

TOWARD REDUCING HEALTH INFORMATION INEQUITIES IN THE CARIBBEAN: OUR EXPERIENCE BUILDING A PARTICIPATORY HEALTH INFORMATICS PROJECT

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Precision medicine seeks to leverage technology to improve the health for all individuals. Successful health information systems rely fundamentally on the integration and sharing of data from a range of disparate sources. In many settings, basic infrastructure inequities exist that limit the usefulness of health information systems. We discuss the work of the Yale Transdisciplinary Collaborative Center for Health Disparities focused on Precision Medicine, which aims to improve the health of people in the Caribbean and Caribbean diaspora by leveraging precision medicine approaches. We describe a participatory informatics approach to sharing data as a potential mechanism to reducing inequities in the existing data infrastructure. *Ethn Dis.* 2020;30(Suppl 1):193-202; doi:10.18865/ed.30.S1.193

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INTRODUCTION

Precision medicine is “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.”¹ This new approach is touted as a mechanism that has the potential to improve health for all.² Precision medicine fundamentally relies on health information systems sharing and integrating data from a range of disparate sources, including data about a person’s individual health and associated social and structural determinants of health, to allow for customization of evidence-based practices.^{3,4}

Despite the promise of precision medicine, in many settings, including the Caribbean, structural inequities exist that limit the usefulness of health data within information systems for improving health outcomes, particularly among marginalized populations. Fundamentally, marginalized populations are regularly under represented in health research and practice, leading to data inequities in health information systems and research-generated data.⁵ Even when collected and available, the information systems may not have been

structured to allow for individual-level analyses. In cases where individual-level data are collected and available, data have often been collected using different standards and levels of granularity, limiting the ability to aggregate data and explore relationships.⁶ These limitations in availability and accessibility underpin the argument that information resulting from currently available data infrastructures may have limited usefulness to individuals who identify as members of underrepresented populations.

Two approaches within the research enterprise, data sharing and community-based participatory research, if leveraged, could potentially improve usefulness of data for underrepresented populations. Data sharing initiatives for health have slowly developed momentum in government-led and research-led initiatives that may stimulate greater accessibility. Yet, the translation of available information to improvement in health regularly takes a decade or longer.⁷⁻¹⁰ This delay in translation is acutely seen in communities in which there has been limited engagement of stakeholders in the research process. Community-engaged or participatory research in the health sciences,

an approach that seeks to involve underserved communities in research from conception to dissemination, is seen as a mechanism to accelerate this translation of research knowledge to health practice. Participatory methodologies, however, remain a work in progress; even among community-engaged research efforts, dissemination of results and data to the community has been limited.^{11,12} As a means to accelerate dissemination of data and knowledge, a few recent research ef-

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orts have merged data sharing and community-engagement activities, developing community-engaged informatics platforms and enabling community members to interact with either their own or aggregated data.¹³⁻¹⁶ These examples of participatory informatics demonstrate some promise in the ability of access to health data from research to make improvements in health knowledge, community

connectivity, and social capital.¹³⁻¹⁵

In this article, we describe our efforts to advance health data sharing by making health data more usable for Caribbean populations, as part of the work of the Yale Transdisciplinary Collaborative Center for Health Disparities focused on Precision Medicine (Yale-TCC). Specifically, we describe our use of a participatory informatics approach to address the structural data inequities for understudied populations within the Caribbean and for Caribbean-descent populations and ensure that data sharing efforts can benefit those beyond the scientific community.

METHODS

The Yale-TCC, funded by the National Institute of Minority Health and Health Disparities (NIMHD, U54MD010711) is a collaboration between academic, policy, public health, and community stakeholders in New York, New Jersey, Puerto Rico, US Virgin Islands (USVI), Trinidad and Tobago, and Barbados. It aims to improve the health of people in the Caribbean and Caribbean diaspora by leveraging precision medicine approaches.¹⁷ The Yale-TCC builds upon the infrastructure and knowledge of the Eastern Caribbean Health Outcomes Research Network (ECHORN), (NIMHD, U24-MD006938), which was established in 2011 to strengthen regional capacity for research on non-communicable diseases (NCDs). This unique partnership created the ECHORN Cohort Study (ECS), the first regional cohort study.^{18,19}

