Driving Change in the Health Sector: An Integrated Approach

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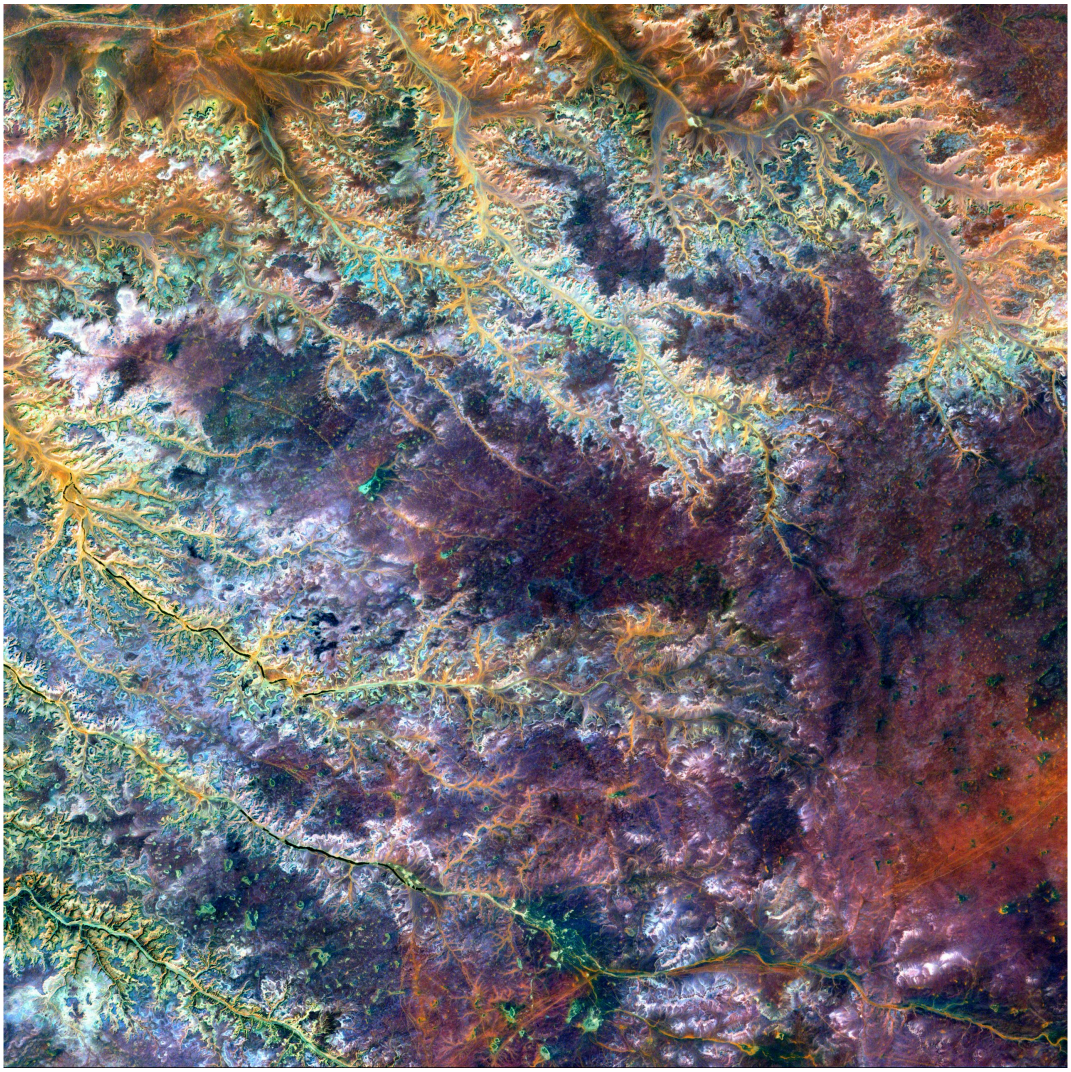
Preface

DR. MADELYN P. LAW AND CAITLIN MUHL



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Are you wondering why we chose this photo for the introduction to this book? Looking at this photo, we see complexity, diversity, and layers of visual information that come together to reveal something beautiful. This photo feels dynamic and ever-changing. As you go through this book, we ask that you keep this photo in mind. Using data to drive change in the health sector is not a linear process. It is complex, diverse, and layered. It is dynamic and ever-changing. What this means is that effectively driving change demands a strong understanding of data (**Chapter 1: Data Literacy**), the use of data as a tool for equity (**Chapter 2: Data for Equity**), how to drive change (**Chapter 3: Implementing Change – Easier Said Than Done**), how to translate research evidence into policy and practice (**Chapter 4: Knowledge Translation and Exchange to Support Decision Making**)**,** and finally, how to use data to inform decisions about resource allocation (**Chapter 5: Using Health Economic Evidence to Inform Decisions About Resource Allocation**). We hope that the diversity of chapters in this book will make one thing clear – it truly takes an integrated approach to drive change in the health sector.

Did you know that it takes 17-20 years to integrate clinical innovations into practice? Or that less than 50% of clinical innovations make it to general use?

Why is this?

We spend a great deal of time and energy (not to mention money) on research to explore and understand new ways of providing health services. When research demonstrates positive outcomes for patients and/or the system, why does it not become adopted into practice right away across the system? If the evidence is there to support something new, why is it not happening?

That is truly the million-dollar question that motivates researchers in the field of implementation science. Eccles and Mittman (2006) define **implementation science** as "the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care". Implementation scientists are those who are interested in the middle ground of how we take what we know works and make sure that this is realized in the practice setting. They focus on the factors that influence the uptake of new innovations in order to successfully drive change based on the latest evidence. We hope that this book, with its chapters on data literacy, data for equitable change, implementing change, knowledge translation and exchange, and health economics, will provide valuable information for students and practitioners to consider when exploring how to use evidence to drive change in the health sector.

The goal of this book is to be interesting, interactive, and engaging in the way that we provide information that will hopefully shape your current or future role in the health sector. We aim to deliver the information in this book in a stimulating and thought-provoking manner through multimedia, case studies, and thought-provoking questions. We hope that you will reflect on your current knowledge and perceptions, challenge your assumptions, and advance your thinking and skills.

As you move through this book, you will see that it has been written in a way that allows for a foundational understanding of the content but with “deeper dive” sections including additional resources in case you would like to expand your learning beyond the pages of this book. We hope that you enjoy this book and use the information that you learn to effectively drive change in the health sector as a change leader. Finally, we want to acknowledge all of the academic, community, and student partners who were involved in the development of this book – this would not have been possible without such an incredible collaborative team.

Dr. Madelyn P. Law and Caitlin Muhl

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If you have any questions about this book, please email Dr. Madelyn P. Law: mlaw@brocku.ca

CHAPTER 1: DATA LITERACY

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Chapter Overview

According to Jackson and Carruthers (2019), **data literacy** is the ability to understand and communicate data as information. It has a wide spectrum, from the data scientist who can take datasets and create insight or information, to the data citizen who can understand and act on those insights because they have an appreciation as to where these insights come from. In an increasingly data-driven world, it becomes increasingly important that everyone – citizens, businesses, and governments – become data literate. The shift to data-driven transformation has happened so quickly that huge parts of society have been left behind in the comprehension of the power of data.

Chapter Objectives

By the end of this chapter, you will be able to:

- Define the terms ‘data’ and ‘data asset’;
- Describe the concept of ‘data literacy’;
- List core data literacy competencies;
- Describe the ‘data journey’ and the specific action(s) required at each step; and
- Examine key data roles in organizations and describe individual responsibilities.

Section 1: Introduction to Data and Data Literacy

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

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Section Overview

This section aims to provide a 'birds-eye view' to understand how data, throughout its lifecycle, needs to be handled, maintained, stored, cleaned, analyzed and disseminated properly, and how insights derived from data can be used in evidence-informed decision making.

In the majority of post-secondary education, there will be discussions about data, statistics, and evidence but, often what is missed is the "how" these aspects fit within the broader **data literacy** learning competencies. It is important that learners have a basic understanding of **data literacy** and how it pertains to their learning to be productive and successful health professionals in the future.

Section Objectives

By the end of this section, you will be able to:

- **Define data literacy;**
- **Understand core data literacy competencies; and**
- **Identify the core steps in a data literacy plan to support the development of an organizational culture that embraces the use of data to inform decisions.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=80#h5p-30

Now try out this Learning Primer to test your knowledge about **data literacy**! This primer quiz has ten questions and provides you with a score at the end. This is followed by a data learning pathway with resources and ideas on how to enhance your **data literacy** knowledge. This is a great resource to engage with in order to see where you are at and what you might need to do to enhance your understanding of **data literacy**.

What is Data?

As we get started, it is important to define a number of terms that you will continual see as you progress through this chapter.

Data is defined as facts and statistics in their raw form, collected for reference, analysis, or decision making. Data is the foundation of information.

Information is data that is processed, interpreted, organized, structured, and presented to make it meaningful. Information is any documented representation of knowledge, such as facts, data, **data assets**, records, or decisions in any medium or form. Information is data with relevance and purpose.

What is a Data Asset?

An "asset" is described as a resource that has value that an organization either owns or is in control of. Like other organizational assets, data has value that can be leveraged. The value that can be derived from data can increase or decrease depending on how effectively it is managed. **Data assets** increase their value by ensuring that the data contained within them is of high quality, easily accessible, shared when possible, and efficiently managed and governed.

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A **data asset** is defined as a named collection of related data elements that is formally managed as a single unit. They may be a collection of facts represented as text, numbers, graphics, images, sound, video and is the raw material from which information can be derived – and decisions can be made.

Within organizations, **data assets** can come from a variety of providers, including internally and if relevant, from external partners. For example, an external partner can be another group or organization that acts as a data provider, such as Home and Community Care Support Services (HCCSS) providing data to an agency that is conducting **data analysis**.

Data and **data assets** are the cornerstones that enable the creation of analytical insights. Data is a strategic asset to any organization, requiring a coordinated approach to management through the development and execution of authorities, accountabilities, and controls to ensure consistent practices that are effective and efficient.

For example, many organizations will have policies and procedures related to the collection, retention, and destruction of data, which must be adhered to or they risk being fined by various agencies. Here is an example from the officer of the Privacy Commissioner of Canada:

> **Personal Information Retention and Disposal: Principles and Best Practices (Revised Aug 13th 2021)**
>
> Principle 5 of the *Personal Information Protection and Electronic Documents Act* (PIPEDA) states that "personal information that is no longer required to fulfill the identified purposes should be destroyed, erased, or made anonymous. Organizations shall develop guidelines and implement procedures to govern the destruction of personal information." (Government of Canada Office of the Privacy Commissioner, 2014)

Please go to **Section 5: Health Data Management and Privacy Legislation** for more information on this topic.

Data Lifecycle

What is the Data Lifecycle?

The **data lifecycle** refers to the sequence of events that data goes through from its initial creation or capture to its eventual archiving or destruction at the end of its usefulness.

Although the steps involved in the **data lifecycle** can vary slightly depending on the source referenced, there are usually six core stages in the **data lifecycle**. We will discuss this in greater detail in **Section 4: The Data Lifecycle.**

The Six Stages of the Data Lifecycle

The six core stages are as follows:

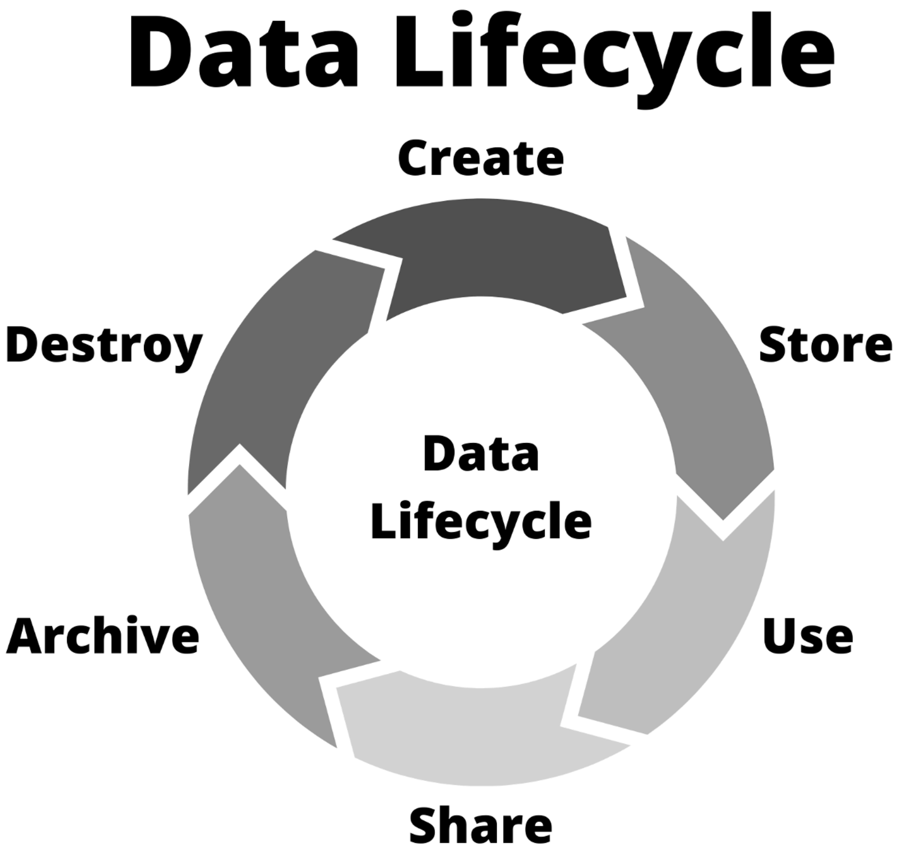


***Figure 1.1** The Data Lifecycle. Source: Caitlin Muhl*

Data Literacy

According to Statistics Canada (2022):

> **Data literacy** is a key skill needed in the 21st century. It is generally described as the ability to derive meaning from data. **Data literacy** focuses on the competencies or skills involved in working with data, including the ability to read, analyze, interpret, and visualize data, as well as to drive good decision-making. (para. 1)

Many learners will touch upon aspects of **data literacy** throughout their education, perhaps without even realizing it – some of you may collect data as part of a research project; some of you may undertake statistics on data as part of a course; some may have the opportunity to work with **data visualization** tools such as PowerBI. These are all aspects of **data literacy**.

But **data literacy** is much larger than this. According to the Data Literacy Project (2015):

> **Data literacy** is the ability to comprehend, create, and communicate data, and is the first level of the tri-level literacy, fluency, mastery scale. Data-literate individuals have the knowledge, understanding, and skills to connect people to data. **Data literacy** spans both qualitative and quantitative data, and is enabled by a broad range of data-related capabilities and learning outcomes, including but not limited to:
>
> - Data collection and grounding in sound methodology; creating data sets with appropriate **metadata**;
> - **Data management** — how to structure, store, preserve, harmonize, and enable sharing of raw data;
> - **Data analysis** — how to transform raw data into usable information and/or knowledge; incorporates the process of approaching an unfamiliar data set, understanding it, and identifying core features or anomalies; performing appropriate summations, aggregations, highlights, etc.; reaching appropriate conclusions and insights; and achieving relevant results;
> - **Data visualization**, and the honest, ethical, accurate, and compelling graphic representation of data;
> - Data policy, regarding privacy, security, retention, organization, openness, integrity, **metadata**, data models, open data, and sharing;
> - Data dissemination and sharing, **metadata**; how to make data open and interoperable;
> - Creation, maintenance, and use of **metadata**, including measures of **data quality**; and
> - **Evidence-based decision-making**, and in general the effective and ethical use of data to inform policy-making, decisions, or even personal opinions. (para. 6)

The Importance of Data Literacy

We live in a time where there is so much information and data available, and health data is no exception. It is important that we harness the strength of this data to make great decisions that will enhance the health services we provide.

The sheer volume of data now available from multiple sources such as electronic records (e.g., hospital-based electronic medical records (EMRs)), Ministry based systems such as mass immunization health data, data from internal and external public surveys, data gathered from apps (e.g., weather apps, GPS apps, etc.), website analytics (social media engagement analytics), data gathered from laboratories (e.g., water testing, biological specimens) in organizations – whether for- or not-for-profit – requires proper management to become useful data.

As previously mentioned, there will be specialists in the organization who will take the lead in areas such as the collection of health data within an electronic health record (EHR) (e.g., health informaticians). Data stewards are tasked with cleaning these data while epidemiologists would then be responsible for the analyses of such data to produce insights. However, the general workforce needs to be aware of their basic responsibilities (no inappropriate data sharing/storing and retaining data for an appropriate period) and have basic levels of comprehension of how to use data pertinent to their business area to inform decision-making.

QUICK SIDENOTE: Historical Context

Historically – these types of health data/health records were only available on paper and would be filed, stored, and shredded – as there are very defined processes for dealing with paper.

Did you know? Paper health records have been found back as far as Egyptian times (1600 BC). Here is a written document on papyrus describing war wounds:

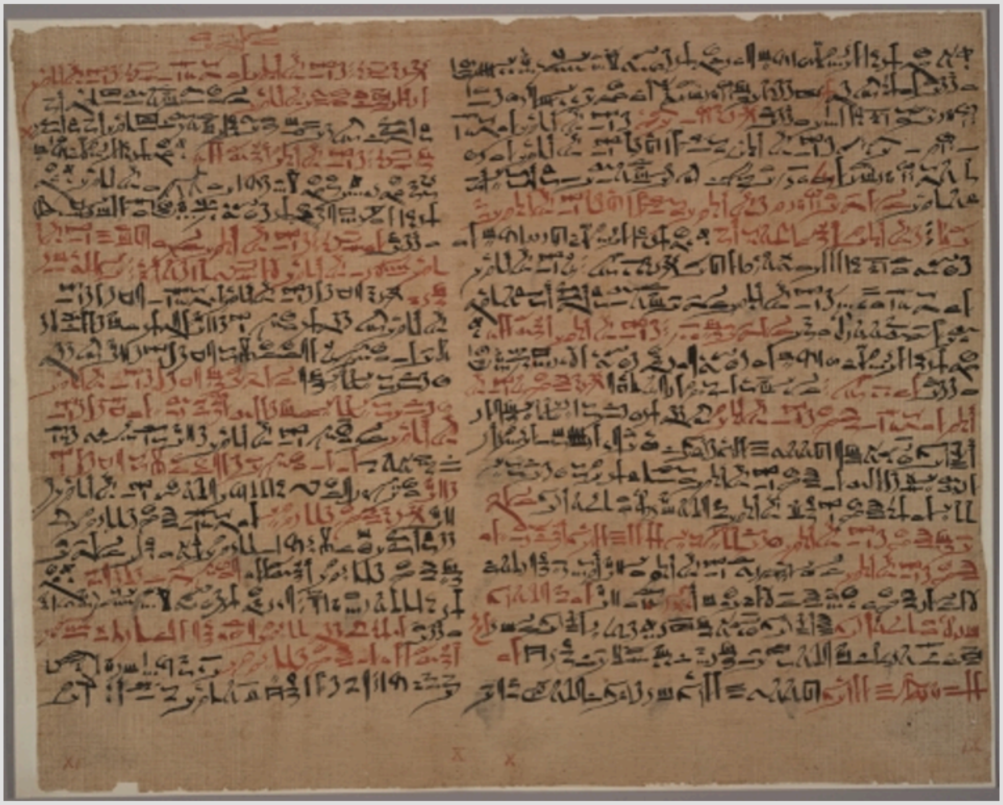


Photo from [van Middendorp et al. (2010)]() is licensed under [CC BY-NC]()

Photo by Alex Gorzen on Flickr is licensed under CC BY-SA

Imagine trying to analyze the data from all these records on paper? How would you do this? How would you even start? Now think about the retention/storage and destruction of this kind of health information? Many of these types of health data need to be retained for long periods of time in a secure location. There are now many organizations across the world that safely store, retain, dispose, and shred paper records in accordance with various legislation, including medical records.

