

Social Media and Clinical Research in Dermatology

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Abstract

Purpose of Review The immense growth of social media has afforded new opportunities in dermatology clinical research. This review serves to outline how social media has impacted clinical research and to explore future avenues for which social media can make a significant impact in dermatology clinical research.

Recent Findings Recent clinical trials augmented by social media have demonstrated increased participant enrollment, shortened recruitment timelines, and decreased recruitment cost. The incorporation of social media into clinical research has also afforded greater access to teledermatology and the initiation of virtual clinical trials.

Summary Clinical research serves as a primary source of evidence for refining healthcare practices by expanding the understanding of patient demographics, methods for improving patient care, and new therapeutic discoveries. Since its initiation, social media has played an integral and ever-expanding role in clinical research.

Keywords Social media · Facebook · Twitter · Clinical research · Clinical trials

Introduction

Over the last two decades, social media has experienced expansive growth, with more than half of the world's population being engaged with some form of personal

online social account [1]. As social media has grown, a gradual, yet extensive overlap between social media and medicine has emerged and continues to evolve. Dermatology, in particular, has seen extensive social media exposure from clinical, educational, and academic perspectives over the last 5 years [2]. As dermatology research on social media continues to expand (Fig. 1), it is important to understand the implications of its growth in dermatology.

While previously considered a way to disperse and share newly discovered therapies, social media is developing into a popular tool for recruitment and conduction of research. Many of the obstacles faced by clinical trials can be overcome by social media with its innate ability to connect with diverse populations previously unreached. In addition, social media can facilitate the dissemination of clinical trial information, reductions in cost and time in enrollment, and greater accessibility to a variety of patient populations [3]. This review serves to explore current social media use for clinical trials enrollment strategies, clinical research cost reduction, dissemination of information, and dermatology specific ethical considerations.

This article is part of Topical Collection on *Dermatology and its Use in Social Media*

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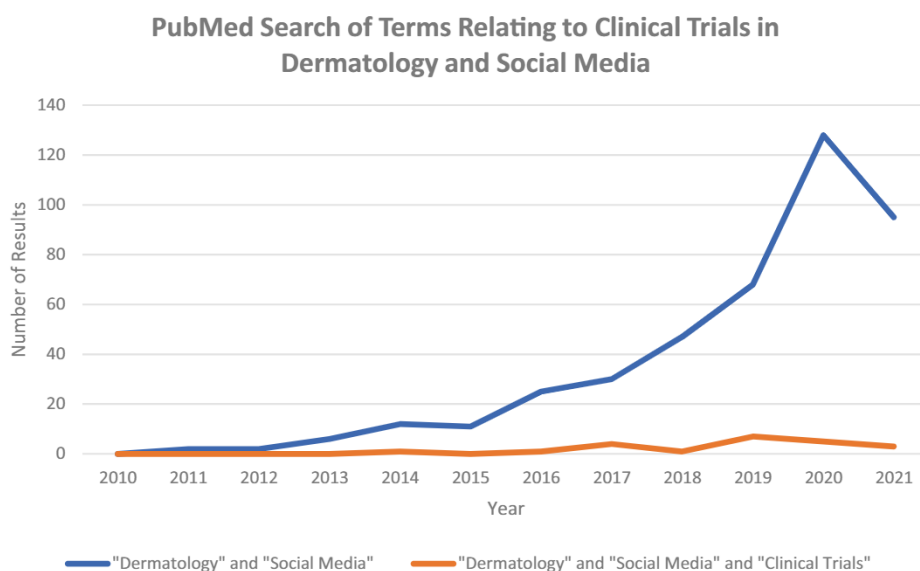
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Fig. 1 PubMed search of “dermatology” and “social media”



*Data was collected on August 21, 2021

Social Media for Clinical Trial Enrollment

Clinical research is a key factor for establishing disease burden and advancing therapeutics for dermatologic disease. An important subsection of clinical research is clinical trials, which have historically suffered as a result of poor recruitment. According to one study, 19% of clinical trials prematurely closed due to failed enrollment [4]. Furthermore, inadequate participant numbers lead to insufficient statistical power resulting in inconclusive outcomes and delay of potential therapies [5].

