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RESPONSIBLE RESEARCH BY DESIGN: WEAVING GOVERNANCE AND EQUITY INTO RESEARCH PRACTICE IN RESPONSE TO AN EVOLVING RESEARCH LANDSCAPE

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ABSTRACT

What is new?

In the current evolving research landscape, the implementation of academic research has expanded into a complex and active paradigm. Research and its output are expected not only to be robust and innovative, but also to be responsive to evolving societal norms and governance requirements. Where there is a disconnect between the expectations and the operational support provided by institutions and other research-related organizations, it is often the role of administrators in research teams to pragmatically translate, design and implement this dialogue into research practice. Referred to as Responsible Research by Design (RRbD) we propose a new framework that draws upon previously documented research governance models that aim to marry ethics, community engagement, data governance, and evolving cultural norms such as transparency, equity and fairness, while supporting research practice.

What was the approach?

Through a case study of a large, Canadian funded research program that focuses on Health Equity and Community Wellbeing (HECW) in Toronto, Canada, we describe the creation of a comprehensive research operational framework that offers unique and critical insights into building rigorous yet pragmatic processes that weave inter-relational dialogue across research operations, governance, participant privacy protections, and equity principles.

What is the academic impact?	The importance of this RRbD case study is that it: a) extends and adapts existing integrated research governance models to interdisciplinary research across the social sciences and health equity academic paradigms; b) creates a comprehensive operational structure that blends ethics, data governance, privacy, and equity, diversity, inclusion and accessibility (EDIA) research principles, imperatives and requirements for funding; c) inserts training and human resources practices into routine practice; d) provides a practical example of how an integrated operational framework can be feasibly created and implemented within a large, interdisciplinary research program.
What is the wider impact?	The RRbD framework is rooted in a set of principles – integrity, responsibility, co-creation, transparency, and capacity – that mirror the research program itself and weaves operational design across the research lifecycle. As such, the RRbD framework acts as both a conceptual and a practical guide for researchers and research administrators by integrating research, governance and administrative imperatives.
Keywords	Research administration; Research governance; Research principles; Responsible research

INTRODUCTION

The implementation of academic research continues to evolve with shifting societal and cultural norms, availability of research funding and rapid technological advances. Governance is currently a research imperative as a measure of good science and respect for human research participants, as institutions, funding agencies, and in some cases, the public expect accountability and oversight of publicly funded research activities (ALLEA, 2023; Canadian Institutes of Health Research (CIHR) et al., 2022; Council for International Organizations of Medical Science (CIOMS), 2016; Curry et al., 2020; Human Research Standards Organization, 2022). Generally defined as: "the systematic approach of defining, implementing, and overseeing the policies, procedures, and standards that guide research conduct" (Shaw et al., 2005), the output relating to research governance implementation design is the creation of "standard systems for documenting *decisions* relating to research projects (accountability), executed according to agreed-upon models supporting best practice in research implementation, including articulation of research purpose, who can take what actions with what information (responsibility), under what circumstances (authority) and using what methods (process)" (based on the Data Governance Institute, n.d.1). In short, research governance acknowledges and aims to mitigate the likelihood of potential harms resulting from research that may affect research participants, researchers, institutions, funders and the public (Shaw et al 2005; Shaw and Barrett, 2006).

Research governance articulates *how* research ought to be responsibly conducted. In the current landscape, the implementation of governance has expanded from ethics and privacy to relatively new key components such as culture, equity, diversity, inclusion and accessibility (EDIA), patient-focused research and co-creation, relevant and useable knowledge mobilization, and focused mentorship, to name a few (Canadian Institutes of Health Research, 2024). Thus, in concert with robust academic research methodology and outputs, research practice has evolved into a complex and active paradigm, requiring not only compliance for obligations put forward by legislation (Government of Ontario (2004), PHIPA; European Parliament and Council of the European Union (2016), GDPR) and academic Research Ethics Boards (Panel on Research Ethics, 2022; Canadian Institutes for Health Research, 2022 - Chapter 1), but also to standards that mirror cultural and societal changes that aim to enhance research relevance across diverse populations and its uptake.

For research teams, responsibility for supporting research practice and governance oversight ought to rest primarily on academic and research-related institutions (like universities, teaching hospitals or organizations who conduct research), with support from Research Ethics Boards (REB), information privacy and security professionals, funding agencies and peer review. In Canada, although there is overarching guidance through the Tri-Council Agency Policy Statement (TCPS (2); Canadian Institutes of Health Research et al., 2022), the system for its implementation is de-centralized and there is much variation across the country and among institutions and research programs, based in part on variations in capacity, budgets, and feasibility. In some research eco-systems there is a disconnect between the expected high bar for research governance set forth by the TCPS (2) and institutional support systems for research teams to achieve it (Dwivedi et al., 2024; Odebrecht, 2025).

In the absence of overarching research systems, it is often the role of research administrators to design and implement research practice governance processes within institutions and research programs. This entails sorting through and keeping abreast of the evolving quagmire of research-related principles, standards, policies, funding requirements and responsibilities, often resulting in reams of spreadsheets and checklists that are time consuming, confusing, and costly to maintain.

Through a case study of a large, Canadian funded research program that focuses on Health Equity and Community Wellbeing (HECW) in Toronto, Canada, we describe the creation of a comprehensive research operational framework that offers unique and critical insights into building rigorous yet pragmatic processes that weave inter-relational dialogue across research operations, governance, participant privacy protections, and EDIA principles. Referred to as *Responsible Research by Design* (RRbD) our framework draws upon: a) previously documented research governance models that aim to marry ethics, community engagement, data governance, and cultural norms with science (Bitsch et al., 2023); b) Canadian and international examples of research governance standards, and research practice imperatives; and c) EDIA ideals and requirements for research. The RRbD framework is rooted in and extends from principles created through the CERC HECW program that anchor each stage of research project practice through standardized processes to support societal opportunities that may benefit from science.

The importance of this RRbD case study is that it: a) extends and adapts existing integrated research governance models to interdisciplinary research across the social sciences and health equity academic paradigms; b) creates a comprehensive operational structure that blends ethics, data governance, privacy, and EDIA research principles, imperatives and requirements for funding; c) inserts training and human resources practices into routine practice; d) provides a practical example of how an integrated operational framework can be feasibly created and implemented within a large, interdisciplinary research program.

