



# Status Update

Using social media as part of a patient recruitment drive may be growing in popularity, but the approach might not suit every study. A feasibility model, based on a three-step framework, can provide clarity

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The growth of social media has been phenomenal. In 2005, a mere five per cent of US adults used social media, but by 2011, that number had exploded to 50 per cent (1). Despite this growth, few adults reported using social media for online health information seeking – that is, until very recently (2).

A newly published survey revealed that a substantial portion of US consumers now use social media to obtain health information on a variety of topics (3). Most notably, 42 per cent of adults reported viewing health-related consumer reviews, making it the most popular of reported activities.

Furthermore, health information gathered via social media is increasingly affecting healthcare decisions. For example, 45 per cent of US consumers reported that social media was likely to influence their decision to seek a second opinion from another doctor. As well as this, 42 per cent reported that social media was likely to affect how they cope with chronic pain or a condition (3). Similar trends have been observed in other countries as well.

Because of social media's popularity and influence, it is garnering much attention among clinical researchers – and so it should. Given the challenge of patient recruitment, clinical researchers cannot afford to ignore any avenue that might expand the pool of potential research participants. However, the numbers don't tell the whole story.

## The Challenges of Social Media

The sheer popularity of social media is not sufficient to justify its use for clinical trial recruitment. Heavy user adoption of social media is by no means a guarantee of access to social media users. A few key barriers to access must be considered.

First, social media user attention is scarce; as social media use has grown, so too has the competition to capture the hearts and minds of social media users. This competition has created an unprecedented amount of noise, thus causing social media users to be very discerning with their attention.

Second, trust is an essential ingredient to social media success, but it is difficult to earn. This statement is true with all social media marketing, but it is particularly true in patient recruitment. Many consumers are understandably cautious with regard to the privacy and security of electronic health information (4).

Third, social media's inherent nature is not aligned with traditional patient recruitment practices, thus requiring a shift in perspective and processes by clinical researchers. As

a form of permission marketing, social media requires that access to users be earned. This mindset is in stark contrast to the interruption marketing approach of patient recruitment advertising, where access is purchased (5). Furthermore, the conversational tone of social media is difficult to engage in given the regulatory and IRB restrictions of clinical research.

These challenges are significant, but worth attempting to overcome. Social media has the potential to transform patient recruitment, providing a better experience for clinical researchers and patients alike. However, that transformation won't occur in the way that many believe.

### **The Potential of Social Media**

Before understanding the potential of social media, it's important to understand what characteristics make social media unique. These characteristics include user-generated content, community and interactive dialogue (3). Note that online advertising does not fit this profile, so it does not qualify as social media, even when ads happen to appear on a social media platform such as Facebook.

This distinction is important because social media, as a form of permission marketing, requires an entirely different approach from advertising. Social media's greatest strength resides in an ability that has largely eluded advertising and other interruption marketing mediums. Put simply, social media is unique in its capacity to help users know, like and trust others. This is clearly a capability clinical researchers could use.

Clinical trial awareness remains a huge barrier to patient recruitment, and even where awareness exists, misconceptions and distrust of clinical research often remain. Contributing factors to distrust and misconceptions include negative experiences with the healthcare system, a perception of participants as 'guinea pigs', and negative press about clinical trials (6).

Meanwhile, study staff play an essential role in patient recruitment and retention. Study participants' relationships with research staff greatly influence their decision to initiate and complete clinical trial participation (7). However, when lack of awareness and distrust inhibit patient contact with clinical researchers, staff have no opportunity to forge a connection with patients and overcome barriers. Thus, research participation never becomes an option for many patients.

To widen the pool of research participants, researchers need an avenue to begin forging this connection before participants inquire about a particular study. And therein lies social media's potential. Social media is a low commitment way for patients to increase their comfort and connection with clinical research and study staff. Because social media allows patients to connect earlier in the patient recruitment process, it could have a profound impact on recruitment.

Despite this potential, now is not the time to blindly or arbitrarily use social media for patient recruitment. Social media is not an easy or quick patient recruitment fix. Nor is it without significant challenges. Like any tool, social media is

only as good as its appropriate application, and in the current climate, clinical researchers need to be extremely selective about social media's use for patient recruitment.

### **Feasibility Model**

The difficulty, of course, is in selecting the most suitable situations for social media use in patient recruitment. Many clinical researchers are confused and overwhelmed by social media's potential and challenges. To create clarity, clinical researchers need a systematic framework to hone in on key variables and assess social media's viability for their project.

