

Social Media in Mental Health Practice

Online network tools for recovery and living well

*A practical guide for health and social care
practitioners working in mental health services*



digital innovation in health

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Preface by Helen Bevan



Social media really is changing our world; it is changing how people with health issues connect with each other, how health practitioners link up and how people who use health and care services and practitioners interact; it is changing how we think about health and healthcare and how we can go about improving things. In the old days, each of us worked in our own (limited) fields of influence and built relationships with people we were in direct contact with. Now we can learn from, share with and build solidarity with others with the same interests or issues in our own localities or all over the globe.

I've been using social media in my professional life in healthcare improvement for less than two years. At first I felt overwhelmed by social media and not sure what to do; I mostly just followed other people until I got the confidence to join in. Now social media has opened up all sorts of possibilities that I could never have imagined previously. I am part of a community of people with the same work passions as me from all over the world who provide a priceless resource and support system to each other. In my experience, there is a very positive spirit around social media such as Twitter; people want to help and assist each other and go the extra mile. Through social media I get access to updates on the latest thinking in my field as soon as they are published and have discussions and solve problems with some amazing people. One of the most powerful aspects of social media is that it cuts across organisational barriers and hierarchies; you can connect with a voluntary advocate as easily as a chief executive as easily as a clinical team member.

This eBook, *Social Media in Mental Health Practice* sets out the kinds of opportunities that social media presents for health and social care practitioners working in mental health services. In our world of health and social care, demand is growing, care needs are becoming more complex and money is increasingly tight. We will struggle to deliver a future system of care for people with mental health difficulties using our previous thinking and methods of delivery. What strikes me about the case studies in this eBook is that they are powerful stories of innovation that show some new ways forward. I define innovation as "doing things differently and doing different things" in order to get better outcomes for the people we serve. Social media has such a key role to play in service innovation.

Helen Bevan

Helen Bevan, chief of service transformation at the NHS Institute for Innovation and Improvement



Introduction

If you did not grow up on Facebook, social media can seem baffling. But for those who have embraced this new world, social media are already proving invaluable in supporting people living with mental health difficulties.

The Mental Health Network of the NHS Confederation says in its paper

E-mental Health: What's all the Fuss About:

By making the most of the opportunities presented by e-mental health, we can address some of the biggest future resource challenges facing the mental health sector.

The impact digital technology has had on the way we live our lives today is immense. 74 per cent of households are online, with the average user spending 14.2 hours a week online. 91 per cent of UK adults use a mobile phone. 30 per cent of all adults use a smartphone, and among younger adults aged 16 to 24 this rises to 52 per cent.

Public expectations of health services, and how they interact with them, are changing. Through greater use of technology, the public are becoming more active, informed consumers in their own healthcare. Service users and their families have different expectations about how their relationships with mental health services, and professionals, should be.

Our ebook shows how health and social care practitioners working in mental health services are using social media – both in their professional careers and to help those experiencing mental health difficulties. While the focus is to help practitioners use social media in day-to-day practice, some of the case studies look at how it is used in a professional capacity as well.

It is important to say what this ebook is not. It does not cover how to use social media to further your career – there are already plenty of guides around on this. It is also not a step by step, 'how to' guide on creating a LinkedIn account or how to tweet. The internet is full of good advice and we point you in the direction at the end of this ebook.

What we do is to give you plenty of case studies, points to consider in day-to-day practice plus references for further information. We help you think through the opportunities and the risks.

Mark Brown, editor of One in Four a lifestyle magazine by and for people with mental health difficulties, points out how satisfying it is for someone who in everyday life would be seen as a 'patient', becoming the 'expert' when talking to others through social media – and both learning from the experience. He says: "I think mental health professionals have to keep up with the aspirations, ideas, hopes and ideals of the people they work on behalf of. Engaging with social media is part of that."

Recently, an NHS Foundation Trust had to apologise to a blogger who wrote about her inpatient experience. Nurses found out about her blog, read it and confiscated her phone. The blogger, who writes under the name of 'Little Feet', wrote: "It became apparent in the complaint response that the trust did not have a policy surrounding the use of social media by inpatients. The great thing to come out of this is it has provided the trust a



good ol' prod and poke to get up to speed on the use of social media by patients."

And Jonny Benjamin, who has used social media as part of his recovery journey, says: "I think mental health practitioners could encourage those with mental health problems to use social media in a similar way that I have... there is nothing quite like finding someone else you can relate to when suffering from mental illness."

So increasingly people using mental health services have expectations about social media. Do you, as a practitioner, have the skills they need?

As Little Feet blogger says: "I would love to see the 'them' and 'us' barriers broken down in mental health; social media has provided the medium for this to happen."

That has to be good for everyone using and working in mental health services.

The authors

Victoria Betton

Victoria Tomlinson

NB social media is full of jargon. We have tried to write this ebook in plain English but if we have used a phrase you don't understand, just check the glossary at the back. And our apologies!

Case study – peer support on Twitter

Sue Sibbald is a service user consultant in Sheffield, living with a diagnosis of Borderline Personality Disorder (BPD). Sue is online on Twitter as @BPDPFFS (FFS – fighting for services) [Facebook](#) and has a [blog](#)

Sue trains mental health practitioners, delivers psycho-education for people with BPD and is a governor of her local NHS Trust. She set up @OfficialBPDchat in 2012 to help people affected by the diagnosis. Each Sunday at 9pm, anyone can take part in an hour long chat using the hashtag #BPDchat – on anything from 'coping skills for the holidays' to coping with difficult times.

Sue sees social media as a powerful tool for people to support each other and build an online community: "It helps people who may have trouble with interpersonal relationships to feel heard and accepted and not feel alone. The stigma associated with the label of BPD means that people can be scared to talk about it to others, but they can be open in an online environment.

"People diagnosed with BPD may have limited or no opportunity to meet others with a similar diagnosis. Twitter means they can share experiences and coping strategies, as well as just having fun."



Chapter 1 What is social media?

Social media is a development of the internet. The phrase 'social media' is used to describe online conversations between people, which became possible with what is known as 'Web 2.0' - the development of technologies that allows anyone to upload content themselves – such as blogs, pictures, sounds and video clips; share these widely through Facebook, Twitter, LinkedIn and so on and others can then leave comments, add to the material and share them more widely.

Social media is immediate and of the moment. Within the space of a minute it is possible for

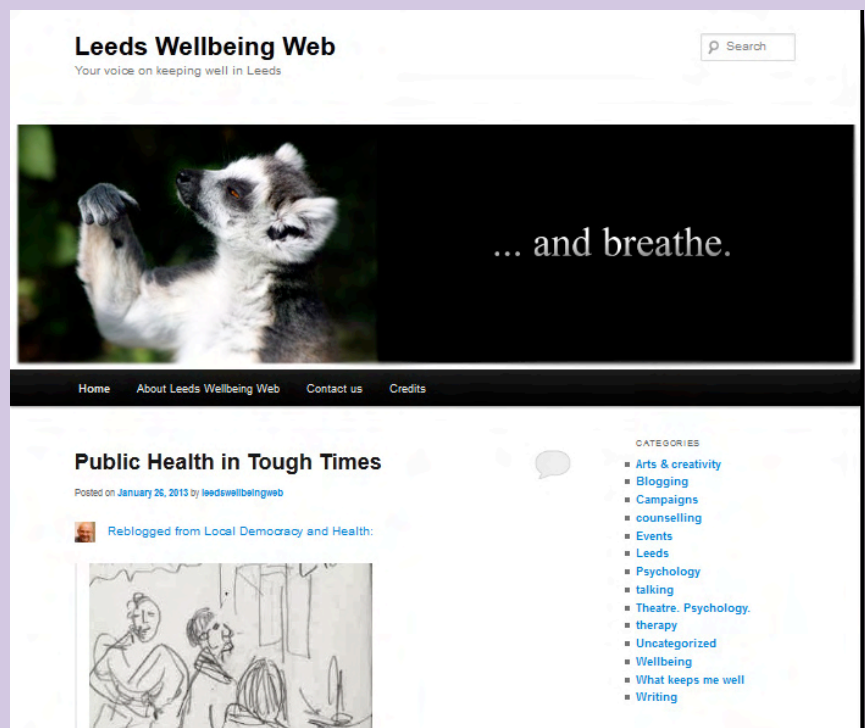
- Someone with mental health difficulties to post a blog on a website
- People who read their blog – 'followers' – to share and comment on it
- At the same time, a dozen other people to read and tweet about it
- Three or more followers of the tweet then re-tweet and send it out to their followers
- Someone else to post a link on their Facebook and lots of others to 'like' it
- And so on. The only limitations are the size of a network of followers and how interesting they find the original material and tweets

This ebook shows just how wide social media is - much more than just Facebook and Twitter.

Case study – community blog

The Leeds Wellbeing Web is a blog by and for people experiencing mental health difficulties. It is run by a group of volunteer community journalists who contribute information, stories, pictures or films about places and activities in Leeds which help maintain their wellbeing. The aim is to create a fantastic online resource where people can share their experiences of staying well in Leeds.

This blog aims to encourage people to think more positively and proactively about their mental health and help them to maintain their wellbeing. It's about giving people a voice to tell their own stories and the story of their city through their own eyes.



Chapter 2 Social media to support practitioners

As we saw in the Introduction, the use of social media continues to grow and can no longer be written off as just a fad.

Younger people engaging with mental health services expect to use the web and social networks for all aspects of their lives, from shopping through to booking a holiday. So why not for mental health services?

