better understanding about how social relationships function in cyberspace is needed. They articulate a view of social interaction that is situated in complexity and social ambivalence and which is characterised by: ‘fragmentation, diversity and a range of individualisation processes’. The questions they raise for further research are: ‘how participants experience the internet: What do they gain from it? What impact does it have on their lives and their sense of self?’ These are questions that I address in Chapter 4 as I explore the

implications of peer relationships for challenging mental health stigma and discrimination.

Hardey (2001) argues the Internet affords users the ability to seamlessly consume and produce their own knowledge which challenges healthcare professional authority. He argues that the medical profession has been cautious and occasionally hostile to this threat to their control and mediation of healthcare discourse. However, he also notes that increasingly healthcare professions are themselves engaging with the Internet and producing their own content. My research explores what happens when people using and working in mental health services engage with each other through producing and consuming knowledge in an online environment. What does this mean for professional identity and power, how are the relationships different and what does this mean for the subjective experience of both groups? My research study explores how a blend of protest, education and direct contact as strategies to reduce stigma, are interwoven in conversations within the *madosphere*. I consider how direct contact is negotiated online and the affordances of social networking sites in which individuals may feel more able to take productive risks with mediation of their identity.

3.0 Online Social Networking, Social Capital, Citizen Journalism and the Digital Divide

In the second half of this chapter I appraise a separate body of communications and new media literature which offers insights into the implications of online social networking for identity and disruption of institutions. The literature provides a separate but equally important grounding to the mental health literature by illuminating how

ordinary people engage in self-mediating practices which challenge traditional authority, particularly within mainstream media. I begin to make the connections between this literature and themes set out in the previous section.

3.1 Affordances of Social Networking Sites

The foundations of online social networking were established with online diary writing which quickly became known as blogging. This was followed by sites such as MySpace in 2003 and Facebook in 2004, as well virtual worlds such as Second Life in 2003 and the micro-blogging site Twitter in 2006. The term 'social media' derives from two related concepts: Web 2.0 and user generated content. The term Web 2.0 was first used in 2004 and describes content that is continually modified through collaboration by users (Baym, 2010, p.14). User generated content can be defined as text, audio or video content which is made publicly available over the Internet, which reflects a degree of creative effort, and which is created outside of professional routines and practices. It includes, but is not limited to: blogs, podcasts, vodcasts, social networking sites, social bookmarking, wikis and virtual world content (OECD, 2007, p.41). It excludes content exchanged in emails and instant messages, as well as replications of existing content and commercial content which tend to be found within mainstream media (Kaplan & Haenlein, 2010).

Social networking sites are characterised by primarily interpersonal interactions, founded on the norms of everyday relations and which are adapted to online settings. They enable people to create a profile, follow or 'friend' others and view other members' connections. They allow people to produce as well as consume content and enable multiple overlapping connections between different social spheres

(Paracharissi, 2011, p.305). Kaplan and Haenlein (2010, p.61) define social networking sites as: ‘a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user generated content’.

The emergence of Web 2.0 has resulted in a lower entry bar for creating content, with potential global distribution at minimal cost and virtually limitless storage space. It signifies a trend towards less passive consumption and more interaction with content and a participatory culture online. People generating content can share their story, produce cultural artefacts (for example, music and film) and influence the media content environment around them (OECD, 2007, p.64). Social networking sites can be used for critical, political and social purposes and tend to span both private and public domains. They are increasingly being used for consumer and commercial purposes as the data we produce is mined by platform providers for the purposes of advertising (Van Dijck, 2015). Social networking sites afford spaces and practices where the mainstream media and institutions such as the NHS are no longer the sole purveyors of information, knowledge, and by implication, authority and power. They afford the possibility for people whose voices have not often been heard to have a global audience and connect with each other without spatial or temporal limitations. They provide a space where shifting public attitudes to authority holders can be expressed and knowledge held by those ‘on high’ can be challenged (Coleman & Blumler, 2008, p.47). However, this is not to suggest a technological determinist view of the affordances of social media or that these affordances are embraced by anything but a small privileged minority. In addition, the act of producing content does not mean that there is a demand or audience for that content. With a saturation of content available

on the Internet, the possibility of garnering attention cannot be taken for granted (Couldry, 2014, p.616).

These innovations have developed within and are shaped by shifting public attitudes towards authority, characterised by reduced public deference to elites from World War II onwards (McNair, 2009, p.220). In this context, the term public refers to 'citizenship, commonality, and things not private but accessible and observable by all' (Paparachissi, 2002, p.11). People affected by mental health difficulties who are discussing their experiences online can be viewed as a specific public articulating particular interests. I am curious about the extent to which this public creates narratives which are in tensions with the institution and mainstream media, as well as where points of connection and tension lie.

According to Bruns (2008), the Internet introduces a number of challenges to the traditional, industrial model of information production and distribution which have been previously described in relation to mental health services and mainstream media. He characterises these challenges as follows:

(i) access to information sources takes place on an information-pull rather than push basis
(ii) access to means of production and distribution is widely available
(iii) enabling peer-to-peer communication on a global scale
(iv) information is easily and rapidly shareable.

He also defines characteristics of collective content as non-directed, orientated towards problem solving, non-hierarchical, granular as opposed to composite, and which is shared rather than owned.

His conceptualisation of the qualitative differences between industrial and new media is useful in considering conceptual parallels between mainstream media and the mental health care system as reflective of a traditional industrial model. Both have traditionally positioned themselves as guardians of legitimate information and knowledge and provided it through a hierarchical authoritative model mediated through narrow channels. In Bruns' analysis, the Internet affords the opportunity for publics to challenge and destabilise these models. Benkler (2006) similarly contends that the Internet has had structural impacts on the cultural, social and political spheres of public life. More recent literature critiques the binary opposites of mass and social media on the basis that increasingly sophisticated advances in computation enable platforms to filter, censor and ultimately control content that is visible to the user, often without their knowledge that this is the case (Sandvig, 2015). Whilst the collective noun 'social media' may be intuitively appealing, platforms such as Facebook and Twitter are first and foremost commercial entities and it is evident that power is increasingly being concentrated in the hands of a small number of global corporations with limited accountability. The fact that many have been found to be guilty of censoring and restricting dissent against governments is salient when considering the affordances of online social networks for social change (Fenton, 2015, p. 353). The tension between commercial and public interests are increasingly the subject of academic scrutiny by academics who interrogate and problematise claims of neutrality by online social network platform providers (Rushkoff, 2016; Couldry, 2014; Morozov, 2013). It is argued, that whilst online social networking platforms are based on different economic

models from mainstream media, they actually operate on a substantially bigger scale that traditional mass media could hope to (Couldry, 2014, p.619). It is easy to forget that as we share our most intimate, views, thoughts and experiences with our 'friends' and 'followers' we are doing so in commercial spaces and the content we voluntarily upload is being mined and monetised. The product is 'us' as much as the creative content we may produce.

Coleman & Blumler (2009) argue that the Internet provides a space and set of mediating practices where tensions between institutions and citizens can be played out. The 'fluidity and indeterminacy' of cyberspace lends itself to enabling citizens to question, challenge and influence institutions. Whilst the authors' focus is on democratic government, I would argue that their analysis of public disengagement can be compared to mental health institutions, which can similarly be characterised as 'remote, insensitive and untouchable' (p.1). They assert that the web is an 'empty space of power' which can be both occupied by corporates and citizens. Their analysis is an optimistic one, namely that the web provides a space where citizens can express themselves and affords the potential for nurturing 'critical citizenship and radical energy' which enables 'a new respect for public discourse and deliberation' (p.3). However, the affordance of participation does not make it a given and the reality is somewhat more mixed, with the majority of Internet users operating as passive spectators and consumers of content. As José van Dijck (2009, p.45) argues: 'The presumption that new networked technologies lead to enhanced involvement of recipients as well as to active cultural citizenship is rather generalizing.' Furthermore, rational discourse is not a given, and Paparachissi (2011) points to 'flaming' and conflict that can occur within and between groups that has the potential to compromise meaningful deliberation. I am curious about the extent to which this happens online between people using and

providing services who have a distinct set of assumed power relationships in place in an offline environment. Does this remain, shift or significantly alter online? And if so, what meaning does it hold for those participants? I address these questions in Chapter 7 where I consider how power and expertise may be fractured online. I consider implications for the role of institutions and the extent to which such deliberation can and should be convened by institutions. What is the difference between deliberative spaces created outside and separate to institutions? I am intrigued by how this may be manifested in a healthcare context, where power relations between institutions and people with mental health difficulties could be argued to be particularly starkly defined. Papacharissi (2002, p.10) questions whether the Internet has the potential to revolutionise the public sphere of political deliberation or whether it will be adapted to the status quo. The same question can be applied to a mental health context and is a key area of exploration in my research.

Over the last decade, the traditional one-way formal communication styles of large institutions have begun to shift under the pressure from the public who have increasingly experienced more two-way relationships in other aspects of their lives, for example in banking and travel (Coleman & Blumler, 2009, p.90). Chadwick and Howard (2009, p.5) suggest that the blogosphere has enabled 'ongoing citizen surveillance' of public figures and institutions on a grand scale. Public institutions, such as NHS Trusts, are established with formalised mechanisms for stakeholder feedback, such as the complaint process at a micro level and a board meeting held in public at a macro level. Whilst NHS Trusts now routinely have websites and, increasingly, have corporate Twitter and Facebook accounts, the different types of public conversations this facilitates are in tension with embedded formal tightly boundaried mechanisms of governance. Coleman & Ross (2012, p.110) suggest that such communications tend to

be constructed vertically as top-down messages to be responded to, which: ‘weakens the potential for spontaneous and autonomous communication, leaving intact the power of the traditional agenda-setters and policy makers’. My research concerns the extent to which social networking sites allow people with an interest in those institutions to engage and challenge and redirect them to agendas which they are interested in. I am even more fascinated in online deliberations by professionals and people with mental health problems which are taking place horizontally and autonomously to those institutions and are may be shaped and configured in different ways. Coleman and Ross argue that:

> There are lots of ways in which people are using the Internet to challenge officialdom, protest, debate, network, produce common meanings, and make their presence felt, but these spaces of democracy are largely disconnected from the old institutions of representation who go on as if this intensifying subterranean buzz can be ignored or patronised (2012, p.122).

How do these points of connection and disconnection manifest in an online environment and what does it mean for challenging or being absorbed by institutional power? During the development of my research the use of social networking sites has moved from the margins towards a more accepted and acceptable position within the mainstream. During the first draft of this literature review I characterised social networking as an activity which was regarded with a slight snigger and mild amusement in the formal and official culture of an NHS Trust. During the final phase of my research the first official report on social networking was produced by an organisation called NHS Providers entitled On the Brink of Something Special (NHS Providers, 2014) which claims to be ‘the first comprehensive analysis of social media in the NHS’. The

report celebrates what it defines as ‘stealth radicals’ whom it applauds for using social networking sites despite the restrictions imposed by the institution:

> [through a] combination of determination, ingenuity, passion, mutual support and sometimes sheer bloody-mindedness has been a stealth revolution whose day is about to come. This stealth revolution may not have been televised. But it has been tweeted, retweeted, favourited, liked, followed, tagged, poked, shared, webcast, thunder-clapped and crowdsourced (2014, p.3).

The hyperbole and elevation of social media is articulated within an institutional frame as something to be embraced and exploited by NHS and therefore within the control of those with power. The report ranks and creates league tables for different categories of social media from ‘stealth revolutionaries’ through to ‘boat-rockers’ which imposes its own hierarchies and controls. Rather than a celebration of social media use, it could be argued that this is an example of the institution attempting to reassert power and control. It could be argued that it is based on unconscious institutional bias in which professionals and organisations rather than individuals and the public are at the centre. This reflects a general move towards professionalising use of online social networks through a plethora of guidance introduced by various regulatory bodies from the General Medical Council to the Nursing and Midwifery Council (NHS Employers, 2014).

Coleman and Ross (2012, p.137) argue that deliberation, which they describe as a space for the public to: ‘question its own values, attitudes, and opinions: to reflect upon its desires, fears, plans and projections with an openness to changing perspectives’ is a prerequisite for media to work in the public interest. To rely on media institutions to do this, made of largely white middle class men is insufficient. So where is deliberation on

mental health topics taking place online? What are the points of tension, the challenges and the disruptions? How are people using social networking to complicate and disturb the order of things? How can the minutiae of day-to-day conversations be harnessed and assembled to have a broader public impact? Does the anonymity afforded by online engagement prevent an evaluation of its value and impact? Are people left feeling they have made a difference when, in fact, they have not? (Papacharissi, 2002, p.16) And do online social networks dissipate the potential for offline subversive action? In Chapter 6 I consider two events whereby people accessing mental health services and professionals challenged mainstream and corporate media and consider the wider impacts of those actions.

According to Coleman and Blumler (2009, p.87) to blog: 'is to declare your presence, to disclose to the world that you exist and what it's like to be you, to affirm that you thoughts are at least as worth hearing as anyone else's and to emerge from the spectating audience as a player and maker of meanings.' Paparacharissi (2012) similarly asserts that expressing personal opinion online, for example in a blog, represents an expression of dissent within a public agenda from a private sphere of interaction. To be able to speak as a citizen, within the safety of a private environment, has particular resonance for people who experience stigma and exclusion and whose stories and experiences may challenge the prevailing paradigms of mental health knowledge production by professionals and institutions. I am particularly interested in the function of social networking sites to provide a space for marginalised groups to have their perspectives 'witnessed' by others and am curious about if and how this may be a feature of the motivation by people whose subjective experience has been distorted by mainstream media (Coleman & Ross, 2010, p.106). Papacharissi (2009, p.238) asserts that 'self-expression' values are an important feature of post-

industrialised society and are connected to a desire for autonomy and control over one's environment. Rather than being 'un-civic' she suggests they have frequently led to subversive or collection action movements; the subjective focus of blogs and online forums: 'encourage plurality of voices and expand the public agenda.' I am particularly interested in the notion of subversion and the extent to which people organising online around issues related to mental health are able to organise, influence or even disrupt institutions.

3.2 Social Capital and Personal Identity

Social capital is particularly relevant to an exploration of how online social networking impacts on the subjective self in relation to others. My premise for undertaking the research is that participating in social networking sites may allow for bolstering self-identity through conversing with like-minded people. The social capital literature resonates with the mental health literature previously discussed in relation to the benefits of peer support and social connection. Core features of social capital can be identified as social networks, norms of reciprocity and trust which facilitate co-operation for mutual benefit (Ferlander, 2007; Blanchard & Horan, 1889). The notion of social ties, their degrees of strength and formality is important to the concept of social capital. Strong and weak ties refer to the level of emotional commitment within a network. Vertical and horizontal ties refer to the degree of hierarchy within a network. Bonding ties reflect communities which are very similar in their social characteristics, such as families. Bridging ties reflect networks of people who have dissimilar social characteristics, such as voluntary associations. Linking ties reflect networks which are based on hierarchies, such as within a work context (Ferlander, 2007, p. 118-119).

What is the subjective experience of living with a mental health diagnosis for people engaging in a community of interest which challenges traditional mental health services and create alternative constructs of mental health? Putman argues that flatter or horizontal networks contribute to social capital, whereas more hierarchical networks decrease social capital (Blanchard & Horan, 1998, p. 294). Shah et al (2005, p.535) explore civic engagement as an aspect of social capital. They argue that the informational use of the Internet encourages community involvement as well as fostering civic engagement through increased access to information and news on demand, the opportunity to exchange ideas and organise. Social networking sites allow for the development of flatter networks which enable people to connect on more equal terms and afford opportunities for marginalised groups to have a voice. Here there is a parallel with stigma literature which suggests direct contact on equal terms is the most effective way of positively influencing discriminatory attitudes (Link & Phelan, 2004). Bringing these different threads together indicates that social networking sites could allow creation of social capital, positive networks and an enhanced sense of self-identity.

Blanchard and Horan (1998, p.297) argue that virtual networks, which also have a common physical location, are likely to have a more positive impact on social capital than those that do not. However, I am curious about whether this equally applies to particular publics which come together as a community of interest, such as people experiencing mental health difficulties, who share a common experience of discrimination and whose offline networks may be consequently compromised. Helping behaviours on social networking sites are visible to the whole group, thus sustaining a group norm of helping, even when it may be a comparatively small number of participants actually doing the helping (Blanchard & Horan, 1998, p.297). Again there is

a salient point of connection with the research literature on mental health stigma. Peer support and direct contact is an important element of challenging stigma (Link & Phelan, 2004). For example, when the actress Rebecca Front (Time to Change, 2011) tweeted: ‘Hey well known Twitterers. Fancy taking the stigma out of mental illness? I'll start: I'm Rebecca Front & I've had panic attacks. #whatstigma’ it began trending in the UK, with people sharing their own experiences of mental distress. To what extent do these virtual activities increase trust and positive social norms which may not always be experienced to the same degree by people with mental health difficulties in their offline networks?

Ferlander (2007) assesses the potential for health returns from increased social capital. She summarises the extensive literature on health and social capital with a number of key points which are relevant to my thesis. Firstly, she identifies a human tendency to ‘follow one’s peers’ and so the particular norms prevailing within a network are important to the extent to which it is health promoting. Diverse and bridging, or inter-group networks are good for health generally, and mental health in particular. Bonding ties, or intra-group networks, can offer emotional support but can be stressful and promote conformity and so have negative health effects. The implications of social capital concepts are therefore helpful to an exploration of the implications of power and identity for people with mental health difficulties and professionals connecting together in a social media environment. I consider and illuminate some of this complexity within my research.

How is personal identity produced and experienced by publics discussing mental health on social networking sites? Qian and Scott (2007) explore the advantages and risks of blogging in relation to the subjective self. Their research suggests that sharing personal

thoughts and experiences in the virtual public domain carries risks, with possible real-life costs, and so anonymous identities and pseudonyms are common-place. In an exploration of the psychological implications of blogging, Sundar et al (2007. p.90) argue that this form of personal expression can be both liberating and positively reinforcing with effects of autonomy and a sense of positive control. The positive cognitive impacts of blogging can have positive effects in managing ill-health and enable positive identify construction. In an analysis of mental health blogs, the researchers conclude that most are produced by individuals with the primary purpose of coping with their mental health difficulty, whilst also welcoming comments and engaging in conversation. They found no gender differences in mental health bloggers, suggesting that blogging affords transcendence of traditional gender roles with a 'truer expression of one's attitudes, beliefs and feelings' (96). A review of the mental health literature clearly indicates that online anonymity for highly stigmatised conditions is one of the primary benefits identified by people with mental health difficulties (Sundar et al, 2007). I am curious about what sort of identities do people choose to present online and what they mean to them? Is this is a similar issue for mental health professionals who are blogging or engaging in social networking activity? What sort of risks to people take in sharing their stories and how do they experience this? The meanings people with mental health difficulties give to how they construct their identities has received limited attention in the research literature and I hope to make a contribution to this area of knowledge (Qian & Scott, 2007). Research also indicates that a censorious attitude to people's use of online social networks by mental health professionals may be counterproductive in so far as it makes people accessing services less likely to discuss use of social media (Yeshua-Katz & Martins, 2013).

The theme of identity online is explored by Miller (1995) who applies Goffman's work on presentation of the self, to the internet. He applies Goffman's ideas about framing identity to the Internet and explores 'developing etiquette' online. He suggests that online settings present new problems as well as opportunities for presentation of the self. He illuminates the differences between electronic and face-to-face communication, characterising electronic communication as instantaneous but asynchronous with place and distance largely invisible. He suggests that the web can have a 'liberating effect for those who are socially or functionally disadvantaged' because if affords the opportunity for people to control what they present of the 'embodied self'. Miller focuses on comparatively static means of online communication, such as web pages. In more recent times social networking sites afford interaction that has more of the quality of a conversation, transient and ephemeral. In two qualitative studies of people's use of consuming and producing health knowledge, Hardey (2001, p.394) found that the desire for anonymity for 'embarrassing problems' was an important factor in people choosing to source information in an online environment. Whilst the study did not focus specifically on mental health, the stigma associated with mental ill-health indicates a similar positive focus for social media. To use Goffman's performative metaphor, the 'backstage' can be shared with minimised risk for embarrassment and discomfort.

3.3 Citizen Journalism and Communities of Interest

Bruns (2007) coined the term ‘produsage’ to describe a paradigm shift towards collaborative, user-led content creation online. Moving beyond commonplace concepts of producers, products and production - produsage has four domains: (i) open participation, communal evaluation – inclusive as opposed to exclusive (ii) iterative process on large scale will increase quality (iii) fluid heterarchy, ad hoc meritocracy – skills and abilities not equal but equality ability to make a worthwhile contribution to the project (iv) unfinished artefacts and continuing process, and (v) common property with individual rewards. They reflect a:

> move out of established knowledge structures into new, more malleable environments, and in the move of participants in the networked information economy from reader to writer, from consumer to user. From user to produser, then is the potential for a profound renaissance … what may result from this renaissance of information, knowledge, and creative work, collaboratively developed, compiled and shared under a produsage model, may be a fundamental reconfiguration of our cultural and intellectual life, and of society and democracy itself (Vickery & Wunsch-Vincent, 2007, p.34).

Whilst active producers are creating content, they are also simultaneously providing rich data that can be used for commercial ends. This is not always immediately apparent or obvious to people, which creates an inbuilt inequity between individual and platform provider, as described by José van Dijck:

> Besides uploading content, users also willingly and unknowingly provide important information about their profile and behaviour to site owners and metadata aggregators. Before users can actually contribute uploads or

> comments to a site, they usually have to register with their name, email address and sometimes add more personal details such as gender, age, nationality or income. Their subsequent media behaviour can be minutely traced by means of databots. More importantly, all users of UGC [user generated content] sites unwittingly provide information because IP [Internet protocol] addresses – the majority of which can be connected to a user's name and address – can be mined and used without limit by platform owners (2009, p.47)

Internet users have no power or control over the use of their data which leads to a less obvious but profound demarcation of their agency as content creators. The algorithms that track and make user of data are employed to shift the producer into a consumer. The data an individual produces is valuable to the site owner but creates no value to the individual themselves. Terms and conditions often specify that the owner of the creative content belongs to the site rather than the person who created it (José van Dijck, 2009, p.49). All these issues problematise the notion of produsage and individually generated creative content.

Citizen journalism is a term which describes the practice of people creating their own version of news, in publically accessible online spaces, and with the ability to draw attention to issues that may be not noticed by the mainstream media (OECD, 2007, p.65). This is of particular relevance to my research in the affordance it creates for people with mental health difficulties to create their own narratives and stories about their lived experiences or to undertake a watchdog function, critiquing and challenging stigmatising accounts that appear in the mainstream media. Chapter 6 sets out a number of examples where mainstream media were successfully challenged by publics conversing about mental health on social networking sites and the blogosphere.

Bruns defines core features of citizen journalism as open participation and communal evaluation of content.. Producers can gain personal rewards and status within a community as a result of producing and sharing content. Given the implications of status loss for people experiencing mental health difficulties, this affords an opportunity to create status and social connections in a different way that may be difficult in their offline world. Bruns argues that:

> The produsage model of citizenship journalism seems significantly better suited to open exploration and evaluation of societal issues and events, to discussion, debate, and deliberation on their implications, than the corporate journalistic model: the latter must necessarily always exist under the threat and suspicion of outside influences exerting their pressure on the journalistic process for commercial or political reasons (Bruns, 2008, p.90).

Participation on social networking sites is largely organised by interests, enabling people to form different groups on the basis of their particular pursuits, views or hobbies. The extent to which online communities have similar qualities to real-world communities is contested in the academic literature, with some arguing that online communities lead to fragmentation, and a lack of diversity, coupled with a deficiency of moral commitment, signified by the fact that one can leave a community in one click; whereas Baym (1998, p.62) argues that on-line groups are often woven into the fabric of off-line life rather than set in opposition to it.

Baym identifies a number of key features for an online community which I set out below coupled with some relevant examples from mental health online communities. The first

salient feature is the forms of expression which become the norm within a group of people. An example of this might be a Twitter hashtag used for a specific topic which people group their interactions around and enable them to follow the thread of that theme. Another example is the term *madosphere* coined as an irreverent permutation of the 'blogosphere' used by a group of people blogging on the topic of mental health and indicates a subversive approach to the subject. Identity is the second feature of an online community, which includes name, avatar and biographies that people choose online and which may reflect their offline identities, be anonymised or entirely different and which may or may not include self-disclosure. An example of this is Twitter biographies that explicitly state a mental health diagnosis or which use a name which references mental health. A third feature is relationships between players within a particular online community, which might move between online and offline, and can be characterised by the degree of reciprocal commitment. A fourth element of an online community is behavioural norms, what is acceptable and not, within a given group. For example, many mental health related blogs warn the reader when there may be specific 'triggers' in the content for people experiencing mental health difficulties. Baym (1998, p.63) suggests that online communities are emergent, in that behaviours develop over time and through interaction. Whilst a specific platform may shape certain norms, it is common for users to adapt and evolve their own, within the limits of the technology. I am specifically interested in communities which form online to discuss issues of mental health, and particularly in those where people with professional and experiential expertise interact.

3.4 Digital Divide – Limitations to Online Social Networking

An analysis of the affordances of online social networking to disrupt traditional hierarchies must take account of the limitations that qualify and constrain them. Coleman and Ross (2010, p.116) suggest there are three core obstacles that complicate the transformative potential of the Internet. They are issues relating to access, such as literacy and skills; the extent to which the Internet is characterised by personal and private versus public practices; and the extent to which alternative discourses actually command public attention. Concerns have similarly been raised about exclusion, cultural fragmentation, content quality and security, as well as privacy. A greater divide between digitally literate users and others may occur and cultural fragmentation may take place with greater individualisation of the cultural environment. Other challenges pertain to information accuracy and quality, including inappropriate or illegal content, when everybody can contribute without detailed checks and balances. Other issues relate to safety on the Internet and possibly harmful impacts of intensive Internet use (OECD, 2007, p.68).

However, a more fundamental divide may be operating for those people who are socially excluded and face discrimination in connection with mental health difficulties. Coleman and Ross (2010, p.146) argue that: 'for many people, obstacles to active citizenship have more to do with low self-esteem and lack of political efficacy than access to computers or technical know-how'. In a study of digital citizenship in the USA, Mossberger (2009, p.179) found that race, ethnicity and education account for statistically significant divisions in internet usage, which to do not appear to be diminishing as internet use percolates society over time. Costs associated with high speed internet use also remain a barrier for those on lower incomes.

As well as digital literacy and social divides, there are also algorithmic divides built into the fabric of many commercial online social networking platforms. For example, whilst Twitter promotes itself as a neutral channel for micro-blogging communication, the reality is more complex. As José van Dijck argues:

> The platform's architecture privileges certain influential users who can increase tweet volume and whom thus garner more followers. Twitter's ambition to be an echo chamber of serendipitous chatter finds itself at odds with the implicit capacity, inscribed in its engine, to allow some users to exert extraordinary influence (2013, p.74).

Twitter's stated neutral objectives are in tension with its commercial interests and an associated imperative to meet the requirements of its investors. Tweets by users with more social status have more potential for commercial exploitation and are therefore algorithmically promoted over others. The potential of online social networks for equitable peer-to-peer conversation and organising must be understood in tension with commercial interests and associated implications for building in inequality to their very fabric.

There is a danger that existing media institutions, with the most resources available to them, will continue to dominate online space, to the detriment of marginalised perspectives (Coleman & Ross, 2012, p.116). Hardey (2001, p.401) raises a concern that the 'technologically rich middle classes' may access information and resources online that enable them to make demands on health services to the detriment of those others. This concern is echoed by Mossberger (2009, p.184) who states: 'low income individuals have greater need for public services, and their isolation from the benefits of

e-government may mean that they are less aware of available resources or are less able to take advantage of services'. This is likely to disproportionately affect people using health services in general and, within that group, people accessing mental health services.

The disruptive affordances of online social networking are influenced by the extent to which people are using them in the private or public sphere. Coleman and Ross (2012, p.117) summarise existing research which suggests the majority of online interaction takes place within the private or personal sphere; which raises a salient question about the extent to which the personal and political intersect and the extent to which subjective experiences shared online have the potential to challenge the hegemony of institutions. As set out in the final section of this chapter, the majority of research in relation to mental health and social media focuses on personal use whilst drawing out implications for rebalancing professional/patient relations, but still very much within the private sphere. My research is concerned with the personal where it has the potential to influence redrawing of power relations in the public sphere; where personal empowerment effects institutional change.

4.0 Online Social Networking and Mental Health

In this section I evaluate the limited research that has been undertaken in relation to how and why people use the Internet and online social networking to discuss mental health. Whilst existing research largely focuses on behaviours in relation to information seeking, it nevertheless provides useful insights into possible affordances of social networking sites for people experiencing mental health difficulties.

A body of research is developing in relation to the concept of Health 2.0, a term coined to describe how user generated content is developed specifically on healthcare topics. In a systematic review, Belt (2012) found seven recurrent themes within this definition:

1. web 2.0/technology
2. patients
3. professionals
4. social networking
5. health information/content
6. collaboration
7. change of healthcare.

Pertinent to my thesis is the fact that both patients and professionals are identified within Health 2.0 alongside the theme of collaboration, suggesting constructive interactions between the two groups. Secondly the theme of change within healthcare, points to the implications of online practices to influence healthcare itself. Eysenbach (2008) similarly identifies five common themes within Health 2.0 which include social networking; participation; apomediation[1]; collaboration, and openness. He argues that these themes contrast sharply with: 'traditional, hierarchical, closed structures within healthcare and medicine' and that Health 2.0 should empower individuals to take responsibility for their own health. Both analyses of key themes within Health 2.0 articulate ideas which closely chime with the heart of my research question – the

[1] apomediation - enabling people to directly access information without the mediation of a professional

tension between the institution and practices on social networking sites as a locus of resistance.

Research suggests that people with a mental health diagnosis are just as likely to use the Internet and mobile technologies as the general population (Álvarez-Jiménez, 2012; Carras et al, 2014). In a cross-sectional analysis of Internet use by people in Germany identified as 'psychiatric patients' by the authors, just over 70% of respondents who did use the Internet reported that they used it for mental health related reasons such as information on diagnosis, medication and services. Just under half reported use of online social networking and 19.8% reported engagement on platforms with peers for mutual support. Results indicate varied opinions about the use of the Internet for mental health with 36.2% reporting a positive effect and 38.4% reporting negatively (Kalckreuth, 2014). Schrank et al (2010) determine that people chiefly use the internet for health-related information because it affords anonymity and egalitarianism. In addition to anonymity, Powell & Cook (2006 & 2007) found that people using the Internet for mental health information value its affordances for providing privacy, convenience and accessibility. These themes are consistently echoed in the literature whereby the Internet is regarded an important source of information and peer support for people with stigmatised diagnoses (Schrank et al, 2010l; Hardy, 2001; Kummervold et al 2002). Powell and Clarke identified that finding out about other people's experience of mental health problems was an important motivating factor for using the Internet in relation to health conditions:

> Understanding and empathy was the third sub-theme relating to the experience of others. Individuals not only wanted to know that they were not alone and that others had got better, but they also wanted to interact with others or read

> material from others. They reported that only other people who had been through the same experiences could truly understand and empathize with them (Powell & Clarke, 2007, p.363).

Additional motivations for using the Internet for health topics include the ability to research causes, alternative diagnoses and treatment options (Powell & Clarke, 2007). However, Kummervold et al (p.63) found that a significant proportion of respondents to their survey on Internet use prioritised general use of the Internet on 'normal topics' rather than specific to their diagnosis, which reinforced a positive self-image of 'normality'. Significantly, Internet use was informed by negative experience of services such as dissatisfaction with therapy and problems communicating with mental health professionals. Telling one's own story anonymously was perceived as a relief as well as discovering similar experiences from others: 'helping to better integrate one's situation and redefine one's identity' (Schrank, 20102). Powell and Clarke (2007) similarly found that online research about mental health diagnoses was undertaken as a result of lack of information available from health services.

In their qualitative study of online mental health support in Norway, Kummervold et al (2012, p.64-65) found that participants had a lower threshold for disclosing embarrassing information that they worried may elicit a social sanction. The researchers argue that healthcare professionals should seriously consider the affordances of online environments to connect with people with mental health difficulties with a view to developing a combination and online and offline services. Reading personal stories of mental distress can provoke or aggravate negative emotional responses such as fear and hopelessness as well as more critical attitudes towards medication. Powell and Clarke (2007) did not find particular concerns about

quality of information on the Internet, with their interviewees expressing confidence in visiting trusted sites and avoiding others. However, they did have a concern with 'misuse' of the Internet in relation to malicious intent in disruptive online behaviour.

Despite some negatives, the researchers found as a result of accessing information about mental health via the Internet some people developed better coping strategies and sought help sooner than they might otherwise have done. However, they found that their interviewees reported an avoidance of talking to the doctor about Internet use for fear of sanction. A salient theme is a positive shift in subjectively experienced hierarchy on the part of the patient. Powell and Clark (2007) similarly found a sense of 'empowerment' in having access to web based 'expert' knowledge which to use in discussion with a professional. Blanch et al (2005) found that patients report that using the Internet for health information decreases anxiety, improves understanding and communication and has an overall positive effect on the doctor-patient relationship. Powell and Clark (2007) found that benefits expressed by interviewees included a sense that people were not alone with their problems and knowing that others in a similar situation have been able to get better. Interviewees reported that interactivity with others enabled them to obtain understanding and empathy, which were also important motivating factors. In an analysis of peer-led online mental health communities, researchers found that the primary purpose was peer support which offered counter-cultural resistance to professional paradigms (Giles & Newbold, 2011, p.426).

Three exclusively positive effects have been identified from the practice of relating to peers online: mutual help, boosting self-esteem and validation through helping others, and reassurance through sharing one's story (Schrank et al, 2010). The researchers

found that people wanted doctors to recommend websites and talk more about information on the web. There was also a desire from people to ask questions via the web rather than face to face. The researchers conclude that:

> The Internet may exert considerable influence on its users by enhancing coping strategies, empowerment, and self-efficacy; by decreasing the feelings of anxiety and isolation; and by affecting the doctor-patient relationship as well as health-related behaviours and decisions, as has been shown in qualitative and quantitative studies with participants suffering from both common and severe mental illness.

The study found that people most frequently searched for the term ‘medication’, with ‘diagnosis’ also featuring highly (Schrank et al, 2010). A research study of content on Twitter, Facebook and forums related to the term ‘schizophrenia’ concluded that valuable information can be found in peer to peer conversations to influence practitioners and service providers. More specifically, the study suggests that there may be a mismatch between that which is reported in the published literature and what can be gleaned from online social networks with regard to what matters to people about their quality of life. This research particularly focused on the implications of online social networks for informing health services (Chalkiadaki & Martin 2014).

Research indicates that health practitioners only rarely integrate the Internet into their daily routine. In contrast, Blanch et al (2005) reviewed the effects of patient’s online searching on various aspects of their interactions with their doctor. Patients reported that use of the Internet decreased anxiety, improved understanding, and had a positive effect on the doctor-patient relationship. Doctors are more likely to note concerns about

accuracy and influence on trust in the relationship. The research found that, for the majority of patients and doctors, the Internet still has little effect on their relationship. Hardey (2001, p.401) argues that the notion of 'quackery' and health care professionals' concerns about quality of information on the Internet can be regarded as an attempt to maintain boundaries and professional knowledge. He poses a question about the implications of the Internet for the emergent reconfiguration of the doctor/patient relationship. The question is not one of whether Internet health information is 'legitimate' but rather the more pragmatic one of how health and illness is understood and the forms of social relationships that stem from it. Burrows et al (2000) assert that traditional institutional authority is being replaced by multiple sources of authority which are being accelerated by the Internet. There are signs that with steady permeation of online social networking in day to day life that there is an infiltration into the professional as well as the personal lives of mental health practitioners. In a study of American mental health professionals, Deen et al (2013, p.461) found that the majority use electronic applications in their personal lives and are increasingly incorporating them into their professional work. However, the scope was limited to a clinical context which was much narrower than the scope of my study.

Shcrank et al (2010) found in their qualitative study of health-related internet use by people with a diagnosis of schizophrenia, that reasons given for non-use included lack of access to a computer, financial problems, difficulties using technology, fear of computer viruses, fear of internet addiction, distrust of unknown people, protection from other people's illness stories; preferences for other sources of information, and the expectation of low quality Internet based information. The prominent illness-related reasons against Internet use were stimulus overflow and the inability to deal with the abundance of information, problems with concentration, lack of energy and depressive

symptoms, paranoid ideas and fear of symptom provocation, and the wish to distance oneself from illness-related topics as part of the recovery process. The research is limited by its biomedical paradigm based on an assumption people with a diagnosis of schizophrenia will use the internet differently to the wider population. In fact, the researchers found that qualitative use of the Internet was similar to general population. Two salient points of interest emerge from the study: firstly that people felt the need to: 'distance themselves from illness-related topics as part of the recovery process'; and that Internet information was perceived by interviewees as having the potential to: 'significantly change attitudes towards medication and relationships with healthcare professionals'. This has obvious significant implications for healthcare professionals and their received practices, if expectations of them by people accessing mental health services are changing.

A body of research is now emerging that explores mental health implications of online social networking. Predominant themes relate to behaviours leading to addictive behaviours and cyberbulling (Koc & Gulyagci, 2013). One observational study makes the case that features of computer-mediated communication could contribute to the development of psychotic experiences of vulnerable people (Nitzan, 2011). However, another qualitative study found positive effects of Internet use for people with a diagnosis of psychosis, alongside a desire for more Internet based interventions (Álvarez-Jiménez, 2012). There is also a developing body of literature related to suicide, which includes prediction of suicidal ideation on the Internet (Bell, 2014; Christensen et al, 2014; Cash et al, 2013; Gilat et al, 2011). Research is emerging which relates to teenage use of online social networking and points to the positive effects on mental health and psychological wellbeing related to increased social capital (Egan et al, 2013; Goodall et al, 2013; Chen & Lee, 2013, Liu & Yu, 2013; Gowen et al,

2012; Norman & Yip, 2011; Kontos et al, 2010). An Australian study of rural teens found a preference for informal sources of help over professional support and over half research participants accessing the Internet for mental health support from peers (O'Dea & Campbell, 2010, 138). Literature arguing for clinicians to include in their practice an awareness of how young people use social media is emerging (Rice & Karnick, 2012) as well as intervening in social networks to offer information and help to people posting about mental health issues (Moreno & Gannon, 2013). A recent article in The Guardian illustrates increasing interest and profile in the role of social media to discuss mental health, and profiles young bloggers and vloggers who talk candidly about their experience of mental distress (Cresci, 2015).

In a qualitative analysis of use of YouTube by people with self-identified mental health problems, Naslund et al (2014, p.6) sought to identify opportunities and risks associated with naturally occurring peer support on the social network site. In analysing comments on 19 videos uploaded by people with self-declared mental health diagnoses, the researchers identified four themes relating to peer support:

(i) Minimizing a sense of isolation and providing hope
(ii) Finding support through peer exchange and reciprocity
(iii) Coping with the day-to-day challenges of severe mental illness
(iv) Learning from shared experiences of medication use and seeking mental health care.

The researchers conclude that peer support on YouTube is ‘an emergent phenomenon where users are unhindered and have individual autonomy to choose their level of disclosure and engagement, from viewing to commenting to uploading personal videos’

(Naslund et al, 2014, p.6). An extension of peer support can be seen as active campaigning with the intention of influencing public attitudes about mental health. In an editorial for the British Journal of Psychiatry it is argued online social networks afford the opportunities for people to come together around a shared concern which blends evidence based anti-stigma strategies:

> Personal stories and unheard voices can be made public and shared without temporal and spatial barriers. They have significant potential to facilitate a dynamic blend of education, contact and protest. This rise in user-generated content means that collective action by individuals has the potential to influence mainstream media and policy without sole reliance on campaigning organisations. It may be that we are more likely to adjust our attitudes because of what our peers think than because of what organisations encourage us to think (Betton et al, 2015).

Whilst use of online social networking by people accessing services dominates the literature, there is a parallel strand of published articles focusing on the ethical implications of social media for health and care practitioners (Bates et al, 2015; Kimball & Kim, 2013; Betton & Tomlinson, 2012; Franksih et al, 2012; Barry & Hardiker 2012; Ginory & Sabatier, 2012; McCartney, 2012). The literature tends to covers themes such as privacy, confidentiality, integrity of the therapeutic relationship, professionalism and the implications of searching for patients online (Clark, 2010). Frankish et al acknowledge the ubiquity of online social networks in contemporary life and argue that psychiatrists should aim to benefit from their potential whilst being mindful of risks (Frankish et al, 2012). This conclusion from an editorial in the British Medical Journal captures the dilemma and the opportunity for health professionals:

> Doctors, like other citizens, are entitled to express opinions online, and one effect of the undoing of the medical god-complex has been to humanise medicine and populate it with doctors who are fallible but professional (McCartney, 2012, 341)

A plethora of articles in professional and health technology journals exploring the opportunities and pitfalls of online social networks are increasingly evident. A systematic review in 2012 found 50 published articles across a variety of clinical groups (Von Muhlen & Ohno-Machado, 2012) and this has continued to expand (Douglas, 2014; Kind et al, 2014; DeCamp, 2013; Farrelley, 2013; Jones & Hayter, 2013; Pirraglia & Kravitz, 2013; Lachma, 2013; Volpe et al, 2013; Herrin & Ingram, 2012; Lifchez et al, 2012; McBride, 2012; Smalls, 2012; National Council of State Boards of Nursing, 2011). An article in a mental health sector magazine Mental Health Today, illustrates how one NHS Trust is utilising Twitter hashtags from its corporate account to promote the organisation and to raise awareness of mental health issues. The opportunities and challenges of social media from an NHS communications perspective are briefly set out:

> Like it or not, Twitter is here to stay – at least for now. For communicators in mental health trusts it is important to keep on top of what is going on in the social media world and incorporate it into goals. But it also needs to be ensured that any pitfalls are considered and the best interests of patients are foremost in everyone's minds (Hall, 2013, 29).

During the course of my research study it is apparent that online social networking has become increasingly embedded within the everyday lives of both people accessing and providing mental health services. This has led to an emerging literature on the ethics and implications of online social networking for mental health and wellbeing as well as the use of digital tools and services in clinical care (Torous et al, 2014).

5.0 Conclusions and Gaps in Research

In this chapter I have reviewed two strands of literature and distinct sources of research pertaining to mental health and communications and new media respectively. An evaluation of these two discrete traditions has points of overlap which generate insights for the foundations of an exploration of my thesis in subsequent chapters.

Issues of power and resistance have been at the core of numerous sociological works on the topic of mental health from the nineteenth century onwards, and Goffman's writing exemplifies this tradition. However, up until now, the primary focus has been on face-to-face in person relationships and has not yet been extended to examine the particular affordances of online social networking for relationships between users and providers of services in the public sphere. There is a substantial and ever growing body of communications and new media literature that evaluates the implications of online social networking for user generated content, citizenship and political participation. More recent literature is concerned with the commercial and monopolistic tendencies of many online social network platforms and the extent to which they manipulate or limit social and political participation.