A social media feasibility model can provide the necessary systematic framework. It should incorporate marketing fundamentals such as demographics, as well as considerations specific to social media and patient recruitment. In cases where social media is determined to be a viable patient recruitment option, this feasibility framework can serve as a foundation for social media strategy, thus positioning the project for success.

Use of such a model requires collection of a variety of quantitative and qualitative data, as well as reflection on the particulars of the project. In some cases, information about specific areas will be lacking. Even so, it's better to identify those areas as unknown variables, rather than be completely unaware of their potential impact.

A basic overview of such a model is provided here, including a description of three major assessment areas focusing on patients, abilities and preferences. These assessment areas should be researched and addressed in order. The bulk of time and energy should be spent on the first area: assessment of patients.

### **Assessment of Patients**

To begin the patient assessment, start by understanding who the target patients are (see Table 1). Determine which demographics are most strongly associated with the patient population, considering variables such as gender, age, race, socioeconomic status and geography. Remember that in some cases, the primary audience may be a caregiver. Demographic variables often influence patient health information seeking behaviour, particularly with regard to social media. For example, women and younger audiences tend to be particularly enthusiastic users of social media when seeking health information (2,3).

In addition, it is important to assess the target patient population's geographic location. A social media presence will need to reach people in the geographic areas from which participants are needed. In the case of a remote or virtual study, geography is less of a consideration because fewer geographic limitations exist.

Consider the target patient population's psychographics, accounting for variables such as interests, activities, opinions and lifestyles. These variables influence online behaviour

because they determine where and how people interact with information, both online and offline.

Assess the health status of the patient population and consider how people with that status are likely to interact with health information. In particular, make note of whether the target population is healthy or has a chronic, acute or rare disease. Also consider relevant comorbid conditions. All of these variables impact online health-seeking behaviour. Rare disease patients, for example, are particularly motivated and engaged online health information consumers (8).

Second, research where the target patient population congregates. Location is key; determine if patients gather on mainstream social sites, patient forums and communities, advocacy groups, blogs or other areas. Also consider the online concentration and organisation of the patient population. When patients have self-organised into concentrated online pockets, fewer patient recruitment resources are required to reach them. Furthermore, the viral nature of social media is easier to make use of when the target audience is organised and concentrated.

Third, research how the patient population prefers to be engaged. Consider their preferred type of content, tone of content, timing and frequency of interaction. These engagement preferences determine the ideal delivery of your patient recruitment message.

Now that a patient profile has been developed, including who the patients are, where they congregate, and how they engage, consider these questions:

- Are these patients using social media? Will they be receptive to receiving patient recruitment information via social media?
- Is social media a good avenue to reach these patients? Are there better avenues?
- Do these patients engage in social media? Am I willing to engage them in the way they prefer?

By pondering these questions in relation to the information gathered, a decision can be made as to whether social media is a good avenue to reach the desired patient population.

### Assessment of Abilities

Now it's time to assess your own abilities (see Table 2). Firstly, do an inventory of social media assets that are potentially accessible. Note assets within your organisation and that of your research partners. Also note social media assets that may be accessible in other organisations, including those on mainstream social sites, advocacy sites, patient forums and communities, and blogs.

If internal social media assets are found to be lacking, consider whether new assets should be strategically developed for use with future projects. Making such a decision is beyond the scope of this discussion, but it is something to consider.

Who they are	Where they congregate	How they engage
Demographics of patient and caregiver <ul style="list-style-type: none"> <li>• Gender</li> <li>• Age</li> <li>• Race</li> <li>• Socioeconomics</li> <li>• Geography</li> </ul>	Location <ul style="list-style-type: none"> <li>• Mainstream social sites</li> <li>• Patient forums and communities</li> <li>• Advocacy groups</li> <li>• Blogs</li> </ul>	Type of content
Psychographics <ul style="list-style-type: none"> <li>• Interests</li> <li>• Activities</li> <li>• Opinions</li> <li>• Lifestyle</li> </ul>	Concentration	Tone of content
Health status <ul style="list-style-type: none"> <li>• Healthy patient</li> <li>• Rare disease</li> <li>• Chronic disease</li> <li>• Acute disease</li> <li>• Comorbid conditions</li> </ul>	Organisation	Timing and frequency of interaction
Are these patients using social media? Will they be receptive to recruitment info via social media?	Is social media a good avenue to reach these patients? Are there better avenues?	Do these patients engage in social media? Am I willing to engage in the way that these patients want?