Few mental health practitioners have had a grounding in social media as part of their training, because it is so new - Facebook was launched in 2004 and Twitter in 2006. Over time mental health practitioners will need to have a sharp awareness of social media for their day-to-day practice – helping people navigate both their online as well as offline lives as part of their recovery journeys.

Do you know how many of the people you support are using social media? And for those that do, are you giving equal weight to helping them think about how they use it to live well, as to other aspects of their lives? If they are not using social media, have you considered helping them think about whether it might be another useful tool in their recovery toolbox?

Social media will not be for everyone. Rather, it needs to be seen as part of your toolbox that could help some with their recovery – and for you to communicate with a number of audiences.

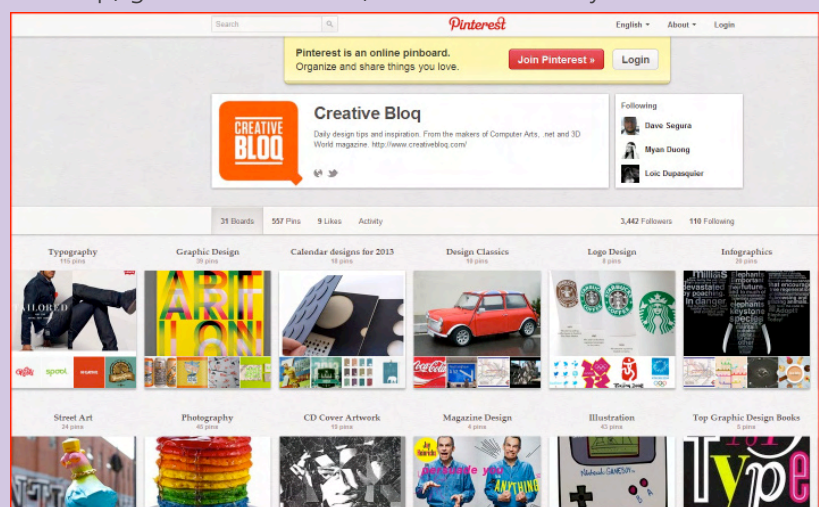
Case study - Occupational Therapist

Emma McKenzie is an occupational therapist at a Community Recovery Service in York. She uses social media personally, professionally and clinically.

Emma says: “I use social media for networking and promoting information. In my line of work we often set up opportunities in the community that are advertised within the NHS trust and rely on health professionals’ referrals. But as health professionals we don’t always know what a person’s interests are.

“There is also a frustration around timing. We have to advertise something at least two months in advance to allow time for teams to pick the information up, give it to the client, wait to see if they are interested and then to make a referral to us. With Twitter I have a direct voice within the local community. At no cost, and minimal time I can promote activities and useful information quickly and directly to our client group, raising awareness and engagement with services.

“This puts our service on the map with other organisations. We were recently discovered by the founders of ecominds who saw our tweets about



our 'ecominds green projects' and have now invited us to run a regional ecominds event with them.

"Social isolation is one of the biggest factors that contribute to mental health problems. I promote the use of Facebook, Twitter and Pinterest on an increasingly regular basis. Used in the right way all three can help link people back in to their interests and peer groups.

"A recent example of this was a lady who is interested in art but couldn't get out due to agoraphobia, so was finding it difficult to get inspired. I introduced her to Pinterest which opened up a new line of inspiration and enabled her to connect with other like-minded individuals. It ultimately inspired her to make the first steps back out of her house to buy new art materials and she is now working towards attending a local art class.

"Social media can help people to engage and be heard in their local community and is a powerful tool to open new doors for them."

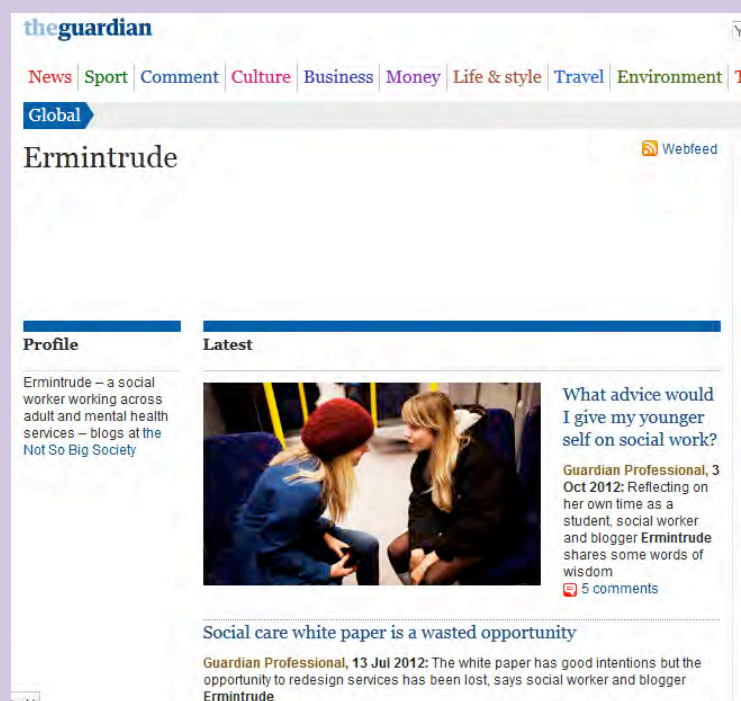
Case Study – using a personal budget to get online

Ermintrude (who blogged until early 2013, using a pseudonym) was a social worker in an older adults' team in London. Here she shares a story about a family who used a personal budget to get online.

She says: "Caring for a family member who has very high care needs can be isolating. As a social worker, some of the work we did directly with carers had some of the highest impact - particularly as budgets were cut and services withdrawn. I worked with Mr Smith and his daughter, Sarah (names changed) for a number of years and as Mr Smith's dementia progressed, Sarah increasingly had to provide more care with less time for any social activities until she eventually gave up work.

"The carer's personal budget was limited in terms of how much money could be allowed but with her, we were able to use it to buy a laptop and pay for monthly broadband access. While that can't replace a social life, she was able to link in with other carers, both those in the local area and nationally to share her experiences, frustrations and hopes.

"She built local networks from using community sites and was able to save money by using cheaper shops. While not making up for the gaps in the services, the possibility of using personal budgets to allow access to a world many of us take for granted was, as she told me, life changing."



Chapter 3 Why is social media important in mental health practice?

Social media is no longer something that a few people do as a remote or separate activity. Its use now weaves into everyday life for the majority of the population.

This level of activity brings both challenges and opportunities for mental health practitioners. Many people are already using social media in their recovery and to live well – from learning critical life and job skills to self-management of their health and making new connections. Many more may find social media useful but would benefit from some help to get started. Others may be accessing sites which they might find supportive but may not be helping their recovery journey as much as others could. You may be able to help them think through the pros, cons and alternative places for information and support.

And for some, going online can be a helpful distraction - contributing to and doing something positive in a shared and safe space.

As a practitioner, how do you respond if a person you are supporting asks you 'Do I...', 'Should I...' or 'What shouldn't I...' do in social media?

Every practitioner is concerned to improve outcomes of the people they support, improve the convenience of their support and facilitate shared decision-making. Social media can help with all these.

And are there risks? Yes, many. But mental health services manage risks day-to-day and help people they support manage risks in their everyday lives. On the whole most of us learn to manage those risks. Social media is the same – with two caveats. The speed of activity in social media is phenomenal. And once a post is published online, it is there forever – often referred to as a 'digital footprint'.

No manual on how to use social media will ever lay down rules on what you should do. It is individual and what works for one person, could be unhelpful for another.

That is why it is so important that practitioners should start using social media themselves, even if you never want to use it in your personal life. You cannot teach the theory without using it. It is like dropping a pebble into a pond and trying to describe the sound of the stone entering the water and the ripple effect out from it. The ripple will be different every time and you have to drop that pebble yourself to understand what is happening.



Case study – social media to engage and educate

Mental Health Cop is a serving 24/7 police inspector blogging in a primarily professional capacity with an informal tone. He is also @MentalHealthCop on Twitter and won the 2012 Mind Media Award for his use of social media.

He says: “I set up a range of social media accounts in 2011 to engage and educate around the role of the police in mental health related scenarios. Originally this was primarily to help police officers to ensure better and more informed responses to incidents. There was an appetite for direct engagement with other non-police professionals but more importantly with people who use mental health and police services.

[My blog](#) is the primary store of information: almost 250 articles on all aspects of policing, mental health and criminal justice. Twitter and Facebook are the vehicles by which to publicise the articles and engage with people who want to discuss them.

“I have also found Twitter has been a space for people to raise whatever issues are affecting them and ask for a police view. This has included patients checking the application or relevance of legal frameworks that are being applied or considered in relation to them, either by the NHS or by the police. I have been delighted to find the resources have attracted awards as a result of their success.

“I prefer to think of social media as a dialogue rather than a broadcasting platform. I keep things quite informal and think that the term ‘cop’ in “MentalHealthCop” indicates this informality. I have been known to jest and joke with people where it seems appropriate because I hear positive feedback about ‘official’ Twitter accounts that show a human side. I think it is important to be accessible and engaging but this is almost always around the main theme of the platforms: policing, mental health and criminal justice.

“I manage the personal/professional boundaries as they emerge - much as I would do at work, actually. When a couple of Tweeters have crossed a boundary I have simply said so and have never yet had to block anyone!”



Case study – a professional profile online

AnneMarie Cunningham is a GP and lecturer. She is @amcunningham on Twitter.

