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Surpassing the Target: How a Recruitment Campaign Transformed the Participant Accrual Trajectory in the Epilepsy Phenome/Genome Project

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Abstract

Participant recruitment challenges pervade the majority of publicly funded clinical trials. However, little is known about methods for enhancing participant accrual. The Epilepsy Phenome/Genome Project (EPGP), a multicenter study funded by the National Institute of Neurological Disorders and Stroke (NINDS), aimed to enroll a total of 5,250 participants to better understand the genetic causes and phenotypic manifestations of epilepsy. However, similar to other trials, EPGP encountered recruitment challenges, and by the end of its first year, net enrollment was only 48% of the target for that time. To address this, EPGP established a National Participant Recruitment Campaign and began implementing and tracking the enrollment outcomes of a variety of proven and relatively novel recruitment methods. At the conclusion of the project, EPGP had successfully enrolled a total of 5,445 participants, thus surpassing its enrollment target. Data pertaining to EPGP's National Participant Recruitment Campaign was analyzed retrospectively, and the results are reported here, so that other multicenter trials may consider these methods in their recruitment planning and potentially avoid the costly repercussions of participant accrual issues. Clin Trans Sci 2015; Volume 8: 518–525

Keywords: clinical trials, participant accrual, study design

Introduction

Human subjects research hinges on the enrollment of a sufficient number of eligible participants. However, more than two-thirds of publicly funded trials fail to recruit as specified in their original plan.[1] Trials that fail to enroll an adequate number of participants face many untoward consequences including, but not limited to, reduced statistical power, increased costs, diminished validity, premature termination, and trial failure (Gul & Ali, 2010).[11] Despite the documented pervasiveness of recruitment challenges and detrimental outcomes, little attention has been paid to assessing the efficacy of participant recruitment methods in the literature.[2]

In 2007, the Epilepsy Phenome/Genome Project (EPGP) set out to begin to unravel the complex genetic underpinnings of epilepsy, one of the most common and serious neurological disorders in the United States and worldwide (Center for Disease Control and Prevention [CDC], 2011).[3] Genomic research often relies on the enrollment of significantly large numbers of individuals from the general population in order to attain the statistical power required to detect relevant genetic variants.[4] Thus, EPGP established a consortium of clinical centers to collectively compile biological specimens and accompanying phenotypic information from 5,250 participants with epilepsy and biological parent controls.[5]

Despite extensive preliminary planning, initial estimates of the availability of patients meeting EPGP's eligibility criteria greatly exceeded the observed supply. By the end of its first year, net enrollment was only 48% of the projected target for that time, and the rate of participant accrual was steadily declining.

To ameliorate the observed participant accrual challenges, the Administrative Core launched EPGP's National Participant Recruitment Campaign, a multifaceted and dynamic undertaking to bolster outreach and increase study-wide enrollment. By November 2012, 5 years after the project's launch, EPGP had surpassed its enrollment target of 5,250 participants. Ultimately, a total of 5,445 participants, 104% of the target, enrolled in EPGP. To date, EPGP is the largest phenotype dataset and biospecimen repository ever compiled to investigate epilepsy genetics.

EPGP's National Participant Recruitment Campaign accomplished this by not only mobilizing strategies that have previously been shown to be successful in accelerating participant accrual, but also by implementing apparently novel recruitment and outreach methods.[6] EPGP employed methods known to be effective such as hiring a full-time participant recruitment director, expanding the network of clinical centers, and modifying eligibility criteria to be more inclusive by increasing the upper age limit, allowing enrollment of additional participant types, and pruning certain medical history and diagnostic requirements. Additionally, EPGP developed an apparently novel, centralized eligibility prescreening process and recruitment method tracking tool; these methods were analyzed retrospectively, and the results are presented here, so that other trials may better address participant accrual challenges.

Methods

A retrospective analysis of the recruitment strategies and participant enrollment in EPGP was performed. The data were collected by the Administrative Core throughout the course of the project. Study-wide enrollment data was accessed through EPGP's reporting server, one of many real-time data visualization tools available on the members' area of www.epgp.org (Nesbitt et al., 2013).[12] Centralized eligibility prescreening and recruitment method data were maintained on a secure Virtual Private Network at the main coordinating center.

