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## Realizing the Promise of Disaggregated Data and Analytics for Social Justice Through Community Engagement and Intersectoral Research Partnerships

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**ABSTRACT** In Canada, community and policy leaders have issued urgent calls to collect, analyze, and mobilize disaggregated data to inform equity-oriented initiatives aimed at addressing systemic racism and gender inequity, as well as other social inequities. This essay presents critical reflections from a national Roundtable discussion regarding how meaningful community engagement within academia–community–government research collaborations offers the opportunity to harness disaggregated data and advanced analytics to centre and address the priorities of equity-deserving and sovereignty-seeking groups. Participants emphasized four key priorities: (1) Building equitable and engaged partnerships that centre community-driven priorities and address structural barriers to community engagement; (2) Co-creating ethical data governance policies and infrastructure to support community data ownership and access; (3) Stimulating innovation and pursuing community involvement to create contextualized, advanced analyses and effective visualizations of disaggregated data; and (4) Building the capacity of *all partners* to effectively contribute to partnership goals. Capacity building was viewed as a bridge across a diversity of lived and professional expertise, enabling intersectoral research teams to collaborate in culturally safe and respectful ways. Beyond identifying key structural barriers impeding the promise of disaggregated data, we present practical opportunities for innovation in community-engaged scholarship to address social justice challenges in Canada.

**KEYWORDS** disaggregated data, community-engaged scholarship, partnerships, science policy, social justice, inequity, big data

What we measure matters. In the absence of robust disaggregated equity data in Canada, systemic inequities faced by key populations and communities are repeatedly rendered invisible in evidence. Community and policy leaders have issued urgent calls to collect, analyze, and mobilize disaggregated data under the principles of ethical data governance and accountability. Such calls aim to inform equity-oriented policies to help address systemic racism, gender

inequity, and other social inequities in Canada (Black Health Equity Working Group, 2021; British Columbia's Office of the Human Rights Commissioner, 2020). Disaggregated data can assist in identifying inequities and examining the intersecting variables influencing these inequities. Such analyses must then be used to drive policy responses and (re)allocation of resources for impact. Disaggregated data can also highlight community strengths that can be further enhanced through dedicated support. Alongside calls for the collection and use of disaggregated data, research infrastructure and analytic capacity are growing at universities across Canada. Such resources and expertise, however, remain largely inaccessible to community leaders with equity mandates, which risks widening power differentials and the digital divide that dictates who has access to, and the ability to use, data. Canada needs an effective pathway for grassroots and social justice organizations to access the power and promise of advanced data analytics to address social justice challenges. Creating new avenues for academia–community–government collaborations to identify research priorities, collect, access, analyze, and visualize disaggregated data, and engage in training offers opportunities to harness advanced analytics to address the priorities of equity-deserving and sovereignty-seeking groups.

Simon Fraser University's (SFU) Equity Data Commons (EDC) initiative aims to work with community organizations and leaders to create a national community–academic–government data partnership hub to provide access to the resources, expertise, and infrastructure needed to support: (1) Community-driven data priority setting; (2) Joint community and university collection, analysis, and visualization of disaggregated data; (3) Use of disaggregated data to inform social justice and equity initiatives; and (4) Community partner training in data collection, analysis, and interpretation.

Central to the EDC initiative is acknowledging and addressing community concerns about potential misuse of disaggregated data. The EDC recognizes the legacy of data being used against Canada's most oppressed communities, including as part of the colonial project, as well as experiences of academic research as "extractive" with little community benefit. We can and must do better.

Historically, digital transformation and disruptive technologies have not been applied in ways that benefit the most structurally marginalized in society. The EDC seeks to ensure that citizens from all backgrounds have the opportunity to benefit from innovations in advanced data analytics by creating an ethical, intersectional data analytics platform and data resource for Canada.