There is less written about online social networks and health and only recently an emerging literature in relation to mental health. This literature is largely limited to the clinical implications of online social networking and does not address its disruptive and resistant affordances. In a recent systematic review of mental health, Internet and social media, the authors point to the absence of research on this theme:

> Although the humanistic impact of social media and communication sites cannot be ignored, and the attractiveness of apps cannot be denied, there is insufficient evidence of efficacy or even validity; it would be useful for clinicians to consider social media and communication sites as essentially possibly helpful (Parikh & Huniewicz, 2015; 16).

My research aims to build on both strands of literature to develop original qualitative insights into the affordances of online social networks for self-mediation of mental health and the implications for relationships between people using and providing related services. My thesis is salient as use of online social networking increases amongst the general population (Dutton & Blank, 2013) and increasingly relationships are mediated through a combination of online and offline communications. The affordances of online social networking for people with mental health difficulties to self-mediate, engage in peer support and collaborate to challenge institutions, needs to be properly understood by professionals in order for them to provide effective and up-to-date help and support. The same affordances need to be understood by professional health bodies and institutions so that they are able to adapt to shifting expectations of them by people accessing services. Policy makers need to understand shifting public and professional practices in order to develop policy and strategy fit for contemporary communication practices in the mental health sphere.

My fieldwork has primarily focused on blogs and Twitter, although a plethora of new social networking channels have emerged during the course of my research and trends have shifted over the four year period. For example, picture and video based channels such as SnapChat and Instagram have become popular and increasingly mental health vloggers on YouTube are taking centre stage (Cresci, 2015). Despite shifts in channels, underpinning motivations and practices appear to have consistencies such as the benefits of peer support. I shall illustrate in subsequent chapters how tensions between activism and the institution are mediated within the *madosphere*. I shall consider the affordances and limitations of online social networking for social change. I will argue that gradual encroachment and engagement by institutions has gathered pace during the course of my research project and I consider the implications for people affected by it. In subsequent chapters I explore how online social networking is disrupting relationships between users and providers of services in ways that could hardly have been imagined before the Internet and emergence of online social networking.

Chapter 3

Methodology

'Some of the most important learning will always have to be done by jumping in to one corner or other of cyberspace, living there, and getting up to your elbows in the problems that virtual communities face'

(Rheingold, 2002)

1.0 Introduction

In this chapter I set out a rationale for employing an online ethnographic research methodology, based on an intention to develop a rich and deep qualitative understanding of social practices within my field of study. Ethnography is defined by Gobo (2008, p.12) as: 'a methodology which privileges the (cognitive mode of) observation as its primary source of information' and includes other sources of information such as 'informal conversations, individual or group interviews and documentary materials'. A virtual ethnography carried out over the Internet is orientated around relationships experienced largely through online rather face-to-face means and with particular opportunities and challenges for the researcher. In this chapter, issues encountered are set out and online ethnographic practice as a highly emergent means of researching identity, community and interaction is considered (Rutter & Smith, 2005, p.91).

I employed three core qualitative methods to gain insights into observable behaviours and practices in the *madosphere*. Firstly, online participant observation has enabled me to discern practices, rules and rituals operating within the *madosphere*; secondly, in-depth qualitative interviews with key actors within the *madosphere* have enabled insights into personal experience, motivations and interpretations of those practices; thirdly, detailed field notes from The World of Mentalists (TWOM) have provided a rich account of design, content and practices at the heart of the *madosphere*. Within my thesis I describe a number of naturally occurring events that emerged during my fieldwork which exemplify practices within the *madosphere.* Lastly, I have used my own blog and Twitter account to engage in informal and serendipitous conversations with others in order to influence and extended my understanding of the research topic.

2.0 Online Collaborative Ethnography

The decision to use an ethnographic methodology is based on a desire to develop a rich and deep qualitative understanding of online interactions within my field of study. To use each of the three research methods in isolation would result in only a partial understanding of the space and related practices. For example, interviews enable insights into motivations and meanings produced by individuals within the space. However, in isolation a comparison cannot be made with the observable practices that those individuals engage in. An ethnographer endeavours not only to understand individual perspectives but also how they are manifested in behaviours and practices. They are concerned with points of alignment and dissonance between what is said and what is observed. Participant observation enables an ethnographer to bring their own experience of engagement with the space into the frame of analysis. Brought together, these methods enable an holistic understanding of the research locus from multiple

perspectives. As a fledgling actor within the *madosphere* before the research commenced, with a deep knowledge of the terrain of mental health services in the United Kingdom, I felt I was in a position to generate a rich and deep understanding of this space and related practices. The choice of an ethnographic approach was based on a judgement that I could create unique insights from my particular position and experience that would generate meaningful knowledge to contribute to the field of mental health and online social networking. I chose to employ qualitative methods because my primary interest was in the practices, meanings and beliefs people hold within the *madosphere*. A network analysis approach that connects large sets of data to explore relationships and connections is an area for future research that would complement the approach I have undertaken within the scope of this thesis.

I have been keen to distance my approach from the privileging effects associated with traditional ethnographic research, that have been critiqued in relation to privilege and perpetuation of dominant discourses, at the expense of those less powerful. The ethnographer's self-appointed role in exploring a particular terrain in which subjects are described and classified is problematic, particularly where those under study are already subjugated objects of a dominant discourse (Dicks et al, 2006, p.29). Whilst my research is orientated towards problematising the dominant institutional discourses of mental health, I nevertheless hold a privileged position as a researcher. Decisions about what is salient, what is included, and what remains unseen are subtle and small judgements made with a certain perspective and set of values. The subjects of this research are made visible through the perspective and interpretation of the researcher and filtered through a set of assumptions, values and agendas which may not be obvious or apparent. A reflexive awareness of my own position as a researcher and NHS manager has been something I've endeavoured to keep at the forefront of my

mind throughout the research process. This has been a constant challenge, in so far as sustaining a high degree of self-awareness and self-critique can be problematic when that privilege is part of one's day-to-day background experience.

My intention has been to understand and amplify often marginalised voices in the mental health system - particularly those people accessing services and practitioners who wish to disrupt or problematise the institution. I have endeavoured to engender a mutual and reflexive relationship between the researcher and the researched. In Goffman's words (1963) I hoped to take the role of the 'wise' between the 'normals' and the 'stigmatised' where my research can broker fresh insights into the experience of people whose points of view have been marginalised. I have been at pains to avoid a 'double subjugation' where the objects of an already dominated group are in danger of being re-dominated through the ethnographer's scrutiny (Dicks et al, 2006, p.30).

I am drawn to the tradition of collaborative ethnography which requires co-production at every step within the research process; here subjects are active participants in producing knowledge, both in conceptualising hypotheses, conducting research and in analysis and presentation. For example, Rappaport (2008) draws on national anthropologies of Latin America as a source of methodological innovation in collaborative ethnography. She argues that Colombian anthropologists privilege the use of workshops and other collective interactions as research methodologies, and engage the researcher in grassroots political and social struggles as 'activist-scholars' bringing together political and ethnographic analysis. According to Rappaport (2008, p.4) this style of collaboration: 'converts the space of fieldwork from one of data collection to one of co-conceptualisation'. However, whilst drawn to a collaborative approach, it would be both presumptuous and inaccurate to claim that this research has been co-

productive; an established research tradition of individual intellectual production has constrained the potential for collaboration within my PhD research. However, it is hoped that an approach informed by collaboration that has been enacted in a variety of ways which I set out in this chapter, is a grounding for more deeply co-productive future research endeavours.

Battacharya (2008, p.305-306) contends that collaborative research must have the aim of bringing about positive change in the lives of the researched. He critiques the boundaries and power relationships between the researcher and the researched for the purpose of bringing about 'social action and social change'. It connects the academic to 'real world agencies and practical projects'. This straddling and connectivity from academic to practice setting, reflects the interplay between my role both as a researcher and working in the field of mental health. I have actively taken learning from my research into a practice setting. For example, I give talks and deliver workshops and training for health professionals on the theme of social media and mental health. I have brought examples and experiences from the *madosphere* into those sessions to help professionals understand how people accessing services are using online social networks to connect and to campaign. I routinely co-design and deliver training sessions with people who have lived experience of accessing mental health services.

A collaborative approach provides an opportunity for research investigation that is congruent with values - an enquiry which simultaneously makes a contribution to academic knowledge, whilst equally providing useful knowledge to people challenging inequities within the mental health system, has a congruence which makes it ethically and morally gratifying. The Internet affords the opportunity to derive data from online communities but it has been argued that 'respectful' research requires the

ethnographer to participate as an active member of the community whilst following the etiquette and social norms of participants (Nind et al, 2012). I have endeavoured to play a part in the day-to-day practices of the *madosphere* whilst acknowledging the limitations created by my role working within an institutional context. This has meant engaging in the *madosphere* on a daily basis during my research project, engaging in conversations on Twitter, blogging and commenting on other people's blog posts. It has also meant giving talks at events and conferences on a shared podium with people living with mental health difficulties who participate in the *madosphere*.

An example of a collaborative approach in action is exemplified in a description in Chapter 4 of Bella who live-tweeted her acute mental health inpatient experience during the course of my research. As well as interacting with Bella whilst she was on the ward via Twitter, I asked if I could interview her about her experience for my research. I also, with permission, curated some of her tweets through screenshots on my phone. Again with permission, I wrote a short post about Bella's experience on the ward which she edited and approved before I uploaded it to my blog. Bella got in touch with me sometime later to let me know that she had used a link to my blog to tweet her concerns about her care to a member of the Board who happened to be on Twitter. As a result, her concerns were addressed by the NHS Trust concerned. I wrote a short postscript on my blog to this effect. Another example is an occasion where I wrote a joint post with an individual who I became aware of through Twitter and who had had her smart phone confiscated by professionals on a mental health inpatient ward. We wrote the post collaboratively through a conversation, mediated via email, where I asked her questions and she asked me them in return. This post then became the subject of a #WeNurses chat on Twitter, in which myself and the individual concerned participated in, where the issue reached an extensive audience. In both instances, I

was able to make use of my existing blog audience and connections to write about, record and amplify people's experiences of accessing mental health services related to my research thesis. At the same time I endeavoured to deepen my understanding of the issues concerned and express my identity as a collaborative researcher through my blog. It was my intention that both individuals mentioned above derived value from our exchanges as well as the value I derived for my research and presence in the *madosphere*. I took care to take a collaborative approach but with a reflexive awareness that my particular role and position would inevitably shape those exchanges and possibly in ways which I could not anticipate.

These examples exemplify an expression of my values and preferences for collaboration and shared enquiry that endeavours to challenge the institution, whilst operating and influencing within it. This is a particular standpoint that I have chosen to adopt but should not be taken for granted or at face value. The online terrain of my research lends itself to virtual collaboration, and social networking sites afford the potential to engage with groups of people who may be geographically dispersed, to co-produce knowledge together, despite temporal and spatial differences. However, a reflexive awareness of both my work and researcher positions are in tension with my personal values, aspirations and desires. Whilst my approach may have had a positive intent, how I am perceived by others and the influence this has on their engagement with me is problematic. Whilst encouraging stories about disruption of the institution, I am myself steeped in an institutional context both as a researcher, an employee and as a middle class white woman. I derive immense benefits from the institution in terms of employment, identity and status, whilst also wishing to critique it. As Murthy (2008, p.839) argues: 'access to these technologies remains stratified by class, race, and gender of both researchers and respondents'.

How far am I willing to critique an institution on which I am dependent for my livelihood and which has funded this research? The interplay between my professional and academic existence has seen each informing the other. The Digital Academy I have established in the city where I work facilitates health care practitioners to develop an appreciation of how people accessing services are using online social networking and how they can engage in the space productively and respectfully. Knowledge derived from my ethnographic research has informed the development of this approach. This research emerges not only from a particular set of values but also from a particular position in society. Rather than a realist descriptive account, the delineation of *madosphere* found in this thesis is one which emerges from the particular position of this researcher.

The significance of the researcher's position and understanding of context is central to collaborative ethnography (Battacharya, 2008, p.314). I have brought myself, if only partially, into the narrative process. Whilst immersing myself in the ethnographic environment, I have actively contributed, participated and reflected on my engagement with experiences within in it. I have endeavoured to test out my underlying assumptions and prejudices as well as manage the tension between my researcher and employee role as a senior manager with an NHS Trust by taking a pragmatic stance along with a spirit of shared enquiry in my public posts related to my research thesis. This has meant asking questions and raising issues rather than directly challenging the institution of which I am a part. I have held back from direct criticism and attempted to offer insights and solutions where I can. Although I do not bring myself into the research in an autobiographical sense, my field of study and focus are intrinsically

linked to my values, personality and preferences. As Dicks et al (2006, p.31) contend: 'the self and the field are interwoven – ethnography and autobiography are symbiotic'.

However, immersion in a space that one knows intimately has its own challenges and limitations. Familiarity can render potential insights invisible and sometimes distance enables the researcher to have a clearer view. This process of distance and reflection have been particularly challenging in so far as I have spent extensive time in a field with which I am already very familiar. There has been no shock of the new to alert my senses and I have rarely experienced impressions for the first time. Familiarity with the language, symbols and jargon of those operating within mental health services has made it harder to notice and critique them. Much is taken-for-granted and not immediately visible (Gobo, 2008, p.9). However, I am not a pure 'native' to use classical ethnographic terminology. I am neither a user of mental health services nor a clinician. I work in the system with both of those groups but in a somewhat detached capacity - I have trained as a social worker and worked as a mental health practitioner in the past and my particular training and hands-on experience has influenced my understanding and interpretation of the field. Whilst I am social work trained, I am situated within a healthcare setting. The cultures are subtly but significantly different in many and various ways and I am therefore familiar with holding perspectives from multiple positions. My natural locus is one of both insider and outsider. I acknowledge this tension and have utilised it in the investigative process. I have endeavoured to create distance for the purposes of analysis through my systematic approach to generating field notes which I describe more fully later in the chapter. A weekly piece of reflexive writing has compelled the creation of some distance from the subject matter and has therefore been an invaluable part of the research process.

The notion of inter and intra-cultural diversity is pertinent to a consideration of balancing multiple perspectives. Fetterman (2009, p. 549) describes 'intercultural diversity' as differences between two cultures, and 'intra-cultural diversity' to the differences between subcultures within a culture. I have attempted to understand diversity on a number of different levels - firstly, the inter-cultural interactions between professional patient played out both online and offline; secondly, intra-cultural interactions between bloggers who may be both professionals, patients, or both; thirdly there are intra-cultural interactions between bloggers blogging from a primarily personal perspective; lastly, intra-cultural interactions between bloggers blogging from a primarily professional perspective. I am interested in the position adopted by Charmaz and Mitchell (1997, p.194) which asserts what whilst there is a merit to deferring to the points of views of others, as well as reasoned and systematic discourse, the author's voice should prevail. This is particularly pertinent within PhD research, where a collaborative approach must be balanced with clear single authorship in order to satisfy the requirements of examiners. This requirement has compromised my desire for a deeper collaborative methodology and that I would like to employ in future post-doctoral research.

3.0 The Research Locus

Online research contains a central dilemma in so far as there is no defined 'place' as a site to undertake fieldwork. Tuncalp and Le (2014) argue that online communities are defined in symbolic rather than physical terms where imagined connections are more significant than physical proximity. Boundaries within social networking sites are particularly fluid and the locus of my research gradually shifted from one blog site to the more dynamic and ephemeral sphere of Twitter.

At the outset of my enquiry, I focused almost exclusively on a primary blog entitled The World of Mentalists (TWOM) and its related ecosystem of blogs. Whilst I expected the surrounding ecosystem to the blog to be continually shifting and changing, the blog itself was well established and I was confident it would remain active for the period of my research. In fact, the blog became destabilised during 2013 and drew to a close at the end of December in the same year. The penultimate blog post on TWOM is entitled: 'How is the world of social media evolving?' and sets out the co-editor's assertion that the *madosphere* has moved away from a primary locus of blogging towards use of a multiplicity of platforms:

> As social media has evolved, I think it's become more complex and multi-platform. Previously people would write a post on a blog, and discuss it in the comments thread to that post. Now, people might have a Twitter conversation, then somebody writes up a blog post to express their thoughts in more detail. The blog post then gets discussed back on Twitter. Later on, somebody does a Storify of it all. Within this interlocking network of networks, I think the focus of conversation has shifted. Where previously blogging provided a focal point (or points) now that focus is on Twitter. I've gradually noticed myself shift from being a blogger with a Twitter feed to promote the blog, to a tweeter who uses the blog when 140 characters just ain't enough.

In ending the TWOM blog, the co-editor drew to a close my main research node. However, my interviews continued and became extended beyond what had been previously a primary focus on TWOM towards other social networks in which mental health was being discussed. Even though the term *madosphere* was coined by people

participating on the TWOM blog, I continued to use the terms as a descriptor for conversations about mental health on online social networks that were characterised by disruption and which often involved people who had previously contributed to TWOM. My enquiry adapted to a shift in conversation from the blogosphere towards Twitter and I was fortunate to be able to undertake a number of interviews with one of the co-editors during this period. This enabled me to gain insights that I had not anticipated as the blog petered out and ultimately was discontinued. It reinforced an awareness of practices within the blogosphere and social networking sites as essentially fluid and ephemeral.

The notion of a 'websphere' is salient in conceptualising the space and set of mediated practices at the core of my investigation. They point to the complexity of web spaces which are often co-produced by multiple actors, and their 'rapid and often unpredictable evolution' which makes attempts to identify a singular unit of focus problematic. The websphere is defined as:

> A set of dynamically defined digital resources spanning multiple websites deemed relevant or related to a central event, concept or theme, and often connected by hyperlinks (Schneider & Foot, 2005, p. 158).

The well-established TWOM blog acts as a robust central point of the websphere for an exploration of my research question. The shifts and changes to practices within the *madosphere* during the course of my research align to the conceptualisation of the websphere characterised in the above quotation.

Online ethnography erodes the more traditional notion of the field site of research as a single boundaried space. The absence of spatial and temporal boundaries online creates a new space based on flows and organised in relation to participation rather than a geographical location (Tuncalp & Le, 2014). Hookway argues that blogs offer significant potential as the locus for research as they are publicly available, a low cost and instantaneous technique for collecting data, they are naturalistic data in textual form and they enable access to populations otherwise geographically or socially removed from the researcher (Hookway, 2012, p.155). The particular characteristics of blogs, as described by Hookway, have enabled me to access an ongoing and often topical discussion by a diverse range of people about issues of mental health. The textual and public nature of these conversations has made visible dialogue between often marginalised actors in a naturalistic setting.

4.0 Selection, Sampling and Entry

In this section I set out how I have sampled, selected and gained entry to the *madosphere*, along with the barriers and challenges I encountered during my research. Garcia et al argue that:

> The process of gaining access to the setting and research subjects is different in online ethnography because of the lack of physical presence and the resulting anonymity provided by the medium. Ethnographers must therefore learn how to manage their identity and presentation of self in visual and textual media and to do impression management via CMC [computer mediated communication] modalities such as email, chat, and instant messaging (Garcia et al, 2009)

The particular qualities of online interaction as described above has meant that gaining entry to the field of research has had particular challenges which have required multiple strategies to overcome. I have used what Fetterman (2010) refers to as 'informal strategies' to begin fieldwork through actively participating in my field of study by establishing my own blog, running related workshops and events, tweeting on the topic, and setting up a related Facebook fan page. At the outset I began interacting with key players both online and offline either through joint blog posts, events and one-to-one meetings. This was particularly important in establishing credentials and gradually building reputation and trust. It should be noted that this was not a strategy with any artifice to it - my research thesis emerged from my genuine interest and engagement in the field and grew out of relationships I had already begun to establish. I have continued many of those relationships and conversations after my research.

Within ethnographic research, the sampling process should initially be 'broad and inclusive to ensure a wide-angle view of events before narrowing down to a more detailed study of a defined group' (Fetterman, 2010. P.552). I employed judgemental sampling in so far that I have used my own knowledge of the subject area, alongside a sweep of the blogosphere, to identify the broad field. I then narrowed down my sample to specific blogs which fulfilled the criteria set to ensure they enabled me to address my research question. Through my engagement in the *madosphere*, I am routinely followed by relevant bloggers so assessed each against the inclusion criteria as I became aware of them. Through this process, I identified TWOM, and its surrounding ecosystem, as the single UK blog fulfilling the criteria required to explore my research question. Specifically, it was an established site co-edited by two individuals who bring lived and professional experience respectively. Its ecosystem was a broad and inclusive one as

it had guest editors and produced a weekly round-up of selected blogs. It often engages with current social and political issues and has a subversive and disruptive style and tone. At the point of identifying TWOM as the preferred node for my research, I did not know and was not in contact with the editors or any of the blog contributors.

How I presented myself as an ethnographer in the research setting, in a way which inspires trust and encourages people to collaborate with me, has been an important concern. In her guidelines for ethical electronic research, Schrum (2012, p.130) states that:

> Researchers should negotiate their entry into an electronic community, beginning with the owner of the discussion, if one exists. After gaining entry, they should make their presence known in any electronic community as frequently as necessary to inform all participants of their presence and engagement in electronic research.

As previously stated, I did not have existing relationships with any of the key protagonists connected to TWOM, so building relationships in order to enter the field was critical. Garcia et al (2009, p.73) in their analysis of online ethnographies, state 'there is no simple recipe for success; the choices ethnographers make must be tailored as closely as possible to the specific issues, participants and technological modalities they are studying'. This resonates for me in particular as my interest in researching the field has arisen from my emerging engagement with it. The public nature of blogs and social networking sites renders that engagement visible and leaves a trail for potential research participants to view and critique. My researcher credibility, or otherwise, is built blog post by blog post and tweet by tweet. As a practitioner, I

always intended to stay within the field post-research. I therefore have had a fundamental and authentic concern with maintaining positive and reciprocal relationships with people who may, for a period of time, opt to become participants in the investigative process. Entry to the field and the research process has therefore been a sensitive one that has taken time and dedication during the four year period of my project. In her essay on digital research within disability studies, Seymour (2012, p.347) argues that the task of recruiting participants using a 'snowballed' approach and related pre-interview negotiations can help promote more equitable 'subject-subject' rather than 'subject-object' relations between researcher and researched. My approach of endeavouring to build egalitarian relations through online interactions was undertaken with the intention of building a frame of shared enquiry in my research process.

Gaining access to the field and then developing sufficient trust is often identified as the most difficult phase in the process of ethnographic research (Gobo, 2008, p.118). This has come about over a period of time and through a variety of actions. Firstly, on commencement of my PhD in January 2012 I began a blog entitled 'co-producing digital mental health'. The primary purpose of the blog was to keep an online diary of my development and thinking both from a practice and academic perspective. I also had in mind that by building an ecosystem of interested people around my blog and related social media, I would have the seeds of an online community to engage in research collaboration, should that be an option. I therefore undertook to publish blogs posts regularly whilst modelling a co-productive style - for example, I invited guest bloggers to bring a personal perspective to the topic and co-wrote blog posts with them. I also undertook to engage in offline co-productive activities on the topic (for example workshops co-delivered with colleagues with lived experience) and then blog about

them afterwards. My blog has been a means for me to announce my intentions, model behaviours and to engage collaboratively with experts in the field, as well as ask questions and gain insights. I have used related social media (i.e. Twitter, Facebook page, Linkedin) to promote my blog and engage with others.

As previously described, early on in my research project I identified the This World of Mentalists (TWOM) blog as having all the key qualities I was interested in exploring. I therefore took the step of contacting one of the two anonymous co-editors via a Twitter direct message and asking if I could email them about my research topic. This was followed by a more extensive email exchange, a telephone call and then a face-to-face meeting with one of the co-editors. The co-editor then posted a public blog post about our meeting, incorporating the issues we discussed, on a sister-blog. They subsequently invited me to be a judge on the panel of the annual TWOM awards, and to guest edit a weekly This Week in Mentalists (TWIM). According to Gobo, the role of 'guarantor' is the trusted member of the group who 'sets up the relation between the ethnographer and the group'. The TWOM co-editor tacitly assumed this role and generously encouraged and supported my involvement in the *madosphere* in advance of anything other than a general discussion about the research protocol. Whilst the other co-editor did initially agree to be interviewed, their circumstances changed and they discontinued the role and did not follow through with an interview.

The co-editor agreed that I could upload a page on TWOM in which I introduced myself as a researcher and left a clear mark on the blog itself that it was the subject of a research project. I employed an informal written style, accompanied by a smiling photograph of myself, and invited people to get in touch if they would like to find out more about the research or participate. This was an important step as it not only gave

legitimacy to the research project by the editors but it meant that my research was publically stated and evident to people who visited the blog. It created a transparency and accountability that aligned with my aspirations for a collaborative approach to my research. The ethnographer, as a participant in the setting, takes on their own social role which gives meaning to their presence within the community. This is then reciprocally constructed by other actors within the field (Gobo, 2008, p.112). This is a dynamic process that can only partly be controlled by the ethnographer and is something that I paid close attention to throughout the process of research, both through my personal reflections and by explicitly asking other participants for their feedback.

At the same time, I made face-to-face connections with other bloggers who are connected to TWOM and I continued to keep in contact with them via Twitter and the blogosphere. I participated in various workshops and conferences where I met the key protagonists in person. This activity was a critical part of developing my reputation, increasing trust and making a contribution to the field in which I was undertaking my research. My intention was to demonstrate the behaviours I meant to display during my research. Anyone could check my behaviours and my interactions in a variety of social networking sites. I have overtly created allegiances with people who have personal experience of mental health difficulties, whilst also obviously being a person with situated authority within an NHS Trust within which professionals operate. I openly presented myself as an individual with academic interests and aspirations. Whilst I did expect some challenge and critique, I only ever experienced encouragement throughout the period of my research.

5.0 Research Methods and Tools

In this section I set out the research methods I used alongside a rationale for employing them.

5.1 Participant Observation

A particular ethnographic feature of participant observation is the added dimension of personally experiencing and sharing the same everyday life of those under study (Brewer, 2000, p.59). Fetterman (2009, p.553) describes the role of the ethnographer as combining: ‘participation in the lives of the people under study with the maintenance of a professional distance that allows adequate observation and recording of data’. The process of establishing distance, or estrangement, is key to uncovering tacit knowledge in day to day behaviours, routines, rituals and other forms of social interaction. Estrangement has the function of revealing: ‘the architecture on which society rests and therefore reproduces itself’ (Gobo, 2008, p.162). This delicate balance of creating connection as well as distance was a particular challenging one for myself, as someone already deeply embedded in the field through over twelve years practice in the field as well as a number of years immersion in social media spaces. I endeavoured to retain this balance through light touch participation and detailed reflexive field notes. As my research progressed I utilised an online collaborative research space a means to test out and clarify the meanings I ascribe to my observations.

Fetterman (2010, P.543) states that ethnographers are: ‘noted for their ability to keep an open mind about the groups or cultures they are studying’ and this is a particular

challenge to balance with immersion in a particular culture when the researcher is simultaneously participating in and contributing to that culture. It is firstly important to understand and make explicit any biases the researcher is operating with in order to be acutely aware of them during the research process. In addition to an 'open mind' and self-awareness. Fetterman (2010) argues that: 'quality controls, such as triangulation, contextualisation, and a non-judgemental orientation' also provide checks and balances for the influence of bias.

My preference for a co-productive style means that any form of covert observation has been out of the question. This counters the trend in much digital social research which often makes use of the 'physical anonymity' afforded by many digital spaces to undertake covert research. A covert approach enables the researcher to be unobtrusive and to avoid influencing the activities they wish to observe. It also enables access to significant amounts of data being produced online without any accountability to those producing it (Murphy, 2008, p.839). However, it has been argued that absence of active participation in online ethnographic research has a negative impact and may result in missing out on aspects of observation that can only be appreciated through participation in the field (Tuncalp & Le, 2014). Active participation enables different insights to be gleaned than is possible by simply observing practices from a distance.

More than being overt in my observation, I have been keen to take this further and create amplification for the voices and experiences of people finding their own voice and identity in social media spaces. My intention has been to collaborate with and encourage participation from the subjects of my research using crowdsourcing techniques, deliberation of my findings through an iterative process both online and face-to-face where possible. Rather than imposing my own interpretations separate

from the field, I have endeavoured to generate meanings through observations and interviews and then test them out collaboratively with participants.

Garcia et al (2009) point to inherent ethical problems with 'lurking' and also suggest that the ethnographic process is compromised by lack of engagement in the field. In their analysis of Internet ethnography, they found that many researchers begin their investigation by initially 'lurking', or in other words observing, to understand the community and then move to participation. I had already both lurked and contributed in small ways to conversations in the *madosphere* in the pre-research phase of my ethnography. I was therefore confident it would be appropriate to continue my participation during the active research phase. The positive benefits of this approach are supported by Garcia et al's (2009, p.59) analysis. They found that either participating as a member in the pre-research phase or showing oneself as a 'sympathiser' was important in establishing a trust period.

My participant observation has taken place almost entirely online, through which I have developed first-hand experience of what it is like to participate in the *madosphere* (Garcia et al, 2009). Data about connectivity between online and offline activity was collected through interviews with participants and a review of the academic literature. Exclusion of participant observation of offline settings is due to a number of factors including lack of time and resources. It is not clear the extent to which people engage offline as well as online and this may be an area identified for further research.

It is commonly agreed that ethnographic research requires extensive participation within the field of study and an ability to respond in the moment as events unfold. However, an online field site, in which blogs are posted periodically and most

engagement is asynchronous, creates constraints to sustained fieldwork in the received sense (Tuncalp & Le, 2014). I engaged in participant observation on the TWOM blog, and its related ecosystem on at least a weekly basis throughout the research period. This was largely asynchronous observation on a set day of each week. I observed and participated in related Twitter and Facebook activity on a daily basis in order to capture the more rapid and regular interactions which took place in these spaces. Downloading data asynchronously has resulted in an archival approach rather than a conventional ethnographic approach with its focus on real time experience (Tuncalp & Le, 2014).

There was at least one post, and often more, uploaded to TWOM every week which made it a rich site to study. I archived TWOM and its related ecosystem each week and then I wrote up a thick description of the blog and the related *madosphere* through drafting detailed reflexive field notes. This level of participant observation was my sole research method within the first six months of the investigative process, which then continued alongside qualitative interviews, for the remainder of the twelve month research process.

Whilst undertaking the observation I continued to participate through comments and contributions to the blog on a regular basis. The definition of 'participant observer' is problematized in an online ethnography in so far as participation does not occur in same way online as it does offline. As the researcher engages in a virtual field of study, it is entirely possible to engage in the terrain invisibly by observing rather than interacting. Alternatively, the researcher may visit the online research field regularly but may not routinely participate. Their presence is not there unless they leave a mark, such as a 'comment' or 'share' of a post (Beer-Sheva & Sade-Beck, 2004, p.48). I decided to leave a light footprint as a participant observer, commenting or sharing

occasionally and only making a contribution when I felt I had a ready observation to make. When participating, I periodically made a point of noting that my interest was related to my research in order to make my position visible.

During the course of my fieldwork, a number of events occurred which were particularly salient to my research question. They were events that naturally occurred during my fieldwork and which I happened to participate in. They therefore took the shape of participant observation but were boundaried by a particular topic and time in which they took place. They serve to highlight more general practices in the *madosphere*. I have included the events because of their intrinsic interest related to my research thesis and because they were significant instances that happened to take place during the course of my fieldwork. The instances I have chosen to analyse are events that I participated in as they progressed in real time. This enabled me to incorporate my own reactions and reflections as events unfolded alongside a review of written material after the event and interviews with participants.

5.2 Field Notes

The creation of field notes in ethnographic research is a means of systematising observations and capturing them in a way which enables both distance and reflexivity (Madden, 2010, p.118). My primary ethnographic research tool has been a weekly reflexive piece of writing in which I developed a thick description of social practices and behaviours operating in TWOM and its related *madosphere*. The importance of reflexivity in ethnographic investigation is highlighted by Hammersley and Atkinson (2007, p.25) who argue that the process of formulating and re-formulating the research problem is a fundamental part of the research process.

Regular writing has enabled deep reflection and a routine of questioning throughout the course of my research project that has enabled me to deepen my understanding of the *madosphere*. It has also been the most challenging aspect of my fieldwork in so far as it has required sustained application and a systematic approach over an extended period of time. With so much background tacit knowledge about the field of study there has been a constant risk of making quick analyses or assumptions based on what I already know or think I know. Bringing reflexivity into the field note process and challenging myself to question my interpretations has been a continuous endeavour at which I became more confident and skilled over time.

Gobo (2008, p.212) advocates four types of note writing: the first is 'observational' notes which are a thin description of observations in the ethnographic setting, the second is 'methodological' notes which are essentially questions or reflections about difficulties that arise during the investigative process; the third is 'theoretical' notes which are ideas, hypotheses or interpretations and explore the possible theoretical meaning of observational notes; fourthly, 'emotional' notes record personal responses to the ethnographic site, which may include personal reflections about issues such as fears, beliefs and prejudices. At the outset of recording field notes I found the process self-conscious and awkward; I was not sure what to focus my attention on, what was salient and what was irrelevant. Over time this became more fluid and I become more discerning and confident.

Utilising the approach set out above, I engaged in a weekly piece of writing between January and December 2013 that orientated around three core themes. Firstly, I wrote a routine descriptive piece in which I described the posts and interactions that had

taken place on TWOM during the previous week. This ‘thin’ description enabled me to begin creating a separation and distance between myself and the posts that I was reviewing. Madden (2012, p.119) argues that ‘faithful’ recording requires ethnographers to consciously check how and when they filter information they capture, to be aware of those choices, and to problematise them. This has been particularly important for my research in so far I was already deeply immersed in the field and the rigour of producing a descriptive piece enabled a more critical perspective to be taken.

A ‘thin’ description, with a heightened awareness of what I was choosing to notice and record, provided the starting point for me to identify methodological questions and reflections, or new research questions from those which I had already identified. I recorded my questions and themed them over the course of the time in which I wrote field notes and was able to then explore those questions through subsequent interviews and blog posts. A systematic weekly reflective piece of writing on methodology ensured that I self-consciously addressed embedded issues of subjectivity and challenged me to call in to question my personal values and beliefs which inevitably shape and form the research field (Madden, 2013, p.120).

Thirdly, I created a ‘thick’ description of the posts and interactions from the previous week which incorporated analysis and theorising based on my reading of the literature. This was a more creative and reflective piece of writing in which I challenged myself to think deeply about the subject matter. Finally, my ‘emotional’ notes enabled me to reflect on my own participation in the field and reactions to it. This latter element of field notes was particularly salient because it enabled me to bring my own participation into the research, which is inevitably limited by the fact of undertaking online research in a space and set of practices which are asynchronous and largely text based. Throughout

the period of fieldwork I endeavoured to consider my own responses and reactions to my participation in the *madosphere* in a diary-like format.

Gobo (2008, p.227) suggests a three step iterative process of ethnographic analysis. These are firstly 'deconstruction' (open coding) where the ethnographer seeks to uncover the conventions regulating the interactions observed. Secondly, in 'construction' (axial coding) one devises a story, or theory, about the phenomenon observed. Lastly, in 'confirmation' (selective coding) the information collected is used to document precisely and systematically the hypothesis contained in the story. Through this process I have developed key themes that I have tested and explored further through interviews and my blog. I have brought these three sources of data together with the intention of developing a deep and detailed critique of the social practices operating in this online space and set of mediating practices.

Compelling myself to write field notes on a set day per week was a challenging process and the discipline of creating notes as described above demanded a rigorous approach. On some weeks there were up to four posts uploaded to TWOM and this generated lengthy field note writing; during other weeks there was only one post uploaded which required much less time. Sustaining field note writing was the greatest challenge I experienced during the active research phase of my thesis. Wolfinger (2002, p.92) identifies two strategies for writing field notes: firstly, salience hierarchy and secondly, comprehensive annotation. An ethnographer who focuses on salience will pay attention to occurrences in the field that particularly stand out or which perhaps confirm their assumptions or prejudices; in contrast a comprehensive approach to field notes is one in which the researcher endeavours to systematically record points as they happened from beginning to end. The examination of blog posts creates a more flat

and even field of study than a set of dynamic in person interactions which have to be recalled and recounted. It is this even canvas that lends itself more readily to a comprehensive annotation whereby the text can be read from beginning to end. This same evenness could also be argued to create a flatness which loses the visceral embodied experience of participating in offline interactions. The experience of participation on TWOM was one of asynchronicity and there was no expectation or technical affordance of real-time interaction on the blog itself. This contrasts with the example of the Twitter conversation about the Asda mental patient costume event, as set out in Chapter 6, in which I was a participant as well as an observer. However, the writing up of field notes had a cumulative effect of bringing depth of knowledge and understanding to the *madosphere* over time rather than just with each separate activity of field note writing.

5.3 Interviews

Individual in-depth interviews are my secondary qualitative data collection technique through which I have tested out my observations gleaned through participation in the online environment. Hammersley and Atkinson (2007, p.170) argue that interviews, in an ethnographic context, should be analysed: 'systematically and coherently in the context of unfolding courses or patterns of action'. In other words, interviews should not be taken at face value as if they give unmediated access to the inner workings of an individual's mind, they should always be evaluated in the context of observable behaviours.

The interview in a virtual ethnography takes a somewhat different format from that situated offline. In a face-to-face setting the interviewee is likely to be already known

by the ethnographer, their interview likely to be impromptu and take place during the course of close proximity in a participant observation context (Gobo, 2008, p.191). In contrast, a virtual ethnography comprises actors who are situated in a dispersed fashion both spatially and temporally. The interview will not arise naturally and will need to be pre-arranged. The participant and researcher may live long distances apart and a non face-to-face interview may be the most pragmatic option available. My initial intention was to undertake the majority of my interviews via email based on a number of factors which comprise ethical as well as practical considerations. My first and major concern was to avoid disrupting the existing ecosystem of the *madosphere*, which is primarily comprised of bloggers using anonymous avatars and biographies. I was concerned that by introducing a face-to-face aspect to the research I would create an asymmetric position to the TWOM participants, who primarily and sometimes exclusively interact online. This could have the potential to disrupt the informant's understanding of the online world and their engagement with me, as a participant observer, in that space (Orgad, 2005, p.53). I was also aware of the fact that many participants use anonymous online personas. By asking for a face-to-face interview, I was concerned that I may potentially compromise participant's self-protective strategies for managing negative implications of stigma and discrimination. There were also a number of practical considerations which informed this initial decision. Firstly, I anticipated that it would be likely that a number of participants would be unwilling to be interviewed face-to-face and so a default email interview would ensure a consistent approach. Secondly, participants are widely geographically dispersed which makes the possibility of meeting face-to-face very challenging within the narrow time limits available to me to undertake the research.

The idea that an interview in person carries more authenticity than an online interview or that it is required to triangulate offline data has been convincingly contested by a range of Internet researchers (Hine, 2005; Kivits 2005; Orgad, 2005). However, whilst I undertook initial interviews via email, I found that keeping participants engaged through asynchronous means was challenging and only one or two interviews were fully completed in this mode. I adapted to a more pragmatic approach of giving the interviewee the option to choose the medium through which they would like to be interviewed. This resulted in subsequent interviews being conducted by telephone, Skype video call, the chat function in Skype and meeting in person. Video conferencing enabled interviews to be undertaken with a wide geographical distance, including overseas, fairly easily and rapport could be developed and non-verbal behaviours observed (Garcia et al, 2009). These methods enabled me to build rapport and engage in a synchronous two way exchange that kept participants engaged over a relatively condensed and short period of time compared to email.

I undertook twenty-three interviews during the course of my research, which I initiated once I had undertaken weekly participant observation over the initial six month period. I began by interviewing one of the TWOM blog co-editors and expanded my reach using a snowball technique following recommendation and introduction by the co-editor. TWOM blog has a tradition of annual online awards and I approached all the shortlisted candidates to invite them to participate in an interview. I also interviewed several of the shortlisting panel. I used the opportunity of having an introductory page on the TWOM blog to invite people to get in touch if they would like to participate in the research. I was approached by several people in this way. Interview participants suggested other interviewees and approached them on my behalf. Sometimes my request for an interview was turned down and this meant I was not able to glean insights from some

very active participants within the *madosphere*. I continued interviewing until I reached saturation point in terms of new knowledge that I was generating.

Garcia et al (2009, p.66) suggest that interviews enable the ethnographer to do a number of things – they can verify information gathered online, check identities of online personas, understand respondent characteristics and fill gaps in online data collection as well as resolving ambiguities or queries. However, Orgad (2009, p.9) argues against the idea of offline data being used primarily as means for veracity or assuming that offline data is more 'truthful or authentic' than the data provided online. She promotes the use of gathering offline data, such as interviews, in so far as they can add context, enhance and create an opportunity for insights which might otherwise not have been gleaned. It has been argued that online email interviews can afford a degree of privacy whereby interviewees are more likely to disclose intimate information with less concern about impression management (Hine, 2005, p.32; Kivits, 2005, p.35). Kivits (p.38) argues that the rules for successful online interviews are similar to those conducted face-to-face; for example, a degree of self-disclosure is an important grounding for reciprocated disclosure and sharing of information. The balance between reciprocation and reassurance was carefully balanced against the need for consistency in framing interview questions so that they could be compared. Garcia et al (2009, p.67) argue that online interviews, using instant messaging for example, can extract more candid responses as well as balancing the power between interviewer and interviewee. However, the lack of spontaneity in an asynchronous online interview may also limit the insights to be gained by the researcher.

Gobo (2008, p.192) asserts reservations about the role of the interview in an ethnographic investigation. In particular, he warns against an over-emphasis on the

interviewee's 'declared' state above their 'actual' state and in particular where there is a strong mismatch between the two. However, this suggestion in itself is problematic in its underlying positivist assumption that there is an objective truth that can be ascertained through observation. I contend that the interviewer may well have a different interpretation of a state or behaviour than the interviewee, and that this should be the focus of the interview. A consideration and a negotiation of what appears to be happening from two parties who may have different perspectives and interpretations is what I find of most interest in this scenario. A guiding principle of co-production would lend itself to the ethnographer faithfully recording both perspectives whilst carefully explaining their own position. Whilst I had a guiding set of questions for my interviews, I undertook a conversational approach framed as shared enquiry in order to engender an egalitarian space. This contrasts with a positivist tradition of neutral objectivity and draws on the notion of 'giving a voice' and collaborative learning as promoted within disability research (Seymour, 2012, p.349).

An important rationale for use of interviews in online ethnographic research is that it creates the ability to engage with 'lurkers' – those people who visit an online space but who do not interact visibly or leave any observable footprint. People who lurk are relevant to my research question. They may not be leaving a trace but they are interacting with content and this may or may not have implications for their sense of identity. Without engaging this group of people I would be missing some of the complexity and nuances of how the madosphere is being engaged with, and its implications (Orgad, 2009, p.12). In the event I managed to interview several people who read the TWOM blog but did not participate in it. These individuals were recommended to me by TWOM participants who brokered contact with them so I could

invite them to participate in an interview. These interviews provided instructive insights into views of the blog and its active participants from outsider perspectives.

