Title: Data Initiatives Supporting Critical Care Research and Quality Improvement in Canada: an Environmental Scan

Short Title: Critical Care Data in Canada

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Implication Statement: Clinical and biological data collection among critically ill patients in Canada is not sufficiently coordinated, lags behind other jurisdictions, leads to inefficient use of health care, research and quality of care improvement resources, and therefore represents a scientific and clinical priority in the care of critically ill patients in Canada.

Abstract

Purpose: Collection and analysis of health data are crucial to achieving high-quality clinical care, research, and quality improvement. The purpose of this environmental scan was to explore existing hospital, regional, provincial and national data platforms in Canada in order to identify gaps, barriers and propose recommendations for improved data science.

Source: The Canadian Critical Care Trials Group and the Canadian Critical Care Translational Biology Group undertook an environmental survey using list-identified names and keywords in PubMed and the grey literature, from the Canadian context. Findings were grouped into sections, corresponding to geography, purpose, and patient sub-group initiatives, using a narrative qualitative approach. Emerging themes, impressions and recommendations towards improving data initiatives were generated.

Principal Findings: Comprehensive international clinical datasets to inform future Canadian initiatives include the Australia and New Zealand Intensive Care Society (ANZICS) adult database, the United Kingdom Intensive Care National Audit and Research Centre (ICNARC) Case Mix Programme and the United States project IMPACT. In Canada, the Canadian Institute for Health Information discharge abstract database contains high-level clinical data on every adult and child discharged from acute care facilities; however, it does not contain data from Quebec, critical care-specific severity of illness risk-adjustment scores, physiological data, or data pertaining to medication use. Provincially mandated critical care platforms in 4 provinces contain more granular data, the ability to risk adjust and link to within-province datasets; however, no inter-provincial collaborative mechanism exists. There is very limited infrastructure to collect and link biological samples from critically ill patients nationally.

Conclusion: Clinical and biological data collection among critically ill patients in Canada is not sufficiently coordinated, lags behind other jurisdictions, leads to inefficient use of health care, research and quality of care improvement resources. An integrated and inclusive critical care data platform is a key clinical and scientific priority in Canada.

Introduction: Importance of High Quality Data to the Care of Critically Ill Patients

Collection, analysis, and presentation of health data are crucial to achieving high-quality clinical care, research, and quality improvement. Within the field of critical care, there are several data platforms in Canada, including hospital, regional, provincial and national databases. However, there is inadequate understanding about the utility, performance characteristics, and best practices in administration, quality control and the potential for coordination among these databases. The purpose of this environmental scan was to explore these issues with the goal of improving the collection and use of administrative health data in critical care in Canada.

Methods

In an effort to improve our understanding of existing data resources related to critical care in Canada, the Canadian Critical Care Trials Group (CCCTG), with support from the Canadian Institutes of Health Research (CIHR), undertook a broad environmental survey of critical care data initiatives across Canada. The goal of this scan was to inform the development of a data initiative that would benefit Canadian critically ill patients, clinicians, and scientists.

Members of the CCCTG were informally surveyed with the purpose of generating lists of existing data initiatives (hospital, regional, provincial, national and international) that would form the basis of a more in depth review of the published and grey literature. We searched both PubMed and the grey literature (using Google) using list-identified names and keywords from the Canadian context (Appendix). CCCTG collaborators were individually queried and provided a list of international critical care-related datasets for further context and exploration. The findings were grouped into sections, using a narrative qualitative approach, corresponding to geography or location of focus (hospital, region, province, country and international), purpose-specific, and, patient sub-group initiatives. Authors subsequently generated overarching emerging themes and drafted informal impressions and recommendations to improve data initiatives in Canada.

Results

International Data Initiatives in Critical Care

The Australia and New Zealand Intensive Care Society (ANZICS) [1] has country-wide routine clinical data collection and inclusion in a national database [2]. The ANZICS Adult Patient Database (APD) de-identifies data before inclusion, without linking information and thus patients cannot be tracked through multiple admissions or transfers involving more than one hospital [2].