Social Media resources	Engagement	Timeline
Within my and partner organisations <ul style="list-style-type: none"> <li>• Sponsor</li> <li>• CRO</li> <li>• Research site</li> </ul>	Engagement restrictions <ul style="list-style-type: none"> <li>• Regulatory</li> <li>• IRB</li> <li>• Organisational</li> </ul>	Short term
Within other organisations <ul style="list-style-type: none"> <li>• Mainstream social sites</li> <li>• Patient forums and communities</li> <li>• Advocacy groups</li> <li>• Blogs</li> </ul>	Level of engagement <ul style="list-style-type: none"> <li>• Listen</li> <li>• Participate</li> <li>• Engage</li> <li>• Extend experience for retention/loyalty</li> </ul>	Long term
Are these social media resources sufficient? Do they overlap with where patients congregate?	Given my ability, can I engage patients as they want to be engaged?	Can my social media options be executed on this timeline?

Secondly, make note of relevant rules and restrictions regarding social media and patient recruitment, with particular attention to the Institutional Review Board (IRB), regulatory and organisational restrictions. IRB's views on social media vary widely. Some IRBs are very receptive to social media, while others are far more uncomfortable and restrictive as a result. Communicate with IRBs as early as possible to determine their individual policies.

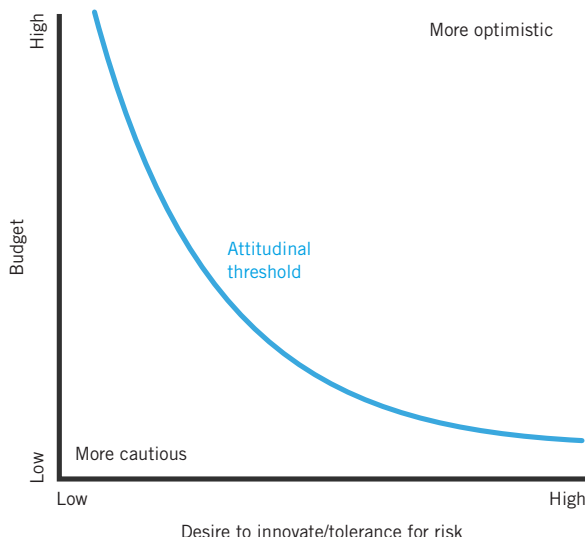
With an understanding of these restrictions in place, determine the level of engagement that can realistically be applied. From least engagement to most engagement, these levels include listening, participating, engaging, and extending the experience for retention and loyalty.

Thirdly, consider the desired enrolment timeline. A social media presence is better suited for long-term timelines, but social media listening can be done in a relatively short timeframe.

Now that ability has been assessed with regard to social media resources, engagement and timeline, consider these questions:

- Are these social media resources sufficient? Do they overlap with where patients congregate?
- Given my ability, can I engage with patients at the level they would prefer?
- Can my social media options be executed on the timeline required?

Figure 1: Assessment of preferences



### Assessment of Preferences

With a clear assessment of both patients and abilities in place, begin the third and final framework stage (see Figure 1). Contemplate your preferences, with particular attention to two big factors. Initially, consider your preferred budget, both in terms of patient recruitment as a whole and that of social media specifically. Then move on to thinking about your desire to innovate and your tolerance for risk.

These preferences will be used as a lens to further analyse the other two stages of the framework, allowing a final determination to be made. A larger budget, desire to innovate and tolerance for risk indicate the need for a more optimistic view during final analysis of the insights gathered. On the other hand, a lower budget, a lack of desire to innovate and low tolerance for risk indicate the need for a more critical view while analysing insights.

Though the first two parts of this feasibility framework are designed to bring some clarity regarding social media, its status as an emerging patient recruitment method still carries uncertainty. Compared to more traditional recruitment methods, little data about social media exist. This final stage is intended to account for your ability and desire to forge ahead in that uncertainty.

If social media is determined to be viable for a project, the research and thought put into this feasibility assessment will strongly inform social media strategy, thus positioning that strategy for success. On the other hand, if social media is determined to be non-viable, use of this model will have prevented frustration and wasted recruitment resources.

### Conclusion

Social media is an increasingly popular online activity, and it is beginning to have an impact on consumer

healthcare decisions. Because of its unique qualities, social media has the potential to transform patient recruitment, improving the experience for patients and researchers alike. However, significant barriers to social media's use in patient recruitment remain. Also, social media is certainly not right for every patient recruitment situation. A three-part feasibility model provides clinical researchers with the systematic framework needed to determine social media viability for particular projects. This framework ensures that clinical researchers make informed and strategic decisions regarding the use of social media for patient recruitment.

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