

SHARE: An ethical framework for equitable data sharing in Caribbean health research

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ABSTRACT

Data sharing increasingly underpins collaborative research to address complex regional and global public health problems. Advances in analytic tools, including machine learning, have expanded the potential benefits derived from large global repositories of open data. Participating in open data collaboratives offers opportunities for Caribbean researchers to advance the health of the region's population through shared data-driven science and policy. However, ethical challenges complicate these efforts. Here we discuss fundamental challenges that threaten to impede progress if not strategically addressed, including power dynamics among funders and researchers in high-income countries and Caribbean stakeholders; research and health equity; threats to privacy; and risk of stigma. These challenges may be exacerbated by resource and infrastructure limitations often seen in small island developing states (SIDS) and low- and middle-income countries. We propose a framework for **S**afeguarding **H**ealth **A**nd **R**esearch data sharing by promoting **E**quity (SHARE) for Caribbean researchers and communities participating in shared data science. Using the SHARE framework can support regionally relevant and culturally responsive work already underway in the region and further develop capacity for intentional sharing and (re)use of Caribbean health data.

Keywords

Ethics; information dissemination; equity; developing countries; Caribbean region.

The Caribbean has achieved important advances in infrastructure and capacity for data sharing in health. Most Caribbean countries and territories have adopted data protection legislation (Table 1), including Antigua and Barbuda (2013), The Bahamas (2003), Barbados (2019), Belize (2021), Bermuda (2016), British Virgin Islands (2021), Cayman Islands (2017), Grenada (2023), Guyana (2023), Jamaica (2020), and Saint Kitts and Nevis (2023) (1). Accordingly, countries and academic institutions in the region now have research ethics committees whose mission includes evaluating risks and benefits of data sharing for human participant research, and several regional bioethics organizations (Table 1) provide support and continuing professional education for researchers and ethics committee members. These country-level regulatory efforts complement established international regulations, such as the European General Data Protection Regulation (GDPR), and guidelines, such as those of the Council for International Organizations of

Medical Sciences (CIOMS). Broadly speaking, these documents seek to promote respect for persons and communities whose data are shared and to promote equity in health research (2).

Data sharing in medical and public health research can advance evidence-based improvements in health care and maximize benefits derived from data for which the costs and risks of collection have already been realized. Potential benefits include demonstrating reproducibility of important findings; repurposing data for other research questions; identifying needs for future research; and applying evidence to clinical, funding, regulatory, and policy decision-making (2–4). The “data-sharing ecosystem” encompasses various entities: facilitators, including providers of infrastructure, analysis tools, indexes, and guidelines; data suppliers (researchers, health systems, and publishers); and end-users, including researchers, practitioners of evidence-based health care, and citizen scientists (5). These entities operate in or are regulated by open or controlled

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TABLE 1. Ethics resources for data sharing in the Caribbean

Organizational resources	URL
Bioethics Society of the English-Speaking Caribbean (BSEC)	https://www.bioethicscaribe.com/
Caribbean Network of Research Ethics Committees (CANREC)	https://carpha.org/What-We-Do/Networks/CANREC/Caribbean-Network-of-Research-Ethics-Committees
PAHO/WHO Regional Program on Bioethics	https://www.paho.org/en/bioethics
Data protection legislation	
Antigua and Barbuda, Data Protection Act, 2013	https://laws.gov.ag/wp-content/uploads/2019/02/a2013-10.pdf
Bahamas, Data Protection (Privacy of Personal Information) Act, 2003	https://www.dataguidance.com/sites/default/files/data_protection_act_2003_0.pdf
Barbados, Data Protection Act, 2019	https://www.barbadosparliament.com/uploads/bill_resolution/7b81b59260896178b5aa976fdb87bfee.pdf
Belize, Data Protection Act, 2021	https://www.nationalassembly.gov.bz/wp-content/uploads/2021/12/Act-No-45-of-2021-Data-Protection-Act.pdf
Bermuda, Personal Information Protection Act, 2016	https://www.gov.bm/sites/default/files/Personal-Information-Protection-Act-2016.pdf
Bonaire, Sint Eustatius, and Saba (BES islands), Personal Data Protection Act, 2010	https://wetten.overheid.nl/BWBR0028067/2015-01-01
British Virgin Islands, Data Protection Act, 2021	https://eservices.gov.vg/gazette/sites/eservices.gov.vg.gazette/files/newattachments/Act%20No.%203%20of%202021-Data%20Protection%20Act%2C%202021.pdf
Grenada, Data Protection Act, 2023	https://grenadaparliament.gd/storage/2023/03/Data-Protection-Bill-2023-8-3-23-with-HOR-amendments-Final.pdf
Guyana, Data Protection Act, 2023	https://www.dataguidance.com/sites/default/files/23760-act_no._18_of_2023_1.pdf
Jamaica, Data Protection Act, 2020	https://japarliament.gov.jm/attachments/article/339/The%20Data%20Protection%20Act,%202020.pdf
Saint Kitts and Nevis, Data Protection Act, 2023 (Not yet in force)	https://www.dataguidance.com/sites/default/files/data_protection_act_5_of_2018.pdf
Trinidad and Tobago, Data Protection Act, 2011 (Partially proclaimed)	https://www.dataguidance.com/sites/default/files/ln2021_220.pdf NB: "only Part One, Sections 1 to 6, and Part Two, Sections 7 to 18, 22, 23, 25(1), 26 and 28, and Part Three, Section 42(a) and (b) of the Act have been partially proclaimed by Legal Notice 2 of 2012 and by Legal Notice 220 of 2021" https://www.dataguidance.com/jurisdiction/trinidad-and-tobago [accessed 30 March 2024]

