

Opportunities for promoting open data in the Caribbean through biobanks

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ABSTRACT

The establishment of a biobank in the Caribbean represents a vital opportunity to enhance biomedical research and tackle health issues in the area. The Caribbean's unique genetic diversity, shaped by migration and environmental factors, underscores a well-managed biobank's potential impact on global health, especially for underrepresented groups. This paper examines biobanking's potential in the Caribbean, focusing on precision medicine, public health improvements and regional scientific self-sufficiency. It analyzes successful models such as the UK Biobank, the All of Us Research Program at the United States' National Institutes of Health, and Human Heredity and Health in Africa (known as H3Africa), hosted at the University of Cape Town, pinpointing key lessons on data-sharing, ethical governance and infrastructure that could be applied to the Caribbean context. The UK Biobank and H3Africa are relevant examples due to their contributions to large-scale data and health research in diverse populations. The UK Biobank project is a large-scale study with deep genetic and phenotypic data from about 500 000 participants in the United Kingdom. It offers unprecedented insights into health data through extensive follow up and collection of genome-wide genotype data. H3Africa focuses on genomics research that addresses health disparities among African populations, which parallels the Caribbean's challenges. Its ethical governance and community engagement focus are crucial for Caribbean biobank development. This article highlights the challenges of developing biobanks, including ensuring sufficient sample storage and data security, and the need for strong governance. It recommends solutions that involve regional collaboration, stakeholder engagement and increased investment in infrastructure. Establishing a Caribbean biobank with equitable data-sharing principles can significantly enhance global genomic data sets and ensure that the benefits of precision medicine reach the Caribbean. This study promotes a strategic, ethical and inclusive approach to biobanking for long-term success.

Keywords

Biobanks; precision medicine; health policy.

In recent years, biobanks have emerged as powerful tools in biomedical research, offering expansive repositories of genetic and health information that drive scientific discovery and improve health outcomes (1, 2). For the Caribbean, with its rich genetic diversity and unique health challenges, the establishment of national or regional biobanks could represent a transformative opportunity (3). By exploring the possibilities

offered by a biobank and how an open access data policy might enhance research and innovation, this paper aims to shed light on the potential for a Caribbean biobank to contribute significantly to global health research. Insights are drawn from international models; their relevance to the Caribbean context is discussed; and challenges and opportunities associated with implementing an open data policy are identified.

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THE PROMISE OF BIOBANKING

Biobanks play crucial roles in contemporary biomedical research by providing a diverse repository of biological samples and associated health data (4, 5). These resources are instrumental in genetic research, facilitating the exploration of genetic factors in diseases and the identification of potential therapeutic targets. They also play a vital role in public health research by enabling analyses of health trends and the effectiveness of public health interventions. Recently, there has been an increasing focus on precision medicine, which aims to personalize disease prevention and treatment strategies based on an individual's unique genetic, molecular and environmental characteristics (6, 7). This approach leverages advanced technologies, including genomics, proteomics and metabolomics, to develop tailored treatment plans (1, 2). However, there are significant disparities in the availability of genomic data, with the majority originating from populations in North America and Europe. This underrepresentation of certain populations raises concerns about the effectiveness of treatments and the potential for misdiagnoses in these populations, such as individuals of African ancestry, who account for less than 3% of data in genomic studies (8).

The Caribbean, with its distinct genetic diversity, is shaped by a history of forced migration, colonial oppression and underdevelopment. Its resilient and mostly heterogeneous populations live in a setting vulnerable to hurricanes, volcanoes and other environmental factors. Its people have been impacted by an epidemiological transition from malnutrition and communicable diseases to having significantly high rates of noncommunicable diseases. A well-established regional biobank would confer significant benefit to the Caribbean's people. Such a resource could enhance understanding of the genetic and environmental determinants of prevalent health conditions in the area. The Caribbean comprises island nations and parts of mainland South America; the islands are classified as small island developing states (SIDS), and they also face socioeconomic vulnerabilities that complicate efforts to address health issues equitably (3, 9). Understanding the Caribbean's genetic diversity requires an understanding of its distinct research needs and the specific challenges that require close attention. The heterogeneous sociodemographic contexts across the Caribbean also add to the disparities in infrastructure, access to health care, capacity development, training potential and research capacity. This variability demands the development of adaptable strategies to ensure that a regional biobank can effectively cater to diverse populations and address their unique requirements. Such strategic frameworks are essential for the effective implementation and utilization of a biobank, as a uniform approach may prove inadequate for the complexities of the area.

