

Co-designing a Preventive Genomic Screening Pilot with an Alaska Native Tribal Health Organization

Authors:

Carrie L Blout Zawatsky - Ariadne Labs, BWH, Broad Institute

Janelle Shea- Ariadne Labs, BWH

Kasey Bellegarde- Ariadne Labs, HSPH

Indigo Miller- Ariadne Labs, BWH

Meagan Elam- Ariadne Labs, BWH

Laura Subramanian- Ariadne Labs, BWH

Nicolas R. Encina- Ariadne Labs (Harvard HSPH)

Jennifer Perkins-SCF

Solana Rolloazo- SCF

Sasha Davis- SCF

Christina Fieldhouse- SCF

Robert C. Green- BWH, Ariadne Labs, Harvard Medical School, Broad Institute

Background: Implementing Preventive Genomic Screening (PGS) in primary care allows health systems to offer proactive medicine. Southcentral Foundation (SCF) exclusively serves an Alaska Native population, historically under-represented in genomics. The Precision Population Health program (PPH) at Ariadne Labs partnered with SCF to co-design, implement and assess a PGS pilot. We present SCF staff reflections on the co-design process and the resulting clinical support tools developed to offer PGS.

Methods: Co-design of the clinical pathway began with literature review and a two-day immersion experience of the PPH team with SCF leaders and staff, many who are Customer-Owners (C-O, aka patients), followed by weekly meetings. Prototypes for the clinical pathway and tools (invitation, frequently asked questions, staff training, and conversation guides) were developed, and a focus group (FG) was facilitated with 10 staff members to iterate. Minutes were reviewed for common themes to update the care pathway and tools. Following co-design, a clinical pilot offering PGS ran from Jan. to March 2024. Staff feedback was collected post pilot through a moderated FG and a brief pre-post survey.

Results: The pilot was launched in one SCF Primary Care clinic returning Centers for Disease Control Tier 1 conditions. To address data privacy concerns, a laboratory contract was negotiated requiring the destruction of samples and data after results reporting. Pre-pilot FGs identified: benefits of PGS, importance of training and communication, privacy concerns, C-O choice in results return, and family testing. To date the pilot has screened 64 C-Os. Post-pilot staff feedback revealed needed improvements to simplify invitation burden, and staff excitement to offer PGS to enthusiastic C-O's. The PGS invitation process helped to bring C-Os back to care who had not been seen recently. Equity issues were identified, specifically the clinical pathway would need to be modified to reach C-Os who lived in villages, requiring approvals from village councils with new expected logistical hurdles. Compared to pre-pilot, post pilot surveys showed reduced concerns and improved confidence explaining results and highlighted suggestions for pilot expansion.

Conclusion: This project highlights the importance of co-design with staff who care for and/or are themselves Alaska Native people, allowing for anticipation of potential logical hurdles that can be controlled for when piloting PGS. This clinical pilot potentially paves the way for improved health outcomes for Alaskan Native people through PGS.