There are a variety of benefits to social media use in clinical trials, including increased public awareness about the study, improved communications amongst involved patients, and increased patient engagement [6]. In comparison to traditional methods (e.g., newspapers, magazines, flyers, commercials), using targeted online resources such as social media affords incredible potential for recruitment on dermatological clinical trials. A 2020 cross-sectional study sought to analyze social media use amongst dermatology patients with various skin conditions. Of the 399 dermatology patients active on social media, 95.2% reported searching for, sharing, or consuming dermatology or cosmetology-related information on a social media platform, demonstrating that dermatology patients are actively searching for health information via social media platforms [7]. When social media is utilized, it can be a superior option to traditional methods. A recent study compared the efficacy of several recruitment strategies for an online trial, including traditional recruitment

strategies, web-based methods, and online surveys. Of the 2637 participants successfully recruited, it was found that 49% of their overall recruitment occurred through Facebook [8]. More specifically, they found that traditional methods had a recruitment rate of 16.5 participants a month compared to Facebook’s superior 92.7 participants per month. Despite the apparent efficacy of social media as a recruitment tool, it is likely not being used to its full potential. For example, an investigation of Twitter found that 18% of tweets regarding lung cancer contained details about clinical trial information, demonstrating that a dialogue of health issues and clinical trials is commonplace, yet virtually, zero twitter posts contained specific links to trials or more information for potential patients or participants [9].

In 2013, the National Cancer Institute and the American Society of Clinical Oncology held a Cancer Trial Accrual Symposium and one of their recommendations included “exploring the use of social media, patient registries, and electronic databases to enhance recruitment to prevention, quality-of-life, survivorship, and rare-cancer studies” [10]. An apparent implementation of this is Antidote, which acts as a bridge between patients and clinical trials. Patients answer a series of questions regarding their current health status, which automatically generates a list of ongoing clinical trials pertaining to their particular health condition. Currently, there are over 500 clinical trials relating to Skin Disease listed on Antidote worldwide, ranging from phase 1 to phase 4 trials, with a mixture of both observational and interventional studies. When searching

for ongoing clinical trials for dermatologic conditions, for example, queries show there to be 46 available for Hidradenitis Suppurativa, 49 available for Acne Vulgaris, and 11 available for Contact Dermatitis. Studies involving in-person intervention (i.e., administration of therapeutics, biopsy submission, genetic testing, or routine examinations) frequently list multiple research locations, and participants are able to visit the site nearest to them. However, the total number of trials for each condition may further be reduced based upon the distance the patient is willing to travel or by selecting for a specific age group or sex [11]. The company also has an active social media presence, with existing profiles on Facebook, YouTube, Instagram, and Twitter, all of which contain a robust list of ongoing trials and patient testimonials and offer an avenue of direct communication with Antidote employees for assistance. The Antidote Facebook page alone has more than 100,000 followers [12]. Similar to Antidote, Smart Patients is an online community dedicated to providing support and connecting patients and family members to ongoing clinical trials related to their disease. Examples of currently available communities on Smart Patients include melanoma, alopecia, and autoimmune disorders. Their company provides a plethora of resources and social media platforms and has also developed a section of the website designed to assist patients in finding clinical trials in the stages of active recruitment [13]. Although compared to Antidote, their following on Facebook is much smaller, Smart Patients still serves a vital role in connecting patients to ongoing clinical trials. With patients likely to initially search online resources prior to consulting a physician, social media may offer a venue for recruitment that has not been fully utilized. The development of effective therapies for rare conditions can be exceedingly difficult, which highlights the importance of developing additional tools for reaching individuals with diseases of low prevalence and recruitment of distinct subgroups.

While the use of social media for clinical trial enrollment appears to allow researchers to reach previously inaccessible demographics, there may still be limitations when attempting to reach older generations. Particularly when social media is the principal method of recruitment, the enrolled group of participants may be skewed toward a younger demographic. A 2019 survey conducted by the Pew Research Center found 68% of adults aged 50 to 64 used Facebook; however, the percentage of users aged 65 + significantly dropped to only 46% [14]. The Pfizer REMOTE virtual clinical trial utilized exclusively web-based means of recruitment, and when failing to achieve satisfactory participant enrollment, Ali et al. speculated patient age was a key barrier. Alternatively, a clinical trial in 2015 employed the same strategy for recruitment and

found the average age of enrollment to be 60 years old. This mixed review of recruitment success in the elderly warrants further investigation and may be deserving of consideration when researchers are selecting recruitment methods [15••].

Virtual Clinical Trials

As the healthcare infrastructure continues to expand, social media provides new opportunities for delivering routine care, health screening, and preventative medicine. One particularly exciting area of development is virtual clinical trial (VCT), which is a relatively new concept of clinical trials to be conducted remotely through electronic modes of communication and monitoring [16•]. VCTs can use a vast array of technologies, including mobile phone apps, telemedicine, social media, electronic health monitoring systems, email, standard written correspondence, and more, often utilizing a combination in a single clinical trial. Provided the various modalities and visual nature of dermatology studies, VCTs can be an effective method for dermatology-related investigations [15••].