The ECS is an ongoing prospective cohort study that seeks to improve our understanding of early predictors and risk factors for NCDs in Caribbean and Caribbean-descent populations. With 3,000 cohort participants, the ECS collects data using survey tools, clinical assessment, and blood testing. Collected data include a wide range of participant and household characteristics, past medical diagnoses, health biomarkers and health outcomes, and health care utilization.^{18,19}

One of the main aims of the Yale-TCC is to create a mechanism to share de-identified and aggregated population-level data from the ECS with community stakeholders and ECS participants. Aligned with a precision medicine approach, the Yale-TCC seeks also to merge publicly available population-level, health-related contextual data (such as social determinants of health, environmental data, or others) with biological, clinical and health-related data from the ECS participants.

For this article, we conducted a review of all project documents and experiences by a small diverse team involved in the data sharing project, as described below.

Structure of the Yale-TCC Data Sharing Project

The data sharing project has been developed over a period of one and a half years, supported by two groups: the Yale-TCC Data Sharing Workgroup (DSWG) and the Yale-TCC Biomedical Informatics Core (BIC) (Figure 1). DSWG and BIC collaborate with a participatory informatics approach to further the data sharing efforts of the Yale-TCC, guided by

principles such as engaging community stakeholders in the informatics process, recognizing the expertise of the stakeholders, having an environment for co-learning, and using an

iterative process to work with the stakeholders.²⁰ We defined community as the members of the Yale-TCC consortium core. The consortium core consists of more than 50 stake-

holders and community members representing more than 30 organizations that work to inform the research priorities and implementation of projects for the Yale-TCC. The