Now consider the principles and practice from a tangible product (paper health records) to an intangible product (health data in a database). In recent decades, there is even more information and data collected electronically by health and health-related organizations. For example, health information can be collected via 1:1 client interaction in a hospital, long-term care home, or mass immunization clinic, and documented within an EMR. Health and health-related information can also be gathered within health surveys by researchers at universities, governments (e.g., Canadian Community Health Survey), or private companies. Aspects of this information are extracted and stored as data for analyses while the remainder stay within the health record. In recent years, many organizations have the capacity to store Terabytes of information and data, both on premise and in cloud format, so new strategies and policies need to be adopted to deal with the amount of raw data and information available digitally and how to collect, use and dispose of this legally, ethically and securely!

According to eHealth Ontario (n.d.):

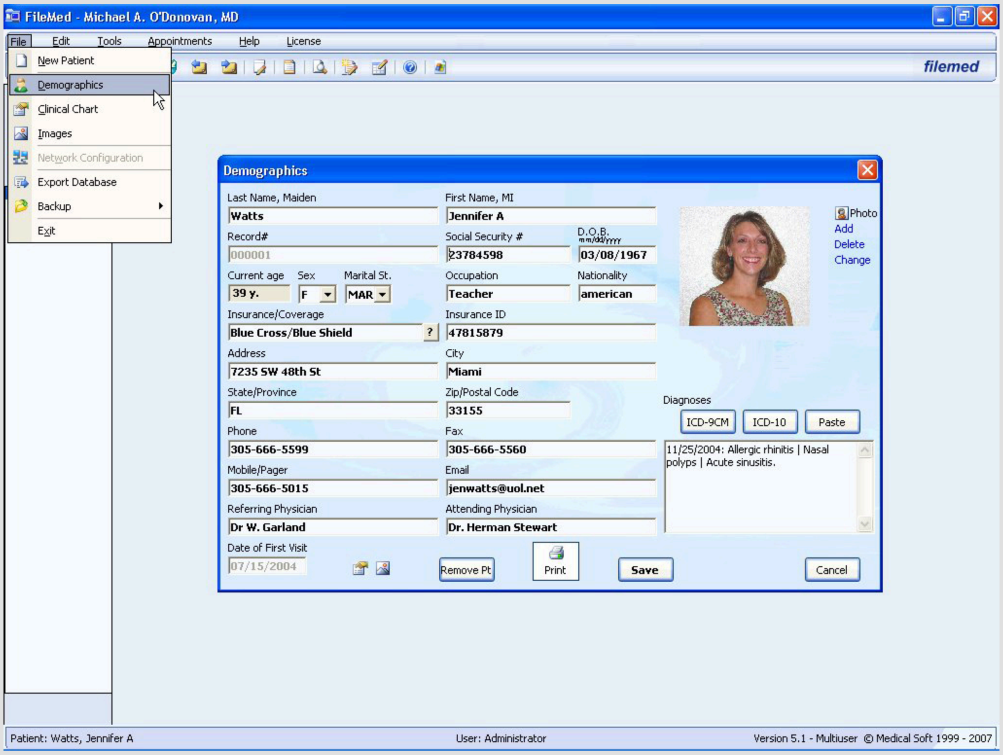
> An EHR is a secure lifetime record of your health history. It gives your health care team, including family doctor, nurses, emergency room clinicians, and specialists, real-time access to your relevant medical information, so they can

> provide the best care for you. eHealth Ontario has built the provincial system that gives thousands of health care providers at hospitals, family practices, long-term care homes, pharmacies and more access to their patients' EHRs so they can quickly look up lab results, publicly funded dispensed medications, digital images (like x-rays and MRIs), hospital discharge summaries and more. (para. 1)

QUICK SIDENOTE: What is the Difference Between an Electronic Medical Record (EMR) and an Electronic Health Record (EHR)?

An EMR is a digital version of a patient's chart. It contains the patient's medical and treatment history from one organization. In contrast, an EHR contains the patient's records from multiple providers/organizations and provides a more holistic, long-term view of a patient's health. Bonderud (2021) states that "EHRs are multifunctional and used for everything from documentation and medication management to clinical decision support, reporting and analytics, and results management" (para. 10).

The image below is an example of a front facing EMR for one patient/client. Imagine thousands of these being gathered by an individual hospital, public health, community health centre, etc., and then imagine how these data would be saved to a large database, ready for cleaning, analyzing and interpreting. Consider then the management of these data from a retention, storage, and destruction perspective.



Last Name, Maiden: Watts
First Name, MI: Jennifer A
Record#: 000001
Social Security #: 23784598
D.O.B. mm/dd/yyyy: 03/08/1967
Current age: 39 y.
Sex: F
Marital St.: MAR
Occupation: Teacher
Nationality: american
Insurance/Coverage: Blue Cross/Blue Shield
Insurance ID: 47815879
Address: 7235 SW 48th St
City: Miami
State/Province: FL
Zip/Postal Code: 33155
Phone: 305-666-5599
Fax: 305-666-5560
Mobile/Pager: 305-666-5015
Email: jenwatts@uol.net
Referring Physician: Dr W. Garland
Attending Physician: Dr. Herman Stewart
Date of First Visit: 07/15/2004
Diagnoses: 11/25/2004: Allergic rhinitis | Nasal polyps | Acute sinusitis.

Patient: Watts, Jennifer A
User: Administrator
Version 5.1 - Multiuser © Medical Soft 1999 - 2007

Photo reproduced with permission from Whitacre et al. (2017)

Technology can only do so much to integrate data-driven decision-making into everyday practice, unless it is backed by an **organizational culture** that understands and values it. Without a culture that values and understands the use of technology and data, the consequences can be crippling, leading to poorly informed decision making, privacy breaches, litigation and penalties, reputational impacts, and loss of customer trust.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=80#h5p-37

Data Literacy and Higher Education

From an institutional perspective, universities gather so much personal and personal health information from their staff and students from medical records, to home and student addresses, to car licence plates, to academic transcripts, so gathering, retaining, and using these data for decision making is very important. Universities, just like hospitals, public health units, and other agencies, must abide by the various federal and provincial laws set to protect our data. Please go to Section 5: Health Data Management and Privacy Legislation for more information on this topic.

But from a student perspective, how does **data literacy** apply to you in higher education? A recent article from McGill University highlights how important this is from a research perspective:

> Effective **data management** is increasingly recognized as being critical for quality research," says David Buckeridge, Professor in the Department of Epidemiology, Biostatistics and Occupational Health; Chief Digital Health Officer, McGill University Health Centre; Scientific Lead, Data Management and Analytics, COVID-19 Immunity Task Force. (Testani & Zhou, 2022, para. 2)

The Canadian Tri-Agencies recently released a draft of the Tri-Agency Research Data Management Policy for Consultation, which will require institutions to create an institutional research data management strategy (Government of Canada, 2021). The agencies stated that research data collected through the use of public funds should be responsibly and securely managed and be, where ethical, legal, and commercial obligations allow, available for reuse by others.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here:

https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=80#h5p-30

Section 2: Data Literacy Competencies

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

Photo by [Trent Erwin]() on [Unsplash]()

Section Overview

This section aims to provide an overview of **data literacy** competencies, which are the knowledge, skills, activities, and competencies required to successfully manage and work with **data assets**.

Section Objectives

By the end of this section, you will be able to:

- **Provide an overview of what is meant by data literacy competency; and**
- **Describe several core data literacy competency skills and activities.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=406#h5p-32

Introduction

We live in a data-driven world. Data is changing nearly every aspect of our lives, from business decisions to how we shop. Netflix is a great example of how the use of data (big data) gathered by the organization has helped it to predict trends in viewing among their audiences and has generated the company billions.

Deeper Dive

- This link contains more information on this topic: https://www.forbes.com/sites/enriquedans/2020/01/15/netflix-big-data-and-playing-a-long-game-is-proving-a-winningstrategy/?sh=593fc57b766e

Data literacy is an essential part of a data-driven culture. **Data literacy** competencies are the knowledge, skills, and activities you need to effectively work with data. These competencies include the knowledge and skills to read, analyze, interpret, visualize, and communicate data as well as the ability to understand the use of data in decision making and to ensure informed decisions are made.

Establishing consistent practices for the management of **data assets** increases their value by ensuring that the information obtained is high quality, easily accessible, and effectively managed and governed.

The following activities, skills, and knowledge represent the basis of **data literacy** competencies. A further explanation of core **data literacy** competencies, as well as some key advanced **data literacy** skills and concepts will be explored later in this section.

Data literacy competencies include:

- **Data analysis**
- **Data awareness**
- **Data cleaning**
- **Data discovery**
- **Data ethics**
- **Data exploration**
- **Data gathering**
- **Data governance**
- **Data interpretation**
- **Data management and organization**
- **Data modelling**
- **Data stewardship**
- **Data tools**

- **Data visualization**
- **Evaluating data quality**
- **Evaluating decisions based on data**
- **Evidence-based decision-making**
- **Metadata creation and use**
- **Storytelling**

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=406#h5p-42

Core Data Literacy Skills

Data Discovery

Data discovery refers to the knowledge and skills to search, identify, locate, and access data from a range of sources related to the needs of an organization (Statistics Canada, 2020).

A gatherer or organization begins by asking questions that can be answered using data to generate insights. The first step is to identify the opportunity or challenge that needs to be addressed or answered. In this step, an individual or member of an organization must identify the need for data and initiate a conversation around the specific data needed, when it is needed, who the audience for the data is for, and ultimately what story or insight will be delivered from the data. The individual or organization identifies the need, the question they are trying to answer or the problem they are trying to solve.

Once the need has been identified, the correct data or datasets must be identified to fulfill the need. **Data discovery** is the process by which data is sought, identified, located, and accessed from a variety of sources, both internal or external to an organization, to best answer the question being asked.

Data Gathering

Data gathering refers to the knowledge and skills to gather data in simple and more complex forms to support the gatherer's or organization's needs (Statistics Canada, 2020). This could involve the planning, development, and execution of surveys or gathering data from other sources such as administrative data, satellite, or social media data.

Photo by nespix on iStock

Data can be gathered, collected, or received from multiple sources and data providers, both internal and external to an organization. The gathering phase involves accumulation or transmission of data. Data can be gathered from surveys or other data sources or for organizations, from data providers or sources. Individuals gathering data may conduct data checks to ensure the integrity of data. For organizations, initial transmission and data quality checks are conducted, and alerts may be triggered if issues with the data are identified. These controls will reduce the risk of bad data being integrated into an organizations larger data ecosystem. If issues of **data quality** are identified and/or alerts are triggered, data quality issues need to be addressed or documented prior to the data being used.

All potential users of the data will also have access to **metadata** that helps describe the data in order to enable the discovery and understanding of the data available. **Metadata** is data about data, including the definitions and descriptions about the data, and makes finding and working with data easier. An example of **metadata** would be the date data was gathered. Users of the data can be notified about data availability and the data can be made available for use by authorized users.

Data Quality and Cleansing

Data quality refers to the knowledge and skills to assess data sources to ensure they meet the needs of the gatherer or organization (Statistics Canada, 2020). This includes both identifying errors and taking action to address the issues with the data.

Data cleansing refers to the knowledge and skills to determine if data is 'clean' and if not, using the best methods and tools to take necessary actions to resolve any problems (Statistics Canada, 2020).

As part of data collection, data quality checks are conducted to identify any issues with the data. Such controls reduce the risk of bad data being integrated or used. **Data quality** represents the degree to which data is accurate, valid, timely, usable, and consistent to make it fit for use. **Data quality** is measured along by its accuracy, validity, timeliness, usability, and consistency. Assessing, monitoring, and managing data quality issues upfront in the data collection process helps ensure that the data being provisioned is fit for its intended use.

Evaluating the quality of data and **cleansing data** are symbiotic. If the quality of data is determined to be poor, action is required to resolve issues and ensure its suitability for analysis. Data quality issues should be documented, allowing data consumers to understand and better use data, keeping in mind any known quality issues.

Click here to watch a video on the Statistics Canada website. In this video, you will be introduced to the fundamentals of **data quality**, which can be summed up in six different ways or dimensions to think about quality. You will also learn how each dimension can be used to **evaluate the quality of data**. Finally, you will learn about basic quality concepts, **data quality** expressed as six dimensions, and the interactions between these dimensions, which will help you gain a basic understanding of **data quality**.

Data Management and Organization

Data management and organization refer to the knowledge and skills required to navigate internal and external systems to locate, access, organize, protect, and store data related to the organization's needs (Statistics Canada, 2020).

These are key enablers of data sharing and use, ensuring sources of data, and consistent use of data. The management and organization, or architecture of data, is a set of rules, policies, standards, and models that establish how data is organized, stored, managed, and integrated within an organization. It includes the development and maintenance of conceptual and logical data models and their entities and relationships. Efficient data organization or architecture management ensures that new data requirements and specifications are integrated and work with the existing organizational **data architecture**. Enterprise data organization and management supports data standardization and integration.

Data privacy and security management includes the planning, implementation, and control activities to ensure that data services provided comply with all regulatory and legislative requirements that an organization is subject to. **Data privacy and security management** helps ensure the privacy and confidentiality of data and prevents unauthorized and inappropriate data access, use, and storage. Apart from complying with current laws and regulations, **data privacy and security management** play a key role in enabling both gatherers of data and organizations to build the trust and confidence of their audience which may be partners, customers, and the public.

Data Exploration

Data exploration refers to the knowledge and skills required to use a range of methods and tools to explore patterns and relationships in the data (Statistics Canada, 2020). The methods include summary statistics, frequency tables, outlier detection, and visualization to explore patterns and relationships in the data.

Once the need has been identified and a methodology developed, data consumers or users of the data create a plan for their work and explore the **data assets** available for use. This stage includes the completion of the data requirements document. The requirements document captures the details of the work being undertaken, the story to be told, and the plan for fulfilling the deliverable. Data sources, concepts, and indicators should be captured in the plan, as well as the measurement strategy and methodology. The requirements document is used in the quality assurance process to understand how the work was done and assess its validity.

The data steward role involves all activities to govern, safeguard and protect data and the knowledge and skills required to effectively manage **data assets**. Data stewards may be consulted at this stage about the appropriate use of **data assets**.

Data Interpretation

Data interpretation refers to the knowledge and skills required to read and understand tables, charts, and graphs and identify points of interest (Statistics Canada, 2020). Interpretation of data also involves synthesizing information from related sources.

Photo by gorodenkoff on Unsplash

This is the process of reviewing data through some predefined processes, which will help assign some meaning to the data and arrive at a relevant conclusion. It involves taking the result of **data analysis**, making inferences on data relationships, and using them to make conclusions. **Data interpretation** and the process of conducting analysis to order, categorize, and summarize data is key to conducting analysis and using data to tell a story.

Data interpretation is the means to help make sense of the data that has been collected, analyzed, and presented. Data, when collected in raw form, may be difficult for the layman to understand, which is why analysts need to break down the information gathered so that others can make sense of it.

Decision Making and Storytelling

Evidence-based decision-making refers to the knowledge and skills required to use data to help in the decision-making and policy-making process (Statistics Canada, 2020). This includes thinking critically when working with data, formulating appropriate business questions, identifying appropriate datasets, deciding on measurement priorities, prioritizing information garnered from data, converting data into actionable information, and weighing the merit and impact of possible solutions and decisions.

Storytelling refers to the knowledge and skills required to describe key points of interest in statistical information (i.e., data that has been analyzed) (Statistics Canada, 2020). This includes identifying the desired outcome of the presentation, identifying the audience's needs and level of familiarity with the subject, establishing the **context**, and selecting effective visualizations.

In the **evidence-based decision making** and **storytelling** phase, data used to draw conclusions and insights from the analyses has been completed and a summary of actionable ideas or answers is provided. Any meaningful features and trends are captured and aligned to the framework identified to solve the problem or answer the question that the organization has brought forward.

Information design is the practice of **storytelling** or presenting information in a way that fosters efficient and effective understanding of it. After the data has been interpreted, a review of the options for presenting information is undertaken and visualizations and graphics are designed that will enhance the understanding of the underlying data and tell a story to the intended audience.

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Deeper Dive

- This Statistics Canada webpage contains more information on this topic: https://www.statcan.gc.ca/en/wtc/data-literacy

Summary

In summary, **data literacy** is the ability to understand and communicate data as information to inform decision-making. There are a wide variety of individuals with specific skill sets involved in this process, from the data engineer who builds pipelines of data from source systems to display on dashboards, to analysts who use a variety of different software to produce accurate and valid statistics, to knowledge translators who, through **knowledge translation** (see Chapter 4: Knowledge Translation and Exchange to Support Decision Making), can understand, interpret these data, and translate these insights to leaders in order to underpin **evidence-based decision making**. Historically, the concept of **data literacy** has not been taught consistently across higher education, however, it is now necessary to have data-literate graduates to support workplaces. **Data literacy** also takes into consideration the ownership of data from an Indigenous perspective via OCAP®. **Data literacy** is acknowledged as a crucial skill for the 21st-century workplace

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Section 3: Data Governance

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

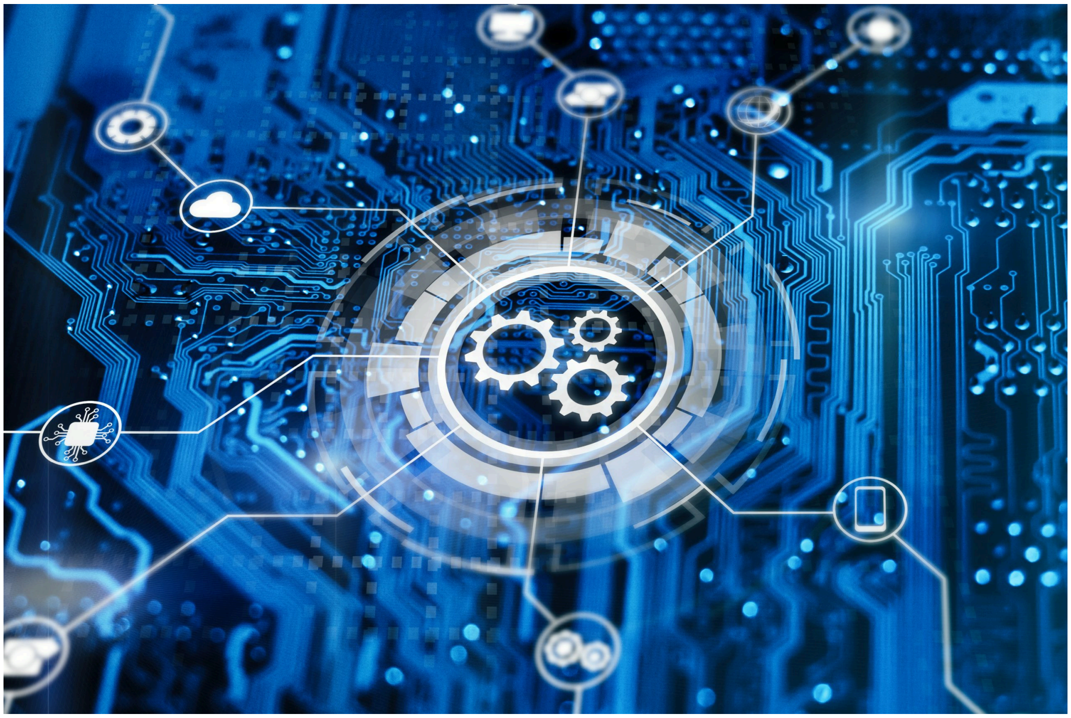

Photo by [Traitov](#) on [iStock](#)

Section Overview

This section aims to provide an understanding of what **data governance** is and how it supports **data literacy**. The importance of **data governance** is highlighted and the concept of **data architecture** and the role of a data architect is explored.

