

## Joining in the conversation – social media and mental health services

### Key points

- The impact of social media on how people now communicate cannot be underestimated.
- Social media can be used both as an engagement tool and to analyse public, stakeholder and service user perceptions.
- Mental health service providers are increasingly using social media to disseminate information, provide preventative and after-care, and reach out to those averse to receiving care.
- Social media can be invaluable as a way of providing 24/7 contact with mental healthcare professionals, A&E or after-hours GP care.
- To be successful, social media activity needs careful planning and to be properly resourced.

The dramatic impact that social media has had over the last five years on how people communicate, both with individuals and with organisations, cannot be underestimated.

Regulator Ofcom's latest annual report into the communications market states that one in five hours spent on the internet by UK users is on a social media site, while nearly half of users claimed to have used a social media site in the past week (up from one in five the previous year). The report makes it clear that social media is increasingly indistinguishable from more traditional communications channels such as TV news and newspapers as a key means to distribute and access information.

Several health and mental health organisations are using social media to provide support on a range of issues such as depression, alcohol and drug dependency, and anxiety disorders. This *Briefing* looks at social media innovations underway in healthcare as a whole and highlights case studies from Mental Health Network member organisations.

### Background

Organisations typically use social media in two ways. Firstly, to better engage with their stakeholders. Secondly, to analyse the huge quantities of data generated by public discussions in order to gain strategically valuable intelligence for the purposes of marketing,

branding, product and service (re)design, and reputation management. The data that is generated in the public domain can be useful for understanding people's needs, expectations, attitudes and thoughts about particular issues, for example, depression or Alzheimer's disease.

Mental health providers are increasingly using social media tools in a wide range of ways, including:

- disseminating information about mental illnesses, healthcare services and campaigns, and combating stigmatisation
- dealing with complaints about services published online
- providing preventative and after-care, particularly by, delivering services that make 24/7 contact with mental healthcare professionals possible without a person visiting A&E or requiring after-hours GP care
- engaging with communities, patients and family members, reaching out to those in need of care but who are averse to receiving it.

### What is social media?

'Social media' is a generic term used to describe a range of online applications that enable interactive communication between users.

In contrast with traditional media, participants can both consume and communicate information through social media.

Examples include the social networking site Facebook, blogs and microblogs (such as Twitter), internet forums and instant messaging services.

## Using social media in mental healthcare

Online forums and communities have for many years been used to provide healthcare information and support to people fighting physical and mental illnesses. However, social media and social networking sites have greatly enhanced the support that can now be provided, so much so that the Mayo Clinic in the USA has set up the Mayo Clinic Centre for Social Media to lead research into how these technologies can be used to more effectively support hospitals and patients.

One successful social networking site that shares information on a wide range of physical and mental health conditions is CarePages. The site also provides bulletin boards where individuals can exchange messages. Friends, family and patients can join online groups, set up their own pages, blogs and diaries, or post videos, free of charge. The site has an extensive library with the latest healthcare information and inspirational stories. A 'drop-box' function allows members to borrow magazines, DVDs and books from each other using a file-sharing format. As well as being open to the general public, 625 hospitals in the US and Canada have created a branded interface with the CarePages site so service users can access the support the site provides as part of a seamless package.

A variety of established online mental health communities cover a range of different illnesses, including depression, alcohol

and drug dependency, as well as anxiety disorders. Social media is also being used in suicide prevention and cognitive behavioural therapy, so that support can be accessed remotely by service users. Anonymity can greatly support mental health outreach initiatives to meet the needs of those who fear being stigmatised.

Charities, social enterprises and other community health organisations in the UK are using social media in preventative mental healthcare. For example, the charity Mind has opened a number of topic categories ('hashtag' addresses) on Twitter in an effort to increase conversations around a specific issue or condition, and the Samaritans have recently begun

### Achieving an effective social media strategy – key points for boards to consider

- Is social media the best response to a challenge?
- Set clear goals, and strategies to achieve them.
- Ensure social media activities are adequately resourced.
- Scope out the project thoroughly.
- Appoint a social media champion.
- Build partnerships with other organisations.