This case study is structured by a background that describes the theory and imperatives in creating our RRbD framework, a description of the framework itself, and a discussion that considers benefits, challenges and next steps to address improvements in research program operational designs that continue to evolve with a rapidly changing world.

BACKGROUND FOR CERC HECW RRBD FRAMEWORK

The creation of this RRbD research operational framework stems from the Canada Excellence Research Chair (CERC) international fellowship program, focused on Health Equity and Community Wellbeing (CERC HECW) at the Toronto Metropolitan University (TMU; Toronto Metropolitan University, 2024). Funded by the Canadian Institutes for Health Research (CIHR), the internationally competitive CERC program provides select Canadian universities with the finances to recruit and support world-renowned researchers to establish broad and innovative research programs in Canada for Canadians (Canada Excellence Research Chairs, 2024). Uniquely applying a critical disability intersectional lens, this research program aims to embed community knowledge into health-care institutions, systems, and models of delivery to promote inclusivity and accessibility for diverse and marginalized populations who have faced long-standing exclusion, discrimination, and stigmatization from the health system. Recognizing the critical significance of disability – as both production and outcome of health inaccessibility – is core to this research program and cuts across all dimensions – research design, project advisory, discrete scientific lines of inquiry, data collection methods and analysis, communities of engagement, and knowledge sharing and implementation strategies.

From the outset of the CERC HECW program implementation in 2024, a robust operational process was needed to respond to the community-focused comprehensive research plan, governance model and data management plan submitted to the program funders. Due to this being a relatively new type of program at TMU, and with the de-centralized research ecosystem in Canada, the CERC HECW program team was tasked with creating and operationalizing an independent governance system, agreed upon by TMU and the program funders, that would support the multi-faceted research, based on international best practices for research governance and robust academic requirements.

The development of our RRbD operational framework rested not only on ensuring compliance with Canadian research institutions and funders, but also on previously published research practice models that reflect the CERC HECW program's aims of robust intersectional science, community partnerships, equity and fairness, mentorship and training, as well as the standard academic requirements for research ethics, protected data collection, and auditing and reporting functions. We needed the framework to be simple and usable by researchers in their pursuit of science and, importantly, by research administrators who manage the myriads of requirements involved in the research process. Thus, our considerations in creating the RRbD framework included: a) existing research paradigms, adapted to an evolving research landscape; b) research and data governance principles and requirements for ethics and funding; c) integration of EDIA principles for broad community-focused research; d) capacity building and mentorship; e) creating principles to support the RRbD framework.

ADAPTING TO AN EVOLVING RESEARCH LANDSCAPE

Canadian Institutes of Health Research (CIHR), a very large funder and source of guidance in the Canadian health research landscape, suggest that research in Canada adopt a broad concept of research excellence that "is rigorous, inclusive and conducted in ways that meaningfully integrates a diversity of perspectives, disciplines, and methods in order to maximize impact and benefit to society", with active inclusion of researchers and research participants to bolster innovative methods for knowledge impact and sharing (Canadian Institutes for Health Research, 2024). As a research program focused on these ideals, it was important for the CERC HECW program to not only highlight these concepts into the academic research plan, but also into the governance and operational structure design.

A working example of such an integrated process is highlighted in the concept of Responsible Research and Innovation (RRI) that emerged in the early 2000's in Europe in response to a public outcry for transparency in agricultural technologies that were perceived as negatively affecting public safety (Stilgoe et al., 2013; Von Schomberg 2013). Adopted into the area of neuroscience and other research sectors, large research innovators like Horizon 2020 expanded the ideal of RRI as marrying ethics, community engagement, data governance, and equity, with science (Bitsch et al., 2023), where "responsibility is … understood as the combination of a responsible process and desirable outcomes" (Stahl et al., 2021). With a large literature base, Pacifico Silva et al (2018) described RRI to include the responsibility of research toward societal health and equity; in particular, the authors aggregated the existing literature to describe RRI as: a process, approach, and ideal … involving scientists, funders, stakeholders and the public …. at an early stage in the research process and throughout the research lifecycle … to highlight risks, benefits, questions, comments, impacts, expectations … through collaboration and inclusivity … to advance science with societal values and public interest (Pacifico Silva et al., 2018; Table 1). By extension, Research Responsibility by Design (Stahl et al., 2021; Ogoh, 2022) extends RRI, by suggesting that the entire pursuit of research ought to intentionally focus on principles of ethical, community engagement and governance values throughout the research lifecycle process so that, once implemented, the process itself inherently enhances scientific rigor, relevant outcomes and useful research knowledge mobilization and impact.

Recently, Zheng proposed the idea of embedding a framework based on fairness, access, inclusion and representation within the research management lifecycle to address the current environment (Zheng, 2025). She suggested that integrating these ideals within organizations, institutions and departments, with an accompanying change management focus, could elicit broader participation directly into research systems for more robust and relevant publicly funded research.

We considered the expansive literature on RRI and the idea of integrating principles as a basis for our RRbD operational framework, while aiming to integrate the mission of the CERC HECW research program, the Canadian context and requirements set out by CIHR, our main funder, and ethics and data protection policies, practices and procedures set by our academic institution and best practice standards worldwide. We desired an operational structure that would inherently facilitate robust scientific methodology for researchers, ethical conduct, community partnership, EDIA principles, and protection of data into the research infrastructure, and to importantly embed research management oversight capabilities across the research lifecycle.

CONSIDERATION OF RESEARCH STANDARDS AND REQUIREMENTS

In Canada, there are multiple entities that provide overarching standards and guidance in the conduct of research, most notably the federal Tri-Council Agencies that outline the ethical mandate for human research in Canada (Canadian Institutes of Health Research et al., 2022), the National Standards of Canada who outline standards for the ethical conduct of human research (Human Research Standards Organization, 2022), the Digital Governance Standards Institute of Canada (2025) who outline best practices for data management governance, as well as supporting professionals who provide guidance in research ethics, security, and jurisdictional and international data privacy law. As an active approach, research and data governance standards highlight the need for dedicated policies and procedures that articulate the definition of roles and responsibilities of people involved, how data are collected, analyzed and stored, how data outputs are created and shared, and how these outputs flow from person to person, or unit to unit; further, routine reporting and evaluation, and articulating the underlying context and values that govern research activities are key to research governance activities. Often, research teams struggle with implementing ongoing compliance with these standards in the absence of substantive operational support.

