

Status of Genetic Services in Puerto Rico: A Qualitative Analysis

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Abstract

Genetic services (GS) serve as an important resource in diagnosing and advising individuals with risk factors for genetic conditions. However, serious gaps remain in providing needed genetic services in Puerto Rico (PR), along with many other areas. The New York Mid-Atlantic Caribbean (NYMAC) Regional Genetics Networks (RGN) aims to collaborate with key stakeholders to create access to quality care and appropriate genetic services. This needs assessment aims to describe the current status of genetic services in PR to identify barriers and potential solutions. NYMAC gathered Puerto Rican stakeholders based on their relation to genetics needs and services and held virtual recorded meetings to gain a better understanding of genetic services in PR and its impact on public health professionals and patients. Herein, we summarize and analyze four meeting transcripts between NYMAC and stakeholders in Puerto Rico using a grounded thematic qualitative analysis. The results identified themes for barriers and solutions for health care professionals, patients, families, and professionals that work with them. These results suggest that expanding access and availability to genetic services, telemedicine and interpreter services can begin overcoming the barriers that exist. Challenges and limitations exist when integrating and improving GS in PR. The public health importance of this needs assessment is that it highlights health disparities that exist in the PR population and describes potential solutions.