

Investigation Gone Viral: Application of the Social Mediasphere in Research



The research paradigm in the United States remains burdened by numerous obstacles impeding the progress of scientific investigation.¹ Barriers to effective and efficient conduct of academic research include growing costs, delayed results, adequate staffing, and regulatory encumbrances.²⁻⁵ Beyond these system constraints, patient recruitment in research studies can be time intensive, costly, and limited by minimal participant diversity.^{6,7} The social mediasphere, an intertwining universe of online social media applications, may represent a new model in research methodology that will bridge current research challenges in all medical fields. Investigators and study staff will require a fundamental appreciation of social media structure, existing methodology, and advantages and limitations to effectively conduct research with this novel strategy.

The Internet is a ubiquitous, continual stream of information to those with means of access. Much of humanity has accepted and now expects readily accessible knowledge and rapid communication. A need for online connectedness drove cyberspace innovation, resulting in the establishment of social networking sites (SNS) such as Facebook, Twitter, Instagram, YouTube, and LinkedIn. These public websites have provided the foundations of digital communities in which users construct personal profiles, create and share user-generated media, and interact with other users virtually.^{8,9} Global membership within SNS has increased tremendously since their incarnation. As of September 2014, 74% of online adults in the United States use SNS and more than one-half report routine use of ≥ 2 separate services.¹⁰ Facebook (www.facebook.com), the largest SNS with

>1.3 billion users worldwide, provides a media platform that consumes 40 minutes of the average American user's day.^{10,11} SNS have quickly become a communication fixture between family and friends for sharing electronic posts, pictures, and videos. However, their spectrum of use has grown, now including vast networks of information providing users a portal to pursue specific questions about individual health, obtain medical information about disease conditions,¹² and participate in active health-related support groups.¹³ Considering the number of individuals engaged in this media, the research community has been slow to recognize the potential of this resource for conducting research and recruiting proactive study participants.

Before the digital age, individuals seeking similar health information commonly gathered together in physical support networks. However, the advent of SNS has simplified formation of these groups, providing online communities where e-patients and e-caregivers can successfully support one another with the provision of information, resources, and outcomes at any time without geographic limitations. Distinct group pages (public or private) on Facebook can be created or identified and joined by users, thus opening communication channels to receive and distribute opinions for group-generated questions and commentary. Gastroenterology-related disease groups are now well-represented on Facebook, often including multiple distinct pages for both common and rare disorders (Table 1). This social support shift has evolved with societal interests, because many patients find it easier to communicate online with strangers rather than to speak with family directly.¹⁴

Application of SNS in research conduct and collection is likely to be the most impactful within the study of rare diseases. According to the National Institutes of Health, these disorders have a prevalence of <200,000 persons in the United States. Despite perceived scarcity, there are approximately 7000 known rare disorders

affecting ≤ 25 million people (7% of population) in the United States alone.¹⁵ Disease underpinnings, optimal treatment, and expected outcomes of rare diseases are commonly limited to studies with minimal patient enrollment owing to low prevalence and population distribution. In 2003, the National Center for Advancing Translational Sciences led an initiative to develop the Rare Disease Clinical Research Network (RDCRN) to overcome well-defined obstacles in rare disease research. The RDCRN, composed of 22 clinical research consortia, has sought to establish study cohorts and collect data on >200 rare diseases. Despite published successes of the RDCRN in forming dedicated research consortia for specific disorders, a majority of recognized rare diseases remain without national initiatives or study incentives to fuel proactive and novel investigation.

SNS enable investigators to quickly establish disease specific cohorts and disseminate research opportunities across geographic barriers in short times with low costs (Table 2). An example of SNS implementation in rare disease research is highlighted in a study of Fontan-associated protein-losing enteropathy and plastic bronchitis.¹⁶ Investigators provided a single recruitment post on 2 existing patient-run and disease-specific Facebook groups, directing interested participants to either a study-specific Facebook group or publically available website that served as a study material repository. The single study recruitment post generated respondent-driven study participation for 1 year, propelled by member discussion and reposts. This simple methodology generated the largest contemporary survey cohort of Fontan associated protein-losing enteropathy and plastic bronchitis patients ever reported (671 respondents) at no cost. Furthermore, sole use of SNS to recruit, disseminate, and collect epidemiologic observations has been successfully used in the study of other rare diseases, including neuroendocrine cervical carcinoma among others. For example, Zaid et al²¹ used Facebook to complete

