

Tips and Tricks for Successful Research Recruitment

*A Toolkit for a
Community-Based
Approach*



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Contents

- Introduction4**
- Preparing for Success5**
 - Setting Goals5
 - Walking in Their Shoes5
 - Hearing from Your Participants7
 - Study Staff Selection and Training8
- The Role of Community Partners in Recruitment9**
- Compensation9**
 - Compensating the Individual9
 - Compensating Community Partners9
- Communicating about Your Study10**
 - Communicating to Potential Participants10
 - Communicating to a Potential Community Partner10
- Digital Platforms- Social Media and Mobile Technologies12**
- Large Clinical Trials14**
- Addressing Recruitment Challenges.....18**
 - Confusion About the Study18
 - Lack of Awareness18
 - Lack of Access.....18
 - Personal Objections, Fear, Distrust, or Suspensions.....19
 - Keys to Retention19
 - Maintain Communication20
 - Listen.....20
 - Be Convenient20
 - Maintain a Positive Attitude.....21
 - Know the Protocol.....21
- Appendix A: Recruitment Flyer Example 1.....22**
- Appendix B: Recruitment Flyer Example 223**
- Appendix C: Recruitment Flyer Example 324**
- Appendix D: Creative Brief25**
- Appendix E: Study Summary Example 126**
- Appendix F: Study Summary Example 227**
- Appendix G: Study Summary Example 328**
- Appendix H: Study Summary Example 4.....29**

Introduction

Despite the investment in eradicating racial and ethnic health care disparities, enormous inequalities still exist in the United States across multiple domains, including access to care and use of services, disease prevention, chronic diseases, health status and quality of care. Whites continue to represent a disproportionate amount of research participants, as compared to any other ethnicity.¹ A 2015 analysis of 2,579 clinical trials found that 19% of trials were either terminated for failed accrual or completed with less than 85% expected enrollment.² This has multiple implications: 1) researchers have difficulty answering questions in a meaningful way due to the loss of statistical power, 2) there are missed opportunities for individuals to benefit from new interventions and medications, and 3) time, funds and other resources are wasted.⁴

Whether you are conducting a traditional clinical trial or a trial in the community, there are common strategies you should consider when recruiting participants for research. This toolkit introduces ideas on how to prepare early in the research process in order to increase the probability of meeting your participant recruitment goals. Subsequently, it will provide specific recommendations for large clinical trials, and the use of social media as well and community based research. It will also address recruitment challenges and keys to high retention.

The recruitment toolkit highlights effective strategies for investigators and others to work in diverse populations. Developed by the Southern California Clinical and Translational Science Institute (SC CTSI), the Clinical and Translational Science Awards (CTSA) hub housed at the University of Southern California, and Children's Hospital Los Angeles, this toolkit aims to develop greater capacity and success in research participant recruitment, particularly in the recruitment of underrepresented populations such as ethnic minorities.

About the Clinical and Translational Science Awards

The CTSA were initiated in 2006 by the National Center for Advancing Translational Science (NCATS) branch of the National Institutes of Health. The more than 60 CTSA around the U.S. are charged with catalyzing academic health centers (AHC) to create a supportive and efficient infrastructure to accelerate the translation of promising clinical practices and innovations into community settings. An important part of this infrastructure is the integration of community organizations, clinics and others into the process in order to ensure that the research conducted at these AHCs is meaningful to the populations for whom they are intended. CTSA are required to have a structure, which can solicit and integrate community input into the research process. To do this successfully, research institutions must collaborate with community organizations to identify and understand public health needs.

Preparing for Success

Throughout the toolkit, we use the word ‘participant’ to refer to those who choose to partake in research. We believe that referring to research volunteers as participants instead of subjects is the first step for researchers and their team to approach the research recruitment process differently, using a more community friendly approach. Viewing individuals as active, willing volunteers and contributors to your research instead of passive subjects can help guide your recruitment and retention approach through the entire research.

Setting Goals

As you consider the feasibility of your study, the participant recruitment protocol should be forefront part of the planning from the start.

- Is your participant recruitment goal realistic for the population and the region in which you are conducting your study?
- Is your recruitment approach tailored to the interests and priorities of the target population?
- Is your study timeline realistic for the number of participants you plan to recruit?
- Are you allocating time and money towards better understanding and developing the necessary partnerships to gain the trust of that population before you begin recruitment? (If you do not already have experience with or access to the particular population you are trying to reach).
- Have you developed an alternative plan for recruitment in case your first plan does not succeed?

Walking in Their Shoes

There is nothing worse than assuming that you know everything about a certain population. Even if you have worked with that population in the past, you may find that over time, trends and values have changed. For example, we have colleagues who have worked with adolescent and young adult men who have sex with men (or gay/bisexual youth) for more than fifteen years. Although they have previously conducted longitudinal studies with this population, when they received a new grant to conduct a multi-year study, they conducted new formative research to identify changes in demographics (e.g., where young men of color hang out), identity (e.g., new terminology for sexual and gender terms such as genderqueer, cisgender), and barriers to care (e.g., stigma, transportation).

There are many factors about the study and your participant criteria that can affect:

- Where you recruit.
- How you communicate about your study.
- How you approach individuals.
- How you compensate your participants.
- The structure of your study team.

These factors will ultimately determine whether you will reach your recruitment goal. It is important to consider each and every one of these factors when planning your recruitment protocol and as you confront recruitment challenges in the midst of your study.

A variety of participant and study factors can alter your recruitment strategies, therefore these factors (see Table 1 and 2, next page) should be considered in the development of your recruitment protocol.

Table 1: Participant Characteristics to Consider for Developing Recruitment Protocol

Participant Factors	Description/Examples
Age	Communicating with an adolescent, an adult, or an older adult can be vastly different, and where you recruit these individuals varies based on age. For example, social media and other digital recruitment methods will likely be more effective with a younger population.
Language	Language might seem like an obvious factor when developing a recruitment plan but there is much more to this than simply translating from English into another language. Spanish for example, uses many different terms for the same thing depending on the country. Literacy level is another very important component to keep in mind when translating. Even when using English, care must be taken to carefully define medical terms that the general population might not be familiar with or understand.
Cultural Norms	Understanding the cultural norms of your participants is key in developing an effective recruitment strategy. For instance, within the population of interest, is the decision-making done as a family, a community or individually? In a study conducting phone surveys with adult Korean women we found they were most responsive when an adult Korean person called and less responsive when a young person called.
Geography	Certain cities and towns have their own culture, popular locations, safe and unsafe areas of town and common hangouts for people of certain ages. Whether the region is urban or rural can also affect your recruitment strategy. For instance, in a rural farming area, recruiting during harvest season might not be effective as farmers and their families are working longer days.
Gender/ Gender Identity	The ways in which you communicate effectively with women can be different from the ways you communicate with men. Remember, women are from Venus and men are from Mars. What motivates one to participate can be different from the other. Therefore, what you highlight about the study and the images you use can draw more men or more women to your study. In addition, society is now beginning to recognize that gender is not always a binary identity – there can be fluidity between the two primary genders. Similarly, transgender identities are also gaining greater visibility in society. New terms that are particularly popular with youth populations, such as genderqueer and intersex, are also becoming more common. Therefore, researchers working with these populations need to be careful not make assumptions about gender and the ways in which someone self-identifies.
Years Living in the U.S.	This factor is often overlooked. Designing a recruitment strategy for a foreign-born person who has been living in the U.S. for 20 years versus someone who just arrived 5 years ago can be completely different, even if they are originally from the same country. Their understanding of and comfort with participating in anything official like research can be different. Their understanding of the English language will likely also vary.
Socio Economic Status	Someone with a higher economic status most likely also has a higher level of formal education, which means they most likely already have an advantage to others in their understanding of research and access to research studies. It probably would not take as much effort to reach this population as it would to reach those of the working class and those in lower socio economic status. It is also probable that those of a lower socio economic status have less flexibility in their job for time off to participate in a research study, which means your study would have to be more accommodating if you want to have a diverse population (e.g., scheduling at nights or other non-traditional hours). Likewise transportation or the lack of it can also be an issue.
Legal Status in the U.S.	Those with no legal status in the U.S. are probably the most difficult group to reach. They do not want to be identified or stand out in any way for fear of being deported. The simple term, “research” gives the idea of being investigated which can be a very scary thought. Finding other terms to explain research and the research process can be helpful. Also reinforcing the concept of anonymity or confidentiality can make people more open to participating.