Historically, the Caribbean has been underserved in genomics research, exacerbated by its colonial legacy, leading to marginalization and inequity in research resources and infrastructure. Although some research efforts exist in the area, these are often limited in scope or sustainability and rely on collaboration with international partners (3).

Establishing a comprehensive biobank from the SIDS across the Caribbean would address several challenges: it would provide the ability to consolidate biological samples from diverse populations within the area, enhance the statistical power of

research findings, build a cadre of locally trained experts and encourage investment in the essential infrastructure necessary to promote self-sufficiency in genomic research across the One Health landscape. Furthermore, a regional biobank could improve representation in global genomic data sets and ensure that Caribbean populations benefit from advances in precision medicine. The development of such a resource must be community-led, and this engagement should consider the ethical, legal and social implications specific to the broad Caribbean context. Issues of social justice, privacy and informed consent are critical and require careful attention to ensure equitable benefits and the meaningful involvement of local populations in shaping and conducting research.

INTEGRATING INTERNATIONAL MODELS OF DATA-SHARING

To effectively implement an open access data policy in the Caribbean, it is essential to draw lessons from successful international models, starting with a comprehensive legislative framework. Cooperation through the Caribbean Community (known as CARICOM) offers a vehicle for the development of a regulatory framework such as that utilized by the Estonian Biobank (10). The UK Biobank is also a leading example of managing extensive data sets from more than 500 000 participants. Its success is largely due to robust ethical and privacy safeguards, ensuring that data-sharing is conducted responsibly while upholding participants' confidentiality (11). Similarly, the All of Us Research Program, part of the United States' National Institutes of Health, has made significant strides in advancing precision medicine through broad data-sharing, emphasizing comprehensive participant consent processes that grant individuals control over their data (12). In a similar vein, the Human Heredity and Health in Africa initiative (H3Africa) offers valuable insights into data-sharing within a diverse, multicountry context. Established with support from the US National Institutes of Health and the Wellcome Trust, H3Africa has enabled genomic research across the African continent by building a network of regional biorepositories and a bioinformatics platform (12, 13). H3Africa's infrastructure supports the collection and distribution of high-quality biological specimens and data across 27 African countries, and includes more than 75 000 participants. H3Africa's success lies in its collaborative approach, which encourages data-sharing among African researchers while maintaining high ethical standards and ensuring that data are handled with sensitivity to local cultural contexts. This initiative has not only advanced research on diseases, such as kidney disease, AIDS and tuberculosis, but has also empowered African scientists to take a leading role in genomic research. The lessons from H3Africa demonstrate how regional collaboration and the development of standardized processes can create a sustainable and ethically sound framework for data-sharing, which could be adapted to meet the Caribbean's unique needs (12–14).

The International Cancer Genome Consortium offers another important model, providing open access to cancer genomics data and fostering global collaboration. This initiative has accelerated advances in cancer research, demonstrating the power of open data in fostering international scientific cooperation (15). The Global Alliance for Genomics and Health further supports this collaboration by developing frameworks to standardize

data-sharing practices and promote global partnerships (16). These frameworks could serve as valuable guides as the Caribbean develops its biobank infrastructure.

ADAPTING INTERNATIONAL LESSONS

While these international examples offer valuable insights, adapting them to the Caribbean context requires addressing specific regional challenges. Privacy and confidentiality are of utmost importance, necessitating robust data protection measures to safeguard sensitive genetic information. Implementing stringent data access controls and aligning with both local and international data protection regulations are crucial steps to prevent misuse and breaches (17). Building the necessary infrastructure and capacity for a biobank in the Caribbean will involve significant investment in technology, facilities and human resources. Securing funding and forming partnerships with international organizations and research institutions are critical to addressing these needs. Ethical and legal considerations, particularly in areas such as consent, data ownership and potential data misuse, must be carefully navigated to ensure alignment with local regulations and ethical standards. This is essential for maintaining public trust and ensuring a biobank's success.