During EPGP's first year, study centers continued to recruit and enroll patients seen at their respective clinical centers, but a National Recruitment Director was hired to oversee recruitment from a central study perspective and initiated EPGP's National Participant Recruitment Campaign. The campaign focused on

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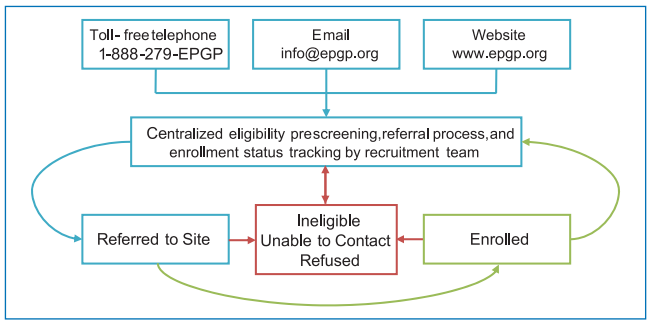

Figure 1. Centralized eligibility prescreening, participant referral process, and enrollment status tracking workflow. Interested individuals and families contacted EPGP via the toll-free line, email, or Website submission form. The recruitment assistant, in consultation with the recruitment director, fielded inquiries, conducted eligibility prescreenings, documented participants' self-reports of referral sources, referred eligible families to study centers, and tracked enrollment outcomes.

fostering collaborations with community groups and healthcare providers nationwide, developing and distributing recruitment materials (e.g., brochures, eligibility summary cards, pens, etc.), and carefully screening additional clinical centers to expand the network. Early on, a toll-free telephone line, Website, and email address were established for interested individuals and families to contact EPGP for more information about participating. In addition, a full-time participant recruitment assistant was available to field all calls and inquiries as well as perform brief eligibility prescreening.

Information pertaining to the potential participant's eligibility prescreen and how they first learned about EPGP was maintained in a database at the central coordinating center. If basic eligibility requirements were met, then the participant was referred to one of EPGP's clinical centers for follow-up and enrollment (*Figure 1*).

All participating study centers obtained IRB approval for the recruitment methods described. Study centers could also opt-out of the referral system by notifying the central recruitment team. If the prescreened participant ultimately enrolled at the clinical center, the Recruitment Director could follow their participation status via EPGP's reporting server to ascertain whether participation was completed or whether the participant was ineligible, refused, or unable to contact.

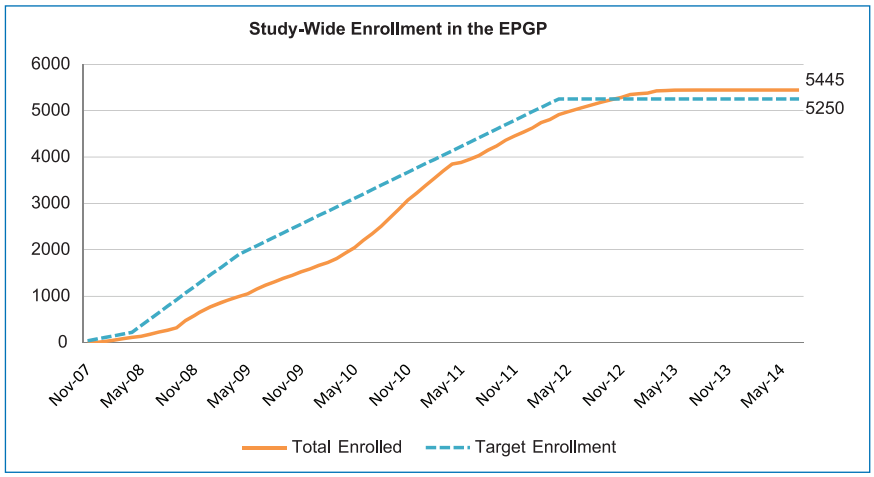

Figure 2. Study-wide enrollment in EPGP over time. The graph displays target enrollment as well as total participant enrollment over the duration of the study. The National Participant Recruitment Campaign was initiated in September 2008, and EPGP surpassed its enrollment target in November 2012.