Table 2: Study Factors to Consider for Developing Recruitment Protocol

Study Factors	Description/Examples
Condition Being Studied	Are there any stigmas associated with the condition you are studying? For example, mental health and HIV issues can be stigmatized among family members and in the general community. Therefore, people with these conditions may not be as willing to participate for fear of others finding out.
Study Participation Requirements	The level of risk and type of involvement required to participate in a study is a big factor in the volunteer's decision of whether to participate. Participating in a 10-minute survey, an interview, or a focus group is viewed differently than more invasive procedures, such as a blood draw, taking medication, or having to see a doctor for other medical procedures. A onetime participation versus a study that requires multiple months or years of commitment is also very different. The latter would require more time and effort on your part to explain the study process and benefits before getting someone to agree to participate.
Study Budget	Allocating study funds from the start to provide extra incentives such as health services, health education, food/refreshments can provide a more pleasant experience for your participants, which can help with retention. Having the funds and flexibility to do community based recruitment and data collection can help you reach underrepresented communities that may have time and transportation constraints.

Hearing from Your Participants

You may not be able to “walk in their shoes” but there are other methods to hearing from your participants. You can do so in a variety of ways, depending on your timeline and budget.

- Convene at least one (or several) focus groups with individuals who meet your study criteria or with individuals who work closely with your potential study participants.
- Convene an advisory board that can help inform your recruitment approach and other areas of your study (see our *Resources for Integrating Community Voices into a Research Study: Community Advisory Board Toolkit* for more information), or;
- Partner with a community organization who works closely with the population you are trying to reach, as they can form part of your research team.

You can take one or several of these approaches to receive feedback during any stage of your study (pre-grant proposal submission [formative research], pre-recruitment and

during recruitment). Ideally, you are consulting and reevaluating your recruitment strategies during all phases of your study, but the pre-proposal phase is by far the most effective when trying to save time and money. Doing so will allow you to determine whether your study is feasible in terms of the timeline, budget and protocol proposed. For example, our friends working with young men who have sex with men (YMSM) populations had originally proposed to recruit a cohort of Filipino young men using the same recruitment techniques used for Latino and White young men. They found that these strategies were not effective and had to work with their funder to explain the challenges. Eventually, they received a separate grant designed to figure out the best approaches for recruiting Filipino and Asian young men into research studies.

This time and effort upfront will help you avoid situations where you are unable to complete the study due to insufficient participation or asking your funder if you can reduce your recruitment participant goal.

Study Staff Selection and Training

The recruitment and consenting team play a vital role in the recruitment and retention success of your study. You could have developed a great, community-friendly flyer, script and consent form but if it is not delivered in a thoughtful manner, then the message will be lost. What we mean by thoughtful is that careful thought and effort has been dedicated to selecting who will be doing recruitment, how (i.e., tone, language) and where recruitment takes place (phone, grocery store, schools, etc...), keeping in mind your study and participant factors.

Studies have shown that people will most likely respond favorably to someone similar to them, and this can be someone similar in age, ethnicity, gender, or life experiences.¹⁰ Therefore, having a study team that reflects your target population may increase your possibilities of having success in recruitment. In our experience, this is truer for some populations than others, and the only way to find out is by asking your target population early in your study. Many times, however, it has been our experience, that the interpersonal skills of the study staff can be a greater factor in recruitment success. Hiring individuals who can easily adapt to any situation, who are flexible, friendly, outgoing and professional is very important. It is not just about hiring someone of the same ethnicity as the population you are trying to reach, they must possess the interpersonal skills necessary for this type of work.

Providing formal training for your staff is very important and often overlooked. With all the pressures of getting your research underway as soon as possible, it is easy to simply have your staff complete the human subjects training online, review the protocol and learn all the recruitment materials on their own. However, in order to have the best results you want to make sure everyone in your team is on the same page about:

- The research study goals in general (not just their specific role and responsibilities).
- The protocol and why it is important to follow
- Any and all financial implications for the potential participant
- Who to turn to if they have questions.

The training topics for your research team, particularly those who will have direct contact with potential research participants, should include the following:

- **Humans subjects certification**
 - *Review and provide examples (using your study) for:*
 - Ethics in research
 - Voluntary nature of participation
 - Beneficence (do not harm, maximize possible benefits, minimize possible harms)
 - Privacy and confidentiality
- **Overview of the study goals and topic**
- **Recruitment, consent and data collection protocol**
 - *Include scenarios and practice for:*
 - How to approach a potential participant
 - How to address:
 - A hesitant participant
 - A “no” response
 - A willing participant
 - Questions asked by participants
 - How to use the study’s data collection tools
- **Cultural Competence (see our *Cultural Competence Toolkit* for more information)**

Include role-plays, modeling of successful and unsuccessful approaches and time to review and digest the material. Training for the research team should be ongoing and should include a review of the protocol and ways to address any challenges phased by the research team as they begin recruitment and data collection. In order to identify these challenges, it is important that you meet with your research team on a regular basis.

The Role of Community Partners in Recruitment

The obvious role of a community partner in research is identifying and recruiting potential research participants. Although they can certainly play a significant role in these tasks, there is more they can and should participate in. For instance, as mentioned earlier, asking a community partner to be a part of the formative work before your proposal is submitted can help you present a feasible study design and timeline. A community partner can:

- Form part of your advisory board.
- Form part of the research team.
- Be a consultant who provides feedback on:
 - *Your recruitment materials*
 - *Outreach strategies and study conduct*
 - *Participant number goal*
- Provide training to your research staff on cultural sensitivity and community outreach approaches.

Compensation

Compensating the Individual

Compensation should be monetary and it needs to be fair according to what is being asked of the participant; taking into account the time commitment and risk of the study.

There are other ways to thank your participants that may be of equal or more value to them. It is important to keep in mind the needs and conflicting priorities of your participants. Without being coercive (and in line with your IRB standards), ensure that the compensation is clearly communicated in recruitment materials and/or when potential participants are approached by the research team. Examples of appropriate compensation may include:

- Providing lunch or refreshments during a focus group can be another form of thanking your participants in addition to monetary compensation, which demonstrates value for a person's time and comfort.
- Providing a free medical examination or consultation can be of great value for someone who does not have medical insurance or simply does not visit their doctor on a regular basis.
- Providing health education about the condition being studied may be of great value to your participants.

