MAXIMIZING IMPACT: LEVERAGING DIGITAL & TRADITIONAL TOOLS FOR RECRUITMENT AND RETENTION SUCCESS

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SC CTSI Clinical Research Support (CRS)

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The Clinical Research Support (CRS) office at the SC CTSI offers a range of services to help make your research study or clinical trial a success:

RESEARCH NAVIGATION

Expert central resource who critically evaluates the needs of clinical research teams, guides them through the various stages of carrying out a clinical study, and connects them with many resources available across USC and CHLA.

CLINICAL RESEARCH COORDINATOR POOL

Experienced fee-for-service clinical research coordinators who provide study-related services ranging from regulatory document preparation, participant recruitment, data collection and entry, phlebotomy services and study monitoring. Available in an effort or hourly based model.

RECRUITMENT SUPPORT

Obtain customized recruitment strategies that fit your study's needs, timeline, and budget. Recruitment and retention strategies involve traditional methods (flyers, TV, radio) and innovative tools (online advertising, social media, etc), customized strategies to engage special populations in research, in-house design of advertising materials, creation of targeted social media posts for your study, assistance with template language for IRB applications, and hands-on training for study's social media manager(s).

BUDGET PREPARATION

This resource helps identify potential sources of funding, as well as provides guidance on the planning and preparation of study budgets.

INTRODUCTION

Clinical research is an important aspect in the process of translating biomedical discoveries into patient care and improved disease outcomes. However, these scientific breakthroughs cannot be tested to demonstrate safety and efficacy without participation by patients and healthy volunteers. Recruiting participants for clinical research studies has become an increasingly difficult and challenging endeavor, requiring creativity and carefully planned strategy on the part of clinical research investigators and their staff.

- Approximately 75 percent of investigators don't meet their enrollment goals, and 90 percent fail to meet recruitment goals within their estimated timeframe (Institute of Medicine Forum on Drug Discovery, Development, and Translation, 2010).
- In a survey of corresponding authors of randomized trials published in *The Lancet* or *The British Medical Journal* between 2000 and 2001, 60 percent failed to meet recruitment goals or had to extend recruitment timelines (Burrell, 2016; Centers for Disease Control and Prevention, 2007). In cancer studies, less than 5 percent of patients in the U.S. take part in clinical research, with even lower rates of participation in minority populations (Jimenez et al., 2013).

This guide is meant to serve as a tool to help clinical research coordinators, as well as researchers at academic medical institutions who handle studies in which they are responsible for patient recruitment. In this guide, the following will be outlined:

- recruitment and retention
- audience analysis and segmentation
- importance of message tailoring
- social marketing and health communication
- measuring recruitment efficacy
- need for education and awareness about study participation opportunities
- engaging diverse populations
- challenges and benefits to participation in health research
- practical information and resources relating to using digital and social media platforms for recruitment.

While clinical trials is the focus of this guide and much of the extant literature on recruitment and retention, all of the best practices also apply to other studies involving human participants.

Throughout this guide, the terms volunteer, patient, and participant are used interchangeably to refer to the enrollees of a clinical study.

RAISING AWARENESS FOR HEALTH RESEARCH PARTICIPATION

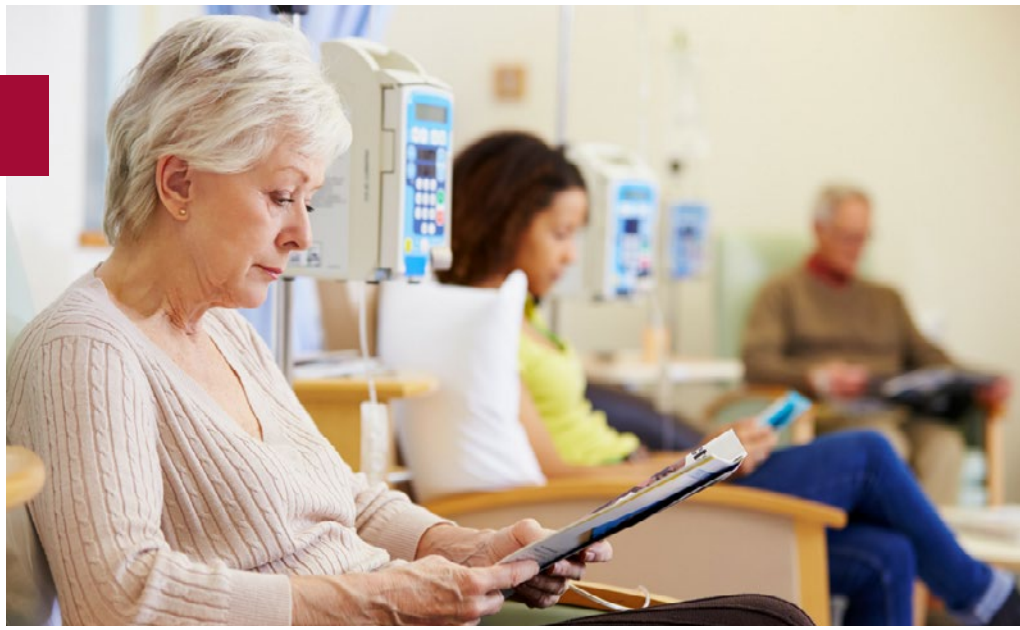
For people to take part in clinical trials or any kind of health research, they must be aware that such opportunities exist. According to 2001 findings from the Harris Interactive Survey, **85 percent** of patients "were either unaware or unsure that participation in a clinical trial was an option at the time of diagnosis," and **75 percent** of those patients said they would have been willing to take part in a clinical trial if they knew the opportunity existed (Harris Interactive, 2001). The Cancer Research Institute has found that only **about 3 to 6 percent** of cancer patients who are eligible participate in clinical trials, which stymies the process surrounding research and development of breakthrough treatments, drugs and devices (Cancer Research Institute, 2016).