Although ensuring the rights and privacy of research participants' research data is not new, embedding research data management (RDM) throughout the research lifecycle is a relatively new and foundational requirement for research funding by granting agencies and many academic institutions worldwide (OECD, 2017; Science Europe, 2024; Canadian Institutes of Health Research et al., 2022; National Health and Medical Research Council, Australia, 2019). Rooted in data protection legislation, privacy, and security best practices, a data management plan includes processes and procedures that support the authority, accountability, and decision-making processes and procedures relating to the collection, use and disclosure of data for research (Panel on Research Ethics, 2024; the Data Governance Institute, n.d.2; Government of Ontario, 2004; European Parliament and Council of the European Union, 2016). Further, as an output goal of data governance, FAIR data principles suggest that research data outputs ought to be findable, accessible, interoperable and reusable as the trend of open data and meta-data platforms evolve (Wilkinson et al., 2016).

Thus, embedding operational processes and actions that respond to research and data governance principles such as authority, accountability, feasibility, data access and protection, and transparency became key imperatives for the creation of our RRbD operational process.

RESPONDING TO EQUITY, DIVERSITY, INCLUSION AND ACCESSIBILITY IDEALS

Canada embraces the research values that enhance equity, diversity, inclusivity and accessibility (EDIA) in the pursuit of academic science and considers this as a key element for improved research practice and knowledge mobilization (Canadian Institutes of Health Research et al., 2022 - Chapter 4), recognizing that institutionalized academic research is a systemic, power construct in and of itself. Routen et al. (2023) and Bowleg et al (2023) suggest that focusing on intersectionality (Crenshaw, 1991) across all areas of the research lifecycle, including operations, is necessary to fully understand the research context so that science and knowledge mobilization is relevant to research participants and the public. To further illustrate this ideal, people living with disabilities are often systemically neglected in research recruitment, design, or may have their disability unacknowledged, furthering their exclusion from evidence-based policy decisions (Bailie et al., 2023; Swenor & Deal, 2022). In research areas where disability may be "hidden", such as populations needing mental health support, populations with developmental disabilities or persons with chronic pain, their confounding experiences and identities need to be acknowledged throughout the research process (Rodriguez & Ridgeway, 2023).

As with data governance, including EDIA plans in academic research and its operations is a requirement for national research funding provisions in Canada (Canada Research Chairs, 2019; Canadian Institutes of Health Research et al., 2022 - Chapter 4). Hence, we wanted to embed the notion of accessibility as a core principle for research operations and as a key consideration in our developing the CERC HECW RRbD framework.

In Canada, the Truth and Reconciliation Commission (TRC) recognizes and addresses the harms done by the settler Canadian state to Indigenous Peoples (Truth and Reconcilliation Commission of Canada, 2015). Some Canadian Indigenous communities have created guidance for how research ought to be conducted and, in particular, how information is to be collected and used, supporting their rights to self-determination and data sovereignty (First Nations Information Governance Centre, 2014; Inuit Tapiriit Kanatami, 2018; Métis Centre at the National Aboriginal Health Organization, 2010) and which are now embedded into national research requirements and standards (Canadian Institutes for Health Research et al., 2022 – Chapter 9; Digital Governance Standards Institute, 2025). Additionally, the principles of CARE (collective benefit, authority to control, responsibility and ethics) (Carroll, et al., 2020) extend FAIR and other data use principles to “actions that align with the ‘people’ and ‘purpose’ for which data exist and are used” and reflect the realities in which Indigenous Peoples live and have lived (Carroll et al., 2021).

Our RRbD operational framework draws from Indigenous research guidance by ensuring that Indigenous approaches are integrated into research (Hardy et al., 2020; Mashford-Pringle et al., 2023); we considered it necessary to specifically ensure the adherence of culturally sensitive processes for researchers and administrators when working with Indigenous communities, and all research participant communities to ensure research integrity, sensitivity and relevant use of research knowledge.

TRAINING AND MENTORSHIP

We wanted our RRbD framework to support training and mentorship within its structure. A diverse and well-trained researcher and staff complement from under-represented communities helps to shape and broaden research innovation and the relevance of science and its utility (Asmal et al., 2022; Sevelius et al., 2024). For example, some research institutions encourage hiring researchers and staff with disabilities to promote inclusive, equitable and relevant science, and to incorporate critical disability perspectives into research operations and design, including accessible knowledge mobilization strategies (Bailie et al., 2023; Anbuhl et al., 2023).

Thus, the CERC HECW research program importantly aimed to embed staff and researchers with lived experience directly into research operations itself to bolster citizen science, co-design and community-based participation for more respectful and beneficial community use, and public policy more broadly (Breland-Noble et al., 2024; Chauhan et al., 2021).

RRBD PRINCIPLES: WEAVING THE STRANDS OF NEEDS AND REQUIREMENTS IN THE RESEARCH LANDSCAPE

Given the research program’s uniqueness that focuses on health equity and community wellbeing, and the lack of formal infrastructure to support research operations, we re-imagined a broad research governance and management framework that would extend procedure-based management processes toward integrated form and function, where the research program's mission and goals, academic rigor, ethics, obligations and reporting are woven throughout and across our research ecosystem.

Further, we aimed to root our framework in a set of principles to foundationally integrate purpose, need, function and operation. In the spring of 2024, guiding principles for the CERC HECW research program were generated through a dedicated staff and researcher workshop that included ideals of intersectionality, co-creation and research integrity. In addition, we reviewed the principles defined by leading international and national organizations that support research governance and practice (Table 1).

