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# Caribbean data-sharing initiatives: activities of the Eastern Caribbean Health Outcomes Research Network

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**ABSTRACT** The dissemination of biomedical research data beyond academia remains limited. In response, funding agencies now regularly require that the projects they fund make research data openly available for reuse. This emerging open data movement aims to democratize data access, often guided by the FAIR data technical standards, requiring that data should be findable, accessible, interoperable and reusable. Recently, participant communities have advocated the idea that improving data democracy does not address the inequities underlying the power dynamics of research enterprises. In contrast, the CARE principles of Indigenous data governance focus on collective benefit, authority to control, responsibility and ethics. We describe the data-sharing infrastructure and initiatives of the Eastern Caribbean Health Outcomes Research Network (ECHORN) for the ECHORN Cohort Study, which longitudinally examines risks and protective factors for noncommunicable diseases among community-dwelling adults in the United States and Caribbean locations. This work has been grounded in a community-engaged process, with the goal of developing robust, sustainable solutions for the dissemination of information. We highlight efforts towards operationalizing greater access to these longitudinal data resources, including the implementation of a regional survey to understand data needs and data-sharing capacities and the development of Explore ECHORN (https://exploreechorn.org), a free public data dashboard. Through these efforts, ECHORN has identified opportunities to expand initiatives that have the potential to encourage data-sharing to inform policy and strengthen the impact of research, particularly in the Caribbean. ECHORN also seeks to reconcile a community-engaged approach with the dissemination of data for secondary use.

**Keywords** Community-based participatory research; data sharing; cohort studies; Caribbean Region.

Data-sharing is known to enhance the quality of research studies (1). In small island states, data-sharing can promote data sovereignty, foster regional and global collaboratives (2), and seed sustainable solutions and partnerships (3-5). Methods for data-sharing are wide-ranging, from the provision of data sets via online repositories to aggregated analytics provided via online dashboards. In the Caribbean, examples of sharing data are uncommon. The Open Data Inventory (ODIN) measures national data openness using a definition that includes the availability of data in a machine-readable and nonproprietary format (6). The latest iteration, from 2022, covered 195 countries, including 15 in the Caribbean. Scores for all but four Caribbean countries fell in 2022, indicating a worsening regional situation. Caribbean countries scored substantially lower than the global

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average and were the lowest in the World Health Organization's Region of the Americas. The highest-ranked countries were Jamaica (ranked 60th) and the Dominican Republic (ranked 78th), with all other Caribbean countries ranked in the bottom 100. Despite these low rankings on ODIN metrics, there are some national and regional initiatives that can form the basis of further data-sharing efforts.

The governments of the Dominican Republic, Jamaica, and Trinidad and Tobago have launched open portals to share epidemiological data. Puerto Rico, a United States territory, has had an open epidemiological data portal for more than 5 years (7-10). These examples represent important advances, but portal maintenance is a major challenge, and the availability of data remains extremely limited. Additionally, an absence of systematic processes and mechanisms to provide regular data updates continues, limiting the quality and relevance of the data that are available (11). Within the Caribbean region in 2023, the PVBLIC (not an acronym) Foundation, the governments of Antigua and Barbuda, and the Alliance of Small Island States committed to the creation of the Sustainable Innovations for Small Island Developing States (or SIDS) Global Data Hub (12). This intraregional platform will help Member States of the Alliance establish or improve national data centers and create data hubs for the Sustainable Development Goals to guide decision-making, build capacity and monitor progress. A second regional initiative is CaribData, funded by the Inter-American Development Bank and operated by The University of the West Indies (13). The objectives of the CaribData project are to build Caribbean infrastructure for regional data-sharing, provide training and mentoring to increase regional data-handling capacity, and encourage the sharing of data through visualization and storytelling.