PATIENT ENGAGEMENT

From the patients' perspective, study participation has risks and benefits. Patients (n=12,009) self-reported their top concerns in a 2015 survey conducted by the Center for Information & Study on Clinical Research Participation, or CISCRP (Getz, 2016). These included the possibility of side effects (43 percent), risks to overall health (26 percent), concerns with receiving placebo (11 percent), risks associated with stopping their existing treatment (10 percent), and privacy concerns about their medical information (4 percent). Conversely, these patients cited the top benefits to clinical research participation, which included the belief that they would be aiding in scientific advancement (28 percent), altruistic motivations for helping others with a similar condition (26 percent), improving disease outcomes (17 percent), idea that they'd receive "special care" from healthcare professionals (5 percent), and receiving financial compensation for participating (5 percent).

Ensuring greater retention involves keeping volunteers engaged from the outset of a study, setting and following strategic communication goals, and being available for feedback, questions, and comments from volunteers. Study teams should understand the importance of flexibility, open communication, periodic "checks" to ensure participant needs are being heard and addressed appropriately from the study staff. Ultimately, taking a step back from the study to view participation from the perspective of the volunteer will help the researchers and coordinators identify any bottlenecks in the study that could slow it down, raise costs, or affect drop-out rates.

DEVELOPING & TAILORING **A MODEL OF ENGAGEMENT**



It is key for each organization to develop and tailor their own **patient-centric model of engagement** that is appropriate for their institution or organization and addresses the diversity and needs of their local population. Taking into consideration processes such as **audience analysis, segmentation, social marketing, and effective health communication** will help with the development of this model. According to CISCRP, an ideal model of engagement contains at least four pillars: **CONNECT, ENGAGE, EDUCATE,** and **ENABLE** (CISCRP, 2016).

1. CONNECTING involves developing relationships with potential volunteers and strengthening existing relationships with patients.
2. ENGAGING entails communicating with potential volunteers while also building trust, in addition to being as transparent as possible throughout the trial process.
3. EDUCATING the public and increasing their knowledge and awareness of medical research will help them understand how they can be part of the clinical trial enterprise.
4. ENABLING participation using open, planned communication, as well as facilitating the process by making it as easy as possible to enroll will improve enrollment outcomes.

Customized messages are shown to be more effective in engaging audiences than generic, generalized messages. Message tailoring can be informed by audience analysis and segmentation as well as appropriate campaign evaluation. Successfully tailored messages refer to communications that are "individualized for their receivers, with the expectation that this individualization will lead to larger intended effects" (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008, p. 454). The authors identified three tailoring strategies to take when creating messages: **PERSONALIZATION; FEEDBACK;** and **CONTENT MATCHING**.

1. PERSONALIZATION suggests to the receiver that this content is meant for them and is not generic in nature—specifically, using someone's name in the communication, explicitly stating that the communication was created for them, and contextualizing the content in a way that suggests it has been personalized.
2. FEEDBACK strategy involves obtaining descriptive information about the audience that can be presented back to them, i.e. targeting individuals for whom a particular health measure or behavior is known, such as healthy blood pressure. This information can be contrasted with information about others to show that the sender understands the receiver.
3. Finally, the CONTENT MATCHING strategy starts with a receiver's known stance on an issue (receiver is a smoker), and provides solutions for the given health behavior or stance, i.e. "Quitting is hard. Here are five tips to help you stop smoking…" (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008).

These three strategies are most effective when used together.

After evaluating the needs and characteristics of the target audience, it is time to identify which traditional and digital methods would be most feasible for the study, taking issues such as **timeline, budget, and staff availability/skillset** into account. Traditional methods of recruitment include use of mass media such as print materials (magazines, newspapers, pamphlets, brochures, flyers) and broadcast (television, radio). In general, broadcast has a very wide reach in terms of audience, but in may yield a large number of ineligible volunteers who don't meet the study criteria due to age, gender, health conditions, and more. Rates of attrition, or dropout rate, may be higher for individuals found through broadcast media for certain studies (Gilliss et al., 2001). As a result, researchers are exploring the possibility of using **digital media** to recruit participants, but that has its own set of regulatory and ethical challenges.

