Title: A proactive genomic screening pilot in a primary care setting serving Alaska Native people.

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Purpose: Alaska Native people are among the underrepresented groups historically excluded from genomic medical research. The Ariadne Labs Precision Population Health (PPH) program partnered with Southcentral Foundation (SCF) in Anchorage, Alaska to implement Proactive Genomic Screening (PGS) in a primary care setting serving an Alaska Native population. We partnered with SCF staff and customer-owners (C-Os, i.e., patients) to co-design and test a clinical PGS pathway that could serve as a prototype in various settings, with the goal of ensuring all individuals have access to life-saving PGS. The pilot results from the first cohort of COs and their experiences with the co-design process are reported here.

Methods: We took a stepwise approach to co-design a clinical pathway and tools that support C-Os. C-O feedback was collected via 2 focus groups. Following design, SCF implemented the Invitae First Tier Population Screen in 1 primary care clinic. C-Os who were 18 years or older and had a primary care visit within the last year were invited to participate by health record messaging, mailed letter, or in a visit (n=525). Interested C-Os had an appointment with their PCP to consent to PGS. Results were returned by their PCP. Following the pilot, C-O surveys were administered, and qualitative feedback was collected.

Results: The PGS pathway was updated based on C-O focus group feedback (n=9) including ensuring a behavioral health consultant was available to support the pathway. Of the C-Os that responded to the pilot invitation (n=83), 83% (n=71) proceeded with screening and 7% (n=6) actively declined. Of those who were invited verbally during a visit, 64% proceed with screening compared to 14% who were invited via health record messaging. 4% (n=2) of C-Os had a positive result for Familial Hypercholesterolemia. Post-pilot C-O survey data (n=23) demonstrates high rates of satisfaction with education tools, ease of the process, many indicated they would recommend participating to others and that the benefits outweigh the risk. C-O qualitative data (n=14) shows C-Os have interest in a larger panel and “knowing if there are more diseases that can be tested for this way”. Decliner surveys (n=2) showed satisfaction with the pathway and main concerns were around insurance and privacy.

Conclusion: This co-designed clinical pathway demonstrated high rates of satisfaction by Alaska Native C-Os and highlighted interest in expanding the PGS offering. C-O pilot feedback will be essential in the design of expanding a PGS offering to Alaska Native people.