Asked how she presents herself online, she says: “I first started using social media because I wanted to network so that I could do my job in medical education better. Yes, I am also a GP but I did not see social media as something that would help me to be a better doctor. I’m still not sure that it does, although I certainly do not think that it makes me a worse one.

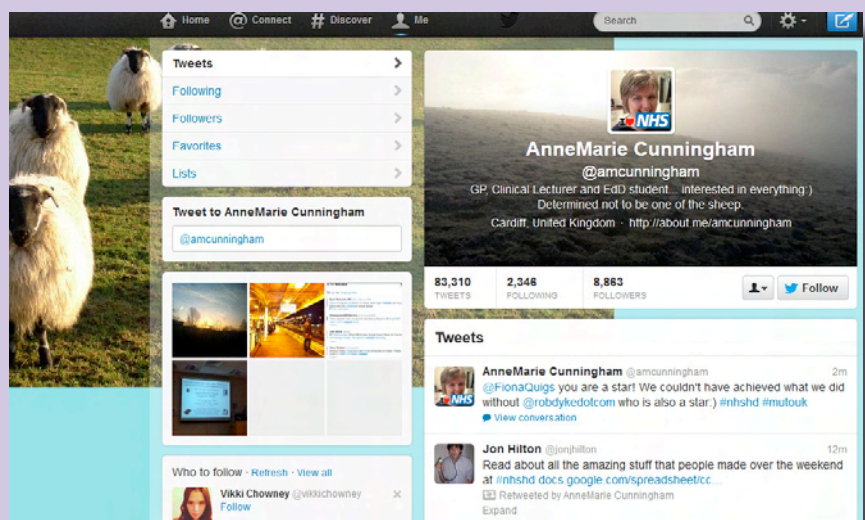
“But I am very aware that most of what I say and do within social media is public. I want it to be that way. I do not aim what I say at my patients (or students) but I’m aware that they might read it, and I do not want them to be shocked or upset or worried by anything that they see me write. I aim to be professional, and I aim to respect professional boundaries.

“When I am in the consulting room I reveal very little personal information. I doubt that patients are really interested. They walk in to see me and want and need to talk about them, not me. They often politely ask how I am. If I’m running late, I might smile and say, ‘Busy!’ But I would not share my own personal woes and worries with a patient. It would be wrong for me to burden them with my personal concerns. Of course, if they ask did I enjoy my holiday we might chat briefly about that. I don’t close down these conversations but I would never initiate talk about myself.

“I share very little personal information online. I do not usually talk about my friends or family publicly online, and this is often to protect their privacy. However, this year I am sharing a photo that I take every day. In some ways this often reveals more personal information about me than what I write. It is something that I am aware of but rarely feel constrained by. I think that in many ways I am quite a private person. So this, maybe more than being ‘professional’, defines how I am online.

“Of course I might share some difficulties online, for example struggling to make technology work just the way I want it to! I don’t think that is a problem. It shows a different side of me and it is unlikely to impact in any way on the professional relationships which are important to me.

“I have thought about how I present myself online over the years. I try to be calm, collected, honest and independent. I hope that I come across as I do when I am offline. I am proud that when I meet people offline, who have first known me through social media, they often say that they feel as if they know me already. I would be unhappy if my online presence was considered inauthentic, so this pleases me.”



Chapter 4 The basics explained

If you are completely new to this world, these are quick overviews of the main social media

4.1 Facebook

Facebook is a free social networking website that people sign up to by opening an account and entering their details – name, age and location at the most basic. Further details can be entered – from relationship status to event invitations – but can be kept private so that only friends who you know can see the information.

Facebook personal

Most people keep Facebook as a personal space to keep in touch with friends and families, rather than LinkedIn which is more for professional use. Facebook is a great place to upload photos and videos.

Facebook fan page/page

Organisations and businesses are increasingly creating Facebook pages to post information – they do this on what is called a ‘page’ or ‘fan page’. Some use their pages instead of a website, others as an additional friendlier type of website that can be updated more quickly and cheaply. In mental health, a clinic could post times, a map, useful information and create special groups.

As with all social media, you need to be aware of and take care with privacy settings - and stay aware of how these settings are constantly changing

Example of a Facebook fan page

Right is a screengrab of the fan page for Leeds and York Partnership NHS Foundation Trust. People can ‘like’ the page for updates about the Trust’s campaigning work, to find out about how they can get involved in events, and for useful information on the theme of mental health and learning disabilities. They can then comment and engage in conversation with the team managing the page.

4.2 Blogs

A blog – abbreviated from ‘web log’ – can either be part of a website or stand alone, almost like a website on its own. The three main blogging platforms (or software) are all free: WordPress, Blogger and Tumblr. Wordpress is by far the most used software for bloggers.

An individual or an organisation sets up a blog (like a simple, free website), designs their header and decides on the categories they want – this helps visitors to the site to find information under grouped headings.

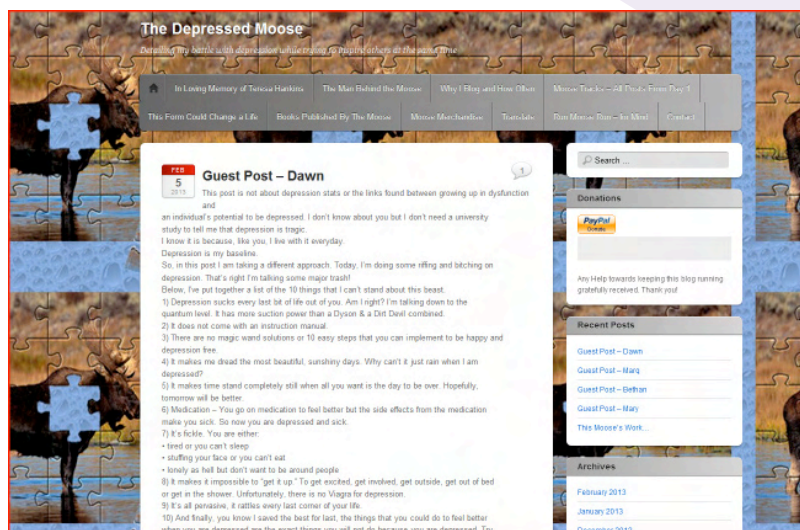


There tend to be two types of bloggers those who post regular articles with views, commentary, insights and information on topics that will be of interest to whomever they decide may want to read it. And then those who post as an online diary for themselves, with no particular concern as to whether anyone ever reads their blog. Some people may post once or twice a day. Others less frequently. There is no rule. The key is to think how often people who subscribe to the blog will want to receive new ones.

Each published blog is called a post. You can lock a blog so that only a few people can view what you post or leave comments. You can also moderate comments to check you are not publishing abusive or defamatory comments.

Example of a blog (right)

The Depressed Moose is a blog about an individual's battle with depression, his thoughts and feelings and his ideas behind improving his state of mind. His posts aim to inspire others especially those battling depression. He makes the point, so important in social media, about being 'honest and open'



4.3 LinkedIn

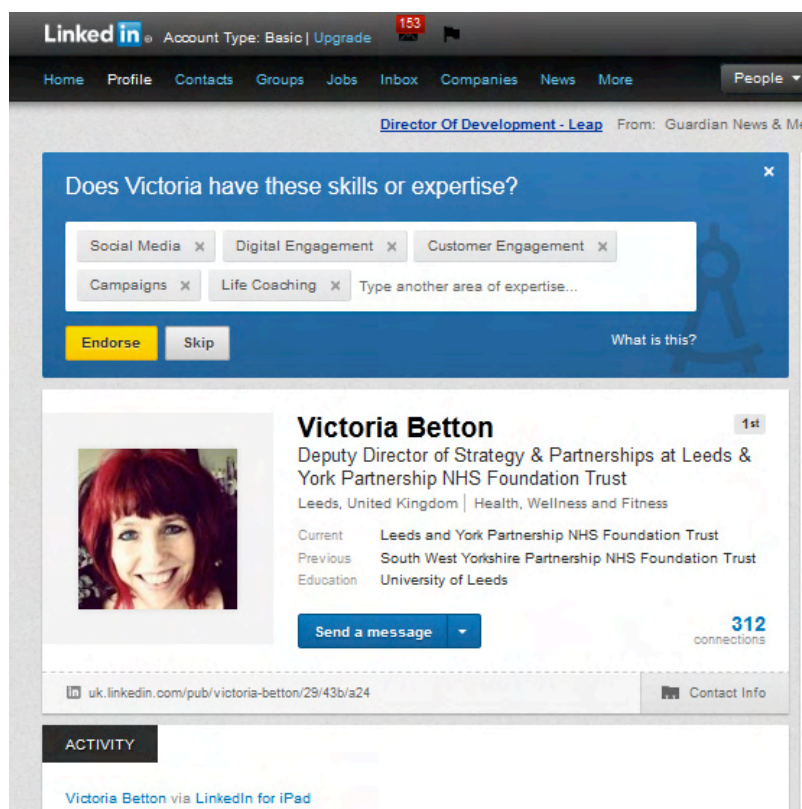
(Example of LinkedIn profile right)

LinkedIn is a social networking site for people who are working or want to work. It costs nothing to open an account.

You create a profile – including your education, current and past jobs and a photo – and then connect to people whom you know and rate.

LinkedIn is a powerful search engine – for instance, anyone on LinkedIn could do an 'Advanced Search' using a keyword such as 'occupational therapist'. The number of people who are found on a search will to some extent depend on the size and quality of your network.

LinkedIn is all about building professional networks. You can post questions, form groups – patient or professional, closed or



open – and use your network to help you with knowledge, introductions and connections.