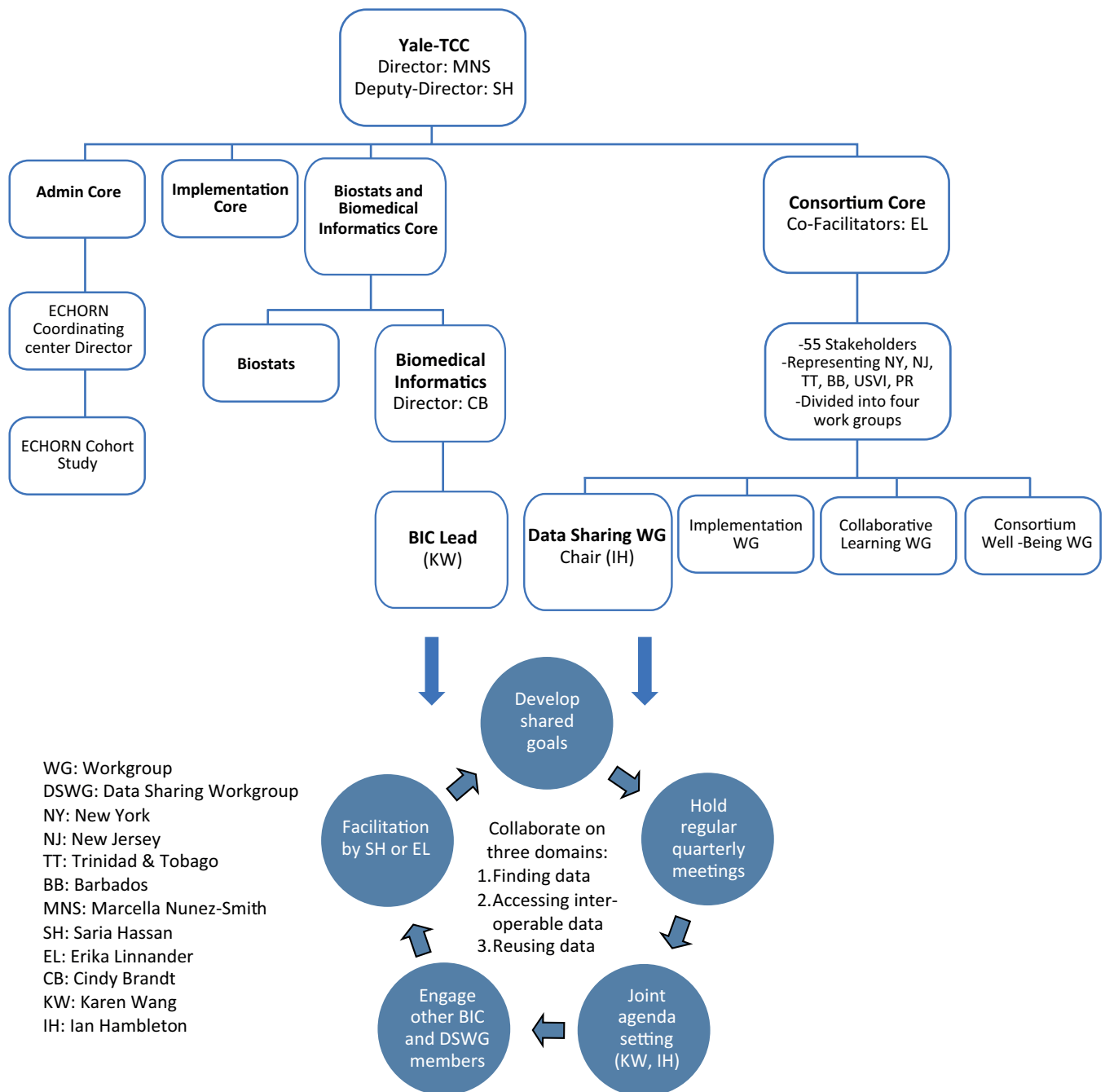


Figure 1. Yale TCC organizational structure and approach to data sharing project

consortium spans academic, policy, public health, civil society, community, and faith-based leaders from across the Caribbean, New York, and New Jersey. Members are divided into four workgroups, including DSWG, based on their interests and expertise and with the goal of ensuring diverse representation of different organization types and island sites within each workgroup. Each workgroup has a lead (the chair) and an assistant (the fellow) who together organize regular workgroup contact, guide agreed group activities, and facilitate information flow between the workgroup and the Yale-TCC researchers.

Data Sharing Workgroup (DSWG)

The DSWG, led by IH, consists of 15 members, with representation from each study site and diversity in organization type. Currently, eight DSWG members have primary academic affiliations and seven members have non-academic affiliations. Of the non-academic members, there are representatives from civil society, public health, health policy, and the community.

Biomedical Informatics Core (BIC)

The BIC goals are to fulfill the operational informatics needs of YALE-TCC, to harmonize and integrate data sources, and to develop and implement a community-engaged web-based platform for data visualization and feedback. The informatics core is led by a director (CB), systems architect (LM), and an informatics lead (KW) who directly engages with the DSWG.

Development of the DSWG and BIC Working Relationship

BIC and DSWG leadership met four times from March 2017 to October 2018. The initial meeting, facilitated by EL, established a common understanding of the goals of the Yale-TCC Data Sharing Project and determined the nature of the working relationship between DSWG and BIC. For subsequent meetings, KW and IH jointly set the agenda for each meeting and invited additional workgroup and team members, while SH provided facilitation. On discussions about data sharing, the DSWG has informed the Yale-TCC informatics strategy on finding and sharing data, including determining what data should and should not be shared with stakeholders, participants, and other parties as well as how shared data might be used and whether any restrictions to use should be in place.

These meetings developed three domains for concrete collaboration based on an initial rapid review of available data resources and 'FAIR' criteria, which are published standards on good data management and stewardship to facilitate data sharing and reusability by individuals. Following the 'FAIR' Guiding Principles for scientific data-management, data should be findable, accessible, interoperable, and reusable.²¹ 'Findable' data must have unique identifiers and accompanying metadata. 'Accessible' data must be easily retrievable and is, therefore, dependent on the quality of information storage and retrieval systems. 'Interoperable' data must use a broadly applicable language for knowledge representation. 'Reusable' data refers to properties that allow

the user to understand where datasets originate, what is in a dataset, and how one might utilize the data.

The three domains for DSWG-BIC collaborative work are to: identify publicly available health data resources (finding data); provide input on the structure and functionality of the data sharing platform (accessing interoperable data); and create a data sharing plan that determines the scope and accessibility of available data (reusing data). Some of work has been completed, and other work is ongoing and planned for the future stages (Figure 2).