- Communicating the lab results from a clinical trial procedure can also be useful to a participant. We have heard from the community that they would like to know the results from the medical procedures performed during a research study, even if it is simply the results of vitals, blood work or weight.

Including additional compensations such as these will allow for a more positive experience for the participant, which in the end will make individuals more likely to participate in future trials or influence others, such as friends or family to participate.

Compensating Community Partners

Collaborating in research with community-based organizations such as advocacy groups, clinics, associations, or other non-profit organizations is a great way to know get to know your target population better, receive feedback on your research protocol and tools, and it is an effective way to gain access to potential research participants. These organizations have already gained the trust of the community, and; building on that trust is invaluable. As a researcher, you should build a relationship with these types of organizations as early in your career as possible. Community

partnerships should be viewed as long term, ongoing relationships (not project based). One relationship can lead to another and as your research evolves so too will your community partnership and their role in your studies. See our ***Toolkit for Developing Community Partnerships*** for specific steps and tips on how to begin a community partnership.

As contributors to the success of your research, the community organization needs to be compensated, no matter how great or small their involvement. There are many

demands on clinics and other community-based organizations, and conducting research is usually not a top priority. Even the most minimal disruption in their workflow should be compensated such as asking front-desk clinic staff to distribute research fliers to patients. Clinic staff are already tasked with coordinating other paperwork and patient flow logistics, so adding another responsibility is not as simple as you may think. Not having these recruitment partners and plan in place pre-proposal can really alter your proposed study plan, IRB protocol and not to mention your study budget.

Communicating about Your Study

Communicating to Potential Participants

You get one opportunity to present your research to potential participants, therefore, the development of recruitment material and scripts should not be taken lightly. Before you develop the marketing materials for your study, it is helpful to complete a creative brief (see **Appendix D**) to help guide you through the important goals and considerations for an effective recruitment tool. It is not just putting information on a flyer or cutting and pasting from your proposal to inform your recruitment script. The participant and study factors mentioned earlier really come into play here. A single word can turn someone away. Certain colors and images (or lack thereof) can draw or discourage potential participants. For example, among the Latino community, using the term “investigation” for research can bring about suspicion or fear, as it sounds like an investigation of their residential status will be conducted. Using other terms like, “estudio” (study in English) can make a big difference. Who approaches the participant and where he/she is approached can also affect how your study information is received. There is no perfect template for this, given the variability among studies and the population. In **Appendices A-C**, however, you will find examples of successful recruitment flyers that can be adapted to help develop a first draft of your recruitment

material. The best way to develop recruitment tools is to work alongside your target population and/or with people that work day-to-day with that population. You can do so by conducting focus groups, convening an advisory board or partnering with a community organization that can provide feedback and give you suggestions.

Communicating to a Potential Community Partner

We encouraged you earlier to partner with a community organization in your study and in particular for your recruitment efforts. How you present your study to an organization is also important. It is not as simple as presenting your study in the same way that it is articulated in a research proposal, abstract or a PowerPoint developed for your colleagues. It is also important to note that engaging a community partner is a bit different from asking a fellow researcher to collaborate on a research proposal. This is particularly true when you are cold calling an organization. Before reaching out to a potential community partner, consider the following questions:

1. How and where do you begin to talk about your study?
2. How do you not overwhelm them with information?
3. How do you avoid confusing them so that they are not left wondering, what exactly would be my role here?

Table 3: Tips: Communicating to a Potential Community Partner

Begin with a brief introductory email	<ul style="list-style-type: none">• This is a simple email, that introduces who you are, your project health topic and overarching goal and asks for an opportunity to meet with him/her to learn more about their organization, the work that they do and explore the possibility of collaborating.• Include bullet points if appropriate to describe your study.
Develop a one-page study summary	<ul style="list-style-type: none">• Appendices E-H provide examples of a study summary. This tool provides an overview of your study using simple terms, bullet points, images and color.• When someone has had an opportunity to read your study summary, they are more informed and therefore better able to understand and engage you in a conversation about your study and their potential role. It gives them time to digest the information and formulate questions for you and possibly explore interest within the organization before even meeting with you, which will make for a more productive first meeting.
Use layman's terms to talk about your study	<ul style="list-style-type: none">• This is particularly important in these first outreach attempts.• We cannot stress this enough, no matter how common certain terms may be for you, step back and think, are there other ways to say or describe the same thing? For example, if your study is looking at health disparities, using the word disparities is not a good idea, say differences in how ethnic/racial groups are receiving services, getting diagnoses, or becoming ill, etc...
When and how you follow up is also important	<ul style="list-style-type: none">• At this point you might want to also give them the option of talking over the phone. It could be a better option for them if they are busy or they might just want to know more about your study before taking the time to meet with you in person.• Either way you want to eventually (sooner rather than later) meet with them in person. If email does not work, do not be afraid to use the old fashion telephone.
Remember that building relationships is a two way street	<ul style="list-style-type: none">• Once you have had the opportunity (over the phone or in person) to briefly introduce yourself and your study, the next step is asking the person to tell you about their organization, their focus area, target population, programs/ services, community needs and research experience.• It is your turn to listen and genuinely (regardless of the outcome) show interest in what they do and what they have to teach you about community needs. Recognize they are the experts in their field. Ask them to tell you about their work, it may become clearer at this point what could be their potential role in your study or you may realize that it is not a good match after all.
Communicating/ creating awareness about research in general	<ul style="list-style-type: none">• It is very likely that the participants you are trying to reach have no or very little knowledge about research, how it works and why it is important. In fact, you are very likely to encounter negative perceptions or misconceptions about research.• Be prepared to provide information or answer questions about the role of research in health and society. Once that is communicated then people may be more open and willing to hear about your particular study and collaborate.
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Digital Platforms- Social Media and Mobile Technologies

With the ever-growing popularity of digital technology and social media among populations of all ages and economic status, it is no surprise that digital technology is now also being used as a tool for research recruitment. There are countless digital tools and social media outlets (and many more being developed as we speak), regardless of which you use, there are overarching strategies to guide the use of these platforms for successful participant research recruitment.

It is important to note that although digital technology and social media have been around for many years, their effectiveness in research recruitment is in its infancy. As a result, we are still learning about the most effective ways to use these tools, which audiences respond to these tools, and the participant protections that need to be considered before utilizing them.

Here are some guidelines to consider, these were adapted from the white paper developed by inVentive Clinical Trial Recruitment Solutions, titled, *E-Recruitment: Using Digital Platforms, Social Medical, and Mobile Technologies to Improve Clinical Trial Enrollment*.³

- **Know your audience** – Similar to any other recruitment approach you should begin by understanding your target population. Using an online platform for recruitment is no different. It is recommended that you spend at least one month monitoring online platforms to know where your target population can be found and what they are talking about. As you monitor, look for what websites and social media platforms your target population are utilizing. This will indicate potential websites to advertise your study on or you may consider opening a study page on Facebook,

for example if you find that it is highly utilized by your target population. Be sure to identify how your audience members prefer to receive information on these platforms (i.e., photos versus videos). Also, be observant of the type of language they are using, as; this will be valuable information when you design your online ad or post. Finding the gate keepers or “opinion leaders” online is also another reason to monitor before designing your recruitment strategy. These individuals may be disease advocates, popular bloggers about the health topic you are researching or the gate keeper can simply be a popular website among the demographic population you are targeting. Partnering and/or consulting with these individuals can certainly be an option. Two free tools that allow users to learn more about what is being talked about on social media are *Social Mention* and *Symplur Signals*.