*Figure 1.* Equity Data Commons

On September 15, 2021, the Equity Data Commons (EDC) initiative (Figure 1) at Simon Fraser University (SFU) partnered with the Canadian Science Policy Centre (CSPC) to convene a national virtual Roundtable to discuss and identify key principles, approaches, and priorities required to conduct responsible, data-driven, and equity-oriented research that addresses community priorities. Invited attendees included intersectoral stakeholders from community, academia, government, non-profit, and computational science sectors. This *Report from the*

*Field* summarizes participant feedback from the Roundtable and puts forward a position paper to inform the development of best practices and policies for building equitable and engaged academia–community–government partnerships to collect, analyze, and use disaggregated data; conduct ethical and responsible data governance; stimulate innovation in the pursuit of meaningful data analysis and visualization; and build the capacity of all partners to engage in these processes.

## Methods

The Roundtable agenda, speaker list, and list of attending organizations are included in the appendices. Briefly, after an overview of the goals of the EDC and presentation of three brief case studies of exemplar academia–community collaborations across different health priorities (COVID-19, climate change, and HIV) (Black Health Equity Working Group, 2021; Hoogeveen et al., 2021; Kaida et al., 2019; Loutfy et al., 2017), participants joined small, moderated discussion groups in which they were asked to reflect on four questions (Figure 2). Notetakers in each group captured the discussion and summarized key points. The small groups returned to the main meeting room where the moderators and notetakers shared the key discussion points from their groups, offering opportunities for other Roundtable participants to comment, clarify, or expand on the points. Elder Valerie Nicholson closed the group discussion with the teaching that “new knowledge is old knowledge to new people,” which informed our approach to intersectoral and interdisciplinary collaboration. After the Roundtable, we collated the notes from each breakout group and the larger collaborative discussion and conducted a thematic analysis to examine participants’ perspectives on the opportunities and challenges across the four questions.

- What do you think are the key considerations for:
1. Building equitable and engaged community–academic partnerships to support the responsible collection and use of disaggregated data and advanced analytics? What are the opportunities and challenges to this approach in Canada?
  2. Advancing ethical and responsible governance of data collection, sharing, access, safety, and sovereignty? What are the opportunities and challenges?
  3. Stimulating innovation in the pursuit of meaningful data analysis and visualization that leverages community–academic partnerships and advanced analytics to examine, expose, and address inequities? What are the opportunities and challenges?
  4. Building the capacity of all partners to contribute to equitable and sustainable academic–community collaborations? What are the opportunities and challenges?

**Figure 2.** Discussion questions for the Roundtable participants

## **Key Findings**

Roundtable participants identified several opportunities and challenges to realizing the power and promise of disaggregated data and analytics to address social justice challenges in Canada. Several identified issues are consistent with those identified by previous analyses of structural challenges to academia–community–government collaborations, while others were specific to collaborations centred on collecting, analyzing, and using disaggregated data.

## ***Partnerships***

Roundtable participants felt that building equitable and engaged partnerships lies at the centre of this work. They felt these relationships are best built on and sustained by trust and mutual value. This process requires the investment of time, care, and—although often left unsaid—resources. Many noted that previous work has pointed to strategies necessary to build trusting academia–community partnerships, including “showing up” in community, which entails centering community needs, being humbly present in the community when welcomed there, and committing to deepening one’s understanding of community priorities and values. Additional practices include supporting each other outside of the specific parameters of the partnership, delivering on promises, spending time together working on common goals, maintaining flexibility, communicating actively, and sharing resources and networks (Nelson, 2021). Participants felt that government partners and policy makers must be similarly engaged early in partnerships to create a sense of shared ownership and the impetus to use the data to inform policy development. Under-acknowledged are the structural barriers that impede this work and reinforce existing power inequities. However, the participants emphasized that acknowledging and actively working towards dismantling such power hierarchies are essential components of building and sustaining equitable and engaged academia–community partnerships.

The participants also described how the existing structure of research funding opportunities introduces barriers to academia–community partnerships. First, research funding opportunities do not sufficiently value the building of academia–community relationships, making it difficult to attain the additional time, money, and other resources that are important in nurturing these connections. In addition, community organizations are often ineligible to hold research funding and reliant on academic partners for budgetary allocations, entrenching power hierarchies between academic and community partners. Moreover, while many community organizations are deeply invested in their work and wish to be involved in research processes, their capacity for investment in relationship building is strained by a lack of dedicated funding and administrative support for research. Participants offered creative solutions to these challenges, advising funders to adopt more flexible funding guidelines, expand the types and nature of allowable expenses (such as community honoraria or community consultation), and extend eligibility to community-based research personnel to hold funds.