Table 1: Examples of research and data governance principles supporting the Responsible Research by Design Framework

Organization	Guidance/standard	Principles	Extracted key ideas
ALLEA, 2023	European code of conduct for research integrity	Reliability, honesty, respect, accountability	Research quality; transparency; fairness; respect for research staff, participants and society; responsibility for process; management, societal impact
Council for International Organizations of Medical Sciences, 2016	International Ethical Guidelines for Biomedical Research Involving Human Subjects	Respect, beneficence, justice	Research participant autonomy; self-determination; respect for persons with diminished autonomy; obligation to "maximize benefit; harm reduction; sound research design and researcher expertise; equal distribution of benefits of research; protection of vulnerable persons
Canadian Institutes for Health Research et al., 2022	Tri-Council Policy Statement 2	Respect for dignity: a. respect for persons b. concern for welfare c. justice	Value of humans; consideration of experience in vulnerable persons/groups; autonomy; "free,

Organization	Guidance/standard	Principles	Extracted key ideas
			ongoing and informed consent”; respect for welfare that includes all life’s experience; fairness and equity
Data Governance Institute, n.d.2	Guiding principles of data governance	Integrity; transparency; auditability; stewardship; checks and balances; standardization; change management	Responsible conduct; clarity around decisions and decision-making
European Parliament and Council of the European Union, 2016	GDPR	Lawfulness, fairness and transparency; purpose limitation; data minimisation; accuracy; storage limitation; integrity and confidentiality; accountability	Data collected according to law and for a specified purpose; only data for a specified purpose are collected; data are collected and maintained for only specified periods of use, ensuring accuracy and security; data must be auditable
First Nations Information Governance Centre, 2014	OCAP®	Ownership, control, access and possession	Connection of culture and cultural knowledge with information and data; autonomy includes the collective community as well as the individual; research control is a right of First Nations, across the entire research lifecycle; right to access data wherever it is held;

Organization	Guidance/standard	Principles	Extracted key ideas
			mechanisms in place for ownership and control of information

Using the inputs from the CERC HECW team, the principles and key ideas identified in Table 1, and the inputs in the Background section of this case study, we developed supporting and guiding principles that are foundational to the RRbD design where process, governance and equity intentionally disseminate within and across the implementation of each research project and throughout the program.

THE CERC HECW RRBD IN ACTION

To address the needs, gaps and opportunities illustrated above, the CERC HECW program created a customized, wholistic RRbD operational framework that is rooted in principles that facilitate robust academic integrity of the program itself, governance and oversight through online project management, community engagement, data management, knowledge mobilization, and EDIA principles throughout the research lifecycle.

The supporting RRbD principles are:

a. Integrity: Community-relevant research, focused on health and wellbeing, and supported by research excellence, community relevancy, and EDIA principles.
b. Responsibility, authority and oversight: Overarching project and data management across the research lifecycle.
c. Community and co-creation: Demonstrated community engagement and research participant co-design; research aims and outputs created by community and researchers together.
d. Transparency and operational effectiveness: Open opportunity and resources; standardized processes for streamlined research project design, implementation and auditing.
e. Capacity and education: A wide range of researchers, interns, community partners and students, with various backgrounds and experiences.

The principles are the backbone of the RRbD framework and embrace the operational actions designed by the CERC HECW program. The operational actions stemming from these principles are described below.

INTEGRITY: COMMUNITY-RELEVANT RESEARCH, FOCUSED ON HEALTH AND WELLBEING, AND SUPPORTED BY RESEARCH EXCELLENCE, COMMUNITY RELEVANCY, AND EDIA PRINCIPLES

The CERC HECW program has developed a transformative research initiative that employs an engaged community partnership approach to expand our understanding, practice, delivery and participation in social and health services to improve health for all members of Canadian communities. The program aims to collaborate closely with Canadian health-care institutions, service providers, and civil society organizations for a health care delivery paradigm shift – one that challenges a siloed, expert-driven approach to health and wellbeing and moves instead towards a community-engaged, preventative model of wellbeing.

The CERC HECW program aim is to ensure that the research agenda can be scaled for population impact and outcomes, nationally and globally, and links back to global health policy agendas that situate health and wellbeing as cornerstones of transformative health systems, infrastructure, design and delivery. The CERC HECW research program foundationally ensures integrity and focus through a comprehensive governance structure that is supported by a broad cadre of academic experts, researchers, and key community groups whose focus span the Canadian and global experience relating to health equity and wellbeing research (Figure 1).

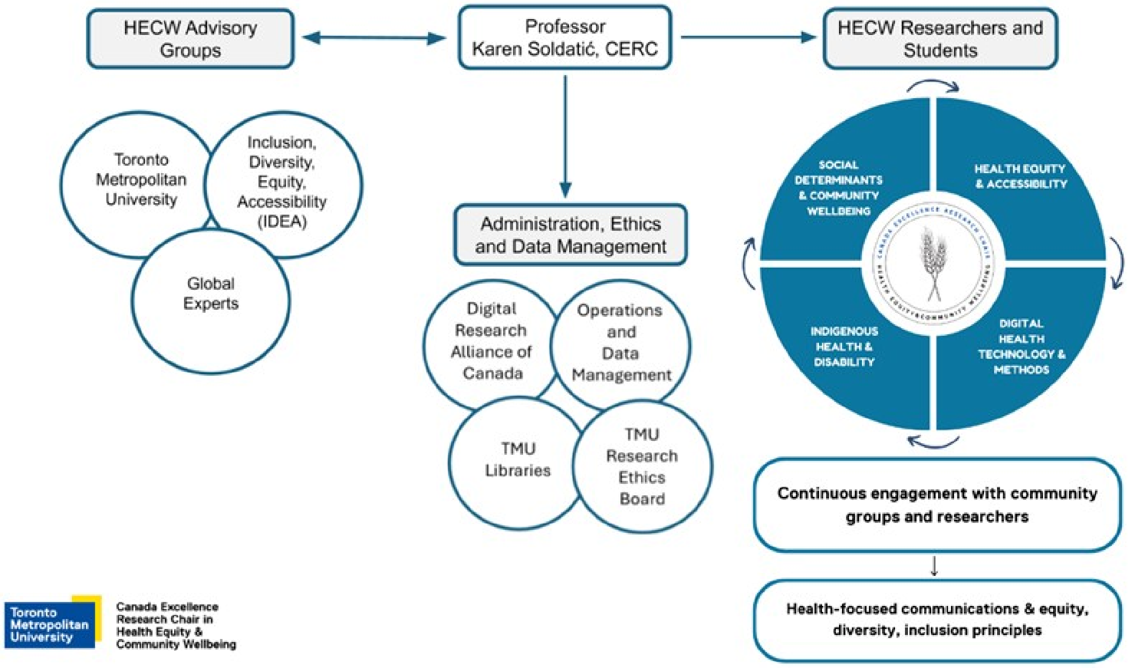

Figure 1: Overarching program governance of the CERC HECW program
Source: K. Iron (2024). Created for CERC Health Equity and Community Wellbeing Program