Another push for data-sharing has been driven by the scientific community to support the dissemination and reuse of scholarly data. The FAIR guiding principles, proposed in 2016 by a collective representing academia, industry, funding agencies and scholarly publishers, have been widely adopted as best practices in scientific data management for the sharing and reuse of data (14). To adhere to the FAIR principles, scientific data must be findable, accessible, interoperable and reusable (14). Specific components of data-sharing that align with these principles include but are not limited to requiring that metadata are extensive and provide information about the quality and characteristics of the data; that data should be readily available and easy to obtain from a public repository; that data must use a standard structure that is broadly applicable and readily understood for knowledge-sharing; and that data should have a clear origin, purpose and permission status, with a clear and accessible data usage license. While the FAIR principles focus on the technical and functional aspects of data-sharing, the CARE principles of Indigenous data governance, developed by Indigenous scholars in 2019, seek to address long-standing inequities within research, including power imbalances in data generation, ownership and use (15, 16). The CARE principles reinforce the idea that tribal nations have sovereignty over their data and that data-sharing must demonstrate collective benefit, authority to control, responsibility and ethics (15, 16). These principles, although originating from Indigenous communities and centered around the sovereignty of tribal nations, are applicable to marginalized communities in any context. For example, the principles state that data should benefit the communities being studied, be aligned with the community's values, and that study communities should lead the data governance and consent processes for engaging with the data. These principles run in parallel with accepted standards for community-engaged research, which have an emphasis on sharing power between scientific researchers and communities (17). While the implementation of the FAIR standards is more commonplace, addressing the power differentials and implementing the CARE principles are in their infancy among biomedical research studies.

The Eastern Caribbean Health Outcomes Research Network (ECHORN), conceived in 2012 with funding from the US National Institutes of Health (NIH), is a research collaborative dedicated to reducing the burden of chronic disease in the Caribbean by generating action-oriented research (18). One of the Network's priorities is to accelerate the dissemination of data from biomedical research to community partners. This paper describes ECHORN's background, infrastructure and initiatives for data-sharing and discusses how ECHORN might advance its data-sharing efforts as potential next steps, while also considering the landscape of the FAIR and CARE principles.

## ECHORN PRINCIPLES AND ADMINISTRATION

ECHORN hosts a wide range of scientific studies and initiatives. This research portfolio, led by an investigator based in the United States, with co-investigators in Barbados, Trinidad and Tobago, and the US territories of Puerto Rico and the Virgin Islands, is anchored by the ECHORN Cohort Study (ECS). This regional cohort study of adults estimates the prevalence of and assesses risk factors for noncommunicable diseases in the aforementioned Caribbean nation-states and US Caribbean territories (18).

The ECS is rooted in the principles of community-engaged research, which integrates science with input from people in the community to accelerate the translation and dissemination of research findings to reduce health disparities and improve community health. The administrative structure of ECHORN has always included formal mechanisms for incorporating community feedback into the research studies (18). Initially, this was accomplished through regional community advisory boards that provided guidance to ensure the work was relevant, culturally appropriate and responsive to the local community's needs and priorities. As the Network grew, these groups became the foundation of the ECHORN consortium, a dedicated structure for informing the design, development, analysis and dissemination of ECHORN research. The consortium includes task-oriented workgroups consisting of Caribbean residents and is a mechanism to ensure that the community has a voice. The consortium is led by a governing board and hosts a fellowship program focused on leadership development for professionals interested in Caribbean population health and health equity.