TIPS FOR ENGAGING PARTICIPANTS

The individuals who take the time out of their lives to complete clinic visits, take medication or receive treatment, keep subject diaries, track their symptoms or medication and talk to you or your study team members on the phone are doing just that—volunteering their time and efforts for the success of your study. Thus, they should be treated as valuable partners in this undertaking. Without their participation, the study could not happen. Research by CISCRP shows that patients want to feel appreciated, and that their participation is valued.

Many patients complain about **lack of communication from the study team,** as it is common for sites (and their patients) not to receive information or results of a trial until after it has closed out and the drug or device has been approved and gone to market. From the patient's perspective, they may feel excluded from the enterprise they are participating in—and PIs and study teams should take greater care to be as communicative as possible with patients before, during, and after the trial using open communication methods. Studies (Stovsky, Rudy, & Dragonette, 1988; Green et al., 2008) have shown that open communication methods, such as planned communication, can greatly increase patient satisfaction during medical procedures, aid in study retention, and/or adherence to a treatment or medication. Sending updates via email when appropriate, taking time to discuss concerns or questions with patients, and sharing results when possible are all examples of planned communication that can help foster greater interaction between the provider and the patients.

Finally, as important as open communication is, active listening is also crucial to the process. Patients may feel apprehensive about discussing something they are concerned about, but engaging in active listening techniques can make them feel more comfortable to bring up issues they otherwise might not have spoken about. Active listening is a crucial part of gathering clinical data, diagnosis, and the patient feeling like he or she has been "heard" (Jagosh, Boudreau, Steinart, MacDonald, & Ingram, 2011). This not only improves the patient-provider relationship, but can also be used in the context of medical research.

ENGAGING DIVERSE POPULATIONS IN RESEARCH

Some studies (Samuel, 2013) have shown that racial and ethnic minority groups are underrepresented in medical research, though there are very little differences in the willingness of minorities to participate in health research (Wendler et al., 2005). A meta-analysis of 20 health research studies that reported consent rates by race or ethnicity found that **ethnic minority participants in the U.S. are as willing as non-Hispanic whites to take part in health research** (Wendler et al., 2005). Based on their findings, the authors suggest that efforts to engage minorities in research should focus on increasing access to studies and trials for all ethnic/racial groups, instead of focusing on changing attitudes toward research in minority populations (Wendler et al., 2005). Increasing access involves presenting opportunities for participation to individuals in underrepresented ethnic groups, as well as engaging minority physicians in clinical trials (Agodoa et al., 2007).

"Ethnic minority participants in the U.S. are as willing as non-Hispanic whites to take part in health research."

(Wendler et al., 2005).

HEALTH LITERACY AND ACCESS-RELATED CONCERNS

It is key to understand access and health literacy, as they are two components that can impact the audience analysis process and the recruitment process. Some populations may have limited access to resources like the Internet and social media, and being mindful of this during the recruitment process can help you focus your efforts on tactics that will be more relevant to the demographic at hand. Most individuals without consistent and reliable Internet access at home use their mobile phones to access the Internet on the go, which is why campaigns and advertisements also need to be mobile-friendly.

Health literacy is another issue to be aware of when designing strategies. Some populations may not be familiar with medical jargon, either due to lack of specialized knowledge in this area or because of a language barrier. For these reasons, it's important that **recruitment materials are clear, easy to understand, and devoid of complex language** that could turn potential participants off. The CDC offers useful resources and training for addressing health literacy—writing for the public, using numbers and explaining risk, creating visual aids such as charts and graphs that are easier to understand, and more (CDC.gov, 2016).

AUDIENCE ANALYSIS & SEGMENTATION

AUDIENCE ANALYSIS involves understanding the target audience of your campaign before designing a strategic communication plan. A campaign is any textual or visual content that function as a call to action to your prospective volunteers—in this case, inviting their participation in the study. Conducting an effective audience analysis involves **obtaining detailed information about the habits, thoughts, literacy/numeracy levels, and behaviors of the target audience** (Brizee & Schmaling, 2016). Knowing and understanding the intended audience will allow you to make informed choices about which communication channels might be appropriate. Determining the channels through which audience members are willing and available to receive messages can save time and money, since your organization won't waste efforts on communication channels that won't work for that audience. For example, investing in a budget to use social media or digital platforms to recruit an elderly population or a rural population without consistent and reliable Internet access would be a misuse of resources. Essentially, you want to go where your audience is. If the target audience is low-income minority populations, building relationships with community agents who have regular contact with members of this population is a good place to start. These community agents have a deeper understanding of the population, can refer them to your study when appropriate, and can hang flyers or distribute other promotional materials.

AUDIENCE SEGMENTATION is the second step to this two-flow process. Segmentation involves breaking the target audience down into distinct and specific demographic groups that can help with identifying their media consumption patterns, habits, preexisting views about medical research, and more. Conceptualizing the target audience as a heterogeneous group with varying racial and ethnic background, socioeconomic status, age, religiosity, gender, sexual orientation, language, attitudes toward clinical research, geography, and access to various communication channels can inform how the segmentation process is conducted. For certain studies, recruitment campaigns must go beyond just the patient—inclusive of caregivers, or family members who serve as primary or secondary caretakers.