From a global perspective, the CERC HECW research program is applied to the Canadian lens underpinning four research themes of: 1) social determinants of health and community wellbeing; 2) health equity and accessibility; 3) digital health technology and methods; and 4) Indigenous health and disability, and operational imperatives of continuous community engagement, health focused communication and EDIA. These are embedded in all aspects of project design, implementation, and outcomes stemming from the CERC HECW research program with the aim to extend social impact of the research outcomes.

A Global Advisory Group of approximately 10 members provides guidance on international excellence in civil society research. Another Advisory Group focused on equity, diversity, inclusion and accessibility (EDIA) supports the program and projects around new and innovative research methods. In addition, Canadian research experts and persons with lived experience participate in these Advisory Groups to support the research from a local perspective, for example, from a uniquely Canadian Indigenous or healthcare delivery lens. The local experts not only bring their expertise in the Canadian research landscape, but also potential network contacts who support and participate in the CERC HECW program. Together, this cadre of research and civil society experts function to move methodology toward innovation – CERC HECW program researchers and trainees are encouraged to discuss and gain feedback from the Advisory Group experts on their research project designs, where possible. From an operational perspective, these groups are chaired by international researcher administrators, are governed through dedicated terms of reference, and meet regularly throughout the year. Their quarterly meeting cycle is integrated into grant funding cycles in Canada, conferences and academic meetings. Their functional process, meeting minutes and action items are tracked and filed to ensure auditability. In this way, research integrity striving for innovation is consistently supported.

RESPONSIBILITY, AUTHORITY AND OVERSIGHT: OVERARCHING RESEARCH PROGRAM GOVERNANCE AND DATA MANAGEMENT ACROSS THE RESEARCH LIFECYCLE

Overview: As Figure 1 suggests, senior academic administrators and faculty participate in a third Advisory Group at Toronto Metropolitan University (TMU). This group supports the CERC HECW program to ensure that university-focused academic and administrative expectations are met. Additionally, the TMU Research Ethics Board (REB) supports the CERC HECW program and its associated projects through its guidance to ensure that each project adheres to Canadian ethical research practices, data collection, use and disclosure data management practices (Canadian Institutes of Health Research et al., 2022), and according to Canadian and provincial data protection and privacy laws and regulations. The TMU REB has been an active participant in the development of the RRbD operational process and has approved its approach and processes for ethical compliance.

The collection, use and disclosure of all data collected and used for the CERC HECW program are governed and managed according to national and international data governance standards and legal frameworks as well as those defined by the TMU REB. An online, unique and customized data management plan/privacy impact assessment (DMP) – a requirement of Canadian national funding agencies for all projects – has been created for the CERC HECW program. It rests on Canadian DMP template standards, complies with data management best practices, is easy to use for researchers, and provides the necessary outputs for overarching data management and auditability (Digital Research Alliance of Canada, 2024).

Funded by the Canadian government, the Digital Research Alliance of Canada (the Alliance) is a non-profit organization that provides digital research infrastructure (hardware and software), and data management support for Canadian researchers (https://www.alliancecan.ca/en). The CERC HECW program has engaged the Alliance to provide secure data collection tools, analytic and storage space and data protection training for CERC HECW researchers for their projects. The CERC HECW program has engaged a dedicated data manager who has created a series of data protection procedures and customized secure data collection tools that are integrated into the Alliance procedures to ensure secure and privacy protected data collection, analysis and storage.

Additionally, through training and research approvals and oversight, every instance of research purpose, design, data collection and use, and knowledge outputs involving Indigenous Peoples of Canada are governed by the communities themselves.

The integrated process for the implementation of research responsibility and accountability is created through the RRbD process itself, as in Figure 2 below.