## ECHORN DATA-SHARING WORKGROUP

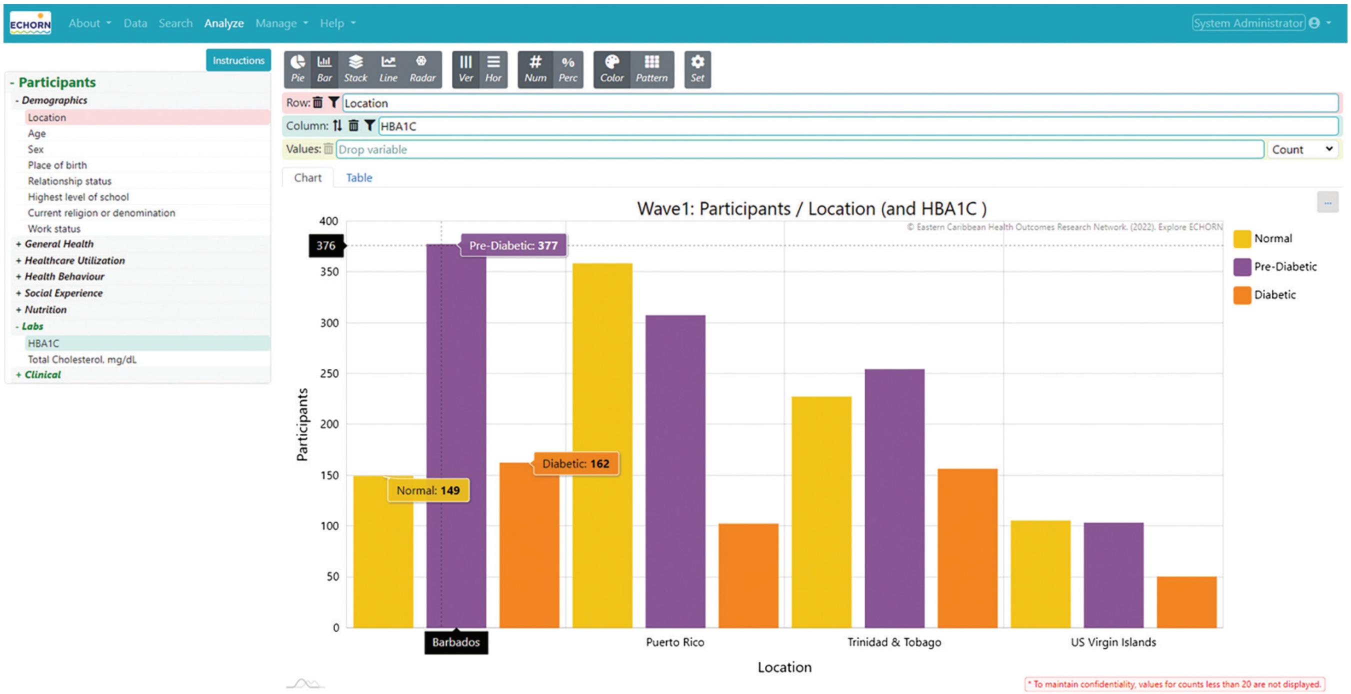
The purpose of the ECHORN Data-Sharing Workgroup (DSW) is to develop policies and collaborations that can guide ethical, effective data-sharing and utilization across Caribbean communities, organizations and agencies. The DSW is chaired by a statistician, supported by a fellow from the leadership development program, and includes members working in or affiliated with academia, civil society, public health, health policy and community organizations, described in detail in a prior article (19). The DSW works collaboratively with the ECHORN Informatics Core, a team responsible for fulfilling informatics operations (19). Their joint efforts have focused on seeking opportunities for data-sharing, described in the next sections. The first initiative, a data-sharing dashboard called Explore ECHORN, demonstrates the role of DSW members in informing the development and implementation of a planned research activity network. The second initiative, a data-sharing survey, was developed and implemented by the DSW, with support from ECHORN research staff.