In the United Kingdom, the Intensive Care National Audit and Research Centre (ICNARC) coordinates a national, comparative audit of patient outcomes from adult critical care units. After extensive local and central validation, ICNARC data is pooled into the Case Mix

Programme Database (CMPD). [3] ICNARC uses a distinct coding system and data dictionary referred to as the ICNARC Coding Method (ICM) for data entry and retrieval. The primary end product of this database is the CMP Annual Quality Report, which describes risk-adjusted mortality and key quality indicators at various levels.

Project IMPACT was launched in 1996 in the United States [4] as a voluntary (for an ICU or hospital to join) and fee-based service. Project IMPACT uses a trained data collector to input data regarding individual patients, processes of care, and hospital/unit characteristics into a standardized, web-based instrument. IMPACT ICUs have been shown to be nationally representative of ICUs in the United States, and prior studies have validated key fields [4, 5]. However, a limitation of Project IMPACT is that the database is not publicly available but may be accessed for a fee.

Canadian Data Initiatives in Critical Care

Canadian Institute for Health Information (CIHI)

As a publicly funded data source, Canadian Institute for Health Information (CIHI) data – critical care related or otherwise – is a major source of healthcare data available on reasonable request to public or private sectors. CIHI also has undertaken a number of critical care specific initiatives, for example "Care in Canadian ICUs"[6], to enable evidence-informed system improvement efforts by providing a baseline of comparable measures of ICU care in Canada. Data from this initiative includes information on patient flow, trends in admissions, patient populations, and processes of care for those treated in ICUs. While this data does not contain validated severity of illness measures for individual patients and is therefore not easily "risk adjusted", it permits longitudinal descriptive studies, basic comparisons across ICUs, and characterizes existing resource utilization and capacity of ICUs.[6]

The Discharge Abstract Database (DAD) is the primary national source of data from hospitalizations produced by CIHI. The DAD captures administrative, demographic, clinical, procedural and hospital outcome information on all hospital admissions, outside of Quebec, in a centralized database. The DAD is populated from acute care facilities or from their respective health/regional authority. All provinces with the exception of Quebec are required to report patient-level hospital information through the DAD. Data from Quebec are submitted to CIHI directly by the ministère de la Santé et des Services sociaux du Québec and appended to the DAD to create the Hospital Morbidity Database (HMDB). Data quality and quality assurance are routinely completed during the submission year and after database closure. The DAD records whether patients were admitted to an ICU, which type of ICU, as well as if and for how long they were mechanically ventilated (more or less than 96 hours) and certain procedures and surgeries received. The DAD does not include ICU admission diagnosis, ICU specific severity of illness score or other risk adjustment mechanism, daily physiology markers, laboratory values, or records of in-hospital medication use. [7, 8]

Canadian Critical Care Research Network

Precedent for a national critical care data initiative exists with the Canadian Critical Care Research Network (CCRN)[9] that successfully supported quality improvement initiatives and research. The network consisted of 20-30 participating ICUs over its history, each contributing data on all admitted patients – characteristics, demographics, admission diagnosis, co-morbid conditions, admission APACHE scores, as well as clinical outcomes. The network has facilitated numerous observational studies and provided the data structure for cluster randomized controlled trials to evaluate new guideline implementation [10]. Furthermore, CCRN demonstrated that bedside data collection could be highly reliable and valid, across a broad spectrum of Canadian academic and community ICUs[11].