Second, research ethics application, review, and approval procedures were identified as introducing structural barriers to academia–community relationship building, particularly with respect to practicing cultural humility and ensuring cultural safety. A research team working with Indigenous Elders shared that they submitted a research protocol to an institutional review

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board (IRB) that described a cultural process to acknowledge wisdom shared by the Elders with a gift of ceremonial tobacco. This gift was challenged by the IRB, requiring substantial effort to educate IRB members on the sacred nature of tobacco among Indigenous communities around the world. Roundtable participants underscored that IRB processes must be adapted to support culturally significant practices as an essential step in creating meaningful, equitable, and trusting relationships, particularly for communities that have been betrayed and harmed by colonial research practices.

A third structural barrier described is the way career advancement and reward structures for academics can be at odds with the time and care that it takes to build academia–community partnerships. The pressure to continuously publish for career advancement can disincentivize academics’ investment in dismantling power inequities and building relationships with community partners. Participants articulated the need to shift the type of work that is valued in an academic setting. University leadership members who are responsible for hiring, tenure, and promotion processes and granting councils can initiate change by redefining expectations for career advancement to include considerations of community engagement and impact.

### ***Data governance***

A second central feature raised during the Roundtable pertains to advancing ethical and responsible data governance. Data governance is the ownership and control of collective data. Distinct from holding or housing the data, data governance entails decision-making about how data are collected, stored, analyzed, and shared (Black Health Equity Working Group, 2021). Data ownership and access are key considerations to using disaggregated data, data infrastructure, and data analytics to advance social justice causes. Community leaders at the Roundtable expressed that equity-deserving and sovereignty-seeking communities must have ownership over data collected from members of their community, particularly over disaggregated data. This includes the ability to mobilize and share (or not share) data—which is often hindered due to silos between researchers, disciplines, and sectors, as well as bureaucratic barriers.

Participants also reiterated that for Nation-based data, there are excellent examples of how data governance can unfold. The First Nations Principles of OCAP<sup>®1</sup> (ownership, control, access, and possession) provide a framework for the handling of data related to First Nations in Canada (The First Nations Information Governance Centre, n.d.). These principles establish clear expectations for how data are stored, interpreted, used, and shared, with an emphasis on data sovereignty. For non-Nation-based equity-deserving groups, establishing a clear understanding of and agreement on how data are to be collected, stored, analyzed, and used is similarly important. Participants also drew attention to the Black Health Equity Working Group, which has provided a framework for data governance regarding race-based disaggregated data, serving as an example for other non-Nation-based groups (2021). The framework outlines four principles: (1) Engagement: the meaningful and continued community consultation throughout the research process; (2) Governance: community decision-making

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1 OCAP<sup>®</sup> is a registered trademark of the First Nations Information Governance Centre (FNIGC).

surrounding engagement and all data processes; (3) Access: communities' rights to determine rules for accessing their data, including who can access them and how they are used; and (4) Protection: safeguarding of individuals' rights across all types of data. Roundtable participants felt that formalizing these principles to apply to broader Canadian policy requirements for those engaged in race-based data collection would be an important step forward. Finally, participants emphasized that determining data governance policies requires recognition of the rich diversity within communities and intentional inclusion of those with dissenting opinions from the majority.

A current opportunity in data governance lies in harnessing academia–community–government partnerships to increase community control over their data. This includes connecting academics with skills and training in data collection, analysis, and interpretation with communities that are seeking those skills. Also important is mobilizing the extensive infrastructure at post-secondary and research institutions to securely capture, store, access, and protect data. Again, Roundtable participants discussed how opportunities for these partnerships and their equitable and safe data governance procedures are hindered by structural barriers and power inequities among and between partners.

