Addressing the Direct-to-Consumer Genetic Testing Knowledge Gap for Non-Genetics Healthcare Professionals

Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG) DTC-GT Project Group

H Ayoubieh¹, K Blazer², R Mills³, K Garber⁴, H Lee⁵, RS Gammal⁶, L Ho⁷, KM Hyland⁸, K Jacoby Morris⁹, MB Massart¹⁰, E Flowers⁸, SM Robbins⁹, GM Kuo¹¹, DM Christopher⁹, C Gunter⁹, M Taylor¹², D Messersmith⁹, T. Weiler¹³

¹Texas Tech Health Sciences El Paso; ²City of Hope Comprehensive Cancer Center; ³University of North Carolina - Greensboro; ⁴Emory University School of Medicine; ⁵Park Nicollet Frauenshuh Cancer Center; ⁶Massachusetts College of Pharmacy and Health Sciences; ⁷National Center for Advancing Translational Science; ⁸University of California - San Francisco; ⁹National Human Genome Research Institute; ¹⁰University of Pittsburgh; ¹¹⁰ Oregon State University - Portland; 12 University of Colorado - Denver; 13 Florida International University.

NIH ISCC-PEG Direct-to-Consumer Genetic Testing (DTC-GT) Project Group

- National group of geneticists, genetic counselors, physician assistants, pharmacists, educators and other healthcare professionals
- GOALS
 - Improve genomic literacy of healthcare professionals (HCPs)
- Enhance the effective practice of clinical medicine in the area of DTC-GT

Background on DTC-GC

- >9 million Americans have used DTC-GT
- Patients are sharing their DTC-GT results with HCPs
- In the past year, 35% of physicians at Kaiser Permanente had patients share DTC-GT results with them
- Only 12% of PCPs agree that physicians have sufficient knowledge to help patients understand DTC-GT results
- 27% of consumers who shared DTC-GT results with their doctors disagreed when asked if their physician understood genetics enough to advise them on the implications of their results.
- Due to this perceived gap in understanding, many HCPs are reluctant to tackle genomic medicine in their clinical practice and would seek opportunities to enhance their knowledge.

ISCC-PEG DTC-GT Project Group Activities

- DTC-GT for Healthcare Professionals Frequently Asked Questions (FAQ)
- 2021 NHGRI Healthcare Provider Genomics Education Week - DTC-GT for healthcare professionals live webinar
- DTC-GT for HCPs educational videos and Youtube channel
- DTC-GT point-of-care tool for HCPs
- Present DTC-GT for HCPs related topics at national scientific meetings

DTC-GT for Healthcare Professionals FAO

- To be posted on Genome.gov
- Survey of non-genetics HCPs
- FAQ content useful
- Difficult to navigate during a clinical encounter.

DTC-GT HCPs - Videos and Youtube Channel

• Youtube Channel: Direct To Consumer Genetic Testing for Healthcare

• Video 1: Direct to consumer genetic testing in primary care



DTC-GT Point-of-Care (POC) tool for HCPs

 Algorithm to help HCPs navigate DTC-GT questions from patients in real time.

Scan for POC details

- Validated with 11 DTC-GT patient scenarios
- · Currently implemented in Qualtrics, as proof of concept
- Intend to develop a responsive website/app

Find out more about ISCC-PEG & the DTC-GT Project Group by visiting https://www.genome.gov/iscc

Addressing the Direct-to-Consumer Genetic Testing Knowledge Gap for Non-Genetics Healthcare Professionals

Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG) DTC-GT Working Group

H Ayoubieh¹, K Blazer², R Mills³, K Garber⁴, H Lee⁵, RS Gammal⁶, L Ho⁷, KM Hyland⁸, K Jacoby Morris⁹, MB Massart¹⁰, E Flowers⁸, SM Robbins⁹, GM Kuo¹¹, DM Christopher⁹, C Gunter⁹, M Taylor¹², D Messersmith⁹, T. Weiler¹³

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Direct-to-consumer genetic testing (DTC-GT) is a convenient method for people to obtain genetic information. Over nine million individuals have used DTC GT services in the U.S., and primary care and specialty physicians are now encountering patients with questions regarding their DTC-GT results. In a recent survey of Kaiser Permanente physicians, 35% of respondents reported that patients had shared their DTC-GT results with them in the past year. Despite the growing need to manage these patient questions, only 12% of surveyed primary care physicians agree that physicians have sufficient knowledge to help patients understand the results of DTC-GT. In a survey of consumers who shared DTC-GT results with their doctors, 27% disagreed with the idea that their physician understood genetics enough to advise them on the implications of their DTC-GT results. Due to this perceived lack of knowledge, many healthcare professionals are reluctant to tackle genomic medicine in their clinical practice and would seek opportunities to enhance their genomic knowledge. The National Human Genome Research Institute's Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG)/ / DTC-GT Project Group consists of a spectrum of genetics professionals who aim to improve the genomic literacy of healthcare professionals and enhance the effective practice of clinical genomic medicine in the area of DTC-GT. The ISCC-PEG DTC-GT Project Group has created a Direct-to-Consumer Genetic Testing for Healthcare Professionals Frequently Asked Questions (FAQ) to be housed on Genome.gov. Non-genetics healthcare professionals were surveyed about the FAQ. They found the FAQ content useful, but remarked that it would be difficult to navigate in real time during a clinical encounter. In addition to the FAQ, the DTC-GT Project Group has participated in the 2021 NHGRI Healthcare Provider Genomics Education Week, presenting an educational webinar and short YouTube videos about DTC-GT. The Project Group is also developing a point-of-care tool for healthcare professionals to facilitate an outpatient encounter pertaining to DTC-GT. The Project Group then created 11 DTC-GT patient scenarios, each of which were used to validate the DTC-GT point-of-care tool. The point-of-care tool has now been implemented in the Qualtrics software, as a proof of concept, with the intention to develop a mobile app/website that can support healthcare professionals as they respond to their patients gueries about DTC-GT results. Products and outcomes from the DTC-GT Project Group's work will be presented.

