An Opportunity to Engage: Large-scale Research Outreach via Email Digest

Emily G. Kelley, Caleb D. Ebert, Sydney Whynot, Sunny Ren, Kelly Tangney Color Health, Burlingame, CA



Introduction

Recruiting study participants based on genetic information poses many ethical and practical challenges for researchers.^{1,2} For example, common outreach approaches such as individual phone calls and emails can be time and resource intensive. With large databases of individuals with genetic test results, clinical genomic laboratories are well-positioned to help facilitate study recruitment. Color has previously collaborated with academic research partners to identify individuals who have opted into receiving invitations to research opportunities and who may be eligible for studies based on genotype and/or phenotype. We did recruitment outreach by personally contacting eligible individuals by phone or email to assess their interest and request consent to share their contact information with the study, with variable success.

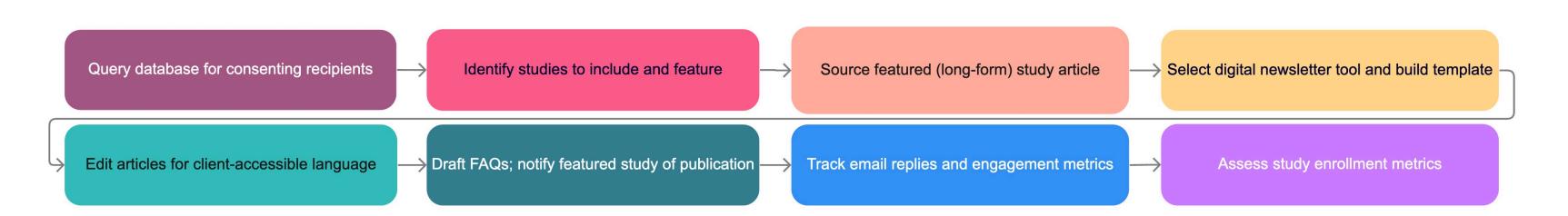
In this study, we developed a newsletter-based approach called the Research Digest that requires minimal time-effort and evaluated its ability to reach a larger audience than is feasible via direct outreach. The ultimate goal was to increase enrollment for our research partners, with the knowledge that research participation can be mutually beneficial for researchers and participants. ^{3,4} We wanted to help participants empower themselves to join research studies and contribute to medical advances that may benefit themselves or their community.

Methods

Ongoing academic research partners were invited to submit a brief description of their study to be included in a visually-engaging, digital Research Digest. In total, six unique studies were detailed across three digests in January, April, and July 2022, spanning gene-specific studies, general genomic sequencing experience studies, and non-genetic studies on conditions such as COVID-19. Each Research Digest highlighted one research study in a feature-length article (average 547 words) and included several other studies in shorter articles (average 125 words). Importantly, each article provided the study contact information so individuals interested in joining could contact study staff directly to enroll or learn more.

The Research Digest was sent via Mailchimp emails to individuals who received clinical genetic testing at Color and consented to be contacted about research opportunities. Engagement metrics were reported via Mailchimp and analyzed with descriptive statistics. After the April distribution, the studies were asked to report on enrollment metrics before and after the emails had been sent. Further analysis was conducted on the ICARE Study, which had previously used personal email invitations to enroll, to compare the impact of the Research Digest on individuals reached, enrollment success, and time effort involved.

Figure 1. A workflow depicting the steps for creation, distribution, and evaluation of each Research Digest.



Conclusions

- The four quarterly Research Digests have been opened by over 100,000 unique individuals, and the study links and contact information within have been clicked by over 10,000 unique individuals, demonstrating that this is an effective method to engage a large audience.
- While featured studies in the Research Digests reported the greatest increase in enrollment, non-featured studies also reported an increase in enrollment, indicating that recipients continued to read "below the fold".
- One featured study, the ICARE Study, saw a greater overall enrollment than had been previously achieved by direct outreach via phone calls and emails from genetic counselors, with the Research Digest proving to be a more efficient approach as well.
- Research Digests are an effective approach for research recruitment at scale, and similar approaches should be considered to help increase visibility of and direct participant engagement in a wide variety of studies.

Reference

- 1. Beskow LM, Linney KN, Radtke RA, Heinzen EL, Goldstein DB. *Genome Res.* 2010 Jun;20(6):705-9.
- 2. Gul RB, Ali PA. *J Clin Nurs*. 2010 Jan;19(1-2):227-33.
- Hallowell N, Cooke S, Crawford G, Lucassen A, Parker M, Snowdon C. J Med Ethics. 2010 Jan;36(1):37-45.
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Results

Figure 2. Examples of a Research Digest sent via email newsletter, with annotations of key features.