Provincial Data Initiatives in Critical Care

Alberta

In Alberta, the primary source of critical care patient-level data is eCritical Alberta. eCritical Alberta is a bedside clinical information system (*MetaVision*^{TM}, iMDsoft for adults; VPS for children) capable of full electronic interdisciplinary clinical documentation and collation of demographic (age, sex), diagnostic/case-mix (comorbid disease, primary diagnostic classification, surgical status), illness severity (Acute Physiology and Chronic Health Evaluation [APACHE] II and III scores, Sequential Organ Failure Assessment [SOFA] scores), laboratory and intervention data (ventilation, vasoactive medications and renal replacement therapy [RRT]) supported by a data warehouse and integrated clinical analytics system (*TRACER*). The *eCritical/TRACER* repository is housed within Alberta Health Services (AHS) and is governed by a provincial multi-disciplinary executive leadership group that oversees its data quality assurance and audit methods.[12] *eCritical/TRACER* has routinely been used to support health services and outcomes research [13-17], education, planning and decision-making.

British Columbia

The BC ICU database was started two decades ago to provide information to assist in day-to-day clinical operations, quality improvement, and health services research and expanded to include approximately 20 of the 30 provincial ICUs. Data elements that are entered by dedicated ICU informatics nurses include demographics (including an automatic link to the admission, discharge, and transfer program at one of the participating hospitals), diagnoses (primary and other ICU admitting, underlying, and ICU-acquired, all using explicit dictionaries of diagnoses), components of severity of illness scores, ICU procedures, safety outcomes, geographic sources and dispositions of patients, avoidable ICU days, and measurements related to management of glucose control, pain, sedation, and delirium. Reliability of data entry has been checked and published [18]. In addition, this database has been used a source for many research studies [19-26]. Recently, a real-time reporting function for ICU decision-makers has been added that produces tables and figures for 15 key variables. This database is governed by a committee that includes leaders from each of the participating health authorities (geographic regions of health service in BC).

Manitoba

The Winnipeg ICU Database (WICUDB) originated in 1988 in the Medical and Surgical ICUs at the Winnipeg Health Sciences Centre. Manitoba's geographic distribution of ICU beds is unique; except for the nine-bed medical-surgical ICU at Brandon Medical Centre in Brandon, all other ICUs in Manitoba are located in Winnipeg. Since July 1999 it has included all patients admitted to all the adult ICUs in the Winnipeg Regional Health Authority, including coronary care units and contains over 121,000 records. The data are currently collected via manual chart review by a cohort of dedicated, trained data collectors, all of whom are former ICU nurses; there are entered into laptop computers and uploaded to a server maintained by the Department of Internal Medicine of the University of Manitoba.

The Winnipeg ICU Database data elements comprise patient demographics, ICU admission and discharge timing, admission source, disposition, an unlimited number of diagnoses (pre-existing comorbid conditions, those related to admission, and acquired post-admission), procedures (related to admission, and occurring post-admission), laboratory test results, information about transfusions and a limited list of pharmaceuticals. It contains APACHE II elements, scores and predicted hospital mortality[27], and all items for each day in ICU from the simplified Therapeutic Intervention Scoring System[28]. The WICUDB has constantly evolved and is extensively documented (https://ccmdb.kuality.ca/index.php?title=Main_Page). Before 2019 it used a custom schema for coding diagnoses and selected procedures; it now uses "reduced" versions of ICD-10-CA[29] and the Canadian Classification of Interventions[30]. From 2019 onwards, in addition to detailed information about the time in the ICU, it includes hospital admission and discharge timing, and hospital admission source and disposition. Of note, as almost one-fifth of ICU patients in Winnipeg experience inter-ICU transfers, identification and construction of complete episodes of ICU care is necessary to accurately assess lengths of stay and mortality rates.[31]

The entire WICUDB has been imported and merged with the Health Research Repository at the Manitoba Centre for Health Policy, which contains over 100 databases, including: vital statistics, the CIHI-formatted Discharge Abstract Database of hospital abstracts, outpatient claims, the Emergency Department Information System, the Drug Program Information Network of all outpatient prescriptions filled, homecare, nursing homes, education, justice, social housing, income assistance, a Cancer Registry and many others. The ICUDB has been used to demonstrate that DAD identification of ICU admission is highly accurate [32].

