

# Behavioral health support and online peer communities: international experiences

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**Abstract:** Online peer support communities play an important part in many people's experience of healthcare. They can be particularly significant in behavioral health/mental health due to the difficulties that people may experience in accessing face to face care for these conditions. There is considerable diversity of practice in service management, target group, and moderation practices of online peer support communities. People using the communities also appear to have diverse aims and experiences. This heterogeneity contributes to a relative lack of data about the value and effectiveness of online peer support in behavioral health, although there is significant research into some aspects of these communities. The digital behavioral health service Big White Wall was launched in the UK in 2007, and in the US in 2015, and is focused on delivering moderated peer support. There are considerable differences in health systems between the two countries, and this has been reflected in different experiences of implementation. The value of online peer support could be maximized if systemic challenges to implementation and adoption were addressed more effectively.

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## Introduction to online peer communities: the consumer landscape

Given the primacy of health conditions to many people's daily experience, it is unsurprising that peer communities devoted to health conditions have been important since the early days of the Social Web. Clear historical data on the number of forums and chatrooms devoted to particular conditions is hard to come by, but it is probably fair to say that for most major conditions—and many rarer ones—dedicated services were available by the early to mid-2000s. Health related discussions in more general forums have also been significant throughout the last decade: topic forums or loosely arranged networks exist on Mumsnet, Reddit, Facebook, Twitter and many more. Because of the scale and diversity of non-health communities, this article will consider health-specific communities only.

In broad terms, health-specific communities may be categorized on three dimensions: the organisation which

runs them, the level and type of moderation, and the specificity of their target group. As an example, the large community at Patients Like Me is designed to appeal to people with any health condition, although it is organized into subgroups so members are connected to others with similar experiences (1). Others focus on conditions with varying levels of specificity, ranging for example to those aimed at everyone living with cancer to those aimed at those with very rare cancers, or at particular stages of a disease. For any type of community, achieving a 'critical mass' of members is vital, so that new joiners feel they are joining an active and engaging group. For this reason, community founders and moderators often need to put considerable effort into attracting a consistent flow of new members: this is of course harder for rarer conditions and unusual situations.

From a consumer perspective, the level and nature of "moderation" is perhaps one of the most significant distinguishing features of different communities. In a digital

context, moderation is generally taken to mean the process of reviewing member or peer-generated content, so that any which is considered inappropriate can be removed or amended. The broad goal is generally to foster the type of interaction that the service feel will be most beneficial. In most cases, comments are posted and then moderated, but in some circumstances, they may be 'pre-moderated' before they can be seen by the rest of the community: this may be used for very controversial topics, discussions which have been subject to 'trolling' or other unwanted and inappropriate behavior, or where children or other vulnerable people are the target audience. This variation in moderation practices reflects the considerable variation and use of facilitation processes for in person peer support groups.

Most mainstream forums have some form of 'light' moderation, although it may only be provided at certain times, at a minimum covering hate speech or discriminatory comments, personal abuse of other forum members, and comments relating to criminal activity. At the other end of the scale, providers like Big White Wall (discussed in detail later in this article) take a strict approach to moderation, barring any information that might identify the contributor, information which goes against standard clinical advice and could prove harmful if followed, and links to most external websites. Communities which focus on mental health face a particular challenge about their policy on text and images which relate to self-harm and suicide, and there is considerable diversity of practice in this area.

Quality moderation will always take time and investment of resources, human and technological, although the extent of this varies hugely according to the size of the community, the extent to which it 'self-moderates' through a set of behavioral principles which are codified and broadly accepted by members, and the nature of the moderation chosen.

### **Introduction to online peer communities in health and behavioral health: the evidence base**

Despite the relatively short period that online services have been available, there is a considerable body of evidence about digital health. This is particularly true of behavioral health, which has often been considered to be well-suited to this type of delivery because of the limited requirement for physical examination and the considerable financial, social and logistical barriers which exist to accessing traditional psychological therapies in many parts of the world (2). The

efficacy of structured online programs for conditions such as anxiety and depression has been well established, although high rates of attrition present a challenge in research and practice (3,4). There is also a growing evidence base for the use of digital programs to tackle unhealthy lifestyle factors such as smoking and being overweight, and to support the management of chronic conditions such as diabetes (5-7).