Finding Data: A Systematic Review for Public Sources of Health Data

The DSWG helped develop the search strategy for all data relevant to the health of the Caribbean and championed the need to develop a systematic framework for assessing the quality of web-accessible publicly available open data, as we found no standard published framework. DSWG-BIC defined "publicly available" data as all data that are Internet-accessible for download and potential use and defined "health" data as encompassing measures of health conditions and determinants of health, defined as the WHO Social Determinants of Health (SDoH).³ These domains broadly included, but were not limited to, environment (eg water quality), transportation, neighborhood safety, employment/labor, incarceration, and food availability. BIC augmented its data discovery process by conducting a systematic searching and evaluation of existing public data sources

from websites focused on the Caribbean and Caribbean diaspora as the population of interest. We searched local (eg Puerto Rico Open Data Interconnection Portal), regional (eg, Economic Commission for Latin American and the Caribbean), and global institutions (United Nations, World Health Organizations) focused on health or health-related social needs for open and accessible data (Table 1). In addition, BIC is currently conducting a systematic review of publicly available datasets on the Caribbean and Caribbean diaspora, leveraging methods from prior research studies.²² The goal is

to ensure the search strategy can be repeated over time to maintain and systematically update the resources.

Accessing Interoperable Data: Building a Platform for Data Retrieval, Analytics, and Visualization

We ingested the ECS survey data and are in the process of ingesting the aforementioned public data. Integration is managed using the Yale-TCC Health Information Resource Equity (HIRE) portal, which will host a repository of publicly accessible health data and aggregated ECS data. HIRE has a public, web-

accessible, FAIR-enabled platform that provides data repository, dataset and data querying, and visualization tools for use by stakeholders. It has internal extraction, transfer, and load modules for private cohort data.

In the future, once integrated, we will focus on the interoperation of the data. For example, in view of the fact there is no common understanding of the measures of SDoH across the stakeholders,²³ our starting point is the PROGRESS-Plus acronym to identify characteristics that stratify health opportunities and outcomes.²⁴ Within our data model, our goal is to leverage existing standards, such as