MESSAGE DESIGN

In terms of designing messages or content, context is important. Messages must be **easily understood** in the language that is appropriate for the population at hand. When an individual feels like information is personally relevant to them, they are more likely to engage with that content (Rothchild, 1987). For content to be persuasive, it must **engage a person's personal values** and they must have "favorable feelings and intentions regarding a brand," (Reynolds, Gengler, & Howard, 1995) and in this case the brand is the persona of your institution or organization. This is also where legitimacy plays a role in content creation and message tailoring. When designing recruitment materials for studies, make sure to include institutional or industry affiliation clearly within all content, especially printed content—i.e., logo of the university/medical school, institute or pharmaceutical company sponsoring the trial so it is easily identifiable to the recipient.

Transparency establishes legitimacy in the minds of prospective participants and helps them understand who is funding or sponsoring a particular study.

FORMATIVE, PROCESS AND OUTCOME EVALUATION

As with any strategic endeavor, proper evaluation and planning must occur to ensure the study enrollment goals are feasible, and to assess the number of potential patient participants available to participate in the current study.

During the formative phase, stakeholders are contacted for their input and guidance on a particular health campaign or message. There are two phases in formative evaluation: PREPRODUCTION RESEARCH and PRODUCTION TESTING. In **preproduction research,** the goal is to "gather information about audience characteristics, the behavior of interest, and/or the potential message channels that can be used" (Truong & Dang, 2016, p. 189). Qualitative methods can prove valuable during this phase. By conducting focus groups and interviews with members of the intended audience (and members of segmented audiences within) will yield insights that can be used to guide content creation. During **production testing,** also known as pretesting, messages are piloted with the intended audience for feedback before they are finalized (Atkin & Freimuth, 2001).

During the formative evaluation phase, feasibility is also determined (Centers for Disease Control and Prevention, n.d.). In developing a target accrual goal, researchers must make sure their goals are realistic and achievable within the proposed study timeframe. Any recruitment planning should start off with an internal focus—i.e. identifying the number of patients that already have an existing relationship with the sites, clinics or private practices and their associated physicians and staff. Next, traditional and digital methods should be identified if appropriate to the goals of the study. These can include printed materials like flyers, brochures and pamphlets, broadcast/radio, social media platforms, search engines, third-party trial promotion tools, and more. Additionally, free or low-cost options should be identified and explored. Examples of these resources include leveraging existing partnerships with community organizations or non-profits that work with or have access to the population you're interested in studying. The SC CTSI has a variety of tip sheets and toolkits on how to identify a community partner, advertising rates, promotional methods, and more.

Process evaluation allows the staff to assess how a program or planned intervention is working and course-correct when necessary. This is of particular importance in multisite studies, to ensure uniformity in how these interventions are being implemented across sites (Linnan & Steckler, 2002). As related to recruitment and retention, process evaluation helps researchers understand why certain interventions can fail, whether they are reaching their intended population, whether they are using the right theoretical framework, and more. When media or communications-related interventions or strategies fail, process evaluation can provide insight into why.

The final step, outcome evaluation, is used to evaluate the efficacy and impact of a designed intervention or campaign. According to Smith (2013), measuring **awareness, acceptance, and action** are essential for determining the efficacy of a campaign. This involves tracking inquiries to the study team from prospective participants and knowing where they received information about the study, which will help determine which channels had the most reach. When using social media, keeping track of these kinds of metrics is easier, as paid advertisements allow

"Evaluation research seeks to answer questions about target audiences for a program or campaign, encompassing the collection of background information about audience orientations before initiating a campaign and assessment of the implementation and effectiveness during and after a campaign."

(Atkin & Freimuth, 2001, p. 125).

study staff to see the number of unique impressions and visitors to the study's social media pages. Logging this data will help inform future recruitment efforts by identifying the most effective avenues for communication and reaching volunteers.

ETHICAL CONCERNS

All materials designed for recruitment must be evaluated and approved by the appropriate Institutional Review Board—and for social media, this includes all posts and advertisements. Furthermore, the content and associated visual images must be appropriate, not contain any coercive or exculpatory language, which is language that somehow waives legal rights of subjects or alleviates researcher of liability for negligence (Shahnazarian, Hagemann, Aburto, & Rose, 2013).

At USC, the HSC IRB requires a screen capture or link to the study's landing page and copies of any content that will be used to recruit volunteers, like tweets and posts that will appear on Facebook and Instagram, for example. In the recruitment materials, they recommend explicitly mentioning the time commitment needed to partake in the study. To avoid being coercive, they recommend mentioning that compensation is provided or available in lieu of listing a dollar amount or saying that something, such as a treatment or service, is "free."

If interested social media users send a Facebook message or tweet to the study team, these live interactions don't need to be IRB approved. At USC, the HSC IRB wants investigators to think of the face-to-face equivalent of social media communication. For example, if an interested volunteer called the study team to inquire about her eligibility for a study, the CRC could provide some general information about the eligibility criteria. If that interaction took place through a private message on Instagram, it would not need to be IRB approved. The SC CTSI has materials relating to subject compensation and recruitment guidelines released by USC OPRS, as well as a tipsheet containing template language and points to consider when writing the recruitment section of your IRB application.