Section Objectives

By the end of this section, you will be able to:

- **Define the term data governance;**
- **Describe the differences between data governance and data management; and**
- **Understand the role of data architects.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Data Governance

Data governance is the set of authorities, accountabilities, and controls to formalize and consistently guide the management of **data assets**. **Data governance** and **data management** are not the same thing. **Data governance** establishes how data should be managed through the creation of policies, standards, etc., while **data management** enacts those policies and standards to gather and use data. It is the organizational structures, data owners, policies, processes, and controls for the beginning to the end lifecycle of data. **Data management** is the implementation of **data governance** and enables the execution and controls to achieve **data**

governance. **Data governance** does not exist without **data management** and vice versa; **data governance** without implementation is just documentation.

Consider the following definition:

Data governance is "a discipline which provides the necessary policies, processes, standards, roles, and responsibilities needed to ensure that data is managed as an asset" (Fircan, 2021b). In essence, it is the creation of consistent processes to define and provide the steps to **clean data**, make it accessible to the right individuals, and ensure that it is secure.

Watch the video below to learn more about the difference between **data management** and **data governance**:

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Data management is the "business function of planning for, controlling, and delivering data" (Fircan, 2021b).

In essence, it is the act of implementing processes using technologies, the act of ensuring the proper management of access as part of the responsibilities of individuals in their role, etc.

Data governance establishes a mechanism to manage, control, and oversee **data asset** management practices. It includes defining the policies, standards, and guidelines for **data management**, monitoring, evaluating, and improving **data asset** management practices, as well as enabling practices through **knowledge exchange** and **translation**.

Data Governance Differs from Information Governance

As outlined in **[Section 1: Introduction to Data and Data Literacy](#)**, **data** are facts and statistics in their raw form. Information is data that has been processed, interpreted, organized, and presented to make it meaningful. Data is used in the creation of information.

The Data, Information, Knowledge, Wisdom Pyramid represents the relationship between data, information, knowledge, and wisdom. Each step up the pyramid adds value to the initial data. The more data is enriched with meaning and **context**, the more information is derived from it, which increases knowledge and creates wisdom. At the top of the pyramid, knowledge, and insights have been turned into a learning experience. This guides our actions, which creates wisdom.

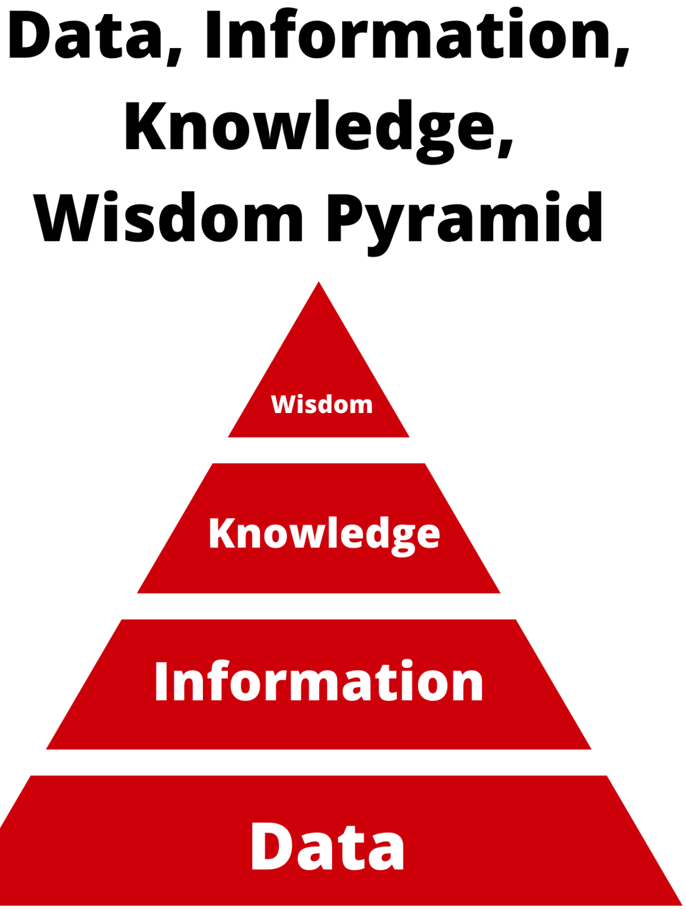

Figure 1.2 *The Data, Information, Knowledge, Wisdom Pyramid. Source: Caitlin Muhl*

Similarly, **data governance** differs from information governance in that it is specific to the governance of data, not information. **Data governance** is specific to the governance of data and does not include an approach to governing information. The term data is not used interchangeably with the term information. The analysis, interpretation, and presentation of data to tell a story makes it information. **Data governance** pertains only to data; information governance pertains to information.

Data governance is the subdomain of information governance that provides for the design and execution of data planning and data quality assurance to achieve the strategic information needs of an organization.

Why is Data Governance Important?

Data is an important asset for all organizations and requires active management. **Data governance** helps to ensure that data is usable, accessible, and protected. Effective **data governance** leads to better data analytics, which in turn leads to better decision-making and improved operations support. It helps to avoid data inconsistencies or errors, which can lead to poor decision-making or integrity issues.

Data governance ensures that data is:

- **Secured:** Data is protected from unauthorized access or tampering;
- **Trustworthy:** Data is correct and consistent;
- **Documented:** Data is described to make it easier to identify, use, retrieve, and manage;
- **Managed:** Data is considered a valuable resource and reliable methods are used to access, cleanse, store, and use data; and
- **Audited:** Data is examined to ensure quality, proper access, and storage.

Data governance also plays an essential role in regulatory compliance, ensuring that organizations are consistently compliant with all levels of regulatory requirements. This is key for minimizing risks and reducing operational and reputational costs.

At its core, **data governance** leads to improved **data quality**, decreased **data management** costs, and increased access to data for all stakeholders. The result is better decision-making and better organizational outcomes.

Key Functions to Enable the Delivery of Data Governance

There are many approaches to developing a data governance program within an organization. In order to better understand the application of **data governance** within an organization, as well as some of the key roles involved, let's start with an example of a possible structure for the delivery of data services within an organization.

Data Governance Steering Committee

To provide strategic direction for the management and use of data, a data governance committee is established. The committee acts as the oversight body for strategic **data management** initiatives that are created to deliver organizational objectives.

The strategy for and organizational wide approach for ensuring governance programs span the whole corporation generally starts with a steering committee comprised of senior management. Templar (2017), author of *Get Governed: Building World Class Data Governance Programs*, says steering committee members' responsibilities include setting the overall governance strategy with specific outcomes, championing the work of data stewards, and holding the organization accountable to timelines and outcomes.

This is an example of a model for data governance:

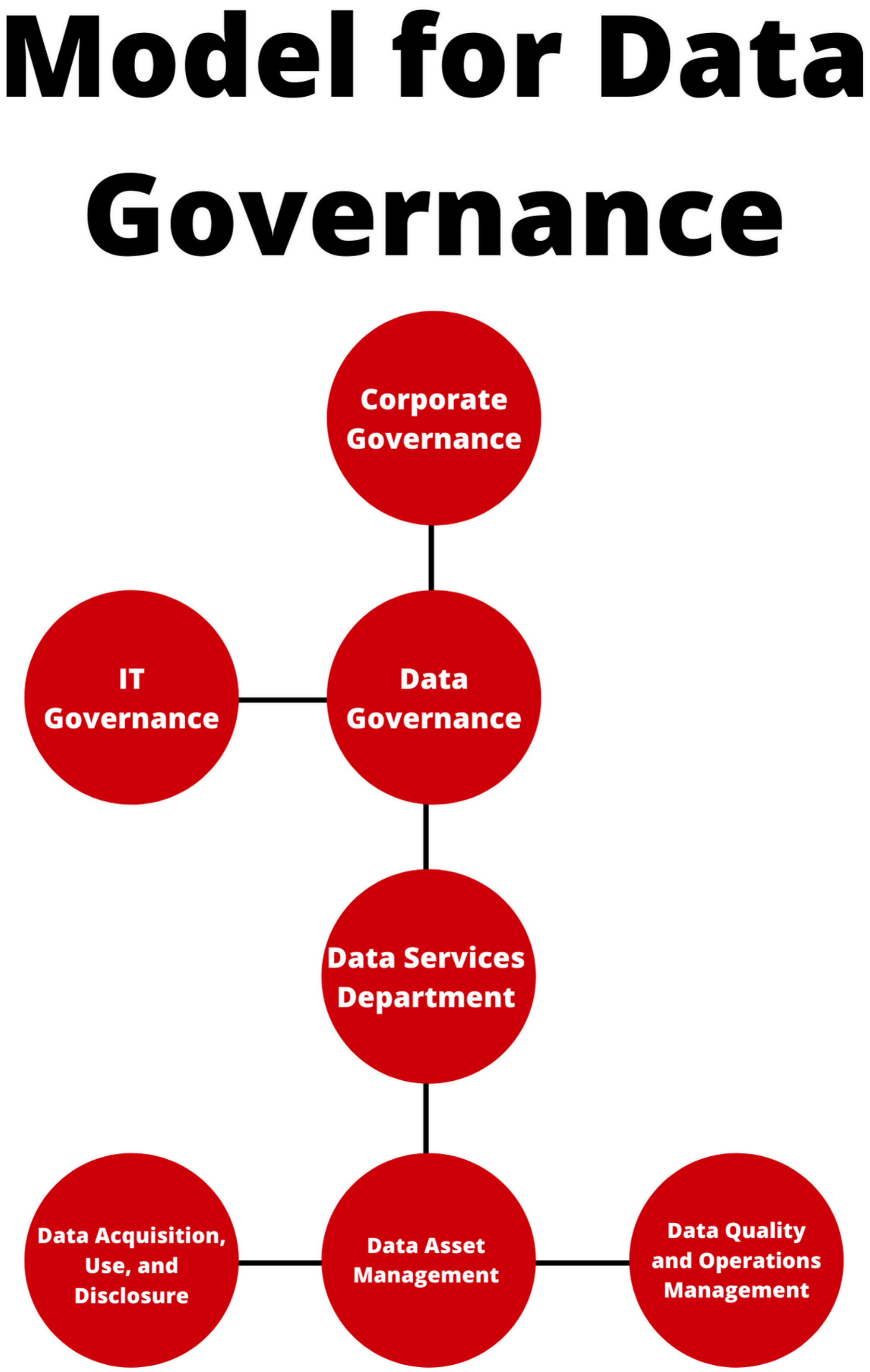

Figure 1.3 *Model for Data Governance. Source: Caitlin Muhl*

Data Owners

Templar says data owners are individuals responsible for ensuring that information within a specific data domain is governed across systems and lines of business. They are generally members of the steering committee. Data owners are responsible for activities such as:

- Approving data glossaries and other data definitions;
- Ensuring the accuracy of information across the enterprise;
- Directing **data quality** activities;
- Working with other data owners to resolve data issues; and
- Providing the steering committee with input on software solutions or policies.

Data Services Department

A data services department may be created within an organization to ensure that data is managed as a strategic asset throughout the organization. Data services departments are the doers. They enable the strategic direction provided by the data governance steering committee. It is the mandate of data services to:

- Ensure that trusted data is used to support organizational objectives;
- Ensure that data is used and managed in a secure and privacy-sensitive manner; and
- Ensure that **data assets** drive value across the organization.

Below is an example of a Data Services Department structure. This is only one example for illustration purposes – Data Services Departments can be structured in various ways.

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The three functions defined above are ultimately responsible for ensuring that **data assets** are secured, trustworthy, documented, managed, and audited, and for meeting the strategic objectives of the data governance steering committee, all of which comprise the delivery of successful **data governance**.

QUICK SIDENOTE: Career Spotlight – Data Steward

Data stewards are accountable for the day-to-day management of data. They are subject matter experts who understand and communicate the meaning and use of information, data stewards drive accountability for **data assets**, helps improve operational efficiencies and reduces risks, misunderstandings and redundancies that arise over who is responsible for **data asset** management.

Accountabilities for data stewards include:

- Works with required stakeholders to translate the intake requirements to detailed data lifecycle management requirements;
- Provides oversight of specific **data assets** with the support of appropriate governance structures to ensure that the **data assets** are efficiently managed and maintained in accordance with any policies and procedures;
- Ensures data lifecycle management requirements are provided to the internal teams to implement and operationalize;
- Facilitates development of data competencies and toolkits; and
- Works with internal teams to implement or modify governance, frameworks and policy, procedure or process requirements for assigned **data assets**.

Data governance ensures that data captured and the subsequent information derived is useful, available, and secure. Good **data governance** equates to better quality data, improved data analytics, and leads to **evidence-based decision making**. It also helps to prevent inconsistencies or errors in data, which can result in data integrity concerns, lack of trust in the data, and poor decision making.

In the video below, Professor George Fircan details his learning journey from a **data governance** perspective:

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Data ethics involves the knowledge that allows a person to acquire, use, interpret, and share data in an ethical manner including recognizing legal and ethical issues (e.g., biases, privacy)(Statistics Canada, 2020). It is important because it provides parameters for what organizations can and cannot do with the data they collect. In this article, Dr. Mark van Rijmenam (2014) writes about the four guidelines organizations should adhere to regarding the ethical use of data: (1) radical transparency; (2) simplicity by design; (3) preparation and security; (4) and privacy.

In this blog, you will hear from Stephen Watts who speaks to the issues of **data governance**. His key messages focus on the importance of a high-quality governance strategy, what this involves, who needs to be involved within an organization, and implementing strategies to ensure data is used properly, securely, and in compliance with regulatory requirements.

A Key Facet in the Delivery of Data Governance: Data Architecture and the Role of a Data Architect

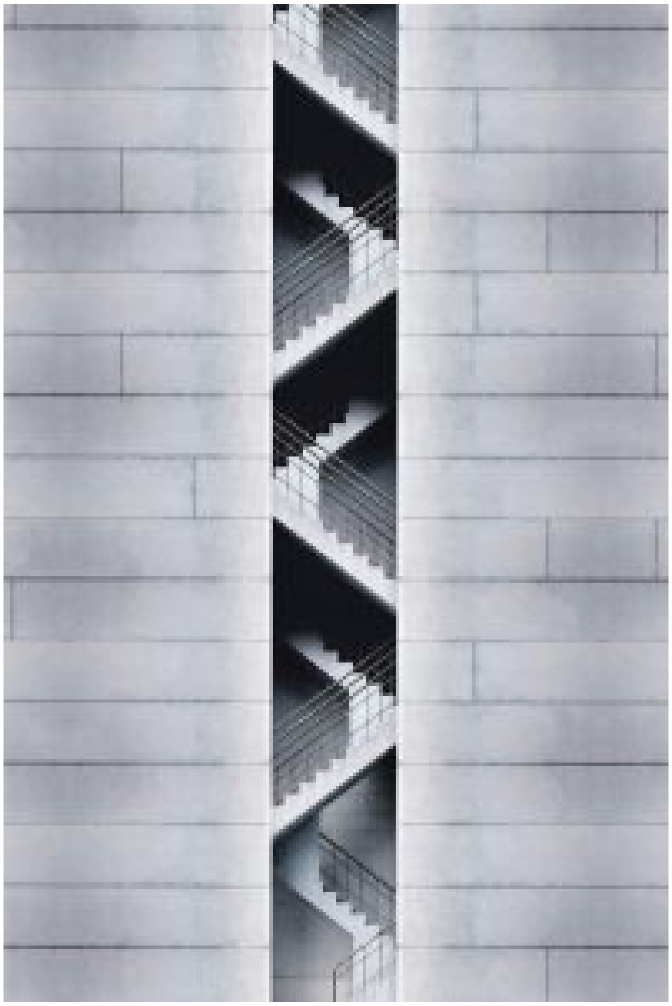

Photo by [Henry & Co](#) on [Unsplash](#)

Data architecture is a one of the key facets of **data governance** and serves as a foundation for the delivery of a data governance model. The diagram below represents a framework for **data governance** and includes **data architecture** and technology as a key aspect to enable governance of **data assets**. The concepts of **data governance** and **data architecture** are interrelated. Amongst other pieces of the framework, such as policies, roles, and responsibilities, it is impossible to successfully deliver **data governance** without a solid architecture.

Data architecture is a set of rules, models, policies, or standards that govern which data is collected, and how it is acquired, stored, arranged, secured, accessed, and used (Olavsrud, 2022). It also involves the technologies used to collect, manage, and store the data and the controls placed upon those technologies.

Data architecture is important as it enables better understanding of the data. It provides guidelines for managing data throughout its lifecycle, from creation to destruction. It provides a "blueprint" of **data assets**, how they are collected, processed, and provisioned. Below is a conceptual example of a data architecture model. It includes the sources of data, data storage and processing within a data lake or data mart, and how data is provisioned and used to deliver business intelligence.

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QUICK SIDENOTE: Career Spotlight – Data Architect

A data architect plays a key role in the creation of an organizational **data architecture**. They design, maintain, and build models to ensure that data is structured and integrated in a way that enables data to be readily used. This role works collaboratively to identify appropriate architectures to manage **data assets** in a secure, efficient, and consistent manner.

According to Olavsrud (2022):

> Data architects are senior visionaries who translate business requirements into technology requirements and define data standards and principles. The data architect is responsible for visualizing and designing an organization's enterprise data management framework. This framework describes the processes used to plan, specify, enable, create, acquire, maintain, use, archive, retrieve, control, and purge data. (para. 1)

For example, public health data is any data relating to both the health of individual patients and the collective population. It is gathered from a series of health information systems. A data architect in a public health unit would support public health objectives by designing dynamic public health databases and information systems to enable effective monitoring and disease surveillance. They would define how the data would be stored, consumed, integrated, and managed by different systems, as well as any applications using the data.

Responsibilities of data architects include:

- Design, maintain, and build models to ensure data is structured and integrated in a way that it is readily consumable;
- Provide **data architecture** (e.g., **data modelling**, database structure) expertise to support discussions;
- Work collaboratively to identify appropriate architecture to manage **data assets** in a secure, efficient, and consistent manner;
- Provide industry best practice and other technical concepts that support the development and improvement of the governance of the **data asset** management lifecycle;
- Key point of contact for additional technical support;
- Provide input (e.g., enterprise risk, issues, impacts, options, etc.) into decisions or assessments

being performed; and

- Advise and inform members on **data architecture** area risks, inefficiencies, quality concerns and other areas requiring improvement.