Ontario

In Ontario, the Critical Care Information System (CCIS) is the most comprehensive source of province-wide patient-level critical care data. The CCIS provides twice-daily data on every patient admitted to the highest-acuity ("level 3") and step-down ("level 2") critical care units in the province and includes an admission measure of severity of illness (Multiple Organ Dysfunction Score) that can be used in risk adjustment [33]. The goal of CCIS is to provide

information on bed availability, critical care utilization, and risk-adjusted patient outcomes. One unique aspect of CCIS is its integration with the Provincial Hospital Resources System (PHRS, is a provincial hospital bed and resource registry used to provide a 24-hour-a-day emergency referral service for physicians across Ontario. Information from the CCIS Bed Availability Tool, which describes ICU capacity, is automatically transferred to the PHRS. Responsibilities for reliability, timeliness, and accuracy of CCIS data are at the hospital and ICU level with the added requirement that bed availability must be updated at least once in a 24-hour period.[34]

Another source of critical care data in Ontario comes from the Institute for Clinical Evaluative Sciences (ICES), an Ontario based clinical and epidemiological research institute. The IC/ES data repository consists of record-level, coded, and linkable health data for the Ontario population dating back to 1986. Most data collected by IC/ES are record level with direct personal identifiers used to create a confidential unique identification number for each person ever issued a health card in Ontario. This ICES number allows linkage across data sets including the CIHI DAD and NACRS and the Ontario Health Insurance Plan database, enabling continued longitudinal study of patients admitted to the ICU through other areas of healthcare. [35] [36] ICES does not contain data that permit ICU patient-specific risk adjustment, but with future linkage to the CCIS, risk adjustment should be possible.

Other Provinces

A standardized data collection process for critically ill patients does not exist on a provincial level in Quebec. At the moment, clinical hospital data for ICU patients are collected through the hospital discharge form – similar to other hospitalized patients. This dataset is similar to the Discharge Abstract Database (DAD) and part of the information contained is shared with the Canadian Institute for Health Information (CIHI). In Nova Scotia, the creation the Nova Scotia Health Authority (NSHA) has allowed consolidation of critical care services on a provincial level. In 2018 a database was created and piloted in ICU's at the Queen Elizabeth II Health Sciences Centre, and subsequently data collection was initiated across the province.

Purpose-Specific Critical Care Data Initiatives in Canada

Quality Improvement and Patient Safety

aC3KTion Net: a Canadian Critical Care Knowledge Translation and Quality Improvement Network

In Canada, there have been sporadic and limited efforts at improving the assimilation of best practice into critical care units and much of the focus on critical care KT has been on patient safety. For patient outcomes to be improved on a broader scale, all best practices as informed by research evidence need to be considered for knowledge translation initiatives in the ICU. The Critical Care Knowledge Translation Network (CCCKTN) (http://www.acktionnet.ca/) seeks to implement a systematic, multifaceted and synergistic knowledge translation strategy, bring

together expertise from across jurisdictions and healthcare backgrounds. Its aim was to periodically audit practice and then provide feedback to clinicians and administrators. Unfortunately, without dedicated resources for data collection, this initiative was ultimately not sustainable and ceased operation. One of the key learnings from this initiative is that although critical care data exists in many jurisdictions, it is variable in composition, focuses on different aspects of critical care and obtaining access to the data is cumbersome and of little use to inform practice in real time.

Toronto-initiated Intensive Care Observational Registry (iCORE)

The Toronto-initiated Intensive Care Observational Registry (iCORE) project is a coordinated effort to create a high-quality registry of critically ill patients in the greater Toronto area, with a quality improvement focus. An important and innovative feature of the iCORE project is the modular nature of data collection, depending on the focus of the issue being studied, so that a tailored data collection module can be added to address a specific question or process of care issue. As a result, iCORE can accommodate distinct time-limited data collection modules that can be designed and implemented to answer new investigator-initiated, hypothesis-driven questions.

