Introduction

Recruiting study participants based on genetic information poses many ethical and practical challenges for researchers. 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 genomics 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 and effort to evaluate. 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. 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, 10 unique studies were detailed across three digests in January, April, and July 2022, spanning gene condition-specific studies, general genomic sequencing experience studies, and non-genetic studies on conditions such as COVID-19, schizophrenia, and diabetes. The Research Digests 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 information so individuals interested in joining could contact study staff directly to enroll or learn more. 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.

The four quarterly Research Digests were an effective approach for research recruitment at scale, and similar approaches should be considered to engage a large audience.

Results

The Research Digest resulted in 452 enrolled ICARE Study participants, while direct contact (phone or email) resulted in 66 enrolled participants.

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.
- A recent study showed that the Research Digest resulted in a 96% decrease in enrollment effort between the direct contact and the Research Digest.
- Clear instructions on the next steps to reduce recruitment friction.
- Ongoing academic research partners were invited to submit a brief description of their study to be included in the Research Digest, with the knowledge that research participation can be mutually beneficial for researchers and participants.
- We wanted to help participants empower themselves to join research studies and contribute to medical advances that may benefit themselves or their community.

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

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

Figure 3. Select digest engagement metrics via Mailchimp.

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

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

Reference


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