Source: Prepared by the authors.

mechanisms for direct sharing of data (5). The promotion of open data has been successful in subsections of the global research community (e.g., United States Medical Information Commons, H3Africa Consortium, and UK Biobank), but truly global data sharing remains aspirational (6).

Activities under the rubric of data sharing globally are increasing in complexity and scope, a process arguably catalyzed by the COVID-19 pandemic (2). However, the distribution of key activities, resources, and legal and ethical environments for data sharing varies considerably across regions (6). In the Caribbean, intra- and extra-regional data sharing is an emerging practice, with evolving organizational and governance mechanisms. Exemplar efforts include the Eastern Caribbean Health Outcomes Research Network (ECHORN), a first-of-its-kind regional cohort study producing shareable data for chronic disease research in Barbados, Puerto Rico, Trinidad and Tobago, and the United States Virgin Islands (7–9). These achievements, in partnership with the Yale Transdisciplinary Collaborative Center for Health Disparities Research focused on Precision Medicine (Yale-TCC), have advanced “participatory informatics” supporting health research for understudied Caribbean and diaspora communities. The work is facilitated by a Caribbean-based data sharing work group aiming to identify relevant data sources and facilitate public sharing of de-identified interoperable data with the wider Yale-TCC team (10). Further, regional health research priorities (e.g., climate health and genomics) also stand to benefit from more robust data sharing with global colleagues. Caribbean research leaders in these areas are articulating ethical considerations for

present and future data sharing (11–12). We aim to contribute to this discussion by reviewing challenges associated with data sharing by Caribbean governments and researchers to propose a regionally relevant ethical framework informed by international structures to advance ethical and equitable data sharing responsive to Caribbean realities.

THE SAFEGUARDING HEALTH AND RESEARCH DATA SHARING BY PROMOTING EQUITY (SHARE) FRAMEWORK

As technical capacity has expanded, funders, publishers, and governments have instituted policies requiring or strongly encouraging sharing of health data (13). These developments raise ethical considerations generally and more specific challenges in the context of low- and middle-income countries (LMICs), including the small island developing states (SIDS) of the Caribbean. Key areas of ethical practice identified by scientists producing and using shared data include considering potential consequences of data use and reuse; respect for rights and dignity of persons whose data are shared; procedural compliance, including maintaining data security; and professional conduct by researchers (14). We consider these issues with an emphasis on equity for Caribbean people and elucidate strategies for ethical collaboration among researchers working with Caribbean data using the Safeguarding Health And Research data sharing by promoting Equity (SHARE) framework, described below and summarized in Figure 1. These are: collaborate to benefit communities whose

FIGURE 1. The SHARE (Safeguarding Health And Research data sharing by promoting Equity) Framework for Advancing Data Sharing in Caribbean Health Research

Source: Prepared by the authors.

data are shared; promote justice for research participants; emphasize privacy protections; and promote equity and balance of power.