From a quality improvement perspective, iCORE contains data on several evidence-based processes of care for critically ill patients, such as sedation interruption, spontaneous breathing trials, delirium screening and incidence, early mobility, lung protective ventilation, and thromboprophylaxis. As a result, iCORE may provide data required to assist in evaluating new QI projects. Finally, having the iCORE infrastructure available for sustained data collection facilitates large-scale knowledge translation (KT); and ensures continuous evaluation of barriers, performance measures, and unintended consequences.

Organ Transplantation and Donation

Collecting high quality ICU data is beneficial to ensure best practices are employed for both organ donors and recipients. This has proven challenging for a variety of reasons. Data regarding donation practices is held by provincial organ donation organizations (ODOs), with varying privacy regulations regarding data sharing with federal registries such as CIHI. The donation data collected is not completely standardized across Canada, with some provinces collecting information on all potential donors and others reporting only on individuals referred to the ODO. Data on donor characteristics or donor management therapies are only occasionally linked to recipient outcomes, both because recipient information is often stored by the transplanting center, and because privacy legislation is often perceived to prevent any linking of donor and recipient data. Canadian Blood Services has recently led an initiative that seeks to create a minimum data set for organ donation across Canada.

Paediatric and Neonatal-Specific Critical Care Data Initiatives

Canadian Neonatal Network Collaboration

Since 1995 the Canadian Neonatal Network collaboration, has used a standardized neonatal intensive care database used for research projects leading to 200 publications and numerous policy impacts.[37] The database collects demographic, severity of illness (for risk adjustment), transportation, diagnosis and procedure and outcome information on neonates admitted to the 31 participating centres. This data is manually abstracted in real-time to provide benchmarking across centres for major morbidities and mortalities, as well as provide extensive research opportunities for researchers across the country.

Canadian Association of Paediatric Health Centres (CAPHC)

The Canadian Paediatric Decision Support Network was created in 2005, under the leadership of CAPHC, to provide hospitals with benchmarking and comparability analyses for hospitals specializing in paediatric care. For critical care, this allows for comparison of total admissions and length-of-stay, as well as case-mix groups; currently, severity-of-illness markers, quality-indicators such as hospital-acquired infections, and other granular patient-specific details focused on paediatric critical care are not collected. CAPHC also collects routinely available data through the Discharge Abstract Database to inform policymakers and hospital leadership. Given the relatively small numbers of paediatric health centres in Canada, securing national coverage of data on paediatric critical illness opens up possibilities for a large number of population health and research initiatives.

A number of Canadian paediatric ICUs currently participate in American-led quality-improvement, research, and benchmarking registries, with Canadian data sharing occurring where possible; more granular data is collected on severity-of-illness standardization and clinical outcomes, expanding the possible research questions that can be asked.

Translational Research-related Critical Care Data

The Canadian Critical Care Translational Biology Group (CCCTBG) was founded by Dr. Michael Ward in 2003 to develop a national venue for collaborative studies to bridge the gap between basic science discoveries and clinical research. The DYNAMICS Study is one of the largest CIHR-funded, investigator-initiated, pan-Canadian translational studies with collaborators from the CCCTBG and CCCTG. Extensive clinical data and biological samples (plasma, genomic DNA) have been collected longitudinally from approximately 800 critical care patients. The data management software used by the DYNAMICS study is idatafax which provides electronic data capture, study setup, system administration, and system validation. The database collects demographics, severity of illness, MODS and SOFA scores, sites and types of infections, and chronic disease history. The biological specimens are stored in -80^{o}C freezers using the Freezerworks barcode-based inventory system. To date, over 20 basic science and translational papers have been published using data and biological samples from the DYNAMICS study.

In Alberta, the Critical Care Epidemiologic and Biologic Tissue Resource (CCEPTR) established a translational biobank that collects samples from plasma, serum, urine, sputum, BAL, and

abscess drainage. The work is funded by CFI, ASRA, AHFMR-ASN, the Snyder Chair, and the Department of Critical Care Medicine. The clinical information is obtained from a combination of Redcap and Metavision. Biological specimens are catalogued using Freezerworks.