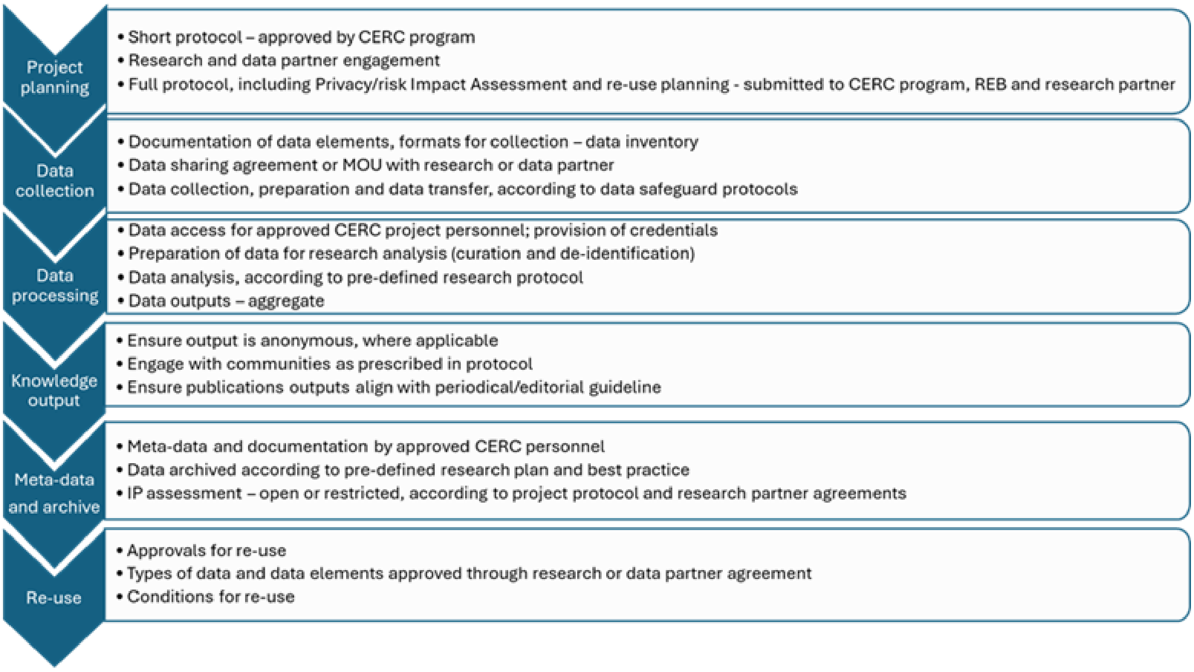

Figure 2: Phases of CERC HECW program project implementation

Source: K. Iron (2024). Created for CERC Health Equity and Community Wellbeing Program

Together, the process addresses the research lifecycle touching upon planning, community engagement, ethics approval, data collection and analytics, knowledge output, project closeout and potential data re-use. Actionable processes and tools supporting each of these phases are provided to researchers and research managers on the CERC HECW website, and through a customized project protocol template and data management plan, which, through process, activates the requirements and compliance for responsible research.

Data flow: As Figure 3 suggests, data flow from the approved research project source to a secure data platform at the Digital Research Alliance of Canada where researchers, analysts and students access the data in a protected infrastructure for their project uses. The types of research data collected and used for this program vary, as the program of research is wide and diverse. All projects and associated data collections and uses are authorized by the CERC HECW program, participant consent and the TMU REB. Data collection, use, storage, and disclosure or knowledge sharing of any data involving Indigenous Peoples of Canada are under the direction of those communities themselves.

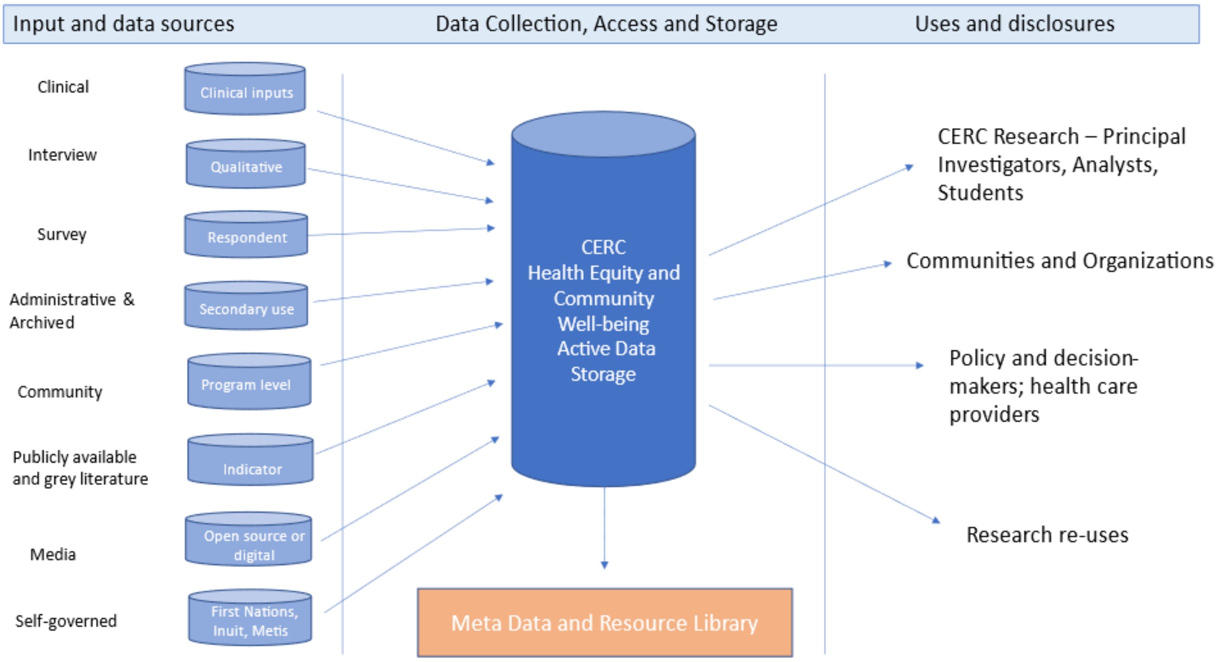

Figure 3: CERC Healthy Equity and Community Wellbeing Program Data Flow
Source: K. Iron (2024). Created for CERC Health Equity and Community Wellbeing Program

The types of data a CERC HECW research project uses may include: clinical inputs from health care providers, interviews, focus groups, online survey data, routinely collected administrative from data providers, community-level data (local or community program information), social determinants indicator data, media, such as photographs, historical notes, and art outputs, or open social media. All data are collected through a pre-defined TMU REB approval process and consent, where required.

Meta data are catalogued according to standard formats, supported by TMU as the governing institution. Re-use of data is permitted only upon approval and/or consent by research participants and in accordance with the defined CERC HECW project. Data are securely stored at the Digital Research Alliance of Canada (the Alliance) network facility, using software that is security approved and maintained with ongoing security backups. Access to project data is provided to approved, dedicated and trained research personnel who are authorized to access only their own research data through the Alliance. Sensitive data are managed according to privacy preserving protocols – training in this area continues to be offered by the Alliance and supported through the TMU REB. Mechanisms for original data destruction, retention and/or re-use are defined for each project according to research participant consent and approval from the CERC HECW and TMU REB.

Data management: Data management plans are often a requirement for funded research in Canada and are considered best practice internationally. Through a CERC HECW customized and mandatory data management Google form (DMP) that is available on the CERC HECW website, project information relating to data collection, use and disclosure is captured by researchers regarding each CERC HECW research project. The information is securely collected and used by project teams, collaborators, partners and their communities to manage their project data assets, according to their research protocol – only the CERC HECW operational administrators have access to all DMPs for reporting purposes.