The utility of telemedicine and other digital communication stretches beyond use in daily clinical practice, but is also paramount in augmenting a successful virtual clinical trial. Digital platforms used in VCTs can progress clinical trials beyond the traditional geographic confines, as a physical research site is no longer necessary. In addition to the benefit of improving overall access to clinical trials, VCTs have larger recruitment rates, increased compliance, and are conducted more rapidly [15••]. It may also provide perspective on epidemiological data for the different burdens patients carry from their dermatological disease based on their region in the world. Growth of social media and virtual clinical trials will likely continue to complement each other going forward, as social media as a recruitment tool is primed to feed virtual clinical trials in coming years.

COVID-19 Considerations

In the unique setting of coronavirus 2019 (COVID-19), disruption of in person activities due to the pandemic led to impedance of multiple dermatological clinical trials, with 9% of all active dermatological clinical trials experiencing suspension, withdrawing, or termination between April 2019 and May 2020 –60% of which occurring within 3 months of the onset of the COVID-19 pandemic [17•]. Discussions of participant safety during a pandemic has led to the need to develop new strategies, including tele dermatology, to recruit and retain participants in studies [18•]. While these delays were largely inevitable, continued and innovative use of social media may improve clinical trial enrollment moving forward.

Social Media and Clinical Research Cost Reduction

Implementation of social media and online platforms as an enrollment tool has the potential to reduce costs associated with clinical research. Until recently, recruitment for clinical trials exclusively utilized traditional methods including promoting trials via television, radio, professional referrals, and print media (i.e., newspapers, magazines, flyers). Social media can reduce the cost per person through faster recruitment time and administration of survey-based studies and serve as a channel for facilitating both traditional and virtual clinical trials.

While there is limited data available explicitly pertaining to dermatology-based clinical trials, there is a preponderance of evidence available from across multiple disciplines of healthcare suggesting trials augmented with social media may lower the cost of recruitment. In fact, 32% of drug manufacturers cite patient recruitment as the largest driver of increased clinical trial costs [19]. To demonstrate the cost burden, Tate et al. analyzed recruitment costs from a randomized controlled trial of weight gain prevention in adolescents. This revealed an average cost of \$233 per participant, of which, the most expensive method of recruitment per participant was television, at \$1094.27 per participant. Additionally, printed media was \$811.99 per participant, radio was \$635.92 per participant, and email was \$37.77 per participant [20]. Compared to these traditional methods of participant recruitment, a systematic review of 35 different studies by Whitaker et al. analyzed the cost per participant for trials using social media for recruitment. The results revealed Facebook as a recruitment tool demonstrated an average cost per participant recruited to be \$14.41, with the mean cost per click on Facebook at \$0.57 [21]. Similarly, a survey-based study by Ali et al. utilized Facebook as a recruitment platform to survey knowledge, beliefs, and practices in the USA related to COVID-19. Ultimately, over 6000 participants completed the COVID-19 survey, with a

total cost of \$906, an average cost per click of \$0.09, and an average cost of full response of \$0.18 [22•]. In 2020, a randomized controlled trial compared the cost of various methods of recruitment when attempting to enroll Spanish-speaking smokers in a smoking cessation intervention program, and also found Facebook to be the most cost effective. Principal investigators, Medina-Ramirez et al., observed the cost of Facebook to be \$74 per participant, in comparison with methods such as website banners and bus advertisements, which were shown to be \$387 and \$643 per person, respectively [23]. Findings from these studies support the utility of social media platforms as a tool to efficiently and effectively recruit large sample sizes and highlight the lower costs associated with online recruitment (Table 1). Together, these findings may lead to reduced costs, shortened recruitment periods, and more rapid dissemination of vital information.

An additional source of increased cost for clinical research is poor participant accrual, which can result in early termination of trials, extended timelines, or indefinitely hindering clinical research. In fact, there are estimates that 80% of medical research is delayed due to poor accrual and 53% of studies had extended timelines, with one of six studies taking more than twice as long as originally planned [24]. One study found that the average timeline for a clinical trial is approximately 7.5 years from the start of clinical testing to marketing, and the average cost for prescription drug-related trials range from \$314 million to \$2.8 billion [25]. The estimated additional cost for each day a clinical trial's enrollment period is extended is between \$600,000 and \$8,000,000 [26]. A recent decentralized clinical trial investigating the use of a probiotic spray as treatment for acne utilized online and social media recruitment methods to effectively screen greater than 8000 prospective participants. There were ultimately 372 individuals enrolled, and the overall timeline of the study was markedly reduced. The trial's success provides further affirmation of the robust online presence of dermatology patients and the aptitude

Table 1 Recruitment cost per enrolled participant by method

Investigator	Method of recruitment	Cost per enrolled participant (US dollar/person)
Tate et al. [20]	Television	\$1094
	Print media	\$812
	Radio	\$636
	Mass mailing	\$332
	Facebook	\$14
Whitaker et al. [21] (Systematic Review-35 studies)	Facebook	\$14
Medina-Ramirez et al. [23]	Public bus cards	\$643
	Website banner	\$387
	Television	\$191
	Facebook	\$74

for social media to serve as an efficient recruitment in dermatology [15••].