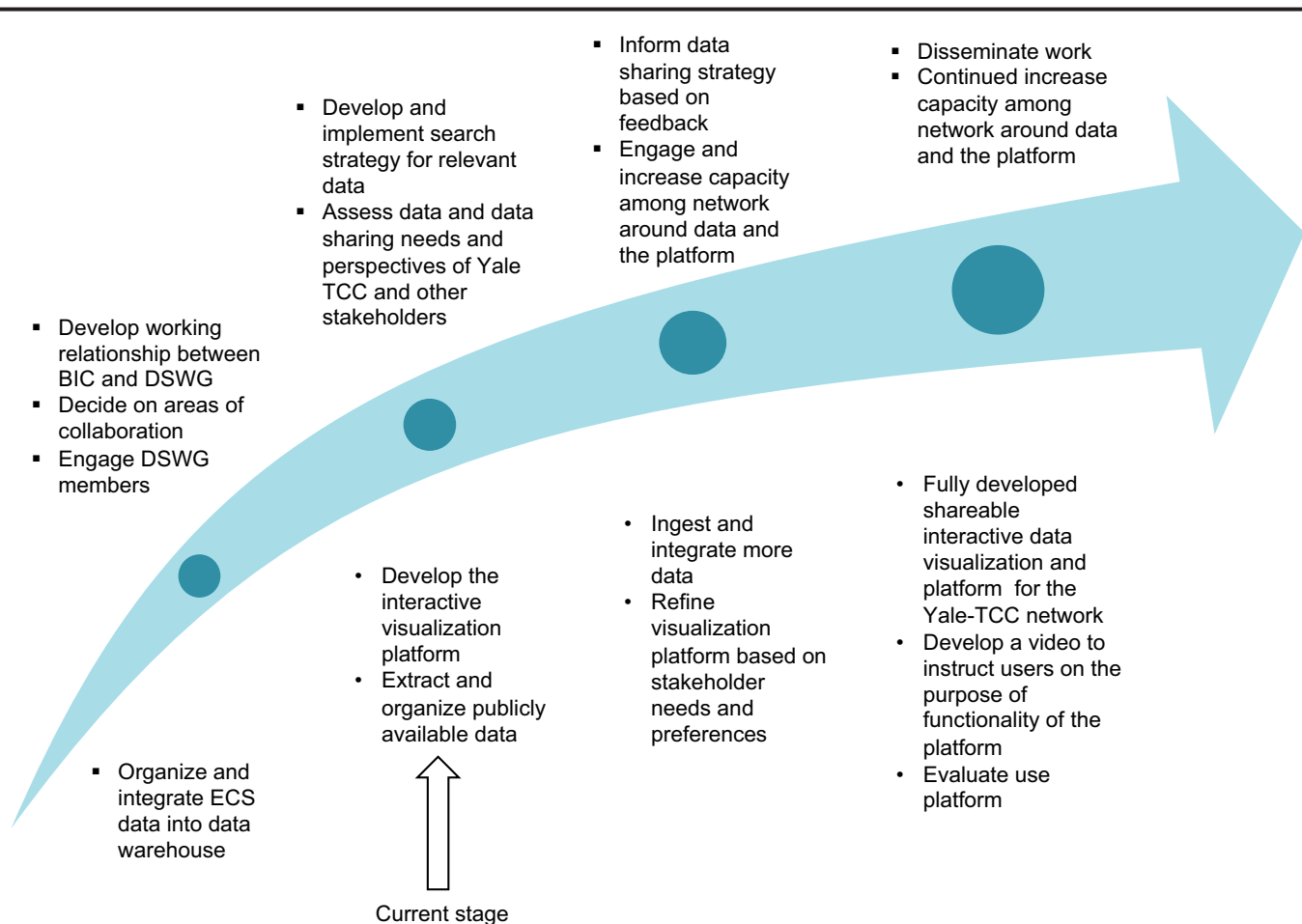


Figure 2. Completed, ongoing, and future work of the Data Sharing Project

Table 1. Example of data sources and domains

Data sources	Host of Data	Domains Examples
Puerto Rico Open Data Interconnection Portal, https://data.pr.gov/en/	Government of Puerto Rico	Use of public insurance, crime statistics
Trinidad and Tobago Central Statistical Office, http://cso.gov.tt/statistics/	Government of Trinidad and Tobago	Primary and secondary school enrollment and dropout rates, crime statistics, land use
CEPALSTAT: Databases and Statistical Publications, http://estadisticas.cepal.org/cepalstat/portada.html?idioma=english	United Nations: Economic Commission for Latin American and the Caribbean	Demographic structure, net enrollment in primary and secondary education, infant mortality rates
Multiple Indicator Cluster Surveys, http://mics.unicef.org/	United Nations International Children's Emergency Fund	Literacy rates, marriage rates of children
School-based student health surveys, https://www.who.int/ncds/surveillance/gshs/en/	World Health Organization	Fast food consumption, substance use, food security
Food and Agriculture Organization of the United Nations, http://www.fao.org/faostat/en/#data	United Nations	Prevalence of undernourishment, food availability

the LOINC,^{25,26} as the ECS cohort survey contains survey items which are represented in the LOINC standards. The DSWG will provide input on how to map and standardize these domains across contexts to better organize the data for interoperation. For data queries and visualization, we leveraged the Web Analytics Research Platform Navigator, initially developed for the Transitions Clinic Network.⁹ This interface allows for users to conduct simple descriptive and bivariate analysis using de-identified aggregated data from ECS. For next steps, the DSWG will help define roles, type of access, use of the visualization platform, and content available on the platform. For example, we do not plan to display results when the total number of individuals with a particular demographic or clinical characteristic are <10 or when a ECS site has <100 individuals. The initial goal would be to ensure testing and use of the platform by the Yale-TCC consortium core members based on traditional measures, including number of individuals, general location of users, queries

made, time spent on the platform, and downloaded figures or datasets. This will further develop a strategy to define and measure outputs from the data platform.²⁷ The end goal would be to enable ECS study participants to interact with data they contributed to, similar to our prior work.¹⁶

Reusing Data: Developing a Data Sharing Plan

In conjunction with this work, the DSWG, supported by BIC, is providing ongoing advice on a regional data sharing plan. Though the BIC-DSWG work is focused on developing the data integration and visualization platform with de-identified ECS data, we recognize the broader context of data sharing and open science movement globally. Therefore, the DSWG will identify regional opportunities and challenges for data sharing, such as the ethical, legal, and social dimension of data sharing and the regulation of sharing different types of data across different contexts.