Most people will want their profiles to be available for others to see - particularly jobhunters – but there are privacy settings to limit who can see your profile or connect with you.

4.4 Twitter

Twitter is another social networking site, called a microblog. You set up a (free) account with a short biography and then post short messages (a maximum of 140 characters) known as tweets from your smartphone or computer.

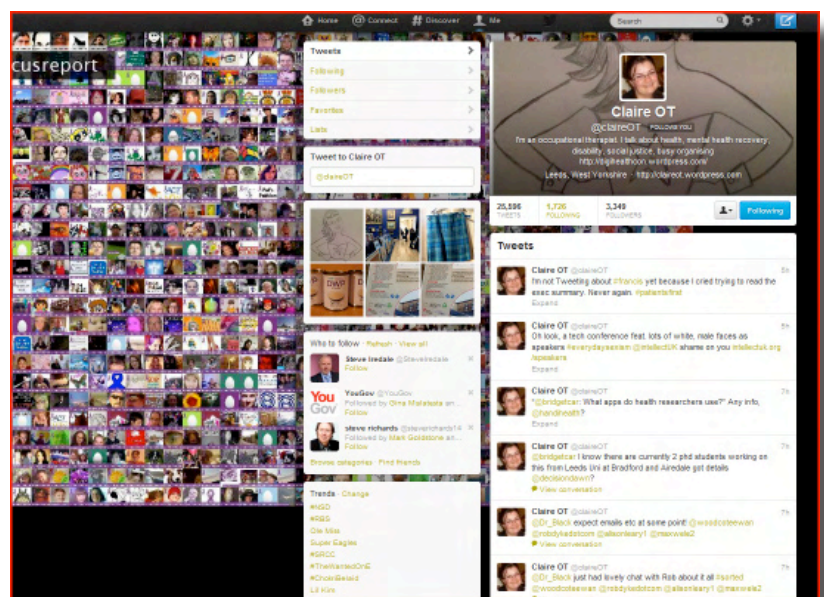
The aim is to build up your own 'community' – you follow people you know or would like to know or who have something interesting to say. And you hope these people and others will 'follow' you.

You can 'talk' directly to someone through Twitter by sending a direct message (DM) - provided you are both following each other. You can retweet (RT) messages that you think are interesting and will be helpful to your followers. You can reply to tweets.

The key issue for anyone starting to tweet is what to tweet about. Decide about the style and content, and in order for it to work you are best with a distinctive 'voice'.

Some people tweet several times a day, others a few times a month. These days most people would say you need to tweet at least once on most days as a minimum. It is possible to use software to automate tweets – you can write half a dozen and then set the times they appear. This can be helpful in managing time, but there is a danger of posting too much – it can become 'shouty' – or not being around when people reply to your tweets.

You can set your Twitter account so that you have to approve anyone who wants to follow you – which seems to defeat the point of Twitter.



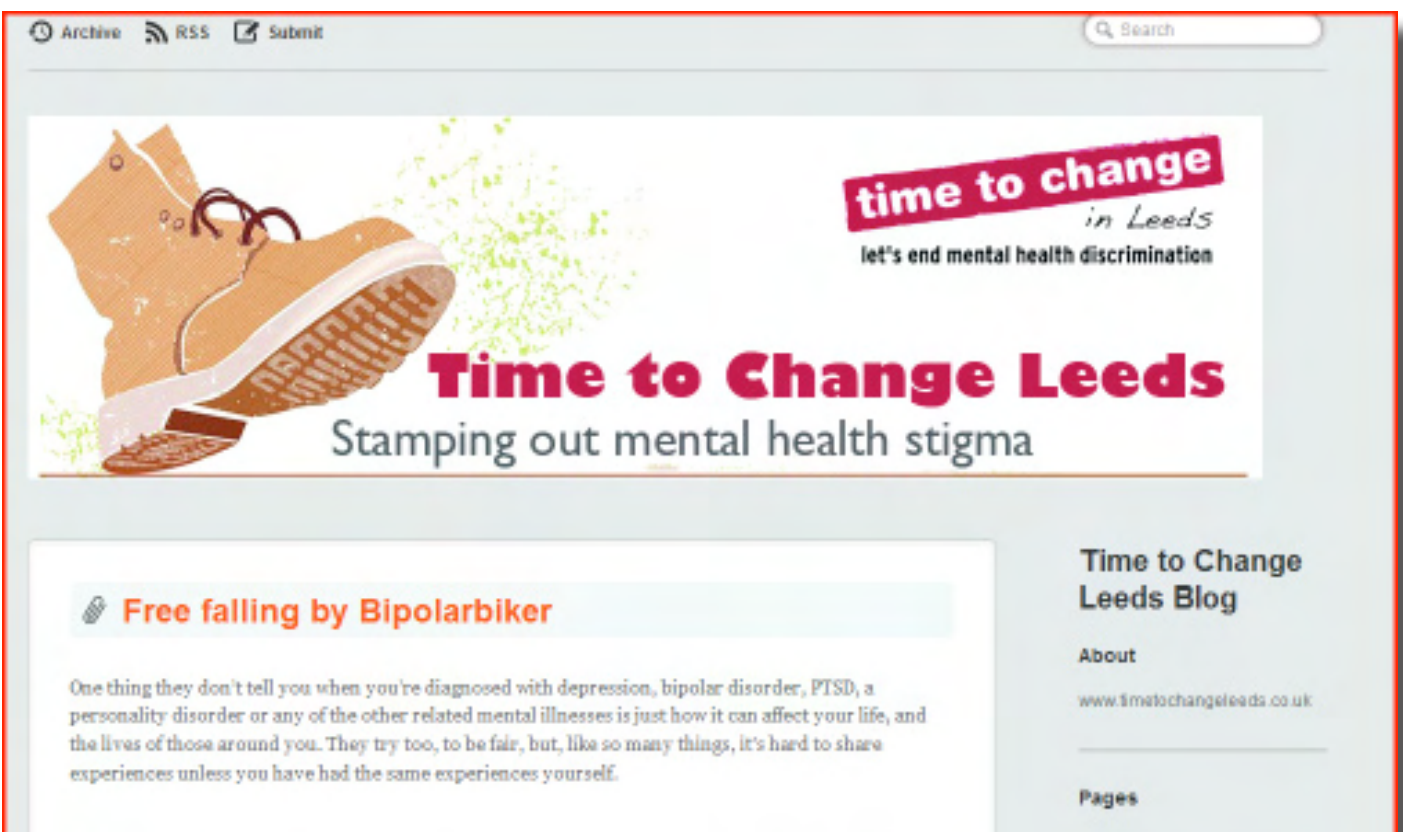
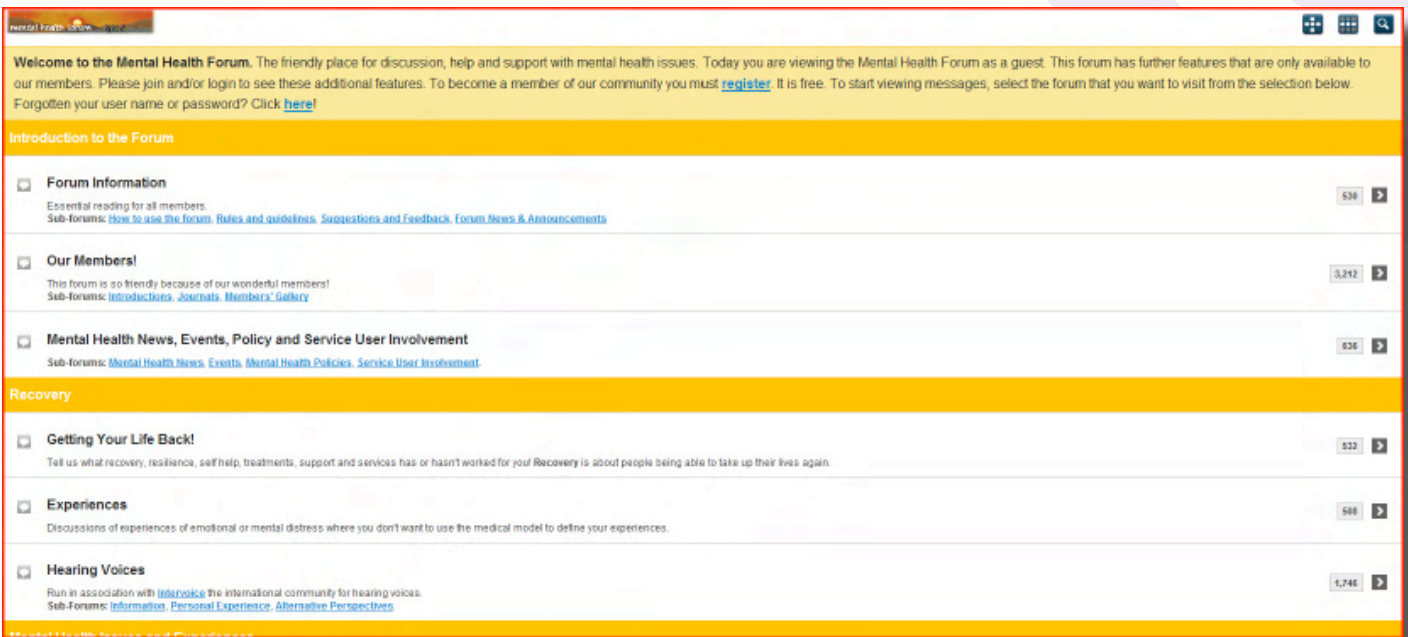
4.5 Forums

A forum (also known as discussion board, discussion group, discussion forum, message board, and online forum) is a general term for any online "bulletin board" where you can leave and expect to see responses to messages you have left. Or you can just read the board. The first discussion boards were available on bulletin board systems.