Data Governance and OCAP® Principles

According to the First Nations Information Governance Centre (n.d.):

> The First Nations principles of OCAP® establish how First Nations' data and information will be collected, protected, used, or shared. Standing for ownership, control, access and possession, OCAP® is a tool to support strong information governance on the path to First Nations data sovereignty.
>
> OCAP® was established in 1998 during a meeting of the National Steering Committee (NSC) of the First Nations and Inuit Regional Longitudinal Health Survey, a precursor to the First Nations Regional Health Survey (FNRHS, or RHS). Originally, OCAP® began as "OCA" with the members of the NSC affixing a "P" soon after to acknowledge the importance of First Nations' people possessing their own data.
>
> There is no law or concept in Western society that recognizes community rights and interests in their information, which is in large part why OCAP® was created. OCAP® ensures that First Nations own their information and respects the fact that they are stewards of their information, much in the same way that they are stewards over their own lands. It also reflects First Nation commitments to use and share information in a way that maximizes the benefit to a community, while minimizing harm.

Watch the video below, which covers the First Nations Information Governance Centre's mission, provides an overview of its work, and explores the importance of OCAP® for First Nations people and communities:

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Please go to Section 3: Indigenous Data Sovereignty in Chapter 2: Data for Equity? for more information about this topic.

Deeper Dive

- For those who wish to learn more, the First Nations Information Governance Centre offers *The Fundamentals of OCAP®*, an online training course developed in partnership with Algonquin College Corporate Training. This self-guided course takes learners through seven modules that are designed to introduce the fundamental concepts of OCAP®, information governance, and First Nations data sovereignty: https://fnigc.ca/ocap-training/take-the-course
- Want to learn more about the many facets of **data governance**? The DAMA Organization (DAMA) is an international not-for-profit, vendor-independent, global association of technical and business professionals dedicated to advancing the concepts and practices of information and **data management**. DAMA International's primary purpose is to promote the understanding, development, and practice of managing data and information as key enterprise assets to support the organization. If you are interested, DAMA has a variety of certifications available for you to undertake with regards to **data management** and these are internationally recognized and would be useful for any student interested in delving into this topic in more detail: https://www.dama.org/cpages/home

Summary

Data governance is a set of accountabilities and controls to ensure that data is usable, accessible, and protected. Effective **data governance** leads to better data analytics, which in turn leads to better decision-making and improved operations support. **Data architecture** is the technology or infrastructure that plays a vital role in supporting **data governance**. The role of a data architect is instrumental in the creation of a viable **data architecture**.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Section 4: The Data Lifecycle

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

Photo by metamorworks on iStock

Section Overview

This section aims to introduce the concept of the **data lifecycle** and its purpose and provide an overview of each of the six stages.

Section Objectives

By the end of this section, you will be able to:

- **Understand what is meant by the data lifecycle;**
- **List five stages of the data lifecycle;**

- **Describe the goals of data lifecycle management; and**
- **Reflect on how the management of data through its lifecycle is a key component of data literacy.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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The Data Lifecycle

The **data lifecycle** refers to the sequence of events that data goes through from its initial creation or capture to its eventual archiving or destruction at the end of its usefulness. The **data lifecycle** serves as a foundation on which **data management** practices are based. It provides a phased approach with a logical grouping of activities to develop and deliver **data management** operations.

Although the steps involved in the **data lifecycle** can vary depending on the source referenced or whether the **data lifecycle** includes analytics, there are usually six stages.

The Six Stages of the Data Lifecycle

As outlined in **[Section 1: Introduction to Data and Data Literacy](#)**, the six stages are as follows:

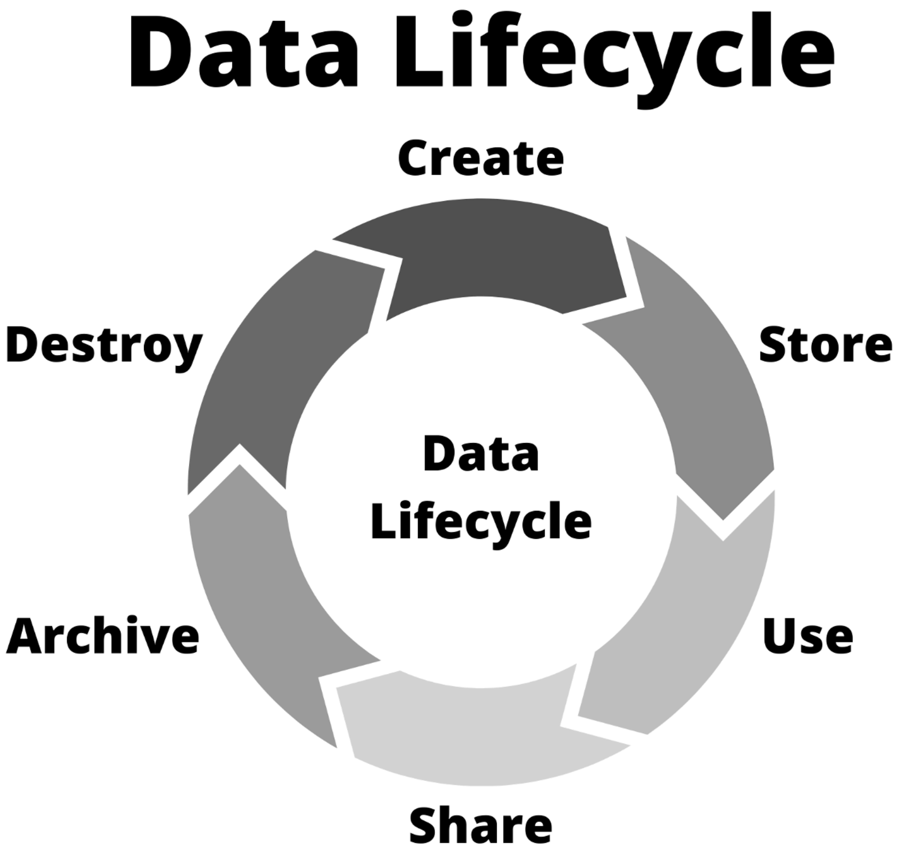

Figure 1.4 *The Data Lifecycle. Source: Caitlin Muhl*

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Having a documented **data lifecycle** process is key to ensuring that an organization practices effective **data governance**. Large volumes of data continue to grow due to generation by an increasing number of devices and applications. Storage costs and compliance issues exert pressure on organizations to destroy data that is no longer needed. Proper oversight of data through its lifecycle is essential to ensure its usefulness, minimize errors and ensure regulatory compliance.

Goals of Data Lifecycle Management

Photo by sdecoret on iStock

Data lifecycle management involves providing planning, control, and support to manage operations across the **data lifecycle** while dealing with issue management and resolution. Data lifecycle management encompasses requirements, change, and data services management and may span different applications, systems, databases, and storage. Data lifecycle management ensures that the life of data aligns with other organizational lifecycles like technology, decision making, and project management lifecycles. Data lifecycle management is triggered when the need for data is identified and goes all the way until retirement of data. Benefits to a managed **data lifecycle** are that it enables a structured flow for data. The main goals of data lifecycle management include:

1. **Integrity**: Maintaining the integrity of data is a key outcome of a structured **data lifecycle**. Data integrity means that the data is ensured to be the most up to date, best quality data for use. Without assurances of integrity, stale or the wrong version of data could be used;
2. **Security:** From creation to deletion, security of data is imperative. Protocols for managing the security of data keeps the data safe from malicious or inappropriate access, addresses privacy protocols, and ensures data remains uncorrupted; and
3. **Access:** The implementation of proper access controls ensures that the right user has access to the right data for the right amount of time. There may be issues pertaining to privacy regarding the use of data, and access controls ensure that data is appropriately made available.

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Data Lifecycle Management Control Frameworks

Organizations use multiple layers of controls to ensure efficient and consistent management practices throughout the **data lifecycle**. Controls enforce and formalize roles, structures, rules, and actions related to **data management**. Controls can be both internal and external in nature. For example, external controls manage data shared or collected from other organizations, and internal controls are created to proscribe how data should be managed within an organization.

Internal controls include the creation of policies and standards, guidelines, and procedural manuals:

- **Policies:** Policy statements are organizational-wide, high-level statements that guide and control **data asset**-related management, actions, and decisions. Policies focus on desired outcomes, but do not specify implementation details. Compliance with policies is mandatory and may be further supported through guidelines or standards;
- **Standards:** Standards have enterprise-wide applicability and consist of mandatory actions, rules, or controls designed to support policy statements. Standards for **data asset** management may specify processes, roles, accountabilities, techniques, tools, etc;
- **Guidelines**: Guidelines for **data asset** management consist of recommended, non-mandatory controls, accountabilities, and recommendations from an organizational perspective, not by area or function within an organization. Guidelines are often developed by an enterprise or cross-functional Data Governance Office or Committee; and
- **Procedural Manuals**: Procedural manuals are **data asset** management controls that are a collection of policy statements and standards that are specific to a business function or a particular **data asset**. Procedural manuals consist of a collection of procedures that provide step-by-step instructions to

assist staff in implementing various policies, standards, and guidelines. Procedures assign responsibilities for implementing each step and help ensure that a consistent standardized process is followed each time.

External controls include agreements, including legally binding arrangements and reference manuals:

- **Agreements:** Agreements are negotiated and possibly legally binding arrangements that organizations make with external parties that detail the terms and conditions that apply to both the organization and external party entering into the agreement; and
- **Reference Manuals:** Reference manuals are a handbook of detailed instructions for external parties to follow when submitting data to, or accessing data from, a partner organization.

Additional Operational Support Artifacts and Resources for Data Lifecycle Management

In addition to data lifecycle management control frameworks, the creation and implementation of operational support resources assist an organization to effectively manage data throughout its lifecycle. In addition to policies, standards, guidelines, procedural and reference manuals, and agreements, the following artifacts can be created to support an organization's data management lifecycle:

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Knowledge management supports data lifecycle management by ensuring that the artifacts that support the lifecycle are available and accessible. It is a discipline that promotes an integrated approach to identifying, capturing, evaluating, retrieving, and sharing all of an organization's data and information-related assets.

These assets may include databases, documents, policies, procedures, products, methodologies, artifacts, and previously un-captured expertise and experience in individual workers. Knowledge management ensures that data and information-related assets are readily accessible, up to date, consistent, and actively managed for use by staff. It ensures that all staff of an organization have seamless access to the information they need to appropriately fulfill the responsibility of their roles.

Summary

The **data lifecycle** is the process that helps organizations manage the flow of data, from creation to destruction. It is imperative that organizations appropriately manage data to guarantee its integrity at every stage of the lifecycle. There are six phases in the **data lifecycle**: create, store, use, share, archive, and destroy. **Data management** control frameworks, artifacts, and resources assist organizations to manage their data throughout its lifecycle.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Section 5: Health Data Management and Privacy Legislation

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

Photo by [marchmeena29]() on [iStock]()

Section Overview

In this section, we will focus more on health **data management** and health privacy laws in Canada and how these combine to ensure our **personal health information** is protected and governed appropriately.

According to the Canadian Institute for Health Information (2020b):

> In Canada's health systems, governance of data and information is critical.

> Strong data and information governance ensures that data is timely, trusted, and fit-for-purpose on a sustained basis. (para. 1)

Furthermore, the Canadian Institute for Health Information (2020a) states the following:

> Health systems across Canada are seeking greater value from their health data and information assets in an effort to achieve sustainable, effective, and impactful outcomes, resulting in better individual and population health and better health system planning and delivery. At the same time, it is essential to continue to keep **personal health information** protected in order to earn and retain public trust. (p. 6)

Section Objectives

By the end of this section, you will be able to:

- **Describe two key privacy laws within Canada;**
- **Understand how personal health information is governed within Ontario;**
- **Describe the differences between personal information and personal health information;**
- **List key terms associated with managing health data from a privacy perspective; and**
- **Describe the implications of a privacy breach for the individual and the organization.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Introduction

There are numerous pieces of privacy legislation across Canada from a federal and provincial perspective and these pieces of legislation differ across the various sectors – public sector, private sector and health sector. It is possible that more than one privacy law could apply to an organization based on the data they collect and province they reside.

Canada has two federal privacy laws that are enforced by the Office of the Privacy Commissioner of Canada. These are the Privacy Act and the Personal Information Protection and Electronic Documents Act (PIPEDA) which determines how businesses manage **personal information**. PIPEDA provides foundational privacy rules for how private sector companies should **collect**, **use**, and **disclose personal information** across Canada while the Privacy Act is only related to Federal Government Institutions. PIPEDA does not apply to organizations that do not engage in commercial, for-profit activities. It is possible that more than one privacy law could apply to an organization. One part of an organization's activities, such as collecting **personal information** within a province, may be subject to a provincial privacy law while another part, such as **disclosure** across provincial borders, may be subject to PIPEDA.

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What is Personal Information?

Personal information is data about an "identifiable individual" (Government of Canada Office of the Privacy Commissioner, 2018). It is information that on its own, or combined with other pieces of data, can identify *you* as an individual such as demographic information (e.g., age, sex, financial information, race, ethnicity, social insurance number, etc.).

What is Personal Health Information?


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Health information may be **collected** and **used** by many different organizations: federal, provincial, private, or public. Therefore, different regulations may be applied depending on the scenario. Health sector legislation, whether federal or provincial, focuses on the **collection**, **use**, and **disclosure** of information within the circle of care by a **health information custodian**.

Personal health information is identifiable health information collected on an individual by an organization on behalf of a **health information custodian** (either orally, documented on paper, or electronically). A **custodian** is prohibited from collecting, using, or disclosing **personal health information** unless consent has been obtained.

Deeper Dive

Check out other pertinent legislation related to granting access to information and protecting the **privacy** of individuals:

- MFIPPA – Municipal Freedom of Information and Privacy Act: https://www.ontario.ca/laws/statute/90m56
- FIPPA – Freedom of Information and Privacy Act: https://www.ontario.ca/laws/statute/90f31
- PHIPA – Personal Health Information Protection Act: https://www.ontario.ca/laws/statute/04p03)

Many provinces have their own legislation pertaining to the **collection**, **use**, and **disclosure** of health information. In Ontario, our legislation is called the Personal Health Information Protection Act (PHIPA).

PHIPA sets out rules for the **collection**, **use**, and **disclosure** of **personal health information**. These rules apply to all **health information custodians** operating within the province of Ontario and to individuals and organizations that receive **personal health information** from **health information custodians**. These rules recognize the unique character of **personal health information** – as one of the most sensitive types of **personal information** that is frequently shared for a variety of purposes, including care and treatment, health research, and managing our publicly funded health care system.

The purposes of the PHIPA Act (2004) are:

- To establish rules for the **collection**, **use**, and **disclosure** of **personal health information** about individuals that protect the **confidentiality** of that information and the **privacy** of individuals with respect to that information, while facilitating the effective provision of health care;
- To provide individuals with a right of access to **personal health information** about themselves, subject to limited and specific exceptions set out in this Act;
- To provide individuals with a right to require the correction or amendment of **personal health information** about themselves, subject to limited and specific exceptions set out in this Act;
- To provide for independent review and resolution of complaints with respect to **personal health information**; and
- To provide effective remedies for contraventions of this Act.

Watch the video below about PHIPA:

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=460#oembed-1

The legislation balances individuals' right to **privacy** with respect to their own **personal health information** with the legitimate needs of persons and organizations providing health care services to access and share this information. With limited exceptions, the legislation requires **health information custodians** to obtain consent before they **collect**, **use**, or disclose**personal health information**. In addition, individuals have the right to access and request correction of their own **personal health information**.

What is the Circle of Care?

The ‘circle of care’ can be different depending on the organization. According to the Information and Privacy Commissioner of Ontario (2015a):

> In the **context** of a hospital, the circle of care may include: the attending physician and the health care team, for example residents, nurses, clinical clerks and employees assigned to the patient, who have the responsibility of providing care to the individual or assisting with that care. (p. 18)

What Happens if an Employee Outside of the Circle of Care Reviews Personal Health Information?

There can be serious repercussions for employees who ‘snoop’ in patients’/clients’ files if they are not part of the circle of care – e.g. fines or losing their jobs.

Deeper Dive

Check out these newspaper articles about employees who ‘snooped’ in patients’/clients’ files:

- https://ottawacitizen.com/news/local-news/ottawa-hospital-fires-employee-after-privacy-breach-involving-30-patients
- https://www.thestar.com/news/gta/2016/05/06/hospital-workers-convicted-for-snooping-into-rob-fords-personal-health-files.html

What is a Health Information Custodian?

According to the Information and Privacy Commissioner of Ontario (2015a):

> A **custodian** is a person or organization listed in PHIPA that, as a result of his, her or its power or duties or work set out in PHIPA, has custody or control of **personal health information**. Examples of **custodians** include: health care practitioners, hospitals, long-term care homes, pharmacies, laboratories, ambulance services, Canadian Blood Services, etc. (p. 7-8)

Collection, Use, and Disclosure

According to the Information and Privacy Commissioner of Ontario (2015a):

> **Collection** refers to the gathering, acquiring, receiving, or obtaining of **personal health information** by any means from any source.
>
> **Use** refers to handling or dealing with **personal health information** as described in previous sections in this chapter such as the **data lifecycle** or **data management**.
>
> **Disclosure** refers to the fact that, as a general rule, consent is required to disclose an individual's **personal health information**, unless PHIPA allows the **disclosure** without consent and it means to make the **personal health information** available or to release it to another **custodian** or person.

Privacy, Confidentiality, and Security

Privacy refers to the right of an individual to control the **collection**, **use**, **disclosure**, and retention of their **personal information**.

Confidentiality refers to the obligation of a health care provider (or other person) to protect the secrecy of **personal information**.

Security refers to the tools and techniques we use to protect the **confidentiality**, integrity, and availability of **personal information**.

What is a Privacy Breach?

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PHIPA contains notification requirements for both agents and **custodians**. If **personal health information** handled by an agent on behalf of a **custodian** is stolen, lost, or accessed by unauthorized persons, the agent must notify the **custodian** of the breach at the first reasonable opportunity (Information and Privacy Commissioner of Ontario, n.d.-a). PHIPA also requires **custodians** to notify individuals at the first reasonable opportunity if **personal health information** is stolen, lost, or accessed by an unauthorized person.

According to the Information and Privacy Commissioner of Ontario (2018):

> In Ontario, **health information custodians** have a duty under PHIPA to protect **personal health information** against **privacy breaches**. A **privacy breach** occurs when **personal health information** is collected, **used**, or disclosed without authorization. This can include theft, loss, or unauthorized copying, modification, or disposal. As a **custodian**, you should have a privacy breach protocol in place so that there is a process to follow in the event of a **privacy breach**. The protocol should be flexible enough to cover a wide range of possible breaches, such as:
>
> - Cyberattacks;
> - Loss or theft of portable devices;
> - Misdirected faxes; and
> - **Collection** of **personal health information** without authority by means of the electronic health record. (p. 1)

Deeper Dive

Check out these newspaper articles about **privacy breaches**:

- https://globalnews.ca/news/4901037/belleville-nurse-terminated-violating-privacy/
- https://www.ctvnews.ca/business/lifelabs-failed-to-protect-the-personal-health-information-of-millions-of-canadians-investigation-1.4999815

Privacy Breach Fines

There are now very heavy fines for individuals and organizations who are guilty of committing an offence under PHIPA. An individual found guilty of committing an offence under PHIPA can be liable for a fine of up to $200,000 or up to one year in prison, or both. An organization or institution can be liable for a fine of up to $1,000,000.

If a corporation commits an offence under PHIPA, every officer, member, employee or agent of that corporation found to have authorized the offence, or who had the authority to prevent the offence from being committed but knowingly refrained from doing so, can also be held personally liable.