My interview questions incorporated themes for exploration which arose from my participant observation in the space itself. A systematic approach to identifying thematic areas for discussion enabled me to compare responses between individual participants. I transcribed and coded the interview data using thematic analysis - that is a search for themes that emerge as being salient to the research question (Fereday et al, 2008, p.82). Themes emerged through close reading of the interview data which I then categorised and grouped together. I endeavoured to take a consistent approach to analysing data gathered offline and online and treated the data similarly, organising by theme rather than by the way in which it was elicited. Orgad (2009, p.17) argues that researchers should regard different types of data as 'mutually contextualising each other' rather than assuming that the 'offline' data makes sense of the 'online' data. He suggests that the 'offline does not explain the online, nor does the online explain the offline. Rather the aim should be to look at ways in which each configures the other' (Beer-Sheva & Sade-Beck, 2004, p.48).

5.4 Collaboration

Throughout the fieldwork I have endeavoured to use my blog to reflect on key issues or problems related to my research. I have invited others to share their thoughts and contribute their ideas. This has been salient in both enabling me to reflect on the process of gathering research data and in points of view others have shared with me about my analyses. This approach has enabled me to reflect, check and refine and has brought a collaborative element to my research. An approach founded on reciprocity

and shared enquiry requires the researcher to disclose personal information and reflections in order to build reciprocity (Seymour, 2012, p.350). Whilst Seymour states this is a challenge for online researchers, I found that the affordances of Twitter and blogging enabled me to build this in small and various ways throughout the course of my research. It is not just the direct connections with potential research participants, but the connections and conversations between others who have credibility in the space, which build credibility over time. Online dialogue in public social media spaces enables potential participants to check and assess credibility through association as well as one's own content.

An example of this collaborative approach is my blog post entitled: 'Are you mad about the *madosphere*? language, humour and power' in which I give examples of comments about use of language from my research interviews and invite people to comment on my blog:

> Are you a mental health practitioner? Someone who has experienced mental health difficulties? Perhaps you've never even thought of these issues before? What do you think about the importance (or not) of language in the mental health blogosphere? Please do comment on this post – I'd love to hear your thoughts.

This request resulted in conversation on Twitter and several comments on my blog that enabled me to glean additional insights from people who otherwise may not have participated in my research. By this I mean that the opportunity for ephemeral participation in my research through comments meant that its reach could be extended beyond the greater commitment required of interview participation. It also meant that

people could engage in conversations who would otherwise be constrained by obstacles associated with their mental health difficulties or other impairments (Seymour, 2012, p.351). This strategy also aimed to demonstrate a sensitivity and responsiveness to cultural norms of sharing and helpfulness on social media platforms.

In addition to my own posts, I invited mental health bloggers to contribute guest posts on my blog which illuminate key issues from my research. The intention was not only to build relationships and reciprocity but also to situate my blog as a site for open deliberation on key themes. For example, one interviewee who participated in an email-based interview told me that they had got a great deal from participating in the interview and that it had provided a useful space for reflection about their participation in the mental health blogosphere. I therefore invited them to write a guest post for my blog which they duly did. I found this a powerful process in building relationships, reach and credibility for my research as well as giving them an opportunity to share their reflections with my audience. This degree of reciprocity felt immensely rewarding and itself part of cohesive mediating practices in the *madosphere*.

In the design stages of my research I decided to establish a private Facebook group where I would invite interviewees to continue to engage in dialogue related to the themes of the research. Whilst a number of people did join the group, and there was some participation, it did not prove fruitful and resulted in only a limited degree of involvement. Whilst I did not ask for feedback about lack of engagement, it may have been influenced by my own lack of engagement with the platform, meaning that I did not post regularly. Facebook is used by many, as well as myself, as a personal space away from professional issues and this may have contributed to the lack of

participation. Using open social platforms such as my blog and Twitter proved more successful in engendering conversation about my research topic.

6.0 Ethical Issues

Many of the ethical issues associated with research conducted on the Internet are similar to traditional research methods. These include issues of informed consent, confidentiality and anonymity. However, there are some specific issues associated with privacy and analysis of data in the public domain which I consider in this section (Whitehead, 2007). My research methods received ethical approval from the University of Leeds whereby the issues I discuss in this section were considered by an independent committee. Schrum (2012, p.128) argues that digital ethnography requires an adaptive amalgam of methods including participant observation, interviews and electronic communications. Ethical issues associated with Internet research remains a live issue - at the time of writing I attended an academic workshop on the subject in 2015 where participants revealed how they have undertaken research using data from online social networks in the previous few years that they would now consider unethical. It is not uncommon to hear of studies in which research subjects were not even informed about their inclusion in projects (Schrum, 2012, p.128).

There are also specific ethical issues arising from an ethnographic methodology related to its provenance from the late nineteenth century onwards, as a Western form of knowledge about far away cultures. It has ingrained associations with colonialism based on a belief that the ethnographer could illuminate objective facts about those studied (Gobo, 2008, p.2). Gobo argues that the predominant cognitive mode utilised

by the ethnographer is that of observation before methods such as the survey or interview. The primary method of observation immediately raises some ethical challenges for my research. How do I undertake observation of a group of people, many of whom have lived experience of objectification, classification and marginalisation by professionals? How do I ensure my research process has co-production at its heart? My aspiration has been for participation in this investigative process to be a positive one from which participants can not only contribute but take away learning that they will find useful for themselves. Such collaborative ethnography necessitates a continual reflexive awareness of issues of power and control.

6.1 Information and Consent

Information about the research project should be provided to all participants within an ethnographic investigation and individuals able to opt out of the research at any time without fear of negative consequences (Hammersley & Atkinson, 2007, p. 210; Whitehead, 2007). This has been comparatively straightforward for the primary TWOM blog but more problematic for the ecosystem of bloggers surrounding it. As an illustration of the complexity of information and consent in this context, individuals may guest-blog on the TWOM and others may have their blog included in the weekly TWIM without their consent or even knowledge.

Whilst my research was certainly not intended to be covert, my participant observation activity did not leave an obvious trace unless I specifically commented on blog posts or guest post myself. One strategy to overcome this constraint would be to comment on every post with a note to provide information about the study and request permission to include it. Whilst this would overcome the problem, I was concerned that it could unduly

encroach on the environment and become overly intrusive whilst compromising rapport. Hammersley and Atkinson (2007, p.211) argue that it is not always possible to ask for the active consent of all participants without being 'highly disruptive, or rendering it impossible'. By virtue of the fact that ethnographies are carried out in 'natural settings' the dynamic nature of who drops in and out of the setting cannot be controlled.

An alternative measure I decided to take in order to raise awareness of the research project was to request a page on TWOM blog in which I introduced myself and my research. I then re-posted the content of the page as a post on my blog. I was then able to draw the attention of bloggers to the post periodically or when it became apparent to me that I would like to include that particular blogger in the study. I provided information about the research as a page on the TWOM website and included my contact details. Consent presents some specific challenges in the TWOM blog where posts are routinely submitted by guest bloggers. I employed the practice of drawing attention to the blog post (for example, via a comment on a post) when there was a regular blogger who I would like to include in the research and/or I would like to interview.

6.2 Public versus Private

The boundaries between public and private spaces need to be understood differently to comparable offline spaces (Garcia et al, 2009h, p.74). According to Hudson and Bruckman (2012, p.137-138) whether researchers conceptualise the Internet as a 'public square' or a 'private living room' lead to very different ethical conclusions. In a public square a researcher may observe behaviour in a general way and write about generalised results. They go on to argue, that in some instances, authors use the

Internet as a public forum to spread ideas and invite debate and so to anonymise them would be to do them a disservice. In the case of minority or marginalised voices, anonymization: ‘reinforces the dominant paradigm from which they [authors] are trying to escape.’

According to Garcia et al: (2009, p.75) ‘ethnographers can increase their chances of making the right choice about how to gain access to archival and other online data by learning the norms of behaviour in the specific environment they are studying’. The Internet blurs traditional distinctions between private and public in which there is a continuum between individuals deserving credit for their work and needing anonymity for protection (Hudson & Bruckman, 2012, p.138-139). Consideration of fairly crediting others for their work raises legal issues of credit and copyrighting. Written materials on the Internet are considered copyrighted and may be studied by academics within the bounds of ‘fair use’ as long as they are properly cited. As a result, a researcher who anonymises such content could be breaching copyright.

My assessment has been that the locus of my research is reflective of the ‘public square’ where bloggers are engaging with social and public issues with the intention of articulating a view contrary to that espoused within mainstream media. Posts are uploaded with the intention of being read by the public and engaged with. I have excluded those relevant blogs which have privacy settings attached to them and which can be regarded as primarily private. This means that the potential to be intrusive could be argued to be limited. I have cited content taken from TWOM and its related ecosystem of blogs so that the author can be properly credited for their content. With the exception of interviews which have been anonymised, I have not captured any data which is more firmly within the sphere of the private realm, such as chat rooms. I have

also not directly quoted content from blogs focused primarily on the daily experience of living with a mental health difficulty, on the basis that this blurs into the private realm. I have focused on content which engages with social issues and topics related to events reported in mainstream media on the basis that authors are posting with the intention of public debate and discussion.

In her guidelines for ethical electronic research, Schrum (2012, p.130) states that: 'researchers must respect the identity of the members of the community, with special efforts to mask the origins of the communication, unless express permission to use identifying information is given'. My intention has been to guarantee, as far as is possible, anonymity to research participants. An online research setting raises specific issues regarding the degree of anonymity afforded to participants and where the line should be drawn. For example, a number of bloggers already use pseudonymous identities and it is not possible to know how connected to their offline identity it may be. As Garcia et al (2009, p.193) suggest:

> Even if the pseudonym is not the participant's real name, it may be possible for members of the online community to identify the person from it. ... [Users] may use the same pseudonym over an extended period of time and ultimately care about the reputation of that pseudonym.

It is also the case that quoted text can be searched for on the Internet and that a third party could trace comments back to the original producer of the narrative (Whitehead, 2007).

I have therefore changed both pseudonymous and non-pseudonymous names to protect the identity of interviewees and those contributing to the TWOM blog. The parameters of anonymity have been negotiated and agreed with individuals during the course of the research. Even before the active phase of research had commenced, potential research participants had chosen to share confidential information with me. For example, a number of anonymous bloggers have shared their real identities and other personal and professional details with me. Agreement about confidentiality is tacit and based on trust. Confidentiality has been made explicit at the commencement of the investigative research process and in the information provided for participants.

The concept of reciprocity in a collaborative and co-productive research process is of prime importance. Relationships and trust are built on self-disclosure. Many aspects of my persona are already in the public domain in social media spaces. Some are explicit and some are implicit. For example, I have chosen not to engage in discussion about public politics in publicly viewable online social networks. However, a cursory glance at who I follow on Twitter would make my personal political allegiances very clear. My intention has been to make contingent judgements, as I do in my practice role on a day-to-day basis, on the degree of self-disclosure appropriate in the setting and at different times. I have endeavoured to keep myself as much in the background as possible without compromising relationships and trust during the research.

Ethnographic research carries the risk of creating emotional harm through the process of participating in the research and in the effects of publication of the research. A significant proportion of the people I have involved in my research study have lived experienced of mental health difficulties and are potentially particularly vulnerable to the harmful effects of participation in my research study. Hammersley and Atkinson point to

the risk of stress and anxiety from being a research participant, as well as the potential harmful consequences of developing close relations during the research process time (Hammersley & Atkinson, 2007, p. 214). A number of potential interviewees have declined to participate in the research on the grounds of their mental health. When this has happened I have been careful to make it clear that there are no negative consequences to non-participation and have continued to engage in conversation with them online.

Concerns about exploitation are important to consider and I have previously set out in this chapter how I have taken a collaborative approach to undertaking my research project. Hammersley and Atkinson (2007, p.218) make a salient point that typically researchers investigate people less powerful than themselves and this has the potential create problems, even where there is an intellectual and emotional commitment to the participants concerned. I have endeavoured to ameliorate the potential for exploitation in a number of ways. Firstly, the collaborative aspect to my research has provided the opportunity for participants who choose to, to become active shapers of the research process. Secondly, I have endeavoured to offer something back to those participants in terms of raising the debate about the affordances of social media in the mental health field, challenging stigma through the campaigning work I do, and sharing useful information and resources.

7.0 Limitations and Exclusions

There are a number of limitations and exclusions within my research which I set out in this section. The research methods employed have been highly qualitative to reflect my primary interest in developing a rich and deep understanding of the space and set of practices coined the *madosphere*, alongside the motivations and meanings to its

inhabitants. For this reason, social networking analysis tools, which would have enabled a quantitative aspect to the study, have not been employed. Qualitative methods prioritise depth over breadth and endeavour to surface subtle nuance within a specific context over aggregated evidence. I have endeavoured to balance the necessarily subjective nature of qualitative research with a thorough and systematic approach to both interviews and field notes (Whittemore et al, 2001).

Quantitative approaches have been undertaken by other researchers (Shepherd et al, 2015) and it is hoped my research adds qualitative depth to emerging research on the theme of mental health and online social networking. As a result of a highly qualitative approach that has been taken with participant observation and a small number of in-depth interviews, I have not addressed issues such as gender and race in relation to the *madosphere*. However, it should be noted that increased exclusion for people who do not or are not able to use online social networking sites is a concern; people from lower socio-economic groups are most likely to be affected (Kontos et al, 2010, 218). Internet users are most likely to be younger, more highly educated and richer, more likely to be men than women, and more likely to live in cities. Whilst the effects of the Internet can be described as democratising, this is more likely to positively affect people who are more prosperous, not just in the UK but across the globe (Fenton, 2015, p. 351).

The 23 people who I interviewed were of equally mixed gender, and between the ages of 30 and 50, with the exception of two interviewees who were in their early twenties. They were all white and held higher degrees. In this regard they are not typical Internet users. Figures show that use of the Internet in the United Kingdom rose substantially between 2011 and 2013, reaching 78% of the population aged 14 years and over.

During the same period there was a decrease in the digital divide with increased Internet access for lower income groups, people with no formal educational qualifications, retired people and disabled people. Social networking sites grew significantly in popularity from 2007 to 2011 and by 2013 there was a plateau in the diffusion curve with approximately two thirds of people who access the Internet in Britain engaging in online social networking (Dutton & Blank, 2013). However, the particular practices of people engaging in the *madosphere* are consistent with only a tiny fraction of the Internet using population. They correspond to the characteristics associated with 'e-mersives' who comprise only 12% of Internet users, followed by techno-pragmatists who make up 17% of Internet users in the United Kingdom. E-mersives are, as the name suggests, immersed in Internet use on a routine basis, and are:

> Pleased to use the Internet as an escape, to pass time online, and think of it as somewhere they feel they can meet people and be part of a community. They see the Internet as a technology they can control - a tool they can employ - to make their life easier, to save time, and to keep in touch with people (Dutton & Black, 2013, p.17).

Like e-mersives, techno-pragmatists also feel in control of the Internet but do not use it as an escape or go online just for the fun of it; their use tends to be located in a more utilitarian approach of efficiency. The characterisation of e-mersives as most likely to engage in social networking and produce content online is reflected in my interviewees. This means that conclusions from this research can only be generalised within these specific boundaries and should be done with caution.

My research has offered a point of comparison between the asylum of the 19th Century and the *madosphere*. A brief analysis of the asylum with historical references in Chapter 4 is necessarily limited and specifically focuses on themes of communication in the private and public sphere by people incarcerated within mental health institutions. It is acknowledged that there is a substantial body of literature on the history of the asylum and the profession of psychiatry which is only briefly alluded to in my study. My research is concerned with identity, roles and self-mediation which has led me to draw extensively on the work on Goffman (1961, 1963) who has brought a sociological perspective to the study of mental health, asylums and stigma.

8.0 Conclusion

Methodological and ethical issues are both contested and emergent in online ethnographic research. I have employed Schrum's: (2012, p.131) 'Ethical Electronic Research Guidelines' as a compass for my research with an awareness that the field is dynamic and new issues continue to be explored and debated.

Schrum's (p.131) states that: 'researchers have an obligation to the electronic community in which they work and participate, to communicate back the results of their work'. I have endeavoured to share insights from my research through my blog over the four years of its duration. This has benefitted my research in terms of gleaning insights through feedback from others. I have also intended to employ my blog as a means of sharing my learning to a non-academic audience. My completed PhD project will be publically available online and I will draw this to the attention of all my research interview participants as well as promote through my blog. The public availability of my

research will also lend credibility to the final chapter, in which I make a series of recommendations to practitioners and institutions in the NHS (Fielding, 2012, p.285).

Chapter 4

Disrupted Relationships – from Silence to Self-Publishing

‘For too long mental patients have been faceless, voiceless people. We have been thought of, at worst, as subhuman monsters, or at best, as pathetic cripples, who might be able to hold down menial jobs and eke out meagre existences, given constant professional support. Not only have others thought of us in this stereotyped way, we have believed it of ourselves. It is only in this decade, with the emergence and growth of the mental patients’ liberation movement, that we ex-patients have begun to shake off this distorted image and to see ourselves for what we are – a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own’

Judi Chamberlain, On our Own,1988.

1.0 Introduction

In this chapter I consider how people with mental health difficulties voice their experiences and engage in discussion about mental distress within the public sphere. I explore the extent to which online social networking sites afford spaces in which a set of mediating practices have emerged whereby people t*alk about*, *talk with* and *talk back* to the mental health profession and related institutions. To disrupt is to cause a disturbance or problem within an event, activity or process that interrupts its flow (Oxford Dictionaries, 2015). In this chapter, I make the case that participants in the *madosphere* generate small, every day, countless interruptions which have a disruptive effect on institutions and mainstream media. I draw on Speed’s (2006) theoretical

framework of mental health discourse to illuminate a spectrum of behaviours which range from acceptance and assimilation through to challenge and rupture of received relationships. I touch on the historical roots of the asylum in order to contextualise contemporary disruption (Goffman, 9161). I also refer to mental health activists who, at different points in history, have *talked back* to authority on behalf of people accessing mental health services (Chamberlain, 1988, Morrison, 2005). I employ some reflections on the development and demise of the asylum, to illuminate how online social networks afford a democratising of disruption that opens it up from the few to the many.

Throughout the chapter I employ a simple communications lens which conceptualises a range of interaction from passive through to active – to be *talked about*, to *talk with* and finally to *talk back*. Speed's (2006) discursive typology of mental health discourses comprises a spectrum which starts with a classic medical discourse of 'patient' through to a contemporary governmental discourse of 'consumer' and then to an anti-psychiatry discourse of 'survivor'. These three styles of discourse represent 'ideal types' and are a site of continual tension and negotiation rather than reflective of a static identity held by an individual. Indeed, in his qualitative analysis of interviews with people accessing mental health services, Speed found that his interviewees routinely drew upon all three discourse types. Each discourse type represents a social construction of mental distress that is socially available for individuals to draw upon. They reflect the extent to which people locate themselves as agreeable users of mental health services through to those who regard themselves as survivors of an oppressive system. Speed's conceptualisation of identity and disruption are salient to my thesis - he argues that the individual who identifies themselves as a 'patient' is more likely to accept and internalise a biomedical paradigm; a 'consumer' can be regarded as someone who neither accepts or rejects their diagnosis; an individual who identifies themselves as a

'survivor' is likely to resist a biomedical diagnosis. Whilst all three *may talk* back to professionals and the institution, it is the latter group who have an agenda for social and/or political change, whilst the middle group may want to work for reform within the system, and the former group may want to give feedback about the experiences within the boundaries made available to them by the institution. Speed argues that: 'different discourses are not mutually exclusive; they function to offer different and overlapping pathways through or around social elements of mental health.' Speed's typology aligns to my research findings which unearthed a continual and consistent interplay between these three discourses by people discussing mental health in the *madosphere*.

Goffman's (1961, p.62) analysis of the relative positions adopted by individuals who are subject to institutional authority is salient in an exploration of disruption to established norms. Positions range from acceptance of one's position through to rejection of one's situation. An acceptance of a patient position can take the form of 'colonisation' or 'conversion' where one adapts and conforms to the expectations and requirements of that institution; a rejection of the patient role and the authority of the institution can take the form of a self-protective 'situational withdrawal' or a more challenging 'intransigent line' where an individual talks back to institutional power. Both are forms of disruption expressed in varying ways. In *Confessions of a Non-Compliant Patient* (1998, p.51) Judi Chamberlain, an American mental health activist, promotes a survivor narrative and critiques what she perceives as the personal cost of compliance:

> A good patient is one who is compliant, who does what he or she is told, who does not make trouble … A 'good patient' is often someone who has given up hope and who has internalised the staff's very limited vision of his or her potential.

Chamberlain argues that being a good patient is incompatible with the process of 'empowerment' whereby people take control of their identity and make decisions for themselves (p.44). She makes the case that being a 'bad patient', which entails *talking back* to the institution and rejecting the patient role, is key to getting back to 'real life'. Goffman's (1956) work on self-presentation is also relevant in an analysis of disrupted relationships, when considering the extent to which social norms of *patient* and *professional* are performed or rejected. Both Goffman and Chamberlain problematise the socially constructed role of patient with its associated expectations, behaviours and internalised constraints. Chamberlain's prescription is to *talk back*, as she did during her lifetime through her extensive activism and published works which range from 1978 to 2004.

I juxtapose the asylum with the *madosphere* in order to illustrate the significant social shifts that have occurred in the sphere of mental health discourse. I illuminate how the emergence of self-publishing affords the opportunity for increasing numbers of people to 'find their voice' and articulate it in the public sphere. Whilst the opportunity to *talk back* in the public sphere is more available than ever before, it is not merely a contemporary phenomenon - records of people *talking back* to the mental health system can be traced back to the early asylums and workhouses - a tradition which goes back to self-advocacy in the 19th Century through to published narratives in magazines and book in the eighties, and then to self-publishing through micro-blogging and blogs today (Morrison, 2005; Nolan, 1993; Porter; 2002; Scull, 1993). The latter have enabled not only self-publishing but also a direct means to debate, challenge and create alternative spaces amongst peers to the institution and media mainstream. In an assessment of the contemporary anti-psychiatry movement, Whiteley (2014) uses the

volume of activism challenging psychiatry in online social networks, as a measure of grassroots activity in this area.

Practices in the *madosphere* disrupt the institution by complicating the binary divisions of mad and sane; inmate and warden; freedom and incarceration. Disturbance and disorder arises through challenge to those binary oppositions which are enmeshed within the fabric of the institution. The rise of psychiatry and the institutionalisation of care through the asylum provide a context and a catalyst for disruption. In his seminal text, *Asylums: Essays on the Social Situation of Mental Patients and other Inmates* Goffman (1961, p.105) offers a detailed sociological analysis of this particular form of institution and illuminates the friction within the professional and patient relationship characterised by segregated roles and requirements for social distance. He argues that institutions construct different categories of person which in turn create a 'profound difference' between for example, a staff doctor and a mental patient. In my research I have been particularly struck by the continuity and similarity of concerns raised by patients from the nineteenth century to the present day. Goffman (1961, p.320) provides clues to this unbroken pattern of discourse through his exposition of the essential dynamics of the institution and constructs of identity and role which contain inherent tensions within them:

> The psychiatrist and patient tend to be doomed by the institutional context to a false and difficult relationship and are constantly funnelled into the contact that will express it: the psychiatrist must extend service civility from the stance of a service but can no more continue in that stance than the patient can accept it. Each party to the relationship is destined to seek out the other to offer what the other cannot accept, and each is destined to reject what the other offers.

Whilst the bricks and mortar of the asylum no longer exist in Britain today, it could be argued that many of its qualities retain salience for construction of individual role and identity. This is suggested through my research interviews and field notes, in which the characteristics of institutionalised relationships are continually deliberated upon, contested and variously accepted or rejected in the *madosphere*. The legacy of the asylum, whereby associated attitudes and beliefs persist, should not be underestimated. Its history is worth briefly reflecting on here.

The development of psychiatry as a profession, and the asylum as a place to contain those considered insane, is a phenomenon that gained momentum in the 19th Century with a predominantly custodial focus - removing those who were dangerous to themselves or problematic for others (Shorter, 1988, p.7). In the early days of the asylum, inhabitants were not only often incarcerated against their will, but were casually objectified as a source of public entertainment. The asylum was a place where visitors could gawp in galleries at the afflicted. The mad were not only silenced, they were the passive objects of prurient observation for the purposes of entertainment. Such practices were based on an underpinning belief that the mad were devoid of reason and were not possessed with the same range of feelings as others. Lunatics were routinely compared to dogs or wolves and assumed to be brutes (Scull, 1993, p.56). Bethlem asylum of the nineteenth century, from which the term ‘bedlem’ derives, positioned the patient as an object of ridicule; the *mad* did not even possess sufficient sentience to be accorded human emotions, let alone a voice: ‘in losing his reason, the essence of his humanity, the madman lost his claim to be treated as a human being’ (Scull, 1993, p.61). Porter (2002, p.158) argues the silencing of the mad was not based

solely on inhumanity, but rather on a scientific discourse that defined madness within a biological paradigm and which:

> reduced the expressions and complaints of the disordered to secondary manifestations, the screeches and judderings of a faulty engine: something was wrong, but nothing significant was being said. In any case, did not the methods of the natural sciences prescribe observation and objectivity, not interaction and interpretation?

Barbaric treatments and restraints were often used, with increasing numbers of people being removed from society. Without a voice of their own, inmates were *talked about* as objects of voyeurism, their stories and inner thoughts were barely worthy of regard. The development of psychiatry, and the history of the asylum, is contested within the literature - some conceptualising a continued move towards reform and improvement with others emphasising social control and repression (Yorston and Haw, 2005, 396). However, more than a century after the dawn of the asylum in the 1900s, and with its demise in the early 21st century, what was once seen as the solution to significant social challenges is invariably looked back upon as being a part of the problem (Freeman, 2010, 314). The remnants of attitudes and assumptions which underpin the asylum not only still linger but are frequently remediated within mainstream media; irresponsible reporting sustains a background narrative of dangerousness associated with mental health which connects directly to arguments related to restriction of liberties, incarceration, and limiting of life opportunities for people affected (Philo et al, 1994). The social attitudes and beliefs which led to the creation of the asylum in the nineteenth century appear to retain a powerful grip in the public imagination and prejudices of contemporary society.

How have people experiencing mental distress found their voice outside of and in resistance to the institution? Braddock and Parish (2001) argue that first person accounts by people with lived experience of mental health problems have been largely eclipsed by professional and institutional accounts. This has, in their view, reflected and legitimated professional behaviour, at the expense of people accessing services and marginalised their perspectives. Disruptive voices of the past have been captured, recorded and persisted only where official media technologies have been used to convey dissent – pamphlets, books and the establishment of organised bodies for campaigning purposes. Those technologies would only have been available to the few. However, there are some exceptions, and archived letters from inmates at the Royal Edinburgh Asylum give an insight from patient perspectives as to what life was like in a Victorian asylum. Rather than posting letters to their intended destination, staff appended letters to a patient's notes where it was felt they displayed a 'mental disturbance' or were critical of the asylum. These are the 'bad patients' as codified by Judi Chamberlain - refusing to accept their position and resisting their incarceration. The variety and purpose of letters is wide but they are typically written to family members asking to be taken home, as well as complaining about the tedium and monotony of the institution. Here is a typical letter written by 22 year old Miss Edilla D on the 21 January 1898 to her parents:

> I feel I cannot stand this place a minute longer and soon I shall lose the brains I had, and not be able to interest myself in others and everything that goes on in the world. The monotony and routine simply drives me wild ... I feel I shall go on degenerating in this environment into an animal, that only lives to eat - as we do

> here! - and has not thought beyond. For really that is all the 'treatment' consists of. (Beveridge, 1998, p.431)

In contrast to the carefully constructed polemical writings of activists such as Judi Chamberlain, these are naturally occurring individual expressions of resistance, which are written in the moment as they are experienced. They are spontaneous communications that never made it beyond the medical notes but which are instructive of the concerns important to inmates at the time. These thousands of letters provide an insight into life within the asylum and the concerns of people incarcerated within them. Whilst censored by the authorities of the day, they have more in common with the personal narrative blogs and tweets in contemporary life, than do the published writings of activists. They are people *talking back*, seeking to be understood and to find their voices, through everyday narratives. The technologies of the day meant that these personal narratives could be intercepted, and contained within a medicalised paradigm. Those narratives that were once locked away can now be surfaced to public view, to be searched for, read, shared and commented upon. The institution cannot control, contain or prevent them. To what extent does online social networking afford a new kind of disruption, *a new kind of madness network* that has tangibly different qualities and affordances to that which has gone before? This is a question I seek to elucidate further in this chapter.

2.0 The *Madosphere* - a New Kind of Madness Network

Writing in 2005, just before the advent of social networking, Morrison (2005, p.89) argues that the Internet creates a space where: 'information flows are instantaneous and access is enormous ... cross national communication is instant and free ...

campaigns of interventions can be put into action overnight'. She describes the Internet as a 'new kind of madness network' where dissenting views can be debated and discussed. As I illustrate in this section, her delineation of the Internet anticipates the emergence of online social networking with its affordances of interruption and disruption.

A dramatic increase in the breadth and reach of public discussion afforded by social networking sites comprises a broad spectrum of discourse from predominantly personal diary-based narrative through to overtly politicised campaigns for social change. This is reflective of the non-centralised and loosely tied UK movement that campaigns for social change in relation to mental health, which can be described as: 'a loose coalition of advocacy and activist groups whose members engage in numerous activities designed to promote mutual support, rights protection, alternatives, advocacy, and information flow that will enhance empowerment and choice for people whose lives have been affected by psychiatry' (Morrison, 2005, p.58). Conversations within the *madosphere* reflect a breadth of conversation aligned to Speed's (2006, p.37) delineation of the accepting patient, the negotiated consumer and the active resistant survivor. The *madosphere* is a space and set of practices in which this spectrum of mental health construction is continually in tension. However, whilst Speed's typology assumes a spectrum of passivity through to agency, the *madosphere* holds a breadth of viewpoints - from a predominantly patient-centric conceptualisation of mental health to those who may have a more resistant survivor-led perspective.

It can be argued that Morrison's optimistic delineation of the Internet is being realised through self-mediating practices in the blogosphere and other social networking platforms. For example, at the time of writing the Big Mad Experience @BradfordsBME

is a relatively new Twitter account, a Facebook fan page, website and a YouTube channel. The channels are not only set up to promote a participatory event 'The Big Mad Experience' but also as spaces for debate and discussion about mental health. @BradfordBME hosts a weekly #BigMadChat each Monday at 8pm UK time where different topics are considered and anyone can participate in real time using the associated hashtag. The account name has resonance with the disruptive language used by the Madness Network News (MNN) in the seventies – giving a dissenting and iconoclastic tone to their conversations. This is a set of practices established outside of an institutional frame and which enables people subject to and part of the institution to engage in public conversation with each other. One of my interviewees involved in #BidMadChat gives an account of the complexity of language and how the name of the chat is intended to give signals about the type of conversation the organisers hope to generate:

> we came to the conclusion that it didn't matter what we call [BradfordBME] there's always going to be someone who doesn't like it, and you can, the harder you work to please everyone the worse the name will get, um and we wanted to talk about people's experience of madness and we were well aware of the connotations of that, but we were also aware that people are trying to reclaim that term too, um we sort of, when we came up with Big Mad Experience we realised that was BME which is typically black minority ethnic, and actually we quite liked that, um sort of hijacking a bit of attention in that kind of way, we just liked the sound of it, we wanted it to be like positive, and there are many different meanings of the word mad, you know getting mad, as in upset angry, having a voice, wanting to speak out, so we wanted that to come in big because we wanted the experience to be immersive and we didn't want it to be quiet, we

> wanted it to be a big experience, and one we settled on it everything became varieties [of BME] such as Big Mad Chat.

This is just one example of loosely distributed networks and conversations that co-exist alongside more formalised bodies such as the World Network of Users and Survivors in Psychiatry (2015) which was established in 1991 and which aims to protect and develop the rights and self-determination of people labelled as 'mentally ill'.

Whilst these more formal bodies are beginning to use social networking sites, my research is particularly concerned with public conversations about mental health which are taking place online by ordinary people rather than those which are mediated by institutions. I contend that it is in these conversations, self-mediated by ordinary people both accessing and providing mental health services, that institutional norms and behaviours are being disrupted. For example, the #BigMadChat is borne out of people who are part of an institution but who wish to engender conversations which are not boundaried or constrained by that setting. The temporal and spatial affordances of social networking sites enable people to engage in that conversation around a shared interest in public dialogue which I argue would be less likely to occur within an institutional context.

The current mental health movement across the world is characterised by a range of activities that are often unconnected and with a tendency towards de-centralised leadership. Leaders tend to be 'people who are most visible' at that particular time and emerge from 'action and inspiration' rather than from form or rank (Morrison, 2005, p.132). This dominant style reflects characteristics of social networking – influence based on persuasive dialogue rather than positional power. Debates about who should

occupy and engage in those spaces remain contested and problematic – who can legitimately disrupt and does their position matter? This is a theme that arises again and again in my interviews and which is explored further in this chapter.

In *On our Own: Patient-Controlled Alternatives to the Mental Health system*, Chamberlain (1978) argues that mental health services should be led and controlled by people experiencing mental health difficulties. She is a proponent of *talking back* as exemplified in her thesis (Chamberlain & Schene, 1997, p.44) on empowerment in which she argues that the ability to resist a patient narrative is essential to recovery. In her working definition of empowerment, she cites a range of necessary conditions which include: 'Learning to redefine who we are (speaking in our own voice)'. This tension between professional and patient voices - who gets to speak and be heard - remains a contemporary site of tension in the *madosphere*. The voices of professionals and institutions in those spaces are not universally welcomed by people with lived experience of mental distress, as exemplified by an interviewee who said: 'To have them actively participate - in whatever way that looks like - I think would divide the community into who's an expert and who's not. I think it would result in taking away from the voices of those who need to be heard the most - people with lived experience. This standpoint is most closely aligned to that of a survivor discourse in which professionals are welcome in so far as they listen to people with lived experience. Rather than a cohesive space, the *madosphere* is continually emergent, continually in tension and continually negotiating many competing discourses about meanings of mental health and mental distress.

I am curious about the extent to which disrupted identities and boundaries in the *madosphere* impact on relationships and interactions between people accessing and

providing mental health services in the formality of the clinic. I am struck by Goffman's (1961, p.104) analysis of the role of ceremony within institutions where formalised and segregated patient/practitioner boundaries may become temporarily disrupted in the context of specific rituals such as the Christmas party. Within these contexts separate identities are temporarily suspended and camaraderie ensues. The same could be said of the smoking shelter in the modern psychiatric unit – a space where patient and practitioner may temporarily exchange those identities for a common bond of smoker; back on the ward the formal boundaries are reinstated. To what extent does the *madosphere* create its own ceremony – a space where established roles of patient and practitioner are temporarily suspended only then to be re-established? Or does *disruption* in the madosphere blend into the day to day practices and conversations within the clinic?

3.0 *Talking With* my Peers – Consciousness Raising and Shared Identity

Talking with affords people whose voices have been subjugated, access to knowledge and information that is not mediated by professionals. It also offers a realisation of shared experiences. Social networking sites enable *talking with* to take place in the public sphere and in view of professionals and the institution. Morrison's (2005, p.60) words about consciousness raising in the liberation movement have direct resonance with the affordances of social networking sites today:

> Private problems are reinterpreted into public issues and participants gather strength to talk back to the power of psychiatry and the mental health system which has silenced them and controlled access to information in the past.

Goffman's (1961, p.47) ethnography of an asylum delineates a system of social control whereby every aspect of *inmates'* existence is regulated, judged and autonomous action compromised:

> Institutions disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world - that he is a person with 'adult' self-determination, autonomy, and freedom of action.

He sets out an institutional context whereby *talking with* is constrained within narrowly defined social boundaries which reinforce respective social roles and *talking back* is heavily sanctioned. The institution demands, through complex processes and practices, a 'mortification' of the self which means one's will and self-determination is broken.

In contrast, Tanya reflects on the significance of connectedness and commonality of experience in a guest post she wrote for my blog. She describes how she works with guest bloggers who contribute to her website and her emerging sense of being part of what she describes as a 'tribe':

> I would work with the guest blogger to support them through the process, and in turn, I would be honoured by having the opportunity to read their story first. I could always relate to at least one experience in their story and this made me feel less alone in my struggle. One day I realized I had found my tribe in my guest bloggers, subscribers and commenters; people who were actually like me. This was way better than group therapy.

A delineation of the *madosphere* as better than therapy is salient to a common experience articulated by interviewees of the therapeutic benefits of blogging. *Talking with* each other is characterised by identification of shared experiences and the practice of mutual support. Tanya provides a powerful example in which she describes how she had come to understand an unusual experience associated with her diagnosis through connecting with others online:

> What I was truly looking for were others like me to say 'hey, I've had similar experiences.' Having trauma with all these weird somatic symptoms didn't seem to be that common and I wanted to find someone who was like me.

A consistent theme in my interviews is that of positive, but also sometimes problematic, peer to peer identity and support. There is a growing body of evidence that peer support plays an important role in mental health recovery (Repper & Carter, 2011) although the focus is predominantly on face-to-face rather than online interactions. The *madosphere* is a space where people with lived experience are able to converse with each other, without the facilitation or sanction of professionals. It is a subtle and incremental disruption – many small voices chipping away at the edifices of power through conversations which bypass the authority of the professional. The intermediary role of professionals is redundant in the *madosphere*. This is a subtle disruption of many small parts but one which creates an alternative space for people accessing mental health services to convene.

The positive impact of connecting with others who have had similar experiences is a powerful theme throughout my interviews. Trudy remembers her first experience of joining an online self-help forum: 'before that I had never connected with others who

had experienced stuff I had. It was difficult but amazing too.' Flora shares a similar point of view: 'I think people are just trying to find a way to deal with something we all struggle to understand, and maybe in the process reach out to and/or connect with people in a similar situation'. The *madosphere* affords a space for ongoing dialogue and shared collaborative construction of mental health generated through conversation which has a sense of possibility and opportunity:

> The latest cool thing that social media help create was striking up a connection with someone I really wanted to meet. I was on Facebook and a friend shared this amazing Tedx Youth talk by a 19 year old kid who experiences depression. He articulated so eloquently many of the things I feel about mental health and stigma and how our pain and suffering in mental ill-health is pertinent to everyone because at the end of the day we're all human beings. After watching the video, I thought "wow, I would so love to meet him." It took me about 30 minutes to remember I have a platform ... that enables people with mental ill-health experience to share their story and I thought "why don't I ask him to guest on [name of blog]?!?" One tweet later and he agreed. Now I am working on interviewing him and I have the opportunity to get to know him just a bit better. And who knows what will come from that. You just never know.

I am curious about what might be the particular qualities of online social interactions that differentiate it from those that take place in person. Much of the literature suggests that the Internet is a preferred option for people seeking out information about stigmatised health conditions because of the anonymity it affords (Kummervold et al, 2012). Is this the same for social networking? My interviews suggest that this is the case for some. Trudy illuminates what she sees as a particular quality of online

interactions for overcoming shame and self-stigma closely aligned to that of peer support: ‘I was ashamed ... didn’t tell many people. I am now very very open, but I think joining the *madosphere* helped that a lot.’ Tanya similarly refers to both the breadth and ease of connections afforded by online social networking:

> I would not have the opportunity to connect with so many people if it weren't for social media. People I can call upon to learn from and for support. It has also been very helpful to be able to form these connections during a time where I wouldn't have be able to do so in person.

Eva describes how social networking sites enabled her to bypass the constraints of her isolation as a teenager and find other people like her:

> I didn’t know what was going on at all, no education at school, no talk about it at home, so it was just me, and so the way I explain it is that I turned to that thing that was right at my fingertips that had helped me with other things, and I thought well maybe this could help with what’s going on in my head, so I went online and I started having conversations and joining groups around mental health … and I actually discovered I wasn’t the only person from my school, that there was a girl in the year below me who was struggling with self-harm and eating disorders as well, and the first person I ever met offline was a person in my school, and that friendship, it was a destructive friendship in some ways, but in other ways it is probably the best friendship I’ve ever had, because I wasn’t alone suddenly.

As alluded to in Eva's account, relationships can be complex and problematic, rivalries and falling out are a constant risk to the equilibrium of the *madosphere*. As one interview described this hidden aspect of the madosphere that is not immediately apparent on the surface:

> [name of individual] is literally idolised by many ... how can they not see what she is like?

Another interviewee described a relationship breakdown between themselves and another person which would not be apparent on the surface:

> I don't know if you know that I don't talk to [name of individual] anymore, that's a sad one, when [they] got dis-regulated[2], [they] just ended up having a go at me and I just say no, not anymore, and we've kept it quiet.

In contrast, Bill believes that the threats of negative interactions on social media platforms are less severe than those which occur offline and the ability to disengage online means the implications of disagreements are less impactful:

> You get hurt briefly, then you block them, get rid of them, engage with them no more, that's the end of it, and that's the beauty of online, the investment in it is very short in somebody that you talk to for an hour, a minute a second.

[2] A 'disregulated' response refers to an emotional response that is poorly modulated and does not fall within the conventional range of emotional response to a given situation.

Despite the tensions and relationship difficulties experienced by some, my interviewees living with mental health difficulties consistently articulated the significance and compelling effects of peer support online. The *madosphere* is a space and set of practices that overcome the constraints of geography and are imbued with possibility for connecting with others and finding shared meaning in experiences. The ability to *talk with* peers is a subtle disruption of the institution in so far as it dispenses with the mediated knowledge by professionals and affords agency and self-determination unconstrained by the walls of the institution.

4.0 *Talking Back* to Authority - #DearMentalHealthProfessional

According to Morrison (2005, p.22) a mental health patient is positioned as an object of psychiatry, their words relevant in so far as they expose signs and symptoms of pathology, filtered through the lens of biomedical training and for the purposes of diagnosis. They are written about in textbooks and in the medical literature as subjects to be studied. In Speed's (2006) typology of mental health discourse, the individual who constructs their experience as a *patient* is only enabled to *talk with* the professional through the lens of clinical discourse. In this instance, to *talk with* the mental health professional requires an assimilation and acceptance of a biomedical paradigm, is based on an unequal relationship, and a subjugation of the self apart from in the terms defined by the profession:

> To be heard by psychiatry one must speak in the language of psychiatrists, reflecting their forms of thought, beliefs and values. This is a skill (a sort of dissimulation) learned by people labelled mentally ill, a language they learn to speak in order to gain their freedom (Morrison, 2005, p.22).

Talking with a mental health practitioner in a one-to-one clinical setting is boundaried and constrained by established power relations and a clinical frame of reference. Chamberlain (1988, p.130) suggests that arguing against the system is commonly perceived a sign of illness and that patients quickly learn to suppress the truth of their internal worlds to subscribe to accepted social norms. She also argues (p.204) that hierarchies in psychiatric institutions can be 'alienating and dehumanising' which detract from agency and self-mediation that challenges the norms of the institution. In Goffman's (1959, p.165) delineation of social interaction through a dramaturgical metaphor, a professional performance of clinical expertise requires a symbiotic performance of receptive patient. This *frontstage* performance requires participation by both parties to be successful and is bolstered by the props of dress and surroundings in a clinical context. The professional is accorded power through their access to the shameful back-region of the patient's difficulties that cement the lack of equity in their exchanges.