There is also a longstanding evidence base for peer support delivered in traditional settings in supporting mental health, although the strength of the evidence is affected by considerable heterogeneity in both project goals and the type of peer support used (8). Generally, peer support relationships may be considered to involve "help and support that people with lived experience of a mental illness or a learning disability are able to give to one another... (which) is mutually offered and reciprocal" and ranges from informal social connections to people with similar experience to formal mentoring programmes (9). As in digital-delivered peer support, facilitation or moderation is often used to support the desired culture of the group, ensure that participants feel safe, and promote equality of access and contribution. Moderation may be by healthcare professionals (often psychologists or therapists) or by people with lived experience of the issue being addressed, who may have received additional training and support (10).

The evidence base for online peer communities is considerably less evolved than the evidence base for more structured programmes, which is largely a function of the different goals of clinicians and service users from involvement in such projects. This of course reflects the heterogeneity of evidence for offline mental health peer support. Members might be seeking emotional support, a reduction in isolation, practical information about their condition, guidance on possible treatments, recommendations for care providers, suggestions for non-clinical coping strategies, distraction from daily worries, or any combination of these. People who contribute to communities may gain a sense of self-worth from supporting others, and this may develop following an initial stage of help-seeking (11-13). As well as the variation in individual goals, there are differences between the stated aims of particular communities, and according to the nature and prognosis of the conditions being discussed: discussions among people with end-stage cancer are likely to have a very different focus to those with a chronic disease (14). This makes consistent research and systematic review and meta-analysis considerably more difficult.

There is a considerable body of research into the

dynamics of online peer communities, focusing for example on experiences of stigma, the nature of help-seeking and help-giving, and the community dynamics of online groups (11,12,15). This research often draws from John Suler's concept of the "online disinhibition effect", which holds that there are both positive and negative elements of interacting online as compared to interacting face to face (16). Positive elements include the opportunity for greater openness that comes from anonymity (which may be particularly significant for communities focused around stigmatized conditions), whereas negative elements include the ease of making harmful or hurtful comments without the social penalties that such comments would attract offline.

### **Example of an online behavioral health peer community: Big White Wall**

Big White Wall ([www.bigwhitewall.com](http://www.bigwhitewall.com)) is an online peer community founded in the UK in 2007. It was designed to support emotional wellbeing and mental health and the only entry criteria are that members are required to be aged 16 or above and to agree to the service's House Rules (17). Although the service is diagnosis agnostic and has members with a wide range of lived experience, the majority do report a diagnosed mental health condition. Just over 40,000 members have joined the service since it was founded. There is considerable diversity of usage patterns and length of time spent using the service: although individual choice is considered important, the general policy is to discourage protracted periods of use, and in the UK people joining are generally offered an initial membership duration of six months.

Big White Wall was initially founded as a peer-led intervention in 2007. In 2009, founder Jen Hyatt determined that members wanted to see more formal moderation and access to advice from clinicians. This led to a joint venture partnership with the Tavistock and Portman National Health Service (NHS) Foundation Trust (TPFT) a relatively small but high-profile state-funded mental health provider with a long history of innovation, based in North London. This joint venture led to clinical and governance elements being managed by TPFT staff, with non-clinical aspects being managed by Big White Wall's in-house team. In 2013, both parties to the joint venture determined that Big White Wall was now sufficiently large and well-established to bring clinical management and governance in-house. At this point, the service successfully

applied to be registered with and regulated by the Care Quality Commission, a key UK healthcare regulator, for its one to one therapy services.

Big White Wall's core service is a moderated online peer community, known as the "Support Network". Self-management information, standard behavioral health assessments, evidence-based structured online courses and (where there is additional funding) one to one real-time online therapy appointments are also available. The one to one service has been available for members with depression and anxiety disorders since 2012, and was created in response to member interest in access to a wider variety of online care. Therapy is delivered in accordance with the model used by NHS Improving Access to Psychological Therapies (IAPT) (talking therapy) services. Moderation is provided 24 hours a day by qualified and registered counsellors, who are known within the service as "Wall Guides" (WG). WG work 6-hour shifts, with support from more experienced "Lead Wall Guides" and supervision, training and escalation pathways to clinical psychologists and psychiatrists. The service takes a person-centred approach and the role of WG is to moderate content in accordance with the House Rules, to respond to content which may indicate risk to the member or to others, and to offer information about other services and crisis support where members send direct "Ask a Wall Guide" messages. Anonymity is strictly enforced and content which could directly or indirectly identify members is barred in order to reduce the risk of grooming and exploitation of vulnerable adults. During the 5 years that the service has been using formal clinical moderation, moderation practices have evolved in response to internal experience and external evidence as WG teams receive ongoing supervision from senior experienced clinicians.