## Data-sharing dashboard

The Informatics Core and the DSW have sought opportunities to share ECS data, guided by community-engaged principles. One of the main dissemination products is Explore ECHORN (https://exploreechorn.org), a free, publicly available website where users can interact with aggregated descriptive data collected during the first wave of the ECS (2013–2018). The vision for the site has been to return study data to Caribbean communities and ECS study participants in a useful and accessible way. To accomplish this, the Informatics Core and the DSW applied a participatory informatics approach, integrating principles from community-engaged research with user-centered design (19, 20). They built a custom platform to meet the preferences and needs of the various interested parties, such as ensuring privacy, security and usability. The site enables users to search for, view and download tables and visual displays in common, ready-to-use file formats (Figure 1). These searches allow access to deidentified data stored in the back-end database. The site utilizes aggregating functions and suppresses values if the number of participants is fewer than 20, based on specific privacy considerations for small study communities. Users are asked to register with a username and password so that ECHORN research staff can monitor registrations, and registrants are asked a few questions about their geographical location, sector of work and their planned use of the site. The Explore ECHORN website and the back-end database are implemented in one of Yale University's secure self-service cloud servers and routinely monitored by the university's Information Security Office. A strong password policy – including a password length of at least 15 characters requiring uppercase and lowercase letters, numbers and other characters, and a unique password for each account – is enforced at registration, as multifactor authentication is not available for users outside of Yale and would not be accessible to all users. The system can perform log-in audits. In addition, per university policy, the website follows minimum security standards. The platform tracks visits to the site and the general location of users, for example noting a United States versus non–United States location.

The site's functionality and content have been refined iteratively through usability testing with Caribbean residents, described in detail in a prior article (20). Members of the ECHORN consortium and the DSW conducted usability testing with community members, paying attention to feedback on visual displays, data labels, usage instructions and ease of

**FIGURE 1. Screenshot of visualization from Explore ECHORN (https://exploreechorn.org) showing location of participants compared with hemoglobin A1C levels (*n* = 2 400) for data collected during Wave 1 of the ECHORN Cohort Study, 2013–2018**



* To maintain confidentiality, values for counts less than 20 are not displayed.

***Source:*** The figure is an Explore ECHORN data visualization, accessed August 2024.

navigation (20). Explore ECHORN debuted at the 2022 Caribbean Public Health Agency Annual Conference and currently has more than 70 registered users. Since this debut in 2022 until the end of March 2024, there have been more than 3 000 visits to the site, with an average of three visits per day.

### Data-sharing survey

The DSW surveyed Caribbean researchers and public health professionals during 2019–2020 to better understand their knowledge, attitudes and needs regarding data management and data-sharing capacities. Among respondents (*n* = 113), 75.2% (85/112) felt confident in their personal abilities to share data. Most respondents agreed that there is a need to share data (97/113, 85.8%) and that their data would be of interest to others (93/113, 82.3%). Nearly 40% of respondents reported that they had helped others share data (44/112, 39.3%). However, respondents were less certain about institutional support for data-sharing, citing concerns around security (78/112, 69.6%), unreliable internet access (68/112, 60.7%), limited encryption access (47/110, 42.7%), lack of funding (37/109, 33.9%) and unclear policies (31/109, 28.4%). They were unsure whether they would be supported by their institution if they shared data (61/110, 55.5%) or receive credit for data they had collected, managed and shared (65/113, 57.5%) (Whiteman SJ, Jeyaseelan SM, Campbell Britton M, Hambleton IR, ECHORN data-sharing survey, 2021, unpublished data).

### Data Access and Scientific Review Committee

The ECHORN Data Access and Scientific Review (DASR) Committee was established in 2014 to evaluate requests for access to ECS data and to ensure that requests are within the scope of ECHORN's research mandate. Having data access and review panels is a recommended best practice for multisite and multi-investigator research collaboratives (21-23). The overarching goals of the DASR are to formulate and shepherd the strategic scientific vision of cohort study research and ECHORN overall. The DASR is a multidisciplinary committee, composed of principal investigators, co-investigators and research staff, that reviews proposals for access to ECS data or access to ECS research infrastructure, such as research sites and equipment. Specifically, the types of requests allowed include secondary data analysis, ancillary study proposals that aim to recruit and enroll ECS participants, and research collaborations that align with ECHORN's goals. Applicants whose proposals are approved by the DASR must sign a data use agreement to access deidentified ECHORN data. The DASR has reviewed nearly 100 submissions primarily consisting of manuscripts, posters and presentations, many of which have been disseminated in peer-reviewed publications and at professional conferences. A list of peer-reviewed ECHORN studies resulting from requests for secondary data analysis and ancillary study proposals can be found on the ECHORN website (https://www.echorn.org/publications). ECHORN data can also be requested and used to inform health policy in the Caribbean region. For example, the Barbados Ministry of Health and Wellness requested deidentified data through the DASR to inform a national nutrition policy.