A prominent protester In the mid nineteenth century, was John Perceval - an ex asylum inmate who authored *A Narrative of the Treatment Received by a Gentleman, During a State of Mental Derangement* in 1838 in which he challenges the treatment he experienced during his incarceration (Harrison & Davies, 2009). With strong echoes of contemporary complaints, he describes how he was not listened to by medical staff and 'barely addressed as a human being' in ways which he argued were therapeutically counterproductive (Porter, 2002, p.160):

> Men acted as though my body, soul and spirit were fairly given up to their control, to work their mischief and folly upon. My silence, I suppose, gave

> consent. I mean, that I was never told, such and such things we are going to do; we think it is advisable to administer such and such as medicine, in this or that manner; I was never asked, Do you want anything? Do you wish for, prefer anything, and have you any objection to that?

Perceval's narrative contains a series of self-advocacy themes which continue to be deliberated upon today - namely that of patients helping themselves; patients knowing most about their mental health; patients views taken into account; and patient behaviour managed without physical restraint (Gaunt, 2008, p.462). This is a disruption of the gentlemanly persuasion, an educated affluent man in a position to challenge the system using its own tools of communication and organisation. He was *talking back* to the authorities on terms that they would understand. This was not a form of talking back afforded to the majority; rather it was a disruption of the exceptional and only perhaps available to the most articulate and educated.

Perceval exemplifies how a lack of agency experienced in the context of the clinic may be resisted in other practices outside of its perimeter. The same person who engages in a *patient* dialogue in one context may critique or resist the same narrative in other aspects of their lives. Whilst *talking with* in a clinical setting is framed by professional authority and power, *talking with* in the context of public spaces may have different qualities. My research suggests that the *madosphere* affords a more fluid space for dialogue and exchange to take place that resists institutional norms and allows access to the back-region as well as the front stage performance of professionals and people accessing services. Rather than being the preserve of those with the background and social standing as in Perceval's time, this is an emergent and networked dialogue in the public domain.

The Twitter #DearMentalHealthProfessional hashtag is a striking illustration of people with lived experience of services convening on Twitter to *talk back* to professionals outside the parameters of an institutional frame. In contrast to a formal complaint or letter to a newspaper, the hashtag engendered a spontaneous naturally occurring conversation between people about their positive and negative experience of accessing services. The hashtag disrupted the front stage performance of the professional by critiquing it to peers and it also relied on participants giving access to the back-region of their own social performance by making their experience of accessing services public. It was generative and emergent in nature and with features of both peer support and protest towards professionals. The hashtag emerged spontaneously one summer day in 2013. It was initiated by a single person irritated by their care and appeared to quickly capture the collective imagination of people who wanted to give feedback to mental health professionals. Alana had received a letter from her mental health team which had frustrated her and she took to Twitter to share her thoughts and asked others to do the same using the hashtag. On her blog Alana writes:

> The hashtag took off in a way that I never expected. Thousands of tweets were tweeted under it. People tweeted from around the world under the hashtag. People wrote blog posts about the hashtag. I never expected any of this. It was amazing ... It has been over six weeks and people are still using the hashtag.

A review on the analytics engine Topsy shows that the hashtag peaked on Twitter with 2,890 tweets in one day and a small but steady flow of tweets that have continued up until the time of writing. The conversation on Twitter afforded the opportunity for participants to take productive risks by sharing experiences and concerns without the

potential for retribution or consequences to their clinical care. Indirect feedback to professionals through the medium of a social network, and with a community of others with shared experiences, created a conversation in the public sphere and removed from the direct confines of the clinic and with safe distance from the institution. It allowed public access to the back-region of the institution where presentation could not be controlled or contained by professionals. It created a narrative in tension with carefully formulated self-presentation commonly manufactured by institutions and validity through the reinforcement of collective experience. Qualitative content analysis of 515 #DearMentalHealthProfessionals tweets over a two day period undertaken by Shepherd et al (2015) led the researchers to conclude that whilst the content of the discussion lacked novelty:

> The spontaneous nature of the discussion is perhaps remarkable - this conversation represented a previously unadvertised event emerging solely through user participation, its themes are representative of a wider discourse and serve to demonstrate the salience of such discussion within modern society and the role of social media in supporting and empowering mental health service users …. Online social media could therefore provide a resource through which barriers to feedback, traditionally encountered by mental health services, can be overcome.

Alana wrote her own blog post in which she categorised and summarised the main themes explored with the hashtag. They ranged from ‘tweets of gratitude’ such as: ‘Thank you for persisting when all I wanted to do was die. I’m glad I’m alive’ through to themes relating to communication, diagnosis labelling, treatment, medication and inpatient wards. They comprise frank views expressed in a direct style, for example:

‘Kindly take the term ‘just attention seeking’ out of your vocabulary’ and: ‘I am NOT incompetent because I have mental health issues. Please listen to me.’ I am immediately struck by the echoes of the pleas made by disrupters of past times - from Perceval through to Chamberlain – a commonality of position, a replay of common themes, a re-articulation of challenges to the system but this time shared by many and visible to all who care to look.

In her blog post, Alana reflects on the mix of opinions and range of views expressed by people with lived experience: ‘A real mixed bag of options – showing just how individual we each are in our experiences’ and it is clear that they range from a dominant ‘patient’ paradigm: ‘You saved my life, I am so grateful’ through to a ‘consumer’ narrative: ‘listen with your ears and your heart, not a pen and paper’; through to a ‘survivor’ narrative illustrated by tweets such as: ‘You have ruined every part of my life with the labels you’ve given me. How do you think that’s been helpful?’ I was struck by the sense of empowerment and agency expressed by Alana in our interview:

> I think #DearMentalHealthProfessionals started as something similar, me just rambling on and putting it under a hashtag, and asking some followers what they would say. Suddenly my phone was hopping with dozens of RTs, replies, and the hashtag really took off. I did not expect that at all. It really shows the power of social media!

#DearMentalHealthProfessionals is a microcosm of a loosely knit movement of disruption each expressed and captured in 140 characters; it is the sum of micro-commentary by separate individuals on their computers, tablets and smartphones; it is people talking with each other as peers and *talking back* to professionals and

institutions. It also has an interplay between the online and offline as characterised by Alana: ‘one thing I think is wonderful is when online mental health stuff has an impact offline ... when one mental health worker said she was bringing it [#DearMentalHealthProfessional] to her team meeting, and one person just tweeted me there now to say ‘suggested dearprofessionals tag be turn into a pin board project in our social room’. There have been a range of responses from mental health practitioners to the hasthag from the supportive and encouraging: ‘I recommend checking out the #dearmentalhealthprofessionals’ hashtag. A great example of best of Twitter to learn from experts as a mental health professional’ through to concern and defensiveness: ‘The #dearmentalhealthprofessionals hashtag is very disheartening. Much criticism. No one happy with much we try to do’. Despite the range of views, it is significant to see professionals engaging with this form of indirect feedback and enabling it to subtly reach back into and inform the institution.

The use of humour and satire to *talk back* is a striking aspect of today’s *madosphere*, whose expression can be traced back to a tradition of dissent typified by publications such as those created by MNN. Morrison describes how ‘resistant identities’ were expressed indirectly through alternative means such as music, art, cartoons and poetry. Reclaiming of subjugating language was a strong theme within publications, employing descriptions such as ‘crazies, post-crazies and pre-crazies from Madness Network News’. Use of humour to challenge the power of those who have the power to define others has echoes of the dissenting MMN in my field of study where protagonists are coined *mentalists* and the discourse is articulated as the *madosphere*. These contemporary terms draw not only on radical traditions of the past, but also on diverse contemporary cultural references. For example, the term *mentalists* within the *madosphere,* derives from both its use by fictional comedic TV presenter Alan Partridge

and also from the rock band Manic Street Preachers who described their fans thus: ‘the devotion of the Manic Mentalist is unparalleled’ (Price, S. 1999, p.58). Ironically, the term *mentalist* was previously used by activist Judi Chamberlain in a similar way to the word ‘racist’ to refer to those individuals and institutions that in her view perpetuate mental health stigma and discrimination. An indication perhaps of the loose knit activist mental health movement – diverse and often not closely connected, drawing on varied cultural reference points to build a shared identity and *talk back* to the institution.

5.0 *Talking Back* to Authority – a Reclamation of Power

In her preface to the UK edition of her book *On our Own*, Chamberlain (1977) bemoans the limited contact between activists in different countries and limited opportunities for exchange of ideas and collaboration – communication channels limited and fractured by the available technologies of the age. Chamberlain not only critiques the mental health system, but also the anti-psychiatry movement as exemplified by RD Laing, for talking about and on behalf of patients. Her thesis is that ‘mental patients’ must speak up for themselves and set up their own alternatives that they control, without the underlying threat of coercion and incarceration underpinning mainstream services. She argues for patients’ voices to be at the centre. She is a proponent of *talking back* to authority.

Chamberlain’s (1988, p.72) rallying cry is one of challenge to the power of professionals to define and label distress. She gives a vivid account of her personal experience of mental health services and the empowerment of sharing experiences with others on joining the Mental Patients’ Liberation Project in New York: ‘as we have told our stories to one another, it has been truly amazing how the same themes, often

the same words, occur again and again.' Chamberlain's (1988, p.159) vision and expectation in the late eighties was for a growth in a patient led liberation movement which would develop alternatives to the dominant mental health system.

Whilst Chamberlain successfully exploited the more formal channels available to her in the 1980s to talk back to authority, there are more everyday disruptions occurring in the *madosphere*. Bella, a mental health nurse, decided to live tweet her experience when she was admitted to a mental health inpatient unit as a patient. I followed her tweets during her stay in hospital and interacted with her on a number of occasions during that time. Whilst live tweeting such experiences appears more commonplace now, at the time it was both novel and seemed highly disruptive.

Sometime after her discharge, I direct messaged Bella on Twitter and asked if I could interview her; I was struck by the fact her experience illuminates the key themes of this chapter – in particular *talking back* to authority, using humour to subvert authority, accessing peer support over clinical support, and in particular the disruptive quality of sharing highly personal experiences in the online public sphere. I was curious about Bella's self-mediated experience of poor care in so far as it appeared to align with empirical research indicating that health professional attitudes remain resistant to positive change (Henderson & Thornicroft, 2013). I wondered if the characterisation of the asylum as delineated by Goffman in 1961 might still have some resonance today.

I initially asked Bella if she would like to write her own post for my blog so that she could articulate her experiences in her own words. However, her preference was for an interview and I therefore attempted to capture the salient points from our conversation as my primary intention was to give a lasting record of her experience. I wanted the

balance of power to be hers in this collaboration, with my intervention offering access to a new audience beyond that which she had already reached through her tweets. In the event, our collaborative post is the most popular on my blog at the time of writing, with just under six hundred unique visitors in the first evening I posted it, plus inclusion on the Society Guardian website.

Bella's experience is one of two competing and contemporaneous discourses - that of the *institution* and that of the *madosphere*. The clinical discourse takes place within the context of the ward and is re-mediated by Bella on Twitter. Her description of interactions within a clinical paradigm are associated with being *talked about* rather than *talked with*:

> They asked me if I wanted anything to go on their pre-ward round planning sheet and I said 'well let me look at it and I'll add anything', and they said 'no you can't read it, it's about you', I said 'what do you mean? I'd like to contribute to it and perhaps maybe do it together', 'well that's not how we work' … I didn't have it in me in at that time to get into an argument about it.

At the same time that Bella was struggling with what she perceived to be an out-moded paternalistic clinical discourse on the ward which she reluctantly complied with, she was simultaneously engaging in a contrasting discourse on Twitter. In this space she was re-articulating and critiquing her experiences, seeking validation from others, and engaging in conversations with a wide range of people as events unfolded. It is apposite to note that whilst she was acting the required role of patient on the ward, she was simultaneously playing the role of activist on Twitter; complying with nursing demands in a hospital context, whilst conversing with the editor of the Lancet and chief

executives of major charities and NHS Trusts about her experiences in another; conversing with her fellow inpatients for support whilst also conversing with her peers online. When I asked her what the experience had meant to her, she described the kindness and validation she had experienced online:

> I think the level of kindness and support people showed me was amazing, and also really validating, when I wasn't in a particularly good place, I kind of was [getting my therapy on Twitter rather than on the unit] which is pretty tragic when you think it costs around £400 a day to be on an inpatient unit ... I've learnt that social media can have such a positive impact on people's lives, absolutely, and what it did, for me it helped me feel connected, it *really* helped me feel connected, I will carry that with me.

Bella's experience exemplifies similar themes to that of Alana - both had negative experiences within the institution which had disempowering effects and moulded them in to the role of patient.

Whilst they were unable to resist the patient role in their contact with clinical services, their self-mediation of that experience in the *madosphere* enabled them to engage in a competing discourse of that of *consumer* or *survivor* where they were able to resist the authority of the institution indirectly. Their individual experience was bolstered by validation from a community of people online who were able to echo or confirm that experience through sharing their own.

In the face of a powerful institution whereby Bella felt she lacked both agency and influence, re-mediating her experience on Twitter was an act of subversion that enabled

her to retain a sense of self. Surreptitious acts of rebellion were both enacted and shared in the *madosphere*:

> Did you see the tweet of the jigsaw puzzle? I ventured in to the OT [occupational therapy] room as I thought I need to do something, I'm so bored. And I never have done jigsaw puzzles because I think they're a waste of time; I found one and it was the engagement photograph of Charles and Diana - that's how old it was - and do you know what I did? and this is really bad, I stole it cos it cracked me up so much; and one of my colleagues - it tickled him, he thought it was hilarious, so he's getting it as a secret Santa - they're not going to miss it. [Stealing] comes from being a kind of activist who's never had a budget but always wanted to do projects. I've always begged borrowed and stole stuff to get things done, so I'm basically a thief (laughs), I don't think anyone's going to miss it.

Bella seized opportunities to perform surreptitious acts of rebellion against a clinical context in which she had very little autonomy and one that had the shadow of deprivation of liberty hanging over her: 'I was persuaded to stay because they'd perhaps think about looking at a mental health act assessment, so I kind of felt things were very much out of my control'. Her use of Twitter enabled her to both share and satirise her experiences and to put some distance between herself and what was happening to her, to source other perspectives and to create a sense of agency and purpose:

> With Twitter I've found so many allies, who have given me hope when I feel there isn't any, finding allies wherever you can, that makes you feel you're never

> alone, and you're all fighting the fight to make things happen and to shift things, and yeah, and those allies that I have and are continuing to grow are amazing so it keeps you positive.

Bella's story illuminates all aspects of the communication lens whereby she was *talked about*, she *talked with* and she *talked back* to the profession. Twitter provided a public arena for her to articulate her inner thoughts when there was not a legitimate space to do it in person. She subverted power and reclaimed a sense of agency, she was both patient and professional, she was powerless and powerful. Her experience was shared with many and remains in the public domain for anyone to see. She chose to keep the name of the NHS Trust a secret and has subsequently given them feedback about what happened to her. Bella effectually exploited Twitter as a tool of disruption to *talk back* to authority and to reclaim a sense of empowerment.

6.0 *Talking with* Each Other – People with Lived Experience and Professionals in One Space

To what extent does the *madosphere* afford a space and set of practices whereby people accessing services and professionals can converse without the constraints and shackles of the institution? Does the *madosphere* have different qualities which enable more equitable dialogue to occur? Can any space be free of the shadow of the institution? These are questions which I have been curious to understand throughout my research.

With the origins of the mental health profession lying firmly within an institutional frame, tensions relating to power, authority and control continue to be contested, and the notion of *institution* and institutional practices remains salient today. Nolan (1993, p.16) asserts that what appears to be a modern notion of the peer support approach, in fact has a much deeper tradition of professional and specialist helpers. It could be argued that notions of peer support and self-management are conveniently appropriated by politicians to legitimise reductions in public spending on health and social care, as is currently the case in the early 21st Century. It is also worthy of note that rather than hospital being the first port of call as in the 19th Century, it is now routinely the last point of call in the 21st Century with services orientated towards keeping people out of a hospital environment wherever possible. Nolan (1993, p.157) points to the essential tension within the mental health profession which is at the core of the schism between patient and doctor and which continues to be a source of friction today:

> The major contradiction within psychiatry is that it is simultaneously part of the regulatory superstructure of our society and a system of care which aims to alleviate personal distress, some of which is iatrogenic. To provide therapy for troubled individuals whilst at the same time controlling them for society's good is a conflict that most nurses have difficulty in resolving.

This discord has been captured in the most recent Time to Change campaign evaluation, where empirical research into self-reported experiences of mental health discrimination by people accessing services, indicates that health professional attitudes continue to be more resistant to positive change than that of the general public (Corker et al, 2013, p.61). The 2008 Stigma Shout Out survey of almost 4000 people using mental health services and carers found that health professionals' attitudes are

commonly experienced as discriminatory (Corry, 2008). Such results are suggestive of the intransigence of institutional paradigms which maintain a grasp in attitudes and beliefs despite the disestablishment of the bricks and mortar that once gave them shape and form. This context suggests the possibilities for reciprocal dialogue, to *talk with*, are compromised. The power imbalance between user and practitioner diminishes the possibility for exchange on equal terms and indicates either a passive position, to be *talked about* or a confrontational position *talking back*. The institution itself provides a context in which *talking with* is resisted and rejected. There is a sense of a longing amongst professionals and users who reject the status quo to have different sorts of conversations. But outside of the formal contexts and published pieces, where can a space be found? New forms are required to enable this dialogue to emerge; spaces outwith the edifices of the institution, and a set of mediating practices which enable exchange on different terms and with different expectations.

A repeated theme arising in my interviews is an intention to engage with the *madosphere* in order to both educate and to learn. This is expressed both by people contributing to the *madosphere* in personal and professional capacities, and often both. The benefits of participating in the *madosphere* as expressed by Mia, a ward-based nurse, are typical:

> I get a lot of information very quickly, I've built some, it's been a confidence building exercise for me, it's helped me connect with people who I simply would not … so I've met nurses and done things that I simply would not have had the chance to do, it's helped me get ahead, get ahead is not quite the right word, but I'm very, I feel much more informed than I was previously and I would not

> have come across um, I wouldn't have come across all the things that I'm looking at now … particularly as I'm ward based.

This desire to share learning is underpinned by a wish to be understood, to articulate one's position and to be heard. This longing to bear witness and to tell one's story has the longest of traditions in the mental health movement, as far back as Perceval's narrative in the 19th Century and perhaps even before. I have been struck that this was a desire expressed equally forcefully by the psychiatrist as by the patient. Both appear to be driven by a desire to show their humanity, to be validated as more than their label, and to make their mark. 'As much as I didn't want people to read [my blog] I really did want people to read it. I wanted to make an impact I suppose' says Tanya. It is also a desire to turn painful experiences into positive ones: 'A motivation for me in getting well was to make something good come out of my experiences, and that's why I started [blog name]' says Alana. The *madosphere* is a space and set of practices that engages with but also resists the institution and refuses to be constrained by it.

People blogging from a lived experience perspective shared with me their satisfaction in being able to influence professionals. As Alana told me: 'I do have the odd practitioner come to [name of blog] and tell me they feel better informed after reading some of the stories.' This is a subtle repositioning from the patient role to that of teacher; from a recipient of expertise to a provider of knowledge and with it associated personal, if not positional, power. Mel consciously places herself in the role of expert by proudly stating that she has more knowledge about her diagnosis than most professionals: 'the amount of professionals who follow me is quite unbelievable ... I'm coming up with solutions.' This is a subtle disruption of roles and expectations, an indirect shift from recipient to expert, a reclaiming of power and a reframing of identity;

talking with on more equal terms than may be possible in the clinic. The *madosphere* appears to afford the opportunity for received roles to be disrupted and for the patient to subvert received performance, and assume the mantle of professional expertise and knowledge.

Tanya actively wants professionals to be positioned passively in this space: 'I think the best role for them is as observers – to use the *madosphere* as a place to actively 'learn and to develop their compassion'. Sandra gently mocks professionals who get involved in her weekly Twitter chats: 'the [name of professional] joined recently and talked about clustering, and we were like 'what's he doing here?!' Tanya, Mel and others create their space in the *madosphere*, on their terms. Bill is similarly unconvinced about the role of mental health institutions in the *madosphere*: 'there's so much reactionary stuff going on that I don't think they [NHS Trusts] can relax down ... and communicate with the outside world – listen we are humans behind the name of the Trust, this is what we do and how we do it.' There is an underlying distrust of professionals and institutions and a subtle scepticism about their ability to engage in these spaces.

Brian, a psychiatrist, both wants to listen and learn but also to state his own position and to be recognised. His intention is to disrupt the stigma and stereotypes he believes are associated with his own profession:

> I got into using it [Twitter and blogging] as a platform, in part because some people have had bad experiences with psychiatrists and mental health, and with the system, the way we've built the system, and then I was able to stand up and say hopefully we're not all that bad, some of us are quite nice, some of us don't think in that whole biomedical way, um some of us do listen.

Brian articulates a desire for a shared humanity, an appreciation of the history of his profession and a desire for restoration, for a different point of view to be articulated on behalf of his profession - to be a person as well as a professional. He is perhaps making his own personal attempts to show an alternative face to a medical profession which has been shown to persist in entrenched discriminatory attitudes to people with mental health problems (Corry, 2008). This sense of humanity, of being a person as well as a professional, is appreciated by Mel when she says:

> It has, it made me think, I could see compassion from people which I hadn't always felt to start with in my Trust, because all I ever saw was my care coordinator and a psychiatrist. On Twitter I saw people who started talking to me, you know, a lot of social workers actually, like chatting, and suddenly saw this human after all, and that was an interesting thing, so you'd sit and talk about what they were doing actually, I'd sit and talk about music, or to [name of professional] about animals and chickens, so you know you have human conversations and human connections I think.

When people tweet about the mundane aspects of their lives they could be perceived as whimsical but I believe something more profound is happening beneath the surface. As Mel suggests, they are sharing a common humanity, building relationships, saying: 'look I'm just like you', and sharing their beliefs and values. They are sharing more than is permissible in the front stage performance of their professional or patient roles, to use Goffman's (1959) dramaturgical metaphor, and allowing each other glimpses of the back region. This is a disruption that brings connection and generates empathy between providers and receivers of care.

7.0 *Talking back* to Society – Re-Mediating Identity and Challenging Stigma

The theme of stigma is a continuous one throughout my research and one that is consistently articulated within interviews. The *madosphere* is a terrain where people are continually navigating identities connected to mental distress with a common purpose of finding meaning and interrupting stereotypes. This is disruption of a different quality – challenging the audience to see beyond the label and see the person.

It is not just people with lived experience who desire to interrupt received truths about mental health - the professionals do too. As Brian explained: 'that is one of the main points of [my] blog I think, to help people change their misconceptions about psychiatry.' His use of the word 'misconceptions' is a significant one, suggesting a defensive position based on a belief that psychiatry is misunderstood and a suggestion that it is maligned. Andrew describes how he struggles to avoid internalising this stigma: 'I've had trouble trying to break that off from hating me, sometimes it takes a while to say 'hang on I'm not like people you've met before.' Brian's plea is for his profession to be understood; for him the mental health blogosphere and Twitter are spaces to play an active part in disrupting them.

Mel vigorously articulates the same agenda, but this time from a different standpoint; that of a person with a little understood and highly stigmatised mental health diagnosis. She draws attention to a hierarchy of diagnostic labels – those which she believes are

commonly discussed and high in the public awareness and those which remain obscure:

> I am so motivated to stand up for people with [diagnosis], because we're so stigmatised, I think we're stigmatised by other people with other mental health issues as well, under represented by MIND and Rethink, you know Rethink hardly talk about us and I do tweet that at them occasionally, going 'you know where's your campaign for us?' there never is one, nothing, and I know they do have people but they don't talk about us, but we're the second poor cousin, um, so my mission is just to help people with [diagnosis] and to raise awareness.

Both Brian and Mel are engaging with social media to fight a cause, to shift attitudes and to disrupt received identities from different ends of the spectrum – both patient and professional.

Others take a different standpoint and emphasise the connectivity rather than the separateness of identities. Trudy articulates a desire for the bonds between people to be recognised: 'We need a sense of 'no them and us', mental health professionals, lived experience peeps, people to which neither applies, all in it together ... after all, professionals can have lived experience too, and often do, and most people who don't have a mental illness struggle mentally sometimes too.' This is a different response to what I believe is a similar question, that is, how can we generate understanding and disrupt stigma? Edward continues this theme by suggesting that the *madosphere* is a space where patient and professional roles can be put aside: 'I guess possibly people in real life people might be more aware of their roles, which on TWOM and TWIM you can let go of those roles, use that as a ... you are able to step away from them.' He

goes on to say about his blog: ‘ [it is] a place where it shouldn’t really matter what perspective you are coming from, we’re all just people having a conversation, we’re not in the role of I’m a professional, I’m a patient, I’m an academic, whatever, it’s just us, we’re having a chat.’

8.0 Is the *Madosphere* a Disruptive Space and Set of Practices?

In conclusion I reflect on the extent to which the *madosphere* is a disruptive space and set of practices. When I first happened upon TWOM I instinctively regarded it is as subversive and was thrilled by its challenge to the discourse of the institution. First and foremost it was edited by someone with lived experience and someone with a professional role – an underpinning disruption of identities – the patient and professional collaborating on equal terms. Its culture of weekly guest editors again smacked of disruption – people from multiple perspectives sharing their accounts of the *madosphere*. Its use of satire and humour I regarded as disruptive challenge to the establishment. I was therefore surprised when it became apparent that most in the *madosphere* did not regard it as a subversive space. When I asked that question in my interviews it did not tend to resonate with others.

It was only Brian for whom the notion of subversion resonated as he regarded himself as subversive in the context of his profession: ‘yeah I think it is subversive, but I’d quite like to be subversive with them, because I agree with a lot of the stuff they say.’ Mel concedes that TWOM could be seen as a subversive space by others:

> Probably mainstream would see it like, that but I wouldn’t, Twitter’s like that anyway, a load of people coming together with loads of different ideas, and you

> can take them or leave them, so I don't see it as subversive, but then I see myself as a subversive person probably! But it probably is [subversive] to mainstream, you wouldn't put what they write in your NHS magazine would you? So it is subversive because it's not mainstream.

Bill points out that the notion of subversion is a relative one: 'how subversive you find the space will depend on how subversive you regard yourself ... and you've got to ask yourself why are you feeling that [subversive] are you doing something wrong, I suppose or if there is any truth to it. The analogy I use is, if someone calls you a dog; check have you got a tail?'

Flora refers to the power of humour as a tool to reclaim agency: 'I think we have to make light of it sometimes in order to take back some control'. She goes on to describe her own use of humour:

> I've posted quite a few images that some people may find offensive, but really, I. But, as I said, context is everything. Within the confines of TWOM, it's completely acceptable. It's like minded people, with something very powerful in common, coping with that very powerful something in whatever way possible. The *madosphere*. But I can see equally how it could cause offence. You mentioned on the page that it could be a generational thing, and I think you're right. I also believe that acceptance of a condition is part of it. Someone who is very reluctant to share or even acknowledge that they have a mental health problem may find it cuts too close to the bone. Likewise, I think in conversation there would have to be familiarity. The blogosphere is safe. It's relatively anonymous, and there is safety in that. If I read something I disagree with, it

> might make me angry, but I don't take it personally. If someone I didn't know well were to call me a mentalist to my face, I think then it would take on very different meaning'.

Others conceptualise it more as a community of interest. The co-editor of TWOM shared his thoughts about disruption on the blog: 'I like the fact that it provides a safe space where certain boundaries can come down, there are places where certain boundaries can come down ... and yes it enables people from different perspectives to share a common humanity.' This coming together on equal terms I would argue is a disruption, a different quality of interaction than might be found in the context of the consulting room or the 'user involvement' meeting. The way the *madosphere* is self-organised encourages people to interact on different terms than they might in other contexts. Whilst the content might not be always subversive, it is the intrinsic elements of the *madosphere* which are subversive. Power is played out in different ways – it might be about label and position but it might actually be more about the content – a highly disruptive notion in the context of an institution riddled to its core with professional hierarchies and positional power.

9.0 Conclusion

In conclusion, there has been a tradition of protest ever since a group of people were defined as 'lunatics', but the means of disruption have been steadily democratised with the development of social media platforms where conversation and debate can take place. The personal narrative blogs and tweets of everyday life with a mental health difficulty are more akin to the personal letters of Edinburgh Royal Asylum of the 19th century, than the more formal and traditionally published narratives of activists. The

immediacy and vibrancy of immediate experience, captured and shared, exemplify resistance at an individual level. The public nature of online social networks mean that those same individual acts of disruption can be read, shared, added to and recorded until they emerge as a networked activity of a loose knit community. There are marked resonances with the themes of disruption today and those in the nineteenth century, but the ability to express them in public spaces continues to open up exponentially and is a defining characteristic of contemporary society.

Chapter 5

An Account of the *Madosphere*: the Asylum Disrupted and Reproduced

1.0 Introduction

In this chapter, drawing on field notes, interviews and my own reflections in the field, I offer an account of the space and set of practices that have been coined the *madosphere*. I explore this ever shifting and malleable terrain as an observer and as a participant who has immersed myself within it over a three year period. My intention is to paint a rich picture with texture and depth that illuminates the *madosphere* for others to understand and which ascribes a value and recognition to this diminutive corner of the Internet which is dynamically created and recreated from the ingenuity and effort of its participants. In a delineation of the *madosphere* I draw on Goffman's Asylums (1961) as a focal point of contrast and comparison. Asylums is both a reference point as a seminal ethnographic piece of sociological research and as a study of the institution. It provides an historical context and a point of reference as to what has changed and what remains the same within discourses of mental health. I also draw on Parks' (2011, p.108) conceptualisation of virtual communities to assess the extent to which the *madosphere* could be understood as a community. In his typology an online community comprises five recurrent themes: the ability to engage in collective action; shared rituals and social regulation; patterned interaction among members; identification, a sense of belonging and attachment; and self-awareness of being a community. I address each of these domains within the chapter.

An account of the *madosphere* charts the ever shifting sands of online social networking – from the rampageous qualities of the *madosphere* in full flow through to its demise and dissipation. My research captures a small set of practices and a point in time which has already morphed into something different at the time of writing and will no doubt be somewhere else as this chapter is read. My early field notes capture a sense of the vibrant, varied and apparently chaotic nature of the *madosphere*:

> [TWOM] is a fascinating mix of academic, serious, professional, deeply personal and comic with a mix of narrative, Twitter screenshots and a series of skittish photographs containing comic political satire. This edition [of TWIM] has everything from an academic directly criticising journals for obfuscating commercial pharmaceutical links; an excerpt from a call to action for mental health professionals and the police and regulators to work together more collaboratively in relation to section 136; a highly personal post from an individual talking about taking their medication; another post about a personal experience of suicide which moves on to wider reference to social issues related to stigma and the implications for carers; lastly a post satirising Nigel Farage which brings a directly political stance to the blog.

The madosphere comprises a melee of serious comment, deeply personal narratives, political satire and factual reporting all contained within one coherent space and set of practices.

2.0 Why the *Madosphere*?

The *madosphere* is just one small space and set of practices in ever evolving and diverse online social networks. It is even a small niche within the social networking spaces where mental health is discussed. But it is a niche I have been drawn to spend time in, contribute to and understand. It is a space where a dynamic and loose network of individuals are traversing contested discourses, engaging with current affairs, sharing their stories, seeking to understand and to be understood. It is a disruptive space where identity, power and labels have a fluidity and a chaotic quality. Diverse viewpoints knock up against each other, spats flare up, people are generous and kind, traditional views are satirised - all in public, all for everyone to see. This is a space worthy of exploration, to be captured and to be shared. To understand this space is to begin to understand the affordances of online social networks to shape and be shaped by people coming together around common passions and common concerns. I began participating in the *madsophere* as my research commenced in 2012 and I engaged in fieldwork between January and December 2013. Since the conclusion of my fieldwork, I have continued to participate in conversations about mental health and online social networking through my blog and on Twitter.

My research captures a point in time, a three year period during which the *madosphere* has evolved and reshaped itself, people have entered and people have departed, conversations have shifted from one platform to another. My research therefore offers insights into the dynamic and fluid nature of online social networks and how and why transitions occur. It offers some clues as to how this space may continue to emerge and develop; but it takes nothing for granted. Changeability and adaptability are the only constants of social networks. If nothing else, my research shines a light on a

particular point xin time that is captured for posterity rather than lost in the ephemera of online life.

The *madosphere* is a term coined by the central blog around which I have orientated my ethnographic research, until its demise in November 2013. It is described by the editors as follows:

> An e-zine of news, commentary and blog digests in the arena of mental health. Our blog digests are known as This Week in Mentalists (TWIM), a feature which been a fixture of the mental health blogosphere for several years ... TWIM is a weekly digest of selected writings from blogs across the Madosphere, our affectionate name for the mental health blogosphere. It is published on Saturday or Sunday, along with relevant news stories from that week. Although this blog is based in the UK, we try to keep the focus as international as possible.

The term ‘mad’, according to the Oxford Dictionaries (2015) is chiefly used to describe someone who is ‘mentally ill’ or ‘insane’ or alternately someone who is ‘extremely foolish’ or in a ‘frenzied mental or physical state’. It can be used as an adverb to describe enthusiasm or intensity or even ‘whacky’ behaviour. Its use combined with the word ‘sphere’ is a play on the word ‘blogosphere’ which is suggestive of an online realm where not only is mental health discussed but where this may be done in an unruly manner. The use of a word used to describe mental distress in a way which is pejorative in everyday use has echoes of language reclaimed by those affected by it. The word hints at a space which is playful, cheeky and suggestive of content that is outside of the official discourse of mental health. The use of a word that is pejorative in everyday conversation to denigrate or to suggest unruliness is striking - as someone

working in mental health in an official or formal capacity it has the essence of language that is forbidden and certainly not available for people in the official public sphere to use. I have therefore been fascinated to see how others in this space understand and engage with it.

The term *madosphere* is not a term that appears to be used outside of this space and network of people. An Internet search for the word *madosphere* (undertaken on 6 December 2013) shows TWOM in the first results closely followed by related mental health blogs which have tagged the same term. The use of a term coined by and used by a defined group of people reinforces a sense of shared identity as articulated by Tanya: 'the sense of inclusion... of 'everyone together', and the recognition it gives people' is central to her experience of the space. It also has a playfulness that gives clues as to the nature of the conversations – sparks of humour and irreverence mixed with the sincere and heartfelt and always eager to puncture the ego of anyone who might take themselves overly seriously:

> Other people started picking it up, and reclaiming the word [madosphere] I always try to make a point of not talking down to people, and trying to use the blog platform as a place where it shouldn't really matter what perspective you are coming from, we're all just people having a conversation, we're not in the role of 'I'm a professional, I'm a patient, I'm an academic' whatever, it's just us, we're having a chat in a tongue in cheek sort of way; it would probably be over egging the pudding to say we're on par with black people reclaiming the 'n' word or gay people reclaiming the 'q' word, you know it was a jokey word [mentalists] that came from Alan Partridge [fictional TV comedy character] after all.

The parallels with reclamation of language by civil rights groups is a pertinent one – the term has a transgressive quality to it; it is a word which can only be used by its members to avoid fear of offence. Those on the margins, such as Bill, have a different relationship to the word: 'I don't have a problem with it but I wouldn't use it myself because I don't want to offend anyone if I can avoid it'. His comments suggest an ambivalence about the term and an awareness of its potential to offend. Brian, a psychiatrist, has a similar position: 'You've got to use language that you find empowering, reclaim language that was used to insult you in the past, I mean every minority has done that, and it's would be arrogant for me to wade in and say that's insulting, it's not my place'. Sam, another psychiatrist had a slightly different take on the notion of madness which relates to transgression of social norms rather than a description of illness:

> For me madness is about doing something that isn't really accepted by everyone, eccentricity might be one end of the spectrum and then it comes more and more disconnected from reality where you might be suffering from psychosis where you have complete disconnect, and at that point you may have a mental health problem and you also might be a bit mad … the more time you spend with mentally ill people you realise there is such a thing as mental illness but beyond that we're all a bit mad, that's the way our lives are, and we all think the way we live our lives is extremely important and very powerful, and therefore others must live like that.

The complex contested nature of language in mental health is illuminated further by Buddy, a police officer who tells me that whilst he is immersed in the *madosphere*, it is not nomenclature he would feel comfortable with:

> It's certainly not a term that I've used, because I learnt early on in my dealings with mental health in the [public sector] that language is really important, and I also quite quickly got myself to a stage where I realised that actually there are certain debates about language in mental health that you'll never resolve, ever, it depends which room you're in as to whether 'mental illness' is … some people actively welcome it as a term as they see mental distress through a medical lens and so for them nothing else will do, and then for others it's absolutely the worst thing that you could ever say, and I sometimes try to make that talk you know if you're giving a talk on ... mental health, whether you say mental health or mental ill-health, mental illness or mental distress.

The *madosphere* is certainly a term which would be frowned upon in a clinical setting and one which I was slightly queasy about using myself in the early days of my immersion in this space. I am similarly struck by the title of the blog itself; the first part of the title - 'The World' - is suggestive of a total and coherent space which contains everything associated with that topic or theme. A search on Google shows that 'The World of ...' is a commonly used phrase used to refer from anything from 'cross-stitching' through to 'interiors'. In this context, the notion of a 'world of mentalists' has instant connotations of irreverence - mentalist can both be a magician with extraordinary mental powers or an 'eccentric' or 'mad person' according to the Oxford Dictionaries (2015). The notion of eccentricity is apposite for the *madosphere* – a space where the norms of society are held up, scrutinised and often rejected. People whose mental health experience marginalises them, and which can place them on the periphery of 'normality', have a space within the *madosphere* to both play and resist.

Just like the asylums of the past, this is a space where the mad and their keepers congregate, but on disruptively different terms. It is a space which defines itself in absolute terms and it is space in which the nature of mental health, power, identity and representation is continually debated. It is therefore a space which, often implicitly and occasionally explicitly, engages with discourses of professionalism and institutionalism - core themes of Goffman's Asylums. In this chapter I draw on this seminal ethnographic writing as a key reference point to illuminate the *madosphere* as it replicates, rejects or simply engages with discourses of mental health. That is not to say that the asylum of Goffman's mind's eye exists today in the United Kingdom as it did then; but I do believe many of the core themes he sheds light on continue to resonate and have relevance today. Where and how are power and hierarchy expressed in the World of Mentalists? What qualities of the asylum resonate in this space? Or is a world of mentalists the alter-ego of the asylum? The asylum subverted, the asylum parodied, the asylum picked apart? A key function of the *madosphere* is to remind us of how the asylum continues to breathe life in institutional practices.

The parallels and divergence between the asylum of the past and The World of Mentalists have salience in so far as one throws light upon the other. The notion of a world of mentalists, at odds with but sharing certain characteristics of the institution, is worthy of further exploration. Goffman (1961, p.15) even delineates the all-enveloping characteristics of the institution in terms of a world:

> Every institution captures something of the time and interest of its members and provides something of a world for them … every institution has encompassing tendencies.

The world of the institution is continually produced and reproduced through behaviours, features and rituals enacted by both doctor and patient and their intertwined but separate social roles. These functions maintain social order in ways which enable people, perceived to be incapable or threatening to the wider community, to be removed from wider society and safely contained. But whilst Goffman's institution is a place of restriction and control, the World of Mentalists is an asylum in the true sense of the world - a space of refuge away from the prejudices and stigma of everyday life. In my field notes on a TWIM post, I reflect on a sense of community mediated and red-mediated within the *madosphere*:

> The post has a warm, light hearted and relaxed style of a regular blogger and contributor to the madosphere. It reinforces a notion of kindness and being part of a 'club'. It encourages bloggers to 'keep on blogging' and argues that all students should study the blogosphere – a very interesting point and pertinent to my research – it is kind, warm and encouraging.

Merlot, a mental health nurse, describes the importance of culture and community:

> What I've realised, is that it's not really about buildings it's about culture , there is a space for asylums, and politically we took a decision to get rid of all the asylums and replace sort of mental health responsibility on to the person who's got mental health issues, so we're expecting the person who is institutionalised for years to suddenly manage in the community, and nothing was done about society; we don't have a society that supports mental health and supports people; we just kind of expect everyone to leave and get on with it … I think that

> the mental health community generally on Twitter, most people seem to have very similar values around breaking down barriers, but you realise that the rest of society is still in that place, and you forget that really.

The World of Mentalists has its own behaviours and rituals that create and sustain a sense of shared identity and connection. Participants play certain roles and exhibit certain norms of behaviour that create a sense of group belonging. The notion of a virtual community can be defined as: 'social groups that display the psychological and cultural qualities of a strong community without physical proximity (Parks, 2011, p.107) and TWOM is imbued with these characteristics. An example of this reciprocal self-sustaining culture is captured in my field note reflection on a call out for volunteer guest editors on TWOM:

> The 'shout out' for volunteers interests me in a number of ways. Firstly, the post reinforces and rearticulates the culture of co-production, of open sharing and participation on the blog. There are no parameters set, no screening or qualifications required. The apparent assumption appears to be that bloggers will adapt their style to fit the tone of the blog or will offer to contribute if their style aligns to culture and style of the blog. Compare this approach for example to an academic journal or a guest blog on say the Guardian Healthcare website – where it is at the very least moderated, edited and posted on behalf of the person producing the narrative. This approach is fundamental to the culture of the blog and I wonder about the extent to which this creates a strong sense of shared community for people engaging in the *madosphere*?

To what extent can the World of Mentalists be conceptualised as an inversion of the asylum; a reversal of the received order; and a rupture of relationships? The *madosphere* recognises and understands the total institution and both shines a light on its shortcomings and seeks to undermine it, whilst at the same time emulating those aspects of an institution that create a sense of community and shared identity. TWOM has an unconscious and possibly unaware relationship to the asylum that I seek to illuminate as a means of shedding light on this space and its practices.

The foundations of a disruption of the asylum can be found in the essential building blocks of TWOM. Unlike Goffman's (1961, p.916) asylum which is built with 'locked doors', the architecture of the Word of Mentalists is grounded in an open source free Wordpress site which is free to set up and equipped to enable people to self-publish and collaborate. In contrast to the enforced separation of social roles in the asylum, TWOM is grounded in equity arising from the shared co-editing roles held by a mental health practitioner and a person accessing mental health services. This brings a particular tone to TWOM, a certain expectation that people come together through shared interests and concerns - everyone is welcome irrespective of social role or professional identity. In Goffman's 'total institution' those barriers are only temporarily removed during certain rituals such as sports day or the Christmas party. In the *madosphere* this disruption of social roles is the norm. It could be argued that TWOM is effectively the Christmas party of the asylum where social roles are temporarily thrown off, only to be resumed in everyday life. However, my interviews suggest this is not the case and that participants are seeking understanding and connection that they can bring back to their day to day professional or patient roles. As Mia describes: 'I feel much more informed than I was previously, as I'm ward based, it's broadened my horizons.'