Researchers must first comply with all rules and user guidelines set forth by the social media they are using for the study, and the privacy of participants must be protected. Researchers must carefully use social media for recruitment purposes by not targeting or singling out users—for example, when a researcher identifies a support group on Facebook for users living with a certain condition, they must not "spam" or individually target users to inquire if these users would be interested in enrolling in the study. In this case, it would be more appropriate to use "snowball" sampling methods whereby existing participants identify other prospective volunteers through their immediate personal network. After that, the researcher would obtain consent from that participant before reaching out to their personal network, or before the participant tells prospective volunteers to contact the study team if they are interested in enrolling. The researchers must also stay **transparent online,** not using deception or creating false accounts to gain access to a group within a social network or to post advertisements for the study in groups for people with a certain condition. As a general rule, Luke Gelinas, Ph.D., clinical research ethics fellow at the Petrie-Flom Center/Harvard Catalyst recommends not "lurking" or joining and monitoring online conversations in social media groups without users' knowledge and not posting content that singles out, embarrasses or stigmatizes any user.

Another challenge to be aware of when recruiting with social media is that by its very nature, social media encourages connectivity and may facilitate conversations between the participants and study team that could compromise the scientific integrity of the study. For example, unblinding may occur in Facebook discussions among participants. These issues can be avoided or mitigated by having a clear and detailed communications plan in place. It should contain a contingency plan—for example, if this type of situation arises, this is how the study team or researcher will handle it. Participants should be reminded regularly about how to protect their own privacy as well as preserve the privacy and integrity of the study, study team, fellow participants, university, institution and/or company sponsor, and/or investigational drug or device being tested, if appropriate.

Beyond the requisite ethical and regulatory concerns, social media can be a viable and cost-effective way to reach a large number of potential volunteers. Currently, the most popular social media platforms include Facebook, Twitter, Instagram, Pinterest, and Tumblr, which will be discussed at length later on in this guide. Some platforms are more niche, and therefore attract a certain demographic (i.e. Pinterest and Tumblr). In general, however, Facebook tends to be the most popular social media platform—and this popularity seems to transcend gender, age, political view, job status, and SES.

According to Pew Research Center, 72 percent of all online adults are on Facebook as of August 2015.

(Duggan, 2015).

Among all online adults 18 to 29 years old, 82 percent use Facebook, as well as 79 percent of 30 to 49 year olds, 64 percent of 50 to 64 year olds, and 48 percent of those users 65 years of age and older (Duggan, 2015). Though Facebook is the most popular in terms of overall usage, other social media platforms can prove to be useful resources when targeting specific populations or demographics. The remaining portion of this guide will detail social media platforms, digital tools, and other resources for recruitment and retention purposes.

USING DIGITAL PLATFORMS FOR **RECRUITMENT & RETENTION**

FACEBOOK

Facebook has been used as a recruitment tool in various types of studies, favored for its cost-effectiveness, larger active user base, and ability to target specific audiences based on advertising parameters such as gender, age, certain pages "Liked" on Facebook, and geographic location.

Most social media platforms allow advertisers to segment the larger population by gender, age, and geographic radius/zip code—but some also allow segmentation by interest, social media behavior such as pages the users follow or have "Liked," and more.

(Ollison, 2015).

A recent change in Facebook advertising is the ability for purchasers to buy "lookalike audiences," or audiences that are similar to existing followers. Advertisers can then run targeted ads to these custom and lookalike audiences, with the option to exclude certain audiences from seeing an ad (i.e. excluding the current audience from seeing a new ad meant to engage a new group of users). This type of targeted messaging should be based on insights gained from audience analysis and segmentation.

As a general rule, each study should have its own landing page, or website that provides information about the study, a brief inclusion/exclusion criterion, way to contact study staff, and compensation details. Advertisers can direct social media followers to a landing page, which serves as a central location for information about the study. The SC CTSI can create a free landing page with information taken from ClinicalTrials.Gov, and this landing page will also be listed for free in the USC Clinical Studies Directory, which will be discussed later in this guide.

TWITTER

An example of how researchers can use Twitter to identify prospective volunteers or individuals who are actively communicating about a topic or condition is by searching under a relevant hashtag, such as "#BreastCancerAwareness." Engaging in social media "listening," to observe and gather information about users communicating about a topic can provide insights for how to best go about advertising or reaching the intended population.

Twitter offers advertising for purchase in the form of promoted tweets. First, the advertiser chooses a target audience based on location, gender, device, interests, by identifying users similar to your existing followers, or by identifying keywords used in tweets (i.e. diabetes, Crohn's disease). In Twitter's model, advertisers have the option to set up a budget in which they only pay when a user follows the account, likes a tweet, retweets, or clicks on the promoted tweet. There is no minimum advertising spend and the campaign can be discontinued at any time. An issue to keep in mind with Twitter is that advertisers should keep a careful eye on measuring how much user interaction (i.e. liking a tweet, retweeting) leads to sign ups from Twitter. Depending on the target audience for some studies, Twitter may not be the most appropriate platform to use because about 23 percent of all online adults use Twitter, and users tends to skew primarily younger, college-educated, and urban dwelling (Duggan, 2015). In terms of gender, the breakdown for Twitter users is 25 percent male and 21 percent female (Pew Research Center, 2015a).