Many websites offer discussion boards so that users can share and discuss information and opinions. Special software is available that provides discussion board capability for a website.



Example of a forum (below)



4.6 Tumblr (example above)

Tumblr is a blogging platform where users can post text, images, videos, links, quotes and audio to their tumblelog.



4.7 Apps

An app is an application program or software, designed for a particular purpose on a computer or mobile phone. There are apps that can help people to assess their moods that day, apps to work out what affects moods and apps to help mental health professionals in their jobs. MoodScope and Buddy are examples of monitoring applications and programmes.

Example of an App

The Mental Elf is an app and website with short summaries of the latest evidence-based publications relevant to mental health practice in the UK – and further afield. The App will send daily updates to your smartphone. It has been developed for mental health practitioners, people using services and anyone with an interest in the topic and is a simple way to keep up to date with and have access to reliable information from credible sources.

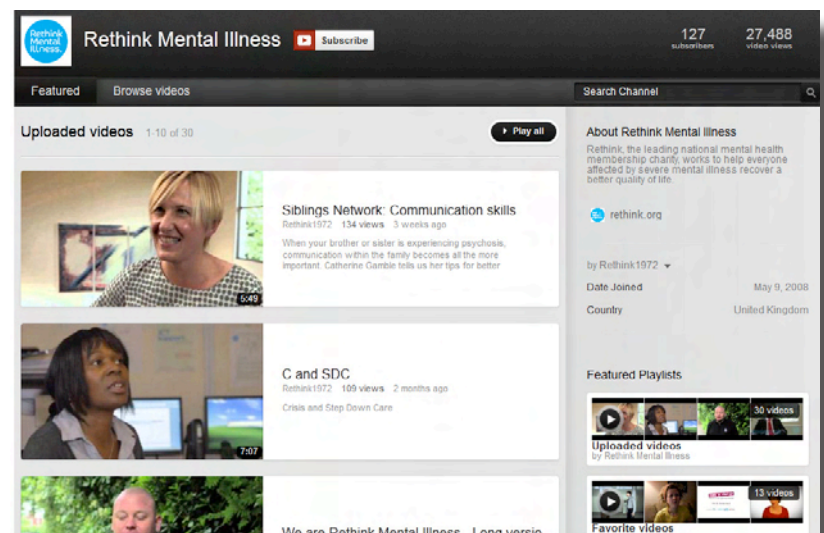


4.8 YouTube

YouTube is a site where you can post and view videos.

Example of YouTube

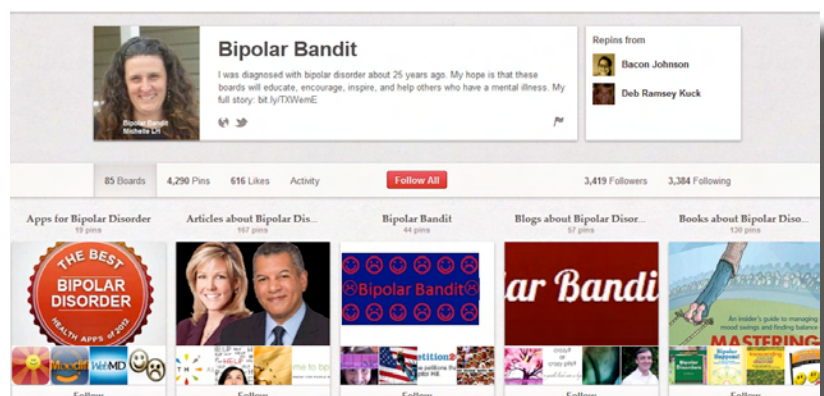
Rethink Mental Illness is a national mental health membership charity, working to help everyone affected by mental health difficulties to recover a better quality of life. Their YouTube channel includes a range of short films on different mental health topics, including people's stories about their own experiences.



4.9 Pinterest

Pinterest is a site where you create a board and pin images around a theme, which could be great visual images for how a clinic might look, through to crafts that might help people who can't get out of the house.

Example of a Pinterest board (right)

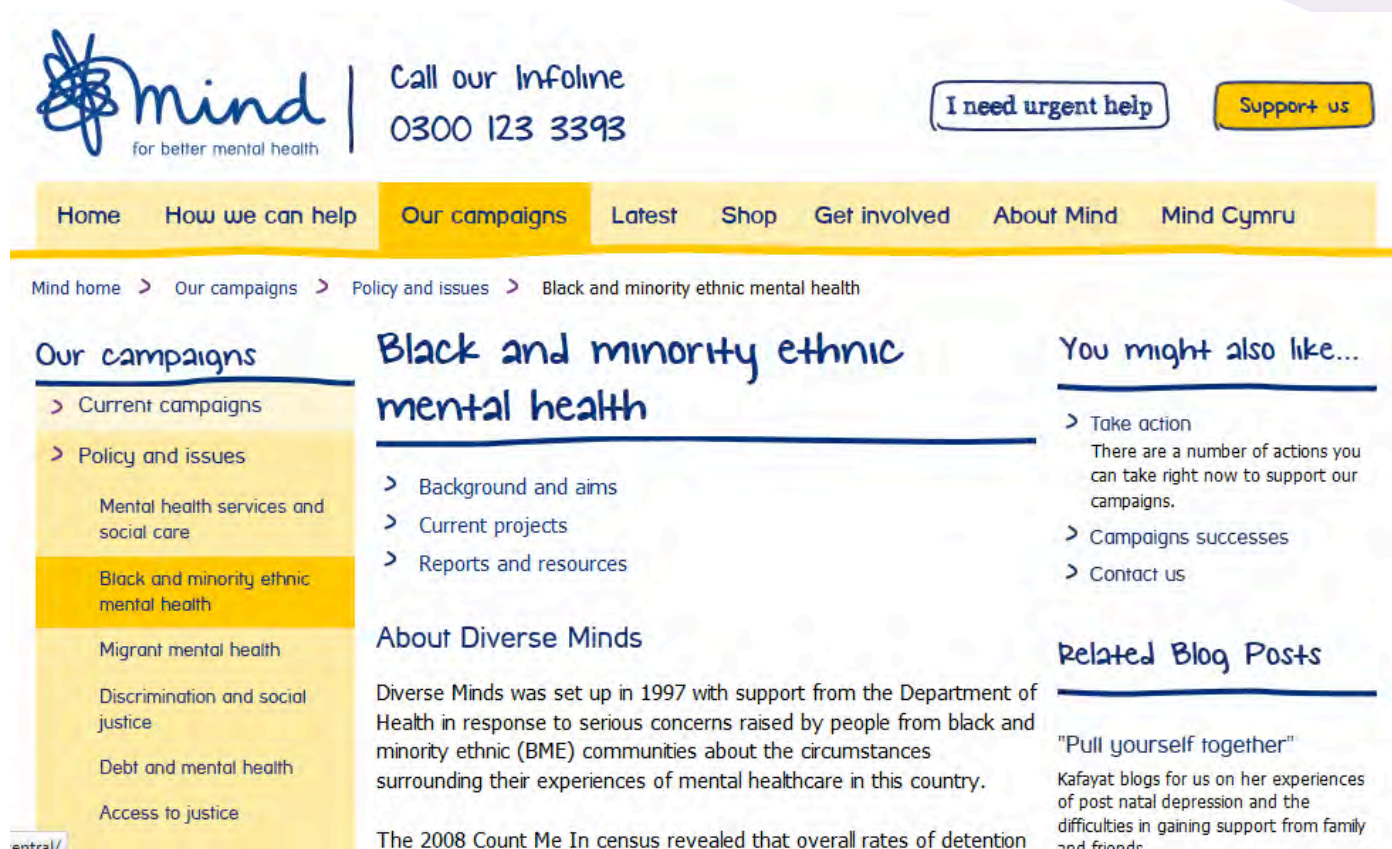


4.10 Websites

Many websites have blogs and other elements of social media integrated within them. They can be useful sources of information for people using services.

Example of website with integrated social media

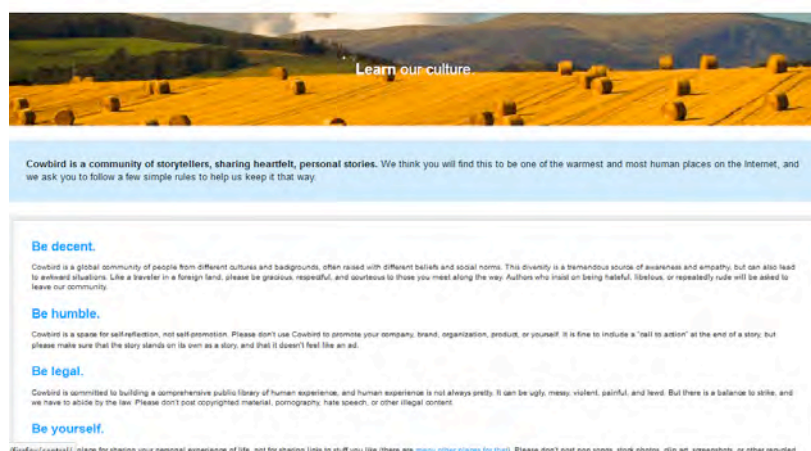
The Diverse Minds section of the Mind charity website provides useful information, links and a blog on the theme of black and minority ethnic communities and mental health.