- **Meet participants where they are** – You cannot open a website or Facebook page for your study, and expect your target audience to find it and visit it just like that. You must be strategic about where you place ads, pop-ups or posts that can then link individuals to your study page. Your initial online monitoring really comes into play here. Using the information gathered from this monitoring, place relevant ads in popular websites, and maintain an active social media presence in those outlets that are popular among your target audience. Creating an online presence can take some time, so; consider partnering with an advocacy and community groups or organizations to build on their online network and established community trust. Posting your study ads on their website and social media outlets can reach many people quickly.

- **Diversify** – You must cast a wide net in order to reach your recruitment numbers. Not only do we suggest that you utilize different recruitment methods such as flyer distribution, clinician referrals and digital platforms, but we also suggest using multiple modes of communication within each of these methods. You want to be consistent and reinforce your message through different outlets. Recruiting on different online mediums can be less expensive than doing so with other recruitment methods given that social media tools are free of cost (unless you want to purchase an ad, of course).
- **Messaging** – The same rules about communication apply to digital platforms as they do to other recruitment methods. Knowing your audience is very important as you craft the key messages for your online ad, website or social media page. You will get a good idea about what language to use (and not use) and how to use it when you conduct online monitoring – what words are your target population using to describe the health condition you are researching? You want to avoid research and medical jargon. Also, be sure to include a call to action within your ad that prompts the reader to complete a simple action to become involved in the study. Also, highlight some benefits of participating in the study that would be attractive to the study population. The colors and images used in the advertisements are equally important. As was mentioned before, getting feedback on your outreach tools (including online messaging) from your target audience or those that work closely with them is invaluable. It is important to know that federal and state laws govern social media recruitment activity. In addition to Common Rule, FDA regulations, HIPPA and HITECH may apply.
- **Make it easy** – Digital platforms present many opportunities to facilitate and automate the recruitment process. For example, a simple click for example can take an interested participant to your study page where

they can learn more about your study, such as inclusion and exclusion criteria and connect them to the study team. It is not recommended to screen for eligibility criteria on social media due to privacy issues. However, if an online pre-screening is desired, it is important to use a secure tool where people can report private information.

- **Ensure compatibility** – Digital platforms are fantastic, when they work properly. If the material, video or other information you are displaying online doesn't display quickly and clearly you will most certainly lose an opportunity for recruitment. Before investing time and money on a mobile recruitment tool ensure that it will work on multiple digital devices in an efficient way. You want to be responsive to people's time and current use of technology.

If you find that you still need further support in this area you can request a consultation from the SC CTSI Digital Innovation and Communication core or the Clinical Research Support core by visiting, www.sc-ctsi.org. The SC CTSI can provide support in the utilization of digital approaches and online communications (digital, social, mobile) such as:

- Developing clinical study recruitment strategies (digital, social, mobile)
- Establishing a web presence to build your reputation, e.g., attract collaborators and study participants
- Using crowdfunding platforms to obtain seed funding
- Managing IRB approval
- Electronic consent
- Managing your online reputation (i.e., responding to negative feedback/reviews online)
- Using novel metrics and tools to measure Digital Scholarship activities, and including this type of data in academic performance reviews

Other tools that can also provide digital recruitment management services for clinical trials include Trial Spark and Trial Promoter.

- Trial Spark's services include: development of custom landing pages, recruitment management, patient registries, targeted advertising campaigns, electronic data capture and analytics, and data insight.
- Trial Promoter is a free, open-source tool developed by the SC CTSI. It automates the process of clinical trial promotion, via Twitter and Facebook by providing support with:
 1. Importing clinical trial data and message templates to generate customized social messages.

2. Scheduling social media messages and automatically publishing them on Twitter and Facebook.
3. Monitoring engagement measures for each social media message.
4. Providing a REST API that allows clinical trial data to sync with an institutional clinical studies directory or other database.

To learn more about Trial Promoter, visit trialpromoter.org. For more information on Trial Spark and other social medial platforms refer to the SC CTSI guide, *Maximizing Impact: Leveraging Digital & Traditional Tools for Recruitment and Retention Success*.

Large Clinical Trials

It is particularly important that early planning for a recruitment strategy occur for large clinical trials given the cost associated with such trials and the high participant enrollment that is expected. In this section, we will discuss tips and approaches for recruiting **for rare disease studies, engaging physicians for referrals, accessing medical records and research registries, and research recruitment campaigns and media options**.

Conducting feasibility study to determine if your study is even possible given your recruitment resources is imperative. There are tools and support services available at the SC CTSI that can help you in this process.

- The **Clinical Trials Units (CTU)** at USC and CHLA are a single point of access to advice and assistance for developing, activating, conducting and reporting clinical research studies and clinical trials. You can request a consultation online at, www.sc-ctsi.org.
- You can also access a free clinical study planning tool called **i2b2**. It is a self-service cohort study tool that allows you to quickly

find out how many patients in the Keck and/or CHLA electronic health record(s) meet your study criteria. Upon IRB approval, you can request contact information for the potential participants of your i2b2 query. It is important to note, however, that no protected health information is provided by i2b2, but it can help you identify where and how many patients fit your criteria to better inform your recruitment goals. For more information and to access i2b2 visit the SC CTSI website at www.sc-ctsi.org.

- Another tool available to researchers is the **Los Angeles Data Resource (LADR)**. LADR is a joint project of major Los Angeles health care provider organizations. This project aims to enable clinical investigators to explore the size of potential research study cohorts across each participating institution. By integrating medical records and clinical research data, investigators in the greater Los Angeles area are able to find sets of aggregated patient information through a web-based application. For more information and to access LADR, you can visit the SC CTSI website or www.ladr.org.

Recruiting for Rare Disease

Recruiting participants for a **rare disease** study can be difficult. A feasibility study and the use of the tools above (i2b2 and LADR) to identify where and if sufficient patients are available in your region is important.

Besides using medical records you may also want to consider partnering with an organization that focuses on a specific disease or patient population such as the Multiple Sclerosis Foundation, March of Dimes or the Sickle Cell Disease Foundation to name a few. Follow the communication approaches mentioned above when contacting these organizations. Their established networks coupled with their community and social media presence can help you reach your study population in a much more targeted and efficient way. You will always find more success in getting organizations to disseminate information about your study to their network, than getting individuals' contact information.

It is also possible that individuals are actively seeking open clinical trials for themselves or for a loved one. This is particularly true for rare diseases. Therefore, make sure that **your institution's website** has updated information about your study and that it is being displayed in a clear, community friendly way and in a prominent or easy to navigate location. Although you may have your study registered on the clinicaltrials.gov website, keep in mind that most people are more likely to search through Google or an individual research institution's website. Making your study easy to find online is key. If you are building a separate study website, it is important to consider search engine optimization (SEO). SEO is a strategy that improves the likelihood of your website showing up in an internet search list based on the common keywords used on the site.