The inherent foundations of the *madosphere* create a fissure in the practices of the asylum and participants are quick to chastise professional behaviours that seek to enact them. Occasional TWOM posts satirise the behaviour of professionals who choose to behave in accordance with the rules of the institution rather than that of the *madosphere*. It becomes quickly apparent that professionals will be challenged for perceived pomposity or behaviours which they may comfortably exhibit in the backstage area of the clinic but which are not welcome in the *madosphere*. The practice of challenging or *calling out* is no better illustrated than in a blog post embedded within TWOM which challenges TV personality and General Practitioner, Dr Christian Jessen, who presents the Channel 4's 'Supersize Vs Superskinny' and 'Embarrassing Bodies'. On receiving tweets in which individuals disagree or challenge Dr Jessen's views or behaviour, he routinely retweets [shares] them to his substantial number of followers [279,152 on 17 February 2014] with capitalised comments such as 'WOW!', with a tone that could be perceived sarcastic and often finished with kisses 'xxx'. These retweets to his followers have resulted in the person who sent the original tweet being extensively 'trolled' [receiving abusive comments]. On one particular occasion this particular ritual was staged by Dr Jessen in a short series of interactions with an eating disorder campaigner when they tweeted that his programmes may be triggering for people with an eating disorder. The resulting conversation on Twitter between Dr Jessen and others was curated and commented on in both a blog and a vlog and these were then embedded within a This Week in Mentalists round up.

This interaction, in part, serves a function of reinforcing cultural *madosphere* norms through a detailed exposition of behaviours between professionals and people with lived experience which are not acceptable within the space. There is nowhere within

the madosphere where expected behaviours are explicitly stated, yet certain behaviours are enacted again and again. Whilst not operating in the *madosphere* space, Dr Jessen is challenged for transgressing a number of the cultural norms which define it and which are then critiqued in the space for others to witness and discuss. Firstly he has received a challenge and refused to engage with it or converse; secondly he has belittled the views of someone with lived experience of accessing a service; thirdly he has encouraged trolling behaviour by retweeting comments made to him; but most of all he has acted with the apparent arrogance of a professional who has no accountability to those enacting a patient role online. His performance within this interaction exemplifies the 'keeper' of Goffman's asylum who is both powerful and able to use their status to retain control. An alternative reading of the above exchange could present the initial tweet from the campaigner as rude and aggressive, with Dr Jessen taking this cue, which then shapes the ensuing interactions. But 'calling out' a professional is a more acceptable norm in the *madosphere*. Those with perceived professional authority who chose to use it in a way which belittles those with less perceived power will become the objects of ridicule.

The *madosphere* is a space where culture and behaviours are routinely scrutinised and reflected upon. The post: 'What makes for a great mental health blog?' (1 February 2013 field notes) and related comments give a fascinating insight. The post, which asks the question: 'what do you think makes for a great mental health blog? What blogs do you like, and why do you like them?' and ensuing interactions enable the culture of TWOM to be simultaneously reflected upon and performed – the editor presents himself as self-effacing, open and transparent, requesting of help, reinforcing the notion that this blog belongs, not just to the editors, but its contributors and readers. It illustrates the emergent nature of the blog – evolving and adapting through inputs from

others to help shape it. It is interestingly (so far) open-ended – there is no conclusion posted from the editors. A tone of light humour and a self-effacing style run throughout the post and the comments. Participants are not dogmatic about their suggestions, they are offered up as ideas and the option to ignore those offerings is provided. They are generous and have a tentative quality to them: 'so in a nutshell, I have no idea what I just said.'

The contrast between the gentle and collaborative tone of conversations amongst the TWOM community, and the sharp ridiculing tone of posts which challenge institutional practices, generate a sense of community which is defined in opposition to the mainstream - a refuge from the day-to-day and a place to critique the world outside of TWOM.

3.0 Barbed Wires and *Madospheres*

Goffman (1961, p.15-16) introduces the concept of the 'total institution' within his ethnography of the asylum, symbolised by the: 'barrier to social intercourse with the outside and to departure that is often built right in to the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests, or moors'. The physicality of Goffman's institution is thickly articulated with its barriers to the outside world comprised of the dense objects from the man made as well as the natural environment. The asylum both contains and confines whilst keeping the sane and mad defined in opposition and materially separate (apart from those employed to occupy that space). The physicality of the asylum of the past and the ward of the present appear on the surface to be at odds with the intrinsic open quality of the *madosphere*. Does The World of Mentalists unlock the asylum door and leave it gaping wide open for roles,

identities and labels to be confounded? To what extent is it a release from normative identities of doctor and patient?

Whilst the rules and regimentation may be implicit rather than articulated within the rule book of the institution, the original meaning of the word ‘asylum’ that is ‘shelter or protection from danger’ may have some resonance in the *madosphere*, for it provides a space for people to perform parts of themselves that may be less permissible in everyday life, a space away from the stigma of the mainstream, and a refuge for people with similar experiences. And it is this notion of shared identity that creates imperceptible yet present borders around the margins of the *madosphere*. Whilst one of the functions of the asylum was to protect the public from the ‘mad’, the *madosphere* protects those deemed ‘mad’ from the stigmatising attitudes of the public. Whilst isolation can be enforced in the asylum, the *madosphere* creates a space to reduce isolation and create connections. Whilst the asylum staff retreat to their homes at the end of the working day, the staff participating in the *madosphere* are drawn towards it in their free time, their evenings and their weekends; the asylum is both simultaneously reproduced and disrupted.

Communication is bureaucratised in an institution where interactions are controlled, not only between inmates and staff, but also between hierarchies of staff. One function of the ‘supervisor’ in Goffman’s (1961, p.19) asylum is to control and contain how and when inmates communicate with staff. Information flows are strictly controlled and the inmate may only be party to limited knowledge about ‘decisions regarding their fate’. The institution enforces minimal contact between the two groups, and when interactions occur, they are boundaried in formalised rituals which reinforce distance.

The permeability of imagined borders between practitioner and patient are replayed to me again and again in my interviews. Sam, a consultant psychiatrist, explains the personal value and insights he gets from inhabiting social media spaces and connecting with people accessing services:

> You have [in the *madosphere*] the daily confrontations with services, and how bad those services can be, what the other side's experiences of services can be, and I think that does really radically change, it certainly shifts your viewpoint, otherwise I could spend my whole day speaking to doctors and nurses and not get a clear view of what's going on for the person on the other side, from multiple different perspectives.

For Sam, online social networks offer new opportunities to create holes in the barbed wires that still exist in the echoes of the asylum, and to interrupt those rules which create and sustain social distance. In this space, Sam is looking to increase social connection, to enhance his empathy, and to enrich his clinical practice.

Whilst the asylum is continually present in the recesses of the *madosphere*, on occasion it moves from the shadows to take centre stage. In the 'Was Thatcher Right?' edition of This Week in Mentalists, the guest editor reflects on the controversial policy of 'community care' introduced under Thatcher's prime-ministerial leadership in the 1980s and which is associated with the demise of institutional care for people with mental health diagnoses and others. The implications of the closure of the asylum for the *madosphere* are articulated in stark and personal terms:

> Most of us would recognise that moving away from big institutions was the right thing to do and that, in a fairly strong sense, many of us wouldn't be around doing what we do now in the *madosphere* if that hadn't happened.

It is not just the technological affordances of social media platforms, but the closure of the asylum itself, that has created space for the voices of inmates to be heard. Online social networking affords a different kind of space, a new kind of asylum.

Another guest editor, when commenting on a mental health story from the LA Times, concludes with the comment: 'but perhaps the dark days of asylum-esque mental health 'care' aren't entirely behind us :(' A trans-cultural TWIM edition illuminates the asylum living and breathing in many places across the world. The guest editor embeds links to 'severe human rights abuses' in psychiatric institutions in many different countries, including this one in Ghana:

> Ghana's three public psychiatric hospitals – in Accra, Pantang, and Ankaful – house an estimated 1,000 people with mental disabilities. In all three institutions, Human Rights Watch found filthy conditions, with foul odors in some wards or even feces on the floors due to broken sewage systems. The hospital in Accra was severely overcrowded and many people spent all day outside the hospital building in the hot sun, with little or no shade (field notes 19 April 2013).

This post is a bleak reminder that the asylum of the British past remains the living and breathing asylum of the present for many people across the world. It is also an illustration of how the asylum is continually present in the *madosphere* as an institution and related set of practices that should belong to the past but maintains currency in the

present. The asylum is remembered from childhood memories and tales by some: ‘the only other connection between the locked wards and the village was the hospital siren’.

4.0 From Community to Cliques - Shared Rituals and Social Regulation

Goffman’s total institution is characterised by a split between a managed group called ‘inmates’ and another group of supervisors called ‘staff’. Each group is inherently suspicious of the other and conceives of each other in stereotyped terms; inmates are perceived to be ‘bitter, secretive and untrustworthy’ whereas staff are ‘condescending, high handed and mean’. Staff are superior whilst inmates are inferior, weak and blameworthy.

Goffman’s (1969, p.18-19) characterisation of the asylum is one of binaries where one group is set against the other, movement between the two is severely restricted, and social distance is the norm. It is pertinent to note that a contemporary desire for social distance remains most pronounced in health care staff (Schulze, 2007, 138). Perhaps institutionalised attitudes and roles are not purely dictated by the brick walls of the institution, but are equally manifest in the walls of minds which are imbued with stereotypes and prejudice. Online social networking sites offer simultaneous distance and proximity - distance which enables people to engage with each other in a controlled way and proximity which is outside the boundaries of a clinical relationship that may be hard for a practitioner and patient to emulate in everyday life. This could hold the clue to why online social networking can be so valuable - it provides an opportunity for two groups for whom distance and boundaries are implicit in one context, to peer round the barricades and peek into each other’s lives and experiences. Perhaps the madosphere

has an important function for people who want to disrupt the norms of the asylum but in a way which is contained and controlled.

How does one arrive at and enter the *madosphere*? An inmate's entrance to the asylum is exemplified by a process of 'mortification' which is engendered through a set of functional and symbolic rituals such as the 'admission procedure'. The individual is orientated into a contained environment and the formalised separation of staff and inmate is quickly established. An individual's conceptualisation of their 'self' is eroded as clothing and possessions are replaced by standard uniform and everyday actions are curtailed or require a humiliating process of request and permission. Goffman paints a picture of control, enforcement and debasement. Whilst many of the symbols of incarceration may no longer be tolerable in the 21st Century (for example, people retain their own clothing) it is nevertheless striking how many customs remain in a modern day inpatient environment – the admission procedure, the ward round, the confiscation of objects, restriction of movement, the staff uniforms (in some units) are all symbols of cleanly delineated roles; the implicit (or even explicit) threat of detention and forced medication remain in the present day. Whilst we may hope that the asylum of the past bears no resemblance to the modern inpatient unit today, the experience of Bella in 2013, who I interviewed for my research, suggests institutionalised practice may still be manifest:

> The day before ward round they asked me if I wanted anything to go on their pre ward round planning sheet, and I said: 'Well let me look at it and I'll add anything', and they said: 'No you can't read it, it's about you', and I said: 'What do you mean? I'd like to contribute to it and perhaps maybe do it together'; [staff member]: 'Well that's not how we work'. And you know I teach around the

> recovery approach, and I didn't have it in me in at that time to get into an argument about it.

Whilst Bella's account indicates that remnants of the asylum may still be at play in the modern inpatient unit, entry to the *madosphere* is distinguished by a wholly different set of characteristics. First and foremost it is an individual endeavour that begins in the private sphere - the *madosphere* must be actively sought out, a small niche tucked away in the recesses of the Internet. If you are taken there, it will be by a friend or a peer, and it is most unlikely that a 'supervisor' will recommend it to an 'inmate' because its politics and its conversation is so removed from the official parlance of the institution.

However, once in that space it is apparent that a whole set of conventions and requirements apply to those wishing to participate. These shared rituals and social regulations are an inherent feature of a virtual community (Parks, 2011, 108). The admission procedure is an implicit one and you may not fully be aware that you have completed it correctly – no one will tell you, you will have to work it out for yourself. When I first offered to write a TWIM post, I was struck by the lack of formal vetting procedures. I was given a password to the TWOM blog and invited to write and upload a TWIM post. Apart from following the convention of writing a 'round-up of the *madosphere*' that week, instructions for which are set out in a page on the blog, I was not given any other direction; nor was there any editorial control. I found this unnerving at first and requested that one of the editors check over my post before I uploaded it. I had imagined I would submit a post which would be approved and upload on my behalf. Instead, I was given complete autonomy and ongoing administrative access to the blog. I was taken by surprise at the apparent lack of formal boundaries and checks to becoming a guest editor for TWOM. I had expected more gate-keeping. I came to

understand that rituals and behaviours in the space are produced and reproduced through cultural practices rather than formal rules. Editors read and imitate conventions that have gone before and which are replicated each week with different TWIM authors. In his interview, Paul describes the blog as ‘project mayhem’ with a particular reference to the transient nature of contributions to the blog. Whilst there are a small number of regular contributors, there are many who come and go and who may only contribute once or twice before drifting off never to return:

> There have always been certain people who have been more key figures, who have been around for a long time, who may be drifting in and out, some people may drop by for a little while and then you never see again, so it is bit ... Fight Club [reference to the film Fight Club]... you decide your own level of involvement.

Edwards’ passing comparison of TWOM to Fight Club gives a possible insight in to the intended mutinous quality of the blog, as well as the common popular culture references that are part of the fabric of the blog itself. In her paper on the cult 1999 film Fight Club, Ta (2006) describes the fictional club as an underground world of rebellion. Based on a book, the film’s plot revolves around a secret club where men reclaim masculinity, ebbed away by advertising and corporate culture, through ritualised fights. The protagonist is railing against a corporatised culture which is then ironically reproduced in the ritualised rule laden culture of Fight Club. Whilst not predicated on violence or masculinity, TWOM could be seen to share certain qualities of Fight Club – a rebellious and subversive space that picks many ‘fights’ but ones related to written arguments and debates rather than one of fists and bruises. The community of TWOM is therefore one which sets itself up self-consciously as counter-culture, a space where

the mainstream can be critiqued and where people on the edges of the conventional can congregate. This culture is reflected and reinforced in the architecture of how the *madosphere* operates - rules and requirements are not explicitly articulated but are reproduced through the sanctions applied to those who transgress them and positive reinforcement from the community when they are upheld. TWOM is fight club for people on the margins of received conversations and paradigms of mental health.

However, whilst roles are not delineated by formal position and pecking order, the *madosphere* has hierarchies and cliques embedded in it. Those at the top of the ladder may not have an official uniform but they will have the traits of power represented by other codes such as the number of followers they have on Twitter, the number of times their blog posts are shared, and people of equivalent influence who are prepared to converse with them. Mel enthusiastically confirms this representation of the *madosphere* as a space teeming with power:

> There is hierarchy, oh my god there is a hierarchy in social media, I could name the people to you, and those people will either talk to you or won't talk to you, they talk to each other as well, and I am probably in a hierarchy of [states name of diagnosis] people, the movers and shakers chat to each other quite a bit and are, erm, sort of tops of their trees.

And what does it feel like to be at the bottom of the tree? Tanya shares her experience: 'I know I have felt it a lot on Twitter, where I have been excluded, don't fit in, people have their own little gangs, over time, frozen out by each one'. Brian has a more neutral interpretation of the notion of the *madosphere* as a cliquey environment: 'Yeah it does [feel like a clique] but it's what you think about that, you shouldn't be insulted by

that, it's just people trying to find other people who have had hard times like they've done'. And herein lies an inherent tension in the *madosphere* – where there is a clique there is also strong sense of shared identity and shared community. This community has qualitative differences to that of the asylum as delineated by Goffman, in so far as it is co-created and endlessly reproduced equitably by the 'inmates' and the 'supervisors'. Those identities have a fluidity to them which has always existed (if one in four of us has a mental health problem then inevitably some of the supervisors will have their own lived experience) but where previously it has not been explicitly articulated. As Tanya explains someone idealistically: 'We have all experienced mental health, and number one thing they are is a person.'

Jessica describes the flip side of the clique - that is the sense of community she experiences within the *madosphere* and what it means to her:

> I consider myself really lucky to be a part of the *madosphere* that people have created, and a lot of the time I have to step back from it, because it's not the real world and it's not how everyone is, because the *madosphere* tends to be a group of very, not academic necessarily, but very well educated people, very sympathetic, compassionate, very inquisitive, they look after each other and look out for each other, and they talk about things in a very different way.

So whilst everyday life is reflected in cliques and hierarchies within the *madosphere*, it also is a space and set of practices which offer a sense of community and refuge away from the prejudices of their day-to-day world and an virtual asylum in the true sense of the word. Reflections in my field notes illuminate my sense of the contrast between this

emergent culture in the *madosphere* and day to day experience of similar conversations in an offline context:

> I went to an event this week called 'Digital Innovation – pushing it up the healthcare agenda'. It was a staid affair, very traditional format which was completely at odds with the subject matter. I was particularly struck by the dissonance between the DIY approach taking places in TWOM and other related spaces, and the bureaucratic, slow, ponderous approach being taken in healthcare, slowed down by huge structural change, new people and roles, insufficient interest and so on. This reconfirmed for me that my primary interest is in this DIY disruptive approach and the disconnect with institutions which appear to be building in their obsolescence in terms of relevance to younger people in particular.

The above comments capture the anomalies I was experiencing at the time between my immersion in the madosphere and a contrasting offline culture of formality and containment which engendered a sense of frustration and concern for the future of health services in an increasingly networked society.

5.0 Rounding up the *Madosphere* - Patterned Interactions and Community

Goffman's (1961, p.91) primary example of a ritual break from routine is in the weekly newsletter or monthly magazine which comprises local news of birthdays, trips and deaths through to original essays, short stories and poetry. The content is provided by the inmates but articulates the official view of the institution and idealised representation of life within it. As I read Goffman's characterisation of the 'house organ'

it was hard not to be struck by the similarity between his description and that of the modern day formal newsletter or magazine produced routinely by any number of NHS Trusts. They too provide a clean and contained narrative of success and achievement, typically with a sanctioned guest piece comprising a story of recovery or redemption – a polished product which arguable fails to reflect day to day life as it experienced by either staff or inmates.

Patterned interactions are a core element of virtual communities whereby they share common practices and rituals. These patterns are expressed within TWIM in tension with the enforced community of the asylum. It may harvest a weekly round-up of the *madosphere*, but employing entirely oppositional conventions. Rather than a redemptive story of recovery, TWIM is more likely to capture the grinding reality of survival:

> Being stuck is not safe. Being stuck means that you are constantly fighting for both sides; for a terrifyingly powerful eating disorder which wants you to cling to it and never let go, and for the part of you that wants to live. Striking a balance between the two might seem like having the best of both worlds: congratulations, you're a functioning eating disordered person, well done! That's not living. It's existing, with the daily struggle of batting off unwanted thoughts and feelings every time you allow yourself to do something you deserve to do; eat, and possibly even enjoy the bloody food too (5 April field notes).

The blog posts curated in a TWIM are routinely from personal diary style narratives that are not necessarily succinct or rounded and certainly do not follow a heroic or redemptive narrative. They are stories of everyday struggle, pain, distress, gallows

humour and the day to day tough realities of life. They are stories of inadequacy and vulnerability and of getting by. The outgoing mail of asylum inmates was subject to the right of staff to limit, inspect, and censor anything that was negative about the institution. In contrast, blogs posts are self-authored, edited and uploaded to the web. Often critical or challenging to services, they are a means of self-expression un-mediated by others. Conventions of the written word aside, blog posts are everything the inmate letter is not.

The TWIM convention of a weekly round-up of the *madosphere*, collects a selection of those posts in one space that facilitates access to an extended audience beyond that of the source blog. Embedded posts are often commented upon by the guest editor by way of a supportive or friendly comment suggestive of an empathic response, such as: 'it [blog post] gives me a bit of 'well, at least I'm not the only one feeling this or that' support' or: 'Man, I felt that pain all day long as it played on my mind … keep telling your stories, please, these things need to be heard and understood'.

A TWIM follows a certain format, a self-effacing introduction with a sprinkling of humour or a light conversational tone suggestive of a friendly chat. For example, one guest editor refers to themselves as: 'someone who's intimately acquainted with madness'; another begins with a typically English reference to the weather: 'I hope you're all enjoying the traditional Easter activities, such as layering up in warm clothing, turning the heating up full blast and clutching hot water bottles'. Another typically witty introduction with a nuanced allusion to mental distress: 'Overnight someone (or perhaps a gang?) in Happyvilleshire were out in force. They painted the sky blue! And there is this big yellow thing in the sky that burns my eyes when I look at it. To distract me from the sky vandals, I am going to round up what has been going on in my Reader

for the week'. The informality of the opening paragraph is usually mirrored by an equally informal 'wildcard' at the end of the blog post, in which the guest editor embeds a link to a YouTube or other clip that more often or not has humorous content completely unconnected to the rest of the post. Edward explains his rationale for introducing it: 'think of all the subject matter in the average TWIM edition, a lot of it can be very heavy stuff, abuse, it's good to have something at the end just to break the levity of it, just to add a touch of lightness to proceedings.'

The format of TWIM is carefully conceived and executed by a guest editor in a similar format each week despite an absence of gatekeeping or formal rules and requirements. In the year that I participated on TWOM I found nuances in terms of style but nothing in terms of aberration from the house style. The peer review process that would take place before publication in a formal journal is perhaps enacted informally in the comments section of the blog after publication. The generative nature of the blog creates its own implicit formality of style, tone and content through implicit expectations set by previous posts. The rules are those reproduced by a shared community rather than those imposed by an institutional force. The framework of TWOM and TWIM is set in the architecture of the blog but generated through the practices of its inhabitants. The self-consciously equitable nature of this world is far removed from that of the asylum.

6.0 Ceremonies, Privilege and Reward - a Sense of Belonging and Attachment

The *madosphere's* prevailing quality is one of transgression - sometimes playful, sometimes serious – but always contesting the assumptions and practices of the

dominant order. Transgression plays a part in Goffman's (1961, p.93) asylum too, through ritualised 'get-togethers' that mark a break from day to day formalities and 'soften' the chain of command. This is typified by the annual party characterised by dancing and party games. It may even be that roles are temporarily reversed with the staff waiting tables for inmates and performing other menial tasks for them. The *madosphere* is the asylum in permanent holiday mode. The asylum is continually present in the *madosphere* as a background echo or barely visible shadow. The *madosphere* needs the asylum against which to define itself; for there would be no rebellion without the reverberation of the institution.

In Goffman's 'total institution' privilege is accorded to staff through role and status, and to inmates for compliant behaviour that allows day to day practices to be carried out efficiently. Privilege also has a role to play in the *madosphere* and on an annual basis the ritual of the #TWIMawards is enacted which showcases 'the best in mental health blogging and vlogging' and the #TwentalHealthAwards which recognise mental health tweeters. The awards generate a sense of belonging within the community by creating a focal point to recognise and celebrate actors within the *madosphere*. This is another essential element of a virtual community in Park's (2011, p.108) typology. The awards process is characterised by a degree of transparency and conversation which actively problematises both how they are conceptualised and enacted. Nominations are made on the comments section of a TWIM awards blog post against a set of categories, a judging panel selected by the editor cast their votes, with the final decision being made by the editor. Winners are giving an online badge to upload to their websites.

The awards adapt and evolve each year as they navigate shifting trends, such as an increase in vlogging, as well as engage with more fundamental paradigmatic tensions.

An example is a shift in category definition that was proposed to reflect blog purpose rather than the label of the person writing it (diagnostic or professional role). This proposal is illustrative of engagement and tension with the language and categories of the institution, which is always in the background of TWOM:

> The diagnostic approach of the TWIM Awards can be problematic at times – particularly in terms of categorising blogs by people with more than one diagnosis, who feel concerned about being overly identified with their diagnosis, who disagree with their diagnosis, or indeed disagree with the medical model altogether.

This particular shift is made through conversation and negotiation on the blog itself where proposals are put up for dialogue. As usual ideas are expressed in a typically self-effacing style: 'Here's a few thoughts from me, for people to agree or disagree with, or elaborate on, or point and laugh at'. The ensuring responses in the comments section illustrate the wide range of views, that are often not in tandem with each other, but which are always respectfully expressed in a diffident manner. This collaborative production and re-production of TWOM as it alters and shifts is an important aspect of community on the site.

The sense of community is not only produced and reproduced within the virtual framework of TWOM but is also connected to face-to-face interactions for some. Ellie describes the ritual of 'madups' amongst core members of the *madosphere*:

> I like it [the term *madosphere*] It's a group of mental health bloggers and tweeters and I don't know if you've heard but we used to have 'madups' they

> still kind of have them, 'tweetups' but for mad people, it wasn't just about tweeters, they do still have them in London and some in Brighton, but they're not always called madups anymore, just this group of people who have met through Twitter or blogs and Facebook and all probably either have a mental health problem or are some way connected to that, and just meeting up in a pub and drinking port.

Parks (2011, p.120) argues that whilst the affordance of connection without the need for proximity is a core component of online social networking, it is more often the case that virtual communities are often simply the online extension of geographically situated offline communities. Whilst the geographical dispersal of my interviewees suggests this is not strictly the case for the *madosphere*, I am aware that a blend of offline and online connections exists for the core participants.

7.0 Humour, Satire and Collective Action

The *madosphere* is characterised by humour and satire – pomposity is rewarded with a serious dressing down and stereotypes are held up only to be mocked and derided. Humour is a self-conscious strategy of the editor to balance the often serious and weighty nature of the subject matter at hand. One such comic ritual is the 'wildcard' in which each TWIM is concluded with a link to an image or film clip that has a comedic or absurd quality to it. As Edward describes:

> I think that is important, as you've probably noticed the wild cards, the reason I brought that in was fairly straightforwardly because think of all the subject matter in the average TWIM edition, a lot of it can be very heavy stuff, abuse,

> it's good to have something at the end just to break the levity of it, just to add a touch of lightness to proceedings'.

Wildcards often have no relationship to mental health themes but often are drawn from current affairs and have a satirical edge which reinforce a staple of the *madosphere* which is to 'call out' arrogance or pomposity. One example is an apparently photo-shopped image from the North Korean military derived from a Guardian article (McCurry, 2013) that is shown alongside a comment: 'Honestly, North Korea, if you're going to photoshop in additional forces, why be half-hearted about it? Add Godzilla to the glorious people's liberation forces!' Wildcards also routinely have an intellectual focus, such as the embedding of two YouTube clips explaining Experimental Psychology. Yet another embeds a Malcolm Tucker YouTube clip that references back to the main body of the post which relates to Thatcher's death and the impact of 1980s policies on community care. On one occasion when I guest edited a TWIM entitled: 'The Does Language Even Matter' edition and embedded a YouTube clip of comedian Bill Hicks with a reference to his use of language:

> And my wildcard is my favourite ever comedian – Bill Hicks – a man who was not afraid of saying exactly what he thought and using the most colourful words to both offend and make people laugh along the way. Here's his take on non-smokers, or whining maggots, as he preferred to call us (please don't watch if swearing offends you).

Another example of the jesting quality of the space which also reinforces a sense of community through a shared ritual, is the 'head clutcher' meme in which participants

routinely satirise the use of stereotyped images used by the mainstream media when running mental health stories.

Stock media photos often entail an image of a person sitting in a corner with their head held in their hands and TWOM takes great delight in satirising what could be perceived to be lazy journalistic shorthand for mental distress. This is achieved by a regular caption competition where participants are asked to create a caption for 'the media's predilection for clichéd stock images' in relation to mental health. It has an ironic tone, challenging mass media representation through humour; appropriating an image used in one context to illustrate a serious topic and then using it for comic purposes to illustrate the predictable way in which the mainstream media visually represent mental distress.

The #headclutcher meme[3] has the function of reinforcing a sense of community in Park's (2011) typology through shared rituals, social regulation and patterned interaction amongst participation, which includes use of satire. Whilst The World of Mentalists does not actively call its members to collective action, it does create the conditions and the shared narrative than can then be brokered into a campaign context. The salience of the #headclutcher meme, which had its origins in the *madosphere,* is that in 2015 it became a campaign focus of the national Time to Change campaign (2015) entitled 'Get the Picture' as described in this press release:

> Very often, we see an image of a person holding their head in their hands. All manner of mental health stories - about anything from talking treatments to

[3] A meme is an image, video or piece of text, typically humorous in nature, that is copied and spread rapidly by Internet users

> scientific research - are illustrated by a 'headclutcher' photo. But what alternatives to the 'headclutcher' and other stigmatising images do picture editors have? We're launching our Get the Picture campaign with a wide range of images that are free to download from our own page on the Newscast website. They are hi-res and suitable to be published alongside news stories and features. We want picture editors to have a real choice of realistic and relevant photos to bring reports about mental health to life.

The campaign was able to take an issue being satirised in the *madosphere* and repackage it so that it can be engaged with by mainstream media on terms acceptable to them. The interplay between the *madosphere*, the campaign and mainstream media is illustrative of the permeability that social media affords between the informal and the self-organised and official mainstream channels. This is summarised by an interviewee from the Time to Change campaign as follows:

> Our role is to be a hub or almost a mouthpiece for those people because we are England's anti-stigma campaign … all those people have those voices, and social media has been fantastic for helping them use those voices but we're kind of here to bring them together and represent them and be the national voice representing people's views on that kind of issue .. we're a big campaign and we have spokespeople and we've got media contacts … people with experience of mental health problems know that we were standing up for them and taking that cause for them.

A search on the hashtag #headclutcher reveals a large number of tweets either critiquing use of stereotyped images of mental health in mainstream news reporting or

'selfies' which show alternative images or ordinary people with mental health difficulties. This is an example of the affordance of a national campaign which can derive themes from the *madosphere* and then package and remediate them to mainstream media.

8.0 Finding the Heartbeat of the *Madosphere*

In this section I explore how the *madosphere* has unravelled, reconstituted and re-purposed itself over the period of my research. Even within a comparatively short period of time the *madosphere* has evolved in ways which I did not foresee on entering this space and no doubt will continue to do so long after I have shifted my gaze away from this piece of research.

When I began my exploration of the *madosphere* I was keen to find its heartbeat, the central locus, the node that people gravitate towards for discussion and debate. In the vast expanse of social networking, I was keen to find a space or set of practices, that I could pinpoint where people converse about mental health as a community. TWOM stood out as an active blog which was topical, current, had high levels of engagement, and which comprised the key characteristics of a virtual community (Parks, 2011). It was well established and I was confident in my assertion to myself and my supervisors that this space provided a firm footing on which to ground my research.

However, within a year the blog had ceased to operate. This is in itself, a salutary lesson in the impermanent nature of online social networking and the way in which communities may adapt practices to emergent trends and technologies - an impermanent state with gradual and sometimes dramatic shifts and endings.

With the demise of TWOM, Edward shares his reflections on the past, present and future of the *madosphere*. It is a story that begins far back and in advance of my entry into the space which is characterised by Edward as a niche activity where 'the majority of health bloggers took a pseudonym' and whose practices were veiled in anonymity. TWOM emerged from a previously well-established Mental Health Nurse blog and then latterly moved to the Mentally Wealthy blog before ceasing to exist altogether.

Edward references the rise in first-person account blogs relating to mental health and how over time 'a loose mix of professional and lived experience bloggers' coalesced into what informally started to refer to itself as the *madosphere*. He refers to the rise and decline of many and varied online social networks change seems to be the way of social media: 'Networks and communities rise, and others fall. It's not hard to rattle off a list of networks that have fallen by the wayside'. Impermanence is a fact of life but it belies some consistent themes of motivation whatever the choppy waters of technological change:

> What I've actually come to value hasn't been simply the opportunity to broadcast my own thoughts. It's been the opportunity to co-create ideas. Social media provides a setting where people who wouldn't previously have interacted come together and generate new insights. It's not the things I've done myself that I've appreciated, but what I've participated with others to help build. I discovered that if I simply posed a question on the blog, then at some point further down the line I'd get an email telling me the answer. I don't spend a lot of time going out trying to uncover secrets. In fact, the secrets mostly come to me. In a world with sufficient eyeballs, there are no secrets, and social media enables those eyeballs to see each other.

Edward shines a light on the unfolding nature of spontaneously occurring conversation and his insights hit right to the heart of online social networks – they are about conversation, they are about reciprocity, and they are about dynamically consuming and producing information. It is salient to note how far removed these practices and motivations are from the world of the institution, where knowledge is imbued with the mystique of professional training and authority.

Edward illuminates a subtle shift in practices within the *madosphere* that have been influenced by the evolution of online social networks as some have emerged and others fallen out of favour or disappeared. Those practices are characterised by the same conversation consisting of dynamic interactions across multiple platforms:

> As social media has evolved, I think it's become more complex and multi-platform. Previously people would write a post on a blog, and discuss it in the comments thread to that post. Now, people might have a Twitter conversation, then somebody writes up a blog post to express their thoughts in more detail. The blog post then gets discussed back on Twitter. Later on, somebody does a Storify of it all. Where previously blogging provided a focal point (or points) now that focus is on Twitter. I've gradually noticed myself shift from being a blogger with a Twitter feed to promote the blog, to a tweeter who uses the blog when 140 characters just ain't enough. I've come to love the real-time immediacy of Twitter.

TWIM signalled its own demise through a decreasing number of comments alongside a comparable decrease in volunteers to guest edit each week. An attempt to rejuvenate it

by moving it to another blog has seen its complete demise. A newer generation of sharing and curation tools such as Storify have made TWIM increasingly out of step and less relevant.

Edward sees the new heartbeat of the *madosphere* where there is a similar ethos of: 'not them and us, but just us' on the #mhnursechat fortnightly Twitter chats. But I am not so sure. #mhnursechat is orientated around a professional group and its identity is more within the institution than without. It is reflective perhaps of the increasing mainstreaming of debate and discussion - more acceptable, traceable back to the individual, and bound by Royal College of Nursing's professional social media guidance that are tweeted as a reminder at the beginning of each chat. Yes people accessing services may contribute, but the frame and context for the conversation is a professional one. This is qualitatively different to the fundamentally disruptive quality of TWOM with its shared ownership between people accessing and working in mental health services at the very core. Has this core sense of equity lost its way in the latest incarnation of the *madosphere*? Would the word *madosphere* even be used in the context of an #mhnursechat? And the answer to that is no, it would not. Therefore an essential quality of subversion has been lost. Is this new version a maturing of relationships perhaps and a subtle signifier that the walls of the asylum continue to recede? Or in reverse, is it a re-fortifying of those walls, a retreat from disruption towards the trenches of the institution? It is nice to believe there is a linear path towards enlightenment and away from the asylum walls. However, my experience tells me this is not inevitable or even likely. Relationships and practices are continually being negotiated and renegotiated – sometimes with a push away from the asylum but sometimes towards. This push pull tension is a continual thread of conversation in the *madosphere* and indeed most if not all dialogue about mental health.

My response on the blog to the post reflects my ambivalence to the ending of TWOM:

> Thank you for this insightful blog. Ironic that you've had so many comments after bemoaning the lack of them in the blogosphere! I have personally noticed a shift in conversations that seem to move between platforms rather than on posts themselves. I'm also reflecting that I tend to comment on blog posts on Twitter rather than on posts themselves as the log in makes it much more effort (oh yes I struggle with a limited attention span too…). I'll be sad to see TWIM go – it is the quick and easy way to dip in to the mental health blogosphere and get a sense of what out there. I've also really enjoyed its topicality, commentary on current media stories, and the variety of people who have edited them, and a sense of community. I've also loved the humour and satire that has been at the core of it as well. I wonder what gap is left with TWIM's departure and how it might be filled?

So where is the new heartbeat of the *madosphere*? I asked this question of my Facebook group and this was one reply:

> Its more respectable than it's ever been, when I first started using social media in mh, if you were a professional the assumption was that you were committing career suicide 'oh no you musn't have a blog you'll be struck off! You'll be fired!' and now I get a regular update from the chief exec of our Trust saying 'my new blog post is out'

Edward echoes and further illuminates this point:

> Another change is that health professionals who blog and tweet are increasingly coming out from behind pseudonyms, and just using their real names and identities. I suspect this is partly due to more mature attitudes to social media. Whereas once it was considered career suicide for a health professional to blog, now it's an everyday thing. In March 2013 'I came out' from my pseudonym and found it a liberating experience that enabled me to truly own my online content. Increasingly I'm no longer [pseudonym] online, I'm just Edward.

But whilst Edward conceptualises this shift towards the mainstream as a means of owning his own content and being credited as an author, for Buddy this move to the centre brings with it increased scrutiny from those in authority coupled with greater caution and self-editing:

> It does feel like it's changed, and I think certainly as the number of followers on my account has grown, I do sense a greater scrutiny from my [employer] of what I'm doing and what I'm saying.

Practices vary from organisation to organisation but in the case of Buddy, his employer has access to log-ins and passwords of all staff using social media in a professional capacity and they retain the right to suspend accounts if they suspect their social media policy is not being followed. This is the institution at its most controlling and risk averse.

Whilst the *madosphere* was once a disruptive space and set of practices, it is now being disrupted in turn by the mainstream. This is evidenced in a plethora of social media guidance from healthcare professional bodies, corporate accounts and even an

#NHSEngage campaign run by NHS Employers insistent on promoting a permissive approach to use of social media in the NHS. The more direct and insistent subversion of anonymous bloggers and rebellious behaviours may be on the decline but perhaps a more subtle subversion of conversational practices in social media spaces is emerging and expanding. From the disorderly to the ordered and from the riotous to the straight and narrow, practices continue to mould and shape themselves to the increasing mainstream appeal of online social networking.

Chapter 6

Re-Mediation of Representation

1.0 Introduction

In this chapter, the means by which mainstream media frame mental distress and how this is contested and re-framed in the *madosphere*, are examined. The ways in which mainstream media construct mental distress and how this is both resisted and alternative representations are constituted are also considered. I argue that mainstream media and the *madosphere* offer competing public discourses of mental health and mental distress, with the latter positioning itself as a site of defiance. Social movement theory is employed to illuminate how participants in the *madosphere* collectively engage in resistance to dominant mainstream media and public narratives.

I draw on existing empirical research about the effects of mainstream media reporting on both public perception of mental distress as well as the impact on people living with mental health difficulties. I go on to explore how participants in the *madosphere* collaboratively produce narratives which create an alternative frame to that found in mainstream media. I particularly focus on news reporting in print media throughout the chapter for a number of reasons: firstly, it has been convincingly argued that news media is the primary source of information for the public about mental health and is therefore a prime site against which resistance occurs (Wahl, 2003). Secondly, print news media employs similar technologies to the blogosphere and Twitter, namely the written word. Lastly, participants within the *madosphere* habitually discuss news items

in the media and actively critique representations of mental distress. This creates an opportunity for clear and rich comparisons to be made between the two media.

I recount two events which illuminate the themes of remediation and representation in respect of news stories in print mainstream media, social media more generally, and the *madosphere* in particular. Both events occurred during the data gathering phase of my ethnographic research and I engaged with them as a participant observer. I conclude by exploring how narratives within the *madosphere* frame mental distress in ways which are antithetical to mainstream media and which give primacy to the voices and perspectives of people living with mental health difficulties. I relate these events to the existing substantial body of research on mental health in the media to illuminate the extent to which they mirror or subvert previously identified patterns of representation.

The first event is The Sun front page story on 7 October 2013, whose headline states '1200 killed by mental patients.' This article is of note as it contains all the key elements of stigmatising reporting that have been extensively critiqued within the academic literature (Philo et al, 1994; Philo, 1999; Wahl, 2003, Thornicroft, 2006; Birch, 2012; Yamaguchi et al, 2013.
). It contains elements which controvert Time to Change campaign guidelines (2011) for media reporting of mental health issues. The study is therefore a contemporaneous example of how some mainstream media providers persist in reporting mental health issues in ways in which empirical research shows have a negative impact on public attitudes as well as on people with lived experience. The article is of note because it was extensively critiqued within other parts of the mainstream media, social media and the *madosphere*.

The second event also took place during October 2013, which I refer to as the 'Asda mental patient' case. This was a significant event as it presents a mainstream corporate

framing of mental distress connected to dangerousness which spread rapidly on Twitter during a twenty four hour period. The volume of discussion on Twitter translated into the event becoming the main headline on all United Kingdom news channels the following day. It represents an interplay between a corporation's official online media, mainstream news reporting, social media and the *madosphere*.

In the final section I draw on field notes and interviews to consider how news reporting is discussed within the *madosphere*. I argue that the *madosphere* gives primacy to first person accounts of mental distress and enables less commonly heard voices to be attended to. These accounts are often framed as personal diaries and are self-mediated and self-published. TWOM curates and supportively comments on these first person accounts in addition to amplifying them for a wider audience. Curation is undertaken by members of the *madosphere* who are highly engaged in discussions about representation of mental health issues and regularly critique mainstream media representations. The *madosphere* contains practices where first person accounts are created and which are unmediated by the mainstream media, disrupting dominant public discourse about mental health.

2.0 Framing: from mass media to social movements

The arguments in this chapter are underpinned by the concept of framing which was originally employed by Goffman (1974, p.10) to signify how experiences and events are made meaningful and related actions are guided. Goffman's conceptualisation of framing aims to:

> Isolate some of the basic frameworks of understanding available in our society for making sense out of events and to analyse the special vulnerabilities to which these frames of reference are subject. I start with the fact that from an individual's particular point of view, while one thing may momentarily appear to be what is really going on, in fact what is actually happening is plainly a joke, or a dream, or an accident, or a mistake, or a misunderstanding, or a deception, or a theatrical performance, and so forth. And attention will be directed to what it is about our sense of what is going on that makes it so vulnerable to the need for these various re-readings.

The notion of framing has been extended to the context of social movements, whereby collective action frames have the function of mobilising activity around a shared theme and engaging support from others (Benford & Snow, 2000, p.613). In the context of the media, concepts of bias and framing are tools for those with power to assert that power and set agendas to their advantage (Entman, 2007). The interplay between media frames and audience frames, as theorised by Scheufele (2006) provide a framework to consider ways in which participants in the *madosphere* engage with and resist predictable patterns of framing habitually promulgated by mainstream media. Lastly, the existing body of empirical research about representation of mental distress in the mainstream media is drawn upon to provide context for appraising the case studies described.

The concept of framing within the mainstream media lends itself to consideration of how mental distress is constructed within journalistic practices and to achieve institutional goals. Empirical evidence has illuminated that the way in which given issues are framed within the mainstream media has a direct influence on public

perceptions of those issues (Zhou & Moy, 2007; p.81). Entman (2007, p.164) proposes a framework for investigating issues of power in mainstream media which incorporates three elements - firstly the theory of framing which he describes as: 'the process of culling elements of perceived reality and assembling a narrative that highlights connections among them to promote a particular interpretation'; agenda setting which relates to defining problems worthy of public and government attention; and priming, that is the intended effect of framing activities. These three concepts provide a framework for investigating issues of power as they relate to mainstream news media, social media and the *madosphere*. Entman's theoretical approach is underpinned by the notion of bias in the media – content bias which favours one side over another in news reporting, and decision making bias which describes how journalistic mind-sets and values result in consistent patterns of biased content. Framing has four functions, namely problem definition, causal analysis, moral judgement and remedy promotion. Agenda setting is the successful execution of problem definition which defines those problems worthy of public attention. Through framing, the audience is primed to think, feel and decide in certain ways. Framing is supported by a range of tactical devices such as use of metaphors, exemplars, catchphrases, visual images and appeals to principle (Zhou & Moy, 2007, p.80).

Sief (2003, p.263) applies Entman's four framing functions to a mental health context where the mainstream media habitually construct narratives of dangerousness and violence. The author argues that problem definition may suggest mental distress makes people violent; causal analysis may suggest the problem is that mental illnesses make people more likely to be criminals; moral judgements may be that people with mental illnesses are not able to care for themselves; and suggested remedies could be that people with mental illnesses should be jailed when they fail to comply with

treatment. The sum of the four functions of framing create a compelling narrative of dangerousness associated with mental health which promotes a solution of increased state compulsion with the effect of further restricting the lives of people living with mental health problems.