The current global data-sharing mandates, which often emphasize minimal restrictions, can perpetuate inequities between researchers and countries. Data generated in low- and middle-income countries (LMICs) do not always result in commensurate benefits due to disparities in local research capacity and infrastructure. These mandates can reinforce asymmetries in power and privilege, creating a dynamic in which researchers in high-income countries benefit disproportionately while researchers in LMICs face challenges that could jeopardize their efforts (17, 18). To address these challenges, a shift is necessary towards equitable data-sharing that acknowledges and mitigates structural inequities in the global health research landscape (19).

Experiences from biobanking in Latin America elucidate both the challenges and effective strategies pertinent to the establishment of a biobank in the Caribbean context. Brazil, for instance, has emerged as a leader in developing one of the area's most well-organized biobanking frameworks, underpinned by comprehensive regulations that systematically address ethical, technical and legal matters. This clarity within the regulatory landscape has encouraged robust governance structures, facilitating collaboration and promoting high-impact research while simultaneously enhancing international partnerships (20). Conversely, nations such as Mexico and Puerto Rico have encountered significant obstacles, stemming from the absence of dedicated biobanking regulations, which restricts standardization, complicates data protection measures and hinders the formal recognition of biobanks as legitimate legal entities (21). Accordingly, the Caribbean stands to gain substantially from custom-tailored biobanking regulations that would provide analogous structural support, thereby assuring consistency and compliance while fostering research independence.

Funding constraints represent a common barrier among numerous Latin American biobanks, frequently obstructing infrastructure advancement and long-term viability. Notwithstanding these limitations, collaborative funding paradigms that incorporate governmental support alongside partnerships

with international research institutions exhibit potential in mitigating resource deficiencies (21). For example, Brazil's achievements with multicentric biobanks illustrate the efficacy of harnessing local initiatives in conjunction with global expertise, an approach that could serve as a model for Caribbean endeavors aiming to secure essential funding. Ethical considerations, particularly those pertaining to community involvement, data ownership and culturally sensitive consent protocols, are equally crucial in fostering public trust (20, 21). The Mexican Biobank of Metabolic Diseases (known as BIOMEM) serves as a salient example, demonstrating how the alignment of consent processes with indigenous cultural values can bolster public support and regulatory approval. These instances highlight that transparent, community-driven methods coupled with adaptable governance and strategic alliances, will be imperative for the successful establishment of a Caribbean biobank, ensuring that it meets international benchmarks while effectively catering to the distinctive needs of the area's population (22).

CHALLENGES IN SAMPLE STORAGE

A significant challenge in establishing biobanking infrastructure in the Caribbean is the inadequate capacity for proper sample storage. Many Caribbean nations lack the infrastructure necessary for long-term storage of biological samples, leading to a reliance on international facilities, predominantly in high-income countries, for sample management and storage (3, 23). This dependence complicates the logistics of sample retrieval and raises substantial concerns about the control, access and ownership of these resources. The reliance on external (i.e. out-of-region) storage solutions introduces risks, including potential breaches of trust, and uncertainties regarding the future use of samples once they have been relocated from local custody. Additionally, there are concerns that material transfer agreements and governance mechanisms may not be adequately enforced, potentially leading to inequities in sample use and benefit-sharing (24).

The absence of standardized protocols for biobanking across Caribbean nations further exacerbates these challenges. Variabilities in sample collection, processing and storage practices create barriers to effective regional collaboration and can compromise the integrity of stored samples. Establishing area-wide standards is imperative to ensure uniformity and quality in biobanking operations. Investing in local infrastructure to build or upgrade biobanking facilities is crucial to overcoming these challenges. Enhancing local storage capacity would enable Caribbean nations to retain control over samples, ensuring that they are accessible to local researchers and used in ways that benefit the area. Moreover, developing the capacity to negotiate equitable material transfer agreements and other collaborative agreements is vital to ensuring that the benefits of biobanking are distributed and that local institutions are not disadvantaged in international partnerships.