INSTAGRAM

Instagram is most effective for recruitment in studies that involve a younger, non-white population. It is popular among young adults and users 18 to 29 years old, as 55 percent of online adults in this age group use the app.

Three different types of ads can be purchased: traditional photo ads, video ads, and carousel ads (in which users can swipe to see more photos, and a call to action button leads them to an external site, like your study's landing page). Advertisers can target users near a certain zip code, get them to download a mobile app (useful if a study has an app component), or drive clicks to a website. These ads appear as "sponsored" content and are marked as such in the app for users to see. The appeal of Instagram is the ability for advertisers to engage potential participants visually and textually.

PINTEREST

Pinterest, mostly appealing to females in the 20 to 30-year-old age range, has also gained popularity among males (Pew Research Center, 2015b). It is split in a relatively even manner across ethnicities, and appeals to a college-educated user base. Overall, this platform is useful for targeting broader populations and would not be suitable for most condition-specific studies, as Pinterest doesn't allow for the textual interaction that platforms like Facebook groups can provide, in which users communicate with each other in communities that function like online support groups.

In terms of paid features, promoted pins can be purchased and advertisers can track how many users are being reached by the campaign. To purchase a promoted pin, a user creates a pin (including brief details of the study, a relevant image, and providing a link to the landing page). Then, the advertiser chooses what types of people should see the pin. Advertisers can segment based on users' location, gender, age, and more. Then, the advertiser can choose to pay for engagements, or visits to the site (in this case, it could be the landing page). For studies, it may be smarter to pay for visits to the site—by getting potential volunteers to the landing page, they are more likely to follow the steps associated with completing preliminary determinations of eligibility or contacting the study team to follow up about eligibility. After purchasing a promoted pin, advertisers can track different aspects of the campaign—which pin(s) are performing the best, number of total impressions, unique viewers, repins, clicks, and likes by date.

OTHER SOCIAL MEDIA PLATFORMS

Other social media platforms can be used for effective recruitment. Tumblr is free to use, and can be used in recruitment to target a younger, primarily female audience.

According to Pew Research Center, approximately 10 percent of total Internet users are on Tumblr, with an equal ratio of males to female users, with a sizable black and Hispanic demographic.

(Pew Research Center, 2015a).

Researchers can develop their own social media presence on Tumblr for free, but the site also offers paid advertising in which content appears on the main "dashboard" or as a sponsored post. These posts can be in the form of photos or videos and targeted by interest, location, and gender, and can appear in Yahoo! searches to increase reach.

A few studies have used the dating app Grindr, which is geared toward gay and bisexual men, to find participants to investigate issues relating to sexual health, sexually transmitted diseases, and disease prevention research. For example, one study (Burrell et al., 2012) used Grindr to find men who have sex with men (MSM) in the Los Angeles area by putting out an advertisement within an eight-mile radius of the West Hollywood area, and another within a 20-mile radius of downtown LA. The ad included a link to the study's landing page that included study email and phone number (Burrell et al., 2012). The researchers also used traditional recruitment methods like flyers and referrals, and online methods such as posts on Craigslist, but using Grindr was highly effective for this study as more than 32,000 users were targeted with their ads, and the app is specifically geared toward the individuals they wanted to target as part of the study (as

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opposed to targeting them more generally on other social media platforms).

Craigslist has also been used as a recruitment tool (mostly for low-risk socio-behavioral studies). To avoid being coercive, ads should only be posted in the "volunteer" section.

Another tool related to Craigslist is Reddit, an online message board and social news aggregation website. Reddit can be used to advertise about studies and trials, as users with specific health conditions may be part of online communities to discuss their condition. A downside with Reddit is that there is no way to ascertain where users live, so there may be quite a few volunteers who meet your study's criteria but do not live near the research site. Another idea is to use a "snowball" referral method and have satisfied volunteers post about their experiences on social media groups and sites in which members also share the same condition or health issue. Hearing someone else's positive testimonial can encourage other volunteers to take part as well.

Consider using apps that are actively used by members of your desired population, and niche online communities, such as condition-specific message boards and online support groups. Above all, remaining transparent about your intentions and about the study will ensure that members of the online communities are not misled, and that the study is IRB compliant.

SOCIAL MEDIA BUDGETING

Each of the aforementioned social media platforms allows advertisers to designate daily budgets and **lifetime budgets**. Daily budgets refer to the amount you are willing to spend in a given ad set per day. Advertisers define goals at the campaign level (i.e. What is your ultimate outcome? Driving more clicks to your landing page? Getting more "Likes"?), then at the ad set level, in which advertisers can target based on demographics, budget, and schedule. Advertisers can choose spaced out "pacing" of ads, in which the budget is spread evenly over the course of a campaign timeline to ensure their budget isn't depleted quickly. When strategizing and creating a social media budget, here are some key questions to consider:

1. Which social media platforms will ensure greatest reach to your target audience (based on formative research, audience analysis/segmentation?)
2. What is your desired paid ad to organic reach ratio? In other words, how much are you willing to spend on paid ads versus how much will you be relying on organic advertising (word of mouth recommendations, referrals, building the social media presence for the study by targeting specific groups, etc.?)
3. What does your recruitment timeline look like? If it is short, you'll want to focus on creating a presence quickly, which will cost more. If the timeline is longer, you can afford to spend more time (and less money) building organic advertising, or having a greater mix of paid to organic advertising.

