Evaluation of Recruitment Strategies for Web-based Genetic Studies

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Introduction

Recruitment into research trials can be difficult, and many studies fail to meet their recruitment targets[1,2]. While many of the hundreds of web-based genetic studies conducted by 23andMe's research arm rely solely on recruitment from the natural growth of the customer database through 23andMe's Personal Genome Service®[3,4], for a few studies 23andMe actively recruits individuals who meet particular inclusion criteria. Two examples are 23andMe's Parkinson's disease and sarcoma studies. Recruitment of participants for these studies is conducted via a number of strategies. We evaluated our recruitment strategies by reviewing the changes in enrollment rate in response to each type of effort.

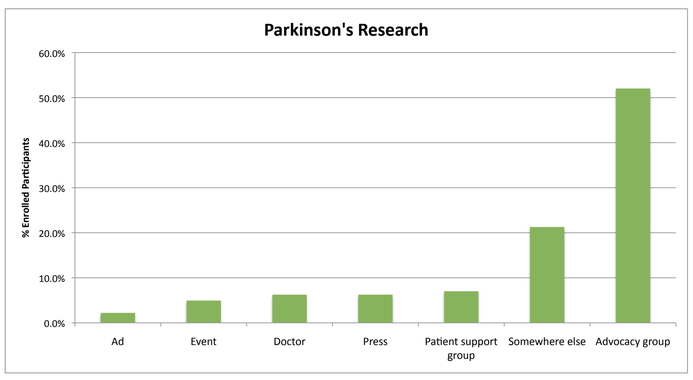

Figure 1. Channels used to recruit people with Parkinson's, including placing ads (e.g., google.com,), attending disease-focused events (e.g., 5k walk), doctor-to-patient referrals, press attention in news and magazine articles, word-of-mouth referral at Parkinson's support groups, and targeted email/newsletter campaigns through advocacy partnerships including The Michael J. Fox Foundation, The Parkinson's Institute and National Parkinson Foundation.

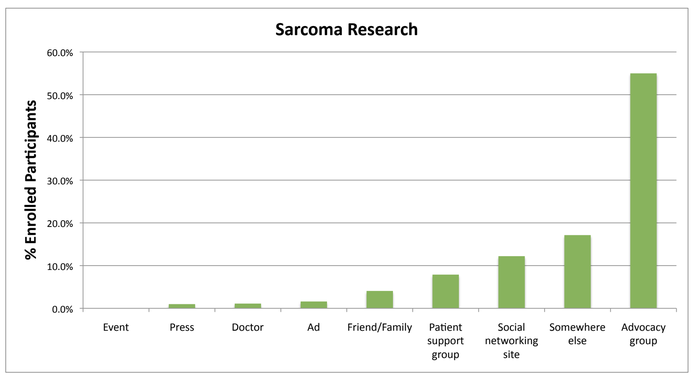

Figure 2. Channels used to recruit people with sarcoma, including press attention in news and magazine articles, doctor-to-patient referrals, placing ads (e.g., google.com), word-of-mouth referral from friends, family and sarcoma support groups, posts on social networking sites like Facebook, and targeted email/newsletter campaigns through advocacy partnerships including Sarcoma Alliance and ACOR.

Results

The recruitment strategies that have been most successful include paper-based mailings from advocacy organizations such as The Michael J. Fox Foundation, and email and website campaigns conducted by advocacy organizations such as Sarcoma Alliance. Grass-roots efforts led by 23andMe members affected with the disease in question have been a significant source of recruitment through online support groups and blog posts. Both studies have garnered attention in the press, which has enhanced enrollment to some extent. The strategies that have been least successful include attending and sponsoring disease-focused events, listing the study on www.clinicaltrials.gov, and speaking to disease-focused support groups (see Figures 1 and 2).