In summary, addressing the challenges associated with sample storage is essential for the successful implementation of biobanking initiatives in the Caribbean. Focusing on enhancing local infrastructure, standardizing protocols and strengthening governance frameworks will help establish a more sustainable and equitable biobanking system that supports regional research and safeguards local interests.

ETHICAL CONSIDERATIONS: CHALLENGES AND OPPORTUNITIES

Biobanking presents a multitude of ethical dilemmas, especially within LMICs, including those in the Caribbean. These ethical challenges cover a broad range of issues, such as the adequacy of informed consent, concerns regarding privacy and data security, and the equitable distribution of benefits (24, 25). Although biobanks hold significant potential to advance medical research – particularly in the context of tackling global health crises – their operations often take place in environments characterized by inadequate or inconsistent regulatory oversight (26). This is particularly alarming in areas faced with socioeconomic disparities and cultural differences, which complicate the process of securing informed consent and may expose vulnerable populations to the risk of exploitation or harm (25, 27). However, in many LMICs and SIDS, individuals may lack a comprehensive understanding of the long-term implications of contributing to a biobank, especially when this involves sharing genetic data that could be at risk of re-identification. Among smaller Caribbean populations, where genetic homogeneity may increase the risk of re-identification, the likelihood of exposing sensitive health information is further compounded (28). The distribution of these biological materials to international research networks or commercial entities also complicates the situation, often obscuring issues related to ownership, control and the potential for misuse.

A paramount ethical consideration is the risk of exploiting economically disadvantaged groups, many of whom may participate in biobank research due to having limited access to health care or for financial incentives. In such contexts, it is crucial to ensure that the benefits arising from biobank research are equitably shared, particularly access to medical innovations or treatments (27). Ultimately, governance structures for biobanks in the Caribbean and in LMICs must prioritize community engagement and capacity-building. This involves establishing transparent protocols to govern the collection and use of biological materials, ensuring that participants retain the right to withdraw their consent and devising clear guidelines for the return of results, particularly in the event of genetic findings that have health implications. The ethical framework guiding biobanks should be tailored to their unique sociocultural, economic and health contexts, focusing on creating systems that benefit local populations without exploitation. By addressing these ethical challenges, biobanks in the Caribbean can contribute to progress being made in global health while safeguarding and respecting the rights and welfare of local communities.

GOVERNANCE CONSIDERATIONS

Establishing biobanking infrastructure in Caribbean LMICs involves unique governance challenges, particularly related to transparency, benefit-sharing and participants' welfare. Comprehensive governance frameworks are necessary to manage participants' contributions fairly, especially when it comes to residual tissue collected for diagnostic or treatment purposes. Without explicit regulatory guidance, biobanks might repurpose this tissue for research without consent, raising ethical concerns. Clear policies are needed to delineate the acceptable uses of residual tissue and to ensure transparency and respect for the donor's intent (28).

A primary governance challenge is ensuring equitable benefit-sharing. Often, the scientific and health benefits from biobanking disproportionately favor higher-income institutions, while local communities bear the burdens associated with participation, such as the collection of their samples and potential privacy risks. To foster ethical and sustainable operations, Caribbean biobanks should adopt frameworks that prioritize local benefit-sharing, which includes commitments to return relevant research findings and health care innovations to the populations providing samples.

Additionally, biobanks must address public misconceptions that can blur the lines between research, diagnostics and treatment. Many participants, particularly in underserved communities, may perceive biobanks as extensions of clinical care, which could create unrealistic expectations about directly benefiting from participation (29). Clear, accessible communication regarding the research-focused nature of biobanking is crucial to manage expectations and build public trust.

In summary, robust governance frameworks for Caribbean biobanks should emphasize transparency, equitable benefit-sharing and protections for participants. By addressing challenges related to the use of residual tissue, public misconceptions, privacy and socioeconomic inequities, biobanks can create an infrastructure that respects both individual and collective interests.

