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Title

Results from Consensus-Oriented Decision-Making Process (CODM) for a Primary Care Based Biobank: The Quebec Experience

Priority 1 (Research Category)

Population health and epidemiology

Presenters

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Abstract

Fundamental research at the primary care level is needed. Medical research has been mostly hospital-based and focused on molecular mechanisms. There is frequently a discordance between primary care based questions and hospital care-based answers. Biobanks, or biorepositories, designed to provide high quality biospecimens and associated data for disease specific research or population studies, have sparked numerous discussions amongst researchers, scientists, policymakers, ethicists, lawyers and even patient advocate groups. In the era of translational research, there has been an increase of biobanks due to higher demand of biospecimens and data enabling translational research. Therefore, the generation of evidence at the primary care level requires substantial networks of primary care practitioners and investigators in the development of a primary care biobank. While there are numerous online resources and courses available to setup a biobank, there is little information available on the “how-to” for integration within an institution or a network. Each biobank’s procedures and plans may be particular to a region or an institution, and the “how-to” may likewise differ. The method(s) used around the numerous meetings and discussions amongst experts to initiate a biobank project is not well described or defined in the literature. The purpose of this paper is to explore the cohesion level of different foundational capabilities identified in a biobank framework using the consensus-oriented decision-making (CODM) process in order to provide guidance in the development of a primary care biobank framework. This study is based on a consensus-based theory. A total of six foundational capabilities were discussed and consensus on cohesions was obtained for each capability. With a number of these capabilities, consensus was achieved, after thematic analysis of the transcript and coding of 120 relevant texts, a number of themes were identified. The involvement of participants at the governance of the biobank, the inclusion of participants in the strategy and mission of the primary care based biobank, as well as ensuring the balance of power for inclusive participation of centres in the biobank are some of the descriptive themes identified during cohesion consensus throughout the foundational capabilities. Determining cohesion levels to develop policies and guidelines is an added tool in the development of a biobank as well as facilitating a “successful” implementation