Individuals can also seek compensation for damages and there are no time limits (e.g., one could have a **privacy breach** from decades ago investigated).

Privacy Officers and Privacy Impact Assessments

Most large health organizations have a dedicated privacy officer who works with all the different business units to ensure that they understand the various privacy legislation and how it applied to them. Privacy officers may lead on or support a **privacy impact assessment** to assess compliance with the legislation. The privacy impact assessment guide can be found on the Information and Privacy Commissioner of Ontario website and is a self-explanatory document to support those in carrying out this assessment (Information and Privacy Commissioner of Ontario, 2015b).

A **privacy impact assessment** is a risk management tool used to identify the actual or potential effects that a proposed or existing information system, technology, program, process, or other activity may have on an individual's **privacy**. By completing a **privacy impact assessment**, you will be able to guide your institution through a process that will identify the privacy impact and the means to address them. Privacy risks or impacts fall into two broad categories:

- Risks to individuals, including identity theft and other forms of fraud, adverse impact on employment or business opportunities, damage to reputation, embarrassment, distress or financial impacts; and
- Risks to institutions, including the financial, legal, and reputational impact of **privacy breaches**.

Carrying out a **privacy impact assessment** does not need to be complex or time-consuming, but thoroughness is necessary to ensure that potential privacy risks are identified and mitigated.

Summary

When managing health data, **privacy** is an enormous consideration to ensure that the data you gather and manage is **collected**, **used**, and disclosed in an appropriate manner. There are many different pieces of legislation protecting personal, and in particular, health information, and these differ according to federal and provincial legislation. **Privacy** is a key consideration from a **data literacy** perspective and needs to be considered at all times. Undertaking a **privacy impact assessment** before you set up a program, data sources, project, or service is crucial and **privacy impact assessments** can also be used as part of a regular auditing process for any health organization to avoid **privacy breaches** and massive fines.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Chapter Summary

DR. SINÉAD MCELHONE; SHERRI HANNELL; AND NOAH JAMES

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Data literacy is an overarching umbrella term that encompasses everything from gathering information from a variety of sources (e.g., health records from clients, research data, data from mobile devices, etc.) and converting these to data, managing these data and information throughout the lifecycle, **data analyses**, data visualization, and the translation of knowledge and insights from the data to inform decision making.

This whole module has provided a very high-level summary of the foundational aspects of the collection, use, and disclosure of information and data and how it needs to be managed responsibly, ethically, and in accordance with legislation.

Knowledge of **data literacy** within the health sector continues to grow, although many will not fully appreciate all the various facets as described in this module. Therefore, it is very important as a student to understand enough to ask the right questions when he/she/they are working with data – either as part of their studies or eventually when they work within an organization. Important questions to ask are; what are the sources of these information and data? Where are they stored? Who is responsible for the cleaning the data? How are we measuring **data quality**? How can we ensure that the data are handled responsibly and shared appropriately? Who are the people within an organization that may be available to support good **data literacy** practices? And ultimately, are we confident in the results of these data to properly enable data-driven decision-making at all levels of decision making?

The authors also wanted students to be aware that this whole area of opportunity also exists for those of you who wish to dive into this in more detail – perhaps you may wish to undertake some learnings in health informatics, health information management, privacy and legislation or perhaps you may wish to enhance your skills in **data governance** and obtain a globally recognized certificate from DAMA. From an employment perspective, there are currently so many opportunities available – if you look up any job search engine and search for terms such as data architect, **data governance**, data steward, data analyst, or data engineer, you will find a multitude of roles available which may help you in your data journey. What is hoped is that in reading this module, this will instill a curiosity about the origins of the data that you are working with and that you will become an advocate for **data literacy** within your college, university, or organization.

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CHAPTER 2: DATA FOR EQUITY?

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LLana James develops and implements interventions to improve clinical outcomes, population health, and data management systems including the Research, Evaluation, Data, and Ethics Protocol for Black populations, Canadian Edition a.k.a REDE4BlackLives Protocol, with the tireless support of Dr. Ciann Wilson. She critically appraises current practices, and seeds new ethical futures; undoing the known, but often ignored issues and emergent harms of artificial intelligence (AI) and machine learning (ML) applications in medicine, healthcare, and public health that undermine human rights, and harm Black populations. LLana's multi-pronged, transdisciplinary, collaborative research occurs at the intersections of AI, ML, data, law, and intervention science and grapples with the historical and ongoing effects of colonization on Black Indigenous life globally. As a Black woman of the diaspora born in Canada, of ancestry indigenous to Africa and the America's, via the Caribbean, love and apocalyptic forces unleashed by transatlantic slavery. LLana is the Chair of the Ontario Black Bioethics Reference Group, leads the Personal Health Information, Justice and the Law Network, Chairs the Canadian Race Correction De-adoption Working Group, and is the Co-Chair of the Canada-US Coalition to End Race-correction in Healthcare. As a result of her ground-breaking work, LLana is the AI, Medicine and Data Justice Post-Doctoral Fellow at Queen's University, her doctoral training, took place at the University of Toronto, Faculty of Medicine.

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Dr. Robyn K. Rowe is a mother of four, a member of Matachewan First Nation, and a hereditary member of Teme Augama Anishnabai. She holds a PhD in rural and northern health from Laurentian University with her dissertation entitled *The Fires we Keep: Honouring the land through Indigenous-led Resistance, Sovereignty, and*

Data. Robyn is an Executive Member of the Global Indigenous Data Alliance (http://www.gida-global.org) and was involved in the co-creation of the '*CARE Principles of Indigenous Data Governance*' with Indigenous partners from around the world through the International Indigenous Data Sovereignty Interest Group as part of the Research Data Alliance (www.rd-alliance.org). Robyn is also the Indigenous Data Team Lead at Health Data Research Network Canada (www.HDRN.ca) and a Staff Scientist at ICES (www.ICES.on.ca). Robyn's work intersects in the areas of Indigenous health and policy, **Indigenous data governance** and sovereignty, and social and environmental justice. Robyn's continued research efforts focus on decolonizing health data environments through the assertion of inherent Indigenous rights and interests.

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Dr. Robert W. Smith is a second-generation Canadian settler of English and Lithuanian ancestry grateful to live, work, and learn on the traditional territory of Lac Seul First Nation in what is now called Sioux Lookout, Ontario. He is an Assistant Professor (Status-Only) at Dalla Lana School of Public Health and public health practitioner working to collaboratively lead the creation of health systems with which everyone has an equitable opportunity for wellbeing. Rob is a social epidemiologist and applied health systems researcher by training, holding a Doctor of Philosophy in Population Health from the University of Oxford.

Chapter Overview

This chapter was written to serve as a critical and conventional overview of socio-legal, ethical, epidemiological, and policy dimensions of data in the health sector as it pertains to real-world **contexts**, versus the sanitized idealistic narratives bombarding us. This chapter encourages learners to evaluate their taken-for-granted assumptions about what data is, how it comes to be, and why it is being touted as a tool for **equity**. More importantly, this chapter seeks to engage learners as active participants.

To support active learning and thoughtfulness, each section header is stated as a question to help learners develop the critical thinking skills necessary for identifying and peeling back the layers of existing and emergent datascapes. This is an opportunity for learners to investigate the way language is seeded by powerful private and public actors and institutions to shape the narrative. For example, the uncertain practice of making forecasts has been renamed and repackaged as prediction and precision, a term that improperly implies certainty and infallibility. This chapter will facilitate learners in decoding and challenging the obscuration of the facts that undermine their ability to think and act ethically, accountably, and responsibly regardless of what stage they are at in their education or career.

Learners will learn to understand data in **context**, located in the historical present, that is simultaneously unchanging, yet dynamic. This chapter offers an opportunity to engage and understand the deep historical relationships between contemporary data efforts, the proposed benefits, and test the claims that imply acquiring data leads to change in health systems and **equity**.

As opposed to a definitive guide on if or how data can or should be used to promote health equity and justice, this chapter puts learners in conversation with contemporary discourses. In order to do so, we will recap key historical facts and **context** (See Section 1: Data and Measuring Health Equity and Section 3: Indigenous Data Sovereignty).

Section 1: Data and Measuring Health Equity: Before describing the basics of how data is currently and commonly used to measure health inequities, we situate the topics of data, **equity**, and justice within the **context** of past and present systems of power responsible for racist violence, genocide, femicide, environmental injustice, and wealth accumulation in what is now called North America.

Section 2: Health Systems, Equity, and Population Health Management: We describe health policy movement towards **“Population Health Management"** as a strategy for building **equity** into health systems.

Section 3: Indigenous Data Sovereignty: We offer a pathway of the words, roles, and principles that are necessary to more meaningfully understand the significance of **Indigenous Data Sovereignty** and its activation within health systems.

Chapter Objectives

By the end of this chapter, you will have a more critical and robust understanding of the socio-legal, ethical, epidemiological, and policy dimensions of using data in the health sector. You will be able to:

- Identify what data is, and how (de)contextualizing data mediates its usage and limitations;
- Critically appraise for whom data is perceived as a (un)helpful tool for achieving equitable health services and systems for people and populations; and
- Understand Indigenous Data Sovereignty and its role in asserting First Nations, Inuit, and Métis rights to self-determination and autonomy.

Section 1: Data and Measuring Health Equity

LLANA JAMES; DR. ROBYN K. ROWE; AND DR. ROBERT W. SMITH

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Section Objectives

By the end of this section, you will be able to:

- **Understand how contemporary discourses of data emerge from and sustain historic and new forms of colonization;**
- **Define, critically evaluate, and make visible the actors and power asymmetries;**
- **Understand the meanings of health equity and justice;**

- **Identify commonly used sources of data for measuring inequity; and**
- **Understand core concepts from social epidemiology on the measurement of health inequities.**

Temporality and Historical Present: How Did We Get Here?

The landmass that stretches from what is now referred to as Canada, the United States, the Caribbean, Central and South America is called the American continent or the Americas. The Indigenous peoples of the Americas have lived here from time immemorial in relationship to the land and the ecosystems that support the web of life. Tens of millions of people inhabited the Americas with official estimates ranging from 60 million to 112 million, with thousands of languages spoken (Koch et al., 2019). A diversity of sophisticated socio-legal and economic systems flourished for thousands of years that did not rely on capitalism.

Many spiritual traditions co-existed without decimation from holy wars. The pristine landscapes, abundance of wildlife, clean rivers, lakes, intact bogs, and wetlands are the evidence that domination over nature was not an organizing tenet of First Peoples' lives. The absence of irreparable environmental desolation, mass homelessness, food insecurity, intractable and ever increasing, social inequity in North America prior to the arrival of colonizing Europeans is further evidence of responsible stewardship, and an active ethic of respect for the earth, skies, water, and all its inhabitants.

Deeper Dive

For more on these processes of colonization, colonialism, racial capitalism, and environmental destruction, here are a few key texts:

- Colonialism (Kroll-Zeldin, 2021)

- The Origins of AIDS, Revised and Updated Edition (2021)
- Racial Capitalism (Melamed, 2015)
- Indigenous ExtrACTIVISM in Boreal Canada (Willow, 2016)
- Colonialism, Rubber, and the Rainforest (Ross, 2017)

Datafication and the New World

In 1455, Pope Nicholas the V signed the Papal Bull on January 8th, declaring that any subject of Portugal willing and able was encouraged to invade, murder, and vanquish any and all Africans in service to the Portuguese crown (Wise & Wheat, 2016). They were also directed to enslave Africans into perpetuity and cease their lands.

However, when the Portuguese arrived on the coast of West Africa, they engaged in deception and stated that they came in peace and to trade. That deception provided the cover to trade and secretly unload massive quantities of guns, and gun powder, while simultaneously incentivizing locals to increase and accelerate the capture of slaves against the wishes of their King, King Alfonso of the Kongo (Hochschild, 2005; Newit, 2010). This began a massive export of Africans into transatlantic slavery that proliferated throughout the coast of West coast and Central Africa.

In 1492, Columbus arrived on what was called Hispaniola Island, but currently hosts two countries Haiti and Dominican Republic. Upon returning to Spain, Pope Alexander the VI issued the Inter Caetera, Papal Bull asserting the rights of both Portugal and Spain to the lands Columbus landed on, cited, as well as territories yet to be known in the New World. The Inter Caetera explicitly authorized the murder, subjugation/enslavement, and theft of land from the Indigenous inhabitants (National Library of Medicine, n.d.). These colonies would be filled by enslaved Africans living under the horrors of chattel slavery. Indigenous peoples of Africa would be kidnapped and sold to the Spanish, as replacements for the Indigenous peoples of the Americas that were dying because of the contagions spreading from European contact, and because a Dominican friar, Bartolomé de Las Casas, successfully petitioned the Crown on behalf of the Taino, to cease enslaving and killing of Indigenous peoples of the Americas (Clayton, 2009). Instead, Las Casas recommended that the Indigenous people of Africa should be enslaved (Clayton, 2009). The Indigenous peoples of Africa were not treated with kindness or compassion, a haunting reality that persists among the many who profit from their blood, sweat, and tears (See **The Motivation**).

With each trip, European expansion brought more and more disease, killing over sixty million people that came into contact with producing what is known as the Great Dying (Koch et al., 2019). To ensure a ready supply of slaves, and to prevent any regulation by African Kings, Queen Mothers or Chieftains, the Portuguese needed to sow chaos and bedlam. They achieved this by offering a ready supply of weapons and other preferred trade items, the Spanish incited violence, that facilitated the raiding of neighbouring villages. This resulted in villages being emptied and some societies collapsed as millions upon millions of indigenous African people, citizens of robust societies were disappeared into the transatlantic enslavement and trade lead by Europeans. By the year 1600, over half a million African slaves had been kidnapped, transported, and sold into chattel.

Deeper Dive

Further reading:

- New World Labor Systems: African Slavery (Battle & Sawula, 2013a)
- New World Labor Systems: American Indians (Battle & Sawula, 2013b)
- Lose your mother: a journey along the Atlantic slave route (Hartman, 2007)

Chattel slavery in the New World, began with the Portuguese, followed by the Spanish then other European countries seeking to acquire wealth flooded into the market over the next four hundred years. The British were the largest English-speaking slave traders in the world, although they abolished slavery within Britain in approximately 1805 and abroad in 1834, slave trading was lucrative business and their greed was potent. Britain continued to ply the trade covertly for several more years after abolition. This required yet another set of data and datafication processes.

Transatlantic slavery required a system of rapid, verifiable documentation, finance, valuation, bankers, and assurances. Assurances were achieved via data that was used for forecasting profits, labour, and materials. These are the same tools needed to curate training data, develop and run Machine Learning and Artificial Intelligence applications in the health sector and business, however, the term prediction is used in the contemporary moment. Extensive cataloging and labeling, via branding of the flesh of the enslaved, and tracking of enslaved people was central to transatlantic chattel slavery. Chattel slavery was the mechanism of datafication that transformed Indigenous African people into data units. This was a massive undertaking that has been unmatched in scale until the arrival of computing power, and materials that can tolerate the rapid calculations, storage, and retrieval needs.

The Motivation

The rationale was to acquire wealth faster, with less labour by Euro-settlers. Ultimately, the desire was to have an easier life, and do away with repetitive tasks, increase convenience and provide more time for leisure. Interestingly these are the same logics underpinning slavery, which occurred from 1455 to well into the 19th century. Despite the abolition of slavery taking effect in 1834, this was a paper dragon, for most enslaved African people because they were without human rights and means to participate meaningfully in the economy.

Throughout the US and the colonial world, most Black people who were enslaved remained so for several years under a range of apprenticeships that were wageless. Their labour was exchanged for food and shelter, conditions that varied little from their previous state of enslavement.

Over 20 million African slaves arrived in the New World, with millions more dying in the interior as they were marched to shore. Many more died at sea from the dehumanizing treatment, cramped and putrid slave ships, and more died after arrival due to the violence of slave owners, and their over seers. The brutal conditions, malnutrition, lack of proper shelter, and clothing lead to short life spans often wracked with pain, unspeakable violence, and inhumane deaths. During the early days of Jamaica's colonial life enslaved Africans lived on average three years, that were kidnapped, and seasoned (a violent and brutal process of dehumanizing a person until they are submissive and without a sense of self). The life span of slaves only improved when prices stayed elevated, and the abolition of slavery was imminent.

Vast amounts of wealth and data were produced from the sale of the enslaved. Further, wealth and data were extracted from the sexual trafficking of the children and women who were forced to bear children as a result of routine rape by and for slavers to increase the labour force and wealth, generating yet more data for forecasting/prediction. Additional wealth and data were generated by the agriculture and vast array of heterogenous products slaves made. This resulted in even more wealth.

The British East India Company one of the largest profiteers of slavery, as of 1805 amassed over $1.3 Billion USD because of the wealth generated by slavery (Richards, 2011). The US plantation economy would have generated massive amounts data, that were to improve profits and efficiency. Chattel slavery is the genesis of datafication and the contemporary data economy we are being swept up in.

The slavers grew into massive plantation economies, but more importantly banking practices arose that created the need for data and datafication, storage, rapid retrieval and the demand increase for more sophisticated accounting, and profit-making instruments. For example, the London stock exchange formally emerged in 1773 to meet that challenge (Smith, 1929).

In summary, the origins of contemporary data, and data discourse in health as well as the process that converts living breathing people into data units is the same process that free Indigenous peoples of West and Central Africa underwent when being converted in chattel slaves. This process of capture, datafication, cataloging, labeling and repurposing of data (and lives) was developed and employed to increase profit, generate wealth, and facilitate convenience. Datafication removed the human (the datafied version/digital twin stands in its place) but allowed for a human stay in the loop (the overseer plantation).

Deeper Dive

Further reading:

- Dark Matters: On the surveillance of Blackness (Browne, 2015)

The logics, rationale, and actors driving current datafication of peoples bodies and health experiences in Canadian health care, often share the same Euro-ancestry, structural social privilege and are the individual as well as collective beneficiaries of the wealth and data systems whose development was catalyzed through the transatlantic slave trade.

> The economic value of the 4 million slaves in 1860 was, on average, $1,000 per person, or about $4 billion total. That was more than all the banks, railroads, and factories in the U.S. were worth at the time. In today's dollars, that would come out to as much as $42 trillion, accounting for inflation and compounding interest. (Saraiva, 2021)

Their descendants continue to bear the brunt of datafication, the process of extracting the human-turning living beings into data units to be manipulated, reconfigured without consent for purposes yet to be decided. The history of data in the New World, has become the historical origin story of data and datafication of the entire world, as the new data driven economy, emerges from the avails of slavery, the only difference is how the process is being repackaged as data for **equity**. But the combined wealth of the Big Six: Alphabet (Google), Amazon, Apple, Facebook, and Microsoft in 2019 was only $900 billion USD, this still falls frighteningly short of the $42 trillion USD value of 4 million slaves in the USA in 1860. Nor does it account for the wealth and data generated from their bodies and lives.

Black people have not benefited from being dehumanized into data. An example of this is with, Henrietta Lacks, (HeLA) journey of datafication (Skloot, 2011). Her cells continue to be exploited for the benefit of universities, corporations and scientists, and white people derive the vast majority of all the clinical advances, as her children and extended family die of poor health care and limited income (Skloot, 2011).