DATA STORAGE: INFRASTRUCTURE AND CONSIDERATIONS

The success of a biobank, particularly within the Caribbean context, hinges not only on the collection of biological specimens but also on the secure and efficient storage of the substantial volume of data linked to these samples. Data storage in biobanking encompasses the safeguarding of genetic information, patient data and other vital metadata essential for research and future retrieval. Given the considerable disparities in technological infrastructure across the Caribbean, the establishment of resilient data storage systems assumes paramount importance. Biobanks necessitate storage solutions that guarantee data integrity, security and enduring accessibility (4). This entails the utilization of high-capacity storage systems adept at managing extensive data sets, including high-throughput sequencing data and various 'omics information. These storage solutions should adhere to ethical standards and legal prerequisites, safeguarding patient confidentiality and ensuring judicious data utilization. Furthermore, in light of the geographical challenges prevailing in the Caribbean, notably the risk of natural disasters such as hurricanes, data storage systems should demonstrate resilience and encompass reliable backup strategies (28, 29). While cloud-based storage presents a viable option that offers scalability and disaster recovery, it is contingent upon a dependable internet infrastructure, which may pose limitations in certain parts of the Caribbean. Thus, hybrid models integrating local storage with cloud-based backup may represent the most practical approach (30, 31). Moreover, the harmonization of data management systems with biobanking operations ensures not only secure storage but also straightforward data retrieval and usability for research purposes. This necessitates scrupulous planning and the adoption of standardized data formats and protocols that are conducive to data-sharing and system interoperability among researchers locally and globally. The

establishment of a biobank in the Caribbean requires a strategic approach to data storage that addresses the area’s distinctive challenges, while safeguarding and ensuring enduring accessibility to the biobank’s data assets for future research endeavors.

In the current context, the Pan American Health Organization’s Information Systems for Health Initiative Maturity Model (IS4H-MM) emerges as a pivotal framework for advancing health information systems and addressing the associated challenges (32, 33). IS4H-MM delineates a roadmap for the progression of health information systems, illustrating how countries and organizations can elevate their capacities to operate, engage with and derive benefits from these systems amid the ongoing information and knowledge revolution (32–34). By integrating IS4H-MM, the Caribbean can strategically steer the development of its biobank infrastructure, ensuring that data management practices align with global standards. This framework will fortify the security and accessibility of biobank data while mitigating regional challenges, ultimately fostering a more efficacious biobank that bolsters future research endeavors.

OPPORTUNITIES TO PROMOTE OPEN DATA

Despite these challenges, there are significant opportunities for advancing open data in a Caribbean biobank. Regional collaboration stands out as a key opportunity, with partnerships that could offer technical support, funding and access to best practices. The Global Alliance for Genomics and Health, for example, offers standardized protocols and tools

for data-sharing, which can enhance a biobank’s capacity and sustainability (35). Community engagement is vital for fostering trust and ensuring that the biobank meets local needs. By involving local communities in a biobank’s development and operation, a sense of ownership and support can be cultivated. This can be achieved through educational campaigns and public forums that highlight the benefits of biobanking and address concerns about data privacy and usage. Capacity-building is also essential for strengthening a biobank’s operational capabilities. Investing in training and infrastructure will enhance data management and enable Caribbean researchers to lead secondary analyses and contribute to publications. Partnerships with international research institutions can further facilitate knowledge exchange and collaborative research projects. Practices identified by LMIC stakeholders to promote equity in data-sharing include appropriately recognizing the contributions of primary researchers, ensuring the fair distribution of benefits and burdens, fostering capacity-building collaborations and securing adequate funding for data-sharing activities. Structural changes are needed to implement these practices effectively, such as reforming how researchers are rewarded and integrating metrics that recognize the use of shared data.

RECOMMENDATIONS FOR EFFECTIVE IMPLEMENTATION

A comprehensive and strategic approach is essential to foster biobanking in the Caribbean. Table 1 outlines crucial strategic recommendations to establish and implement biobanks within

TABLE 1. Strategic recommendations for effective implementation of biobanks in the Caribbean