4.11 Other social media

There are no end of specialist interest-based social networks, for instance Etsy for crafters and Cowbird for storytellers.

Example of specialist interest network



Chapter 5 Getting started in social media

For anyone new to the world of social media, you want first to get a feel for what goes on before jumping in.

It is not a place to advertise yourself or your organisation; more to listen, share, learn and be helpful. And this is why it is such a good medium for all those working in mental health. A good rule of thumb is to put in more than you take out.

Good phrases to use in social media are

- ☁ Can anyone help us on....?
- ☁ Can I ask for your help to ...?
- ☁ Thanks for your help on ...
- ☁ Thought this might be useful
- ☁ What do you think of ...?
- ☁ Want to share this with you ...

Social media is two-way – about conversations and building relationships. It is important to be honest and authentic.

For the newcomer, the following may be useful first steps, both for practitioners and people you support

- ☁ Look at some of the blogs mentioned in this ebook – include a practitioner and someone using social media to talk about their mental health difficulties jot down what you like, what you don't and if anything worries you. Why?
- ☁ Sign up for the RSS feed so you get new blog posts emailed or sent to your smartphone
- ☁ Post a comment on some of the blogs. What does it feel like? What could the risks be?
- ☁ Open a Twitter account. You can start by creating an 'anonymous' name for yourself at first*. Follow some of the Twitter accounts mentioned in this ebook. Also follow some of the people they are having conversations with. Look at tweets, retweets, what people respond to
- ☁ Again, make notes about what looks helpful and you like – and conversations that you don't like or understand
- ☁ Open a Facebook account – initially it is probably best to set all your privacy settings so that only a few close people can 'see' you
- ☁ Find a few professional organisations on Facebook and 'like' them. This means their status updates will appear on your Facebook timeline
- ☁ When you start to get a feel for how social media works, you may want to open a LinkedIn account. Bear in mind that this a professional site, so your details will be about your professional life and career
- ☁ Anything you are not sure about, just do a Google search 'how do I ...'. There is an answer to most questions out there

*One problem with social media is that when you open an account, you have to name the account and link it to an email address. It may help to do this anonymously first – call yourself Jane Newbie or Ahmed Explorer or whatever and use a new email address just for this. That way you don't need to feel exposed while you watch and learn.



Social media are very good at recognising email addresses – it can be difficult to rename or shut down accounts and set up a new account because cookies on your desktop continue to recognise you. That is why it is useful to use a temporary email address until you are ready to go 'live'.

Case study– consultant psychiatrist

John Roche, consultant psychiatrist, set up [Leeds Club Drug Clinic](#) in December 2011 at Leeds Addiction Unit in response to increasing referrals for 'party drugs' such as ketamine, mephedrone and GHB/GBL.

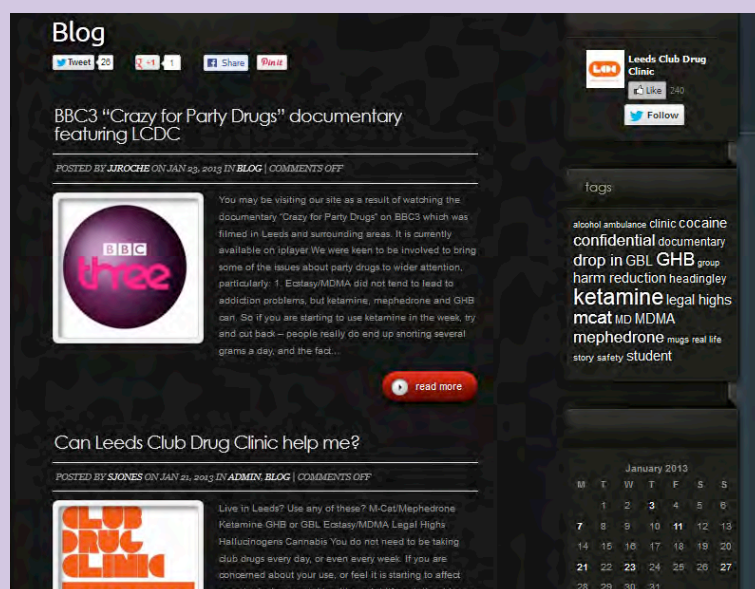
He explains: "The typical age for referrals was 18 - 25 and with very poor engagement - many not attending their first appointment or dropping out of treatment quickly. Some found it intimidating to seek help and these drugs were less well understood than alcohol and heroin. Although the substances might be different, there are many similarities in how we can help someone, but people need to be engaged with their treatment and feel that the service is meeting their needs.

"We know that this age group has grown up with the internet and many use social media and smartphones on a daily basis. Studentbeans.com recently asked 1401 UK students where they would turn for help and advice about drugs – only 15% said their GP, 31% said FRANK, 43% said friends and a huge 67% said the internet.

"We decided to develop a blog with information about drugs for both potential users and concerned others. Social media has been key in developing our online resources – a way of reaching people who might benefit from the service and to inform other health professionals. We have promoted the clinic by handing out mugs with a QR code on this side, which can be scanned by a smartphone and takes you to our blog.

"Twitter has been fantastic for keeping up to date with developments around the country and the globe. Through Twitter we have made connections with services in London, Bristol and Edinburgh who are doing similar work, as well as keeping up to date with developments in Australia, New Zealand and the rest of the world.

"The speed at which ideas can bounce around and be developed is breathtaking, and the development of online tools and smartphone apps to aid addiction problems is very exciting. This technology can bring easy to access help and real benefit to those who might never have got help through traditional pathways."



Chapter 6 Social media to live well

Recovery means different things to different people. Not everyone likes the term 'recovery' but most people can agree that hope, self-identity, finding meaning and personal responsibility are key aspects of living well when experiencing a mental health difficulty.

[100 Ways Towards Recovery](#) identifies four tasks in supporting an individual in their personal recovery journey. Here we suggest how social media can play a part in each of them

Recovery task 1: developing a positive identity social media can help people to shape their identity in ways which are personally valuable to them. For some this might mean an identity connected to their diagnosis and through which they can connect with others with similar experiences. For others this might mean an identity completely separate to their experience of mental distress. Whatever it is, social media can help to determine their identity in ways which might not be possible in face-to-face relationships. Helping people to think about an online identity will be an important part of your role .

Recovery task 2: framing this is about finding meaning in one's experiences, which may be connected to professional roles (such as diagnosis and formulation) or may be completely separate. Connecting with others can be an important part of this journey, finding out useful information and learning from others with similar experiences. The stigma and discrimination often associated with mental distress can make it difficult for people to speak openly and this is where social media can play a part. It may be surprising that increasing online connections tends to help increase offline ones (ie meeting people in the 'real' world) – they are not mutually exclusive.

Recovery task 3: self-managing learning to take control and personal responsibility through self-management is an important part of an individual's recovery journey. Part of this can be asking for help and helping others. People can connect with others all over the globe through social media– not just in their local communities. Helping people think about how they use social media as part of their day-to-day self-management is a key role for you as a mental health practitioner. For example, the Mental Elf app is a great way to have the latest mental health evidence at your finger-tips and people can talk to them on Twitter @Mental_Elf – invaluable for both people using mental health services and practitioners.

Recovery task 4: developing valued social roles this is about the importance of having a positive social role which may, or may not, have anything to do with an individual's experience of mental health difficulties. Some people use niche social media platforms to connect with others who have similar interests. Others use social media to campaign for improved understanding about mental health. Social media can be a great way of bypassing face-to-face communication channels and connecting with people you would not ordinarily meet in day-to-day life. This ebook includes some great examples of people using social media to raise awareness and challenge perceptions of mental distress.

The sorts of questions you might want people you support to think about (as well as yourself) when using social media are:

- ☛ How much do you want to reveal about yourself online? Who are you happy to see what you post on social media platforms? Is there anyone you don't want to see your updates and how will you manage this? This question will help an individual think about what platform will work best for them and what privacy settings they may wish to set
- ☛ Have you thought about what a future employer might see online – and might help or hinder you to get a job? And could anything you write upset your partner, parents or children?
- ☛ What will you do if something you see, or a conversation you have, triggers your own distress? Who can you turn to for support if this happens?
- ☛ How will you feel, and what will you do, if someone says something online which you find hurtful? Some platforms are more notorious than others for 'trolling' and it is good to think in advance how you will handle this situation if it happens to you
- ☛ What if your use of social media has unintended consequences? Some people can feel an increased sense of isolation on social media, particularly when people don't engage with them. Thinking through relationships online is as important as helping people think through relationships offline. And it is important to understand that social media is not a quick game - even 'gurus' in this field say it takes years to build up a strong following
- ☛ Would it be helpful to plan, when you are well, for how you want to relate to social media when you are unwell. You may find it helpful to include this in a crisis plan, Advance Decision or Wellness, Recovery and Action Plan (WRAP)

Case study - social media as a tool for change

Mark Brown is editor of One in Four, a lifestyle magazine with and for people with mental health difficulties, as well as development director at [Social Spider](#). He is @markoneinfour on Twitter.

He says that social media has 'added rocket fuel to my real-life networks, professionally, intellectually and personally.'

He continues: "My intellectual life and experience has broadened and it's brought me together with other people in ways that I never would have expected. In social media spaces you can pitch beyond the people you know and get to the people you'd love to know. Without social media I would never have 'jumped the rails' from where my life looked as if it was going to finding a place in the world doing stuff that I care about and which I hope makes a difference.