Engaging Physicians for Patient Referrals

Getting access to a patient population beyond your own patients is not always easy. Physicians are protective of their patients, as they rightfully should be. If you are interested in engaging a physician, there are three common options: 1) collaborating with a physician at another site or department as a co-PI in order for him/her to access his/her patient population, 2) asking physicians to refer their patients, or 3) engaging a physician for permission to recruit at their clinic site.

The SC CTSI **Clinical Research Support** and the **Community Engagement** cores can help you identify and connect with physicians. You can visit the SC CTSI website to request a consultation, www.sc-ctsi.org. By far however, the most effective method is communication between a physician/researcher to physician/researcher, and direct communication can often be the simplest and most successful engagement strategy.

If you want to reach several physicians at one time, you may consider contacting a **physician group** to ask if you can be added to their meeting agenda to present your study. As you prepare to contact a physician, keep in mind the tips discussed above in the *Communicating to a Potential Community Partner* section. You should have a one-page summary of your study and the study flyers available for their review.

Recruiting from Medical Records

Medical records are never made available to others, other than the patients' medical provider or authorized medical or research staff. Therefore, you would need to engage a physician as a Co-PI in your study in order for him/her to access his/her patient population.

However, using the i2b2 or LADR tools, will allow you to query medical records to help you find the number of patients at CHLA, Keck and/ or other collaborating institutions that meet your study inclusion and exclusion criteria. You can also extract identifiable patient information for screening or recruitment purposes if you have IRB approval to do so.

Recruiting from Registries

Most researchers opt for creating their own homegrown investigator initiated registries because accessing existing registries can be difficult. However, creating, populating and maintaining a registry can also be a huge undertaking. You may want to begin by contacting existing registries to ask if they can disseminate information about your study to the people in their registry. As mentioned earlier you will always find more success in getting organizations to disseminate information about your study to their network, rather than getting individuals' contact information. A list of national registries can be found at <https://www.nih.gov/health-information/nih-clinical-research-trials-you/list-registries>.

Patient Recruitment Campaigns and Media Options

Investigator initiated research studies normally do not have the budget for recruiting via media campaigns on television, radio or large newspapers or magazines. These types of recruitment tools are often used in industry studies where the sponsor initiates the advertising. Although recruitment campaigns

like these can reach a large audience, it is a passive approach to recruitment, often ineffective for finding participants with specific criteria.

Other effective and less costly options include advertising in clinic waiting rooms, hospital hallways, and bulletin boards. Paying for ads in community magazines that are often found in doctor's offices is also less costly and can get you the participants you need.

Social media such as Facebook, Twitter or Instagram can be one of the most inexpensive ways to advertise your study if you know how to use it correctly. Facebook can be effective if you connect with existing and popular disease specific pages or pages that are popular among your target population. Having people forward or re-post about your study can be a good way to recruit. Those affected by a common illness, in particular those affected by rare diseases often form very strong and close knit communities. A re-posting by one person can result in many research participants. To enhance the reach of your ads/posts on Twitter or Instagram, using appropriate or popular hashtags can help raise awareness about your study (i.e., #icebucketchallenge, #cancerawareness, #pinkarmy)

Table 4 developed by Forte Research Systems, Inc. that presents the strengths and weaknesses of the different advertising research recruitment options.⁶

Table 4: Advertising Research Recruitment Options: Strengths and Weakness

Advertising Medium	Strengths	Weaknesses
Digital	<ul style="list-style-type: none">• Lower cost• Trackable• Numerous advanced targeting options• Frequency in exposure to study	<ul style="list-style-type: none">• Slow buildup of reach• Some users “tune out” online ads• A lot of competition for the audience’s attention
Magazines	<ul style="list-style-type: none">• Audience selectivity• Relative efficiency• Allows for complex messaging• Potential for re-exposure through pass-along and shelf life	<ul style="list-style-type: none">• Long lead times for space and material• Slow accumulation of audience and reach• Circulation patterns may vary by market
Newspapers	<ul style="list-style-type: none">• Builds audience quickly• News environment• Short lead times for space and material	<ul style="list-style-type: none">• High out-of-pocket cost• Relatively inefficient• Cluttered environment• Circulations are in serious decline• Short shelf life
Network/Broadcast TV	<ul style="list-style-type: none">• Sight, sound, and motion• Highest reach potential of all media types• Immediate reach• Audience selectivity in certain programs	<ul style="list-style-type: none">• Highest out-of-pocket costs• Highest production costs• A lot of competition for the audience’s attention
Cable TV	<ul style="list-style-type: none">• Sight, sound, and motion• Audience selectivity by network• Lower cost than Broadcast TV	<ul style="list-style-type: none">• Lower ratings on a per network basis• More cluttered than broadcast TV• Extremely low local reach
Radio	<ul style="list-style-type: none">• Efficiency• More segmented audiences - easier targeting• Lower out-of-pocket expenses• Low production costs	<ul style="list-style-type: none">• Non-intrusive/background medium• A lot of competition for the audience’s attention• Not suited for getting an immediate response• More limited reach versus TV

Addressing Recruitment Challenges

Confusion About the Study

Regardless of your recruitment strategy (phone calls, TV ads, flyers etc...), if you do not communicate clearly about your study and the individual's potential role within the first few seconds, then you have missed an opportunity for recruitment. As we have mentioned before, there is a general lack of awareness about research and many misconceptions exist among community members.⁹ Therefore, your challenge is to evoke interest and curiosity from an individual who may have fear about clinical trials. As we have said before, the best way to tailor communication for your target audience is to hear from them. Taking your recruitment tools to a community group for feedback will provide you with a unique perspective and ideas you and your team may have not considered otherwise.

Lack of Awareness

Similar to confusion about the study, lack of awareness about the condition or topic you are studying can become a barrier in reaching your recruitment goals. There may be a need to use simpler or more commonly used terms to describe your study topic, or you may need to include a brief introduction about the condition you are studying, what it is, its symptoms and why it is important, and you may even need to include visuals of what this condition looks like. For example, in a study recruiting patients with eczema, it may not be enough to say, "Do you have Eczema? ...". You may need to include photographs of what eczema looks like in White, African American, Asian and Latino patients (if your criteria include these racial/ethnic groups).

As was already mentioned, there is also a lack of awareness about research and clinical trials in general that can become a challenge in your recruitment. Depending on your timeline, you'll want to consider investing time

to provide education to the general public, your target population and/or your community partners about the research process and the benefits of research. Doing so could not only benefit your current study but will benefit your future research recruitment efforts, as well as the recruitment efforts of your colleagues. Creating awareness about research in general can be as simple as including a sentence or two about what research is in your recruitment tools, using it as an opening question to engage a potential participant or training your research staff on how to talk about research when they receive a question or confront hesitation from a participant. On the other hand, you may want to take a more proactive approach, which could entail providing a brief research 101 workshop, developing a research awareness campaign for your target population, engaging your academic/research/medical institution to include research information on their website and in clinic waiting areas are just some ideas.

Lack of Access

The literature suggest that minority groups are not less likely to participate in medical research as is often assumed, but rather they are less likely to be asked by researchers to participate.⁸ Perhaps, physicians or research staff do not approach certain populations due to language barriers, assumptions about their willingness to participate or the idea that they may need to spend more time to explain the process or the study topic. You need to think about what you may need to do differently to bring the information to the population you are trying to reach. These questions will help you start you off: Where do they congregate, who or what do they trust, and what is the best way to present the research opportunity so that everyone who meets your research study criteria has equal access to your study information. How do you make sure you are reaching certain populations? You got it! Ask them!