Repetition and reproduction of negative frames of mental health in the media translate into common sense normative negative assumptions in everyday public discourse. Consistent patterns of framing of mediated communication are known as content bias which has the effect of promoting the influence of one set of beliefs over another (Entman, 2007). Entman argues that the media's biases operate both within the minds of individual journalists and the institutions within which they work. They are embodied in rules and norms of their journalistic practices as well as production norms encouraged by market competition. These factors set the boundaries for public discourse on particular themes. They have the effect of enabling elites to further particular policy decisions whilst reducing the potential for protest or sanction by their voters. In the case of mental health, an outcome may be greater restriction of individual liberty or reduction of welfare benefits. The demonisation of individuals experiencing mental distress obfuscates the underpinning social and economic issues, which may be in the government's interests to avoid addressing.

Scheufele (1997, p.105) conceptualises the interplay between media framing and individual framing through which mass media messages are interpreted. Individual frames guide how individuals interpret and make sense of information. His typology of media framing conceptualises this interplay as an on-going process between mass media and audiences. He argues that individuals make sense of mainstream media

constructs through a mixture of personal experience, interaction with peers and interpreted elements of mass media.

Scheufele's conceptualisation of an active audience and construction of reality as a dynamic interplay between the individual and mainstream media is pertinent to my research in that it theorises active audiences who engage with mainstream media content. Engagement is further activated when individuals move beyond consuming and critiquing media content through to producing their own content which engages with, and provides alternative narratives to those found in traditional media frames. Online social networking platforms provide online public spaces where given issues can be discussed by citizens and which are open to empirical investigation. The way in which groups of citizens engage with mainstream media frames can therefore be subject to examination.

My research suggests that participants in the *madosphere* actively and self-consciously deconstruct and reframe mass media messages about mental distress. Secondly, alternative frames to those provided by mass media are given a platform through self-publishing sites such as blogging and Twitter. Scheufele's paradigm allows for a more active and engaged audience rather than the passive publics suggested in much of the mental health literature in relation to mass media which tend to simplify publics as passive receivers of negative frames and people accessing services as passive recipients of the negative consequences of those frames. The public nature of discourse in online social networks enables a light to be shined on engagement with negative media frames, which I argue is common practice within the *madosphere*.

In his typology of media framing Scheufele (1997, p.117) identifies the importance of journalists as audiences and their own susceptibility to the very frames they themselves use in their journalistic practice. These can be both conscious but also operating at the level of the unconscious mind. Sieff (2003, p.67) argues that frames are so pervasive that 'for journalists to learn to write about people with mental illnesses as productive members of society, when there is so much pressure to write negative, sensationalist news may also be difficult'. Whilst I was not able to interview any journalists in my research, the impact of competing discourses in online social networking sites, and the implications for journalists who are also engaging in those spaces, is worthy of further attention.

Numerous studies have produced empirical evidence that newspaper reporting of mental distress contain a predominant frame of either dangerousness or reduced responsibility. Positive stories are found to be significantly less frequent and connected to more well-known and accepted diagnoses such as depression and anxiety; these tend to be confined to the health pages as opposed to crime reporting which tend to be front page headlines (Philo et al, 1994; Wahl, 2003;Yamaguchi et al, 2013; Thornicroft, 2006; Birch, 2012; Philo, 1999). People identified as having a mental illness are portrayed first and foremost as a negative exemplar and only secondly as individuals rather than stereotypes. (Sieff, 2003, p.262)

The most recent evaluation of the Time to Change campaign has identified some changes to reporting of mental health in the mainstream media in the United Kingdom (Henderson & Thornicroft, 2013). There was a significant increase in the number of anti-stigmatising articles between 2008 and 2011. It is also the case that people with mental health problems were more likely to be quoted in mental health related stories.

However, there was no decrease in stigmatising articles over the same period. The authors draw a tentative conclusion that the increase in anti-stigmatising articles may be a result of increased public demand of journalists for this type of frame. It could be postulated that practices by ordinary citizens in online social networking sites take personal views into the public realm which then have the potential to influence journalistic practices.

In an age of global news reporting, research from other parts of the world is also pertinent. In an analysis of news media framing of gun crimes between 2007 and 2012 in the United States, it was found that gun violence reporting is likely to negatively influence public attitudes. Of stories that associated 'serious mental illness' with gun crime, only 16% clarified that most people with mental health problems are not violent. The authors argue that:

> The focus on SMI [serious mental illness] in news coverage of mass shootings may lead policymakers to emphasize addressing SMI as a solution to gun violence, as opposed to addressing other factors that contribute to the high overall burden of gun violence in the United States-only a small portion of which involves mass shootings-such as substance abuse, concentrated poverty, gang activity, and gun availability (McGinty et al, 2014, p.499).

A news media frame of 'mad' or 'mental illness' has associated expectations and interpretations of behaviour. If an individual is categorised as 'mentally ill' it is anticipated that they will act in violent, criminal and unpredictable ways. If an individual is reported as behaving in violent, criminal or unpredictable ways it is therefore also assumed that they must be 'mentally ill' (Coverdale et al, 2013). Coverdale et al argue

that we draw on cumulate narratives of mental illness when interpreting events and experiences and this strongly influences our common sense interpretations of events. When we see the term ‘mentally ill’ we therefore unconsciously draw on accumulated references to badness and dangerousness. News reporting takes place within the context of a back-drop of pervasive popular negative fictional representations of mental distress as typified by the films such as Psycho and Halloween (Anderson, 2003).

A ‘mentally ill’ frame not only has toxic implications for influencing negative public attitudes, it also increases the likelihood that individual explanations will be sought at the expense of understanding social or cultural issues that may impact on criminal behaviour (Coverdale et al, 2013). Reporting tends to include medical professional opinion at the expense of non-medical professionals, which Coverdale argues leads to an emphasis on medicalised approaches to mental distress. This marginalises community and psychosocial approaches which are an increasing part of ‘recovery focused’ mental health provision and can be seen as a more positive frame for understanding mental distress (Wahl, 2003).

Writing before the advent of social media and associated online self-publishing, Wahl (2003) critiques newspaper reporting for not routinely representing the voices and opinions of people with lived experience. He argues that that absence of views from people with mental health problems: ‘reinforces the public suspicions that those with mental illnesses are unable - too disordered, too disorganized, too unreliable - to speak for themselves’ (Wahl, 2003, p.1598). Wahl found that some reporters ‘express frustration that confidentiality issues and reluctance to disclose mental illness make interviews with consumers difficult to obtain’ (Wahl, 2003, p.1598). Wahl’s research indicates that journalists tend to carry the same views as the general public; they look

for information and interpret them into stories in ways which reflect public norms and attitudes about mental health. Their reliance on medical professionals to interpret stories and lack of access to people with mental health problems only service to reinforce this cycle.

The Press Complaints Commission's (2006) online guidance for reporting mental health issues encourages responsible reporting and advises journalists that inaccurate reporting could result in a potential breach of the Code of Practice, particularly Clause 1 (Accuracy) and Clause 12 (Discrimination). The guidance refers specifically to reporting that links mental health problems to violence and its effects on the public:

> In some circumstances epithets such as, but not limited to, "basket case", "nutter", and "schizo" may raise a breach of Clause 12 of the Code of Practice in discriminating against individuals who are mentally ill - whether detained or not - or a breach of Clause 1 (Accuracy). Not only can such language cause distress to patients and their families, by interfering detrimentally with their care and treatment, it can also create a climate of public fear or rejection.

England's Time to Change campaign has produced guidance for journalists which includes recommendations such as: 'Include contextualising facts - Remember people with severe mental illnesses are more likely to be victims – rather than perpetrators – of violent crime' and 'consider consulting people with mental health problems as part of your research, not just as case studies. They are experts in their own conditions' (2011). Guidance for responsible reporting of mental health provide a useful context in which to analyse the following case studies in which archaic stigmatising portrayals of mental distress are delineated whilst also resisted in the *madosphere*.

3.0 The Sun '1,200 Killed by Mental Patients'

In this section, theories of bias and framing are employed to examine ways in which The Sun newspaper uses journalistic techniques which exemplify stereotyping and stigmatising representations of mental distress in their front page story entitled: '1,200 killed by mental patients'. The Sun's front page headline on 7 October 2013 is followed with the subtitle: 'shock 10-year toll exposes care crisis' and article begins with the following paragraph:

> A SUN investigation today reveals disturbing failings in Britain's mental health system that has allowed high-risk patients to kill 1,200 people in a decade. The crisis has been highlighted by the killing of 16-year-old Christina Edkins — knifed to death by paranoid schizophrenic Phillip Simelane while heading to school on a bus.

The full article contains 22 images comprising sets of paired head shots with a photo of the perpetrator and the victim side by side. All but one image show the aggressors in unflattering and hostile poses juxtaposed with the victims with warm and happy expressions. The top image is of an informal smiling photograph of a young white woman alongside the unsmiling picture of a young black man in the style of a police 'mug' shot. Not only does this pairing reference background schema of innocence versus evil, it draws on prejudices of the reader in relation to colour and gender – the innocent white young female victim and the disturbed black male aggressor. In each description the perpetrator is referred to solely in relation to their diagnosis 'paranoid

schizophrenic' which frames the individual entirely and reductively in terms of their psychiatric diagnosis.

An application of Entman's (2007) four framing functions to the article illuminates a predictable pattern of stigmatising reporting as set out in the previous section. The problem definition is a failing health system that is allowing dangerous people with mental health problems to commit murders of innocent people; the causal analysis is that people with mental health problems have to be contained by health services to protect the public; moral judgements are that people with mental health problems are not in control of themselves and cannot be trusted to abide by society's rules; the suggested remedy is that there should be increased resources for services and improved communication between them. An appeal for increased funding is buried within the article and outweighed by the primary focus on an array of murder cases. The voices of people with lived experience of mental health problems are completely absent from the article and only 'experts' and families are included, both objectifying people and rendering their first-person experiences invisible.

A common syntactical structure in news reporting uses an 'inverted pyramid' format which begins with a strong headline in order to draw attention to key issues. The least important elements of the article can be found towards the end of the article and the busy reader can get the essence of the story by focusing on the headline and opening paragraph (Sieff, 2003, p.264). In this case the article opens with a dramatic headline which defines the perceived problem, namely that people with a mental health problem are violent. The highly stigmatising term 'mental patient' begins with a derogatory colloquial idiom and defines the protagonists of the piece in terms of institutional care. The combination of headline and sub-headline directly associates 'mental illness' with

violence and provides a connecting causal analysis to a failure of crisis care. More balanced content acknowledging that people with mental health problems are more likely to be the victims of violence than perpetrators is only found towards the end of the article. Use of the passive tense when describing perpetrators of the violent acts suggests responsibility lies with a failed system which has 'allowed high risk patients to kill' perpetuating a further common stereotype that people with mental health problems are not accountable for their actions or in control of themselves.

The article is framed as an 'exclusive investigation' crime story related to the impact of service cuts in the NHS. The framing of dangerousness and mental health problems in relation to government policy is not new. Anderson (2003) references a stream of homicide reporting in the 1990s that were explicitly related to the then government policy of 'care in the community' with the closing down of institutions. It could be argued that the frame of crisis care is a convenient one to justify a highly provocative and stigmatising article in relation to people with mental health difficulties. The agenda setting within the article makes a superficial argument to increase resources for mental health services; however the audience is primed to both be fearful of people with mental health problems and therefore, it could be argued, to demand more coercive treatment of mental health services. The implicit demand is for more emphasis on restrictive services over recovery-orientated services. For people with mental health problems, the article reinforces a public perception likely to increase stigma and possibly even violence towards them, whilst also reducing the likelihood that they will ask for help from mental health services due to shame and fear of coercion. In effect, the article increases the problem that it claims to be attempting to decrease.

The article is an example of not only content but decision making bias in its decisions about what is newsworthy. The Sun claims it has: ‘discovered 1,216 people were killed by patients with mental illness from 2001-2010 — an average of 122 deaths a year’. The remainder of the article draws on existing data sourced from The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness whose headline facts are drawn from data in 2010 and indicate that homicides are at their lowest since data gathering began in 2006 but that suicides have increased (Appleby et al, 2013). There is therefore a dissonance between the tone and presentation of the Inquiry report and editorial decisions by The Sun about what aspects to draw the audience’s attention to in the article. The headlines in the two pieces are in fact directly in opposition to each other with The Sun article showing a strong bias in presenting information to create a predictable narrative of dangerousness designed to reinforce beliefs and prejudices of their readers.

The Sun story was critiqued by The Guardian (Chalaby, 2013) in a sympathetic piece which called in to question the figures and referenced the stigma faced by people with mental health problems. The Independent reports on the response from charities and campaigners to the article, sourcing much of its content from Twitter:

> Labour’s health team wrote on Twitter that the front page “disgracefully reinforced” stigma, while Rethink Mental Illness wrote "Dear @TheSunNewspaper the number of homicides by ppl w/mental health problems has gone *down*. Front page is irresponsible & wrong." Sue Baker, director of mental health awareness charity Time to Change wrote “We are still picking up the pieces from terrible headlines 'mad psycho killers' mid to late 90s. Whatever the agenda this coverage harmful.” Alastair Campbell tweeted:

> “Constant media linkage of violence and mental illness leads to violence against the mentally ill rather than by them. #stigma #timetochange.

On the same day, an article in The New Statesman (Penny, 2013) led with the headline: ‘The Sun's fear-mongering about mental health is what's really monstrous.’ These headlines are just some of numerous articles and blogs that can be found on the Internet critiquing this story. A Google search undertaken on 18 July 2014 produced 228,000 hits with the search term ‘the sun 1200 killed by mental patients’ illustrating that it was widely discussed on the Internet. An online petition was started on change.org by a psychology teacher who explained in her introduction that she has family experience of ‘mental illness’. The petition reached 84,603 signatures (Lockley, 2013). The Sun published a correction on 23 October in their ‘clarifications and corrections’ section of the paper in which the following is stated: ‘The Sun recognises that the vast majority of people with mental health problems pose no threat to anybody and are much more likely to take their own life or self-harm than be a risk to others’ (Bloodworth, 2013).

The Sun article bears all the hallmarks of clichéd and negative reporting which associates mental distress with violence. The article is not only inaccurate but uses clichéd frames to invoke fear and emotional distance between people with mental health problems and the public. The article is emblematic of agenda setting bias in the mainstream media. The most recent research in newspaper reporting in relation to mental health has found that journalistic association of people with mental health problems with dangerousness has reduced over a four year period between 2008 and 2011. In 2011 14% of articles included danger to others compared to 21% in 2008

(Henderson & Thornicroft, 2013, p.66). This article therefore appears to belie a more positive trend in news stories related to mental health.

Whilst the broadsheet mainstream news media responded to The Sun article using received journalistic standards, the *madosphere* engaged in quite different ways. At the time of the article, the World of Mentalists had been incorporated into another blog entitled Mentally Wealthy and a number of articles were posted on this site. Rather than engaging in debate over use of accurate figures and so on as in articles within mainstream broadsheets, the blog leads with the headline: 'THE SUN has got it's tw*t on – @TheSunNewspaper hacks at #MentalHealth again' followed by the capitalised sentence in bold red font: 'HERE WE GO AGAIN' and then a screen-shot of the front page of The Sun headline. Underneath the photograph are the words: 'pretty certain I don't need to remind most of you 'why' this kind of reporting is not acceptable, and I'm sure you'd like to tell them some facts.' The blog post ends with the address and telephone number of the newspaper.

The blog is followed by a longer piece posted on the same day entitled: 'The Sun hacks #MentalHealth and I was worried about using the 'T' word.. #whatstigma #ukmh @TheSunNewspaper'. The article opens with the introduction: 'There's just not enough outrage or affront in this entire universe to cover just how much injury is caused by the desecration of people who have encountered mental ill health'. The post then goes on to compare The Sun article with a television documentary called 'Inside Broadmoor' aired on Channel 5 the night before and is summarised as follows:

> This type of TV or the hack reporting from The Sun… it's the 'thick' end of the wedge which bites into every prejudice currently being played against the

> disabled; unemployed; and mentally ill. It reinforces societal beliefs which allow for the marginalising of the perceived underdog or the undeserving poor. It's how divide and rule works and how the tide of disability anti-stigma campaigning is being turned back 150 years…

The article also includes a series of tweets about the documentary showing the reaction on Twitter by some people watching the programme. It includes tweets such as: '#insidebroadmoor Why simply lock up people too dangerous to release? Use them to test medical drugs for cancer/aids/etc.' The embedded tweets offer a visceral insight into what is already known from the empirical research on the effects of public attitudes by negative media reporting, namely that it can adversely influence people's views.

Shcheufele's conceptualisation of framing at an individual level and as a process of feedback to journalists, is pertinent to an exploration of the *madosphere's* response to The Sun's headline. Individual framing is based on people's pre-existing schema of mental distress, and in the case of the *madosphere* it is evident that participants are highly engaged in discourses related to disability activism. The tone of both posts is one of resistance and the apparent purpose is to challenge and ridicule The Sun article. Both posts are predicated on a readership with similar views as indicated by the fact that neither attempt to state a coherent position or make a logical case to challenge the article. Instead they show a highly emotive rejection of the article followed by a call to action, namely to complain directly to The Sun newspaper. Both articles perform a function of building a frame that resists that deployed by The Sun. Entman's four stages of framing are also pertinent here – the problem is defined as The Sun's 'not acceptable' reporting; the implied causal analysis is that mainstream media reporting is prejudiced as suggested by the phrase 'here we go again' the moral judgement is that

The Sun stigmatises people with mental health problems, the remedy is to challenge The Sun newspaper with ‘some facts’ and this call to action is followed with contact details. Frustration and anger towards The Sun newspaper are indicated by use of swearwords and capitalisation of the phrase: ‘HERE WE GO AGAIN’ in red font.

In conclusion, theories of framing as conceptualised by Entman and Scheufele illuminate The Sun article as containing all the hallmarks of stigmatising reporting familiar within the mainstream news media. The *madosphere* is a site of resistance where individuals re-frame and resist the discourse of dangerousness and violence with a call to action to their compatriots. Unlike other parts of the mainstream media which rely on facts and argument to state the case against The Sun, the *madosphere* is speaking to peers and assumes a community with similar knowledge, values and beliefs. The *madosphere* therefore reinforces those beliefs through and expression of anger and an emotive rejection of the article. Its purpose appears not to be to engage with a mainstream audience but to reinforce a sub-culture of resistance and strengthen ties amongst a group of people already actively engaged in resisting dominant public discourse in relation to mental health.

4.0 Asda ‘Mental Patient’ Costume

The ‘Asda mental patient’ event illuminates the interplay between an official online corporate channel, social media and the *madosphere*, as well as the mainstream news media. In this case study I draw on both theories of framing, active citizenship and social movements as analytical tools. I consider the extent to which social media provide what Loader (2008, p.1930) refers to as ‘interactive communications channels for interpretative framing and identity politics which may increasingly mash-up activist

digital creations and mainstream media outlets'. I particularly focus on the role of humour as a subversive tactic in challenging dominant mainstream paradigms of mental distress.

Firstly I begin with a brief description of the key events within this case study. The episode took shape on 26 September 2013 and was precipitated by a consultant psychiatrist making a complaint to Asda George when he came across a Halloween costume on their Internet site entitled: 'Mental Patient Fancy Dress Costume' with the caption:

> Everyone will be running away from you in fear in this mental patient fancy dress costume. Comprising of a torn blood stained shirt, blood stained plastic meat-cleaver and gory facemask it's a terrifying Halloween option.

Not satisfied with the response from Asda George which indicated that he may get a response within two weeks, the psychiatrist emailed the chief executive of his local Trust and with a link to the website and a request that the profile of the issue should be raised through formal channels. However, instead of employing formal channels, the chief executive tweeted Asda his disapproval and later on that evening the story 'went viral' on Twitter as it expanded beyond the mental health community. A review using the analytics engine Topsy shows that during the twenty four hour period from 12am on 26 September there were 22,371 tweets mentioning the word Asda, compared to 3,779 in the twenty four hour period before. The measurement and analysis of tweets to ascertain evidence of social action is in its infancy but the Demos analysis tool Digital Observation suggests that this is a growing area of development in social research (Milner, 2015, p.2).

The next day the Asda ‘mental patient’ story was the top headline in virtually all UK media across print, radio and TV. According to Time to Change’s in-house (unpublished) information that was made available to me, the story was featured in the following national print media: Daily Mail, Daily Mirror, Metro, The Independent, I, Guardian, FT, Independent; national broadcast media: Channel 4 News, BBC News, Sky News, Radio 1 Newsbeat, BBC Radio 5 Live, BBC Radio 4 Today programme, BBC Radio 2 Jeremy Vine Show; online media: ITV.com, Channel 4 Online, Huffington Post, Metro.co.uk. mirror.co.uk, Yahoo; regional print and radio included Evening Standard, LBC, Yorkshire Post, Yorkshire Evening Post. It was also featured in to a number of trade publications, including Retail Bulletin, Marketing Week, Wired, Grocer, Mental Health Today. Asda not only apologised, but agreed to give the profits that they estimated they would have made from sales of the costume, towards the campaign. Tesco followed suit and also made a donation. Amazon and eBay were stocking similar items which have all since been removed.

This event is noteworthy in that it signals a disruption of mainstream media controlled framing and agenda setting as articulated by academics such as Entman (2006). In Scheufele’s (2006, p.115) process model of framing, the building of media frames is influenced by both audience expectations and frames suggested by interest groups with journalists also acting as audiences of public opinion. Journalists are increasingly willing to make use of user generated content in mainstream media and this has implications for social movement activists who increasingly need to create topical, relevant and easy to use content in order to compete successfully in interpretive framing (Loader, 2008, p.1982).

Consideration of the potential power of engaged citizens to influence mainstream media agendas, is pertinent here. The interplay between mainstream media and citizens who engage in discussion about given issues online is described below:

> A news event that, for whatever reason - whether it be journalists' judgment of newsworthiness or censorship - initially receives insufficient coverage. However, netizens show great interest in this event and discuss it intensively online. Online discussion adds meaning and news value to the event and turns it into an issue. Subsequently, the media come back to report this issue (Zhou & Moy, 2007, p.83).

The affordance of online social networks to remove spatial and temporal limitations of communication, enable activism based on identity politics that are not solely geographically bound to issues of place (Loader, 2008, p.1928) are relevant to this case study. People who may have been loosely connected were able to communicate on this topic and in effect amplified it to the extent that it moved into the mainstream media.

In contrast to conventional wisdom within social movement theory, it could be argued that activists took a key role in influencing the agenda setting of national and international media organisations in this instance (Benford & Snow, p.626). Unlike The Sun case study, where conversations in the *madosphere* focused primarily on strengthening common bonds, on this occasion information sharing also had an external focus with the intention of influencing sentiment and action.. The use of protest by social actors who have weak political power is not uncommon and their intention is often to mobilise groups and corporations as well as politicians to take action. Twitter

was an effective channel to mediate this protest to a mainstream audience (Loader, 2008, p1929). In his typology of socio-technical capital, Resnick (2001, p.1) argues that existing connections and interactions between people in online social networking sites can be effectively leveraged to promote social change:

> A network of people who have developed communication patterns and trust can accomplish much more than a bunch of strangers, even if the two sets of people have similar human, physical, and financial capital available. The productive capacity can be used to benefit individuals, the network as a whole, or society at large.

It could be argued that the *madosphere* was the bedrock of established communication patterns between people talking about mental health, from which conversations about Asda could emerge. The *madosphere* was a space and set of practices where people were already discussing the issues and so relationships and networks in place from which the conversation could grow and expand. Despite this external focus, it was also an opportunity to strengthen existing bonds according to Merlot:

> It [Asda mental patient event] was also used as a platform for a lot of people to talk about stigma, so it was also quite cathartic for people, to pin it on to Asda.

An interview with the Time to Change Team communications team indicates that not even the main anti-stigma campaign in the UK was prepared for the extent of discussion that took place on Twitter:

> I think, I picked up on it on my own Twitter seeing someone else tweeting about it fairly early on in the evening, maybe 8 or 9 o'clock, the evening before the day where it all kicked off. ... I remember the evening ended with me sitting on my laptop about midnight writing a statement because [name] had been asked to go on the Today programme the next morning, which is when we knew it had become … because sometimes at the beginning you can't get a sense, there are so many things bubble up on social media or a couple of people comment on and then it goes away again, kind of when you get a sense 'this is actually huge' I think, my personal take on it was 'oh my god I cannot believe they're actually selling this!' you kind of know it's something so outrageous that it kind of deserves our attention … so it was clear very early on that this was something that we would want to say something about, partly because of the outrageousness that the costumes were being sold, also because the sense that something was building on Twitter about it.

The social media community interested in discussing mental health engaged in specific tactics aimed at diffusing the conversation to public figures with a mental health association and to journalists. This had the effect of networking the conversation to new networks as well as connecting it to mainstream media. Key public figures associated with the Time to Change campaign, such as ex-footballer Stan Collymore and political pundit Alastair Campbell engaged in the conversation with the effect of further dispersing it to additional networks whilst also framing it in terms of moral judgements about the costume and the actions of Asda. The mainstream news media drew extensively on Twitter for the content of their stories on this issue.

The Asda ‘mental patient’ case study can therefore be seen as a successful example of citizens and mental health activists using Twitter to distribute their message across networks and ultimately into the mainstream media. In this instance it was thousands of ordinary people who influenced journalistic decisions about what was newsworthy and set the agenda for news on that specific day. Whilst the event may illuminate opinions of Twitter users who are sympathetic to mental health issues, it is not possible to draw broader conclusions about public opinion. The case study is noteworthy in the context of my research as it illustrates how people engaged in conversations about mental health in the *madosphere* were able to distribute their message effectively and influence mainstream media reporting.

The use of humour and satire as subversive tactics is a continuous thread in my exploration of the *madosphere* in which levity is frequently employed to throw light upon an issue or to puncture the ego of a professional’s misplaced pomposity. The use of humour has been theorised within the social movement literature as a core communicative and emotional strategy for activists. Kitz-Flamenbaum identifies two primary types of humour, that directed externally in the form of tactics and frames and that directed internally within a group as a tool of leadership and to sustain collective identity (2014; p.295). Ellie used humour as a means of sustaining relationships within the *madosphere* and satirising what she regarded as an everyday banal experience of stigma in her response to the event:

> I did change my Twitter profile to say something about the meat cleaver, I often walk around with them.

The notion of ‘incongruity theory’ in relation to humour is particularly pertinent to social movements, where two incongruous ideas are put together in order to challenge predictable expectations, therefore disrupting received beliefs in order to attain a goal of social action (Loader, 2008, p.1929). People within the mental health community on Twitter deployed a number of memes to create this dissonance during the Asda ‘mental patient’ episode.

Firstly, they took the #chosenbyme hashtag that was being used by Asda to promote engagement on Twitter with their products and used a culture jamming technique in which protest is manifested through the adoption of commercial artistic and design practices to invert the original media message of the advert often through the use of satire, irony, parody or spoofs’ (Loader, 2008, p.1929) to disrupt it with a new meaning. This tweet is a typical example:

> ‘My absolute @Asda favourite product is your mental patient fancy dress costume because, you know, that's just what I look like! #chosenbyme’

As well as disrupting an Asda advertising method and shifting its meaning, activists also increased the potential for the meme to spread to Asda shoppers who might look at the hashtag and see unfamiliar tweets which raised their awareness of the issue.

Secondly, the #mentalpatient selfie meme employed the ubiquitous social media phenomenon, the ‘selfie’ as a satirical tool. People with lived experience of mental health problems took photos of themselves and uploaded them to Twitter with comments such as:

> Dear @asda, this is what a #mentalpatient looks like. End the #stigma. It's 2013 not 1813.
>
> This is one of my #mentalpatient costumes. I have a range of other styles & colours. @MindCharity #whatstigma.

A ‘selfie’ is described in the online Oxford dictionaries (2013) as: ‘A photograph that one has taken of oneself, typically one taken with a smartphone or webcam and uploaded to a social media website’. It was named as the Oxford dictionary’s ‘word of the year’ in 2013. It could be argued that the classic selfie is intended by the creator to present themselves to others looking in ways and in contexts that increase their standing and social capital. The ‘selfie’ could be argued as the ultimate expression of a self-obsessed individualised society seduced by the need to look good and be seen to be having fun at all times. In contrast, much of the literature on mental health and Internet points to the affordance of anonymity as having a central role in enabling people to access information without disclosing shameful information about their mental health history (Schrank, 2012). When people with experience of mental health problems began sharing selfies with the hashtag #mentalpatient they were therefore disrupting received practices on a number of levels.

First and most obvious there was a direct challenge to the #mentalpatient costume – subverting this stereotyped portrayal with that of an ordinary person. A selfie was a shortcut, a simple embodied visual means of creating incongruity and challenging the stereotype and was one which was well suited to the limited word count of Twitter. Secondly, implicit in the sharing of ‘selfies’ was a sense of pride and defiance and shared sense of collective identity. People were ‘outing’ themselves as having a mental

health problem. They were choosing to defy the affordance of anonymity and choosing to share their identity and to connect it with mental distress. They were making a public act of sharing a photo of themselves a political act. An individual act became part of a collective act as the meme grew during the evening. The use of costumes to create humour through incongruity is a regular feature of social movement activism (Kutz-Flamenbaum, 2014, p.298). However, in this case the ritual was reversed as the activists parody the Halloween costume by posting ordinary pictures of themselves.

The use of humour has been theorised as a tactic used by activists to relax and engage audience members in a way that may allow them to hear a new message that they may be unfamiliar with (Kutz-Flamenbaum, 2014, p.298). This feature of the 'mental patient selfie' was identified by the Time to Change campaign interviewees as anticipating challenges from accusations of being 'killjoys' or censoring by those who were not offended by the costume:

> I think that [humour] had a huge role to play in making seem like it's not just the PC brigade, will people just think 'oh they're the PC brigade just trying to tell us what we can't do and what we can't say and trying to stop us having any fun, it's just a joke, why can't they see that'. So I think bringing the humour in through the mental patient selfie helps to head that off a little bit, we showed… our movement showed… that we did have a good sense of humour, people weren't being po-faced about it, um which I think worked really well, and it was an effective way of getting a serious message across, more effective than just saying this wrong.

The #mentalpatient ‘selfie’ meme was considered by the Time to Change campaign interviewees as setting a benchmark in citizen led protest that both strengthened collective identity whilst offering simple visual messages that could be used by mainstream media:

> Because the whole thing about the selfies was that there were lots of levels to it that were really conducive to um gathering people together to make a change, so it had a picture of a person who could look very normal, so other people could see ‘oh people with mental health problems look like me’ then it was also people giving their stories, some people were coming out for the first time and saying ‘actually I’ve been a mental patient and this is what I look like’ or ‘did you know this?’ and telling it to their followers’ it had the humour as well and I think it’s given people an idea of a formula which can make a change, if you involve people’s stories and get them behind it then maybe being diplomatic about it rather than pointing the finger maybe using humour if that’s appropriate, and also it was very digitally led and journalists have seen this as well, it must have been great content for them as they’ve got load of people posting pictures that you can then use and celebrities are getting involved, hopefully it seems to be that it’s been a bit of a benchmark about what can be achieved.

The ‘Asda mental patient’ episode also became the content for a number of well-known comedians who comment on current issues in the media via their Twitter accounts. It is not apparent that these comedians were motivated by a social cause or particular concern about representation of mental health in the public sphere. However, their jokes on Twitter did have a social impact in so far as they expanded the message to wider audiences than might have otherwise been possible. Their humorous asides such

as Jack Dee's: 'Just got my Halloween costume. Going as the managing director of Asda' lent themselves to being shared by people who might not have a view about the social impact of the costume, but who shared it because they were entertained. It may have translated into a different narrative – one that takes pleasure in the 'dressing down' of powerful corporates – rather than the narrative of mental health stigma. Therefore the message was distributed far beyond those people than might have actively cared or been personally affected by the actual issue, which in turn may have spread it to people who do care about the issue but might not have otherwise become aware of it. This billowing effect created a virtual tornado, swirling the conversation up and spitting it out in unexpected places. Humour enabled it to be shared more widely than if the issue had been solely framed as a serious concern, which meant it extended beyond a narrow group of people primarily concerned about the topic of mental health stigma.

5.0 TWOM and re-mediation of mental distress

In this section, I draw on interviews and field notes to consider how TWOM mediates and frames discourses of mental distress in ways which resist those found within mainstream media. I use Entman and Sheufele's theories of framing as a framework to understand how alternative narratives are created which deconstruct patterns found in mainstream media.

Whilst patterns of mainstream media representation of mental distress primes the audience to evoke feelings of shame, fear or pity, remediation within social media spaces produced by people connected to mental health tends to do the exact opposite. As Tanya told me: 'it's easier when you know that you're speaking with people who get

it, aren't likely to judge you …. It makes it easier for people to be more open and less ashamed in offline situations too'. For Tanya, social media spaces are safe spaces to build confidence and resilience to manage the offline world. This is mediation of mental health produced by and for people with mental health problems.

Both Henderson and Birch argue that people with experience of mental distress need to become active participants in the media productions process in order to influence its content (Henderson, 1996, p.36; Birch, 2012, p. 57). My research indicates that, in the *madosphere*, people with mental health problems are self-mediating their experience through creation of user generated content. However, there is no evidence, beyond exceptional events such as the 'Asda mental patient' episode, that such content influences mainstream media production. In fact the majority of the content is not intended for a mainstream audience – it appears to be, as Tanya's comments suggest, primarily focused on building and sustaining relationships between participants who hold non-mainstream views about mental health and service provision. This collective action of deliberating the representation of mental health in the madosphere may in itself have positive effects of the wellbeing of participants. Social action theory suggests that collective action can confer skills on participants such as problem solving, resilience and compassion that enable them to succeed in other parts of their lives. (Miller, 2015, p.1) It could be argued that participation in the *madosphere* has a protective and positive effect on the mental health and wellbeing of its participants.

Whilst the *madosphere* does not actively attempt to influence mainstream news media, it does habitually remediate news stories and critique news reporting of mental health. Edward describes how this works:

> Sometimes things are dealt with, with a more informed perspective [in TWOM], people are bringing in their own lived experience and actually I think one kind of really good example was with the murder of Lee Rigby, and you may remember on the news there was a guy whose name I can't recollect, giving a long rant to the camera, with a blood stained knife in his hand, saying why he'd killed this guy. [In the media] people were saying he's obviously mentally ill, and then on TWOM people were saying well he's obviously not mentally ill, he's very lucid, given a clear account, he's not thought disordered or paranoid, he's given a very logical, within his own frame of reference, rationale of why he's killed this man.

This example illustrates how a stereotyped mainstream media frame of madness associated with mental illness is deconstructed in the *madosphere* by people who are experts in mental health either as a result of professional training, lived experience, or both. The problem definition which associates dangerousness with mental distress is deconstructed in the post entitled: 'Why the #Woolwich murder is most certainly not mental health related'. The author critiques reporting of the murder of Lee Rigby which took place on 22 May 2013, and conversations about the murder taking place on social media sites such as Twitter by the non-mental health community:

> Much more well-intentioned, but no less wrong, has been the insistence I've seen repeated on social media that this atrocity 'must be' due to a mental health issue. I've even seen this suggested on Twitter by some doctors (though they weren't psychiatrists). The bottom line though is that there simply isn't any evidence for that.

The author goes on to argue that the association of unspeakable acts with ‘mental illness’ is part of a desire to find individualised explanations when society can’t accept actions that people take which have their own intrinsic logic: ‘The suggestion that they were mentally ill seems to boil down to the idea that if people do something that the rest of society finds difficult to fathom, then the only explanation is that they’re mentally ill’ and then brings an alternative assessment of the likelihood of someone experiencing mental distress to commit a crime: ‘You don’t need to be mentally ill to commit an atrocity. In fact, mental illness can be a severe hindrance. Just try organising a pogrom of the ghetto when you’re too paralysed by social anxiety to leave the house’. This theme is continued in the comments section under the post: ‘I always remember when Bin Laden was referred to as ‘psychotic’ as if to add greater heinousness to his crimes, good grief I’ve never met anyone defined as psychotic who would be organised enough to orchestrate worldwide terrorist activities. It’s like ‘loony left’ and all the other political and media slurs, using mental illness language is somehow acceptable where racist slurs are not. Mentalism is the last civil rights struggle’.

It could be argued that this form of remediation comes from a social and political stance, it is arguing against individualised meaning making that provides simplistic narratives for the mainstream media to articulate. The *madosphere* actively deconstructs simplistic media frames of dangerousness and mental illness and attempts to expose bias and agenda setting within the mainstream media.

An example of a topical mental health issue taken into the TWOM space and deliberated upon can be found in a TWIM post about the Hyundai advertisement that came under the gaze of the mental health community and media more widely when a

woman called Holly Brockwell (2013) wrote an open letter, an extract of which is included in the post:

> When your ad started to play, and I saw the beautifully-shot scenes of taped-up car windows with exhaust feeding in, I began to shake. I shook so hard that I had to put down my drink before I spilt it. And then I started to cry. I remembered looking out of the window to see the police and ambulance, wondering what was happening. I remember mum sitting me down to explain that daddy had gone to sleep and would not be waking up, and no, he wouldn't be able to take me to my friend's birthday party next week. No, he couldn't come back from heaven just for that day, but he would like to if he could. I remember finding out that he had died holding my sister's soft toy rabbit in his lap.
>
> Surprisingly, when I reached the conclusion of your video, where we see that the man has in fact not died thanks to Hyundai's clean emissions, I did not stop crying. I did not suddenly feel that my tears were justified by your amusing message. I just felt empty. And sick. And I wanted my dad.

Rather than review the mainstream media response to the open letter and the subsequent removal of the advertisement, instead the editor references conversations about the event that have taken place in the *madosphere*. One such blogger had taken some of the comments on the Brockwell's blog post such as 'she has no sense of humour' and then appraised the underlying values beneath. The blogger presented an alternative narrative which points to the complexity of suicide. Despite the fact that Hyundai had removed the advert and issued an apology, the author noted that it is still

easy to find in an Internet search. The post does not go into any depth on the issue but finished with a question: why did they make such an advert in the first place?' Employing a typical blogging method, the author invites comment, question and a discussion on the topic rather than giving a polished article with a polemical stance. This open conclusion to the piece invites conversation and opinion to be expressed as well as reinforcing a sense of community through invited reciprocation. It also lowers the bar for participation in the blogosphere due to its incomplete nature – putting a comment or a piece up and inviting dialogue.

In conclusion, the *madosphere* actively positions itself a site of resistance to mainstream media reporting of mental health which perpetuates negative and stigmatising frames. Not only does it give primacy to first-hand accounts of mental health by curating bloggers in the weekly TWIM, it also critiques mainstream news reporting on a habitual basis. The *madosphere* comprises a number of elements of a social movement in that it is characterised by fluidity, flexible membership, comprising networks of individuals who do not have fixed or hierarchical structures (Loader, 2008, p.1922). However, unlike many social movements, predominant activity within the *madosphere* prioritises strengthening relationships and building shared identify over externally focused protest. It is only in exceptional circumstances that conversations within the *madosphere* permeate non mental health focused social networks and the mainstream media.

6.0 The Institution - Retreat or Reassertion?

To what extent do the events described in this chapter signal a positive shift in public attitudes towards mental health associated with increased pressure for mainstream

media and corporates to adapt media frames and bias? It is pertinent to note that exactly ten years previous to these events, The Sun newspaper was similarly berated for its highly stigmatising front page headline which included the phrase ‘Bonkers Bruno’ in relation to Frank Bruno’s admission to a mental health inpatient unit. The phrase was changed in later editions to the more sympathetic ‘sad Bruno’ as a direct result of a public outcry at the headline (Bailes, 2004).

In his editorial on Frank Bruno, Bailes (2004) posed the question: ‘Genuine compassion at last… or had they [The Sun] just made a bad judgement call on public opinion?’ or even more uncomfortably, was it less about public opinion and more the fact that the ex-boxer was a much loved public figure that resulted in such outrage?. The fact that The Sun’s front page headline on 7 October 2013, and just after the ‘mental patient’ events, was ‘1200 Killed by Mental Patients’ suggests that perhaps things have changed less than might be expected. A recent content analysis of local and national newspaper articles between 2008 and 2011 found that whilst there was a significant increase in anti-stigmatising articles during that period, there was no significant decrease in stigmatising articles. The researchers were not able to ascertain whether the increase in anti-stigmatising articles was reflective of increased awareness of journalists or shifting public demand for articles that represent mental health; they conclude that the latter is more likely (Thornicroft et al, 2013, p.68). Scheufele’s (2006) framing process which conceptualises active audiences feeding back to, and influencing, journalists and mainstream media, provided a theoretical framework to understand this process.

A frame analysis suggests that public opinion needs to influence bias and agenda setting in the mainstream media in order to shift journalistic practices. However,

background narratives of associating mental illness with dangerousness seem to be too embedded in the public consciousness to be easily erased. Public opinion is increasingly convenient for journalists and corporations to gauge as it is made visible through public conversations taking place on platforms such as Twitter. Whilst in 2003 the outcry was from charities, in the 2013 the outcry was led by ordinary people and only then harnessed by charities and campaigns.

Dom's [Head of Social at Asda] reflections on the extent to which the incident affected Asda are illuminating: 'What's that lasting legacy out of it? It's hard isn't it to pinpoint has anything been materially changed? I'd hope so, um but my slight worry is that, without that corporate memory, uh what will the next iteration of this be?' The legacy of this event is perhaps for a corporation to work out how it can organise itself sufficiently to respond in an agile way to public opinion, rather than whether its practices might have changed to be less stigmatising towards representation of mental distress.

It could be argued that the primary concern for an institution or corporation - whether it is The Sun newspaper or Asda supermarket chain - is profitability; in order to remain profitable it must align itself with public demand and public expectations. This point of view is argued cogently within one of the last TWIMs before TWOM came to an end:

> There's probably a strong degree of sincerity to the [Asda's] apology, and it sounds as though their head of social media is a decent guy who does care about mental health issues. Even so, I'm sure the board of directors at Asda will have their gigantic Walmart profits to console them.

Speaking in general terms about how the mainstream media discuss mental health, Tanya reflected: ‘Mainstream media is business. They have different aims – ratings, selling newspapers, making money. They will have different priorities. They are more likely to sensationalise, rather than give an accurate picture’. Bill also recognises the gap between everyday experiences of mental distress and its representation in the mainstream media where people who are ‘hurt individuals’ don’t conform to media desires for a dramatic story: ‘we want to know about someone who’s gone into the playground and killed a load of children because that’s going to sell a paper’. Bill bemoans the negative impact of sensationalised reporting on the day to day experience of people with mental health problems. He believes that such reporting: ‘casts intolerable, incalculable damage on some many others who are suffering’. Tanya and Bill’s viewpoints are typical of those expressed by my interviewees and are indicative of a highly sceptical attitude towards mainstream media representation of mental health. Their views are encapsulated by (Trish’s) damning and dismissive comment: ‘mainstream media is driven by a hidden agenda and I have a low tolerance for bullshit’.