Another initiative aimed at facilitating translational ICU research is the Focus on Research and Clinical Evaluation (FoRCE) project [38], which merges clinical data with large-scale genomic and physiologic waveform data obtained from bedside monitors. FoRCE can be populated with data derived from routine care, as well as from dedicated studies, and utilizes open source tools for data querying and analysis, including REDCap, Elasticsearch, and Python.

Discussion

Characteristics of High-quality Critical Care Data in Critical Care

Several criteria emerge as being critical to a high-quality database and might inform future initiatives and collaborations. First, a standardized data dictionary with data quality control procedures is a prerequisite to reproducibility and reliability, allowing standardization of elements for comparison. Second, a high-quality clinical database must be sufficiently detailed, collecting information on severity of illness at admission in order to help risk-adjust among patients, and on processes of care and care while critically ill rather than limiting data to admission characteristics and discharge outcomes. Third, a high-quality database does not operate in isolation but can be linked with administrative databases to enable long-term outcomes and resource utilization to be tracked longitudinally. Alternately, if linkage is not possible, collaboration among individual dataset custodians is still feasible [39] Fourth, harmonization of data dictionaries between administrative and research needs is key to enhancing database utility. Finally, a high-quality database must be accessible in a timely manner and without significant administrative barriers, which may compromise utility and novelty of data for research, comparative and quality-improvement initiatives.

Potential Benefits of High-quality Data in Critical Care

Longitudinal and inter-institutional critical data initiatives will improve our ability to estimate the incidence and prevalence of critical illness, describe its course over time, variations in treatments and outcomes across ICUs and examine the impact of interventions and on outcomes. Comparisons across ICUs also generate further insights into the variations and gaps in care, providing an opportunity to improve performance across institutions and providers. These comparisons require that data be valid and contain a mechanism to risk adjust among patients – typically severity of illness measures at admission to ICU – and among health system – containing institutional characterises – in order to be most helpful to stakeholders.

Presently, the most common mechanism employed to improve outcomes is the adoption of evidence informed clinical practice. We can do so only if we build the necessary infrastructure to define best practices, systematically monitor and evaluate care, and translate knowledge

from research and quality improvement studies to practice. Data on patient preferences, patient health-related quality of life, and costs would permit a more robust examination of the real-world effectiveness of many ICU interventions and technologies, in addition to our research interventions and their collective consequences in relation to other elements of the healthcare system.

Improving the availability and quality of baseline patient data in critical care data has implications for research feasibility and workflow. The time to perform data collection and to train research coordinators and assistants in data collection might be lessened if we improve and automate some elements of data capture. Additionally, standardization of procedures and practices could ensure a more uniform baseline among centers and improve efficiency of remote or central monitoring. At a very practical level, improved data quality could provide valuable information in determining the number of eligible patients for a new study, which could lead to more efficient trial design and more data-driven research funding. Lastly, there is an underlying need for better translational data and specifically its linkage to clinical data. Translational studies often exist in isolation from clinical research, losing the advantage of efficiency and the ability to link translational data to clinical outcomes

Potential Challenges and Barriers to High-quality Data in Critical Care

A national database with a common data dictionary has inherent efficiency for large-scale research, comparative and quality improvement initiatives; however, comes with logistical challenges. Data collection must serve their intended purpose, but not be overly burden the bedside clinicians, researchers and research coordinators, or jeopardize the completion of research with added costs. Other impediments to progress can be grouped into two major categories: technological and organizational.

Considering currently available databases and data capture systems among hospitals, health authorities, and provinces, incompatibility of data types, data dictionaries, and standardized terminologies are barriers to integration. On a larger scale, hospital-wide electronic medical record systems and capabilities vary widely, with the potential for automatic data uploads between critical care and hospital-wide platforms limited in some jurisdictions. Notwithstanding, procedures, protocols, infrastructure and regulations to enable data sharing are often not in place, despite data being available in some format.