## STRATEGIES FOR ADVANCING DATA-SHARING: ENHANCING INFRASTRUCTURE, INITIATIVES AND SYNERGIES

As a long-standing regional research collaborative based on principles of community engagement, the Network has made strides to involve the community and develop infrastructure to foster data-sharing. Further opportunities to improve and advance access to biomedical research data through data-sharing have been identified through the development and implementation of Explore ECHORN, the data-sharing survey and the DASR.

These include increasing the adoption and usage of Explore ECHORN within Caribbean communities. Although smaller technical solutions may increase access to the platform, including removing the need to log in and complete a registration survey, initial feedback from interested parties focused on the delivery of targeted communication to specific sectors that would be likely to engage with and benefit from the data, for example governmental bodies and educational institutions. Based on its data-sharing survey, efforts led by the DSW are increasing data capacity in the region. The DSW, supported by ECHORN and regional partners, is promoting data-sharing exemplars, creating data-sharing mentorship opportunities to foster advocacy and growth, and potentially developing short courses on data management. These initiatives seek to improve individual skills in data literacy and institutional changes that can begin to strengthen the data infrastructure and actualize regional data-sharing efforts (Table 1). The DSW is working on creating "data stories" to synthesize scientific findings into accessible narratives for interested communities.

The DASR can also focus on processes to enable data-sharing for requests that require data beyond what is easily accessible through Explore ECHORN (Table 1), such as improving access to metadata from the ECS. By fulfilling the request from the Barbados Ministry of Health and Wellness, the Network has identified a need to create a process for requesting ECS data to develop data-centered policy briefs, with hopes that this process can be leveraged across the region for policy change. Through Network members' requests to the DASR for ECS data, ECHORN is positioned to better assess and uncover synergies and challenges around data governance and sharing across different institutional structures and policies.

During the first wave of ECS data collection, investigators worked together to navigate the human research protection programs across five different academic institutions to engage community advisory boards in the research process and discuss the shared goals of and benefits for the community. With continued growth, the DASR discussions have focused on data governance, including aligning requests for data with the original purpose of the research and its community-engaged process. Due to the US NIH's policy mandating data-sharing to accelerate biomedical discovery and with the well-established FAIR standards, there are concerns about whether and how to operationalize the mandates for those who conduct community-engaged research (17). One primary concern about widespread data democratization is that the secondary use of deidentified data removes the responsibility of using these data to benefit the original community who contributed to the research. Another concern is that the findings will be interpreted and translated without an understanding of the

**TABLE 1. Examples of current efforts and future opportunities for improving data-sharing in the Eastern Caribbean Health Outcomes Research Network (ECHORN), 2024**

| Framework | Examples from ECHORN | Current limitations | Future considerations |
|---|---|---|---|
| FAIR: findable, accessible, interoperable, reusable (14) | • ECS data are stewarded by a dedicated data manager at the ECHORN Coordinating Center.<br>• ECS Wave 1 data are available through Explore ECHORN, a free and publicly available data-sharing platform.<br>• Explore ECHORN data can be downloaded in different presentation formats (e.g. tables, bar graphs, pie charts).<br>• Requests to the DASR for ECS data must include a clear research question with specific aims and analytic plans. | • Explore ECHORN is limited to data collected in completed waves and appropriate for descriptive statistics.<br>• Explore ECHORN does not include granular data due to concerns about participant identification (e.g. rare conditions and small populations). | • The DASR is developing a data glossary describing all items collected through the ECS.<br>• Explore ECHORN will be updated as additional waves of data collection are completed.<br>• The DSW is providing training on how to structure data sets to support ethical data-sharing. |
| CARE: collective benefit, authority to control, responsibility, ethics (15) | • DSW members advise on data-sharing activities.<br>• Data shared through Explore ECHORN is designed to be accessible, regardless of research skills.<br>• The ECS and related studies are reviewed and approved by local institutional review boards.<br>• Requests to the DASR for ECS data must include a description of the practical value that the work will have for Caribbean communities. | • Awareness of the ECS and Explore ECHORN is not widespread.<br>• The ECS data request process is oriented towards research studies. | • The DASR is working to develop a data-sharing policy.<br>• Membership in the DASR will be expanded to include people who are not affiliated with academic institutions.<br>• The DASR is developing a standardized process for requesting ECS data for non-academic purposes (e.g. policy development).<br>• ECHORN is increasing awareness and use of ECS data and Explore ECHORN beyond the current network.<br>• The DSW is publishing data stories that introduce ECHORN, explicate values and provide examples of how ECS data can be used. |