Data such as referral source trends and enrollment outcomes were compiled, analyzed, and reported to the Administrative Core monthly. These data were used to track and modify recruitment strategies throughout the course of the National Participant Recruitment Campaign. The effectiveness of recruitment methods were then ascertained based upon the total number of contacts and the proportion of those individuals who were determined eligible and subsequently enrolled. Recruitment methods that were determined to be the most effective were further cultivated, while those that were found to be less effective were modified or discontinued entirely. Thus, the active, centralized tracking of participants' self-reports of their referral sources contributed to a tailored and intelligent recruitment campaign as well as its overall success.

Results

Identifying and enrolling eligible participants emerged as a looming obstacle for EPGP early on. Enrollment commenced in November 2007, and by September 30, 2008, 311 participants had been enrolled, which accounted for 34% of the projected enrollment target at the time. Furthermore, these participants constituted an initial bolus of participants who were already known to the sites' epileptologists and nurses.

EPGP's National Participant Recruitment Campaign was launched by the Administrative Core and Participant Recruitment Director to enhance outreach and identify eligible participants beyond the realm of EPGP's network of clinical centers. As a result of this effort, as well as the continued recruitment efforts of individual sites, EPGP succeeded in meeting its enrollment target by November 2012 (*Figure 2*).

A fundamental component of the campaign was the ability to identify eligible participants through a centralized prescreening process. Between September 2008 and December 2012, 2,001 families contacted EPGP by calling the toll-free telephone number, emailing info@epgp.org, or submitting a form via www.epgp.org. While the majority was determined ineligible, 566 families, nearly 30% of the total number of central contacts, were found to meet initial eligibility criteria and referred to a clinical center for more detailed eligibility review and enrollment. Ultimately, a total of 769 participants enrolled in EPGP via this mechanism. Hence, the National Participant Recruitment Campaign and centralized prescreening process resulted in the identification of 14% of the total number of participants enrolled study-wide.

Another fundamental component of EPGP's National Participant Recruitment Campaign was the ability to track the outcomes of the more than forty individual outreach methods in terms of number of contacts and participant accrual. Appendix A provides a comprehensive list of all specific recruitment methods utilized and their general recruitment category. Self-reports of referral sources were collected and analyzed routinely. *Figure 3* shows the total number of contacts per general recruitment category of the National Participant Recruitment Campaign for those who provided details about their referral source.

Approximately 36% of families who contacted EPGP centrally reported first

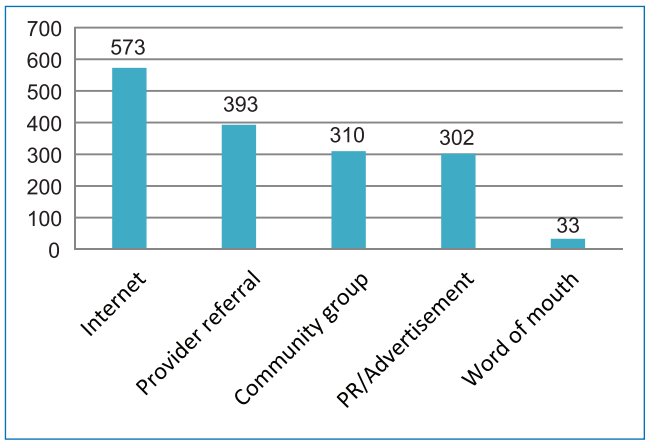

Figure 3. Total number of contacts for each recruitment method category. General recruitment method categories that yielded 10 or more contacts are shown.