Recommendation	Action points	Comments
Conduct a comprehensive contextual analysis.	<ul style="list-style-type: none">• Conduct a thorough assessment of each Caribbean country’s socioeconomic, cultural and health care landscapes.• Identify variations in local governance structures and infrastructure, and identify community-specific needs.	Tailoring biobank strategies to each country’s specific context ensures that implementation is feasible and sustainable. This will also enhance community engagement and local ownership, ensuring that biobank initiatives align with national priorities.
Develop comprehensive data-sharing and governance policies.	<ul style="list-style-type: none">• Create robust data-sharing policies with clear guidelines on data access, privacy protection and ethical use.• Ensure informed consent and data confidentiality are integral to governance frameworks.	Data-sharing policies must integrate international best practices while addressing local needs. Ensuring that participants’ rights are protected through culturally sensitive consent processes is key to building trust in biobank initiatives.
Strengthen research ethics frameworks.	<ul style="list-style-type: none">• Establish dedicated ethical oversight bodies.• Broaden the scope of ethics governance to include all research with human participants involving materials stored in a biobank.	Ethical oversight ensures that the research conducted adheres to the highest standards, which is crucial in maintaining public trust. By strengthening ethics governance, research will contribute positively to both scientific and social development in the Caribbean.
Invest in infrastructure and build robust governance structures.	<ul style="list-style-type: none">• Secure funding for technology, facilities and skilled personnel to support biobank operations.• Develop strong governance structures to ensure ongoing oversight of biobank activities.	Infrastructure investment is crucial for a biobank’s success. Establishing a governance framework that ensures compliance with ethical and regulatory standards is essential for the sustainability of a biobank and its operational success.
Foster regional and international partnerships.	<ul style="list-style-type: none">• Cultivate partnerships with regional and international entities.• Collaborate with organizations that offer expertise and resources and follow best practices.	Regional and international collaborations will enhance a biobank’s capacity, provide knowledge exchange and help integrate global best practices while addressing local health priorities and fostering collaboration.
Engage stakeholders and promote community awareness.	<ul style="list-style-type: none">• Involve stakeholders such as policy-makers, researchers and community members in developing a biobank.• Implement educational campaigns and public forums to raise awareness.	Community engagement and awareness are critical for ensuring that biobank initiatives align with local values; they are also important to building trust. Stakeholder involvement helps address concerns and ensures ethical practices throughout a biobank’s life cycle.

(Continued)

TABLE 1. (Cont.)

Recommendation	Action points	Comments
Address ethical and cultural considerations.	<ul style="list-style-type: none">• Implement informed consent processes that respect local cultural sensitivities.• Ensure that data confidentiality and privacy protections are upheld.	Consideration of ethical and cultural norms is essential to ensure that participants' rights are respected and to promote the success of biobank initiatives. Adapting informed consent processes to the local context ensures that participants are fully aware of the implications of contributing biological materials.
Develop educational and training programs.	<ul style="list-style-type: none">• Establish training programs for biobank staff, researchers and stakeholders.• Ensure that programs include best practices in biobanking and data management, and information about ethical considerations.	Education and training programs are necessary to build a knowledgeable workforce. Providing continual learning opportunities will ensure that stakeholders remain informed about developments in biobanking and are equipped to manage and analyze data effectively.
Ensure long-term sustainability and impact.	<ul style="list-style-type: none">• Secure diverse funding sources to ensure long-term viability.• Regularly evaluate a biobank's impact, effectiveness and adherence to ethical standards.	Long-term sustainability is key to the ongoing success of biobanks. By securing funding from diverse sources and implementing regular reviews, biobanks can adapt to evolving needs and ensure continued ethical compliance.
Implement national regulations and standards.	<ul style="list-style-type: none">• Develop national regulations addressing all aspects of biobank research, including consent, data access and participant protection.• Ensure that regulations adhere to international quality standards and address specimen integrity.	National regulations are crucial for ensuring that biobanks operate ethically and effectively. These regulations should align with international standards while respecting local contexts and ensuring the protection of participants.
Invest in capacity- building and training programs.	<ul style="list-style-type: none">• Focus on specialized education in bioinformatics, data management and biobank operations.• Collaborate with international experts to deliver workshops and hands-on training.	Capacity-building ensures that local professionals possess the necessary skills to operate and manage a biobank. Providing specialized training will enhance the Caribbean's ability to manage and utilize biobank data effectively, by incorporating both global best practices and regional needs.