In Canadian law, the definition of **equity** is analogous to substantive equality, and the term describes a disequilibrium that must be remedied. Substantive equality, rather, is aimed at "recognizing and responding to difference and remedying discrimination and stereotyping" (Law Society of Ontario, 2022). It requires "acknowledgment of and response to differences that members of a particular group might experience" in order to be treated equally" (Law Society of Ontario, 2022).

What Do We Mean By Health (In)Equity?

Health Inequality or Inequity or Injustice: Trifles of Language?

Photo by Brittani Burns on Unsplash

The jargon surrounding injustice places unfairness on a scale of how much is minimally acceptable through the divergent uses and intended meanings of the words equality and **equity**. Often, health inequalities are defined as measurable differences in health between individuals or groups in a population. Some inequalities may even seem reasonable and not raise concerns around fairness. Over time, a transformation of perceived justice led to the mainstream usage of the term **equity**.

Equality versus **equity** has become a topic of conversation within many sectors, but at their core, both definitions include an overall lack of fairness through systemic and avoidable differences in treatment. Western medicine defines health as the absence of disease, but complicated that same thinking when it comes to what is *just* and *fair*. Inequities and inequalities are the absence of justice. Where that absence falls on a scale is largely irrelevant to understanding that the system is unjust for some and not others. Intersections of social determinants of health, including race, gender, class, and ability are factors that interact to determine how visible and measurable those injustices are.

However, health inequity is not just about unfair differences in health outcomes or exposure to health threats, but also the complex social, political, and economic processes and ideas that determine whether optimal health is distributed fairly across societies.

Health inequity also refers to the mechanisms that concentrate power among a privileged few (e.g., colonialism, white supremacy, capitalism, sexism) and the resulting process of exclusion of others from the same access and rights to optimal health as that privileged minority (Breilh, 2021).

Deeper Dive

For key terms and overviews of key concepts on social determinants of health and health equity, check out:

- A Glossary for Health Inequalities (Kawachi et al., 2002)
- World Health Organization "Closing the Gap" report (Commission on the Social Determinants of Health, 2008)
- World Health Organization "COVID-19 and the social determinants of health and health equity" report (World Health Organization, 2021)
- National Academies of Science, Engineering, and Medicine "Communities in Action" Report (National Academies of Sciences, Engineering, and Medicine, 2017)

Where Does Data Come From?

Many different data sources are used for quantifying or qualifying the extent of, predicting the likelihood of, or trying to explain the processes causing health inequity. Generally put, this data is produced by measuring people, places, and systems.

People

A common approach to collecting data is asking people questions and then recording their responses using words or numbers. Table 2.1 shows a few ways data is collected and created to measure inequities.

Table 2.1 Methods of Collecting Data From People to Measure Health Inequity

Method	Example	Further Reading
Public and Community Surveys	• Census • First Nations Regional Health Survey • Canadian Community Health Survey	• First Nations Information Governance Centre (2022) • Statistics Canada (2021) • Statistics Canada (2022b)
Health Care Setting Surveys and Interviews	• Social needs screening • Questionnaires asking people about their demographic identity and experiences of discrimination • Patient experience surveys and focus groups	• Gottlieb et al. (2018) • Kirst et al. (2013) • Sinai Health System Human Rights & Health Equity (2017)
Interactions with Service Providers	Information recorded in: • Electronic medical records • Police records • Other administrative records (e.g., government identification or loans)	• Adler and Stead (2015) • Cook et al. (2021) • O'Neil, 2016 • Owusu-Bempah, 2011 • Patra et al. (2021)
Interactions with Technology	Information extracted through: • Social media • Internet access and browsing • Digital health applications	• Benjamin (2019) • Sieck et al. (2021) • The Lancet Digital Health (2021)

Places

Data from people can also be summarized to create data on the places we live. Survey or registry data are often summarized (i.e., by calculating percentages, means, medians, or other statistics) across everyone living within specific postal codes to examine how health and the determinants of health vary across geographic areas and neighbourhoods (Centres for Disease Control and Prevention, 2022; Diez Roux, 2016; Statistics Canada, 2022a).

Publicly available or "open" data collected by governments and public organizations through routine processes, evaluations, and required reporting can also serve as data sources on employment, businesses, housing, transportation infrastructure, crime and criminalization, water sanitation, recreation space, natural resource extraction, land management among many other areas (City of Toronto, 2022; Government of Canada, n.d.; OpenStreetMap, 2022).

Geographic information systems are a tool for visualizing and generating data on people's social, built, and natural environments, access to services and essentials of daily living (Green, 2012; Wang, 2020).

Systems

Data detailing the characteristics of, and priorities advanced by, health, economic, justice, political and other systems in society are harder to pin-point (e.g., organizational structure, enacted values, governance, financing).

However, with some effort, this data can be gathered from, for example:

- People performing or experiencing functions of a system (See **Section 3: Indigenous Data Sovereignty** for information about **"Indigenous Peoples' Data"**);
- Written and unwritten policy or rules; and
- The presence or absence of publicly available legal documents (Krieger, 2020).

Take a look at the approaches Dr. Nancy Kreiger (2020) compiled in Table 3 of their paper specifically for measuring racism, sexism, heterosexism and gender binarism. Another interesting resource is the Canadian Institute for Health Information's Cultural Safety in Health Systems Indicators (Canadian Institute for Health Information, 2021). This document aims to support health system administrators and researchers in assessing strengths and areas for improvement in addressing anti-Indigenous racism within their organizations.

Measuring Health Inequality and Inequity

Three key tasks in the field of data science are generally to describe, predict, and understand cause and effect relationships (Hernán et al., 2019). These tasks are also commonly used to assess health inequity.

Description – How Big Is the Issue?

Statistics like percentages and averages are used to compare differences in health across predefined categories of social, demographic, geographic and other characteristics (e.g., race or gender or income or place of residence). Similar statistics can also be mapped using geographic data to describe inequity.

In May 2020, journalist Matt Elliot tweeted this photo of a map of Toronto with its bus routes highlighted according to their levels of overcrowding early in the COVID-19 pandemic. The routes with greater overcrowding were lit-up and shown as thicker lines as if they were "hot" compared to routes with less or no overcrowding. A subsequent article in *The Local* described how the patterns of overcrowding and risk of COVID-19 exposure were not random but the latest example of inequitable distribution of health risk that largely working class and racialized communities navigate compared to higher-income and largely white communities (Huynh, 2020).

Prediction – Who Is at Risk?

Analytic approaches like regression modeling or machine learning algorithms are used to see whether social and demographic factors are correlated with and can improve the prediction of health outcomes.

QUICK SIDENOTE: Intersectionality

It's important to remember that if you're grouping people using social and demographic characteristics, you are assuming:

1. That there are meaningful "cut-offs" or differences between people identifying (or being made to identify) with each category; and
2. That there are no meaningful differences between people within categories.

Socially constructed categories of gender, race, and class don't have objective boundaries (Krieger, 2020). Furthermore, our expressions of femininity and masculinity, the darkness and lightness of our skin, and our economic resources–and thus our experiences of privilege, oppression, **inclusion**, and marginalization–overlap and intersect in complex ways and evolve over time (Bowleg, 2012; Krieger, 2020). Henceforth, analyses of **equity** need to carefully consider and apply intersectionality.

For more on intersectionality theory and analysis see:

- Abrams et al. (2020)
- Bauer et al. (2021)
- Bowleg (2012)

Cause-And-Effect – What Is Causing Inequity?

To estimate whether social determinants of health cause or influence the physiology of health and specific illnesses, or put another way, whether statistical tests suggest the arrows in Figure 2.1 connect the boxes, approaches like regression analysis (carefully using a causal inference framework) may be used. Click here to see a larger image of Figure 2.1.

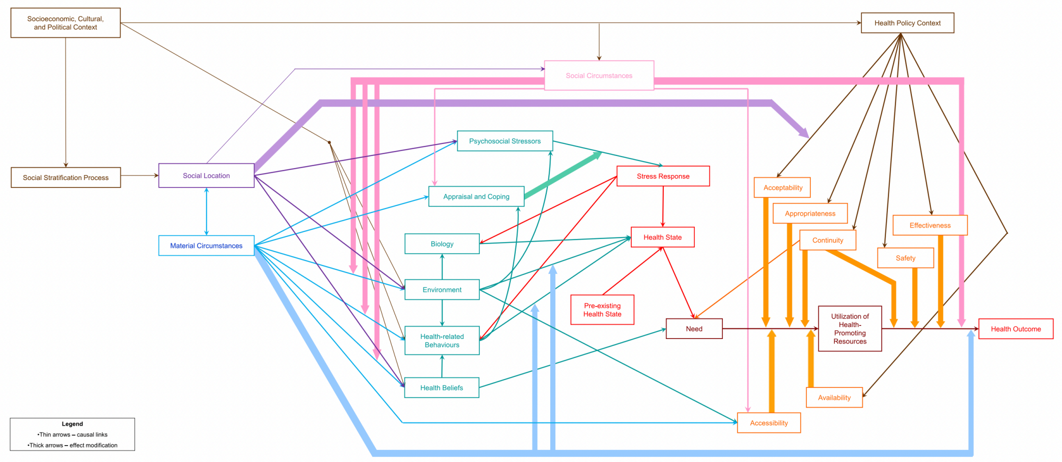
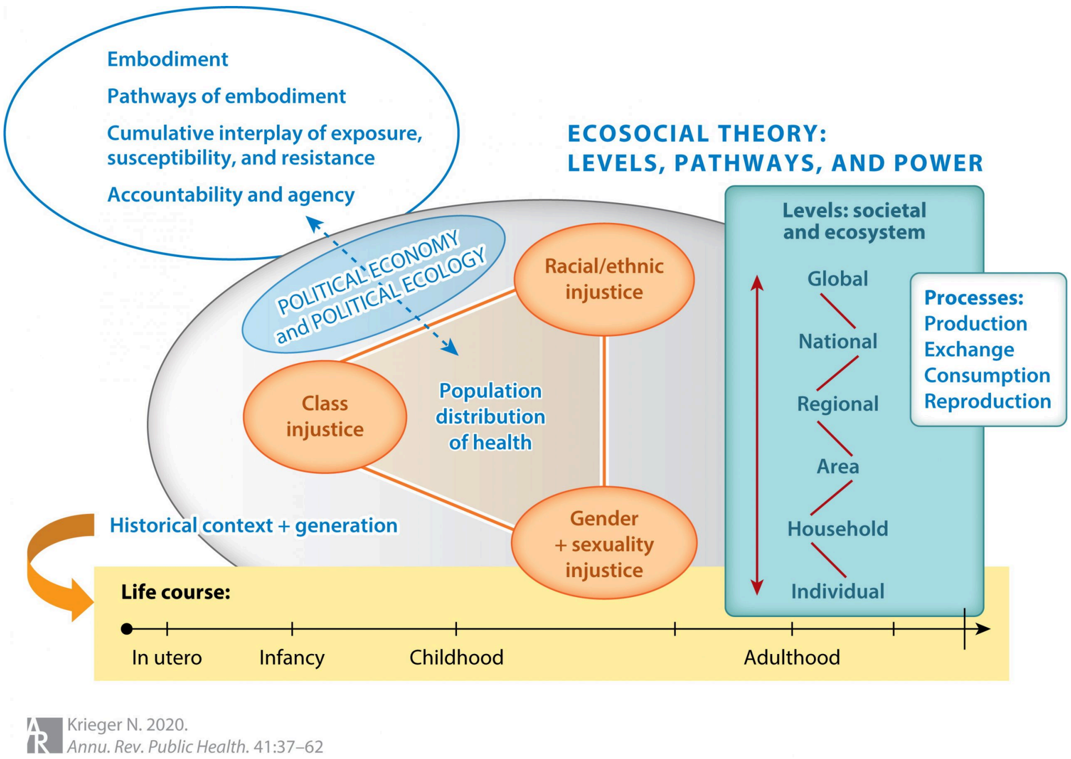


Figure 2.1 *Health Equity Measurement Framework. Source: Illustration by [Dover and Belon (2019)] is licensed under [CC BY]*

Another approach used to examine cause-and-effect relationships is testing whether, under specific conditions, changes made to policies (e.g., segregation) or services (e.g., models of health care that support patients with affordable housing) are followed by improvements in health. Take a look at Figure 2.2 below – this is a diagram of the ecosocial theory of disease distribution (Krieger, 2020). Approaches like interrupted time series analysis can be used to assess whether policy changes addressing forms of injustice (represented within the blue shaded oval labeled "Political Economy and Political Ecology") result in changes in the population prevalence of illness and distribution of health.



Krieger N. 2020.
Annu. Rev. Public Health. 41:37–62

Figure 2.2 *Ecosocial Theory of Disease Distribution. Source: Illustration by [Krieger (2020)] is licensed under [CC BY]*

Deeper Dive

To learn more about the strengths and limitations of these descriptive, predictive, and causal inference approaches to analyzing health inequity, here are a few key books:

- Social Epidemiology 2nd edition (Berkman et al., 2015)
- Rethinking Social Epidemiology: Towards a Science of Change (O’Campo & Dunn, 2011)
- Modern Epidemiology 4th edition (Rothman et al., 2021)
- Critical Epidemiology and the People’s Health (Breilh, 2021)

Test Your Knowledge

1. How is data related to colonization and intersecting forms of oppression and unfairness?
2. How are health inequality, inequity, and injustice the same?

3. What are three sources of data on social determinants of health that can be collected by measuring each of the following: people, places, and systems?
4. What are three general types of analysis used to examine health inequities?

Section 2: Health Systems, Equity, and Population Health Management

LLANA JAMES; DR. ROBYN K. ROWE; AND DR. ROBERT W. SMITH

Photo by Joshua Rawson-Harris on Unsplash

Section Overview

The purpose of this section is to unwind a thread of health policy history that may help explain where current interest in designing equitable health systems comes from. We spotlight **Population Health Management** as an approach being increasingly adopted within health systems in North America.

Section Objectives

By the end of this section, you will be able to:

- **Explain a few important policy moments and ideas from which Population Health Management emerged;**
- **Describe the key components and aim of Population Health Management; and**
- **Identify strengths and limitations of Population Health Management as an approach to creating equitable health systems.**

Background

Today, it is more common to see governments and health organizations include "health equity" or "population health" as key goals for their work.

This shift has catalyzed over many decades by civil rights and Indigenous Peoples' rights activism, advocacy, and most recently by movements, such as *Black Lives Matter* and *Every Child Matters*, and tragedies, like the murder of George Floyd by police in Minneapolis and uncovering of children's remains buried in unmarked graves at former Canadian Indian Residential School sites (Bailey et al., 2020; Hahn et al., 2018; Lavoie et al., 2016; Richardson & Boozary, 2021).

If we rewind 20 years, there were a few important health policy moments that also help explain how **Population Health Management** has emerged as a strategy for making health systems more equitable.

Population Health Policy Moments

Six Domains of High-Quality Health Care

In 2001, the Institute of Medicine published the "*Crossing the Quality Chasm*" report, which defined “equitable” as one of six core domains of high-quality healthcare (Institute of Medicine, 2001).

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=1394#h5p-50

Unequal Treatment

In 2003, the Institute of Medicine published the “*Unequal Treatment*” report led by Drs. Brian D. Smedley, Adrienne Y. Stith, Alan R. Nelson and colleagues (Institute of Medicine, 2003b). This report detailed the substantial and long-standing health inequities experienced by peoples made racialized in the United States due to racist beliefs, behaviours, law, and policy shaping peoples’ opportunities for optimal health, access to health services, and experiences receiving care. Among the report’s key recommendations for reducing inequities was collecting data on race and ethnicity and monitoring health system performance and population health outcomes in relation to these data.

> Having data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities. In addition, collecting appropriate data related to racial or ethnic differences in the process, structure, and outcomes of care can help to identify discriminatory practices, whether they are the result of intentional behaviors and attitudes, or unintended – but no less harmful – biases or policies that result in racial or ethnic differences in care that cannot be justified by patient preferences or clinical need. Data collection and monitoring, therefore, provides critically needed information for civil rights enforcement. (Institute of Medicine, 2003a, p. 215-216)

Accountable Care Organizations

Also in the early 2000s, interest was also growing in health system reforms that bring hospitals, physicians, and non-physician health service providers together to work in collaboration with shared responsibility for financial and health service outcomes for a defined population; these would later become known as Accountable Care Organizations (Tu et al., 2015; Wilson et al., 2020).

The Triple Aim

An issue with the six domains of high-quality health care was that it only applied to people already receiving services for their health concerns. This prompted reflection on what people who are not yet seeking health care should expect of their health systems.

In 2008, Dr. Don Berwick and colleagues (2008) coined "The Triple Aim." This concept introduced three fundamental goals for health systems, to simultaneously:

1. Promote and protect the population's health;
2. Improve the experience of health care; and
3. Reduce the cost of health care.

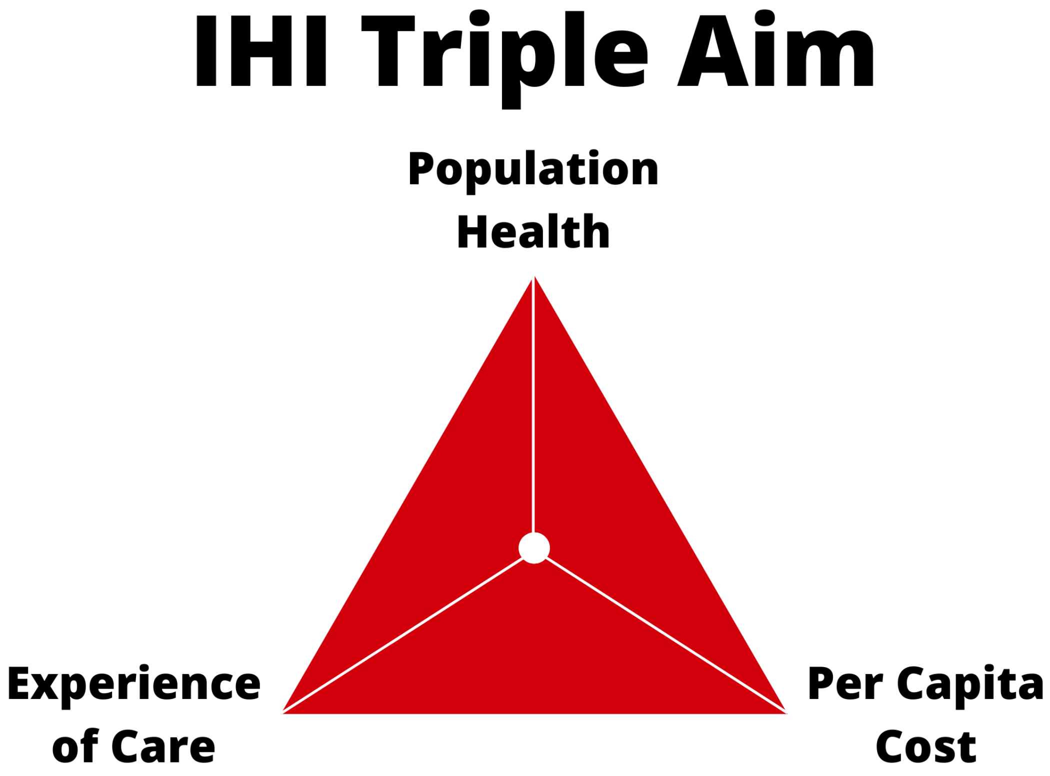


Figure 2.3 *The IHI Triple Aim. Source: Caitlin Muhl*

QUICK SIDENOTE: Population Health Without Equity?