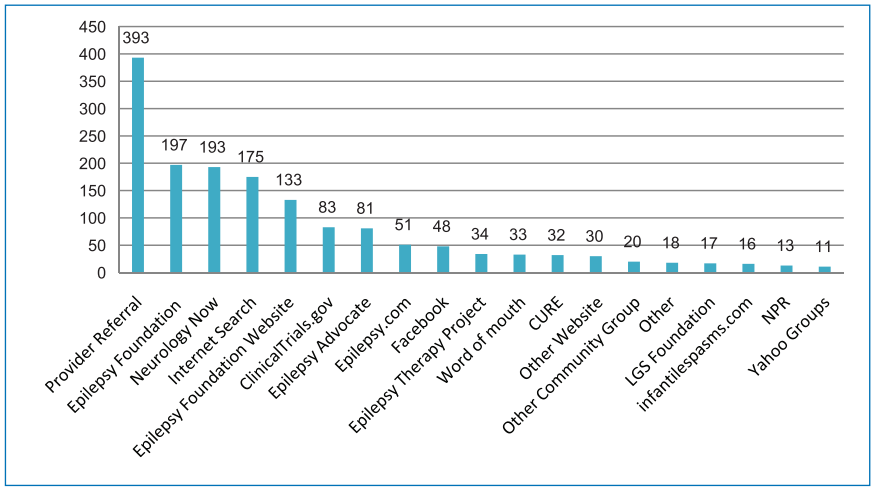

Figure 4. Total number of contacts for each specific recruitment method. Specific recruitment methods that yielded 10 or more contacts are shown.

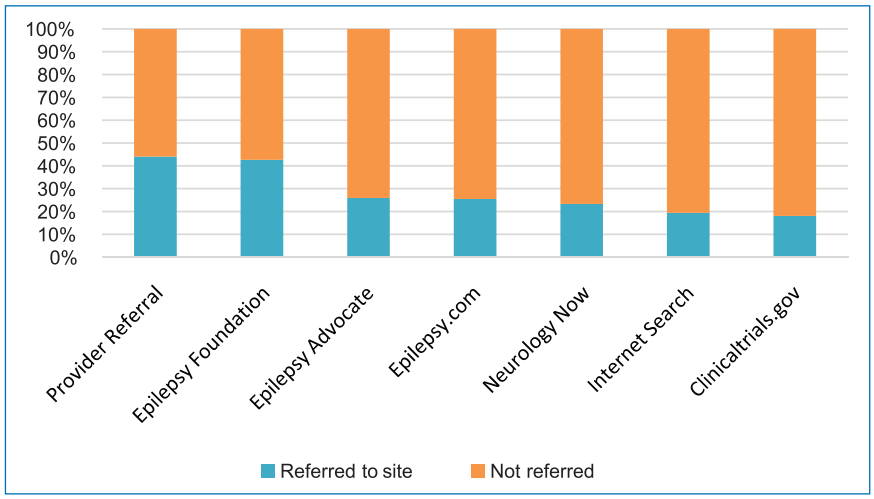

Figure 5. Percentage of families referred to clinical centers by specific recruitment method. The proportions of referred families out of the total number of contacts for specific recruitment methods that yielded 50 or more total contacts are shown.

learning about EPGP via an Internet source (e.g., Website, blog, support group forum, social media page, or search engine). Provider referrals were the second most reported recruitment method category, accounting for 24% of contacts. Community groups and public relations strategies or paid advertisements yielded near equivalent results. When subdivided by specific recruitment method, provider referrals yielded the greatest quantity of contacts (*Figure 4*).

After provider referrals, the most frequently reported specific recruitment methods included mass mailings, email blasts, and newsletters distributed by the Epilepsy Foundation, a nonprofit patient advocacy group; a recurring, paid advertisement in *Neurology Now* magazine; and general Internet searches. For each specific recruitment method, the percentage of families that were screened centrally and subsequently referred to a clinical center is shown in *Figure 5*.

Provider referrals not only yielded the greatest total quantity of contacts, but also the highest proportion of families who met prescreening eligibility requirements (*Figure 5*). These trends were apparent to the recruitment director and Administrative Core early on, and thus cultivating awareness among epilepsy medical professionals became a central focus of the National Recruitment Campaign. EPGP Administrative Core reserved exhibit hall booths at major neurology and epilepsy conferences to promote awareness among professionals in the field. The booth staff offered providers and research professionals with information and complimentary materials containing EPGP's contact information (e.g., pens, brochures, coffee mugs, magnets, eligibility cards, and post-it notes). At the booth, providers could leave their business cards and contact information to request packets of informational materials be mailed to their clinics for patients and their families. When families contacted EPGP and reported first learning about EPGP from their doctor, nurse, or other provider, the recruitment assistant would mail a handwritten thank you note to the provider to thank him or her for their support.