Source: Table developed by the authors based on their research.

the Caribbean. Each recommendation is accompanied by action points detailing the practical measures required for execution. These action points are specifically formulated to address the distinct socioeconomic, cultural and health care environments of the Caribbean, ensuring that biobanks are aligned with the needs of various Caribbean nations. Furthermore, the Comment column provides additional context and justification for each recommendation, explaining its significance and applicability within the Caribbean context. The information in the table seeks to assist stakeholders in navigating the complex process of biobank development, thereby promoting long-term sustainability and success. By following the recommendations outlined in Table 1, the Caribbean can establish biobanks that supports innovative research while respecting ethical standards and addressing regional needs. Effective data-sharing, robust governance and stakeholder engagement are critical for a biobank's success and its contribution to advancing global health research. Integrating these strategies will help build a sustainable and ethically sound biobanking infrastructure in the Caribbean.

CONCLUSIONS

Establishing national biobanks or a regional biobank in the Caribbean holds significant promise for advancing biomedical research and addressing regional health challenges. By adopting an open access data policy and learning from international models, the Caribbean can enhance its research capabilities and drive innovation. However, careful consideration of privacy, ethical and practical issues is essential to ensure a biobank's success and sustainability. Addressing structural inequities and promoting capacity-building in data-sharing practices are critical to ensuring that the benefits of biobank data are equitably distributed.

Similar to their counterparts in Latin America, public health agencies and funding bodies in the Caribbean face significant challenges in fully implementing open access data for a biobank (20, 21). These challenges include limited financial resources, inadequate infrastructure and varying regulatory frameworks that try to balance the need for data transparency with the necessity of privacy protection. Many nations in the Caribbean have enacted strict data protection laws to safeguard individual privacy, which complicates the unrestricted sharing of sensitive health data. Additionally, these legal frameworks often require extensive informed consent procedures, data anonymization protocols and ethical review processes before any data can be shared, thus hindering the progress of open data initiatives.

Moreover, public health agencies in the Caribbean need to improve their technical infrastructure and expertise. Despite opportunities to share data through international collaboration, effectively managing and analyzing large-scale genomic and health data sets remain significant challenges. For example, there is frequently a lack of local technical proficiency in bioinformatics, data security and sustainable data management practices, all of which are essential for maintaining the integrity and accessibility of biobank data over time. To make biobank data truly accessible, significant investments in both human capital and technological resources are essential. Considering these challenges, Caribbean public health agencies and funding bodies must invest in developing sustainable data-sharing models that can protect participants' privacy while also enabling the use of data for research purposes. This requires adopting global best practices, such as the FAIR principles (referring to digital assets that are findable, accessible, interoperable and reusable), that create a balance between openness and the need for strong ethical oversight (36). By implementing these measures, the Caribbean can begin to establish a biobank

data-sharing paradigm that fosters both innovation and ethical governance.

Future efforts should focus on addressing these challenges while maximizing the benefits of biobank data for research and public health. Collaborative partnerships with international bodies, such as H3Africa, could also play a pivotal role in developing these frameworks. By addressing these challenges, the Caribbean can maximize the benefits of biobank data for advancing public health and biomedical research, while ensuring that the area is equipped to meet the ethical and logistical demands of open access data.

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Oportunidades para promover los datos abiertos en el Caribe por medio de los biobancos