DASR: Data Access and Scientific Review Committee; DSW: Data-Sharing Workgroup; ECS: ECHORN Cohort Study.
***Source:*** Table developed by the authors based on their research.

underlying context of the research, the communities involved and their priorities (17). ECHORN leadership can begin conversations about CARE standards in a community-engaged way. These conversations can consider how secondary users of the data will benefit the community who contributed to the data and what that means for a US-based NIH-funded study with community participants across two US territories in the Caribbean and two Caribbean nation-states.

While ECHORN leadership operationalizes the mandates within their community-engaged process, there may be an opportunity to advance the science of community engagement and data-sharing. The goals of data-sharing initiatives are to accelerate the generation of knowledge and facilitate improvements in health, yet how data-sharing facilitates these improvements needs better measurement to enable evaluation. The FAIR standards have measurable outcomes (14), but the methodology for measuring the CARE principles has not been developed (15, 16). For example, in addition to the ODIN methodology of measurement (6), there is only a small body of literature that characterizes interactive public health dashboards and provides the detail necessary to establish standards (24). As this body of literature grows, measures are also needed to gauge progress made towards CARE standards, such as collective benefit or authority to control. The development of measures will require a community-engaged process with in-region involvement, as these concepts may differ across communities. As other Caribbean-led data-sharing initiatives, such as CaribData (13), advance data capacity, access and sharing in the region, a key goal will be to ensure that ECHORN is aligned with these regional efforts. Together, ECHORN, CaribData, community organizations and other interested parties can begin to envision how a community-engaged process and CARE principles might be operationalized in biomedical research in the region, at what level (e.g. at the study level), and how progress towards these standards might be measured. With limited data-sharing in the region, ECHORN and CaribData could convene conversations about data-sharing to begin this regional dialogue.

ECHORN leadership is continuing to expand and explore opportunities to enhance data-sharing and access to ECS data beyond academic research. Although few models exist for data governance in biomedical research that crosses academic and geopolitical borders, the existing ECHORN infrastructure – through both the DSW and the DASR – could be leveraged to expand data access in a way that uses community-engaged processes and strives to achieve the CARE standards for greater collective benefit.

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# Iniciativas de intercambio de datos en el Caribe: actividades de la Red de Investigación sobre Resultados de Salud del Caribe Oriental