### **International comparisons: implementing Big White Wall in the UK**

Big White Wall was founded in the UK, and for the first few years of its existence was available only to UK customers. More recently there have been relatively small contracts with providers in New Zealand and Canada, with members from both countries joining the same network as UK members. Recent expansion to the USA necessitated the creation of a new community, distinct from the UK membership. Because Big White Wall came to the US market considerably later in the evolution of online peer support, and because of the different

healthcare environment in the two countries, experience of implementation was very different.

The moderation and clinical oversight model adopted by Big White Wall, together with the need for ongoing technical development to ensure good user experience, means that the intervention is relatively expensive to provide compared to more static online services (such as information directories). There is historically relatively little precedent for self-payment for health services in the UK beyond the exceptions set out by the NHS, such as dental care and some prescription medications. The vast majority of members have joined through institutional subscriptions provided by various branches of the NHS, their university or employer, or through a contract which supplies services to armed forces personnel, veterans, and their families. The largest single group of members are from NHS organisations.

Although funded as a national service through general taxation, very few services are funded centrally by the NHS. In England (other UK nations have different systems), the majority of funding, including all funding for routine mental health care, is delegated to local commissioning organisations, called Clinical Commissioning Groups (CCGs). These CCGs are generally responsible for funding care for a few hundred thousand people, although a new programme from NHS England requires them to work with other health bodies over wider areas (18). As part of this, they are required to provide a primary care talking therapies service for adults, known as the Improving Access to Psychological Therapies Program (IAPT). Although funded locally, these IAPT services are required—and financially incentivized—to conform to strict national targets for the number of people accessing care, and the mental health outcomes they achieve. Big White Wall is sometimes commissioned directly by CCGs, and sometimes sub-contracted by IAPT services. The majority of delivery contracts run for one year. There are also a number of regional and national organisations involved in innovation and research, which sometimes fund digital pilot or exemplar programmes in the short term.

The complexity of this landscape, with relatively small commissioning populations and strict governing rules, has the advantage of allowing services to be designed which fit local needs, and providing a level of local accountability. However, it creates challenges for the implementation of digital products like Big White Wall, as considerable time is needed to build relationships with each commissioner, and variations in local requirements can be

costly to accommodate or even mutually contradictory. Furthermore, commissioning for small populations can be uneconomical, as most digital products are most cost-effective at scale. If the British health system is to derive the maximum benefit from digital products, it will need more joint commissioning arrangements over longer periods, consistency of technical requirements, and integration and interoperability of data pathways.

## Outcomes and research in the UK

Delivering services online offers exciting opportunities for understanding the impact of a service, as it is possible to collect data on a huge variety of aspects of members' service use, although there can be challenges around finding direct equivalents of offline collection measures such as the NHS Friends and Family test (19). Data from the times of members' postings compared to their Patient Health Questionnaire 9 item (PHQ9), depression scale scores (from optional tests) shows that members with PHQ9 scores of 20 or more, indicating severe symptoms of depression, are considerably more likely to post during the early hours of the morning between 12 am and 4 am than members with lower PHQ9 scores. This accords with the clinical association between depression and sleep disturbance, but would be difficult to demonstrate in an offline service. More traditional service outcomes are available from the one-to-one therapy service, which shows recovery rates from depression and anxiety disorders in line with those achieved by offline NHS services [Recovery is defined by the NHS as starting from 10 or above on the PHQ9 (depression) scale or 8 or above on the GAD7 (anxiety) scale and ending below both of these scores.]. Member feedback in large scale surveys indicate that 70% of respondents achieved improved wellbeing in at least one domain, most commonly reduced isolation, and that 46% shared an issue or feelings that they had not shared elsewhere. This accords with the belief that there is a significant role for online services in reducing stigma and increasing access to care.