It is not possible to draw general conclusions from the two events I have explored in this chapter. However, the historical context of the ‘Bonkers Bruno’ case does suggest that public opinion and journalistic practices may have changed less than might be hoped by mental health campaigners. The key conclusion from my ethnographic research is to understand how people having conversations about mental health in the *madosphere* and in Twitter and on blogs provide alternative frames for mental distress. In the case of the Asda ‘mental patient’ case study, citizens were able to influence all of the agenda from problem definition, causal analysis, moral judgement and remedy promotion. This is significant both in terms of strengthening collective identity for people

having conversations about mental health in the public sphere, and in terms of influencing public discourse about mental health.

Chapter 7

Fractured Power and Expertise

The technology that makes virtual communities possible has the potential to bring enormous leverage to ordinary citizens at relatively little cost – intellectual leverage, social leverage, commercial leverage, and most important, political leverage. But the technology will not in itself fulfil that potential; this latent technical power must be used intelligently and deliberately by an informed population. Most people must learn about that leverage and learn to use it, while we still have the freedom to do so, if it is to live up to its potential. The odds are always good that big power and big money will find a way to control access to virtual communities; big power and big money always found ways to control new communications media when they emerged in the past. The Net is still out of control in fundamental ways, but it might not stay that way for long. What we know and do now is important because it is still possible for people around the world to make sure this new sphere of vital human discourse remains open to the citizens of the planet before the political and economic big boys seize it, censor it, meter it, and sell it back to us.

(Rheingold, 1993, xix)

1.0 Introduction

In this chapter I offer an account of disrupted relationships and fractured expertise between people accessing and providing services in the *madosphere*. Drawing on my

own experience as a participant observer, in addition to field notes and interview data, I ask who is participating in the *madosphere* and what does their participation mean to them? What do they get from the *madosphere* and what are the points of commonality and difference for people with mental health difficulties and practitioners? I consider the extent to which individual practices are in alignment or tension with institutional practices, and to what extent is deference to professionals and the authority of the institution being disrupted. I ask how people living with mental health difficulties view professionals and professional expertise in the *madosphere*? And how do mental health practitioners relate to people with expertise from their lived experience? Who are the imagined audiences of participants in the *madosphere* and how does this shape how they present themselves? What choices do people make about what to share and what to keep hidden in the *madosphere*? Drawing on literature related to social capital, I examine interview data which illuminates the meanings, benefits and drawbacks people experience from their practices in the *madosphere*. Lastly, I explore the extent to which power and expertise is fragmented or reinforced.

2.0 Purpose and social capital

A key theme in my interviews has been to understand people's purpose for participating in the *madosphere*, their reasons for engaging in online social networks and what they get from them. A number of common themes emerged in my interviews which suggest participants experience a sense of community and peer support, benefit from exchange of resources and gain personal status and career progression. These experiences are both different and similar for people accessing services and mental health practitioners. They are all characterised by a tension with institutional practices and a fracturing of the traditional locus of institutional or professional expertise. The gains people

experience from participation in the *madosphere* can be understood within a theoretical framework of social capital which conceptualises networks of relationships in everyday life.

Baym (2010) draws on theories of social capital to illuminate the benefits that people get from their relationships in digital contexts and I draw on her work to explore issues of power and empowerment in the *madosphere*. Social capital is defined by Putnam (1996, p.34) as: 'features of social life — networks, norms, and trust — that enable participants to act together more effectively to pursue shared objectives'. According to Baym (2010, p.82) the Internet lends itself to 'bridging' social capital whereby resources are exchanged between people who do not have strong relationships and who differ from each other. However, 'bonding' social capital is also a feature whereby online communities offer each other emotional support often found in close relationships (Ellison et al, 2010, p.128; Zhao et al, 2013). As we shall see, bonding capital between peers can be a particularly strong aspect of support between people experiencing mental health difficulties online, to the extent that some people became quasi-professionals; taking significant responsibility for others' emotional wellbeing. In the *madosphere* expertise is not only the preserve of the trained professional but also of the individual derived from lived experience and empowered by their engagement with the *madosphere*. Expertise is not only fractured but it is reversed and reconstituted. Bridging social capital enables people, who may be isolated due to stigma and discrimination as a result of their mental health diagnosis, to find others with similar experiences. With a reduction in health and social care services characterised by closure of day centres and other places for people experiencing mental health problems to connect with peers (Wahlbeck & McDaid, 2012) the affordances of social networks to accrue social capital come in to sharp relief. In a blog post for BBC Ouch

online, Charlotte Walker (2015) an award winning mental health blogger, describes the benefits of peer support online:

> Loneliness and isolation are major issues for people with mental health problems. Many people who I follow on social media are housebound by conditions like depression, obsessive compulsive disorder or anxiety. Others have partners and friends yet, despite this, don't get the level of support they sometimes need. Well-meaning loved-ones can inadvertently belittle people's difficulties, expect an instant recovery or simply not know how to respond. Social media can help to fill that gap.

The affordance of online social networks to open up new pathways of communication enable people accessing mental health services to share information, knowledge and experiences with each other; knowledge that is self-mediated rather than mediated through an exchange imbued with power from professional to patient. Eva explains how professional restriction of access to the Internet can negatively impact people accessing services:

> It’s so hard to get access to the Internet on [mental health] units, and yet for a lot of people, especially young people with mental health problems it is one of their main sources of support, because if you don’t feel you can tell your school, or talk to your family and friends, if you don’t have a GP who listens, or if you haven’t told anyone, no one apart from your family knows you are there, or if you’ve got depression, anxiety, can’t speak on the phone, don’t want to leave the house, have agoraphobia, the Internet is your lifeline.

Mel captures the powerful potential of peer sharing and learning on Twitter - expertise born out of experience where teaching and learning are reciprocated equitably:

> I see people with [diagnosis] come on, they are acting out and doing this and saying that, and you actually see people learning on Twitter about how to be. So instead of coming on and going 'I've just slashed my wrists' or 'I've...' you know, and not everybody learns, but they come on but they may talk about it after the fact, as they may realise they may be triggering other people, they learn interpersonal skills, and then you watch them start recovering, and teaching other people, about sharing stuff.

Social capital can operate at a structural level in relation to social structures such as networks and associations, and a cognitive level in relation to more subjective aspects such as trust and reciprocity (Baum & Ziersch, 2003, p.320). This interplay between the structural and the subjective aspects of social capital are pertinent to my thesis - the *madosphere* provides a coherent, if fluid, network for people to recognise and associate themselves with; the *madosphere* is continuously produced and reproduced through practices which enable trust to be built and for support to be shared.

The implications of online social networking sites for social relations, and to facilitate social capital, are theorised by Resnick in his paper, Beyond Bowling Together: Sociotechnical Capital (2001) in which he argues against a normative belief that the Internet increases social isolation. He coined the term socio-technical capital to refer to productive social relations, information and communication technology combining a number of affordances such as removal of spatial and temporal boundaries. The *madosphere* is a virtual space carved out within social media platforms, such as Twitter

and blogs, where shared practices emerge which create a sense of community – an interplay between the structural and the cognitive. Whilst Putnam's conceptualisation of social capital operates at a community level, Bourdieu defines social capital as the resources accrued by individuals as a result of their participation in social networks. In this definition individual may amass resources at the expense of others (Baum & Ziersch, 2003, p.320). Sundar et al (2007) identify that the act of blogging can bolster a sense of self and agency, in so far as one's self becomes the source of content, with positive psychological implications which strengthen identity. This is particularly pertinent when considering the experience of so many people accessing mental health services as one of losing status and control (Thornicroft, 2006). Blogs provide an opportunity to create one's own narrative unmediated by others and perhaps in opposition to dominant discourses. To have control and self-mediate one's identity when that identity is a 'discredited' and imbued with social stigma, is an imperative that should not be underestimated (Goffman, 1963, p.42). In a qualitative analysis of people blogging about living with an eating disorder, researchers found three core thematic motivations and gains experienced by their interviewees, namely social support, coping with stigma, and self-expression (Yeshua-Katz & Martins, 2013). Whilst these align with the findings of my research, a key additional factor I have identified is one of achieving externally validated social status.

3.0 Star status and mixed blessings

The achievement of 'star status' in the *madosphere*, as accrued by certain individuals because of the success of their blog, awards they have won, or number of followers on Twitter, is a site of contestation. The potential for individuals to accrue influence and status through online social networks is a consistent theme in my interviews amongst

both people with mental health difficulties and professionals. For professionals, online social networks can disrupt received routes of career progression - either accelerating or curtailing them. For those with positive experiences, this is often articulated in terms of visibility and career progression through access to influential people. As Brian describes: 'I've been to conferences and they say 'are you that guy from Twitter?' I don't think I'd have half the career without Twitter … I reckon it's helpful to be on social media, good to get yourself out there with a public face.' Sam, another medic, sets out a similar scenario: 'I've seen the benefit it [social media] can bring me in terms of knowledge and meeting interesting people and opportunities, I've got a job out of it, and that's I think where I've got to with it, it seems to be able to do quite a lot for you in terms of knowledge, networks and opportunities'.

However, Buddy's experience is not so positive; he explains how he finds public recognition for his work through blogging and Twitter that he does not experience from his employer. For him the *madosphere* is a space in which he can attain the status he feels he deserves but which his institution does not accord him. He shares a story which illuminates his frustration with his employer whereby the expertise and recognition he has accrued online is minimised and bypassed. In his account, the organisation contracts with a management consultant to advise on issues he has carefully already researched and written about on his blog:

> So they've recently sent off for some kind of work to be done on [topic] and they've done that directly as a result of my challenging an email that a [manager] sent out … and in response to that I've had no reply to my email and they've now commissioned a specialist piece of work from an external consultant, and what they don't know because they've never asked, is that all

> the blogs I've ever written on [topic] have been run past solicitors, barristers and mental health professionals, Best Interest assessors and others, so the blogs I've written are not just my point of view, they've been bounced off very eminent people, more so probably than the person they'll commission to do the work for them, so that just feels like a futile position for me to be in.

Buddy's story suggests a tension of status between knowledge developed in a formalised context and that developed in an informal context, with the former accorded more credibility than the latter by the establishment. In sharp contrast to other interviewees, Buddy believes his use of social media is limiting his career advancement: 'I think originally I would have said it was career enhancing, but I certainly formed the view over the last 12-18 months that it is career limiting without a doubt'. This limitation arises from the tension between Buddy's 'star status' online and the institution's desire to control and contain. It is suggestive of a situation whereby the capital he has accrued online exists in tension with this allotted place and seniority within a hierarchical institutional context. Through his engagement in online social networks he has inadvertently stepped over the boundaries of position and rank and created a ripple of displeasure within the institution he is employed. Buddy's expertise is fractured by an institution that appears reluctant or unable to validate knowledge derived and shared in an informal social context. His story illuminates a fracturing of power and expertise for those working within the institution whilst also engaging in the *madosphere* - the personal gains and the personal costs of 'star status'.

4.0 Expertise in the *madosphere*

How do people living with mental health difficulties view professionals and professional expertise in the *madosphere*? In my interviews, a consistent theme emerged about the utilisation of social media for self-advancement, whilst unearthing a degree of antipathy towards professionals. Bella expressed a concern that professionals can take ideas from the Internet and pass them off as their own. She shared her discomfort when professionals ask questions on Twitter such as, in her words: 'going to be a meeting about so and so, what do you think?' and gave an example of witnessing a senior manager present an idea as their own which she was sure they had read on a blog:

> There is so much good and rich stuff out there now and it's on the internet and it's free, and there are not just even blogs, but rich dialogues, rich conversation, and you don't even have to be part of that dialogue; you can just read it after it's happened and you can pass off other people's viewpoints as your own.

Bella is describing a breach of etiquette in which it can considered inappropriate in online social networks for people to not credit others for their ideas. The acronym 'HT' which stands for 'hat tip' is routinely included in tweets which are shared, or retweeted, from another person's timelines. Given some professionals' self-confessed desire to boost their careers through the public nature of social media, this concern would seem to be a legitimate one. Whilst Lauren wants professionals to learn compassion from her mental health blog, she also has reservations about them taking without also making a contribution. Relationships, reciprocation and trust are clearly key in the *madosphere*:

> I'm not suggesting they harvest the data from our blogs and tweets and shares, to do some Big Brother thing, that's creepy. There has to be some peer to peer interaction going in with the intention of learned compassion on their part for what we need.

Mel describes the intrusion of professionals to peer conversations in a wry way: 'professionals come on the chat occasionally, [name of professional] joined recently and talked about clustering, and we were like 'what's he doing here?!'' For Bella, Lauren and Mel there is an ambivalence towards professionals; they believe the *madosphere* is a place where professionals are not in charge and they should acknowledge the *empowered* identities of people with mental health problems; respecting them and engaging with them rather than taking from them. They characterise the *madosphere* as a space where power is in the hands of the people accessing services and in which professionals need to 'know their place'. This could be argued to be a reversal of the professional and managerial hierarchies within an institutional context. Both people accessing services and professionals find hierarchies in tension between informal online social networks and the unwritten rules and cultures of the institution. Expectations and experiences of power are yet again reworked and reimagined in the *madosphere*.

Despite their wariness of professionals, it is apparent that concerns from people accessing services are more about what they see as bad practices in the *madosphere* rather than the inherent identity of professionals themselves. A number of interviewees did appear however, to make a presumption that professionals would behave in less acceptable ways. When professionals conduct themselves according to the etiquette of the *madosphere* then they are more likely to be accepted. For example, one nurse

online was consistently referred to and held in high regard by my interviewees. When I asked him to explain why this might be, he talked about the sorts of beliefs and attitudes which informed his practices online:

> I always try to make a point of not talking down to people, and trying to use the blog platform as a place where it shouldn't really matter what perspective you are coming from, we're all just people having a conversation, we're not in the role of I'm a professional, I'm a patient, I'm an academic, whatever, it's just us, we're having a chat.

A number of professionals articulated a purpose that was less about career advancement and more about a desire to deepen understanding and learning. Merlot, a nurse, told me how she uses Twitter and blogs as a source of validation of her views and ideas which she felt would not be accepted by her employer:

> It gives me a broader perspective, it stops me being institutionalised, and makes me, keeps me seeing things through the eyes of somebody using services, I think it's quite validating because you're talking to someone who has similar views and opinions and I think also gives you strength, if I need to go back into work and challenge something, and often being a lone voice, you can kind of have that wobble and think 'should I be challenging that because nobody else thinks this, I'm the only person who thinks it' it's good then to be able to back then to a community who all share that view, and actually it kind of reinforces for me that that is my view.

For Merlot, the informal expertise of people accessing services gives her the confidence to go back into the institution and challenge the status quo. Mia, another nurse, describes how her participation in the *madosphere* has increased her confidence and broadened her horizons, as well as building her supportive networks as a nurse based on a ward: ‘it has helped me connect with people who I simply would not have met otherwise’. Even though he is a qualified psychiatrist, Brian echoes the view that participation in online social networks has enhanced both his knowledge and understanding of mental distress:

> I think it’s a great way to make yourself a better doctor. I’ve learnt more about people, I’ve learnt more about what people think about what my profession does, and I’ve learnt more about the systems we use. People used to say to me ‘you don’t know how it is when you go home at five’ figuratively, but now I think I do, stepping outside of the office.

Participating in the *madosphere* requires both figuratively and literally stepping out beyond the institutional boundaries of set working hours and the confines of professional practice within the office. It takes professionals out of formal settings and into informal, conversational and often messy contexts where they are required to adapt their style and tone. This contrasts to the clinic where a professional might expect a patient to adapt to thenorms and practices of an institutional setting.

Professional viewpoints echo the themes of tension between formal learning and knowledge generated through informal social networks. Mental health practitioners describe their participation in the *madosphere* as a means of sustaining and developing their professional identity and as a learning tool, as well as increasing public visibility

and career advancement. All my practitioner interviewees articulated a similar point of view that participating in online social networks is a means to develop and deepen their professional identity and abilities. They are choosing to develop and enhance their expertise in novel and non-traditional ways, outside of the boundaries of institutionally accredited professional development. This is a new kind of learning that fractures traditional transmissive routes and requires immersion and participation, right at the outer edges of institutional practices.

5.0 Managing identity at a distance

Whilst less interested in professional advancement, there were similar themes for people with mental health difficulties, who found affordances in online social networks related to presenting and managing self-identity. Micro-blogs and blogs require use of language as a primary tool for managing identity and participants may be rewarded for clever, witty or insightful writing style, over embodied aspects of identity such as accoutrements of status or physical attractiveness. This may have particular affordances for people experiencing mental health problems who may isolate themselves or be shunned as a result of social anxiety, stuttering or the physical effects of medication (Rheingold, 2000 p.11; Baym, 2010, p.109; McKenna, 2002; p.10). Eva exemplifies this point in a description of her first foray into the Internet to discuss mental health:

> I started going online probably when I was 12 or so, actually using it and um when I was about 13 I wasn't very well, I started getting mental health problems, and I didn't know what was going on at all, no education at school, no talk about it at home, so it was just me, and so the way I explain it is that I

> turned to that thing that was right at my fingertips that had helped me with other things, and I thought well maybe this could help with what's going on in my head, so I went online and I started having conversations and joining groups around mental health … and actually when I was 13 I set up my first support group online, because I was struggling with stuff and not feeling that great and not knowing what was going on, and no one, I couldn't talk to anyone at all, not my friends at school, and I didn't really know anyone else, so I looked around and I could see loads of people struggling all over the place and I thought it can't just be me where I am, so I set up a support group ... and actually I started telling other people, and no one knew that my username was me, and you can be completely anonymous.

Social networking sites afford the opportunity to restrict information flows, such as physical appearance, which allow people to transcend assumptions and stereotypes. It also allows them to take productive risks with their identity in ways which can be managed and controlled (Resnick, 2001, p.11). They enable connections whilst at the same time affording maintenance of distance (Rheingold, 2000, p.11). Social networking sites expand the props available through photos, text and multimedia content, allowing greater control of the distance between the front and backstage areas of the self – what is presented and what is kept hidden (Papacharissi, 2011 , p.307). Similarly, the suppression of certain sensory information (smell, tone of voice, facial expressions) can, in some circumstances, allow people to transcend emotional reactions that would interfere with embodied interactions (Turoff, Hiltz et al. 2001). Whilst it is often experienced as a deficit in day to day life, a mental health diagnosis can become a tangible asset in the *madosphere*, with the potential for income generation and substantial status.

Some bloggers in the *madosphere* have won awards and accrued status and influence online as a result of their writing about mental health. They tend to have more followers, higher levels of engagement from those followers, and are more frequently invited to appear in the mainstream media to comment on mental health issues. Eva describes this experience as someone who has developed a career from her use of online social networks:

> I mean I kind of often look back and if I told 14 year old me that you're going to get paid for blogging, and get paid to be on the computer doing work, and people are going to see the journals and the blogs you do as work and you're going to get taken seriously for being on social media, I would have laughed in your face honestly, you know your parents and your school saying you're just wasting time chatting to your friends, and I've kind of made a career out of this, it's amazing.

However, just as some people with mental health problems critique personal advancement ambitions in professionals, so it is the same for peers. Ellie was particularly critical of the prestige amassed by 'celebrities' in the *madosphere*:

> There are some blogs which seem to be written to try and get an award, professional mental health bloggers, and I'm not so keen on that. And maybe not talking about certain things because they're scared of being ostracised and they'll reduce their chances of getting an award, they're more safe.

Ellie's view is that some people may blog purely for external recognition which she believes compromises their authenticity. Their imagined audience are perhaps the bestowers of awards rather than peers sharing support. The issue of authenticity is a consistent one for identity in digital spaces and one where there can be suspicion about motives or compromises in performance of the self for assumed aims, such as career advancement. Employing a performative metaphor, Goffman (1959) illuminates how we attempt to self-manage the presentation of our identities in different contexts, and how at times we may give off clues to our motivations inadvertently. These are issues we continually negotiate in our everyday lives, however a critical aspect of performance in online social networks is that of persistence – the fact that it can be revisited, relooked at and re-interpreted. Motivations, ambitions and goals can be guessed at and ruminated upon. The normative mantra that says 'we're all equal in this space' is disrupted when some people appear to get more benefit from others, particularly if there is question mark over their authenticity. This is where embodied issues of status and identity creep into online spaces and are replicated from offline life. Who are the imagined audiences of participants in the *madosphere* and how does this shape how they present themselves? These are unspoken questions that underpin conversations in the *madosphere* and which are a subtle, almost invisible source of tension.

Is what people living with mental health difficulties gain from participating in the *madosphere* the same or different to professionals? Whilst mental health practitioners often talk about what they can gain from social media and what it can do for their careers, people accessing services often frame their purpose in relation to its therapeutic benefits, in terms of helping others manage or avoid similar experiences, and in terms of positively influencing public attitudes. For example, Tanya explained how her motivation has changed over time:

> When I was extremely unwell, a motivation for me in getting well was to make something good come out of my experiences, and that's why I started [name of blog]; many people blog about their everyday life, and that's good 'cos it's right for them; for me, I want to educate.

Making connections and developing community in an offline life is constrained by geography. Amongst our day to day connections we may find others with similar passions, interests and concerns. Social networking sites afford a different means to developing connections around interest over physical proximity. As Rheingold (2011, p.11) asserts:

> In a virtual community we can go directly to the place where our favourite subjects are being discussed, then get acquainted with people who share our passions or use words in a way we find attractive.

The *madosphere* is a loose knit community based on shared experience, shared interests, and shared concerns. Support from peers is a strong theme which emerged in my interviews, particularly amongst people accessing services, although some professionals explained that they used it for support as well. Time and again people told me of the positive sense of self that came with sharing a narrative of their life and having it validated by others, as exemplified by Tanya:

> I feel like I tweet constant crap about my life, I worry about that sometimes, particularly if I'm having some drama that feels major to me at the time, and also tweeting about what a mess I am (or feel I am) and I don't want people to lose

> faith in me and what I'm trying to do; but people have said that it gives them hope, that I'm doing good things out of my own experiences, that they can see me struggle, but that I always get through it, come out the other side and try to learn from it.

Whilst it is evident from my interviews with professionals that they often read blogs and Twitter feeds of people with mental health difficulties to sharpen their empathy, they do not appear to be the imagined audience for those who are producing that content. Tanya's imagined audience is clearly her peers: 'it's easier when you know that you're speaking with people who get it, aren't likely to judge you'. It is notable, therefore that a professional audience might be put into the category of those likely to judge, but the act of reading content produced by people like Tanya will make them less likely to do so; an unintended but progressive effect.

6.0 Revealing oneself

McKenna (2002, p.12) argues that a sense of being able to reveal one's 'true self' in a shared interest Internet group can engender a sense of wellbeing. Using this notion in the context of a shared personal interest in mental health, is suggestive that peer support could have positive impacts on both sense of self and improved mental health and wellbeing and further research is required to understand if this is the case. However, existing research on the positive impacts of face-to-face peer support indicate this is likely - for example, Mc Kenna's (2002, p.23) longitudinal survey based study found self-reported reductions in feelings of depression and loneliness for people participating in a shared interest Usenet group over a two year period. McKenna argues that where the ability to share one's 'true self' is limited by stigma in everyday life, the

felt need to express it online is greater, and the sense of true identity online can be stronger than that experienced offline where aspects of the self are hidden. Ellie described to me the benefits she got from Twitter and Facebook:

> I was kind of housebound through anxiety, so I was using it really to connect with people and I think in that respect it helped me a lot because I wasn't just on my own I was actually meeting people and I created friendships with people I'd never met before, people from all over the world. I would never tell anyone about my mental health, I was embarrassed, I wanted to be this certain kind of person and that didn't involve being mental you know (laughs) but it felt like I could be myself really without anything getting in the way. It's good to be able to talk to people, but actually not talking directly to them, I think 'cos I had mental health problems such as anxiety and depression which means it can be hard to socialise, but with social media I can just talk to people whenever I want and there's not that anxiety barrier so much.

Ellie's anonymous identity on Twitter is quite powerful and 'larger than life' on Twitter which belies her diminutive physique and anxious self-presentation in person. She describes how her online identity created a sense of security and robustness that she does not feel in other aspects of her life:

> It is safer and it's more … I can say more that I want to say. I'm not as fearful, scared of being criticised over Twitter as I would be face to face. If someone said 'what you're saying is complete rubbish, I hate you' you know, it's not as scary over social media.

However, McKenna also posits that developing a sense of one's true sense of self online can lead to an increase desire and even confidence to integrate it into to one's offline self. Tanya described to me how her participation in the *madosphere* had had positive benefits in her day-to-day life: 'When I first started struggling … I was not very good at talking about my mental health, I was ashamed etc. and didn't tell many people. I am now very very open, but I think joining the *madosphere* helped a lot'. Bella conveys a similar sentiment: 'with Twitter I've found so many allies, who have given me hope when I feel there isn't any … that makes you feel like you're never alone'. In a Guardian article entitled 'Is Social Media Helping People Talk about Mental Health?' (Cresci, 2015) 21 year old vlogger Laura Leujeune talks about the limitations of professional expertise in comparison to peer support:

> Turning up to therapy felt very shameful, one of my psychiatrists wouldn't even say 'self-harm' she'd just do a motion with her hands to suggest it which made me even more embarrassed by what I was trying to deal with ... I soon came to despise the idea of professional help and started to search for answers elsewhere.

The article goes on to state that Laura's own YouTube videos, with focus on mental health, have over six million views and a total of 76,000 subscribers. This is yet another example of fractured expertise whereby a young You-Tuber can have more access and influence than many professionals or institutions could hope to attain or access. The *madosphere* fractures professionally mediated expertise and afford a voice to people whose starting point is to help their peers, from knowledge borne out of their lived experience.

It is evident that for many of my interviewees, online peer support is a vital component of developing the resilience to live with mental health difficulties day to day. This is starkly juxtaposed with the notable lack of engagement or understanding of online social networking by so many professionals - in a recent report by Skills for Care, a consistent theme expressed by care staff was a concern about lack of digital skills with managers reporting a significant shortage of basic digital skills across all levels of the workforce (Dunn et al, 2014). Expertise is yet again fractured with practitioners being constrained by their institutional contexts, from engaging in practices in which many of their users take for granted. A fracturing of access is emerging in which professionals appear to be increasingly left behind. This is a salutary reminder that professional participants in the *madosphere* may be the exceptions to the rule.

Despite the validation which can be experienced through interacting with other people who have similar experiences, participation in the *madosphere* is not a uniformly positive experience. As Tanya describes: 'I think it's probably just a normal human thing – like in school there were cliques and hierarchies' and she told me about experiences of feeling excluded from groups and private direct message conversations on Twitter where people talk behind another person's back that they are polite to in a public arena. A contrary aspect to the affordances of peer support and connection is the potential for increased distress and negative aspects of personal mental health circumstances as a result of online conversations about mental health. Ellie told me about the negative consequences she experienced:

> I used to follow a lot of people who had specifically mental health accounts, in that they would just talk about that, I knew someone who would often post up that she was suicidal and you know tweet implying she was about to do

> something, and I had to find details about her, I had to find someone who knew her better to call the police, and it happened quite a few times, and in the end I just felt I couldn't be responsible for that person, because she was putting the responsibility on her followers, and we tried, me and other people who knew her, we tried to say 'what shall we do if you get like that, give us contact details or something like that' and she wasn't willing to do that so it just continued, I stopped following her.

In a blog post for the BBC Ouch blog (2015) award winning blogger Charlotte describes the more negative implications of online social networks for her mental health difficulties:

> There are disagreements, sometimes as deep as whether psychiatry or psychology is the better way of addressing mental distress. Differences of opinion are fine, but sometimes things take a nastier turn and I've experienced attempts to undermine my reputation by those who have set up fake accounts and "trolls" who've pretended to be me or my family members. If people are outspoken while online, they are more likely to be a target. I'm learning to tolerate them - at least when I'm well. Having bipolar means I sometimes become paranoid, unsure of whether something is real or the product of my own mind. Dealing with fake accounts can feed that paranoia, making me question my perceptions, and it can leave me upset and scared.

Tanya observes that the people giving the support are also experiencing distress themselves and that people's expectations of each other might be more than they have of professionals: 'you can expect more from those who get it, forgetting they have their

own issues too'. This sense of peer to peer commitment and responsibility is expressed by Flora as an important responsibility to those who may rely on her blog for their wellbeing and she articulates this in clinical terms: 'so I suppose to that extent there is a duty of care. If I decided to stop [blogging] I would need to give notice'. For some, the informal nature of peer support becomes an almost professional responsibility. This informal and unpaid obligation to people in similar circumstances is particularly striking when explained by Sally:

> Often I create relationships with people as well where people will go through a patch where they'll be contacting me every day for a month or two, um and it's just to check in with me, it's just for moral support, it's not that they're on the verge of suicide every night, but you know they want to know somebody understands them.

The way she describes her support to peers on Twitter is to all intents and purposes an alternative to a professional service. She is using her expertise born out of personal experience to offer free informal care to others. She has both expertise and actual responsibilities to her peers online and she is providing a service that she believes formal services are unable to deliver:

> My motivation is to help people who are in a place now that I was in before, a very dark place, because I've been there I'm not afraid of it anymore, and I can walk out of it, and lead other people out of it, and it's really reassuring to other people to know it's not as scary as other people think it is, and they can deal with it, and you know it's certainly helpful to help people and share the links, I help people directly and indirectly you know, it's not all me talking to people, and

> I think there's a gap in services that I'm filling, I get a good feeling knowing that people are looking for help out there that I'm available because the suicide agencies – none of them offer suicide counselling on Twitter – as a policy, they don't want to do it, so the peers are stepping up.

For some, their self-mediated expertise through micro-blogs and blogs has switched the power relationship entirely whereby they feel more professionally knowledgeable than the professionals. Sandra describes this effect:

> The amount of professionals who follow me is quite unbelievable, all professionals and people with BPD follow me these days, this morning another psychiatrist followed me, and a lot of psychologists follow me, do you know [the reason is] I don't think a lot of them know what to do with people with [diagnosis], I've discovered this, a lot of psychiatrists and our Trust really don't know a lot about [diagnosis] really, or they don't know what to do about it, and so, and I think that's why people follow me on Twitter, because I'm coming up with some solutions.

The affordance of anonymity and distance is a significant characteristic of social networks which has implications for people whose identities are stigmatised. Whilst non face-to-face communication is often regarded as impoverished, where stigma plays a role it can actively have positive value:

> Just as people spill their secrets to strangers seated beside them on airplanes, the anonymity of online interactions makes some people more willing to disclose and fosters new relationship formation (Baym, 2010, p.102).

Online social networks interrupt the norm of forming relationships through shared place and proximity, by enabling bonds built through shared interests, experiences and identities. Whilst a stigmatised identity might be one that one tries to mask or hide in everyday life, for some the affordance of social media is a performance of one's stigmatised identity. Whereas one's stigmatised identity may be rejected in an offline context, it can be both accepted and prized in an online context; it can create social bonds and a sense of shared experience and connectedness that has value for people who may feel isolated in their embodied lives. Empirical research has shown that, in contrast to a popular belief that anonymity increases the likelihood of dishonesty, it can actually be an important factor for honest self-expression (Kummervold, 2002). McKenna (2002) argues that being able to reveal one's 'true self' in an online shared interest group can engender a sense of wellbeing. Participation in patient online communities has been shown to influence health outcomes through the effect of shared empathy between members (Zhao, 2013, p.1042).

7.0 Self-presentation of professional identity

It is evident from my interviews with people working professionally in mental health that they give detailed thought to their identities and behaviours online; in particular which bits of themselves they chose to share and which they chose to keep hidden. For example, Brian who has his own history of mental health difficulties is careful to keep this aspect of his identity concealed: 'for me Twitter, is already, um, verges far enough in to my personal space …I think talking about my own mental health problems would be just too much'. In contrast, Tom believes the part of his identity as someone who has used services in the past is less salient than his contemporary professional identity.

Although his experience of accessing services can be found, he explains that he opts to keep it in the background of his online persona: ‘I do have lived experience myself and I’m an ex service user too, but I don’t really play that card and I don’t play that particularly strongly on Twitter; it’s referenced on there, and you can find it out if you bother to look’. When asked about his Twitter avatar, Brian frames his response in terms of the General Medical Council social media guidance which caused controversy in 2014 by suggesting that it was never acceptable for doctors to be anonymous on social media channels:

> [the requirement to use one’s own name] is now it is in the GMC guidance, which not everybody likes, but I can see their point, I don’t really disagree with it, cos I was using my own name anyway. Their [GMC] point was we’ve got to be held responsible for what they say, and we can’t have people going on to Twitter when they’re not, I use my name anyway because I wanted to stand by what I said, I wanted to be responsible for it.

The emergence of social media guidelines for health practitioners, and the General Medical Council’s (2013) assertion that doctors should not have anonymous accounts: ‘If you identify yourself as a doctor in publicly accessible social media, you should also identify yourself by name’ was debated extensively on TWOM with reference to extracts from an illuminating letter to the British Medical Journal in 1968 by an Arthur Wigfield:

> In the interests of all of us someone should remind others of us that it is better to earn lifelong respect and adulation of colleagues than achieve ephemeral notoriety in the eyes of a sensation-lapping and morbidly curious public.

This extract from a letter, which also suggests that ‘humility and quiet dignity’ of the medical profession might become a thing of the past, illustrates how concerns about professional standing and the public gaze have been a consideration over decades for the medical profession. Issues of power and expertise in the public domain remain an issue now as they were in 1968 - this is a well-rehearsed debate and site of tension, but just with a fresh context and new technologies.

Many participants chose to keep their everyday identities hidden and in the early days of my research some professionals I interviewed told me how they engaged in the *madosphere* with a degree of subterfuge from their employer. Over the space of a few years, a plethora of guidelines and policies have emerged from professional bodies in health, dictating how, when and what is acceptable in social media practice. For example in 2014 the establishment publication The Health Service Journal ran a ‘social pioneers’ supplement in partnership with the Nursing Times, in which leading lights in social media were celebrated. NHS Employers (2014) have produced numerous briefing papers and a toolkit for the NHS in relation to social media use; well-known figures in the *madosphere* have been castigated for alleged misdemeanours and the consequences have reverberated and ricocheted around the community. I have been curious about the extent to which this institutional encroachment is shaping the remnants of the *madosphere*, or what might more accurately and more neutrally be identified as ‘people discussing mental health online’.

Challenging professional expertise as a patient in a clinic context is difficult - the symbols of power and expertise are all around – from the sterile corridors to the formal seating arrangements; all are geared to confirm clear boundaries and suggest acceptable behaviours - doctor knows best. So how are the roles of professional and

patient performed on social media sites, where disembodied selves provide distance and the physical emblems of power are absent? Tanya describes this shift in perspective:

> Change comes along when you realize that the power lies in you; what you need, what holistic approach needs to take place; what tools you have access to that can get to the root and help you to resolve the cause and not just treat the symptoms. For me, this has come with acceptance of what is and no longer wanting to be fixed because I no longer believe there is something wrong. From this perspective, I can see that the tools to help myself are found within and supplemented by treatment that works with my skills to heal and with people who respect that.

Charlie, a mental health nurse and academic, consciously employs social media to increase access and engagement with his writing through blogs and Twitter. He defines his purpose is motivated by a desire for greater equality of access to academic writing:

> Actually a blog is a really really good way of bringing research findings to audiences who have a really legitimate interest and stake in what those findings are, but don't necessarily have access.

However, this more worthy aim is offset by a sense of enjoyment in sharing his work: 'the truth it's quite a compulsive thing, I enjoy it'. Charlie's honesty chimes with both my reflections and those of others I interviewed – to blog is to make a mark in the public sphere, both a creative process but one which affords recognition and a bolstered sense of identity.

Bob criticises professionals who don't engage in social media and argues that those who avoid social networks do so because they are fearful of giving up power or having their expertise challenged: 'people are fearful of what they don't know'. However, it is not only professionals who consider their online presence, boundaries and privacy very carefully. Flora described how she separates her online presence in which she talks about mental health from her online presence where she talks about non-mental health aspects of her identity and pointed out the apparent contradiction in this: 'maybe that doesn't make sense considering what I share – but there you have it!' Even when Bella live-tweeted her mental health inpatient experience she carefully edited what she put in to the public domain: 'I didn't put it in such a personal way if that makes sense, I didn't give too much detail. I put some distance, I didn't put the content, because that felt too personal'. This impression of careful boundaries and considered identity management is in stark contrast to discriminatory beliefs in the public consciousness and mediated through mainstream media, that people experiencing mental health problems are not in control of themselves and a danger to others (Coverdale et al, 2013). I found quite the opposite in all of my interviews – a mindful and nuanced self-mediation informed by sensitive consideration of others.

8.0 Empathy

A striking, and unexpected theme arising from my interviews, is the self-reported empathy built over online conversations, which was articulated time and again by my interviewees. The theme of empathy is particularly salient to the sphere of mental health because relationships are so critical in the success or otherwise of clinical interventions. As Brian, a psychiatrist, reported:

> If you don't have the relationship you're knackered from the start. It doesn't matter what tablets you give someone … you're on to a loser if the person doesn't like you … if you've got a therapist you hate it doesn't matter what model you use; and if you really get on with them, you feel like they connect with you, it's more important.

Brian explained how connecting with people with lived experience on Twitter and through his blog had actually changed his approach and behaviours in medical practice: 'hopefully I was always a considerate doctor who would ask what they wanted, but it has taught me to be completely and utterly aware' and also increased his understanding of what it is like to live with a diagnosis of borderline personality disorder and schizophrenia:

> There are more people with those types of problems who have recovered than I thought, more people who are angry and objecting to diagnosis than I thought … it's taught me to be much more careful about how I use those labels … it's taught me to qualify them quite heavily and explain them.

The affordance of online social networks for conversations between professionals and people with lived experience to influence clinical practice strikes me as highly significant. For a professional to have access to and interact with a continuous personally self-mediated story of another person's life is profound in how it may shape their beliefs and working practices. The most recent Time to Change campaign evaluation found that reported discrimination from mental health professionals remains intransigent as a result of a number of factors. These include the fact that professional

contact is often with people experiencing the most severe difficulties, occurs in the context of an unequal power relationship and that prejudice is one aspect of burnout, which is not uncommon in mental health professionals (Corker et al, 2013, p.61). It could be argued that online social networks are part of the answer - they afford professionals and people with lived experience the possibility to interact with each other outside of received institutional boundaries, opening up possibilities for more nuanced and empathic understandings not readily found in the context of a clinic or ward round environment.

Baym (2010, p.104) argues that social networks afford relationship formation that blurs social boundaries and enables bonds to be built, where the relationship is its own reward, rather than serving a useful function of maintaining social order. She also argues that relationships created online may be easier to maintain online and harder to take offline. It is striking that stories of increased empathy through conversations on Twitter reported by people accessing services and professionals were not reported as taking place between people who had offline relationships, or more specifically, relationships in a clinical context. Maybe there is a distance afforded by social networking that allows for rapport to be developed that would not translate to an offline context. In the offline context the professional is bound by their institutional role and context which proscribes a certain type of relationship. A disruptive aspect of social networking is that it unsettles those relationships but in a way which is safe and distanced. The point of commonality is a shared interest is mental health, whether it be as a user or provider of services. This enables increased empathy to be brought back into the clinic whilst the online relationships remain at a safe distance and boundaried. Tanya expressed a desire that a common interest in mental health should be what

binds people having conversations about the topic online, rather than the labels that people have:

> We need a sense of 'no them and us', mental health professionals, lived experience peeps, people to which neither applies, all in this together. After all professionals can have lived experience too, and often do, and most people who don't have a mental illness struggle sometimes mentally too.

However, in some instances online and offline worlds can collide, particularly for those who share peer support through shared experiences rather than who build relationships with very different offline roles. In their survey of Usenet users, McKenna et al (2002) found that people building connections through online shared interest groups, tended to bridge those relationships into offline settings. This is described by Ellie in relation to her experience when the *madosphere* was at the height of its powers:

> We used to have 'madups', they still kind of have them - 'tweetups' but for mad people. It wasn't just about tweeters, they do still have them in [name of place and some in [name of place] but they're not always called madups anymore, just this group of people who have met through Twitter or blogs and Facebook and all probably either have a mental health problem or are some way connected to that, and just meeting up in a pub and drinking port.

During my research I have observed a steady encroachment of professional and institutional practices in social media spaces, and in particular on Twitter and blogs. For example, @wenurses is a community of nurses on Twitter who hold weekly 'chats' on various nursing topics. Their website includes guidance for nurses about how to

record their participation in chats for the purposes of evidencing continuing professional development. Practices that once took place within the institution are increasingly performed online and in public view. Online practices such as tweeting are being shaped and boundaried in ways which align with institutional expectations and requirements. Both these practices are creating a blurring of informal and public with the formal and private. Not only are continuing professional development practices publically observable, they also allow and often invite the public to participate. Such practices are both stretching organisational boundaries whilst at the same time taking the organisation into online social networking spaces. For some this is a welcome extension of organisational transparency and accountability; for others it is an unwelcome expansion of bland corporate trespass which limits the potential to have free and authentic debate online. Dylan shares his thoughts about what he sees as the 'professionalisation' of social media:

> There's a sense in which a Tweet chat is an activity in and of itself that is measurable and quantifiable ... there's a different sort of understanding of what Twitter's there for, cos certainly I get the feeling with things like #wenurses and stuff like that, for all that it's social media towards an aim, towards a specific thing, it turns it into a machinery, so the point of a tweet chat is that it makes nurses better nurses or it brings a particular issue to light. I think that *isn't* the same as people doing it in their leisure time, or doing it because they want to be doing it, it's a bit like, there's a difference between sitting in a seminar and going to the pub, I think it's interesting for me as a non-medical person being involved in those sorts of things, because I can literally say whatever the fuck I want, in a way that the other people can't, and I think there's a tension with the sort of

> professionalisation of things like tweet chats, because they become an extension of your working day.

In the mental health sphere, the @WeMHNurses chat focuses specifically on mental health nursing. The @WeMHNurses chats could be argued to be the new heartbeat of the *madosphere*, albeit one with a more conventional professional nursing frame, particularly as regular contributors to TWOM are now active in this online community. Given what I perceived to be the subversive nature of TWOM, with equity demonstrated through co-editing at its heart, I had a personal sense of melancholy that the blog would no longer be active. I asked Edward for his view about the ever changing shape of the *madosphere*:

> I see the @MHNursechat [previous name of the chat before it became @WeMHNurses] as my tribe when it comes to Twitter, I can't claim any credit for this, and I don't think TWOM can claim any credit with this, but @MHNursechat has been very good at breaking down the barriers between "I'm a patient and I'm a professional" … the chat we did on borderline personality disorder was actually a fantastic exemplar of it, and if you think that a lot of professionals think they're going to be demonstrative or whatever, and a lot of people with personality disorder feel very stigmatised, they're disparaged and labelled, this hour of nurses and people with personality disorder talking together in very equal, respectful way of each other, there were some incredibly supportive comments.