Table 1. The Spectrum of Gastroenterology-related Diseases with Active Private Groups on Facebook

Specific Gastroenterology-Related Diseases	Number of Private Groups on Facebook	Range of Members per Group	Mean Number of Members per Group
Eosinophilic esophagitis	5	113–3923	1197
Barrett's esophagus	1	431	431
Celiac disease	13	510–9860	2503
Crohn's disease and ulcerative colitis	27	2154–20,169	5752
Nonalcoholic fatty liver disease	4	504–3895	1633
Primary biliary cirrhosis	3	391–2567	3682
Primary sclerosing cholangitis	4	872–2773	1911
Autoimmune hepatitis	7	188–1377	620

cross-sectional epidemiologic and quality of life survey data among patients with neuroendocrine carcinoma of the cervix. Fifty-seven women across 8 countries and 4 continents completed an 81-question study instrument in a single month, thus solidifying the feasibility of SNS to collect patient response data.

Overall growth in US funding for medical research has slowed to 0.8% per year between 2004 and 2012; therefore, innovative approaches to reduce research expenses without impacting study design or time are paramount.¹⁷ Outside SNS specific groups, investigator-purchased study advertisements on SNS can effectively target users based on a number of inclusion criteria, such as age, gender, geographic location, and even specific SNS group memberships. Study-specific ads, configured and distributed through SNS, can be displayed directly on a user's Facebook portal or content feed. Selecting or "clicking" on

an ad can provide means for an interested patient to participate. This approach existed as a minor adjunct to physical study recruitment until 2013, when Kapp et al¹⁸ used Facebook advertisement as an exclusive study recruitment mechanism. In 11 days, 3 separate study ads on mammography were displayed for 374,225 women between the age of 35 and 49 with a total study cost of \$300.

Twitter (www.twitter.com), another popular SNS that allows registered users to communicate with others using short messages, has also proved to be a powerful tool to distribute epidemiologic surveys. Web services such as Qualtrics, REDCap, and SurveyMonkey can be used to design and collect survey responses via posted survey-linked web addresses. Twitter was recently used in the development of a cross-sectional survey examining the pregnancy experiences of mothers of advanced maternal age.¹⁹ Investigators tweeted (posted on their Twitter

account) a web-based questionnaire accessible via a link to national organizations that were thought to have an interest in patient-related research. Recruited participants were then asked to retweet (post the study link to be shared with their network of followers), creating a modernized snowball sampling technique. Study participation was not driven by monetary reward and no mention of payment was included in the study advertisements or given at study conclusion. In <3 months, 529 mothers were recruited from 359 investigator tweets and subsequent retweets from study participants. This not only highlights social media's effectiveness in study recruitment, but also demonstrates the participants' willingness to contribute to web-based research studies with no compensation.

SNS may also represent a viable mechanism to recruit populations that have been historically challenging to engage with the traditional research

Table 2. Advantages and Disadvantages of Social Networking Sites in Research Methodology

Advantages	Disadvantages
Minimizes social stigma attached to disease or minority status.	Historically, populations tend to be younger, more educated, and from higher socioeconomic classes.
Cost is contained via reduction of staffing needed to recruit, conduct, and follow-up with patients.	Requires baseline knowledge of social networking sites and linked applications.
Extends recruitment to rural areas and across international borders.	Sample and self-selection bias may have impact on external validity.
Facilitates exchange of information between researchers and participants.	Recruitment is dependent on patient review of inclusion/exclusion criteria, data is patient-reported.
Alternative contact method for study follow-up.	Local institutional review boards may be unfamiliar with methodology.
Data can be collected quickly and study recruitment can occur 24 hours a day.	
Development and conduct of study is easy and intuitive.	
Collaborator recruitment is feasible via the same approach.	
Allows patients to engage research opportunities and maintain a proactive role in disease efforts.	

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