The DSWG is conducting a needs assessment survey to understand perspectives of sharing data among

diverse stakeholders. The survey will attempt to create a hierarchy of importance for these challenges and opportunities using an analytic hierarchy process, a method to help quantify the process of choosing subjectively between alternatives.²⁸ The DSWG will also conduct a landscape analysis using key informant interviews and review of the literature to better understand the regulatory and legal landscape for data sharing in the Caribbean region. These two initiatives will be instrumental in guiding the mechanism to increase capacity in the network and the development of a data sharing strategic plan for the Yale-TCC to optimize future work around data sharing and use of data. The data sharing plan will be offered as a living document, subjected to continual assessment and regular revision.

DISCUSSION

In our efforts to share data with stakeholders beyond traditional academic and scientific communities, we have developed an initial partici-

participatory informatics approach and are operationalizing the FAIR data standards. Our efforts will focus on three domains of finding relevant public health data for the Caribbean, building a data sharing process and platform to make data more accessible and usable, and ensuring that our work reflects and incorporates the larger data sharing knowledge and efforts in the Caribbean region. Our experience suggests that this type of regional collaboration is a feasible approach toward developing a data sharing platform. In this process, we have experienced several technical, policy-related, governance, and engagement and inclusion issues to address to ensure that the platform with the public data and de-identified ECS data will become a useful, regional resource with actionable health data.

Technical Challenges and Opportunities

To effectively implement a data sharing platform for multi-resource heterogeneous data using the FAIR principles, all relevant data need to be found, catalogued, and integrated into a comprehensive data model to facilitate meaningful dissemination to stakeholders. However, automated mechanisms for finding and ingesting data do not exist. Instead, we must actively search for relevant data resources and then manually catalog their content provenance. This developed system will allow us to record metadata and align common data elements from the many identified data sources. Given the realities of data availability in the Caribbean, the model will also allow us to identify information gaps to inform fu-

ture data searches or the generation of new information. To assess quality of publicly available data from websites, we will rely on existing standards for observational data, such as STROBE and the developing FAIR metrics.^{29,30} Moreover, as we develop the HIRE web-platform interfaces and visualization tools, we anticipate challenges in the visualization of information for meaningful exploration and dissemination. Using an iterative participatory design approach, the DSWG will test the interface, provide feedback on design and content, and increase its overall usability.^{14,26,31}

Policy-related Challenges and Opportunities

The Yale-TCC is a cross-institute, multi-national network, and understanding the legal and regulatory frameworks governing data-handling among the many represented network entities is critical to the success of this work. Despite a call for an international legal framework for data sharing, there has been limited action in this area, with a recent study finding that existing data sharing policies are fragmented.³² Currently in the United States, sharing of research data is guided primarily by research funders with the specific goal of sharing data for research purposes. The National Institutes of Health (NIH), who funds Yale-TCC, published a policy and accompanying guidance governing the sharing of data collected using NIH funds in 2003.³³ This guidance recognizes the special case of data collected outside of the United States and advises researchers to be aware of different national policies of data sharing. Using this general guidance,

NIH-funded cohort studies have published their own data sharing policies and have also specified requirements for data access.³⁴ The DSWG, drawing on its review of Caribbean data policies, will inform Yale-TCC researchers how to best operational-

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ize guidelines for regional data sharing, leading to wider data accessibility and dissemination while meeting the governance and legal framework of the contributing entities. Though our work is currently focused on unidirectional transfer of NIH-funded aggregated data to our community of stakeholders and participants, we envision a future of greater complex-

ity as additional sources and types of data, which are funded, owned, and housed by different entities, become part of this data sharing system.