**RESUMEN** La difusión de los datos de la investigación biomédica más allá del ámbito académico sigue siendo limitada. Ante esta situación, en la actualidad los organismos de financiamiento suelen exigir que los proyectos que financian pongan los datos de investigación a disposición del público para que puedan ser utilizados de nuevo. Este movimiento emergente a favor de los datos de libre acceso pretende democratizar el acceso a los datos y suele regirse por las normas técnicas de los datos FAIR (por su sigla en inglés), que exigen que los datos sean localizables, accesibles, interoperables y reutilizables. Recientemente, las comunidades participantes han propugnado la idea de que una mejora de la democratización de los datos no subsana las desigualdades que subyacen en las dinámicas de poder de los proyectos de investigación. En cambio, los principios del enfoque CARE de gobernanza de los datos indígenas se centran en el beneficio colectivo, la facultad de controlar, la responsabilidad y la ética. Se describen la infraestructura de intercambio de datos y las iniciativas de la Red de Investigación sobre Resultados de Salud del Caribe Oriental (ECHORN, por su sigla en inglés) para el estudio de cohorte ECHORN, que examina longitudinalmente los factores de riesgo y los factores de protección para las enfermedades no transmisibles en la población adulta que vive en comunidades de Estados Unidos y del Caribe. Este trabajo está basado en un proceso de participación comunitaria y tiene como objetivo la elaboración de soluciones sólidas y sostenibles para la difusión de la información. Se hace especial hincapié en los esfuerzos para lograr un mayor acceso a estos recursos de datos longitudinales, incluida la realización de una encuesta regional para comprender las necesidades en materia de datos y capacidades para difundirlos, así como el desarrollo de Explore ECHORN (https://exploreechorn.org), un panel de datos público y gratuito. Mediante estos esfuerzos, ECHORN ha identificado oportunidades para ampliar las iniciativas que pueden fomentar el intercambio de datos para fundamentar las políticas y fortalecer el impacto de la investigación, especialmente en el Caribe. Asimismo, ECHORN trata de compatibilizar un enfoque comunitario con la difusión de datos para un uso secundario.

**Palabras clave** Investigación participativa basada en la comunidad; difusión de la información; estudios de cohortes; Región del Caribe.

# Iniciativas de compartilhamento de dados no Caribe: atividades da Rede de Pesquisa sobre Resultados de Saúde do Caribe Oriental

**RESUMO** A divulgação de dados da pesquisa biomédica fora do meio acadêmico continua limitada. Para responder a essa situação, as agências de financiamento passaram a exigir que, via de regra, os projetos por elas financiados disponibilizem os dados da pesquisa de forma aberta para que possam ser reutilizados. Esse movimento emergente em favor dos dados abertos tem como objetivo democratizar o acesso aos dados, geralmente orientando-se pela norma técnica FAIR, que exige que os dados sejam localizáveis, acessíveis, interoperáveis e reutilizáveis. Recentemente, as comunidades participantes têm defendido a ideia de que melhorar a democracia de dados, por si só, não resolve as iniquidades subjacentes às dinâmicas de poder das iniciativas de pesquisa. Por outro lado, os princípios CARE para a governança de dados indígenas se concentram nos benefícios coletivos, na autoridade para controlar os dados, na responsabilidade e na ética. Descrevemos aqui a infraestrutura de compartilhamento de dados e as iniciativas da Rede de Pesquisa sobre Resultados de Saúde do Caribe Oriental (ECHORN, na sigla em inglês). Em particular, sublinhamos como essa infraestrutura foi utilizada no estudo de coorte da ECHORN, que examina, de forma longitudinal, os fatores de risco e de proteção para doenças não transmissíveis em adultos que vivem em comunidades nos Estados Unidos e no Caribe. Este trabalho se baseou em um processo de envolvimento da comunidade com o objetivo de desenvolver soluções robustas e sustentáveis para a divulgação de informações. Destacamos os esforços para operacionalizar um maior acesso a esses dados longitudinais, incluindo a implementação de um inquérito regional para entender as necessidades de informação e as capacidades de compartilhamento de dados. Descrevemos também o desenvolvimento do Explore ECHORN (https://exploreechorn.org), um painel de dados público e gratuito. Através desses esforços, a ECHORN tem identificado oportunidades de expandir iniciativas com potencial para promover o compartilhamento de dados para fundamentar a elaboração de políticas e fortalecer o impacto da pesquisa, especialmente no Caribe. A ECHORN também procura conciliar a abordagem de envolvimento da comunidade com a difusão de dados para uso secundário.

**Palavras-chave** Pesquisa participativa baseada na comunidade; disseminação de informação; estudos de coortes; Região do Caribe.