"The perfect way to use Twitter is to create bite-sized updates often, maintain a presence, get involved with conversations, and give a sense of who you are. The first rule of any social media space is always to put in more than you take out. Following exciting conversational tweeters and talking to them about their interests and activities enriches your understanding and broadens your horizons. I see a lot of people with mental health difficulties using social media to report from the front line of their own life with amazingly immediate results.



"I think social media is creating a discursive space where a 'new' mental health is being hashed out collectively as sum of millions of tweets, blogs, videos, discussions and podcasts. There are a huge number of voices all, whether they realise it or not, asking the same question: 'How can we make life better for people with mental health difficulties, or in many cases, ourselves?'

"Mental health professionals have huge knowledge assets to contribute to this conversation. In social media it is less 'them and us' and more 'just us'. There is something hugely satisfying in seeing someone who offline would be seen as a 'patient', discussing online with someone who would be seen as an 'expert' - and both learning from that experience.

"I think mental health professionals have to keep up with the aspirations, ideas, hopes and ideals of the people they work on behalf and engaging with social media is part of that."

ONEinFOUR
Lifestyle, health, mental wellbeing

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Chapter 7 Professional ethics in social media

If you are using social media in a professional or personal capacity then it is important to be familiar with the code of practice or guidelines for your professional group. The same goes for your organisation's internet or social media policy.

If you are using social media in a personal capacity then it is important to think carefully about your privacy settings and not to 'friend' or 'follow' anyone who you are working with directly as a practitioner. Always respect confidentiality.

Many of us working in mental health services will have personal experience of mental health difficulties and, as we know, at any one time, one in six of us experiences a mental health problem. This means that the boundaries between people working in and using mental health services are not always clean cut. And this is a good thing. It also means it is unrealistic to suggest that you should never 'friend' or 'follow' someone using services provided by your mental health organisation.

The important thing is to use your judgement, follow the relevant guidelines, and never compromise the relationship you have with people who you are directly supporting in your practitioner role. We would suggest having a sensible discussion with the person you support and mutually agree boundaries with them from the outset.

Be aware that on public platforms, such as Twitter, anyone can follow you and see your updates. Think carefully about how people you support, your colleagues, or even your manager might view your status updates. A good rule of thumb is to think, would I be comfortable saying this in front of that person? How might they interpret it and what might their reaction be? The more familiar you become with social media, the more intuitive and straightforward this is likely to be. If you do get it wrong, our advice is to own up and say sorry. You can remove a status update or tweet but sometimes this is counterproductive – it is often better to leave it there and apologise – others are likely to appreciate your honesty.

Social media platforms tend to have an informal and conversational style. Many people choose to blend their professional and personal identities, showing others their humanity and quirks. For some it is okay to share a status update about the latest professional news and then follow it by something more personal about your favourite TV programme. For others they want a purely professional profile and not to confuse this with bringing in their personal identity. There is no right or wrong on this. Everyone has to work out their own boundaries for their online identity. It can be helpful to observe how others you admire behave, and take the lead from them.

We have listed current guidance from a range of professional bodies in the Further Information section at the end of this ebook.



Case study – blogging with mental health

'Little Feet' has her own blog in which she charts her progress through treatment in relation to experiences of depression, delayed onset post-traumatic stress disorder (PTSD) and disassociation. She can be found on Twitter as @chaosandcontrol. [Chaos and Control](#)

She explains why she blogs and how it is good for her mental health and wellbeing: "When I first started blogging, I thought I would give up once I was recovered. (I was holding out hope for The Fairy Godmother to appear and wave her magic wand.) Now I realise that I'm probably about as recovered as I'll ever be. For me, recovery is about managing the bad days and living life to the full on the good days.

"I need to write. I need to write to clarify what it is I'm thinking. I can stop myself getting upset by writing about it. The process of writing enables me to become clear about what it is I am mulling over or thinking. Writing helps me to take proactive and productive action. The difference between a blog and a journal is that blogging opens a dialogue; readers can and do comment. Comments are usually empathetic and supportive. Comments also allow my readers to provide me with a different angle on a subject, an angle I might not have considered without them.

"My sister reads my blog. We don't see each other that regularly but we do speak on the phone regularly. When we speak on the phone, we don't have to cover how my mental health is. Instead, she can gauge how I'm doing via my blog. It also means when we talk, it's not all focused on me and my mental health. We can short cut that bit because she knows how I am doing.

"When I first started blogging, I didn't know whether I would have much to say about anything. Sometimes I don't have much to say and things go quiet. Other times there's loads of stuff I want to blog about. As a result of blogging, I discovered a whole network and community of like-minded people."

At the beginning of 2012 'Little Feet' considered closing her blog down because of staff reactions to her blog when she was an inpatient and they became aware of the blog's existence.

They confiscated her mobile phone and asked her not to blog again for the duration of her stay. After a formal complaint against the NHS trust, she received an apology for the action that was taken against her.

This story emphasises the importance of mental health practitioners appreciating and understanding the role that blogging can play in an individual's recovery journey. And that colleagues need to understand and learn skills to deal with the public side of social media.

Chaos and Control



Blog Award and 13 Things For 2013

Posted on 13/01/2013



Along with [Bourach](#) and [Crazy in the Coconut](#), Chaos and Control was shortlisted for the 'Best Anxiety, Stress or Trauma Blog' on the [The World of Mentalists](#) awards. When the winners were announced on 1 January, I was delighted to read that [Bourach](#) had won. To my great surprise and delight, I discovered that Chaos and Control had also won the wildcard award. It was totally unexpected so thanks to folks for nominating me and the judges for doing a grand job of, err, judging.

I am not one for New Years Resolutions. But I do like the idea of setting personal development type goals for myself. The plan for 2013 is to make a list and do the 13 things on the list. It's not a big deal if I don't manage them all but it's always good to have a goal to be working

Password

Please do not hesitate to contact me (chaotic.little.feet REMOVE @ gmail [dot] com) if you would like the password to any of the protected posts.

Blogroll

- 5 Quid for Life
- a girl's ruminations
- A Life in The Day Of A Basics Doc
- A little piece of me
- A Multitude Of Musings
- A Path With Heart
- A Put Together Mess
- Amickalater.co.uk
- Astrid's Journal
- Bearing, Eating, Being...
- Behind The Facade
- Between Living and Existing
- Between The Minds - The Beehive
- Bipolar and Biting your Teeth
- Bipolar on My Mind
- Bipolar! Crazy Mermaid's Blog



Glossary of Terms

Bit.ly a useful website that shortens long website addresses. This is particularly important for Twitter which only has 140 characters and means you can post a link to a useful website

Blog shortened from web log, a blog is part of a website or stand alone. An individual or a company posts regular articles with views, commentary, information

Blogroll a list of blogs that you like, listed in a section on your blog – often with headings such as ‘Blogs we like’ or ‘Favourite blogs’

Category your blog topics need categorising into themed topics – Google searches on categories so this is important

Comment most blogs have a box at the bottom for you to leave a comment. You can also ask to be notified as others comment further on that blog

Closed privacy settings on an account so that only selected people can see and engage with content

Delicious sign up and save websites, pictures, information that you find useful or want to share

Direct message (DM) when using Twitter – a direct reply to a particular Twitter account, that can only be seen by the two of you. You can only do this if you are both following each other

Facebook is a popular free social networking website that allows registered users to create profiles, upload photos and video, send messages and keep in touch with friends, family and colleagues. The site is available in 37 different languages

Facebook page, also known as fan page is a public profile specifically created for businesses, brands, celebrities, causes and other organizations. A ‘fan’ is someone who ‘likes’ that page or post

Flickr is an image and video hosting website, web services suite, and online community. In addition to being a popular website for users to share and embed personal photographs, the service is widely used by bloggers to host images that they embed in blogs and social media

Follow to follow someone in social media (Twitter, blogs, Facebook etc) means to subscribe to their Tweets or have RSS feeds to your phone or email

Google most popular global search engine

Hashtag (#) groups of people with a similar interest create a group with a hashtag so they can easily follow conversations on a theme on Twitter. Examples could be #WorldCup, #bescared, #HSJlist, #mentalhealth, #eatingdisorders - and often a particular event or conference is given its own hashtag to share discussions

Hyperlink also known as links, a link from a highlighted word or phrase to a relevant website. You can insert a hyperlink into a document (go to Insert, Hyperlink and insert the website URL address in the box). The link usually appears on screen as underlined and in a different colour. If you hover over it with your mouse, it will say to click on the word to operate the link

Instagram is an online photo-sharing service that enables users to take a picture, apply a digital filter and share it on a variety of social networking services, including its own

Microblog Twitter is often referred to as a microblog because it allows people to update their status using only 140 characters

Mistweet accidentally sending a tweet to the wrong person or wishing you hadn’t sent a particular tweet

Pinterest lets you organize and share images that you find on the web – you create a series of pinboards

Post is an entry made by someone on their blog

QR code (quick response code) is a type of 2D bar code that is used to provide easy access to information through a smartphone.