Some scholars suggest the aim of "population health" is problematically vague since the goal of equity is not explicitly included (Lantz, 2019; Nundy et al., 2022). Furthermore, "population" may be used to describe a narrow group of people (e.g., people living with heart failure) instead of every community member living in a geographic area, or whole societies (Lantz, 2019).

These distinctions are important because while a population's health may on average be improving, health benefits may be concentrated among a privileged few. For example, a large study by Shahidi et al. (2020) recently found that:

> Canada has made no overall progress toward the goal of reducing socioeconomic inequalities in premature and avoidable mortality. In fact, the strength of the association between socioeconomic status and mortality appears to have increased substantially between 1991 and 2016. (p. E1126)

Check out the video below from the Institute for Healthcare Improvement on the Triple Aim and the social determinants of health:

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=1394#oembed-1

So, how does a health system achieve this population health aim?

Today, Accountable Care Organizations and health systems across North America are developing approaches to what the Institute of Healthcare Improvement call **Population Health Management** (Fraze et al., 2016; Hacker & Walker, 2013; Institute for Healthcare Improvement, 2022; National Academies of Sciences, Engineering, and Medicine, 2019; Waddell, Reid, et al., 2019).

Population Health Management

There is no universal definition for **Population Health Management**, but it can be described as processes within health organizations that use data on the people they serve to:

1. Measure health status, unmet health and social needs, and healthcare experiences and outcomes;
2. Group patients or community members according to health and social and demographic characteristics, healthcare use, or likelihood of needing healthcare in the future;
3. Proactively design and advocate for services and policies that promote health, prevent disease, reduce inequities, and improve healthcare outcomes; and
4. Implement changes and evaluate whether they are leading to improved health or healthcare outcomes in a population (Primary Health Care Performance Initiative, 2018; Social Care Institute for Excellence, 2018; Waddell, Reid, et al., 2019).

Check out the video below, specifically between 8:22-21:00 minutes, where Dr. Rob Reid, Chief Scientist of Trillium Health Partners' Institute of Better Health, describes core concepts of **Population Health Management** in Ontario:

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QUICK SIDENOTE: Other Health Sectors Performing These Roles?

Population Health Management roles have similarities with what the World Health Organization call "Essential Public Health Operations", such as population health surveillance and health promotion. These have traditionally been performed by Public Health Departments, local Public Health units, or public health professionals working in government and non-governmental organizations, municipalities, and healthcare organizations (Hacker & Walker, 2013; World Health Organization – Europe, 2022).

A key difference between public health and health care sectors is that public health tends to focus on promoting and protecting the health of society and preventing disease and injuries *before* treatment is required, whereas healthcare providers (e.g., primary care, hospitals, long-term care) primarily provide treatment *in response to* individuals' immediate health needs.

A core idea within **Population Health Management** is that collecting better data on patients, community members, and the environments where they live (e.g., race and ethnicity, income, housing, food availability, transportation infrastructure, and policing), improving how this data is analyzed, and acting on the knowledge developed through analysis, will help health system leaders understand the populations they serve, and will equip them with tools for identifying and addressing health inequities.

To date, various **Population Health Management** approaches have been developed (Butler et al., 2020; Fraze et al., 2016; National Academies of Sciences, Engineering, and Medicine, 2019). Healthcare Hot-Spotting is one popular example.

Below is a short documentary describing how Dr. Jeffrey Brenner and the Camden Coalition of Healthcare Providers used hospital billing data, zip codes, and other social and demographic data to identify and respond to "hot-spots" or patterns of increased healthcare use by neighbourhood. Using information generated from the data, the Camden Coalition team, which includes social workers, doctors, nurses, and other service providers, developed a holistic model of healthcare. That means that patients receive services and support accessing services that address their physical and mental wellbeing as well as social conditions (e.g., financial support programs, affordable food and housing, legal aid).

In this video, Dr. Atul Gawande interviews Dr. Jeffrey Brenner, Camden Coalition team, and community members supported with long-term health and social services at home in an effort to improve health and prevent avoidable hospitalizations:

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=1394#oembed-3

Cautionary Notes

Photo by [Markus Spiske](#) on [Unsplash](#)

It is important to note that it remains unclear whether social and demographic data collection within healthcare organizations itself leads to actions that address health inequities (National Academies of Sciences, Engineering, and Medicine, 2019).

Developing effective and equitable change within health systems is challenging not least because of the time, people, knowledge, funding, and equipment (e.g., data collectors, analysts, information systems) required for, and the complexity of:

- Collecting and collating robust health, social, and demographic data, then;
- Conducting rigorous analyses informed by seminal theory, ethics, and a comprehensive understanding of existing scientific evidence, then;
- Translating this knowledge into health service design, then;
- Implementing effective and equitable models of care.

Indeed, a major randomized controlled trial found no statistically significant effect of the Camden Core Model on risk of returning to hospital, length of hospital stay, or health care costs within six months of discharge (Finkelstein et al., 2020). Other models designed with similar intentions have also produced null or mixed results (Berkowitz & Kangovi, 2020; Iovan et al., 2019; Purnell et al., 2016).

Furthermore, whether or how action is taken among policy makers and health system administrators to address inequities also depends in part on the priorities, world views, and power relationships of individuals and organizations gathering and/or responding to inequities identified using data (Lorenc et al., 2014; McGill et al., 2015; Petticrew et al., 2004; Smith, 2014; Turner et al., 2013; Whitehead et al., 2004).

Finally, it's important to remember that even the act of collecting social and demographic data in health settings and sophisticated analyses that follow can cause harm to community members.

Deeper Dive

- Harvard Data Science Initiative Bias^2 Seminar on racial bias coded into a machine learning algorithm used to determine who gets certain types of health care (Obermeyer et al., 2019): https://www.science.org/doi/10.1126/science.aax2342
- Commentary on harms and opportunities to improve screening for unmet social needs in health care (Butler et al., 2020): https://catalyst.nejm.org/doi/full/10.1056/CAT.19.1037
- *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present* (Washington, 2006)

Ethical Engagement of Black Communities in Data Collection and Evaluation Processes

To support community members, learners, health system workers, and researchers with avoiding harmful and unethical data collection, research, and evaluation with Black communities in Canada, LLana James and Dr. Ciann L. Wilson are launching the REDE4BlackLives Research, Evaluation, Data Collection, and Ethics Protocol for Black Populations in Canada (James & Wilson, 2020).

James and Wilson (2020) state that the objectives of REDE4BlackLives are to:

- Build upon our growing interdisciplinary and multi-sectoral collaborative partnerships;
- Craft and implement a research, evaluation, and data collection protocol to guide the ownership, control, access, and sharing of information about Black individuals and communities collected for the purpose of research, evaluation, and community engagement; and
- Assist Black communities in Canada, researchers, evaluators, data collectors, scientists, policy makers, funders, and donors in public, private, and public-private initiatives, partnerships, collaborations, and/or organizations to think through the nuances of conducting ethical and beneficial research, evaluation, and/or data collection with and for Black communities.

Ontario Health System Reform

In 2019, the Government of Ontario announced plans for substantial health system reforms that involve:

1. Bringing six provincial health agencies and 14 Local Health Integration Network agencies under one roof–within the new Ontario Health "super agency" (Waddell, Wilson, et al., 2019);
2. Creating Ontario Health Teams, which are networks of health, social, and other service providers that work together to deliver services that span the care continuum, and share responsibility for a defined patient population (Ministry of Health, 2019); and
3. Consolidating 34 local Public Health Units into 10 regional public health agencies – however, these plans were subsequently put on hold due to the COVID-19 pandemic (Smith et al., 2021).

When fully up-and-running, Ontario Health Teams may look and function like Accountable Care Organizations (Waddell, Wilson, et al., 2019). **Population Health Management** is already being introduced to Ontario Health Teams as a mechanism for identifying and addressing health care and population health inequities (Waddell, Reid, et al., 2019).

When this is considered alongside Ontario Health's mandate to "[improve] how the agency uses data in decision-making, information sharing and reporting, including by leveraging available and new data solutions…" (Ministry of Health, 2021, p. 3), it may be reasonable to suggest that data collection, analytics, and sharing are foundational components of the Ontario health system's strategy for reducing health inequities.

Take a moment now to read the following case study, which gives a local example of some of the changes taking place in Ontario, Canada.

CASE STUDY: Trillium Health Partners and AI for Population Health

Born in 2012, Trillium Health Partners (THP) is among the largest community-based hospital systems in Canada serving a population of around two million people (Trillium Health Partners, 2019). It operates on the traditional territories of the Mississaugas of the Credit, the Anishinabek, Huron-Wendat, Haudenosaunee, and Ojibwe/Chippewa peoples in what is now called the Region of Peel, Ontario. Peel Region's geography remains home to vibrant communities of Indigenous and non-Indigenous peoples from many nations and speaking over 133 languages (Trillium Health Partners, 2019). However, many communities are also experiencing growing income insecurity (Dinca-Panaitescu et al., 2017).

In their 2019-2029 strategic plan, THP states: "Our mission to build a new kind of health care for a healthier community means discovering the potential of better health for all" and their strategic priorities are to:

- Deliver high-quality care and exceptional experiences;
- Partner for better health outcomes; and
- Shape a healthier tomorrow." (Trillium Health Partners, 2019, p. 24)

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To shape a healthier tomorrow, "THP will embark on several major investments…including: building capacity for the future; adopting new technology and sharing information across the community and beyond; and, strengthening the broader network, or ecosystem, that influences the health and prosperity of the community." (Trillium Health Partners, 2019, p. 52)

The Institute for Better Health is THP's innovation and research arm which is "focused on generating cutting-edge science and innovation in health service delivery and population health." THP and the Institute for Better Health are making unprecedented changes to its information systems and leverage artificial intelligence technology with the goal of improving health care.

- **October 2020:** THP overhauls its electronic medical record (EMR) system purchasing the Epic EMR developed by a major American vendor called Epic Systems Corporation (Laugheed, 2019; Trillium Health Partners, 2022).
- **October 2021:** Institute for Better Health announces the adoption of cloud-based technology for predicting hospital bed occupancy developed in partnership with the University of British Columbia and Amazon World Services (Trillium Health Partners, 2021).
- **November 2021:** THP attracts a $1 million donation from TD Bank Group and establishes the Health Care AI Deployment and Evaluation Lab (Trillium Health Partners Foundation, 2021).

Hypothetical Scenario:

To realize its priorities and implement **population health management**, THP in partnership with Mississauga Ontario Health Team, explore ways to expand social and demographic data collection, to develop AI algorithms that can identify unmet social needs (e.g., income insecurity) from patient medical histories written in EMR notes, and collate data from various sources for analysis using its cloud-based platform.

Reflection Question:

What are some potential benefits and risks of using EMRs for sociodemographic data collection and AI and cloud-based analytics for **population health management**?

Summary

Wider recognition of the role that health systems play in preventing and perpetuating health inequities is a positive development for health policy in recent decades. There are many ways health systems can approach enacting espoused values of health equity. **Population Health Management** is a concept and evolving collection of approaches that emphasize data analytics as a tool for realizing health equity. As **Population Health Management** enters the Ontario health system, it is essential that health service providers, administrators, and policy makers carefully consider the complexities and potential harms of these approaches. Work involving the collection, analysis, and evaluation with communities made marginalized by racism and intersecting forms of oppression should be guided by ethical protocols developed through deep engagement with community members. **Indigenous Data Sovereignty** is another key area that learners need to understand firmly when approaching or being approached by this type of work. For more on this, proceed to Section 3: Indigenous Data Sovereignty.

Test Your Knowledge

1. What are two strengths of having “health equity” as an explicit aim of health systems versus “population health” alone?
2. What is Population Health Management?
3. Does the collection of social and demographic data in health care settings guarantee action will be taken to address identified health inequities? Why or why not?
4. What are three risks related to the collection and analysis of social and demographic data in health care settings?

Section 3: Indigenous Data Sovereignty

LLANA JAMES; DR. ROBYN K. ROWE; AND DR. ROBERT W. SMITH

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Section Objectives

By the end of this section, you will be able to:

- Understand key terminology relevant to the Indigenous data space;
- Understand some of the historical context of Canada and its impacts on Indigenous Peoples' lives; and
- Recognize existing Indigenous Data Governance Principles that are leading the Indigenous

Data Sovereignty movement around the world.

Background

For centuries, prior to Western European arrival, Indigenous Peoples were rich in culture, traditions, languages, and lived off the land in what we now call Canada (Truth and Reconciliation [TRC], 2015). With Western European arrival making way for settler expansion, policies were created in order to strip First Nations, Inuit, and Métis of their ethnocultural and linguistic diversity (TRC, 2015). Through means of cultural genocide (also known ethnocide), settler policies were aimed at universal assimilation and Indigenous elimination (TRC, 2015; Nelson, 2008; Davis, 2003). Many of these policies and ideals persist today, making way for data environments that are inherently inequitable and perpetuate colonial narratives that do not benefit the lives of Indigenous Peoples.

By the end of this section, you will have a deeper understanding of some of the key terms relating to the **Indigenous Data Sovereignty** space, have a base understanding of the historical and ongoing impacts of colonization, while beginning to understand how those experiences create innately inequitable data environments that require decolonial and anti-colonial perspectives in order to improve the outcomes and experiences of Indigenous Peoples in Canada and around the world.

Key Terminology

Who are Indigenous Peoples?

In Canada today, **Indigenous identity** is loosely defined within *the Constitution Acts* (1867) as First Nations, Inuit, and Métis (though the outdated term Aboriginal is used in Section 35 of*the Constitution Acts*). First Nations, Inuit, and Métis have their own distinct histories, cultures, languages, and traditional knowledge systems.

The experiences of First Nations, Inuit, and Métis people in Canada as a result of enfranchisement efforts (see *Gradual Civilization Act*, 1857) as well as patriarchal and colonial policies that were consolidated in the *Indian Act* (1985), have altered individual and community perceptions of identity.

Deeper Dive

To learn more about **Indigenous identity** and the appropriate use of language when speaking about **Indigenous identity**, check out:

- Amnesty International. (n.d.). Indigenous Peoples
- Government of Canada (2022). Indian Status
- Journalists for Human Rights. (2017). Style guide for reporting on Indigenous People. Indigenous Reports Program

What are Indigenous Peoples' Data?

Carroll et al. (2020) define **Indigenous Peoples' data** as:

> (1) information and knowledge about the environment, lands, skies, resources, and non-humans with which they have relations; (2) information about Indigenous persons such as administrative, census, health, social, commercial, and corporate; and (3) information and knowledge about Indigenous Peoples as collectives, including traditional and cultural information, oral histories, ancestral and clan knowledge, cultural sites, and stories, belongings. (p.3)

Examples include data about health services, education outcomes, locations of trails, historic areas, spiritual sites and harvesting areas, traditional place names, membership lists, community stories, and more (Rodriguez-Lonebear, 2016).

What is Indigenous Data Sovereignty?

Through collaboration, relationship, and trust building, Indigenous Peoples around the world are applying mechanisms that take back the autonomy of Indigenous Peoples' lives, including our research and data. **Indigenous Data Sovereignty** is the right of Indigenous Peoples to own, control, and use Indigenous data (Rainie et al., 2019).

Deeper Dive

To learn more about **Indigenous Data Sovereignty**, check out:

- Rainie et al. (2019). Chapter 21: Indigenous Data Sovereignty in *"The state of open data: Histories and horizons"* (pp. 300-313)
- Kukutai & Taylor, (2016). Indigenous Data Sovereignty: Toward an agenda

What is Indigenous Data Governance?

Indigenous Data Governance refers to the governance or stewardship of data itself, and the processes that are needed in order to implement Indigenous control over Indigenous data (Carrol, Rodriguez-Lonebear, & Martinez, 2019). Many mechanisms are in place around the world that enable the activation of **Indigenous Data Sovereignty**. **Indigenous Data Sovereignty** is enacted through the application and assertion of Indigenous Peoples' governance over data. Governance cannot be learned or asserted simply from reading; it requires a deep and meaningful understanding of Indigenous Peoples' experiences, rights, and interests.

Decolonize your Mind

In order to effectively understand the role and impact of data on the lives of First

Nations, Inuit, and Métis, it is important to have a deep understanding of the experiences of Indigenous Peoples. Settler European colonies have asserted dominance through violence, land dispossession, and oppression in countries around the world in order to create and sustain their colonial agenda. In our efforts to counteract some of these historical and ongoing wrongs, we must take the time to understand and reflect on what that history entails and how it continues to impact our lives today.

Deeper Dive

To learn more about the experiences of Indigenous Peoples, check out:

- The Truth and Reconciliation Commission of Canada, (TRC; 2015). Reports and Findings
- [Video] Wade Davis' 2003 TED Talk entitled *Dreams from endangered cultures*
- Nelson, M. K. (Ed.). (2008). *Original instructions: Indigenous teachings for a sustainable future*. Bear & Company. [Book]
- Explore the International Work Group for Indigenous Affairs website, importantly the most recent years' Indigenous World edition
- Indigenous Corporate Training Inc.'s list of free eBooks
- [Video] Martin Defalco and Willie Dunn share an eye-opening 42-minute video from 1972 entitled *The Other Side of the Ledger: An Indian View of the Hudson's Bay Company*

Efforts to Dismantle Colonial Systems

The competitive nature of capitalism has been the primary driver of data discourses in recent times. However, the exploitation and commodification of Indigenous Peoples and territories is as old as colonialism. Global recognition of the ongoing social, cultural, economic, and political injustices experienced by Indigenous Nations resulted in a need for an Indigenous-specific human rights document.

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the United Nations General Assembly in 2007. The UNDRIP outlines 46 Articles that set out the minimum standards for the "dignity, survival and well-being" of Indigenous Peoples (General Assembly resolution 61/295, 2007). The application of articles within the UNDRIP are leveraged to support international and national momentum that asserts Indigenous sovereignty, including data sovereignty.

For decades, efforts to address ongoing inequities experienced by Indigenous Peoples have been outlined in national level documents. The Royal Commission on Aboriginal Peoples (RCAP) was released in 1996 and outlines 444 calls to all levels of government on how to better support Nation-to-Nation relationships. The Truth and Reconciliation Commission of Canada (TRC) released in 2015 includes 94 Calls to Action, and includes many of the same points of discussion shared decades prior in the RCAP. The National Report on Missing and Murdered Indigenous Women and Girls (MMIWG) released in 2019 again, highlights 231 Calls for Justice.

While the specific calls may not speak explicitly to the data space, the spirit of the messages within these documents outlines the ongoing need for First Nations, Inuit, and Métis justice in this country. The endurance of colonialism is evidenced by the sheer need for such documents and calls for action in the first place.

Deeper Dive

To learn more about calls to action that support and assert Indigenous rights and interests, check out:

- The UNDRIP (2007). General Assembly resolution 61/295
- Department of Economic and Social Affairs. (2019). State of the world's Indigenous Peoples: Implementing the United Nations Declaration on the Rights of Indigenous Peoples
- Carpenter, K. A., & Riley, A. R. (2014). Indigenous Peoples and the jurisgenerative moment in human rights
- Dussault, R., & Erasmus, G. (1996). Report of the royal commission on aboriginal peoples
- Missing and Murdered Indigenous Women and Girls. (2019). Reclaiming power and place

Indigenous Data Governance Principles

Indigenous data governance, as defined under Key Terminology, necessitates mechanisms by and for Indigenous Peoples to ensure that **Indigenous Peoples' data** are protected and sovereignty is asserted. Around the world, **Indigenous data**

sovereignty initiatives led by Indigenous Peoples and organizations are asserting the rights and interests of Indigenous Nations (see for instance, The Care Principles for Indigenous Data Governance).

