

Recommendations on Responsible Sharing of Genetic Research Results with Participants

Summary

The Global Parkinson's Genetics Program (GP2) has developed best practice recommendations for the responsible sharing of individual genetic research results within GP2, focusing on ethical considerations, the need for validation, and the commitment to participants' well-being.

Introduction

As GP2 continues to grow, we have identified particular needs, including responsible sharing of individual genetic research results, aligning with our strong commitment to achieving excellent scientific outcomes through standardized methods while guaranteeing the highest standards of ethics. Currently, GP2's genetic analyses are conducted using research standards rather than clinical diagnostic standards. While we recognize the unmet need to return individual results with participants (especially in areas with lower access to genetic testing), any positive results should be confirmed on an independent sample through a clinically accredited laboratory before being used to inform clinical care.

Potential Consequences of Unverified Results

It is imperative to consider the potential adverse consequences of returning results to participants without proper laboratory validation, which include:

- Incorrect diagnoses and genetic counseling leading to potential psychological distress, missed diagnoses, inappropriate treatment, and stigma to participants and their family members
- Potential discrimination in areas such as insurance, employment, and social contexts
- Potential non-compliance with local and ethical regulations

GP2 Commitment and Collaborators' Responsibilities

Our consortium is committed to developing protocols and training resources for the responsible return of individual results to GP2 participants. Meanwhile, **GP2 site investigators should refrain from returning GP2-generated results to participants** without confirmation from a clinically certified laboratory. Even after clinical confirmation, the **GP2 logo, or references to GP2 should not be included** with results shared with participants. All practices must strictly adhere to what has been outlined in the consent form and approved by the ethics committee locally. It is the responsibility of the local study leads to ensure that any results shared with patients have undergone the necessary validation.