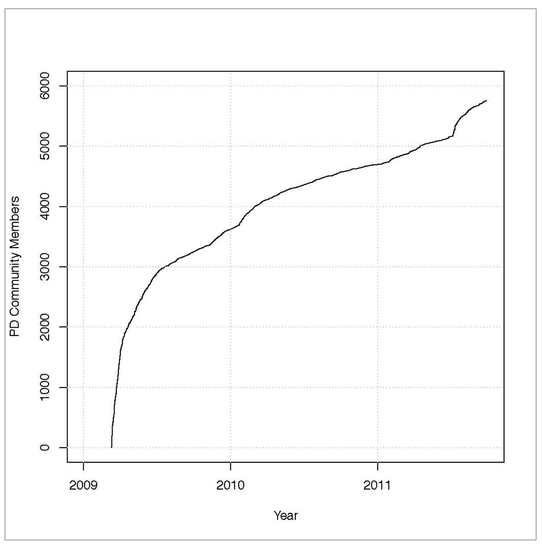

Figure 3. Growth of the Parkinson's research community from launch in April 2009 to September 2011. Currently, 5,850 people with Parkinson's are enrolled.

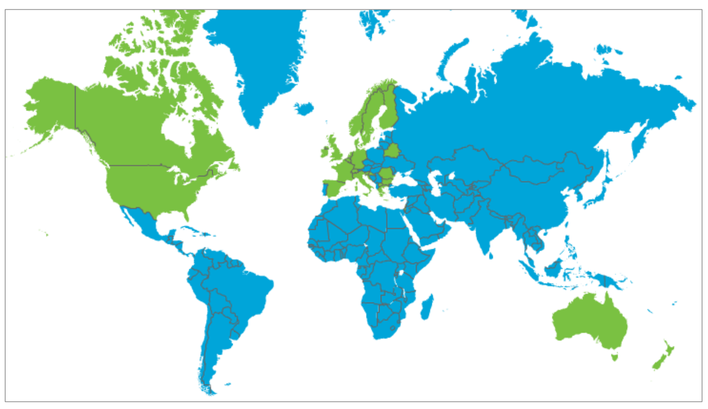

Figure 4. Global demographics of Parkinson's participants, who come from 26 countries (shaded in green)

Conclusion

The combined set of recruitment channels has resulted in rapid recruitment for both studies. In the two months after the Parkinson's study was launched, more than 2,000 people with Parkinson's enrolled[5]. Two years later, the study includes 5,850 people with Parkinson's, the largest single cohort of people with Parkinson's to date[6]. Since the sarcoma study was launched in April 2010, 23andMe has enrolled 665 people with sarcoma, again, the largest cohort of its kind. Web-based genetic studies allow for global recruitment and require no participant travel. However, such studies do require participants to have Internet access and to navigate the Internet. These requirements are likely correlated with the relative success rates of the recruiting strategies in that individuals who learn of the study via the Internet or email are likely to successfully navigate the recruitment and participation process. Understanding which strategies are most effective for recruitment of web-based genetic research will inform future efforts to engage participants and develop large cohorts for research covering a variety of diseases and conditions.

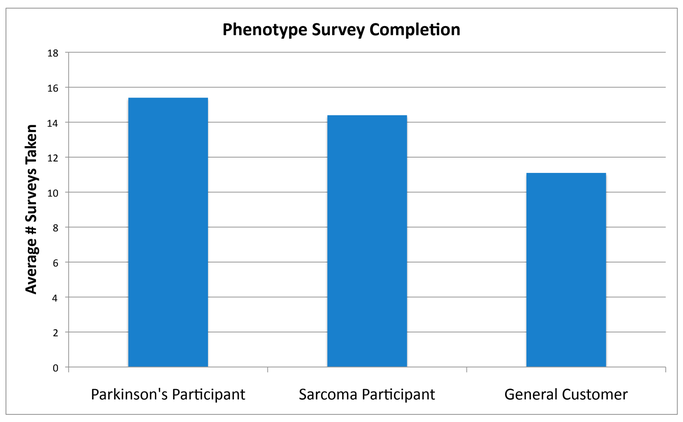

Figure 5. Survey completion by research community participants as compared to general customers in the 23andMe database. Research community participants are encouraged to take a disease-specific survey (i.e. Parkinson's or sarcoma background survey), and are free to take any of the 23andMe surveys, which cover a variety of topics. Survey completion is voluntary and does not result in compensation.

Acknowledgments

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