Recently, a growing body of evidence indicates online recruitment can shorten the overall timeline and alleviate the financial burden associated with lengthy clinical trials. In a phase III trial evaluating the efficacy of a therapy for moderate to severe atopic dermatitis, Katz et al. supplemented the traditional methods of participant recruitment with the Studies&Me (online patient recruitment platform) as an additional channel for participant recruitment. Moreover, this trial also utilized teledermatology as a means of pre-screening participants after their initial enrollment through Studies&Me. This combination of digital media offered a notable increase in efficiency and shortened the recruitment time for this phase III trial by over 2 weeks [27•]. Provided social media's ability to reach a variety of populations, low cost of recruitment, and ease of use, social media is primed to serve as a tool for reducing costs of clinical research.

Dissemination of Study Results Through Social Media

Social media has an estimated 3.96 billion users worldwide as of 2021 [28]. With this high number of users, social media serves as an effective platform for researchers and institutions to rapidly disseminate research findings to the public. Compared to more conventional methods of sharing research through scientific journals, sharing via social media allows researchers to inform a broader audience, thus potentially increasing the impact of the particular research. For instance, research sponsored by cadamia.edu showed that sharing a research article to this social networking site was associated with 69% more citations in 5 years [29]. An additional study by Eysenbach also showed a positive correlation ranging from 0.57 to 0.89 between the number of tweets an article received on Twitter and the number of citations ($P < 0.001$) [30]. Although these values do not determine causation, it is unsurprising that increasing an article's presence on social media is linked to an increase in the number of citations an article will subsequently receive. As the number of citations directly influence the impact factor of a specific journal, it is recommended that researchers aim to promote their research and findings from these studies suggest that social media can be a powerful tool in doing so.

Ethical Considerations with Social Media and Clinical Research

The integration of social media platforms, amongst other online communities, with clinical research will undoubtedly be met with institutional guidelines and restrictions

imposed by regulatory agencies. As it stands, there are no clear federal regulations addressing the use of social media in patient recruitment, and there is little guidance for Institutional Review Boards and investigators when evaluating social media recruitment [31]. Likewise, there is not yet a standardized set of guidelines for implementing virtual technology into clinical studies, with VCTs being conducted on a case-by-case basis and under regulations that vary by region and country. The lack of concrete recommendations and requirements may result in the preclusion of harmless and valuable research investigations or, conversely, permit the initiation of fruitless experiments with deleterious effects on participants [16•].

The use of social media in clinical research also gives rise to new ethical considerations regarding the methods of obtaining participant information, the scope of trial data that is shared publicly, remote digital communication, reliability of information shared online, and exposure to privacy risks regarding health data [32]. Advancement of digital media and social media platforms has made the personal information of millions readily accessible to Internet users. In most cases, this information is willingly shared online; however, this gives rise to a series of ethical questions surrounding how researchers should go about obtaining and utilizing this data. To avoid violating the privacy or autonomy of potential research subjects, it would be prudent to develop universal standards regarding participant consent for data extraction from online platforms, as well as the types of information shared in the publication of the study results. In addition to the ethical concerns regarding the collection of Internet user data by well-purposed investigators, there are novel cybersecurity concerns regarding the safety of data provided by participants through digital or virtual methods by those with more malicious intentions. As digital means become further incorporated in clinical research, appraising the vulnerability for data to be accessed by unauthorized third parties in studies involving online collection and storage of private participant health information is becoming increasingly paramount [33].

Conclusion

Looking beyond the challenges of utilizing social media in clinical research, there appears to be promising preliminary evidence displaying the aptitude for social media and other digital media to alleviate the multitude of barriers to clinical trial enrollment. With dermatology relying heavily on visual diagnostics, platforms where images are easily shared and distributed add a facilitated layer of networking between providers and the public. The development of online platforms designed to increase awareness of ongoing clinical trials, for both patients and physicians, enhances the probability

for those interested in participating in clinical trials to effectively identify and enroll in studies specific to their respective medical conditions. The concurrent evolution of VCTs further enables individuals to become involved in clinical trials, irrespective of geographic location. Social media in clinical trials is an extraordinarily active area of research with growing literature demonstrating social media as a viable, primary, or supplementary tool for connecting with a wider audience and expediting study recruitment. Implementation of digital media and social media advertisements as a means of hard-to-reach demographics and targeting specific populations shows encouraging outcomes. The use of social media and digital communication in clinical research is an extremely broad subject, and further exploration of the full extent of its role is warranted.

Compliance with Ethical Standards

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of Interest None.

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