Concept 1: Collaborate to benefit communities whose data are shared

Establishing anticipated benefits for countries and communities where data are collected is a key ethical obligation (15). Engagement regarding health priorities and how participation in research might provide tangible benefit is especially important, since collaborations should lead to improvements in health care and maximize benefits of collecting and sharing data for which there are associated costs, including burden for Caribbean taxpayers and local funders. Therefore, communication with stakeholder communities (e.g., national health authorities, local health practitioners, consumers, and researchers) is essential to evaluate the balance of risks and potential benefits to people and health systems. Stakeholder consultation should be conducted early in the research planning process, while formulating research goals and objectives, and followed by robust monitoring, evaluation, and reporting processes. These actions minimize the likelihood of exploitative or extractive research, even when benefits outside the region are significant incentives. Although researchers stand to benefit from the ability to use and combine costly data, which may lead to research discoveries not possible with siloed regional studies, current and potential future benefits (including sharing of intellectual property rights) of data sharing for regional stakeholders should be clearly articulated. How that balance is determined may vary, and a broadly collaborative research model underpins both ethical practice and practical success of data-sharing initiatives. In this sense, collaboration is a crosscutting practice that enables achieving other ethically desirable data-sharing practices, including the others discussed in this article.

Concept 2: Promote justice for Caribbean research participants

Deontological imperatives to fairly manage distribution of risks and burdens require researchers to safeguard privacy, autonomy, and freedom to choose whether to participate in data sharing, especially in vulnerable communities. Promoting justice by providing equitable research benefits to studied communities may present greater challenges, particularly when populations are marginalized economically or in other ways that present barriers to access of research-driven improvements in health care. Notwithstanding these challenges, the duty to share benefits with communities from whom data are obtained is fundamental. With sufficient resources, data sharing promotes equity by increasing representativeness and participation from relatively neglected areas, benefiting understudied communities (e.g., African ancestry populations in cancer research) through enabling researchers to access and aggregate data from diverse populations to achieve signal detection, strengthen analysis and evaluation, and inform relevant programs and policy development in LMIC and SIDS settings, including the Caribbean, where a locally relevant evidence base is needed, especially in genetic and genomic research (12, 14, 16). However, threats to equity in health include possible commercial exploitation and stigmatization (especially in relatively small countries or communities). These threats are greater when decisions about research goals, funding, and design are made without adequate consultation with stakeholders to understand the needs, vulnerabilities, and desires of research participants and their communities (15).

Concept 3: Emphasize privacy protections in Caribbean communities

Promoting equitable distribution of risk and benefit requires practical actions by researchers to ensure that research protocols

and, especially, proactive and clear informed consent procedures provide flexibility for future use of data (16). Operational steps to set the stage for data sharing and reuse include careful preparation of research ethics protocols, and individual consent processes and materials to include explicit broad (or tiered) consent for storage and future use. Elements of broad consent include not promising to destroy or otherwise prevent data from being shared, and not promising that research will be restricted to particular areas of study. This requires affirmatively framing consent for broad future use of data with appropriate protections such as minimizing risk of re-identification. Further, researchers and their institutions can benefit from developing relationships with data repositories whose policies are acceptable and responsive to the concerns of the communities in which they work. This is especially important in the Caribbean, where data and biological samples frequently leave local jurisdictions for analysis elsewhere. These measures are emerging as best practices globally and should be incorporated in capacity-building for Caribbean researchers and research ethics committees.

Safeguarding private health information merits singular attention here, because the risk of re-identification is magnified in the Caribbean, where many communities are small, and even more so in the context of research concerning rare diseases, infrequent events, or small (or marginalized) demographic groups. Bioethics scholarship in this area originated in high-income countries (HICs) and has emphasized the need to achieve balance between risks to participants and benefits in terms of health for individuals and communities, including advances in diagnostics and treatment (17). More recently, emphasizing the promise of machine learning, research collaborators from both LMICs and HICs have argued that the cost of limiting access to data needed to produce medical innovations is disproportionate compared to the relatively small risks of re-identification and “especially great for developing countries where the barriers preventing inclusion in such databases will continue to rise, further excluding these populations and increasing existing biases that favor high-income countries” (18). Although some researchers have perceived or characterized these risks as minimal (14, 18), they are not trivial, and, particularly in small societies such as SIDS, risks to confidentiality and vulnerabilities of communities whose data are shared may be exacerbated.