Personal Objections, Fear, Distrust, or Suspicions

Distrust in research is a real challenge. Begin by recognizing that the fear and distrust that exists is valid. There are several examples in the history of research (i.e., Nazi experiments, Tuskegee Syphilis study) and others more recent (Guatemala Syphilis experiment, HIV in pregnant woman study in India) that have given research a bad name. It really does only take a story in the news or one bad experience to make someone or an entire community turn away from any future participation.

There are also researchers who have engaged the community in research but never return with the research results (helicopter research). These instances make fear and distrust even greater barriers to conducting research. How do you address this challenge? Be prepared to answer questions like:

- Will I just be a guinea pig?
- Will they sell my blood?
- Why are you just focusing on my ethnic group?

Be willing to ask a hesitant participant about the source of their hesitancy, and; several questions can help clarify this issue: What is their understanding of research, what is their hesitation due to, have they experienced or heard of anything negative in research? It is also possible to address certain fears held by the particular population you are trying to reach in your recruitment materials, if clear and appropriate messages used. How do you identify those fears and how do you address them in your recruitment tools? You guessed it again! Ask them.

Dealing with personal objections can be difficult to overcome because of the influence of factors outside your control. "For some, the cost associated with participation and the time away from work are too great. Other times, it may be a deeply rooted personal belief that standard care is better. And yet, in other situations, language of communication barriers

exist."⁶ Fear, distrust, suspicions or myths about research can also become so ingrained in a person that it becomes a personal objection. Research is voluntary and therefore there is not much one can do to recruit individuals with personal objections to research. However, there is a possibility that by engaging individuals in conversation and clarifying any misunderstandings you can get them to change their mind or simply be more open to research in the future. Training the research team about how to respond to these objections is very important. Learning and practicing the proper response and approach is important to creating a positive research culture in the community. It is a fine line that one must keep in mind in these situation to ensure you are not being coercive or tempted to embellish the research benefit of your project.

Keys to Retention

Participant drop out is unavoidable. Participants may drop out for a number of reasons such as:

- Lack of motivation
- Difficulty complying with research protocols such as clinic visits and other study procedures
- Health complications
- Work or family life changes, loss of insurance
- A bad experience including a negative interaction with a research staff
- Adverse effects
- No positive effects of the study intervention

Participants may drop out by notifying the research team that he or she wishes to drop out or they may simply not show up to research activities or not respond to any outreach efforts. There is not much one can do about the latter. However, if given the opportunity to speak to the participants, you can identify their reason for dropping out which can inform your current and future retention efforts. You may even be able to clarify any misunderstandings and keep the participant in the study. Below are some tips on how to increase your retention rates.

Maintain Communication

We discussed the importance of communication in recruitment, but communication is important throughout the duration of your study. The research team plays a very important role in maintaining communication. If possible, the same person who recruited the individual should also be the person who maintains communication throughout the study, as it allows for the building of trust and rapport. At the very least, it should be the same person who communicates updates or reminders for consistency reasons. Developing a study newsletter (online and/or print) to keep your study participants informed about news and literature regarding your research topic and study updates can be a great way to maintain communication.

It is also important to provide participants with adequate reminders about clinic visits, interviews or any other study protocol activities. Remember your study is not a priority for these individuals. Therefore, they may need 3-4 reminders about their appointment, including one the day before to ensure compliance. With that said, it is also important to find a balance between maintaining communication and not overwhelming your participants with emails or phone calls to the point where they are no longer being responsive.

You may consider asking each participant as they join your study their preferred method of communication (email, text, phone call). Be mindful that asking if they have an email address or a cell phone is not enough. You want to also ask how frequently they check their email, or if they know how to text, or if they share their cell phone with another family member. Knowing this information will allow you to tailor your communication and will allow your communication efforts to be more effective. In a longitudinal study, it is also a nice gesture to send birthday cards and/or holiday cards to your participants to build rapport and stay in contact. Developing a plan for regular check-ins, for example, on monthly basis, is important to not only build rapport but also to ensure you have the most recent contact information as some families tend to be very mobile.

Listen

Having the same research staff maintaining communication with participants can help in being a better listener. Listening to your research participants includes but is not exclusive to taking the time to hear their concerns, and being sympathetic and responsive to their comments. It also means being intuitive to their needs even when the participant has not brought it to your attention. By the time a concern is communicated, it has probably been a problem for him/her for some time. For example, the participant may have problems with lack of transportation, bad or no housing, lack of childcare or he/she may be needing health services for themselves or a family member.

These issues, although not directly related to your study, can impact your participant's retention and their ability to comply with study procedures. Having a study team that knows where to refer individuals for these and other services is very valuable. Also, simply having staff that are caring, sympathetic and willing to help can make a big difference. Communicating a genuine concern for the participants' wellbeing is important, asking how he or she is doing and taking the time to listen to their response helps you identify any possible problems and to address them in a timely manner. Having a comment box or some other anonymous way for feedback can also be a good way to identify problems and figure out the best approach to resolve them.

Be Convenient

Being convenient means being accommodating and flexible. Remember, these are volunteers and like we mentioned before, your research study (regardless of how important and innovative it is to you) is not their priority. Each participant has his or her own set of responsibilities and challenges. Being convenient also entails being mindful of where the data collection takes place. Is it possible to collect the data out in the community or at other locations convenient to them? Having different

options for when data collection can take place; mornings, evenings and weekends should be considered for this aspect of the study. Provide free parking or public transportation vouchers if possible. Do not make people wait, stick to their appointment time and do not go over time in an interview or focus group, plan accordingly. Provide food or snacks, especially if you are scheduling around common eating times (8 a.m., 12 p.m. or 6 p.m.). Make sure your participants know how they can reach the research staff; be available on that medium and reply in a timely manner.



Maintain a Positive Attitude

“In order for your participants to have a positive attitude about the trial, staff need to have a positive attitude. Sometimes when a trial first begins, there can be a lot of excitement built up about it. But, as the trial wears on – especially long-term ones – that excitement can diminish.” Recruitment and retention challenges can bring down team morale. “This can cause everyone to lose interest – including your participants. Make sure that you keep enthusiasm up and reward success when it is achieved. A happy site can make for happy participants! Providing positive feedback and encouragement to the participants can also go a long way.”⁶

Know the Protocol

“Take the time to ensure that you and your staff are well educated about the protocol. Are there any additional procedures that require further training? If there is additional training that needs to be done, work with your staff to complete it before the study gets underway.” Beyond knowing the steps to follow in a study protocol ensure that your team feel confident about their ability to explain the process to others and are prepared to answer questions. “Having everyone on the same page and working towards the same goal will create unity within the site, and will show in the way patients view the site and the study.”⁶

Appendix A: Recruitment Flyer Example 1



We believe our bodies and our voices matter.
We believe better health for all young men is possible.

We are Healthy Young Men.

Join Us
#WEAREHYM

Healthy Young Men's Study

What?

HYM stands for Healthy Young Men and is a five-year research project.

Why?

The focus is to improve the health and well-being of young men of color by exploring what we think about health and how we connect to health care.

Who?

HYM is for: Black, Latino or mixed race young men ages 16-24 who are gay, bisexual or same gender loving and live in the greater Los Angeles area.

Get \$55-\$100 per study visit.


Participation in this research is VOLUNTARY.