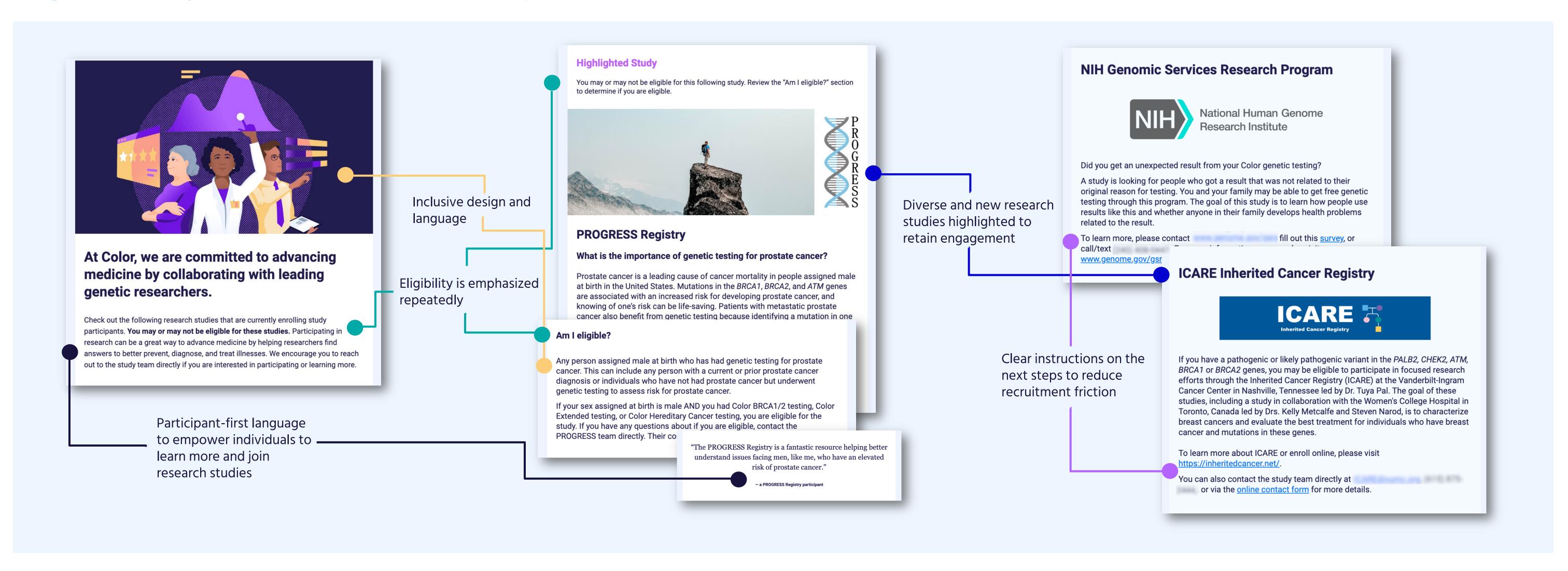


Figure 3. Select digest engagement metrics via Mailchimp.

Opens is the number of individuals that opened the email. Clicks is the number of individuals who clicked one or more link(s) in the Research Digest. Unsubscribes is the number of individuals who unsubscribed via Mailchimp.