Responsive stakeholder engagement is key to incorporate the hopes and concerns of communities whose data will be shared, which involves understanding empirical risk of re-identification and other contextual nuances that extend beyond probabilities. Among these are the role of health-related stigma in influencing risk and risk perception; the real and perceived security of private health information; local conditions regarding infrastructural capacity for secure collection, storage, and transmission of data; the role of local researchers in design and execution of data collection; and the capacity of local health systems to implement recommendations stemming from research findings.

Concept 4: Promote equity and balance of power for researchers

The recent work by Evertsz and colleagues (19) framing criteria for equitable data sharing through the lenses of stakeholders

in LMICs has particular relevance for the Caribbean. They extend consideration of potential benefits and threats to equity from individuals and communities to include health systems and local researchers. Existing data-sharing schemes, with few restrictions, contribute to a system in which “rich data production in LMICs does not necessarily translate to rich rewards” (19), especially when countries where data are collected have limitations in research capacity. Although Caribbean tertiary institutions, governments, and nongovernmental organizations have a demonstrable track record of building (and continuing to expand) research capacity (e.g., 7–12), disparities in research resources relative to HICs persist. Conceptualizing and achieving equitable data sharing necessitates leadership and intentional decision-making by Caribbean researchers, policymakers, and communities when considering collaborations with funders and researchers from outside the region. Exercising agency in this way requires a commitment to procedural fairness and epistemic justice when planning and conducting data sharing.

Both the 2023 scoping review by Evertsz and colleagues (19) and the proceedings of the 2018 Global Forum on Bioethics in Research (15) offer useful exploration of more specific risks and benefits of data sharing for LMICs that are likely to resonate with Caribbean stakeholders. Potential benefits for LMIC researchers include fair reward or compensation for data provided through their efforts, access to resources, fruitful collaborations with global colleagues, and increased research output (and associated career advancement). However, unfair data-sharing practices may perpetuate or exacerbate unfair power dynamics between LMICs and HICs. This is likely if research costs place disproportionate burden on limited resources and when LMIC researchers are relegated to a repetitive cycle of data production, in which lack of recognition negatively impacts professional reputation, funding acquisition, and, ultimately, career advancement (19). These unfavorable power dynamics present considerable barriers to data sharing and are disincentives for international research collaborations more broadly.

Researchers themselves have identified key supports for equitable collaboration that can facilitate data sharing in LMIC settings. These include equity-informed development and implementation of data-sharing policies and procedures; mechanisms to acknowledge all intellectual contributions to research, including those of primary researchers; academic recognition and promotion criteria that are aligned with data-sharing mandates; bolstered capacity for curation and secondary analysis of data in LMIC settings; sustainable and inclusive data platforms; and culturally informed review and governance of data-sharing activities (15). Similarly, constructing governance policies to include features supporting equity is possible and achievable with inclusive multisectoral consultation. Harmonized guidelines are important for transparency and accountability, and governance procedures should incorporate safeguards against exploitation when power differentials may privilege views of HIC researchers and funders (10, 15). However, governance structures require flexibility to be responsive to changes in technology and community contexts, and to provide adequate protections without placing unnecessary bureaucratic burden on researchers. These goals depend on sustained dialogue among regional and international stakeholders (9, 15). Proactive communication is essential for clear understanding of data ownership, subsequent rights to use and publication, and use of findings for improvements in health.

DISCUSSION AND RECOMMENDATIONS

Caribbean research participants and their communities benefit when research using open data results in improvements in available care and public health systems, particularly when the research process includes participant communities in formulation of data-sharing policies. Through participation in open data, the Caribbean also contributes to advances in global health. However, threats to equity in health include possible commercial exploitation, stigmatization (especially in relatively small countries or communities), and the potential that benefits derived from research are not shared with communities from which data were originally obtained. Power differentials can distort epistemological, methodological, and procedural understandings of data sharing that are potentially marginalizing to Caribbean researchers and participants. Open discussion of these considerations at all stages of research and data handling, from inception to reporting, promotes equity and quality of research processes and outcomes. The SHARE framework, presented here as an adaptation of emerging scholarship on ethical production and use of open data, may be useful for researchers and research ethics committees to evaluate benefits and risks of data sharing in the Caribbean.

Conclusion

Global collaborations producing and using open data have reached a level of maturity that requires guiding principles for

research partnerships involving LMICs and other resource-limited settings. The SHARE framework is useful for Caribbean researchers and their global partners to identify and address ethical concerns in the planning and conduct of research in Caribbean communities, as well as in the dissemination and application of research findings.