SEARCH ENGINE ADVERTISING

Search engines such as Google, Bing, and Yahoo! can be used for recruitment purposes, though they can be pricey. When Internet users use Google to search for certain search terms or keywords, Google AdWords will show relevant ads to users based on the keywords. Advertisers can bid on relevant keywords. For example, an advertiser can bid on the term "skin cancer study LA" to capture potential volunteers with local interest in the study topic.

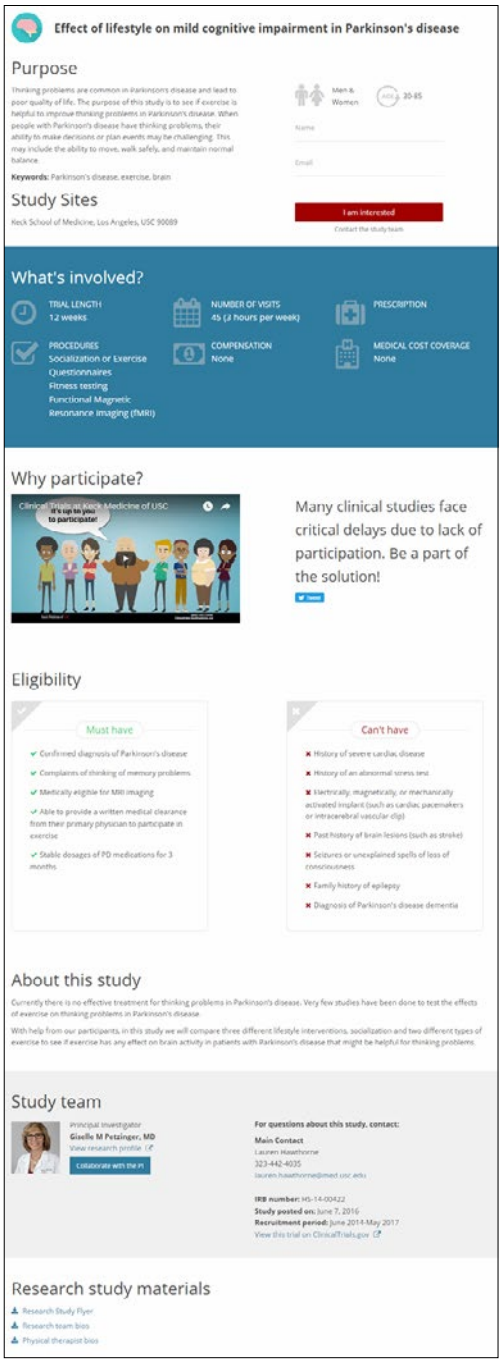
Google uses a **pay-per-click** model, so advertisers only pay when users are searching for relevant keywords and clicking through. AdWords budget depends on the advertiser's bidding strategy, and their website provides an overview of pricing options. Analytics and tracking is available so advertisers will know how well their ads are performing.

Bing and Yahoo! also offer paid advertising services. Bing allows advertisers to narrow their demographic with criteria such as geographic radius, and allows for streamlined integration with existing ads on Google AdWords. Bing also operates with a cost-per-click model.

There are a few data-driven trial promotion tools that have been developed to streamline the recruitment and management process, and to automate some aspects, such as sending appointment reminders. The main benefit of using such a tool is that the company takes care of creating the study landing page and custom advertising, as well as collecting data about user engagement, efficacy of ads, and more automate laborious aspects of recruitment and advertising using sophisticated algorithms. These services can be a worthwhile investment if the study has poor yield or cannot get recruitment efforts off the ground because of the narrowness of the inclusion criteria or because the target population is hard to reach.

RESEARCHMATCH

A related study promotion tool is ResearchMatch, an online service that matches interested volunteers with active studies. Created by Vanderbilt University, ResearchMatch is a free tool for both the researcher and the volunteer. Promoting ResearchMatch to cohorts of possible volunteers and to researchers who can encourage their existing volunteers to sign up if they are interested in partaking in other studies will be a key factor in increasing the number of volunteers in the database. To activate a study on ResearchMatch, the researcher must attach a copy of his or her IRB approval letter before a designated ResearchMatch liaison at USC can approval his or her account.



CLINICAL STUDIES DIRECTORY (CSD) AT USC

The **Clinical Studies Directory** is a public, patient-facing website for investigators to advertise their studies and for patients to find actively recruiting studies at USC. It allows users to search for studies based on physician name, disease, geographic location and drug name. Investigators can utilize this free tool, pictured on the left, to host their study online through this publicly visible landing page, to which they can refer interested volunteers. Research teams can also direct online ads to this landing page. This landing page can help with recruitment by providing a centralized hub of information about the study, including a simplified explanation of the study, brief inclusion/exclusion criterion, and way to contact the study team. The tool automatically creates pages for USC studies that are listed in ClinicalTrials.gov, but the recruitment specialist simplifies content so that it is simple, lay-friendly, and easy to understand for prospective volunteers. This content is then put on a website mockup by the SC CTSI digital team. Once the study team obtains IRB approval for the landing page, the page can be made live. Investigators can get additional studies listed in the CSD by contacting the recruitment specialist.