RESUMEN

El establecimiento de un biobanco en el Caribe representa una importante oportunidad para mejorar la investigación biomédica y abordar los problemas de salud en esa subregión. La diversidad genética particular del Caribe, moldeada por la migración y los factores ambientales, pone de relieve el impacto que puede tener un biobanco bien administrado en la salud mundial, en especial para los grupos subrepresentados. En este artículo se examina el potencial que ofrecen los biobancos en el Caribe, haciendo hincapié en la medicina de precisión, las mejoras en la salud pública y la autonomía científica regional. Se analizan algunos modelos exitosos, como el Biobanco del Reino Unido, el Programa de Investigación All of Us en los Institutos Nacionales de Salud de Estados Unidos, y Herencia y Salud Humana en África (H3Africa, por su sigla en inglés, alojado en la Universidad de Ciudad del Cabo), y se indican algunas enseñanzas clave sobre el intercambio de datos, la gobernanza ética y la infraestructura que podrían aplicarse en el contexto del Caribe. El Biobanco del Reino Unido y H3Africa son ejemplos relevantes debido a sus contribuciones a los datos a gran escala y la investigación en materia de salud en diversos grupos poblacionales. El proyecto del Biobanco del Reino Unido es un estudio a gran escala con datos genéticos y fenotípicos profundos de aproximadamente 500 000 participantes en el Reino Unido, que ofrece una perspectiva sin precedentes sobre los datos de salud mediante la recopilación y el seguimiento amplios de datos genotípicos sobre secuenciación pangenómica. H3Africa se centra en la investigación genómica que aborda las inequidades de salud entre las poblaciones africanas, similares a los desafíos que se enfrentan en el Caribe. La gobernanza ética y la participación comunitaria son cruciales para el desarrollo de los biobancos en el Caribe. En este artículo se destacan los retos del desarrollo de los biobancos, incluida la garantía de que el almacenamiento de muestras y la seguridad de los datos sean suficientes, así como la necesidad de una gobernanza sólida. Se recomiendan algunas soluciones como la colaboración regional, la participación de las partes interesadas y una mayor inversión en infraestructura. El establecimiento de un biobanco en el Caribe con principios equitativos de intercambio de datos puede mejorar de manera considerable los conjuntos de datos genómicos mundiales y garantizar que los beneficios de la medicina de precisión lleguen al Caribe. En este estudio se promueve un enfoque estratégico, ético e inclusivo de los biobancos para el éxito a largo plazo.

Palabras clave

Bancos de muestras biológicas; medicina de precisión; política de salud.

Oportunidades para promover dados abertos no Caribe por meio de biobancos

RESUMO

A implementação de um biobanco no Caribe representa uma oportunidade vital para aprimorar a pesquisa biomédica e lidar com problemas de saúde na região. A extraordinária diversidade genética do Caribe, moldada pela migração e por fatores ambientais, ressalta o potencial impacto de biobancos bem gerenciados na saúde mundial, especialmente em grupos sub-representados. Este documento examina o potencial dos biobancos no Caribe, com destaque para medicina de precisão, melhorias na saúde pública e autossuficiência científica na região. Analisa, ainda, modelos bem-sucedidos — como o UK Biobank, o Programa de Pesquisa All of Us dos Institutos Nacionais de Saúde dos Estados Unidos e a iniciativa Hereditariedade e Saúde Humana na África (H3Africa, na sigla em inglês), sediada na Universidade da Cidade do Cabo —, identificando as principais lições em termos de compartilhamento de dados, governança ética e infraestrutura que poderiam ser aplicadas ao contexto do Caribe. O UK Biobank e a H3Africa são exemplos pertinentes devido às suas contribuições para dados em larga escala e pesquisa em saúde com populações diversas. O projeto UK Biobank é um estudo em grande escala que utiliza dados genéticos e fenotípicos aprofundados de cerca de 500 mil participantes do Reino Unido, oferecendo insights inéditos sobre dados de saúde por meio de extenso acompanhamento e coleta de dados de genótipo de todo o genoma. A iniciativa H3Africa se concentra na pesquisa genômica para abordar disparidades de saúde entre as populações africanas, com desafios semelhantes aos enfrentados no Caribe. A governança ética e o foco no envolvimento da comunidade são cruciais para o desenvolvimento de biobancos no Caribe. Este artigo destaca os desafios envolvidos na criação de biobancos, inclusive no que se refere à garantia de capacidade adequada de armazenamento de amostras, à segurança dos dados e à necessidade de uma governança robusta. Recomenda soluções que envolvem colaboração regional, participação das partes interessadas e maior investimento em infraestrutura. A implementação de um biobanco caribenho fundamentado em princípios equitativos de compartilhamento de dados pode aprimorar significativamente os conjuntos de dados genômicos mundiais e assegurar que os benefícios da medicina de precisão cheguem ao Caribe. Este estudo promove uma abordagem estratégica, ética e inclusiva da gestão de biobancos para que tenham sucesso em longo prazo.

Palavras-chave Bancos de espécimes biológicos; medicina de precisão; política de saúde.