Caribbean thought leaders and stakeholders have opportunities to lead and shape these guiding principles informed by their professional expertise and lived experiences. The intensification of global knowledge sharing has the potential to improve health in the Caribbean, and strategic forecasting activities for sustainable development should include rapid expansion of research capacity responsive to the socioeconomic, cultural, and geographic vulnerabilities of the region. Ethical data sharing is a key driver of evidence-based advances in health and development.

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SHARE: Un marco ético para la puesta en común equitativa de datos de investigación en el ámbito de la salud en el Caribe

RESUMEN

Cada vez es más frecuente que la puesta en común de datos sirva de base para la investigación colaborativa destinada a abordar problemas complejos de salud pública, a nivel tanto regional como mundial. Los avances realizados en las herramientas analíticas, entre las que se encuentra el aprendizaje automático, han ampliado los posibles beneficios derivados de los grandes repositorios mundiales de datos de libre acceso. La participación en iniciativas de colaboración basadas en datos de libre acceso ofrece a los investigadores del Caribe la oportunidad de mejorar la salud de la población de la región por medio de la ciencia y las políticas basadas en la puesta en común de datos. Sin embargo, hay desafíos éticos que dificultan estos esfuerzos. En este artículo se analizan los principales desafíos que, si no se afrontan desde una perspectiva estratégica, podrían obstaculizar el progreso. Entre ellos se encuentran las dinámicas de poder entre los financiadores y los investigadores de los países de ingresos altos y las partes interesadas del Caribe; la investigación y la equidad en la salud; las amenazas a la intimidad; y el riesgo de estigmatización. Estos desafíos pueden verse acentuados por las limitaciones de recursos e infraestructura que suelen darse en los pequeños Estados insulares en desarrollo (PEID) y en los países de ingresos bajos y medianos. Se propone un marco para salvaguardar la puesta en común de datos de salud e investigación mediante la promoción de la equidad (SHARE, por su sigla en inglés) para los investigadores y las comunidades del Caribe que participan en la ciencia basada en datos de libre acceso. El uso del marco SHARE puede apoyar los trabajos de interés regional y dotados de una perspectiva cultural que están en curso, así como contribuir al desarrollo de la capacidad para poner en común y reutilizar de manera deliberada los datos de salud del Caribe.

Palabras clave Ética; difusión de la información; equidad; países en desarrollo; región del Caribe.

SHARE: estrutura ética para o compartilhamento equitativo de dados de pesquisa em saúde do Caribe

RESUMO

Cada vez mais, o compartilhamento de dados é a base da pesquisa colaborativa voltada para a resolução de problemas complexos de saúde pública de âmbito regional e mundial. Os avanços das ferramentas analíticas, como o aprendizado de máquina, expandiram os possíveis benefícios derivados de grandes repositórios mundiais de dados abertos. A participação em iniciativas colaborativas de dados abertos cria oportunidades para que os pesquisadores do Caribe promovam a melhoria da saúde da população da região por meio de ciência e políticas compartilhadas orientadas por dados. No entanto, há desafios éticos que complicam esses esforços. Neste artigo, discutimos os desafios fundamentais que ameaçam impedir o progresso caso não sejam abordados estrategicamente, como a dinâmica de poder entre financiadores e pesquisadores em países de alta renda e as partes interessadas do Caribe; a equidade em pesquisa e saúde; as ameaças à privacidade; e o risco de estigma. Esses desafios podem ser exacerbados pelas limitações de recursos e infraestrutura frequentemente observadas em pequenos Estados insulares em desenvolvimento (PEID) e em países de baixa e média renda. Propomos uma estrutura de proteção do compartilhamento de dados de pesquisa e saúde mediante a promoção da equidade (SHARE, sigla em inglês) para pesquisadores e comunidades do Caribe que estejam participando de iniciativas científicas com compartilhamento de dados. O uso da estrutura SHARE pode apoiar o trabalho regionalmente relevante e culturalmente apropriado já em andamento na região, além de desenvolver ainda mais a capacidade de compartilhamento intencional e (re) uso dos dados de saúde do Caribe.

Palavras-chave Ética; disseminação de informação; equidade; países em desenvolvimento; região do Caribe.