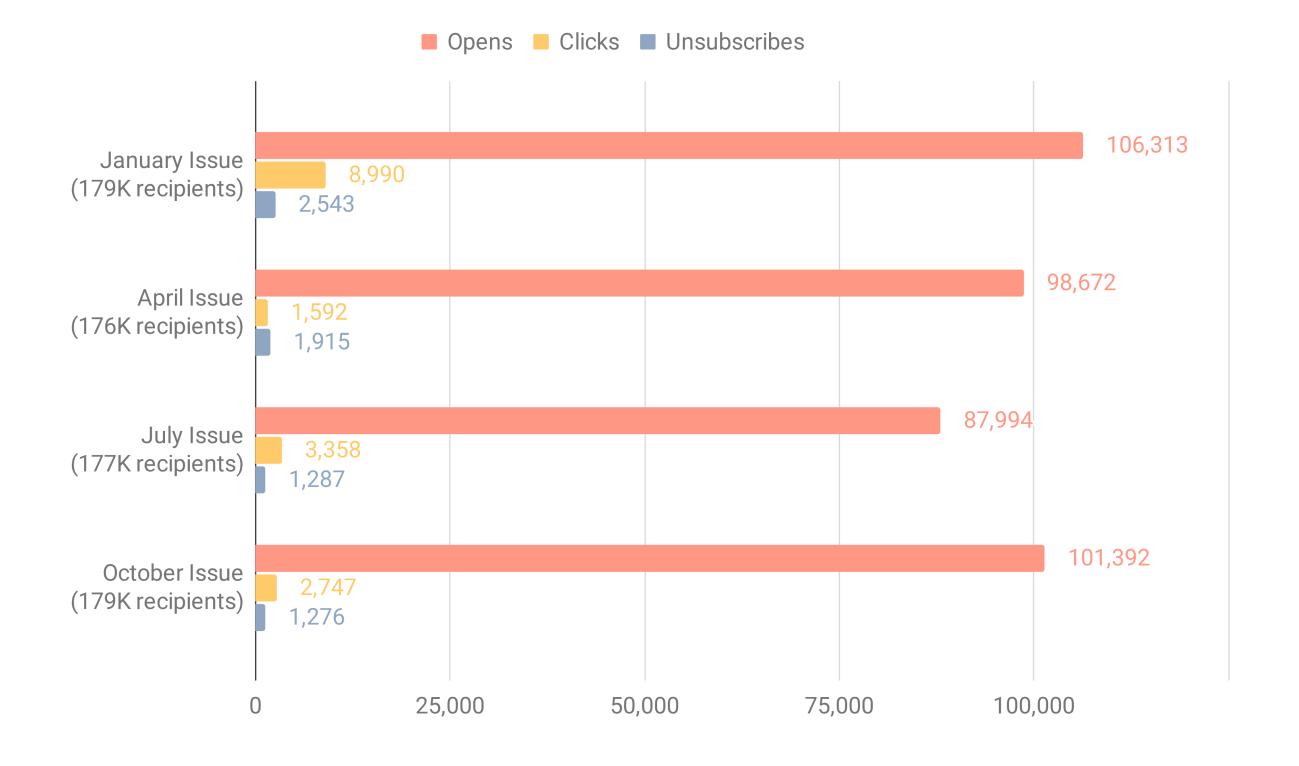


Figure 4. Individuals who enrolled in one of the featured studies, the ICARE study, by recruitment outreach method.

The Research Digest resulted in 452 enrolled ICARE Study participants, while direct contact (phone or email) resulted in 48 enrolled participants.

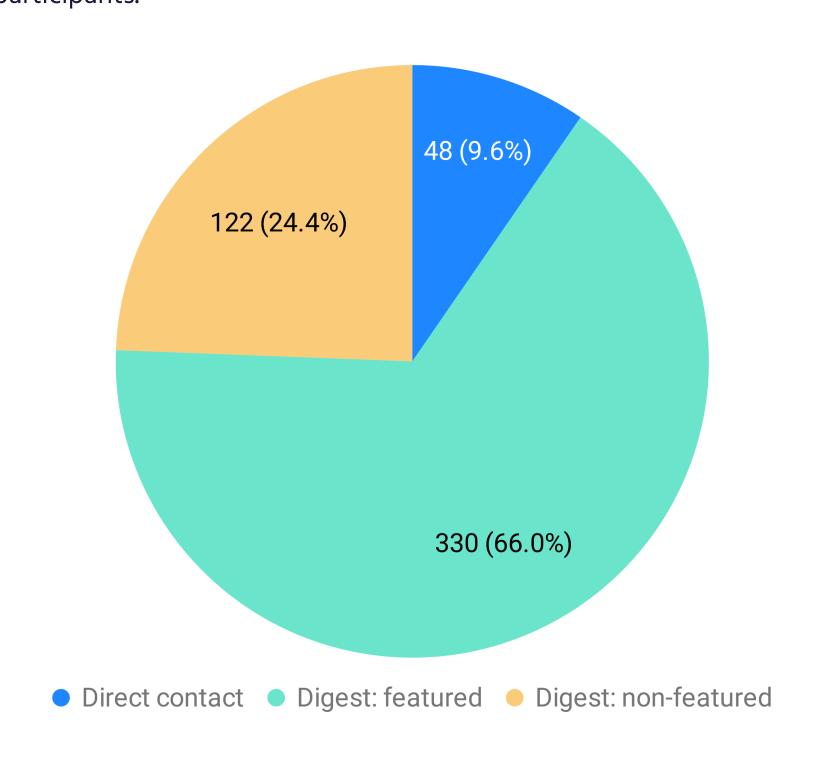


Figure 5. Effort in minutes per enrolled ICARE Study participant by recruitment outreach method.

There was a 96% decrease in effort between the direct contact approach and the Research Digest.