Reply when using Twitter is to send a message responding to one you have seen on another person's Twitter account. It will appear with their @address at the start of the message

Retweet (RT) A Retweet is a repeated tweet. It is sometimes used in a reply to allow everyone to see the original tweet. It is also used to forward a message onto one's own followers

RSS (Really Simple Syndication) – you may spot orange RSS feed buttons on blogs and other sites. Often it will say 'subscribe to this blog by RSS'. Click on the button and the 'subscribe now' button. You will then be notified when a new post goes on that website

Search engine designed to search for information on the World Wide Web. The search results are usually presented in a list of results and are commonly called hits. The information may consist of web pages, images, information and other types of files. Google is the most famous, also Yahoo, Ask Jeeves and Bing in the UK

Search engine optimisation (SEO) is the process of improving the volume or quality of traffic to a web site from search engines via "natural" or un-paid ("organic" or "algorithmic") search results as opposed to search engine marketing (SEM) where you pay for online advertising

Secret as with Closed above, privacy settings on an account so that only selected people can see and engage with content

Trending topics are the most talked about topics currently being discussed on Twitter

Trolling is a phrase for people who post unpleasant or harmful comments on Twitter – taken from the Norse characters who are bent on wickedness and mischief

Tumblr is a blogging platform where users can post text, images, videos, links, quotes and audio to their tumblelog

Tweet a post or status update on Twitter/a message posted via Twitter containing 140 characters or fewer

Tweet Back bringing an older tweet back into the conversation

Tweeter a person who tweets

Twilert lets you monitor specific keywords and send you an email when someone mentions that word

Twitpic is a website that allows users to post pictures on Twitter and share them

Twitter an information network made up of 140-character messages from all over the world

Twitterer an account holder on Twitter who posts and reads Tweets. Also known as Tweeters

Unfollow to stop following another Twitter user. Their Tweets no longer show up in your home timeline

Youtube a popular video sharing website that lets anyone upload short videos for private or public viewing

Case study – vlogging for recovery

Jonny Benjamin was a finalist at the 2012 Mind Media awards for his [YouTube films](#) about his recovery journey. He tweets as @MrJonnyBenjamin.

He explains how a lot of people now use social media as a medium to talk about their mental health difficulties. He says: "It not only gives an outlet for such difficulties, but I think it also contributes to breaking down the mental health stigma.

"I had been hearing a voice and experiencing paranoid, delusional thinking throughout my teenage years. However, I never got the help and support I needed. This was partly because I was too afraid to ask for it, but also because when I eventually did seek it, I wasn't given the support I needed.

"Eventually I had a breakdown and was finally diagnosed with schizoaffective disorder at the age of 20,



and admitted to a psychiatric hospital. I had never even heard of the term 'schizoaffective disorder' till then. I remember feeling very alone in what I was experiencing; I felt there was nothing I could relate to.

"With the right treatment and support, I began to feel better. I still found it incredibly difficult to communicate with anyone about what I had been through. So, In 2010 I decided to make a video on YouTube to share my story. There is something about recording a vlog (video blog) that is very different to talking to someone face to face. Simply, there is no stigma there, no judgement. You can talk at will without interruption. It was liberating and I found it to be therapeutic.

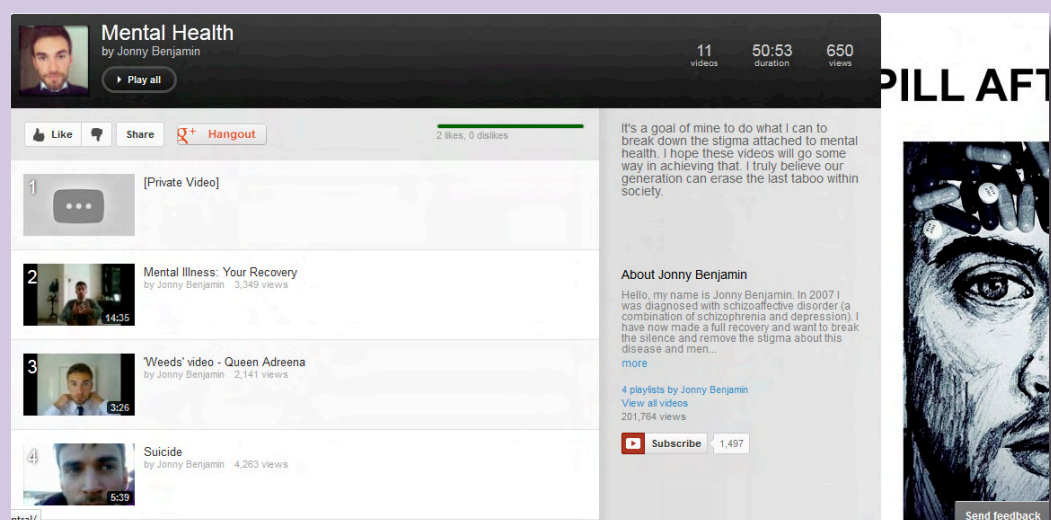
"I made further vlogs and eventually produced a short film about my journey with mental illness. The response I received was overwhelming. Finally, there were other people I could relate to. People that had experienced what I had were connecting with me. We were able to give each other hope and support.

"There were responses too from people who had also never heard of schizoaffective disorder, but who had come to learn and understand about it through watching my films. This shattering of the stigma was a huge achievement and something I am proud to say I've helped contribute to.

"Sharing my mind through the recording of my videos has actually allowed me to become more open and communicative with people around me. Before, I was apprehensive about even saying the words "mental illness" or "schizoaffective disorder" but now they are a common part of my vocabulary thanks to the medium of vlogging.

"There have been difficulties using social media this way. I have experienced stigma from time to time and this has been hard to deal with. On a couple of occasions, I have received death threats. I have spoken to friends about this though, and this often helps alleviate my concern when it has occurred.

"I think that mental health practitioners could encourage those with mental health problems to use social media in a similar way that I have, as long as they have their constant support. Perhaps if they do not want necessarily to vlog or blog, they could at least be encouraged to connect to others who are using social media. It will no doubt help them feel less isolated in their experiences. There is nothing quite like finding someone else you can relate to when suffering from mental illness."



Further information

Social media generally

- [Mashable](#) – the world's largest site for all things on social media
- [LinkedIn](#) – 'how to' sections on creating a LinkedIn account
- [Northern Lights PR](#) – download free ebook on social media for professionals and academics
- [PR blog](#) – 'how to' blogs on social media
- [Michael Hyatt](#) – beginner's guide to Twitter

Social media for practitioners

- **Royal College of General Practitioners** – [Social Media Highway Code](#)
- **BC Patient Safety and Quality Council** – [Twitter for Healthcare Professionals](#)
- **British Association of Occupational Therapists** - [social media strategy and guidance](#)
- **British Association of Social Workers** – [how to deal with social media](#)
- **British Medical Association** – [social media use: practical and ethical guidance for doctors and medical students](#) and [Using Social Media](#)
- **British Psychological Society** - [e-Professionalism: Guidance on the use of social media by clinical psychologists](#)
- **General Medical Council** – [social media: what does it mean for you?](#) (doctors' guidance – available from 22 March 2013. [Draft document](#) being reviewed at time of going to print)
- **Mental Health Network NHS Confederation** – discussion paper, [E-mental health: What's all the fuss about?](#)
- **NHS Employers** – [HR and social media in the NHS](#)
- **Nursing and Midwifery Council** – [the use of social networking sites by nurses, midwives and students](#)
- **Risk Awareness and Management Programme** - [delivering mental well-being services online](#)
- **Royal College of Nursing** – [congress discussion](#) on social networking sites (social media)
- **Royal College of Psychiatry** (At the time of going to print, the College's guidance was still in draft stage)
- **The Health and Care Professions Council** – [social media guidance](#)

Case study links

- [Buddy](#)
- [Cowbird](#)
- [Ermintrude](#)
- [Etsy](#)
- [Leeds and York Partnership NHS Foundation Trust](#)
- [Leeds Club Drug Clinic](#)
- [Leeds Wellbeing Web](#)
- [Little Feet](#)
- [Mental Elf](#)
- [Mental Health Cop](#)
- [Mind – Diverse Minds](#)
- [Rethink Mental Illness](#)
- [Moodscope](#)
- [One in Four](#)
- [The Depressed Moose](#)



Thank you

The wonderful aspect of social media is that it often reflects the most generous and helpful side of people. We have certainly felt that with this ebook.

Our thanks go to everyone who has generously responded to our requests for case studies and written so openly about their experiences.

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***Institute for Innovation
and Improvement***



About the authors



Victoria Betton is deputy director of strategy and partnerships at Leeds & York Partnership NHS Foundation Trust. She has responsibility for the corporate functions of strategy, member engagement and communications to diversity, arts and minds network and business development. She also looks after support services including volunteering and spiritual and pastoral care.

Victoria holds two Masters - in Women's Studies and Social Work - and is studying for a doctorate in social media and mental health at the University of Leeds. Her dissertation is on professional and personal identities and power in mental health and social media.

She is responsible for a range of initiatives relating to recovery and social inclusion. She coordinates a local Time to Change campaign (challenging mental health stigma) and directs the Love Arts Leeds festival www.loveartsleeds.co.uk.



Victoria Tomlinson is founder of Northern Lights PR, a purposely small communications consultancy focused on business, education and community engagement. Their clients have included The Faculty of Medicine and Health at the University of Leeds; Kirklees PCT and housing associations and Northern Lights has created a number of award-winning campaigns to engage with disadvantaged people.

An early blogger and user of social media, Victoria has set out to interpret its risks and opportunities for senior management, communications teams and those in education. A recognised speaker she is author of two ebooks [Why you can't Ignore Social Media in Business](#) and [From Student to Salary with Social Media](#) with an aim to make social media easy to understand and use as well as relevant to each audience.

Victoria's early career was spent in manufacturing and as a director of Ernst & Young on the London management team. She sits on the boards of Northern Ballet, University of Leeds enterprise board, Bradford University School of Management - a top ten UK business school, as well as mentoring start-up businesses and ex-offenders. She is a member of the patient panel for Leeds Teaching Hospitals NHS Trust.



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