For more detail, see page 6.

to collaborate with Facebook to provide an early intervention service that lets an individual's friends, who become suspicious of a person's posts and expect that they might need support or an intervention, anonymously report the issue. Having received over 250 such referrals since March, it appears this is an innovative support mechanism that extends into people's online social support networks.

**'Charities, social enterprises and other community health organisations in the UK are using social media in preventative mental healthcare.'**

## What mental health providers are doing with social media

The case studies below outline four online social media tools that have been designed to meet the needs of mental health service users, specifically people dealing with depression, anxiety and stress. The Patient Opinion case study focuses on how social media can effectively be used to engage patients from a customer service point of view. There are undoubtedly more examples among Mental Health Network members, but these five case studies illustrate some of the innovation that is occurring within the NHS as well as amongst those organisations that provide services in partnership with mental healthcare providers.

Full versions of these case studies are available at [www.nhsconfed.org/socialmedia](http://www.nhsconfed.org/socialmedia)

### Case study: The Big White Wall, in partnership with Tavistock and Portman NHS Foundation Trust

The Big White Wall (BWW) is a multi-function social networking site that brings peers and professionals together so that support can be readily available at any time. It enables talking therapies (with the online community, in groups and through one-to-ones), art and writing therapies, self-administered clinical tests and guided groups based on cognitive behavioural therapy and interpersonal psychotherapy.

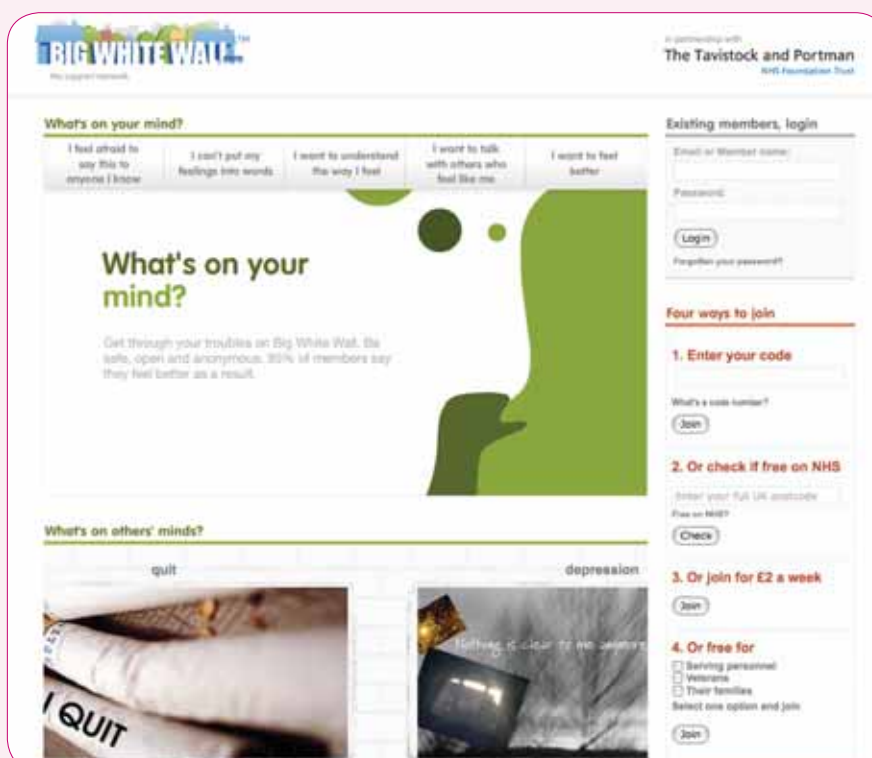
Seventy-three per cent of BWW members share an issue for the first time on the wall, which suggests that it has become a key gateway for people to access mental healthcare services.

An independent analysis found that the project saves the NHS an estimated £37,000 per 100 members. With 6,500 current members on the site, this equates to an estimated £2.4 million in savings. These savings are due to:

- a reduction in demand for face-to-face or other therapies
- a reduction in the use of out-of-hours GP services or A&E visits
- prevention of psychiatric hospitalisation
- improved self-management.