A concern central to data governance is that current leadership in academic and government organizations in Canada does not demonstrate adequate racial, gender, or class diversity and is not representative of the general population. This distance from equity-deserving and sovereignty-seeking communities presents challenges to proposed academia–community–government partnerships, given that the data are usually collected from underserved, oppressed, systemically marginalized, and equity-deserving communities but are analyzed, interpreted, and owned by individuals who may have little understanding of community priorities. On the other hand, community organizations are often led by members from equity-deserving and sovereignty-seeking communities tasked with designing and delivering policy and programming to serve the needs of their communities. This creates a system where those who hold power and shape research and policy lack accountability for the impact of data/findings on communities, fueling community concerns about sharing data and engaging in data-driven partnerships. Roundtable participants emphasized the central role that transparency plays in navigating this dynamic. Researchers need to be accountable for clearly describing how data are being used and how conclusions are reached while ensuring the security and privacy of sensitive data. Accountability mechanisms are also required for researchers using disaggregated data to report to data-safety advisory boards consisting of community members.

### ***Stimulating innovation***

At the Roundtable, participants expressed strong agreement and excitement regarding the enormous potential of academia–community–government partnerships to overcome barriers to stimulating innovation in the pursuit of meaningful disaggregated data collection, analysis, and visualization. Participants felt that such partnerships could generate new questions driven by community priorities; insightful, nuanced, and contextualized analyses; and effective visualizations of data to serve our collective understanding and action on addressing social

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injustice. By definition, innovation means doing things differently—in this case, participants encouraged a reimagining of what research looks like through all phases of the process. Participants described areas that need innovative change across macro, meso, and micro levels.

At the macro level, entrenched biases within the structure of academia need to be examined and re-envisioned. As highlighted above, funding structures are currently more accessible to academics than to community members or organizations. This prioritizes the pursuit of research questions deemed important solely by academic researchers, potentially limiting the generation of knowledge driven by community priorities. Shared models of research leadership may create opportunities for community organizations to pursue research questions important to the populations they serve. Additional funding would enable community organizations to partner with researchers to evaluate and publish results from their culturally relevant programs serving a diversity of equity-deserving and sovereignty-seeking populations.

Participants detailed that existing funding structures tacitly rely on labour provided by community partners or explicitly request uncompensated “in-kind” contributions from these partners. Prevailing research models provide little room for meaningful support of those giving their time to these projects. For partnerships to thrive, funding structures must include adequate compensation for community partners. This means providing financial supports for activities that address barriers to community engagement in the research process beyond those included in the traditional funding schema. The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) offers a compensation framework that models community-informed practice (Kaida et al., 2019). CHIWOS compensated Peer Researcher Associates (women living with HIV who completed study-related research training) for time spent in training, as well as food, accommodation, and travel expenses incurred while participating in the training. Additional funds were provided for childcare where needed. Participants were encouraged by the learnings of this work and felt that this example could be developed into policy or guidelines to reduce barriers to engagement for broader academia–community–government partnerships.

Finally, the institutions that fund, publish, and assess ethical considerations within research may undervalue non-Western understandings of knowledge and cultural practices, as well as the living/lived experiences of community members. Roundtable participants expressed concern that impact on community is commonly not a key evaluation metric for prioritizing funding. Additionally, participants underscored that the peer review system for publishing does not sufficiently incorporate community knowledge, expertise, or priorities—authors and reviewers may have limited insider knowledge of the community involved in the research. A broader recognition of the value that community partners contribute to the research process was deemed essential. Across these macro-level barriers, power lies with editorial boards, ethics boards, and funders to realize innovation by restructuring processes to include an understanding of the value of relationship building and community insight across research.

On a meso level, Roundtable participants emphasized that research teams have the opportunity to reimagine knowledge translation (KT) and data visualization efforts. Traditional KT efforts can struggle to balance making information accessible and understandable to



community members with preserving the nuance and full meaning of the research findings. Participants emphasized the importance of communicating in culturally relevant formats and pointed to the immense value of storytelling in KT efforts, describing how it can connect people much more deeply to the data and contextualize the findings in terms that are readily accessible. As one participant shared,

The story of Indigenous people in the country was told in numbers and now their stories are being told differently. We are hearing their voices; we're hearing their stories and it is resonating very differently than all the numbers we've had before".  
(Roundtable participant, September 15, 2021)

Additionally, data visualization must be cognizant of the audience being served and strive to be interpretable by the diversity of community members. Communities need to guide the understanding and interpretation of research through "hand-in-glove" leadership and participation in its development at every stage, including broad community review and commentary on results.