The DMP takes about 20 minutes to complete and is created as a living document and a foundation to promote conversation with research partners as data collection and assets are discussed around a co-created research project. Training modules relating to data management and DMPs in general are provided to all researchers on the CERC website.

The information within the DMP outlines the authority and responsibility to collect and use data for research. This includes: legal and regulatory authority to collect, use and disclose the research data, roles of persons responsible for data assets, types and purpose for proposed data collected, data collection processes (consent) and anonymization protocols, data analysis software, storage, archiving, meta-data that may be used for open use (with research participant agreement) and data security measures, for example. The DMP information aligns with requirements by the TMU REB and its Privacy Office and, aside from the research protocol, are an integral part of the application for TMU REB approvals. The DMP information is also used by the CERC HECW program administrators to track and manage both project requirements and the implementation of the data collection, use and disclosure actions, according to project aims. The DMP is also a source for auditing and reporting requirements focusing on data-related matters and oversight.

COMMUNITY AND CO-CREATION: DEMONSTRATED COMMUNITY ENGAGEMENT AND RESEARCH PARTICIPANT CO-DESIGN; RESEARCH AIMS AND OUTPUTS CREATED BY COMMUNITY AND RESEARCHERS TOGETHER

The CERC HECW program rests on research partnership and project co-creation, acknowledging that many marginalized communities face a range of barriers that impact their access to opportunities, services and resources within academic and educational settings, across the development, output and impact of research.

Co-creation with research partners, including civil society organizations and their clients, is intrinsically integrated into the CERC HECW program through an initial partner agreement that documents the purposes and *how* co-creation will take place, from project design, implementation and knowledge mobilization efforts. This type of initial documented dialogue ensures that expectations of any aspect of the research undertaking are agreed upon. As a requirement, researchers access community engagement training modules provided on the CERC HECW website, and are required to include community engagement plans in their research protocols.

Knowledge translation and mobilization (KTM) is a central feature of the CERC HECW program, integrating co-creation activities with communities and stakeholders and simultaneously building research capacity and networks. Agreement and documentation of knowledge-to-action plans with communities within agreements and research protocols ensures that research and dissemination activities are relevant to research participants, communities and other stakeholders. Agreed upon research outputs are delivered in the most appropriate format, dependent upon audience, venue, and platform with a focus on its strategic aims and intent. Some examples of outputs in appropriately accessible format (based on audiences and purpose) are workshops, academic presentations, conferences, and journal articles, community-based public awareness campaigns and policy briefs.

TRANSPARENCY AND OPERATIONAL EFFECTIVENESS: OPEN OPPORTUNITY AND RESOURCES; STANDARDIZED PROCESSES FOR STREAMLINED RESEARCH PROJECT DESIGN, IMPLEMENTATION AND AUDITING

Project initiation: The CERC HECW program has developed public-facing, standard, online and mandatory project initiation, approvals and implementation process for all CERC HECW projects. All research projects require prior approval by the CERC (i.e. the Chair), specific research partners, and the TMU REB. The activities for approved project implementation include six phases as highlighted in Figure 2: project planning, data collection, data processing, knowledge output, meta-data and archiving, and data re-use, if applicable. The detailed activities for operational research are described below.

A CERC HECW program project begins via a visually accessible, public-facing website that allows researchers to learn about and engage with the program. The webpage provides a guide for researchers that describes the program and the operational expectations of project initiation, design and implementation. There are three aspects to CERC HECW project design: community engagement, project registration, project protocol development, and REB approvals.

As discussed above, project initiation begins with community engagement. Once an agreed upon research project-in-principle is articulated between researchers and a community partner, an electronic project registration and approval request is submitted. This Google form submission serves as an online collection of basic information about a project that allows CERC HECW project administrators to decide on approval (based on a variety of factors such as funding, capacity and alignment with the CERC HECW program mission). The information submitted also serves as a registration of all project requests, whether approved or not, allowing for transparency, auditing and efficient program operations. A unique project number is provided for each initial submission that is used by researchers and program administrators throughout the research operational lifecycle that allows administrators to manage the program.

The CERC HECW program administrators review all project initiation requests, following up with researchers within one month of submission with either: a) approval to proceed to the next phase of the program process; b) a suggestion that more information is required, or c) a refusal to continue with the research partnership due to misalignment with program ideals and/or mission or limited resources. Once projects are approved in principle researchers may move to the next phase of the process – the creation of a detailed project protocol.

The project protocol template is accessed through the public CERC HECW website. It has been customized using standard components of research design with headings such as: project aims and objectives, research team expertise, methodology and analytic plans, data sources and data partners, types of data, expected results outputs, budget and timeline (CIOMS, 2016; CIHR et al., 2022). Unique to this program the project protocol must include implementation plans focused on EDIA, community engagement, knowledge mobilization, and data management. The inclusion of each of these plans is a mandatory component of the CERC HECW program and must be in place before a project can be approved by the program; once a project is approved by the CERC, it may be submitted to the TMU Research Ethics Board for final approval.

All of this activity is organized and noted through a Google form used by the responsible researcher as an online project tracker which includes the completion date of project plans as they unfold, recording additional information that clearly outline research project decisions that were adjusted according to community and scientific learnings throughout the project lifecycle. This information is also available to the program administrators and may be used as a resource during project-related meetings to ensure that research activity is on-track and that all requirements are met from all stakeholder perspectives.

Finally, the TMU REB has approved the CERC HECW approach to research projects. Researchers and administrators can easily access the appropriate links to the TMU REB's requirements, as well as additional ethics training modules, through the CERC HECW website. This promotes the idea that research ethics is not just a formality, but a component of research and administration that ought to be woven into all aspects of research. Addressing this notion, allows for more efficient and effective REB interactions. The transparency of this process also supports research administrators in their efforts to guide researchers toward effective and timely processes and for auditing and reporting functions.