Interested?

Call us at
323-336-1168 or
email us at
HYM@chla.usc.edu

Principal Investigator
Michele D. Kipke, PhD

HYM is funded by
the National Institutes
of Health

Children's Hospital
LOS ANGELES 

Appendix B: Recruitment Flyer Example 2

Looking for Parents...

Autism Disparities Research Study



What are we doing?

We want to learn how families receive a diagnosis of autism for their child. We are also interested in learning about the types of services families receive and need.

Why are we doing this?

We want to learn why some people experience more difficulty in receiving treatment for their child. We hope that in the future we can develop interventions and programs that can help families get ALL of the services they need.

Who are we looking for?

1. Hispanic/Latino or African American parents
2. English or Spanish speaking
3. Has a child diagnosed with an autism spectrum disorder

What do I have to do?

1. Participate in a focus group to share about your experience in obtaining a diagnosis for your child and the services you are receiving
2. Complete a short survey at the end of the focus group.

Your identity will remain confidential. Your participation is voluntary.

Will I receive compensation?

You will receive \$35 for your time.

*This research is being conducted by Dr. Michele Kipke (Principal Investigator) of Children's Hospital Los Angeles. Please contact **Mayra Rubio** by calling 323-442-1157 or emailing her at mayrarub@usc.edu to learn more.*

Does your child suffer from asthma?

Please join us for a short meeting to learn more about a community-based asthma research project. A free dinner will be provided and a gift card will be raffled at the meeting!

Asthma is a chronic, inflammatory disease of the lungs in which the airways narrow, often in response to a trigger such as exposure to an allergen, irritant, exercise, or emotional stress.

Asthma symptoms can include:
coughing, wheezing (a whistling sound made during breathing), chest tightness, and shortness of breath.

There is no cure for asthma, but its symptoms can be controlled. Come learn about participating in a project which aims to help manage childhood asthma.



If you know or you think that your child has asthma, we invite you and your child to attend this meeting to learn about participating in an asthma research project which will help us understand how to best manage childhood asthma. If you or your child are eligible to participate, you and your child will be compensated for your time.

When: Date 2011
Time

Where: Location MAP
Address
Address

RSVP: Phone

This Community-Based Research on Asthma Prevention and Management is a collaborative project between Children's Hospital Los Angeles, Southern California Clinical and Translational Science Institute at USC, BREATHE California of Los Angeles County and Camino de Salud from COPE Health Solutions.

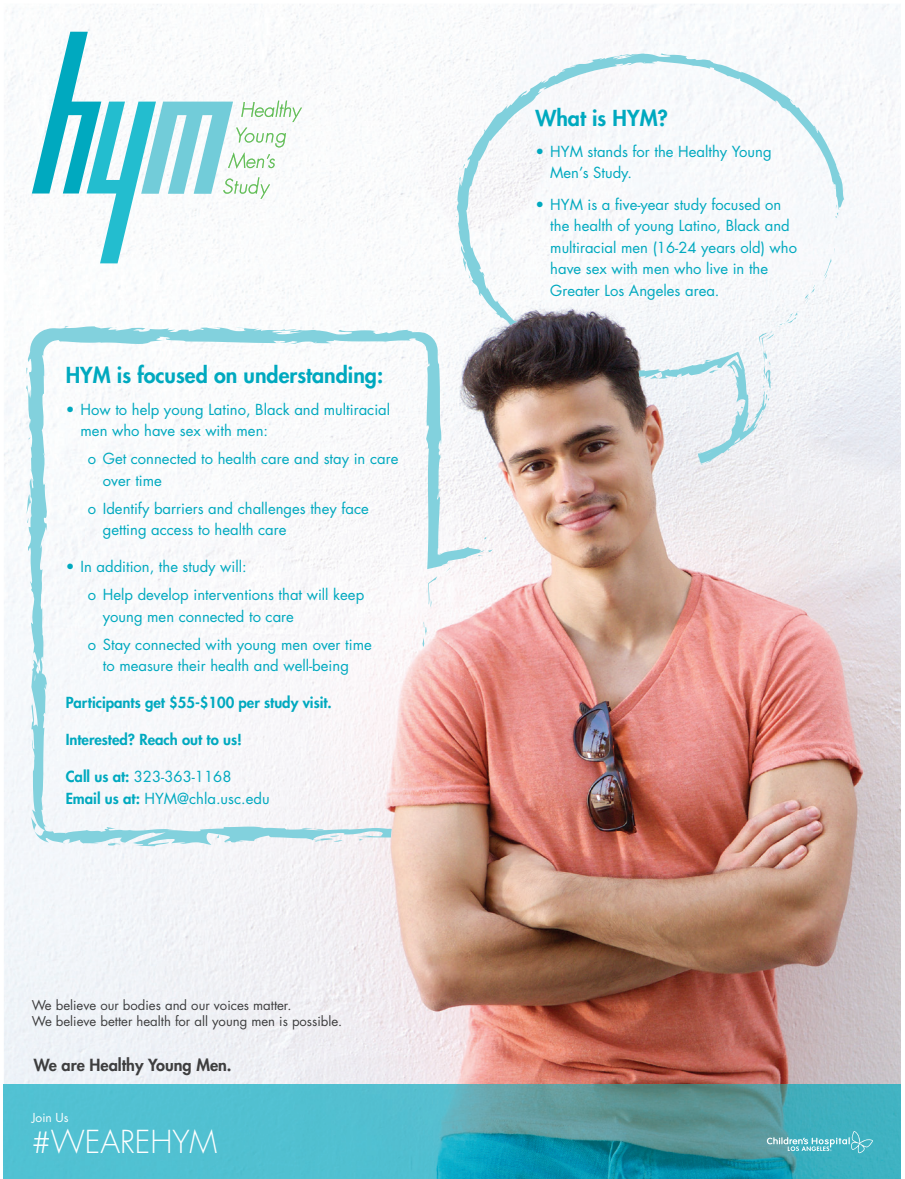
Principal Investigator: Katrina Kubicek, 323-442-1245, kkubicek@chla.usc.edu
Study Contact: Marisela Robles 323-442-2105, mariselr@usc.edu
Children's Hospital Los Angeles, Human Subjects Protection Program office. (323) 361-2265



Appendix D: Creative Brief

CREATIVE BRIEF	PROJECT:	DATE:
1. Target Audience(s) <i>Describe the person that you want to reach with your communication. What do they value? How do they see themselves? What are their aspirations? Include a primary & secondary (influencer) audience if appropriate. Include any relevant audience research.</i>		
2. Objective(s) <i>What do you want your target audiences to think, feel, or do after experiencing the communication?</i>		
3. Obstacles <i>What beliefs, cultural practices, pressure, misinformation, etc. stand between your audience and the desired behavior?</i>		
4. Key Promise <i>Select one single benefit that will outweigh the obstacles in the mind of your target audience. Suggested format: If I (<u>desired behavior</u>), then (<u>immediate benefit</u>).</i>		
5. Support Statements <i>This is the substantiation for the key promise; i.e.; the reasons why the promise is true. Oftentimes, this will begin with a 'because'.</i>		
6. Tone <i>What <u>feeling</u> should your communication have? Should it be authoritative, humorous, emotional, etc...?</i>		
7. Communication Channels <i>What channel(s) will you employ for the communication? TV spots? Radio Spots? Print Ads? Point-of-purchase (service) materials? Promotional giveaways? Earned Media (PR)? Interpersonal? Interactive Theatre? Community Mobilization Meetings? Broadcast Drama? All of the above?</i>		
8. Openings <i>What opportunities (times and places) exist for reaching your audience? When is your audience most open to getting your message? Examples: World AIDS Day, Mother's Day, etc...</i>		
9. Creative Considerations <i>Any other critical information for the writers & designers? Will the communication be in more than one language or dialect? Should it be tailored to a low-literate audience? Are there any political considerations? Any red flags/words or visuals to stay away from? Should there be space or time available to include local contact information?</i>		
NOTE: All creative briefs must be accompanied by a page summarizing the background & program.		

