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Genomics informatics — Challenges and standardization needs for secondary use of clinical genomics data

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Foreword

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Introduction

Clinical genomics data can have primary and secondary use based on the goals for which they are collected. In general, primary utilization is the use of genomics data that is directly applicable to individual patients, whereas secondary use is the use of large-scale data to understand disease and develop treatments.

The secondary use of clinical genomics data involves the use of genomics information obtained from patients during clinical care for purposes extending beyond the individual patient care. These purposes can encompass research endeavors, quality enhancement initiatives, public health surveillance, and population health studies.[3] However, there is currently a lack of standardization around utilization criteria and related policies for these secondary uses of clinical genomics data.[4-9] The first step would be to survey the international status, challenges, issues, and need for standardization in the secondary use of clinical genomics data.

This document contains the results of a survey, provides an overview of the current international perspectives on the secondary use of clinical genomics data based on responses from a limited group of participants, and highlights the need for international standardization efforts. This document can serve as a valuable resource for advancing the application of clinical genomics technologies and promoting the development of essential standards by providing insights into the current state and complexities of secondary use of clinical genomics data.

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