

Digital Cohorts Within the Social Mediome: An Approach to Circumvent Conventional Research Challenges?



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We are becoming comfortable with the concept of a sharing economy, where resources are shared among many individuals using online forums. Whether activities involve sharing rides (Uber, Lyft, and others), accommodations (Airbnb), or information (social media), underlying attributes include reduced transactional costs, enhanced information transparency, dynamic feedback, and socialization of opportunity. As health care systems realize that they are changing from direct-to-business to a direct-to-customer model, their ability to connect directly with individuals will become a foundational strategy.

This month's Road Ahead column introduces us to social media as a research tool. Information derived from social media sites can be harvested for critical clinical information (the Centers for Disease and Control tracks the spread of influenza using social media analytic tools), research data (patient preferences), and as a recruitment method for clinical studies. Kulanthaivel and colleagues have described their experiences and literature review to help us imagine new ways to collect data at markedly reduced transaction costs (compared to a formal clinical trial). While there are many cautions about the use of social media in your practice or research, we are only beginning to understand its potential.

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Medical knowledge, culminating from the collection and translation of patient data, is the primary objective of the clinical research paradigm. The successful conduct of this traditional model has become even more challenging with expansion of costs and a dwindling research infrastructure. Beyond systemic issues, conventional research methods are burdened further by minimal patient engagement, inadequate staffing, and geographic limitations to recruitment. Clinical research also has failed to keep pace with patient demands, and the limited scope of well-funded, disease-specific investigations have left

many patients feeling disenfranchised. Social media venues may represent a viable option to surpass these current and evolving barriers when used as an adjunctive approach to traditional clinical investigation.

The term social media (SM) most commonly refers to relatively public Internet-based communication platforms that enable users to consume and disseminate information. The most popular SM venues currently include Facebook, Twitter, YouTube, and independent online forums (Table 1). These digital platforms support sharing multiple forms of media including text, images, and videos between users who interact within a wide realm of medical groups and genres (eg, specific diseases, symptoms, and so forth). This collective mediome¹ is a relatively untapped resource for clinical study, but research applications using SM methodology have begun to produce real study benefits in an array of diseases. Effective implementation of this technology by interested investigators will require an in-depth working knowledge of digital venues beyond their own online social presence. A firm grasp of these applications can enable contact with previously out-of-reach study participants, promote patient engagement and disease investment, and cultivate a community of interacting patients and researchers. This data-rich resource already has facilitated various aspects of biomedical studies, including dissemination of epidemiologic surveys,² direct recruitment into clinical trials,³ collection of biologic samples,⁴ and extraction of patient-provided data, all within SM platforms.⁵

Advantages and Pitfalls in Social Media Research

SM is a new frontier containing a wide spectrum of clinical and qualitative data from connected users

Abbreviations used in this paper: AHRN, Autoimmune Hepatitis Research Network; AIH, autoimmune hepatitis; SM, social media.



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Table 1. Statistics, Use, Advantages, and Pitfalls of Social Media in Research

	Facebook	Twitter	YouTube	Internet forums
Official website	www.facebook.com	www.twitter.com	www.youtube.com	N/A
Available since	2004 (college students) 2006 (general public)	2006	2005	Early 1990s
Operated by	Facebook, Inc	Twitter, Inc	Google, Inc	Independent web server owners
Popularity (reach)	Best (1+ billion)	Good (100+ million)	Very good (800+ million)	No reliable estimate, not as popular but more targeted
Types of media supported	Typed text; images, embedded videos	Tweets (messages of up to 140 characters), linked images, linked videos	Videos, some typed text in video comment sections	Typed text, linked images, linked videos
Customizability	Very little	Very little	Very little	Usually high
Financial cost	Virtually zero	Virtually zero	Virtually zero	Cost of a web server (typically \$15–\$50 per month)
Data extraction difficulty	Qualitative: easy; big data: difficult	Qualitative: easy; big data: difficult	Qualitative: easy; big data: difficult	Qualitative and big data extraction are easy if the forum is database-driven
User privacy	Groups feature: reasonable Remainder of site: marginal (users typically use real names)	Marginal/reasonable (users typically use real names but may be masked by screen names)	Reasonable (users masked by screen names)	Best (can be kept completely private except to invited users only, users are masked by screen names)
Communication direction	Usually highly multilateral	Somewhat multilateral, no formal post-reply structure	Relatively unilateral, users may post comments on videos	Usually highly multilateral
Advantages for clinical research	Broad cohort of users, can form private groups	Quick, text-based communication	Multimedia (audio/video) communication and feedback of health information	Privacy is easy to ensure, complete control of the venue, data extraction is simpler
Potential pitfalls for clinical research	Most users use real names on the site (privacy risk)	Health discussions hampered by short (140-character) limit	Few chances for patient interaction (limited to comments)	Requires minor but nontrivial technological support to set up, has financial costs

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