Tavistock and Portman has determined that it is feasible to provide therapies anonymously and the positive impact of online contact is transferable to offline behaviours.

[www.bigwhitewall.com](http://www.bigwhitewall.com)



### Case study: Treasure Your Wellbeing, Mersey Care NHS Trust

Mersey Care NHS Trust wanted to build the concepts of recovery, well-being and health more visibly into people's care plans and to innovatively connect people in times of stress.

With this in mind, treasureyourwellbeing.org was designed as an online tool to enable service users to monitor, improve and sustain their well-being on their own, primarily on discharge from acute mental health wards. The approach is geared to support and enable people on their recovery and

well-being journey by promoting hope, increasing individuals' sense of agency and control, opening up opportunities for people to find meaningful things to do, and adding structure to their

day-to-day routines. It is still too early to quantify its benefits, but anecdotal evidence has been positive.

[www.treasureyourwellbeing.org](http://www.treasureyourwellbeing.org)



Designed to encourage recovery amongst mental health service users and promote wellbeing amongst the general public.

### Case study: Talking Sense, Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH)

Talking Sense is a social media application similar to Facebook Messenger or MSN Messenger. It allows one-to-one communication between registered patients and therapists in real time. The application is somewhat different to the other case studies in this Briefing, in that it was completely designed, built and launched by the RDaSH IT team. The trust views this as a real strength of the service because it incorporates all of the suggested guidelines of the International Society for Mental Health Online, as well as the NHS governance guidelines. As such, RDaSH believes the application,

which could be described as an 'e-clinic', could benefit other trusts who are looking to expand the range of services they offer to patients without wanting to

duplicate work that is already being done in other parts of the NHS.

[www.talkingsense.org](http://www.talkingsense.org)



### Case study: Moodscope, in partnership with The Priory

Moodscope is an online personal mood management tool that helps people grappling with depression or mood disorders to measure and track their moods. Users of the site can share their mood scores with friends and family, which makes the management of their moods a collective process aided by those closest to them. The site has 37,000 registered users and has grown exclusively on the back of referrals from other Moodscope users. Its strength is that it is completely designed, implemented, managed and shared among those who need support in the management of their moods and who experience improvements from it. Taking into account the NHS's

massive expenditure on anti-depressants and secondary mental healthcare for mood disorders, and compelling evidence that people suffering from low mood would use an online platform,

Moodscope believes there is a sound argument for wider adoption of the tool.

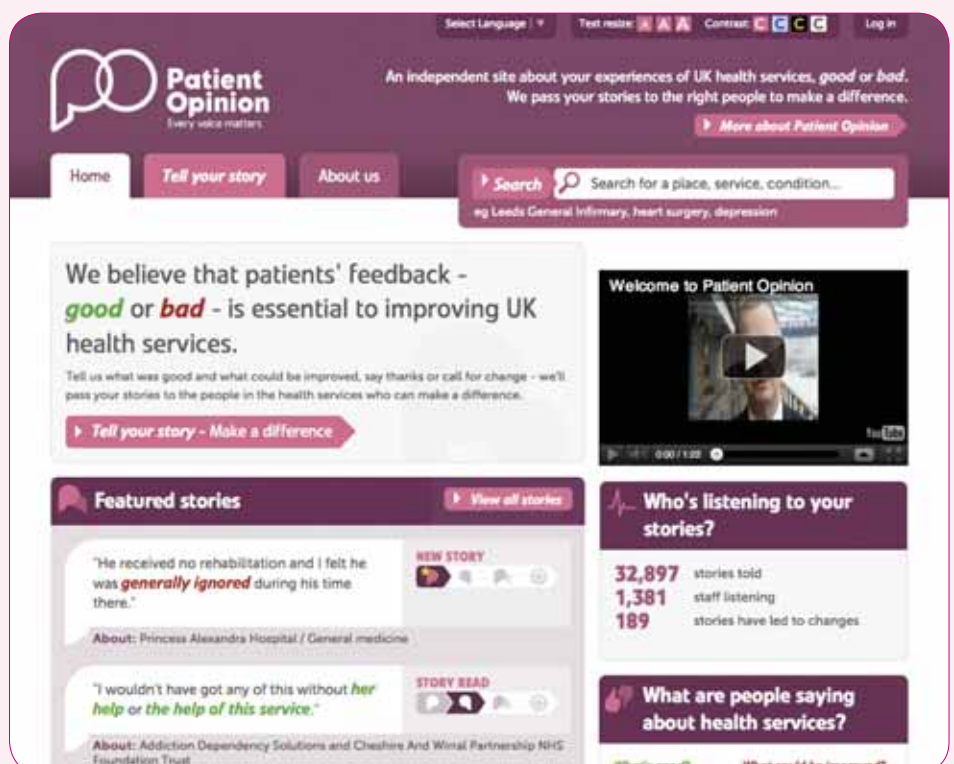
[www.moodscope.com/springboard\\_new.php](http://www.moodscope.com/springboard_new.php)