Capacity and Education: A Wide Range of Researchers, Interns, Community Partners and Students, with Various Backgrounds and Experiences

RRbD ideals suggest that excellent research is not only the result of robust research methodologies and technical expertise, but also in the breadth of diversity and intersectionality among research participants, researchers, students and staff. Through wide distribution and barrier-free recruitment strategies, the core CERC HECW team is diverse, largely comprised of women and racialized individuals, mirroring much of the diversity of the TMU student population, and the City of Toronto as a whole. Through voluntary self-disclosure, the team includes people with visible and invisible disabilities, trans persons, people of all ages and religions, and people with diverse lived experiences. The CERC HECW team members have collectively created an onboarding/orientation package for team members, including voluntary identification of EDIA based accommodation: language, learning, physical disability, religious practice, preferred pronouns, for example. Additionally, new staff orientation is provided in multiple formats based on accessibility needs, and includes a rigorous feedback system, including a staff check-in after 30-60-90 days into the initial work period.

CERC HECW researchers and research teams are encouraged to actively examine their research needs and identify gaps in expertise relating to co-creation, digital literacy for accessible and inclusive research co-design, and intersectionality research training. External partners are encouraged to support researchers in these areas, ensuring that the research program and projects they create together are respectful, supportive, and aligned with community needs. The goal is for the research outputs to be relevant and actionable, enabling community organizations and their constituents to effectively engage with and utilize the co-created findings across professional, policy and advocacy contexts in their communities. Training modules in this area are available on the CERC HECW website.

The CERC HECW environment prioritizes inclusivity, fostering open dialogue among team members to discuss their work and accommodation needs during weekly meetings if they are comfortable sharing in a group setting. Examples include barrier-free physical space (computer cords are tucked away), large screen reading resources, and respect for cultural and religious practices, with quiet spaces available for prayer and meditation as needed. Scheduling and timing of onsite work may be adjusted to accommodate diverse disability needs, persons with small children or elderly parents, and for staff who identify as neurodivergent and require additional workplace accommodations. TMU supports this inclusive approach as a globally recognized academic institution committed to diversity among students and faculty.

RRbD ideals are implemented to induce robust research through diverse and broad human resource capacity. Dedicated funding for personnel who support RRbD activities is an essential component of the CERC HECW budget, such as in the areas of communications, accessibility, training and data management.

SUMMARY AND NEXT STEPS

The RRbD framework is fully transparent and easy to implement for both researchers and research program administrators; its application intentionally integrates research context and integrity, process, governance and equity within and across the implementation of each research project and throughout the program. As standard practice, the RRbD framework itself ensures that community engagement, data management and EDIA principles are woven into research design and operational practice across the research project lifecycle, allowing the richness of research to unfold within and as an outcome of process. Finally, the RRbD framework provides research administrators and managers with an easy, flexible and integrated method for engaging with researchers and stakeholders, and facilitating accountability, auditing and reporting as the research process unfold.

Table 2 summarizes the CERC HECW program's RRbD principles with pragmatic and evolving actions taken to continuously build and solidify the program's commitment and dedication to RRbD. The summary table further illustrates the utility of the integrated RRbD framework and how governance and fairness are woven into the CERC HECW research program operations itself and are not simply "add on" activities to check off as completed. The RRbD principles align with actions that are integrated, reiterated and perpetuated within and across the entire research lifecycle. Through focused discussion and team training, all participants in the research process – researchers, community partners and research administrators – have a role in implementing the RRbD framework.

Table 2: CERC Health Equity and Community Wellbeing Responsible Research by Design (RRbD) principles and associated intended outcomes.

Principle	Description	Intended Outcomes
Integrity	Community-relevant research, focused on health and wellbeing, and supported by research excellence, community relevancy, and EDIA principles.	o Defined and demonstrated social utility o Research guidance and review by world-renowned academics, communities and persons with lived experiences o Integrated EDIA principles as a requirement of research
Responsibility and oversight	Overarching project and data management across the research lifecycle.	o A program-wide governance plan is created and tested over time o Researchers and community project and data owners continue to be named and held accountable o Required project approval by the HECW program prior to research implementation o Research ethics approvals

Principle	Description	Intended Outcomes
		o Data risk assessment and management plan requirement
Community and co-creation	Demonstrated community engagement and research participant co-design; research aims and outputs created by community and researchers together.	o Engagement with community members prior to research o Inclusive requirements when working with Indigenous Peoples of Canada o Defined community engagement plan required for projects o Research plan, data use plan and knowledge mobilization plans created with community partners are required o A mutually beneficial signed agreement between researcher and community partner to ensure expectations are met o Integration of community partners throughout the research lifecycle
Transparency and operational effectiveness	Open opportunity and resources; standardized processes for streamlined research project design, implementation and auditing.	o Open and online project guidelines and resources for research o A diverse and engaged research staff with accompanying procedures o Integrated program information collected for easy accountability and reporting on projects and associated data

Principle	Description	Intended Outcomes
Capacity and education	A wide range of researchers, interns, community partners and students, with various backgrounds and experiences.	o Student, post-doc and staff opportunities o Training and educational resources for researchers and staff for undertaking projects o Program-wide workshops provided focuses on EDIA in theory and research practice, communications and data management, for example

The CERC HECW RRbD framework continues to be refined through continuous feedback and discussions with the program's operational staff and managers, Advisory Groups, its researchers, and the communities that engage with the program, at the local, national and international arenas. Consistent communication among researchers and program administrators is key to its general uptake. RRbD is not a one-time activity – its design and implementation are considered "living" as environments and requirements change. The RRbD framework must remain feasible and flexible to remain useful and to meet the rigors of science and the demands for inclusive and accessible practices from community and thus, a dedicated owner of the process itself will ensure its success.

Currently, the implementation of the RRbD framework is simple and still quite manual, with the use of Google forms and static templates. As the framework matures, and with additional capacity, the implementation of the RRbD framework could be more automated and efficient, with considerable feedback from users, as new ideas emerge. As such, the RRbD framework acts as both a conceptual and practical guide for researchers and research administrators by integrating research, governance and administrative imperatives.

The emerging dialogue relating to fairness, equity and governance in research, and how to ideologically and pragmatically translate this dialogue into research practice is relatively new, layered on top of ethics and practices regarding data privacy and security. With RRbD principles and actions integrated into the research process itself, the opportunity for new RRbD-focused ideas, methods, digitization, and automation will emerge; these must be openly integrated, tested and re-tested to ensure that they are reproducible and valid in a variety of environments, contexts and research paradigms.

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