Although it has its origins in peer-led delivery rather than in the academic world, Big White Wall is now involved in a number of clinical trials. The largest current trial is comparing the impact of Big White Wall with the use of self-management information provided on the NHS website on wellbeing and depression. It aims to recruit over 2,000 participants in the central English region of Nottingham and Nottinghamshire, and is being run by the University of Nottingham with a grant from Collaboration

for Leadership in Applied Health Research (CLAHRC) East Midlands, which is ultimately funded by government through the National Institute of Health Research. Clinical trials like this are of great importance to both the organisation itself and to potential commissioners, although the time taken for academic studies means that less formal data collection and regular project delivery must continue while research is ongoing: this issue is common to many digital health providers.

### **International comparisons: early experience of Big White Wall in the USA**

BWW was launched in the USA in early 2015 with the attainment of several contracts with health plans and provider organizations. Several environmental factors appear to be influential in garnering the interest of these early adopters. First, the implementation of the Mental Health Parity Act which requires health insurers to reimburse the treatment of behavioral health disorders at the same levels of physical disorders appeared to be a motivating factor. It is presumed that patients seeking mental health treatment will increase their utilization of these services and therefore providing early recognition and self-management support may serve as an effective vehicle to assist patients with these needs. In addition, there is growing recognition that self-management and peer support, while effective as adjuncts to treatment, is underutilized and difficult to meaningfully scale. Adding to this is the behavioral health workforce shortage in the US. Having a digital platform that can be easily accessed for services and support 24/7 and 365 days a year becomes a viable addition to traditional office based services. Finally, there is a small but rapidly accelerating shift to measurement informed care (PHQ9, GAD7) similar to the UK IAPT program, and technology platforms like BWW are highly efficient and effective in this type of measurement with significantly less staff burden.

One of the early concerns with a digitally moderated platform like Big White Wall is whether moderators are providing clinical treatment in their role as moderators. This is not the case for Big White Wall, as members are anonymous to the moderators and it is not possible to perform a diagnostic assessment. As in the UK, individual interactions between members and moderators are mainly nondirective and use behavioral activation principles and motivational interviewing techniques that are consistent with good care management tasks and not the performance of psychotherapy. Unlike the UK, one to one real-

time therapy is not available: this is due to the different regulatory environment.

A key role of US service moderation is facilitation of members' management of their health conditions—according to the Agency for Healthcare Research and Quality's Handbook on Self-Management Support, this is defined as the patient's ability to deal with everything that having a chronic condition entails. It also includes a patient's beliefs in the ability to overcome and manage their condition including working within the health system to get the care they need, and managing their own behaviors. As the handbook points out, self-management is key to outcomes: *“An individual with chronic disease is in the medical office an average of 6 hours a year. The patient spends the remaining 8,754 hours a year outside the medical office. Self-management support is about helping patients improve or maintain their health during those 8,754 hours.”*

Since its launch in the U.S., Big White Wall has served more than 2,300 members. So far, the average early US member is White (88%), female (70%), aged 45 to 64 (40%), living with a partner (48%), and with a history of being treated by a clinician for symptoms related to anxiety or depression (52%). On average, just over 100 members join Big White Wall monthly: as noted above, continuing to attract a steady flow of new, engaged members will be crucial to the long-term success of Big White Wall in the US. The time spent on the wall per month by an active member averages 1.8 hours. The time is spent viewing educational content (about 86 pages per member) and interacting with other members (5 posts on average).

A recent satisfaction survey of Big White Wall members in a large health plan found that 49% experienced at least one wellbeing improvement as a result of using Big White Wall. The most common improvements reported were reduced isolation (64% of those experiencing improvement) and reduced anxiety and stress (31%). Other benefits reported included, sharing an issue or feelings on Big White Wall which have not been shared elsewhere (44%), and finding Big White Wall as helpful, or more helpful, than other sources of support (31%).

### **Conclusions**

Digital health programmes in general, and digital peer support services in particular, are widely used in both the US and the UK. Platforms specifically targeted at behavioral health (in the US) or mental health (in the UK) and may be particularly significant given the considerable



personal, social and logistical barriers to accessing care for these conditions. The pace of adoption has at times been faster than the pace of research, although the evidence base is developing rapidly. While the need and desire to scale behavioral/mental health peer support communities appears to be broadly similar in the US and UK, the countries' health systems are set up very differently, and this presents different challenges and opportunities for the implementation of digital services as an integrated part of routine care. Addressing these issues is likely to significantly enhance the potential benefit of novel technological approaches to population health.

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### Footnote

*Conflicts of Interest:* C Harding was working full time for Big White Wall when the manuscript was being prepared; H Chung is a medical and strategic consultant to Big White Wall.

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