Data security and appropriate mechanisms to perform valid analyses on data are other important challenges to overcome. Social and organizational challenges are equally present. Collaboration between healthcare institutions, systems, and across provincial borders faces significant logistical and regulatory barriers. These concerns are being addressed in many jurisdictions outside of Canada, including mechanisms to access high performance computing platforms for analysis to operationalize deep learning and other emerging techniques.[40] Harmonizing data sharing agreements, and research ethics protocols requires significant human resource investment. Issues regarding data ownership and access remain to be clarified. Human factors such as fear of abandoning current investments in time and money that have already

been made present additional inertial barriers to the creation of better systems. The need to securing funding to support any new infrastructure and ongoing data collection platforms is an ever-present challenge.

Conclusion

Considerations for the Future of Critical Care Data and Information Initiatives

There are a few obvious potential approaches in pursuing the aim of improving critical care data in Canada. A single, national database modeled after previously outlined success stories would make large scale collaboration easier and has the advantage of efficiency and generalizability using unified data dictionaries; however, a new national clinical database would have significant initial and ongoing investment requirements. Bringing together and/or harmonizing common elements of the existing provincial/regional databases – in the form of a minimal data - is another approach, but will require substantial collaboration among regions. An added value of such a collaboration might be that the most successful aspects of any one system are more visible and more likely to be taken up by other regions. Another avenue might be to focus on specific patient populations, for example, paediatrics where there are fewer centers and national initiatives may be more feasible. Other initiatives might leverage existing population-level data sources (e.g. CIHI's DAD) and aim to supplement the DAD with granular patient severity of illness data – one of the key limitations currently that prevents robust risk adjustment and inter-ICU comparisons.

Another example might be a modular minimal data set collected for a period of time with the goal of quality improvement (in the PDSA cycle), transitioning to a new set of data focused on a next challenge or common problem among critically ill patients or ICUs. Databases such as iCORE have been successful in this approach at a local level. Translational biology is yet another area where a specific data initiative linking specimen and clinical data, ensuring common standard operating procedures for data collection, sample collection, and processing, has the promise of assisting discovery research for the sickest patients in Canada as we enter into a era of greater basic and translational scientific precision in diagnosis and treatment.

This review of existing Canadian data initiatives relevant to critical care provide context and a baseline upon which to consider improvements in data collection and utilization with the goal of improving care for critically ill patients. The outlined initiatives are not exhaustive and are presented to stimulate discussion en route to appropriate, responsive-to-needs and purposeful proposals for comprehensive and sustainable national data initiatives in Canada. Despite past success and efforts, Canada lags behind a number of jurisdictions in the science of using critical care clinical and translational data effectively on a national level. As healthcare costs rise and the population ages, improving the collection and use of health data in critical care in Canada should be one of our scientific and clinical priorities.

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Table 1: Purpose-specific Critical Care Data Initiatives in Canada