To realize innovation on macro and meso levels, individual commitment to disrupting power inequities was discussed by participants as equally vital. On a micro level, participants emphasized that individual researchers need to make decisions about their research practices that challenge the status quo. The practice of reflection, reflexivity, and active work to address and dismantle power inequities is standard in academia–community partnerships. Participants emphasized that individual researchers' efforts to relinquish the power imbued by their positionality are essential in this process. Roundtable participants offered a clarion call that true innovation in academia–community partnerships includes researchers stepping away from the forefront and centering community partners as leaders.

### ***Capacity building***

Capacity building was discussed by participants as an opportunity through which to address some of the challenges outlined above. Critically, capacity building was viewed as necessary for *all* stakeholders in partnership projects. Capacity building can act as a bridge across different disciplines and groups, enabling teams to come together in safe, respectful ways with a shared understanding of the work to be done.

Capacity building for researchers prepares them to work in trusting partnerships that are grounded in respect. Participants highlighted that many researchers may have never worked in partnership with a community. To prepare them to engage in this work, important training topics include cultural safety and humility, recognizing and reflecting on power inequities within research teams, and strategies to dismantle such inequities. This is also an opportunity for community members to be experts and train researchers, which not only emphasizes the value and complexity of their knowledge and experiences, but also helps rebalance power in the research relationship.



Participants felt that, in a sense, community-engaged research is transitional as we create a more diverse and inclusive academic research community, with, for instance, Indigenous research led by Indigenous researchers. Participants felt that capacity building also requires universities and other well-resourced institutions to support community growth. One outcome participants said would come of the transformation would be having more diverse faculty and students who will transform how justice-oriented research is conducted in Canada. This includes opportunities for community partners to build skills around disaggregated data collection, storage, analysis, and visualization. A goal of building long-term capacity within communities is to increase community control of their data and sustainable social justice efforts.

### **Conclusion**

The findings from this Roundtable discussion point to the need to learn from academia–community–government partnerships in other fields, adapting these strategies to build trusting and effective collaborations to benefit from the collection, use, and mobilization of disaggregated data in order to address social justice challenges. Innovation means reimagining how research has been conventionally conducted to create community-driven solutions that address power inequities and advance the priorities of equity-deserving and sovereignty-seeking populations. In this report, our intent is not to present these academic, government, and community spheres as mutually exclusive, for there is a multitude of intersections and inequities that exist within and outside each of these stakeholder groups. Rather, the intention in summarizing the Roundtable findings is to identify key nodes for innovation and transformation so that we as a research community can overcome systemic barriers built into evidence formation now and into the future.

### **Acknowledgements**

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## Authors' Contributions

All co-authors made substantial contributions to this work. AK, MH, and KN contributed to the concept and design of the work. AK and ZO contributed to the data analysis and wrote the first draft of the manuscript. All co-authors contributed to data acquisition and data interpretation and substantively reviewed and revised the manuscript.

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## APPENDIX A: Roundtable Agenda September 15, 2021

*How can academic-community collaborations help realize the power and promise of big data to address social justice challenges in Canada?*

