Integration of personalized medicine into primary care clinics: A path to make large scale population genomics studies successful

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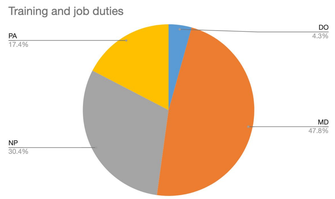
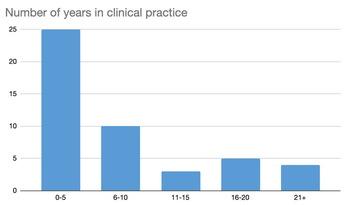
Introduction

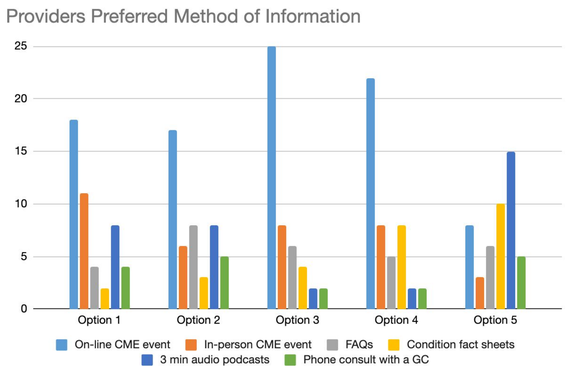
Renown Health, the largest medical center in Northern Nevada, is recruiting hundreds of thousands of patients to participate in The Healthy Nevada Project. In addition to contributing to longitudinal translational research, all participants receive clinical-grade CDC Tier 1 results that are integrated into their electronic health record. All individuals who are identified with a likely/pathogenic variant in one or more of the conditions are offered genetic counseling, at no cost to the patient, provided by a third party service. For those who complete a GC session, a clinical action plan is generated. To successfully integrate actionable test results into clinical care requires that primary care providers (PCPs) are aware and prepared to address clinical care needs to support results including questions from patients, screening and prevention recommendations, and appropriate referrals. To address these needs, a quality improvement project was conducted with the aim of assessing PCP understanding and needs in order to provide that education in order to improve the ability of PCPs to manage their patients effectively.

Methods

We surveyed 80 primary care providers at Renown Health to understand their comfort level with genetic information. All questions were based in the context of the Healthy Nevada Project. The survey was sent via the internal Renown Health email system and was open for 6 weeks. The survey was sent by the lead of the provider advisory group. After launching the survey, 2 reminders were sent.

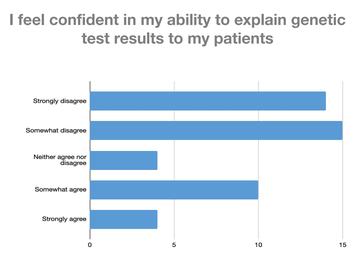


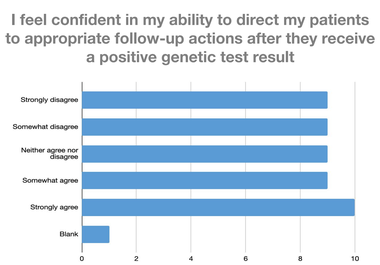


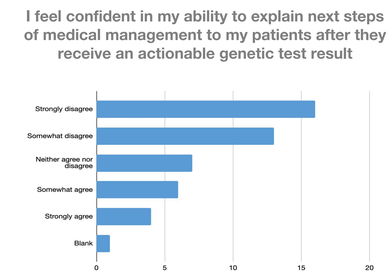


Results

The participation rate was 59% (N=47). Of respondents, 48% were physicians, 30% were nurse practitioners, and the rest identified themselves as physician assistants (17%) and osteopaths (4%). Almost half of the providers (N=25) had 5 or less years of clinical experience, and about a quarter (N=12) had 10 or more years of experience. 85% of the providers had either never discussed genetic test results with a patient or had previously seen less than 5 patients with a genetic result. 70% did not feel confident in their ability to explain genetic results to their patients. 77% did not feel confident in their ability to explain medical management to their patients. 76% did not have a clear understanding to which specialists they should refer their high risk patients. These results were independent of the provider's training or number of years of clinical experience.







Providers were also asked to rank order what tools or resources they would find useful to bridge this education gap. The most common answer was one page FAQs, followed by one page gene guides, CME events, and short audio education modules and consultation with a genetic counselor.

Discussion

This quality improvement project represents a baseline needs assessment, and clearly identified challenges and potential barriers to the success of population genomics initiatives involving primary care. Despite brief awareness training campaigns broadly among providers in the health system, we found that Renown Health PCPs were not familiar with the CDC Tier 1 conditions and reported low confidence in tasks related to discussing genetic test result information or managing their patients with a genetic condition. This assessment sets the stage for additional phases of awareness education and engagement strategies among PCPs.

PCPs requested various just-in-time education materials such as one page gene guides, FAQs and CME events to help bridge the education gap. They were less likely to want to engage with brief audio clips or directly with a genetic counselor. Additional research is required to determine if there is a lack of understanding as to the value of these resources, if there is a perception of additional time investment to use these resources, or other reasoning.

Currently, a range of educational resources have been developed and made available to PCPs including: comprehensive FAQs, 11 gene guides for the CDCT1 conditions, and six four-minute audio education modules on various topics including how to discuss a positive or a negative result, emotional impact of genetic testing, impact to family members, importance of genetic counselors. All the education materials were developed with provider feedback and are available on-demand through Renown Health's intranet system. Subsequent work to assess the effectiveness and utility of the identified education materials will be conducted in follow up studies.