As more and more participants reported first learning about EPGP from a medical provider, the Administrative Core developed a Provider Referral Network on http://www.epgp.org to acknowledge the more than 100 medical providers who participants listed as their referral sources. General informational email blasts, newsletters, and updates were sent periodically to a more comprehensive database of epilepsy and neurology healthcare providers across the United States. As a result, provider referrals yielded the greatest number of participants prescreened centrally, determined eligible, and ultimately enrolled in EPGP.

Figure 6 displays the specific recruitment methods of participants prescreened centrally and ultimately enrolled in EPGP.

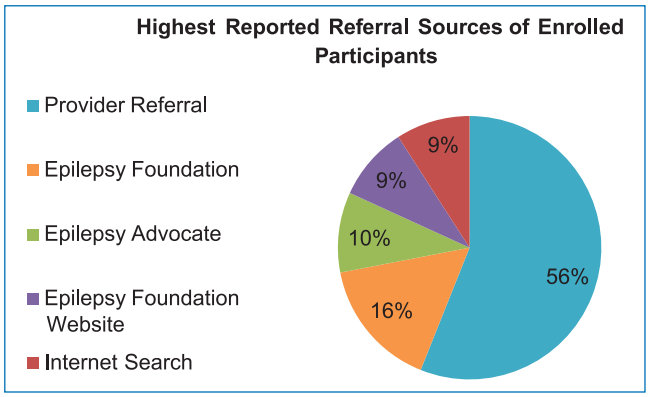

Figure 6. Highest reported referral sources of enrolled participants. The top reported recruitment methods of participants who were prescreened centrally and enrolled in EPGP are shown.

The contribution of provider referrals exceeded the combined contributions of the next four specific recruitment methods combined. Through EPGP's efforts to cultivate rapport and widespread recognition throughout the epilepsy medical community, many families were able to learn about and participate in EPGP.

Discussion

At the start of EPGP in 2007, the original recruitment plan was to primarily rely upon the individual efforts of clinical centers to meet enrollment goals. However, this recruitment paradigm lends itself to various participant accrual barriers, including, but not limited to, a restricted pool of eligible patients receiving medical care at the recruitment venue, inadequate training of research personnel, and other site-specific limitations, such as time and resources, that hinder the ability to identify and approach all eligible patients.[7] Within the first year, EPGP Investigators and Administrative Core recognized these barriers and intervened.

EPGP hired a full-time participant recruitment director who, with the support of the Administrative Core and consortium of clinical centers, initiated a nationwide recruitment campaign. As previously discussed, a central component of this campaign was the eligibility prescreening, referral, and enrollment status tracking process. As a result, 577 participants identified and enrolled via this mechanism have completed all study activities and their data is available for analysis.

Furthermore, the centralized prescreening process lightened the workload for research personnel at study sites and promoted overall productivity. Prior to its implementation, research coordinators shared the responsibility of conducting initial eligibility prescreenings for anyone who contacted EPGP via the toll-free number, email, or website submission form. However, excluding those who do not qualify through an efficient and thorough telephone prescreening process can save significant time and effort for research coordinators and participants alike.[8] The centralized eligibility prescreening of potential participants outside of the network's patient pool allowed for just that, thereby enabling research coordinators to focus their time and effort on enrolling participants who met prescreening criteria and completing other study activities.

The centralized prescreening process also allowed for referral source tracking, analysis, and strategic refinement throughout the course of the project. Partnerships with community organizations and patient advocacy groups proved valuable. On the other hand, the majority of those who reported first learning about EPGP via a general Internet search, ClinicalTrials.gov, or the recurring advertisement in *Neurology Now* magazine were determined ineligible during prescreening. Based on these observations, the most effective recruitment methods arose from developing partnerships with groups that have direct and frequent access to the target patient population, most notably healthcare providers. Research has shown that the trust a patient has in his/her healthcare provider is a motivating factor in making the decision to participate in a clinical trial.[9] EPGP dedicated considerable time and resources to encourage healthcare providers to inform their patients about EPGP.[5] As a result, provider referrals were found to be instrumental in enhancing participant accrual in EPGP.