Appendix E: Study Summary Example 1



hym *Healthy
Young
Men's
Study*

What is HYM?

- HYM stands for the Healthy Young Men's Study.
- HYM is a five-year study focused on the health of young Latino, Black and multiracial men (16-24 years old) who have sex with men who live in the Greater Los Angeles area.

HYM is focused on understanding:

- How to help young Latino, Black and multiracial men who have sex with men:
 - Get connected to health care and stay in care over time
 - Identify barriers and challenges they face getting access to health care
- In addition, the study will:
 - Help develop interventions that will keep young men connected to care
 - Stay connected with young men over time to measure their health and well-being

Participants get \$55-\$100 per study visit.

Interested? Reach out to us!

Call us at: 323-363-1168
Email us at: HYM@chla.usc.edu

We believe our bodies and our voices matter.
We believe better health for all young men is possible.

We are Healthy Young Men.

Join Us
#WEAREHYM

Children's Hospital
LOS ANGELES

Appendix F: Study Summary Example 2



What is HYM?

HYM stands for Healthy Young Men's Study. HYM is a project of Children's Hospital Los Angeles. CHLA received funding from the National Institutes of Health to conduct a study with Black, Latino, and multiracial young men who have sex with men (YMSM), ages 16 to 24 years.

Why does this matter to you?

We would like to screen eligible participants outside of your venue.
Our screening takes two minutes and involves a quick survey done on an IPAD.
All we ask is to be able to be outside of your venue, at times that are approved by us both.

What is the purpose of HYM?

- Improve the health and wellness of young men of color in Los Angeles.
- Develop new tools and interventions that may prevent new HIV infections and improve health outcomes.
- Identify & better understand barriers that keep young men of color out of care, and also understand what factors keep young men of color in care.
- Develop best practices for engaging young gay men of color.
- Study over time young gay men of color's: substance use; use and access to HIV testing and treatment services; insurance status; retention in HIV/AIDS care and adherence to ART; and use of biomedical interventions, such as PrEP and PEP.

Who are we Recruiting for HYM?

Young men are eligible to participate in the study if they:

- Are a male, 16 to 24 years of age.
- Self-identify as gay, bisexual or are uncertain about their sexual orientation, and have had sex with a man in the previous 12 months.
- Self-identify as Black/African American, Latino/Hispanic, or multiracial.
- Consent to an HIV rapid test (if recruited from a community site).
- Live in Los Angeles

What do young men get for participating?

HYM members receive incentives, as well as make a great contribution to improving health care for other young men of color.

If you have any questions, contact:

Field Manager: Wendy Hawkins: (323) 336 1168

Project Manager: Yolo Akili Robinson: (323) 397 9298

Principal Investigator: Michele Kipke: (323) 361 8487



Appendix G: Study Summary Example 3

Autism Disparities Research Study



The cost for autism intervention can be a burden on a family resulting in limited access to care. Autism Treatment Networks (ATN) were designed to provide a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions Children's Hospital Los Angeles (CHLA) ATN site in California. Given the diversity in the CHLA patient population, compared to other ATN sites, we have a great opportunity to better understand the disparities related to diagnosis and care that exist in children with autism.

There is increasing evidence that children of color (e.g., Latino, Black/African American) are diagnosed several years later with an Autism Spectrum Disorder (ASD) compared to their White/Caucasian counterparts. The delay in receiving a diagnosis and treatment for ASD may be because there is a lack of knowledge from the primary providers and parents. These disparities in diagnosis may also contribute to differences in outcomes due to delay in treatment and care.

In order to better understand this problem and develop appropriate interventions and programs for parents and providers, we will conduct up to 6 focus groups with parents of children with ASD. At least two focus groups each with: 1) monolingual Spanish speakers; 2) bilingual and English only speaking parents; and 3) African American families. We will also ensure that we engage families who live in the areas of Los Angeles County who make up the majority of the CHLA patient population.

This research is being conducted by Dr. Michele Kipke (Principal Investigator) of Children's Hospital Los Angeles.

For more information, please contact **Marisela Robles** by calling **323-442-2105** or emailing her at mariselr@usc.edu.

Appendix H: Study Summary Example 4



Community-Based Research on Asthma Prevention and Management



This is a collaborative project between the **Southern California Clinical and Translational Science Institute (SC CTSI)** at USC, **BREATHE LA (BLA)**, a community-based organization specializing in education and outreach around asthma and other chronic pulmonary conditions and the Camino de Salud from **COPE Health Solutions**, a non-profit organization designed to improve operations and integration of clinical care. This project builds upon the vision of the SC CTSI and its Office of Community Engagement (OCE), which is to conduct research to improve health in the diverse urban environment of Los Angeles; the OCE's vision is to serve as a bridge between research and the community, ensuring collaborative solutions to Los Angeles' most pressing health challenges. The SC CTSI is located in Los Angeles County (LAC), the second most populous county in the U.S. and among the most diverse. In 2004, almost 3 million children and youth lived in LAC, which accounted for a third of California's child population (54% of all children in LAC were under 10 years of age). Asthma impacts 15.6% - 21.9% of children in LAC. This project will focus on Long Beach and South Los Angeles, the two LAC areas most impacted by the environmental influences that increase asthma risk.



While programs and education have been developed and implemented for children and parents affected by asthma, the rates continue to increase in our communities. This speaks to the need for additional research and community-engaged collaborative work to address this ongoing issue. This project will be accomplished through three phases. Given the evidence that exists of the growing issue of childhood asthma.

Phase 1 will determine community knowledge and perceptions of asthma triggers and management with the goal of nurturing the development of culturally relevant prevention education and interventions using a community based participatory research (CBPR) approach.

Using a Photovoice technique, we will implement a CBPR study to better understand knowledge and perceptions of asthma risk factors, management, triggers and symptoms, and identify education and training needs for parents and families in our targeted geographic area. This study will also be used to identify assets, strengths, and resources that are available to promote child health and well-being within the community.

Phase 2 will focus on refining the current BREATHE LA asthma curriculum to fit the existing evidence based models and adapt the curriculum to reflect the needs and suggestions identified in phase 1. In doing so we will promote the delivery of evidence-based approaches to treatment, prevention, and health promotion within our partner clinical and community agencies.

Phase 3 will entail a proposal of recommended interventions and next steps based on the information gathered in phase 1. We will form two community advisory boards (CAB); one comprised of health care providers (HCAB) and one other comprised of parents (PCAB). These partners, will assist in identifying recommendations based on the data collected in phase 1 and on their personal experiences and expertise.

For more Information
contact

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Office of Community
Engagement, SC CTSI
323-442-2105
marisela@usc.edu

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