### Case study: Patient Opinion, a national patient engagement service for the NHS

Patient Opinion is similar to other consumer review sites like Trip Advisor. It allows patients to feed back on their experience of the NHS and for trusts and other organisations, including commissioners and patient groups, to acknowledge and respond to comments. If experiences are negative, service providers can explain why an incident occurred and, importantly, demonstrate how they will use the feedback to improve services in future. As such, it is not only a reputation management mechanism, but a tool for co-creation and innovation that puts patient experience at the heart of service improvement design.

See [www.patientopinion.org.uk](http://www.patientopinion.org.uk)



## Achieving an effective social media strategy

Organisations often develop social media strategies and activities without fully evaluating whether it is an appropriate response to a business objective or whether they have adequate resources. Many organisations have launched a social media initiative only to find that take-up with target stakeholders is relatively poor.

For mental health providers, there are some points to consider in order to achieve an effective social media strategy. These are detailed below.

## Is social media the best response to a challenge?

Organisations often launch social media strategies because they want to increase engagement with their various stakeholders at relatively low cost. Although social media can be highly effective for out-reach, and the case studies in this *Briefing* show positive results, too few organisations properly investigate whether the people they want to reach are even using social media to engage with organisations. It is important to consult with end users to see if a social media communication channel will suit their needs, and how they expect to use it. A relatively small market research exercise can be especially helpful to determine what a user group's appetite is.

## Set clear goals, and strategies to achieve them

Before setting up a social media programme, it is important to

define the programme's goals. Key performance indicators which are in line with an organisation's broader strategic objectives for the project are essential.

For example, has a mental health providers social media initiative:

- improved other organisational processes?
- improved operational efficiency and cost savings?
- improved responsiveness to queries and/or complaints?
- increased patients' use of resources in the community?

Such performance indicators are more difficult to measure but they are fit for purpose. It is very important to determine early on what the key performance indicators should be for a project and build in suitable evaluations in the pilot and launch phases, as these will help the project team to stay focused on what needs to be achieved.

## Ensure social media activities are adequately resourced

Organisations often misjudge how much work social media engagement entails and end up with under-resourced project teams who cannot meet ambitious targets. If a mental health provider compromises on cost, this can substantially increase governance risk, jeopardise service user safety and result in lower usability and appeal, which in turn exposes the organisation to reputational risk and the project to failure. If the target audience finds an interface difficult to use or unengaging, they

will be unlikely to use it and any investment won't generate the best return.

If a provider is considering using social media to treat patients or provide preventative mental healthcare, it is important to make sure that sufficient mental healthcare workers are available to support technical teams, and that they are adequately immersed in the particular qualities of online communication.

If a mental health provider wants to use social media as a communication and marketing tool, teams need to take the following into account.

## Collect and analyse the trust's existing social media data

Information generated from incoming links, comments, blogs and tweets should be constantly monitored and updated. Building rapport online can be time consuming but, as the case studies above show, it can generate cost savings by reducing the need to meet service users face to face over large geographic areas.

## Uncover the topics that are important to stakeholders

In social media, listening and understanding the 'big picture' is crucial for creating a two-way dialogue and engagement. As much as a social media team should develop their own content, they also need to post comments on what others are saying to show that the organisation is interested in them.