The findings presented highlight successful recruitment strategies and methods in terms of the quantity of eligible participants identified and enrolled. However, data pertaining to the cost and efficiency of such methods are lacking. Therefore, the results are limited by an inability to assess the resources required to initiate and carry out the recruitment methods described. An additional limitation is that only one recruitment method was recorded when families were asked how they first learned about EPGP, whereas families may have learned about EPGP through multiple ways. Additionally, data on site-specific recruitment methods, staffing, and other variables that may have influenced participant accrual were not systematically collected, and thus, not reported. Lastly, the systematic data collection on referral sources did not commence until well over a year into the project, so data pertaining to general and specific recruitment methods may be slightly misrepresented. Despite these limitations, the results of implementing a rigorous, multifaceted recruitment campaign contributed to EPGP exceeding its total enrollment target within its specified timeframe, and therefore are likely to be relevant to other multicenter clinical trials.

Conclusion

The ability of EPGP to identify and enroll a sufficiently large cohort of eligible participants was, in large part, due to the steps taken early on to initiate and carry out an elaborate, widespread participant recruitment campaign. It's been estimated that one-third of trials conducted in the United States manage to enroll at least 70% of their target.[10] Based on this estimate, EPGP outperformed the majority of trials by successfully enrolling 104% of the target. Despite some enrolled participants being lost to follow-up or excluded after careful data review, 4,037 participants, 77% of the target, have completed the study and their biospecimens and data are available for the research analysis phase.

To date, EPGP has successfully compiled the largest phenotype–genotype dataset on individuals with specific forms of idiopathic epilepsy and first-degree relative controls. Even though the interventions to bolster participant accrual in EPGP were successful, it is likely that these would have been even more beneficial to participant enrollment in EPGP had they been implemented from the start. Given the pervasiveness of recruitment challenges observed in trials and the lessons learned during the course of EPGP, these findings are presented for other multicenter trials to consider during their study design and recruitment planning phase.

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Appendix 1

General recruitment method	Specific recruitment method
Community group	Citizens United for Research in Epilepsy (CURE)
	Dravet Syndrome Foundation
	Epilepsy Alliance of Orange County
	Epilepsy Foundation
	Epilepsy Therapy Project Event
	Finding a Cure for Epilepsy and Seizures (FACES)
	IDEA League
	Lennox-Gastaut Syndrome Foundation
	PatientsLikeMe
	PVNH Support & Awareness
	People Against Childhood Epilepsy (PACE)
	The Seizures & Epilepsy Education (S.E.E.) Program
Internet	The Antiepileptic Drug (AED) Pregnancy Registry (www.aedpregnancyregistry.org)
	The Charlie Foundation (www.charliefoundation.org)
	Clinicaltrials.gov
	Craigslist
	Epilepsy Foundation Website (www.epilepsyfoundation.org)
	Epilepsy.com
	Facebook
	Infantilespasms.com
	Internet search
	Los Angeles Times Website (www.latimes.com)
	Twitter
	Wikipedia
	Yahoo Groups
	Youtube
PR/Advertising	American Academy of Neurology (AAN)
	The DANA Foundation
	Epilepsy Advocate
	EpilepsyUSA
	Google pop-up advertisements
	Los Angeles Times
	Neurology Now
	Newsweek
	National Public Radio (NPR)
	San Francisco Business Times
Provider referral	American Epilepsy Society (AES)
	Association of Child Neurology Nurses (ACNN)
	California School Nurses Organization
	Child Neurology Society (CNS)
	National Association of School Nurses (NASN)
	Provider referral
Word of Mouth	Word of mouth

Author	Email	Institution	Study PI	Clinical Site PI	Clinical Site Co-PI	Referral Center PI	Administrative Core	Pharmacogenomics Core	Genomics and Data Analysis Core	Data Review Core	Neurophysiology Core	Imaging Core	Phenotyping Core	Publications Committee	Detailed Analysis of Data	Writing of Manuscript
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