Database	Rationale	Aim	Advantages	Challenges
Quality Improvement and Patient Safety				
A Canadian Critical Care Knowledge Translation and Quality Improvement Network (aC3KTion Net)	In Canada, there have been sporadic and limited efforts at improving the assimilation of best practice into critical care units and much of the focus on critical care KT has been on patient safety.	The Critical Care Knowledge Translation Network (CCCKTN) (http://www.acktionnet.ca/) sought to implement a systematic, multifaceted and synergistic knowledge translation strategy, bring together expertise from across jurisdictions and healthcare backgrounds. Its aim was to periodically audit practice and then provide feedback to clinicians and administrators.	For patient outcomes to be improved on a broader scale, all best practices as informed by research evidence need to be considered for knowledge translation initiatives in the ICU.	Without dedicated resources for data collection, this initiative was ultimately not sustainable and ceased operation. One of the key learnings from this initiative is that although data critical data exists in many jurisdictions, it is variable in composition, focuses of different aspects of critical care and obtaining access to the data is cumbersome and of little use to inform practice in real time.
Intensive Care Observational Registry (iCORE)	The Toronto-initiated Intensive Care Observational Registry (iCORE) project is a coordinated effort to create a high-quality registry of critically ill patients, with a quality improvement focus.	An innovative feature of the iCORE project is the modular nature of data collection, depending on the focus of the issue being studied, so that a tailored data collection module can be added to address a specific question or process of care issue. As a result, iCORE can accommodate distinct time-limited data collection modules that can be designed and implemented to answer new investigator-initiated, hypothesis-driven questions.	For quality improvement, iCORE contains data on several evidence-based processes of care for critically ill patients (sedation interruption, spontaneous breathing trials, delirium screening and incidence, early mobility, lung protective ventilation, and thromboprophylaxis). Having the iCORE infrastructure available for sustained data collection may facilitate large-scale knowledge translation, assist in evaluating new QI projects, and ensure continuous evaluation of barriers, performance measures, and unintended consequences	Sustainable funding. Sustaining high-quality data collection. Lead time required to demonstrate tangible benefit.
Organ Donation and Transplantation				
	Collecting high quality ICU data is beneficial for the identification of	To improve the quality of care for organ donation and transplantation	Systematic, consistent data from all jurisdictions would help to improve the highest standard of care across Canadian	The donation data collected is not well standardized across Canada, with some provinces collecting information on all

	potential organ donors, and to ensure best practices are employed for both organ donors and recipients.		organ donation and transplantation networks.	potential donors and others reporting only on individuals referred to the ODO. Data on donor characteristics or donor management therapies are only occasionally linked to recipient outcomes, both because recipient information is often stored by the transplanting center, and because privacy legislation is often perceived to prevent any linking of donor and recipient data. Data regarding donation practices is held by provincial organ donation organizations (ODOs), with varying privacy regulations regarding data sharing with federal registries.
Paediatric and Neonatal-specific Critical Care Data Initiatives				
Canadian Neonatal Network Collaboration (CNNC)	Since 1995 the CNNC, has used a standardized neonatal intensive care database for research projects. It includes neonates at 31 centres.	The database collects demographic, severity of illness (for risk adjustment), transportation, diagnosis and procedure and outcome information on all patients.	This database has lead to 200 publications and has had substantial health policy impact.	This data is manually abstracted in real-time to provide benchmarking across centres for major morbidities and mortalities, as well as provide extensive research opportunities across Canada.
Canadian Association of Paediatric Health Centres (CAPHC)	The Canadian Paediatric Decision Support Network was created in 2005, under the leadership of CAPHC, to provide hospitals with benchmarking and comparability analyses for hospitals specializing in paediatric care.	Allows for comparison of total admissions and length-of-stay, as well as case-mix groups. CAPHC collects routinely available data through the DAD to inform policymakers and hospital leadership.	Given the small number of paediatric health centres in Canada, securing national coverage of data on paediatric critical illness opens up possibilities for population health and research initiatives. A number of Canadian paediatric ICUs currently participate in American-led quality-improvement, research, and benchmarking registries, with Canadian data sharing occurring where possible; more granular data is collected on severity-of-illness standardization and clinical outcomes, expanding the possible research questions that can be asked.	Currently, severity-of-illness markers, quality-indicators such as hospital-acquired infections, and other granular patient-specific details focused on paediatric critical care are not collected.

Appendix

Search strategy

1. Critical Care
2. Intensive care
3. ICU
4. Or/1-3
5. Data*
6. Canad*
7. Ontario
8. Alberta
9. British Columbia
10. Quebec
11. Nova Scotia
12. New Brunswick
13. Manitoba
14. Saskatchewan
15. Newfoundland and Labrador
16. Prince Edward island
17. Or/6-16
18. 4 and 5 and 1