Time (PDT)	Time (EDT)	Length (min)	Details
9:00 to 09:05	12:00 to 12:05	5 min	<b>Welcome and introductions</b> <ul style="list-style-type: none"> <li>Angela Kaida, Simon Fraser University (SFU)</li> <li>Mehrdad Hariri, Canadian Science Policy Centre (CSPC)</li> </ul>
9:05 to 09:10	12:05 to 12:10	5 min	<b>Elder opening and welcome</b> <ul style="list-style-type: none"> <li>Elder Valerie Nicholson</li> </ul>
9:10 to 9:20	12:10 to 12:20	10 min	<b>Overview of SFU's Equity Data Commons and the Roundtable</b> <ul style="list-style-type: none"> <li>Angela Kaida (SFU)</li> </ul>
9:20 to 9:50	12:20 to 12:50	30 min	<b>Short case studies of Academic-Community Collaborations</b> <ul style="list-style-type: none"> <li>New ways of measuring the impacts of climate change on equity deserving populations in Canada - Maya Gislason and Dawn Hooegeveen</li> <li>Race, ethnicity, equity, and COVID-19: Learnings from the Black Health Equity Working Group - Kwame McKenzie</li> <li>Community-based research by, with and for women living with HIV - Valerie Nicholson and Angela Kaida</li> </ul>
9:50 to 10:30	12:50 to 13:30	40 min	<b>First Breakout Discussion</b> <ul style="list-style-type: none"> <li>Attendees will breakout into 4 discussion groups with 6-8 participants each, moderated by a pre-assigned facilitator and supported by a pre-assigned notetaker (Chatham House rules in effect).</li> <li>Introductions (brief)</li> <li>Discussion will centre on two focus questions</li> </ul>
10:30 to 10:40	13:30 to 13:40	10 min	<b>Break</b>
10:40 to 11:20	13:40 to 14:20	40 min	<b>Second Breakout Discussion</b> <ul style="list-style-type: none"> <li>Attendees will breakout into 4 different discussion groups with 6-8 participants each, moderated by a pre-assigned facilitator and supported by a pre-assigned notetaker (Chatham House rules in effect).</li> <li>Introductions (brief)</li> <li>Discussion will centre on two remaining focus questions</li> </ul>
11:20 to 11:50	14:20 to 14:50	30 min	<b>'Harvest'</b> <ul style="list-style-type: none"> <li>Groups return to main room, facilitators/notetakers share key discussion points and learnings with time for questions and clarifications</li> </ul>
11:50 to 12:00	14:50 to 15:00	10 min	<b>Closing remarks &amp; next steps</b> <ul style="list-style-type: none"> <li>Angela Kaida</li> <li>Closing by Elder Valerie Nicholson</li> </ul>
<b>End of event</b>			

## **APPENDIX B: Organizations Participating in the Roundtable**

1. ArcticNet
2. BC Centre for Excellence in HIV/AIDS
3. BC Women's Health Foundation
4. Black Equity Working Group
5. Canadian Institute for Health Information (CIHI)
6. Canadian Science Policy Centre
7. Canadian Statistical Sciences Institute
8. Compute Canada
9. Natural Sciences and Engineering Research Council of Canada (NSERC)
10. New Digital Research Infrastructure Organization (NDRIO)
11. SFU
12. SFU's Big Data Hub
13. Social Sciences and Humanities Research Council
14. St. Paul's Hospital
15. Statistics Canada
16. Universities Canada
17. University of Calgary
18. University of Illinois at Urbana-Champaign and Carle Illinois College of Medicine
19. University of Ottawa
20. University of Waterloo
21. WAVAW Rape Crisis Centre
22. Wellesley Institute
23. Women and Gender Equality Canada
24. YWCA National

## **APPENDIX C: Additional Resources**

Included below are additional resources that helped inform the design of the focus questions and framework of this SFU's Equity Data Commons Roundtable meeting.

1. The GovLab works to improve people's lives by strengthening the partnerships between institutions and people to work openly, collaboratively, effectively, and legitimately to make better decisions and solve public problems.
2. The Kirwan Institute for the Study of Race and Ethnicity is an interdisciplinary engaged research institute at the Ohio State University established in May 2003. It was named after former university president William E. "Brit" Kirwan in recognition of his efforts to champion diversity at OSU.

3. The Black Health Equity Working Group includes Black health sector leaders and health equity experts advocating for the collection of race-based COVID-19 data and thorough, responsible governance. The group began meeting early in the COVID-19 pandemic to develop a governance framework for health data collected from Black communities in Ontario that addressed concerns from Black communities about the continued extraction of data from them without the return of tangible benefits.
4. Disaggregated demographic data collection in British Columbia: The grandmother perspective outlines the role of disaggregated data in addressing systemic inequality, states the importance of building respectful relationships, and offers recommendations that suggest legislative changes to protect communities, standards for all data processes, and areas for immediate action and collection of data.
5. The CHIWOS study outlines perspectives on community benefits to research, describing the team's approach to community-based research and the meaningful involvement in their work of people living with HIV.
6. Statement from Canada's Parliamentary Black Caucus calls on all levels of government to take action to minimize the impacts of systemic racism, offering concrete actions to do so, including the collection and mobilization of disaggregated data.