Edward refers to conversation about mental health on online social networks as: 'more respectable than it's ever been' and characterises this respectability in terms of maturity

and a sense it has come of age: ‘social media has matured, there’s a greater awareness of the rules to it; how you have to conduct yourself as a professional online’. Merlot acknowledges the tension that professionalism and professional practices online can create when performed in online and in public:

> Twitter’s quite subversive in the sense that it creates an equal space where everyone comes together regardless of whether you are kind of using mental health services, but I still kind of wonder if there’s any underlying power dynamic in terms of where people, which side of the fence people sit at, I really appreciate that probably a year ago, not in relation to mental health, but when I did a [name of condition] chat which was more personal … and I realised when I crossed over on Twitter into the role of being a relative rather than as part of the health community, there were definitely dynamics between where you sat and things like professional language which can be quite excluding at times.

Whilst use of professional terms and acronyms may strengthen a shared sense of community amongst some, it may also impoverish those at the edges – namely people accessing services. It is striking that professional practices bring the character of the institution with them, implicitly dragging with them established patterns of relationships between the practitioner and the patient. Whilst they may be laudably endeavouring to increase institutional accountability and transparency online, are they simultaneously impinging on the very qualities of the *madosphere* that have been experienced by many as more equitable? Who does this trade off benefit the most? Laverne, a senior nurse, told me how she conceptualised her practices on social media as an extension of her professional practice:

> The idea suddenly dawned on me that I was nursing in a social media space. It's the bit about where you ... so I'm not actually attending to a patient now, and I'm not on a ward, but people think of a nurse that you've got a big cross on and you're attending to the sick, but that's not what nursing is all the time, it can be what I'm doing now with you, so this is nursing too, but it took me a while for the penny to drop to think I was nursing in social media and that that was a nursing activity.

She goes on to describe in detail how she thoughtfully and carefully employs her professional practices in online social networks in terms of her application of professional boundaries online, as expressed in how she responds to criticism of other professionals by people accessing services:

> My response to that type of thing would be, not necessarily to collude with that idea because I don't know the person's history, often there's not enough history to come to a decision. So I might say "that's really sad to hear, did you tell them how upset you felt" so it might be along those very broad lines, but I wouldn't necessarily go along with saying there was anything wrong with the nurse. You have to keep it quite neutral, but that happens within inpatient environments, you don't collude with, well collude is the wrong word, you wouldn't want to undermine another professional by saying well that was terribly wrong of them … unless I've got a very clear understanding of what went on.

My interview with a senior mental health professional, who had been castigated by his employer for perceived improper behaviour on Twitter, provides a fascinating insight of the sorts of tensions experienced by people using online social networks in relation to

their work role. With resonances of the intrinsic motivations of many people living with mental health difficulties, Buddy started writing a blog and using Twitter to raise awareness of issues being faced by his profession in relation to mental health: ‘I just decided there was stuff that needed to be said’.

As with many employers, it was the inventive attitudes of one senior person that meant Buddy’s employer developed a progressive attitude towards their employees using online social networks in a professional capacity. According to Buddy, they were also impressed by the reach and reputation he was beginning to achieve through his blog and Twitter account. They not only recognised the reputational benefits but they also appreciated that an individual account can achieve more reach and engagement than a corporate account. However, approval and endorsement for Buddy’s activities online have come at a cost: ‘It does feel like it’s changed, and I think certainly as the number of followers on my account has grown, I do sense a greater scrutiny from my [name of organisation] of what I’m doing and what I’m saying.’

Buddy’s employer is unusual in requiring that all employees using social media for professional purposes share their login details with the organisation. For Buddy, this meant that his blog and Twitter account were suddenly suspended without warning whilst an apparent complaint was investigated. As far as Buddy was concerned there was nothing controversial or different in the content he put online. What *was* different was the level of scrutiny and the wariness of his employer:

> I’m absolutely confident, and many people who follow me will say, there’s nothing I did on Twitter in February than is any different to what I did last February or the February before that, and yet two years ago they wouldn’t have

> blinked if I'd said [describes accusation]. In fairness I was saying that two years ago, one year ago, 18 months ago, and nobody blinked an eye, I think the level of scrutiny that the account has now because of the number of followers it has, it's now the most followed individual [name of profession] account in the country, um and it's consequently under greater scrutiny, which I understand, so it has changed.

For Buddy, with renown and recognition come constraints and scrutiny. The institution is wary of its reputation and has low tolerance for individuals expressing viewpoints or engaging in debate which might present a challenge to the image it wishes to present to the world. Individual practices are increasingly constrained, not just by professional guidelines, but also by witnessing sanctions applied to high profile bloggers such as Buddy. Insidious practices such as this put individuals on their guard and constrain one of the great affordances of social media described by many of my interviewees, that of debate on issues and the softening of barriers that are experienced in everyday life. Buddy describes the effect this has had on his practice online:

> Since they reinstated my account there have been numerous instances where I've typed something, and deleted it and rephrased it, and I have been more cautious in the last month and a half than I ever have been before, and I've also deliberately avoided contributing to things, discussions that are on-going or things that people are saying, I've avoided making any reply at all to things that three months ago I wouldn't have blinked, I'd have gone in there and said 'hang on a minute'.

Buddy's experience suggests that institutional reticence can impoverish debate and discussion online; the very presence of the institution in an online social network can create a degree of circumspection. When institutions assert their authority, as in Buddy's experience, they risk compromising the very benefits that they have identified as positive. The constraints felt by professionals may force them to resurrect the very barriers they have felt online social networks have enabled them to put to one side. Buddy's experience is suggestive of a continuous negotiation and contestation of boundaries between the personal, professional and institutional. In some ways Buddy achieved a small victory - when his account suddenly disappeared without explanation there was a huge outcry and massive speculation which began on Twitter and the blogosphere and ended up on mainstream media channels such as national press. The organisation concerned was forced to put a statement on their website and the accounts were re-instated. The very actions they took to presumably contain their institutional reputation resulted in an assault on the very thing they were attempting to preserve. This is reflective of the power of individual identity and capital over that of the institution.

Whilst writing this chapter, I tweeted a question about institutional encroachment into social media spaces, and this was one tweet that immediately came back in response: 'IMO [in my opinion] Twitter relies on trust, contextual awareness and transparency, some institutions seem categorically incapable of it'. The tweet was accompanied by a link to one of many blogs posts on the topic of a campaign entitled #JusticeforLB led by a mother whose learning disabled son died a preventable death whilst in the care of an NHS Trust. The subsequent actions by the NHS Trust concerned, have been the subject of countless blogs posts by various different people, and which have often been based on information gleaned through Freedom of Information (FOI) requests. One

such FOI request revealed that the NHS Trust had been monitoring and reporting on the mother's blog and Twitter feed in order to 'help in shaping a tailored media response to the incident and monitoring of potential media interest in the incident' (Taylor, 2014). Whilst this case is only mentioned in passing here, it is an apposite example of the tension between institutional desire to control and contain information and the affordance of social media to make not only public but to discuss it publically as well. The Internet as a site of tension between individual and institution was noted by Rheingold (p. xix) in his early 1993 work on virtual communities: 'the odds are always good that big power and big money will find a way to control access to virtual communities; big power and big money have always found ways to control new communications media when they emerged in the past'. Whilst his focus is on corporations and commercial interests, institutional power also exists within public sector institutions as can be seen by this example.

9.0 Conclusion

In conclusion, a fracturing of power and expertise is evident between the institution, professionals and people living with mental health difficulties, in the *madosphere*. Tensions are mediated, conversed upon, and experienced in multiple ways. Professionals engaging in the *madosphere* often do so despite and in tension with the practices of the institutions they are constrained by. People accessing mental health services participate in the *madosphere* in collaboration with but also in tension with professionals. People living with mental health difficulties can take on the role of expert within the *madosphere* in ways which are unavailable to them within an institutional context and this brings advantages but also challenges and personal costs. Lastly, power and expertise between people living with mental health difficulties also exist in

tension in the *madosphere*. The madosphere is both a site of resistance to and is defined by the institution. It fractures and problematises expertise and challenges the power of the establishment. It is a site of resistance to the mainstream for many of its participants; it is a means of peer support where identities are stigmatised in everyday life, and it is a means to accrue not online social capital, but ‘star status’. It is a space to share, illuminate and educate. It is a space and set of practices occupied by atypical Internet users, deeply engaged in online social networks as part of their everyday personal and professional lives. The institution attempts to assert authority, to command the madosphere, to create parameters and to assert control; but it is only ever partially successful. The madosphere is a dynamic and fluid space which resists control and containment.

Chapter 8

The Sociable Practitioner and the Sociable Organisation - Conclusion and Recommendations

I consider myself really lucky to be a part of the madosphere that people have created, and a lot of the time I have to step back from it, because it's not the real world and it's not how everyone is, because the madosphere tends to be a group of very, not academic necessarily, but very well educated people, very sympathetic, compassionate, very inquisitive, they look after each other and look out for each other, and they talk about things in a very different way.

Jessica

1.0 Introduction

I began my thesis with an account of Samaritans Radar - an event which saw a well-respected charity attempt to extend their suicide prevention support online. The charity emerged badly bruised and reprimanded by the community they naively sought to help. They failed because they lacked a nuanced understanding of the social practices engaged in by many people with mental health difficulties on the micro-blogging site Twitter. Over the course of my research between January 2012 and December 2015, I have sought to understand and elucidate these practices and their meanings to people participating in them. It is only through understanding these practices that mental health practitioners and institutions can take steps to engage with online social networks in ways which are acceptable to people living with mental health difficulties. However, it should be noted that participants in the *madosphere* who I interviewed were atypical

users of the Internet in so far as they were both heavily immersed and routinely produced their own original creative content through blogs and microblogs. It is therefore not possible to generalise my findings to a wider group of people accessing and providing services, although some of the broader lessons may be transferable. My research makes an original contribution to an as yet largely un-researched area by illuminating the practices of this group of people and the meanings they hold to actors within them.

The Samaritans Radar event is emblematic of the challenges faced by institutions which endeavour to extend their communication practices into online spaces. As set out in Chapters 2 and 4, the sphere of mental health has been a site of tension and conflicting beliefs since the inception of organised efforts to both treat and contain people whose behaviours sit outside or are in conflict with societal norms. These competing paradigms are conversed up, disputed, argued about and deliberated upon in online social networks as they have been since the advent of the asylum. The emergence of Web 2.0 and online social networks afford the possibility for those conversations to be self-mediated in the public sphere rather than through officially sanctioned channels. Online social networks, at least in principle, open up these conversations to anyone who wishes to participate in them. The potentially accessible and equitable characteristics of online social networks create a shift from the past which deserve to be studied and illuminated.

The cautionary tale of Samaritans Radar suggests that institutions cannot assume the hegemony they may have previously expected and enjoyed before the emergence of Web 2.0 and user generated content. The very public humiliation of The Samaritans intimates that institutions are not always welcome in online spaces, particularly when

those spaces are predominantly characterised by informal and personal interactions between individuals. The charity failed to appreciate how *some* people living with mental health difficulties use online social networks to engage in self-mediating practices characterised by peer support and collective action. Those practices are in tension with and occasionally in opposition to formal care offered by professionally-led organisations. They were not able to comprehend that those people have not only developed a sense of agency and collective identity, but that they are willing to resist any encroachment which is not sensitive to their social norms and practices. It is these practices that need to be understood by institutions so they can find appropriate and acceptable ways to shift from the formality of the clinic to an emergent stream of online conversations. My research is original in that it seeks to understand a space and set of practices, engaged in by a particular group of people, that have previously been hidden from view and which are easily misunderstood and underestimated by mental health professionals and institutions.

2.0 Relationships and disruptions

The Samaritans Radar event strikes at the heart of my research question - **to what extent is the relationship between users and providers of mental health services being disrupted in the *madosphere*?** My ethnographic research, combined with immersion in this topic through my role running an NHS digital health programme, has generated new knowledge about the nuances and subtleties of practices in online social networking sites by a group of ‘e-mersives’, that have not previously been surfaced and understood. Whilst my thesis is a deep qualitative investigation into a diminutive corner of the Internet, within it are pointers worthy of consideration by mental health professionals and institutions endeavouring to understand ever emergent online

territories. Through my research I have identified two distinct but related forms of online disruption engaged in by both people accessing and working in mental health services who were participating in the *madosphere*:

> (i) The production of self-mediated identities and development of online communities that operate outside the boundaries of the institution and sometimes in tension with it
>
> (ii) Collective challenge to the institution which is predicated upon pre-existing social relations and practices that have been developed outside an institutional context.

The first form of disruption is not necessarily a conscious or deliberate one, but rather arises from naturally occurring conversations in online social networks. The second form of disruption is more deliberate and focused with the intention of directly challenging institutions which broadcast negative mediations of mental distress. However, this second form is, in part, dependent on the networks and connections developed through the first.

My research has comprised two overarching themes concerned with identity, self-presentation and self-management of stigmatised identities online; and secondly with power and resistance between people and institutions both at the level of the individual and through collective conversation and action. I have considered the affordances of social networking sites to enable people to converse, resist and subvert traditional mediations of mental health as participants in networked publics. My research illuminates themes which have profound implications for professionals and institutions and which disrupt professionally driven narratives and mediations of mental health. I

have found relationships and practices online by a small group of people which subvert institutional received wisdom. Online collective action by a group of people subject to stigma, discrimination and a lack on enfranchisement in the public sphere is significant as part of a wider movement towards digitally networked participation by citizens wishing to influence public and political life:

> Digitally networked participation can be understood as a networked media–based personalized action that is carried out by individual citizens with the intent to display their own mobilization and activate their social networks in order to raise awareness about, or exert social and political pressures for the solution of, a social or political problem (Theocharis, 2015, p.6).

A review of the literature has brought together two discrete strands of research pertaining to mental health, communication and new media respectively. Issues of power and resistance have a substantial provenance in the mental health literature; however there is as yet a paucity of research considering the implications of relationships between people accessing services, professionals and the public mediated through online social networks rather than face to face. There is similarly a substantial body of communications and new media literature that evaluates the implications of online social networking in terms of user generated content, citizenship and political participation. However much less is written about health and only recently a literature is emerging in relation to mental health. My research has endeavoured to build on both traditions of research to develop original insights into the affordances of online social networks for self-mediation of mental health and the implications for relationships between people using and providing related services. As increasingly relationships are mediated through a blend of online and offline communications, it is

imperative that research moves beyond a purely analogue context and accounts for a Web 2.0 social context and beyond. These affordances should be understood by mental health institutions so they can adapt to shifting expectations from people accessing services and professionals working within them. Policy makers should appreciate shifting practices and expectations of the public and professionals so they can develop policy and strategy fit for the contemporary mental health sphere.

In Chapter 4 I endeavoured to delineate the affordances of online social networking in the mental health sphere through points of contrast with the asylum of the nineteenth century - what remains the same and has altered from a previous analogue age. In this chapter I considered my first research thesis sub-question - ***disrupted relationships - who is participating in the madosphere, how do participants experience and understand their engagement, and what meanings does it carry for them?*** I have drawn heavily on the work of Erving Goffman throughout my thesis, from which it is evident that issues of institutional power, stigma and of resistance have a long history and which retain salience today. How has technology shaped this tradition and how have people shaped technology to meet their needs? I have touched upon a long tradition of protest from the advent of the asylum onwards and identified how the means of disruption have been accelerated with the emergence of online social networks where conversation and debate can take place in the public sphere. The public nature of online social networks mean that self-mediated acts of disruption can be read, shared, added to and recorded until they emerge as a networked activity of a loose knit community. There are marked resonances between the themes of disruption today and those in the nineteenth century. However, the ability to express them in public spaces continues to open up exponentially and is a defining characteristic of contemporary society. I have employed a simple communications lens to understand

the sorts of practices actors in the madosphere are engaging in and what it means to them from passive through to active – to be *talked about*, to *talk with* and finally to *talk back*. Through interviews and field notes I identified a number of themes – the salience of peer to peer interaction and support; the empowering effects of talking back to the institution; the positive effects of understanding and empathy from conversations between people accessing and providing mental health services.

In Chapter 5 I addressed my second research thesis sub-question - ***an account of the madosphere - what are the behaviours, practices and social norms in the madosphere?*** I gave a detailed account of the *madosphere* and described how it metamorphosed during the period of my research as practices evolved and The World of Mentalists (TWOM) blog ceased to exist. An account of the *madosphere* captured a point in the ephemeral and ever shifting nature of online social networking. Despite the fact that platforms and blogs may come and go, I identified underpinning themes related to agency, identity and collective action. I found a loose knit community of people conversing about mental health and continuously reproducing the *madosphere* through shared social practices and rituals. I found tensions, jealousies, cliques and hierarchies but I also found the empowering effects of community and connection. Finally, I witnessed the demise of The World of Mentalists (TWOM) and the emergence of new sets of practices through which mental health is discussed, exemplified by #mhnursechat on Twitter. I asked whether what was once a subversive space was now being disrupted and appropriated by the institution as the increasing mainstream appeal of online social networking continues.

In Chapter 6 I addressed my third research thesis sub-question - ***re-mediation of representation - how do participants engage with and resist mainstream media***

reporting of mental health issues? I considered the ways in which mainstream media frame mental distress through an exploration of two examples of contestation and resistance in online social networks. I argued that practices in the *madosphere* are orientated towards self-mediated first person accounts which provide an alternative discourse to the objectifying accounts which still dominate mainstream media. In the case of one example, the Asda 'mental patient' event, it is evident that ordinary people shaped the mainstream media agenda through naturally occurring online protest. This is significant both in terms of strengthening collective identity for people having conversations about mental health in the public sphere, and in terms of influencing public discourse about mental health. However, despite the democratising effects of protest online, I raised questions about the extent to which they affect practices by mainstream media and I gave examples about how they have continued to mediate stigmatising stereotypes of mental distress.

In Chapter 7 I addressed my final research sub-question - ***fractured power and expertise - how do participants engage in themes of identity, power, stigma and discrimination? How are participants resisting and subverting institutional paradigms and discourses relating to mental health?*** I gave an account and analysis of disrupted relationships, power, identity and expertise in the *madosphere*. I considered the extent to which identities and conversations in online social networks are similar or different to those in everyday life. I argued that practices in the *madosphere* are orientated towards increasing empathy between people accessing and providing mental health services; however, suspicions and barriers in everyday life are also experienced in this space. I explored the affordances of social networking sites to enable a group of people with lived experience to engage in peer support separate to, and sometimes in spite of mental health services. I explored the extent to which power

and expertise is fragmented and reinforced. A disruption of power and expertise is evident between the institution and a group of professionals and people living with mental health difficulties in the online social networks I investigated. Tensions are mediated, conversed upon, and experienced in multiple ways. Professionals engaging in the *madosphere* often do so despite and in tension with the practices of the institutions they are constrained by. People accessing mental health services participate in the *madosphere* in collaboration with but also in tension with professionals. People living with mental health difficulties can take on the role of expert in ways which may be unavailable to them within an institutional context and this brings advantages but also challenges and personal costs.

3.0 Thematic Insights and Characteristics of the Sociable Professional and Institution

In this final section I set out and summarise thematic insights that have arisen from my research. I bring them together here in order to extract key learning points to inform awareness and appreciation of a space and set of practices in the *madosphere*. Whilst these practices are specific to the participants, they illuminate an imperative for mental health professionals and institutions to pay attention to and understand how the specific publics they engage with are making use of online social networks. I distil these insights into a set of characteristics embodied by the *sociable professional* and the *sociable organisation*. These insights are gleaned from deeply qualitative ethnographic research methods including my own participation in the field, alongside empirical evidence from the literature. It should be noted that these insights are not necessarily generalisable but they do point to the salience of health professionals and institutions endeavouring

to understand how people accessing services are using online social networks in relation to their health and wellbeing. It should also be noted that in my research interviews, the conversations between people accessing and providing mental health services did not take place in the context of direct one-to-one care and support. Insights relate to people having general conversations about mental health in the public sphere as opposed to engaging in clinical interactions online.

3.1 The Salience of Agency

Whilst normative views may hold that an identity expressed online is an impoverished version of our embodied selves, this is not always the case and can in fact be untrue for some. Online social networks afford possibilities to carefully self-manage identity and presentation unencumbered by the trappings of the embodied self. Whilst the corporeal self may leak social anxiety through unwanted physical signs, or reveal the unwanted side effects of medication through an unsteady gait, in an online space self-mediation can be more controlled and choices made about what is and is not shared. Here limitations associated with a mental health diagnosis may be transcended and productive risks taken that one may not feel able to achieve in day to day life - building relationships whilst maintaining distance (Resnick, 2001, p.11). An expanded set of props available through photos, text and multimedia content, allow greater control of the distance between the front and backstage areas of the self – what is presented and what is kept hidden (Papacharissi, 2011, p.307). A choice can be made to hide a mental health diagnosis or conversely for that to be the primary aspect of identity shared online. ‘True identity’ can be revealed online which moves beyond the day to day stigma and shame often experienced in everyday life (McKenna, 2002, p.12). The creative act of producing original online content can bolster a sense of agency with

associated positive psychological implications (Sundar, 2007). This is particularly pertinent when considering the experience of many people accessing mental health services, associated with a loss of status and control alongside an erosion of a positive sense of identity (Thornicroft, 2006). For those with the access, skills and motivation, one's own narrative can be shared online, unmediated by others and perhaps in opposition to dominant discourses. Whilst it is often experienced as a deficit in day to day life, a mental health diagnosis can become a tangible asset online - a source of expertise and help to others.

The *sociable professional* understands the positive and negative affordances of consuming and producing online content and managing identity online - this enables them to support people in navigating the online aspects of their lives as effectively as they might do their offline lives. An appreciation of the nuances of online identity - what it can be and how it might help and how it might hinder - are fundamental to care and support in contemporary society. This appreciation will enable the *sociable professional* to pay attention to the online identities they develop for themselves and which is congruent with their new found knowledge.

3.2 To be understood

Threaded throughout my research findings has been a desire to be understood, as a core motivation for people I interviewed to engage with online social networking sites. For those people is not only an opportunity to self-mediate one's identity as an act of agency, it is also about the educating the public about mental health and a restorative process for stigma experience. For professionals I interviewed, it is a desire for a shared humanity, an opportunity to self-mediate identity beyond the constraints of

professionalism, to be a person, and to present a more nuanced performance of professional identity than that which might be familiar in the public consciousness.

As examined in Chapter 4, to bear witness and to tell one's story in the hope of being understood has a long tradition in the mental health sphere. This is a desire expressed equally forcefully by the psychiatrist as by the patient. Both appear to be driven by a compulsion to show their humanity, to be validated as more than their label, and to make their mark. In an analogue age, disruptive voices persisted only where official technologies were employed, and these were only available to the privileged few. However, online social networks afford potential access to an unlimited audience, visibility, searchability and persistence - this is what marks such a significant change in the potential to have one's point of view articulated in the public sphere - with the hope of being understood.

Online social networks afford the potential for people accessing mental health services and professionals to not only self-mediate their identities, but to do so as a person, beyond and possibility in resistance to the labelled and constrained identities imposed by the institution. Online social networks offer space and possibility for understandings beyond the confines of diagnoses or professional titles. However, those possibilities are inevitably constrained by many factors, including literacy, motivation and confidence as well as access to digital technologies.

The extent to which the affordance of self-mediation is a challenging notion for the institution should not be underestimated, for it requires a relaxation of an inherent impetus to control. For the *sociable professional* it means a willingness to reveal one's humanity alongside one's professionalism. To seek understanding is to make oneself

vulnerable, but the rewards can be great; the *sociable professional* understands that to bring humanity and nuance to one's online personas can open the door to understanding others and to being understood - understandings emerge from relationships, and a rounded and adaptive self-mediation allows for deeper relationships and understandings to be forged. The *sociable organisation* recognises that a transactional emphasis on policies, procedures and defensive practices quashes the potential for those relationships and to take root and thrive. An emphasis on the potential for deepening of relationships within the context of light touch protocols and a permissive approach to online social networking will strengthen the lifeblood of care and support - relationships and trust.

3.3 Who is in Charge? Authority and Power Online

A research thesis focused on disruption invokes the question of who is in charge - whose power and authority is being disrupted? As discussed in Chapter 2, issues of power and control are fundamental to academic writing in the sphere of mental health; a sphere in which it is possible for any one of us to have our liberties removed in order to keep ourselves or others safe - a profound loss of agency. Goffman's (1963, p.367) ethnographic work on asylums exposes the polarised roles of professional and patient in which each enact and reproduce roles of the expert provider and passive recipient of care. To challenge the status quo and to be non-compliant can be interpreted as signs and symptoms of the diagnosed illness itself - a double bind. Issues of power and authority are expressed through this power-imbued relationship which can operate on a spectrum from detached and paternalistic through to an emphasis on collaboration and sharing of power (Slade, 2009). Slade (2011) invokes professionals to engage in 'boundary violation' in which risks are taken with institutionally and professionally

framed boundaries, in order to build more authentic and meaningful relationships for effective care and support. I argue that online social networks afford technological possibilities and emergent practices to facilitate the disruption suggested by Slade's notion of boundary violation. The question of who holds power and authority is problematised in online social networks where command and control hierarchies of the institution cannot be taken for granted. Whilst it would be overly simplistic to suggest that professional and institutional hierarchies do not influence online spaces, it would also be incorrect to suggest they are simply bridged across into social networks. Therein lies the possibility to disrupt them.

Online social networks afford not only the possibility of agency - to self-mediate one's identity and to be understood - they also allow for the development of influence and authority beyond the traditional channels of professionalism – particularly for those who are motivated and confident engaging in the public sphere through online social networks. Those with lived experience of mental health difficulties can find themselves in a position of informing and influencing professionals through their blog posts or Twitter chats; they can find themselves in the position of taking personal campaigns to people in positions of organisationally mediated authority, and influencing them to make changes through their conversations. This is a subtle repositioning from the patient role to that of teacher; from a recipient of expertise to a provider of knowledge and with it associated personal, if not positional, power. This is a subtle disruption of roles and expectations, an indirect shift from recipient to expert, a reclaiming of power and a reframing of identity. Online social networks afford news spaces and possibilities for received roles to be disrupted and for the patient to subvert their expected performance, and assume an expert mantle. The order of official channels is ruptured and reimagined through the meandering flow of conversation, it has a chaotic and

unpredictable quality that cannot be contained or anticipated. The only constant as one is buffeted and swept along this path can be an integrity of identity and purpose - an orientation towards collaboration and a sharing of power and development of authentic and meaningful connections. These disruptive possibilities can only be realised through an interplay between those producing content and audiences willing to engage with that content and this is an important limiting and constraining factor.

The *sociable professional* and the *sociable organisation* recognise that the authority and deference they may expect and even assume in their received contexts cannot be taken for granted in online social networking spaces. They self-mediate their identities in online social networks with a degree of deference and humility which avoids attempting to bridge the assumed authority of the clinic or boardroom into the sphere of blogs and microblogs. With this repositioning of power and authority comes the potential not only for agency and understanding, but also for an orientation to a partnership approach to care and support, with an emphasis on collaboration, sharing of power and knowledge. The *sociable professional* and *sociable organisation* are not just curious about who is engaging in online social networks, they are also curious about who is *not* engaging; they are concerned about where the associated gaps and blind spots might be and what this means in terms of the viewpoints and experiences they are exposed to. They actively seek out hidden and marginalised voices.

3.4 My Tribe - the Power of Peer Support

The importance of support by peers, with an emphasis on egalitarianism, equality and collective social action, is an increasing feature of policy writing and service development in the mental health sphere (Slade, 2007, p.103). Research indicates a

clear relationship between social support and positive physical and mental health, whereby people with higher social participation and strong relationships are more resilient than those who do not (Burrows et al, 2001, p.99). To be able to self-mediate one's identity, to be understood, and to experience a sense of empowerment are closely connected to the affordance of engaging with peers in online social networks. Talking with people 'like me', particularly those whose voices have been subjugated, affords access to knowledge and information that is not mediated by professionals, alongside realisation of shared experiences. My research reveals a constant thread, consistently articulated, about the significance and compelling effects of peer support online. Online social networks afford those with stigmatised identities to overcome the constraints of geography, connect with others and find shared meaning in experiences. The ability to *talk with* peers is a subtle disruption of the institution in so far as it dispenses with the mediated knowledge of professionals and is unconstrained by the walls of formality and order. It is the possibility of peer support, unfettered by the need for proximity that creates a step change from an analogue age. However, it should be noted that these possibilities not one uniformly exploited by people accessing services and the space and set of practices I investigated were characterised by a small group of confident 'e-mersive' Internet users.

Rather than the normative assumption that online social networking increases social isolation, shared practices and conversations can create a sense of community and shared identity which reduces isolation and builds social capital (Resnick, 2001) Online social networks interrupt the norm of forming relationships through shared place and proximity, by enabling bonds built through shared interests, experiences and identities. For some, online peer support can be a vital component of developing the resilience to live with mental health difficulties day to day. This is starkly juxtaposed with the notable

lack of engagement or understanding of online social networking by so many professionals (Dunn et al, 2014). Mental health practitioners are often constrained by their institutional contexts from engaging in practices which many of the people they support take for granted. How can a professional undertake their role effectively when they cannot understand or engage with a significant aspect of day to day existence for the person they are endeavouring to support? This is beyond a simple understanding of the technical or functional components of social networking platforms; it is a more nuanced understanding of how *some* people are using online social networks to enhance and bolster their mental health and wellbeing.

Professionals who do not understand those spaces may caution against using them. In my day to day work it is not uncommon to hear professionals declare that they advise people they support to avoid using the Internet in relation to their mental health. This is an unacceptable abrogation of professional responsibility to keep their knowledge up to date and relevant to the people they support. It is also a failing of institutions to act as an enabler in facilitating access to this knowledge. However, because online social networks are outside traditional professional channels of clinical guidance, and are not routinely embedded within training and development, they may not always be taken seriously. Online social networks are informal everyday channels that are easy to minimise or ignore. Engagement in online social networking is neither neutral nor uniformly positive and whilst increasing numbers of people are making use of online social networks, practices within them vary. Online social networks offer challenge and complexity, and this is in itself a reason for professionals to understand and engage with them. The *sociable professional* and the *sociable organisation* understand the potential of online social networking to afford access to peer support with its implications for improved mental health and wellbeing. They account for this potential in

professional practice, development and institutionally mediated training and development. They seek to keep their knowledge up-to-date and endeavour to appraise themselves of the online social networks and related practices engaged with by the people they support and care for.

3.5 Learning beyond the Boundaries of the Institution

Participating in online social networks requires both figuratively and literally stepping out beyond the institutional boundaries of set working hours and the confines of professional practice within the office. It takes professionals out of formal settings and into informal, conversational and often messy contexts where they are required to be adaptive in juxtaposition to expecting the adaptation of others to their establishment and clinical norms.

My interviews illustrate how some mental health professionals actively engage in social networking to gain new kinds of knowledge outside of the boundaries of the institution; they consciously seek understanding and connection that they can bring back to their day to day professional or patient roles; they seek to broaden their horizons beyond institutionally mediated knowledge. This knowledge informs their professional and clinical practice and it enables them to challenge the received understandings of the institution. There is a tension between formal learning and knowledge and that which is generated through informal social networks in terms of validity. Online social networking afford a means of sustaining and developing professional identity, a means of learning, and a means of increasing public visibility and career advancement. This is a new kind of learning that fractures traditional transmissive routes and requires immersion and participation, occurring right at the outer edges of institutional practices.

The *sociable institution* recognises the affordance of online social networking to generate new kinds of knowledge and deepen as well as challenge existing knowledge. The *sociable professional* who engages within online public networks to gain, share and contribute learning is arguably a better equipped professional in contemporary society. As new technologies blend working and non-working lives, the *sociable institution* does not stand in the way of a new emerging sociable professionalism and provides the requisite tools and conditions to facilitate rather than resist - namely a permissive attitude towards online social networks, frameworks to support professional self-mediation and learning that do not unduly hinder or constrain, access to smart devices to be both used for professional development and as part of a collaborative clinical relationship, free public Wi-Fi in health and care settings. With these conditions in place, alongside opportunities to engage in learning about the role of social networks in professional practice, new forms of *sociable professionalism* will emerge which are appropriate to a contemporary networked society. *Sociable* provider and commissioner organisations, professional bodies and educational bodies embed a permissive and supported approach to online social networks that consistently enable a blending of offline and online professional identities.

3.6 Empathy - Relationships Redefined

One of the most striking and unexpected insights arising from my research is the way in which my interviewees told me how the exploit online social networks to deepen their empathy for each other. It is an inversion of the total institution delineated by Goffman in which a group called ‘inmates’ and a group of supervisors called ‘staff’ exist in state of inherent reciprocated suspicion and mistrust from an embedded demarcated

separation of roles (Goffman, 1963). Some people are actively engaging with online social networks to step in to the shoes of others in ways which may be not permissible in an institutional context. This is expressed both by people participating in online social networks in personal and professional capacities, and often both.

A normative view routinely expressed is that mediated practices in online social networks are frivolous and capricious. When people tweet about the mundane aspects of their lives they could be perceived as whimsical but I believe something more profound is happening beneath the surface - people are sharing a common humanity, building relationships, saying 'look I'm just like you', and sharing their beliefs and values. They are sharing more than is permissible in the front stage performance of their professional or patient roles, to use Goffman's (1959) dramaturgical metaphor, and allowing each other glimpses of the back region. This is a disruption that brings connection and generates empathy between providers and receivers of care. It is a disruption that affords the possibility to generate a depth of understanding beyond prescribed roles and labels.

The permeability of imagined borders between practitioner and patient become possible online in a way that they are not possible, or arguably appropriate, in a clinical context. Online social networks offer new opportunities to create holes in the barbed wires that still exist in the echoes of the asylum, where unspoken rules serve to create and sustain social distance. What makes us similar as opposed to what makes us different can be expressed and employed as a means to connection. Multiple aspects of our identities can be performed beyond the limited boundaries of the labels accorded to us in an institutional context. Online social networking sites offer simultaneous distance and proximity - distance enables people to engage with each other in a

controlled way whilst also at the same time creating proximity that it may be hard for a clinician and patient to have in everyday life. This could hold the clue to why online social networking can be so valuable - it provides an opportunity for two groups for whom distance and boundaries are implicit in one context, to peer round the barricades and peek into each other's lives and experiences.

The affordance of online social networks for conversations between professionals and people with lived experience to influence clinical practice strikes me as highly significant. For a professional to have access to and interact with a continuous personally self-mediated story of another person's life is profound in how it may shape their beliefs and working practices. It could be argued that online social networks are part of the answer - they afford the *sociable professional* and people with lived experience the possibility to interact with each other outside of received institutional boundaries, opening up possibilities for more nuanced and empathic understandings not readily found in the context of a clinic or ward round environment. The *sociable professional* is open to the possibility for deepening their empathy through online social networks and *sociable organisations* recognise this as a valid and legitimate enterprise. The *sociable professional* pays attention to *who* they are learning from and *how* this is influencing their practice. It is this reflexivity that means they seek out diverse voices and ensures they are not unduly influenced by a privileged minority who are the most confident and articulate.

3.7 Resistance! Stigma and Public Attitudes

Public attitudes towards mental health may be steadily changing but stigma and discrimination remains a contemporary social issue that has negative repercussions for

people living with mental health difficulties and wider society (Thornicroft, 2006). The remnants of attitudes and assumptions which underpin the asylum of the past not only still linger but are frequently remediated within mainstream media. Irresponsible reporting sustains a background narrative of dangerousness associated with mental distress which connects directly to arguments related to restriction of liberties, incarceration, and limiting of life opportunities for people affected (Philo et al, 1994). The social attitudes and beliefs which led to the creation of the asylum in the nineteenth century appear to retain a powerful grip on the public imagination and prejudices of contemporary society.

My research suggests that a blend of empirically proven anti-stigma strategies are self-mediated within online social networks - namely protest, education, and contact (Corrigan, 2006). Protest operates as a reactive strategy that reduces negative attitudes but fails to promote positive ones; educative approaches that provide information to the public can be effective in reducing negative stereotypes; direct contact between people with mental health problems and those without is most effective in engendering positive attitudes and greater general acceptance. As set out in Chapter 4, whilst direct contact is shown to be the most effective strategy, the pre-influencing factor of stigma itself can reduce willingness to engage in social contact and self-disclosure (Sayce, 2000). Online social networks have a particular affordance of allowing the possibility of direct contact without physical proximity. This enables both people affected by mental health difficulties and the public to take productive risks in direct contact and discuss issues in the public sphere from the comfort of the private sphere. My research suggests that a blend of all three strategies for challenging and reducing mental health stigma are found in online social networks and that people,

rather than institutions, are leading the way in challenging mental health stigma (Betton et al, 2015).

The role of individuals engaging in online social networking sites to challenge and interrupt mental health stigma should not be underestimated. Mental health professionals, institutions and campaigning bodies should seek out, support and amplify sel.f-mediated practices which challenge stigma. They should also endeavour to learn from diverse publics discussing mental health to generate a reflexive understanding of what matters to people most to many people living with mental health difficulties, not just the privileged few. For mental health institutions, even small campaigns, such as the Twitter #DearMentalHealthProfessionals described in Chapter 4, offer salient insights into experience of stigma within services for those people who participated.

Campaigns to challenge mainstream media mediated mental health stigma are already well established. *Sociable campaigns* recognise the power of socially networking self-mediated practices by ordinary people and seek to provide a vehicle to amplify and bridge their concerns into mainstream media. It is important that mental health activists recognise their latent collective power and capitalise on it where possible to influence mainstream media. In this context there is an argument for people accessing mental health services, professionals and institutions to join forces with a shared purpose of challenging the significant grip of negative mediations by mainstream media. However, in order for the *sociable professional* and the *sociable organisation* to play this supportive and facilitative role they need to have engaged in the conditions described above to have an authentic voice. Participation in online social networks is developed through trusted relationships and can be built with dedication and care.

3.8 Being a Bad Patient (and Professional)

According to the activist Judi Chamberlain (1999, p.51) being a good patient, a compliant patient, a willing patient, can come at a personal cost particularly if it is in the context of low expectations from those people providing care. Being a 'bad patient' is not a pejorative position, rather it is one in which one takes control of one's identity and make decisions for oneself, sometimes without the approval of those in the role of care provider. To reject the role of patient is to embrace a life beyond that defined through a relationship to mental health services. To critique the role of patient and professional and to understand their socially constructed nature is to create the possibility of new types of relationships. Both the socially constructed role of patient and professional have associated expectations, behaviours and internalised constraints within the boundaries of the institution.

Talking with a mental health practitioner in a one-to-one clinical setting is boundaried and constrained by established power relations and a clinical frame of reference. The professional is accorded power through their access to the shameful back-region of the patient's difficulties that cement the lack of equity in their exchanges (Goffman, 1963). Online social networks afford the opportunity for a rupturing of received relationships, to be a bad patient, to question and to challenge through connections with others who have similar experiences, unhindered by temporal or spatial boundaries. Online social networking sites offer affordances for different conversations to emerge on more equitable terms than may be possible in the context of the institution.

The *sociable professional* and the *sociable organisation* understand that online social networks afford unprecedented opportunity for the role of patient and professional to be discussed and debated in the public sphere. Rather than dismiss or avoid those conversations, it is incumbent on professionals to engage. Online social networks create a visibility to conversations which can be learnt from and participated in - after all the notion of sociability is at their core. Online social networks afford an opportunity for practitioners to be more social in their learning and in their professional identity. By participating in social networks, the *sociable professional* has an opportunity to be influenced by and question themselves beyond the constraints of the institution. This opportunity requires a parallel responsibility to seek out diverse voices and to engage in learning that is informed by a wide range of voices with diverse experiences and points of view.

3.9 Fight Club - Is Disruption a Good Thing?

My research thesis has been developed from my own immersion in blogs and micro-blogging sites and personal observations of disruption in online social networking spaces, and in particular in a space and set of practices once described as the *madosphere*. This space has now ceased to exist but many of the people and the practices remain albeit in through more dispersed means than a point at time in which The World of Mentalists (TWOM) blog offered a focal point. The *madosphere's* prevailing quality was one of transgression - sometimes playful, sometimes serious, but always contesting the assumptions and practices of the dominant order. What is the role of disruption in online social networking and is disruption something to be welcomed and supported?

Like the ‘fight club’ of the film with the same name that I elaborate upon in Chapter 5, the *madosphere* could be characterised as a rebellious space that picked many ‘fights’ but ones related to written arguments and debates rather than one of fists and bruises. TWOM established itself consciously as counter-culture, a space where the mainstream could be critiqued and where people on the edges of the conventional could congregate together. TWOM was fight club for people on the margins of the conventional - often part of the institution and often at odds with it - it engaged with the mainstream and was part of the mainstream, run as it was by a mental health practitioner and a user of mental health services.

Whilst institutions are increasingly developing a presence on social networking sites, my research has been particularly concerned with conversations about mental health in the online public sphere which are taking place online amongst ordinary people rather than those which are mediated by institutions. I have argued that it is in these conversations, self-mediated by ordinary people both accessing and providing mental health services, that institutional norms and behaviours are being disrupted. The *madosphere* was a space and set of practices where normative views in the mental health sphere were held up, scrutinised and often rejected. A group of people whose mental health experience marginalises them, and which can place them on periphery of ‘normality’, had a space to play and resist. I believe that sites of resistance to the dominance of the establishment are a necessity for social progress. Political changes in the legal rights of people with mental health problems have only been achieved through active campaigning by organised bodies. What has changed is that people no longer require their cause to be solely mediated by those formal bodies. They can produce their own content to challenge the mainstream. And through collective action, such as

that described in Chapter 6, they can make gains and inroads into mental health stigma and discrimination.

4.0 The institution fights back

Is it inevitable that the mainstream, the institution, will seek to make inroads into and appropriate disruptive activities wherever they may emerge? Is it ever in the interests of the establishment for people to be able to self-mediate, organise and challenge their hegemony? These are wider political points which are outside the scope of my research but it is salient to consider how institutions appear to be responding to and engaging with people talking about mental health online.

During the course of my research I have observed what I perceive to be the qualities of self-mediating practices in online social networking sites subtly shifting as institutions have entered these spaces, engaging in practices which are more redolent of traditional broadcast mediation, often failing to understand the social nature of those networks. The very presence of institutions must influence the behaviours and practices of mental health professionals. Since 2012 there has been an influx of guidelines, policies and toolkits for use by professionals and organisations online. This has become a space subject to scrutiny and a space where practices are increasingly regulated by professional bodies and institutions. Professionals have been rightly held to account by professional bodies in cases where they have exhibited inappropriate behaviours such as breaking patient confidentiality online. However, I wonder to what extent, along with that accountability and regulation some of the positive disruptive potential of online practices have been compromised, contained and even lost. In my thesis I describe a number events in which networked protest through blogs and microblogs provided

challenge to mainstream media and institutions. But a question remains as to the longer term impact of those challenges. Short terms protest may have an immediate impact but analysis of protests in the political sphere (for example, the Arab Spring) mediated through online social networks suggest that they do not necessarily appear to translate into long term change (Couldry, 2014, p.610)

It is a compelling notion that there is a linear path towards enlightenment and away from the asylum walls. However, evidence suggests that this is not inevitable or even likely. Relationships and practices are continually being negotiated and renegotiated – sometimes with a push away from the asylum but sometimes towards. This push pull tension is a continual thread of conversation in the *madosphere* and indeed most if not all dialogue about mental health. For some this is a welcome extension of organisational transparency and accountability; for others it is an unwelcome expansion of bland corporate trespass which limits the potential to have free and authentic debate online.

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