## Publish content that allows for a dialogue to develop

A common mistake when delivering social media activity is to

simply cut and paste authorised press releases onto a blog or to tweet a link back to a statement. These one-way messages do nothing to encourage people to engage with an organisation. Social media policies need to be relatively flexible, so that communicators can transform the essence of what the organisation wants to achieve into content that encourages conversations and sharing.

A platform must meet the needs of a target audience and mental health providers need to thoroughly understand those needs.

### Scope the project

As with any project, a social media strategy needs to be thoroughly scoped. Within the NHS, IT governance, risk management, privacy, and data protection are all significant challenges that must be dealt with early on. In the set up of a large programme like a patient-directed service, the impact on the development team's time and unexpected costs should not be underestimated. It may be significantly cheaper for a provider to commission a service from another organisation servicing the NHS than to develop a product on its own.

For further information on how mental health providers have managed risk, data protection and governance, please see the case studies at [www.nhsconfed.org/socialmedia](http://www.nhsconfed.org/socialmedia)

### Appoint a social media champion

Organisations as large and complex as the NHS are inherently resistant to radical change. Not all NHS leaders are familiar with, or advocates of, social media.

Where there is a significant gap in understanding between senior executives and those who can implement the strategy, the appointment of a social media champion can be invaluable. The champion needs to be highly motivated and to understand social media; and they need to have direct contact with key decision-makers, who influence budgets, as well as with the technical team. The power of service user input should also not be underestimated – patients can provide invaluable feedback in the design of social media services.

### Build partnerships with other organisations

Rather than spending considerable sums of money growing social media teams in house, an organisation could consider building partnerships with organisations that already understand social media and the complexities associated with online social networks. The Big White Wall, Health2Works, Patient Opinion and Moodscope are just some of the enterprises that are emerging around the NHS with sufficient expertise in designing social media platforms to the NHS's specifications.

### Mental Health Network viewpoint

Social media can have a very positive impact on how organisations deliver care services, for example, by providing out-of-hours support or encouraging service users to manage their mood and condition more effectively. It can also influence future service development as it enables trusts to capture and analyse patient voice and respond accordingly.

Early indications are that there can be significant cost savings embedded in social media tools if these are properly managed and resourced without compromising existing services. The greatest benefits appear to be in the introduction of light-touch mood disorder services that can alleviate pressure on secondary mental healthcare services.

But whether or not you have a dedicated strategy and programme in place, and whatever the new trend turns out to be, social media in some form or other is here to stay.

The case studies in this *Briefing* show what can be done to provide a seamless service for service users online, such as out-of-hours support, something which has been difficult and costly to organise in the past.

For more information on the issues covered in this *Briefing*, contact [steve.shrubb@nhsconfed.org](mailto:steve.shrubb@nhsconfed.org)

## Further information

Full case studies and further information is available at [www.nhsconfed.org/socialmedia](http://www.nhsconfed.org/socialmedia)

The Mayo Clinic Centre for Social Media: <http://socialmedia.mayoclinic.org>

CarePages: [www.carepages.com](http://www.carepages.com)

The International Society for Mental Health Online: [www.ismho.org](http://www.ismho.org)

## Acknowledgements

This *Briefing* was written by Richard Kunzmann, Research Manager at FreshMinds Research, specialising in healthcare, education and social media; and Annika Wong, Research Analyst at FreshMinds Research; with initial ideas from Ben Hart, social media consultant at Symmetric SD.

## FreshMinds Research

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## Mental Health Network

The Mental Health Network was established as part of the NHS Confederation to provide a distinct voice for mental health and learning and disability service providers.

We aim to improve the system for the public, patients and staff by raising the profile of mental health issues and increasing the influence of mental health and disability providers.

For further details about the work of the Mental Health Network, visit [www.nhsconfed.org/mhn](http://www.nhsconfed.org/mhn) or email [mentalhealthnetwork@nhsconfed.org](mailto:mentalhealthnetwork@nhsconfed.org)

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