SOCIAL MEDIA RECRUITMENT: DEVOTING APPROPRIATE TIME & RESOURCES

Studies using social media for recruitment purposes need a devoted social media manager whose daily responsibilities involve checking each platform for new messages and engagements (i.e. Likes, reposts, etc.), answering and following up with volunteers and interested participants, posting content regularly, and checking metrics to make adjustments as needed. The clinical research coordinator can also serve as a social media manager for the study if they are devoting full effort to the study, but typically they will be too immersed in their own responsibilities that they will not have the time to devote to keeping up with requests and reposting content across platforms if they are only working part time on the study or splitting their effort across multiple studies. If the PI wants to designate the research coordinator as the social media manager, they will have to make this part of their assignment and work with them to create a social media strategic plan and posting calendar that addresses issues such as:

1. How often will we post?
2. What kind of content will we post (and has been IRB approved)?
3. When our content changes (i.e. wording for social media posts), who will ensure these are submitted as an amendment to the IRB for approval?
4. Will we budget enough time for these approvals?
5. What images represent our study well and can we include with our posts (ensuring the photos belong to the researcher or are stock photos that have been purchased by the researcher and have been IRB approved)?

Making sure content stays consistent in terms of tone and regularity of posting is also important, and when multiple people are managing the social media accounts, this can become an issue. Therefore, clearly defining expectations for social media management upfront is necessary.

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SOCIAL MEDIA MANAGEMENT TOOLS

Daily maintenance involves checking the accounts for new followers, following them back, identifying other related accounts to follow (and possibly asking them to promote the study), responding back to requests or communications from other users, and posting content as outlined in the social media posting calendar. Social media management tools such as Hootsuite, Buffer, and SocialFlow can help streamline this process by allowing you to schedule posts in advance across multiple platforms. Although the majority of the more sophisticated engagement tools are not free, researchers can do a great deal of social media management with the free tools. In addition to scheduling tools and analytics-driven engagement tools, another useful social media management tool is Bitly, which is a link shortener (shortens URLs so they take up less characters on Twitter and look "cleaner" on Facebook, and allows you to track how many times the link is clicked), and is free.

Most social media automation or promotion tools allow managers to **track metrics and engagements**. By frequently evaluating the metrics on the accounts, the team can gain insights about what is working and what needs to be improved or discontinued. After a couple of months of running a paid-for campaign on Instagram targeting 18 to 30-year-old e-cigarette users, for example, you may realize you are not meeting your target accrual goal using that platform. At that point, it is time to take a step back to reevaluate your messages (Are they appropriate? Culturally competent? Easy to understand?), but to also reevaluate where your target demographic is on social media. Being present and active on the platforms that are frequently used by target audience is the best way to ensure you are reaching them.

Stigmatization and privacy are other issues that can stall social media recruitment. Potential volunteers may not feel "safe" connecting with the study on social media, especially for studies involving sensitive health issues. For example, a researcher examining recovery in young women being treated for eating disorders may think it is a good idea to recruit participants using social media given the age and gender of the target population. Although this population is active on social media, they may not feel comfortable publicly following or interacting with groups or users that can draw more attention to their condition. They may be connected with friends, family, coaches, and teachers on social media who don't know of their condition. As a result, more traditional (and private) recruitment methods may be more appropriate for this type of study—i.e. referrals through counselors, nutritionists, or other healthcare professionals who regularly interact with the patient and have gained some level of trust and familiarity, posters or pamphlets in waiting rooms of psychiatry clinics, etc.

Finally, researchers and social media managers must know when to discontinue a social media campaign or refocus their efforts. Luckily, the use of analytics and data can make this process easier. As health researchers create best practice guidelines for social media recruitment and retention, taking a multi-pronged recruitment approach works best for most studies—a combination of carefully crafted, appropriately tailored messages and content using both traditional and digital methods.

TRADITIONAL

- Flyers/posters/pamphlets (make sure they have plenty of tear-offs with contact info). QR code may be appropriate with link to study landing page.
- Direct mailings (from clinic/hospital, insurance company, etc.)
- Physician referrals
- Advocacy/community/nonprofit group partnerships
- Hospital or insurance newsletters
- Health fairs/outreach events
- Newspapers/print
- Television
- Radio

DIGITAL

- Social media (Facebook, Twitter, Instagram, Pinterest, Tumblr, Internet message boards, other types of apps)
- Search engine keyword ad campaigns; Craigslist
- Posting on condition-specific message boards
- Third-party trial promoting tools (TrialSpark; Trial Promoter)
- Hospital or insurance email listservs/ digital newsletters
- EHR/EMR databases (i.e.i2b2, etc.)
- ResearchMatch
- Clinical Studies Directory at USC
- Video storytelling/Interactive patient care systems

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