Introduction

As genetic testing has become less expensive and more readily available, it is becoming increasingly accessible to individuals all around the world. However, one important requirement for expanding testing globally is providing genetic counseling (GC) support. GC availability is variable and evolving by country, which presents a variety of challenges for the appropriate provision of GC.1

Color has adopted a technology-supported delivery model that allows GC to be delivered in geographically diverse settings. Using this model, Color has provided genetic testing, genetic counseling, and other personalized health information to individuals all over the world. It is vital for result interpretation and overall participant support that GC be personalized to each individual. Of note, very little modification to Color’s standard workflow is needed to accomplish a personalized experience.

In order for GC services to be flexible, Color has adopted a telephone-based delivery model. Telephone-based sessions have been shown to be efficient and effective for GC delivery.2,3 To date, Color has provided telephone-based GC to over 15,000 individuals, including over 1050 individuals from 53 countries outside the US. Here, we present two case studies and review the customization of the Color GC workflow for two international cohorts with different ascertainment.

Methods

The cohorts described here were from the United Arab Emirates (UAE) and Trinidad and Tobago (T&T). The T&T cohort received genetic testing with a 30-gene next generation sequencing (NGS) panel for hereditary cancer, most of whom were ascertained through a high-risk study. The UAE cohort received genetic testing for hereditary cancer risk as well as a 30-gene NGS panel for hereditary cardiovascular disease that was offered as an employee benefit.

In both cohorts, GC was conducted by telephone, with translation services available. Color GCs also met with healthcare providers from T&T and UAE to better understand their healthcare systems to ensure cultural competency. Qualitative feedback from Color GCs was collected for both cohorts. All individuals consented to have their de-identified information used in anonymized studies. Age and gender was reported by the individual.

Conclusions

- Providing access to high quality genetic information and GC regardless of geographical location requires personalization based on access to technology and local care providers
- Specifically, providing GC in an international setting requires consideration of the unique needs of each country, including time zone and language as well as cultural competency.
- Leveraging technology can help enable access to high-quality GC in countries with disparate levels of healthcare.
- Building partnerships with local healthcare providers is crucial to ensure a warm handoff for individuals, particularly those with a positive result to receive appropriate follow-up care.

Results

Figure 1. International genetic counseling, by country

Color has provided genetic counseling in six continents and 53 countries outside of the United States.

Figure 2. Workflow customization

Genetic testing and GC workflow was customized to meet the required needs of programs in T&T and UAE.

Table 1. Program characteristics

Programs differed in many aspects including mode of access to Color, setting, test order, and technology access.

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<tr>
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<th>UAE</th>
<th>T&amp;T</th>
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Figure 3. Cohort demographics, by program

Overall, the UAE cohort was younger in age and had a more equal distribution of males and females compared to the T&T cohort.

References