Governance Challenges and Opportunities

A governance structure for Yale-TCC data sharing is currently being established. This structure will help guide decisions central to the data sharing platform, such as data finding and assessing quality of the data. We recognize that the platform operations for data ingestion must incorporate a pragmatic assessment of data quality and a transparent process in the form of thorough metadata documentation between data producers and data consumers.³⁵ The governance structure will incorporate best practices for data de-identification and data security, maintaining the ethical obligations of originating research.^{36,37} Our participatory process dictates that this governance structure and policies will be freely available to stakeholders and subject to regular review and modification. We also recognize the evolutionary nature of governance issues and anticipate additional challenges on the horizon as funding mechanisms change, different data are added to the repository, and ECS participants seek their own data compared to aggregated data.

Engagement and Inclusion Challenges and Opportunities

In the initial work, we focused on building a working relationship between BIC and DSWG leaders, as we recognized and navigated the initial power dynamics influencing the work and our working relation-

ship in the context of partnerships in which the funded organization is situated in a higher-income country.³⁸⁻⁴¹ Though the DSWG is over-represented by members of academia, the chair and fellow reach out to individual members of the DSWG for one-on-one meetings when they are unable to attend larger group meetings. This process ensures representation of all members. The activities of the DSWG are shared with the greater consortium, with diverse academic and non-academic members, through biannual progress reports. In addition, the DSWG will actively seek input from our diverse consortium of stakeholders through a planned needs assessment survey. The engagement of non-academic stakeholders from other sectors represented on the Yale-TCC consortium core is an important next step, especially as we seek feedback on various aspects on the work, including the needs assessment and the interactive visualization platform. Based on our prior experience, we will plan webinars for the Yale-TCC consortium core on data sharing and the work of the BIC-DSWG to increase capacity regarding data and informatics in our network and to increase community interest in the DSWG.

Limitations

We need to acknowledge our limitations. This article reflects the views of the DSWG and BIC leadership. Our main limitation is that it is not a systematic assessment of stakeholder experiences. We will endeavor in the work ahead to engage more consortium core members' perspectives in this process. Though

we can only attest to our progress and do not have current measures for success, we plan to conduct an evaluation of our partnership. A logic model was developed at the start of the Yale-TCC to guide evaluation of the Yale-TCC consortium. Results of the evaluation will be disseminated to all consortium members and inform the future structure and direction of the consortium and the workgroups.

We have endeavored to describe a sustainable approach to a participatory informatics project. Though we are early in our work, there is value in sharing our implementation experiences and lessons learned to date, as using a participatory informatics approach to build data sharing partnerships is an emergent field.⁴²

CONCLUSION

Our experience suggests that regional collaboration may be the right scale to begin to understand, uncover, and dismantle barriers to data sharing in the Caribbean. Our specific effort to share aggregated de-identified cohort level data and potentially integrate public health data sources provides a tangible and discrete project by which to discuss the principles and implications of health data sharing in the region within our network. These initial efforts in developing a participatory data-sharing platform and understanding the context of health data sharing in the Caribbean will hopefully increase the likelihood of greater dissemination and its in-region sustainability, ie, to see the platform used to inform real-world health questions and to become an accessible online

space for providing health information and new health insights for all Caribbean people. Moving forward, the Yale-TCC will benefit from other multidisciplinary, multi-sector teams who have called for greater data sharing, interoperability and public access to health information.⁴³ We will use these experiences to continue to refine our approaches to data integration and sharing within Yale-TCC and believe they can inform ongoing global discussions on an informatics framework to ensure that the benefits of precision medicine are available to all.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Wang, Hambleton, Marengo, Hassan, Kumara, Fredericks, Harrigan, Brandt, Nunez-Smith; Acquisition of data: Wang, Fredericks, Brandt, Nunez-Smith; Data analysis and interpretation: Wang, Hambleton, Linnander, Marengo, Brandt, Nunez-Smith; Manuscript draft: Wang, Linnander, Hassan, Kumara, Harrigan, Brandt; Statistical expertise: Wang, Hambleton, Marengo, Nunez-Smith; Acquisition of funding: Wang, Brandt, Nunez-Smith; Administrative: Wang, Linnander, Hassan, Kumara, Fredericks, Harrigan, Brandt, Nunez-Smith; Supervision: Wang, Nunez-Smith

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