Deeper Dive

To learn more about **Indigenous Data Sovereignty** groups around the world and their various governance initiatives, check out:

- The Global Indigenous Data Alliance (GIDA) formed in 2019 bringing together many of the world's leaders in Indigenous Data Sovereignty
- Te Mana Raraunga, Māori Data Sovereignty Network in Aotearoa (New Zealand).
- The United States Indigenous Data Sovereignty Network
- Maiam nayri Wingara, Indigenous Data Sovereignty and Governance in Australia

In Canada, First Nations, Inuit, and Métis each have their own unique ways of ensuring their research and data practices align with their unique political and territorial situations and worldviews.

Examples of Indigenous research and data governance models include:

- Inuit Tapiriit Kanatami. (ITK; 2018). National Inuit Strategy on Research
- Indigenous Innovation Initiative. (2021). Nindokiikayencikewin: to seek learning or Knowledges.
- First Nations Information Governance Centre. (2020). A First Nations Data Governance Strategy.
- The Tui'kn Partnership's website also offers a variety of resources and materials.

As outlined in **Chapter 1: Data Literacy**, the First Nations Information Governance Centre (FNIGC) has been a leader in advancing the data rights and interests of First Nations Peoples in Canada through the development of the First Nations' Principles of Ownership, Control, Access, and Possession or OCAP® in the 1990s (FNIGC, 2019; 2014). The First Nations Principles of OCAP® are increasingly woven into the fabric of mainstream research (see Chapter 9 of the Tri-Council Policy Statement, 2018 *Research involving First Nations, Inuit, and Métis Peoples of Canada*).

Indigenous Methodologies in Research and Data

Indigenous data and research practices require approaches that are rooted in what Johnston et al. (2018) highlight as the five Rs. While many variations of this sort of model exist, this one in particular points to the important role of relationships, respect, relevance, responsibility, and reciprocity when conducting Indigenous research. If you are interested in doing equity-engaged Indigenous research, you will require a deep and meaningful understanding of the work of many well-respected Indigenous scholars. Across every sector – health, education, social work, management, and more, there are well recognized Indigenous scholars who speak of the important role of Indigenous worldviews and approaches to respectful and appropriate ways of working with Indigenous Peoples.

Deeper Dive

If you are interested in learning more, and continuing your own decolonial work, here is a non-exhaustive list of how to apply Indigenous methodologies in your sector:

- Kovach, M. (2010). Indigenous methodologies: Characteristics, conversations, and contexts. University of Toronto Press.
- King, T. (2003). The truth about stories: A native narrative. House of Anansi Press.
- Smith, L. T. (2021). Decolonizing methodologies: Research and Indigenous Peoples (3rd ed.). Zed Books.
- Tuck, E. & Yang, K. W. (2012). Decolonization is not a metaphor. Decolonization: Indigeneity, Education & Society, 1(1), 1-40.

Test Your Knowledge

1. Upon reading this section and reviewing some of the suggested external materials, what are some of the notable ways that your views on Indigenous data and research have shifted
2. Upon reflection, how are Indigenous data different from mainstream data? Why is this understanding so important?

3. In what ways does your institution apply Indigenous-led Data Sovereignty priorities and are there ways to improve them?

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CHAPTER 3: IMPLEMENTING CHANGE - EASIER SAID THAN DONE

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Chapter Objectives

By the end of this chapter, you will be able to:

- **Understand core definitions and their associated applications related to implementing** change based on evidence;

- Identify and critically assess frameworks and their application to various contexts;
- Understand factors that influence change at the micro, meso, and macro level; and
- Develop an appreciation of the complexity of bringing about improvement in the health sector.

Section 1: Introduction to What It Means to Improve a Health System Based on Data

DR. MADELYN P. LAW; DR. ELAINA ORLANDO; AND LIDIA MATEUS

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Section Overview

In this section, you will be introduced to the foundational definitions of **implementation science**, **improvement science**, and **change management**. This is an evolving field of study in the health sector where these bodies of literature intersect, sharing similarities while also possessing distinguishing characteristics. However, all have the goal of understanding how to further improve health services and programs – thus the health outcomes for the population.

Section Objectives

By the end of this section, you will be able to:

- **Define implementation science, improvement science, and change management;**
- **Distinguish between implementation science, improvement science, and change management; and**
- **Understand the role and importance of these fields in advancing health system improvement.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Introduction

Have you ever wondered how the research that is done in the university setting is realized in practice? Or how are new innovations in health care delivery implemented in an organization to help advance the health of a patient? Or maybe you have wondered about how you get someone to change the way they work after doing something a certain way for many years? These questions and many others are where **implementation science**, **improvement science**, and **change management** theories, principles, and concepts come into play.

It is important to acknowledge that there are many terms, theories, and concepts aimed at “making things better” in the health system. It is easy to become confused with trying to understand the differences between words like change, improvement, implementation, diffusion of innovation, and **knowledge translation**. It is noteworthy that they are not working in parallel, but rather, when looked at together, these concepts support each other in helping to achieve the goal of this book – using data to drive improvements in health services. This section review the areas of:

1. The body of research that studies how best to implement change – **implementation science**;
2. The practice of **improvement science**, which lends to the methods and tools to create change – **improvement science**; and
3. The people side of the change, which requires tailored and focused management – **change management**.

Understanding these three areas together provides a robust understanding of how best to use data to impact the way in which health services are delivered and to successfully implement changes that are based on the best available evidence.

CASE STUDY: A Demonstration of the Linkages of Implementation Science, Improvement Science, and Change Management – Peds-TECH

Photo by Sharon McCutcheon on Unsplash

Niagara Health and McMasters Children's Hospital embarked on a project to connect pediatric emergency specialists at McMaster with emergency physicians in Niagara Health through telemedicine for children in need of **resuscitation**. This collaboration, titled Pediatric Telemedicine Connecting Hospitals (Peds-TECH), started after an extensive focus on how to improve care for these patients. As the program rolled out, an **improvement science** lens was used to learn from the cases, report any technical issues, and obtain physician perceptions of the service so that these could be fixed in real time. This Model for Improvement approach allows the collaborators to improve the service over time. This process also enacted principles from **change management** to engage local health professionals in the development of the process, provide opportunities for feedback, and share successes of the program. This has helped to support the project to continue and the program to be used across the multi-site hospital system. With the program up and running successfully, there became an opportunity to study the implementation, hence **implementation science**. Assessing the program through rigorous qualitative and quantitative data to understand the factors associated with implementation can then lead to further enhancement while also lending to our scientific knowledge regarding factors that enhance implementation success of an innovative technology. This knowledge can then be used to support the sustainability and spread of this effective health service delivery model. To read more about Peds-TECH, click here.

Topics Defined and Explained

As outlined by Eccles and Mittman (2006) in the inaugural issue of Implementation Science, **implementation science** is defined as:

> "the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care." (p. 1)

This field of **implementation science** takes the idea of using data to drive change to another level. One can think of it as the study of that "middle ground" between data identifying the need for change and the outcome of achieving human behavior change; **implementation science** allows us to understand individual and organizational factors that are more likely to enable successful change. Understanding the mechanisms in the process of implementation is its own science. It addresses the "know do gap". As outlined by the University of Washington's Implementation Science Program, the fundamental question of **implementation science** is: "How do we get 'what works" to the people who need it, with greater speed, fidelity, efficiency, quality, and relevant coverage?" (University of Washington, 2022).

Watch the video below on **implementation science**:

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=73#oembed-1

Similarly, **improvement science**, which includes ideas such as the Model for Improvement, is an "applied science that emphasizes innovation, rapid-cycle testing in the field, and spread in order to generate learning about what changes, in which **contexts**, produce improvements" (Institute for Healthcare Improvement [IHI], 2022c, para. 2).

As you can see these two fields are complementary as both focus on improving something, are systematic in the approach, and are concerned with the **context** in which the change is being implemented. **Implementation science** is the actual "study of methods" to promote uptake of evidence. This might mean that there is a study of the perceptions of staff on how well the Model for Improvement was enacted to create change which would allow for an understanding of the Model for Improvement in that **context**.

Linking this back to the telemedicine case study, an implementation scientist might conclude that by using the Model for Improvement, where the team was able to obtain data on specific outcome measures each month, that this was the most effective strategy in enhancing the use of the telemedicine service over time. Therefore, if others were to implement a similar service at another hospital, there should be a consideration of the data systems before embarking on the implementation of this service.

Change management comes into play with a focus on supporting people through a change. People are inextricable from our organizations and our processes; when we introduce change, it often requires behaviour and attitude change, which can be challenging. According to the American Society for Quality (2022a), **change management** is defined as "the process, tools, and techniques used to manage change, including planning, validating and implementing change, and verifying effectiveness of change". The World Health Organization (2019) defines **change management** as "the practice and process of supporting people through change, with the goal of ensuring that the change is successful in the long-term. **Change management** helps people to change their behaviors, attitudes, and/or work processes to achieve a desired business objective or outcome" (p. 3).

The video below is a nice demonstration of the Large Scale Change Model, in which you will be able to appreciate the **change management** approach and see how **improvement science** and **implementation science** links into these concepts:

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Change management is this overarching framework to which **implementation science** and **improvement science** can be situated.

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All of this is to say that if an individual is looking to promote the uptake of evidence that is an inherent change to clinical practice or service delivery, they should look to **implementation science** and **improvement science** to understand how they can best do this and think about these approaches in a broader **change management** framework. The conscious application of these three perspectives is especially valuable in a complex environment like the health sector.

Motivating Change

Photo by Chris Lawton on Unsplash

Improving the health system seems like it should be a no-brainer! It should be easy to get buy-in for a great new clinical therapy or an innovative practice. But health systems are complex and human behaviour is notoriously hard to modify. Hence, asking someone to change their behaviour just because some researchers say it is better is not the carrot for change. Motivating change comes in the form of policy, funding, organizational structures, and appropriate improvement methods.

Over the years, health system researchers have come to understand that the creation of evidence through clinical trials, in very controlled settings, although important, is not the solution to closing the loop to ensuring that all patients are provided with evidence-based care. In fact, the uptake of research evidence to practice is so slow, it has been widely noted that it can take upwards of 17-20 years to realize research being translated into practice, and oftentimes, only 50% of new evidence-based strategies make it to practice (Bauer & Kirchner, 2020).

For years, much of the focus of researchers was to develop evidence and then have this published in scholarly journals as an indicator of their success. However, this minimalistic approach to **knowledge translation** of research findings and the relative lack of impact on practice that was arising out of research that was costing millions of dollars has been questioned by many. To this end, many funders now require that researchers demonstrate how they will act upon the results to ensure they are realized.

Extending Your Thinking to Implementation With a Health Equity Lens

Ensuring a health equity lens to all health system planning is essential. Kerkhoff et al. (2022) have provided an overview of the steps and questions that need to be asked as one begins an implementation process. This framework could be used to evaluate current efforts, but more ideally could be used to guide implementation. Considering health equity in the planning stages through these questions will help to ensure that vulnerable populations are considered throughout the planning process and in turn will help support the reduction of health inequities in our communities.

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Please go to **Chapter 2: Data for Equity?** for more information about this topic.

Summary

What we know about working in the field of implementation, improvement, and change is that it is messy: It is never a straightforward process with easily defined boundaries. Acknowledging and being mindful of this messiness is one of the most important things we can do when trying to work on health systems change. There are numerous approaches that have been developed and tested to achieve the desired results, many of which will be discussed throughout the next two sections: **Section 2: Frameworks for Improvement** and **Section 3: Factors Influencing Change Efforts.**

To say that one approach is better than another other is wrong. What is important to consider is the **context**. This is what makes implementation and improvement so interesting (and so complex)! One size does not fit all. Health sectors are not controlled environments where you can simply take, for example, one intervention from a hospital in Northern Ontario and implement it the exact same way in an academic hospital site in downtown Toronto. Although the idea for a treatment (e.g., drug) is the same, the process by which the treatment is administered may differ significantly from start to finish. This is not to say that one is better than the other – but it is to say that **context** matters and needs to be on the top of everyone's mind when working to improve health systems.

In the next two sections, **Section 2: Frameworks for Improvement** and **Section 3: Factors Influencing Change Efforts**, you will be introduced to a number of frameworks that are used in **improvement science** together with factors that need to be considered when implementing change.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=73#h5p-22

Deeper Dive

- Check out some open access articles from the Implementation Science Journal: https://implementationscience.biomedcentral.com/
- The Institute for Healthcare Improvement provides a wealth of resources focused on improvement science specifically with a focus on the Model for Improvement: www.ihi.org
- The document that can be sourced at this link provides a Toolkit for Change Management in Public Health. This toolkit was put together by the Department of Evidence and Intelligence

for Action in Health – Pan American Health Organization and the World Health Organization: https://www3.paho.org/ish/images/toolkit/IS4H-KCCM-EN.pdf

Section 2: Frameworks for Improvement

DR. MADELYN P. LAW; DR. ELAINA ORLANDO; AND LIDIA MATEUS

Photo by [Dakota Roos](#) on [Unsplash](#)

Section Overview

In this section, we present a breakdown of frameworks that are used to implement evidence-based changes in health organizations. Interestingly, these frameworks often overlap, are conceptually intertwined, and can be used together to inform processes to achieve the change that is desired.

Section Objectives

By the end of this section, you will be able to:

- **Identify and critically assess frameworks and their application to various health sector contexts that support organizations and individuals in their efforts to make evidence-based changes;**
- **Differentiate between the formative and summative approaches to change and critically assess how they should be applied; and**
- **Understand the elements of these approaches and how they are operationalized in practice.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Overview of Formative and Summative Frameworks

There are so many different frameworks that exist to support evaluation and the use of evidence to inform decision-making in the health sector and in other industries. To help streamline thinking and support one's decision on what framework to choose and use, we have organized them into three groups: formative, summative, and guiding frameworks.

A **formative framework** is one that allows for **formative evaluation** to occur throughout a change effort in a rapid way. Real-time changes can then be incorporated into the project or intervention to respond to challenges or unintended outcomes that may be encountered throughout implementation. This approach relies strongly on data at baseline, constant measurement, and use of data to understand and modify the approach. For example, using the formative approach of the Model for Improvement (described below), we would develop a patient discharge form together with practitioners and patients which is then trialed and reviewed after being implemented on one unit with a few patients. The information from this trial is then used to improve the processes related to the implementation and then trialed again. This cycle would continue until it has been refined and reaches a stable state that is achieving the desired improvements. This constant use of data helps to direct the next steps, all with the goal of enhancing the processes to affect the outcomes. These **formative evaluation** features, in theory, would help to support more effective and successful implementation of health innovations (Elwy et al., 2020), given the ongoing attention and iterative approach to improvement.

Summative frameworks, on the other hand, are those that allow for evaluation at the end of an implementation. This **summative evaluation** allows one to understand if something did or did not work at the end of a specified time or the end of the implementation. Often the focus is to examine the impact or efficacy of a program once it is in a stable condition. If you are a student, one example of this is the end-of-term course evaluation that you fill out. In a health setting, this could come in the form of an evaluation of data related to smoking rates after the implementation of the Smoke-Free Ontario Act, which prohibits smoking and vaping in enclosed workplaces in Ontario (Public Health Sudbury, 2021). Reviewing data on how this helps to reduce smoking rates would be an example of a **summative evaluation**.

Both approaches are important. They are not mutually exclusive. For example, there were numerous changes to processes, because of **formative evaluations**, to the roll-out and implementation of strategies to help organizations align to the Smoke-Free Ontario Act (e.g., improving awareness campaigns, enhancing signage, etc.), with the **summative evaluation** being smoking reduction. That said, relying only on one is not ideal. Simply evaluating a project in the end can be a waste of resources and effort if within a week or month the intervention is simply just not working. Why wait for the program funding at the end of 6 months to make changes? Having a formative mindset is important at the outset of a program, service, or policy creation to ensure that things are working throughout.

There are numerous **formative** and **summative framework**s that have been developed and described in the literature and mainstream reading to support this complex notion of making change. As the purpose of this book is to provide a foundational understanding of the use of evidence to drive health sector improvements, we have summarized some of the main frameworks and approaches that we have encountered in practice and in the literature. Next, we provide you with an overarching understanding of guiding frameworks, including the Consolidated Framework for Implementation Research (CFIR) and the Practical, Robust Implementation and Sustainability Model (PRISM). These are two commonly used frameworks that outline factors to think about before, during, and after implementing a change.

Guiding Frameworks

Consolidated Framework for Implementation Research (CFIR)

When looking to implement novel changes into any organization, including health care, it is important to truly understand the **context** in which these changes will be made. The CFIR is a conceptual framework based on previous literature that has identified aspects that influence the implementation of interventions. This framework can be used by individuals to assess potential issues so that mitigating strategies can be developed, used as a framework to assess current barriers within implementation or to evaluate the contextual reasons for successes or failures in a particular intervention.

From an **implementation science** lens, this framework can be used to study and understand common factors that influence uptake and adoption of the interventions to help further the science while organizations can examine their own **context** and data to understand how to foster quality improvement.

The CFIR includes five broad categories that are said to influence implementation (CFIR, 2022). These include:

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Now that is a long list! It is important to consider these five domains at any level of implementation.

Deeper Dive

- Check out the CFIR website to see how each of these domains is defined. This website provides an overview of the foundational work that was used to create the CFIR, together with definitions, recent articles, and tools and templates: https://cfirguide.org/constructs/

Using the CFIR allows an organization to think about the factors that are influencing their change efforts and subsequently address these factors through change strategies.

This video interview below provides a great overview of the CFIR from Laura Damschroder, one of the authors of the framework. She outlines what **implementation science** is in relation to quality improvement as well.

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An example of where the CFIR has been used in a way to support rapid-cycle evaluation for improvement is found in an article by Keith et al. (2017). Keith and colleagues incorporated the CFIR into the launch of a Comprehensive Primary Care initiative in the United States, which was a four-year program with the goal of strengthening primary care to improve health, lower costs, and enhance the patient and provider experience. The project team interviewed core personnel and asked about their experiences of how components of Comprehensive Primary Care were operationalized in practice, as well as challenges and support for implementation. They also engaged in direct observations with a checklist that was based on the five CFIR domains. This was a large-scale change project spanning multiple years and areas in the United States, and the CFIR was effective at supporting the identification of areas for improvement, making refinements, and sharing this information across sites to enhance learning.

Formative Evaluation

Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) Framework

RE-AIM is the acronym for Reach, Effectiveness, Adoption, Implementation, and Maintenance. As one of the most widely used implementation frameworks (Glasglow et al., 2019), the RE-AIM framework has a long-standing 20-year history in healthcare and health promotion. The framework was first published in 1999 by the American Journal of Public Health, reflecting the importance placed on understanding issues related to implementation and the lack of adoption of effective interventions by organizations (Gaglio et al., 2013). The framework was initially developed to understand the internal and external validity of interventions and programs with a more summative type of approach. The RE-AIM framework is somewhat like the CFIR in that it can be used to evaluate an existing program, or in the planning stages of an intervention, to highlight aspects that should be considered. Authors have suggested that it should be considered for a more iterative application to support the work done at the implementation phases of an intervention (Glasglow et al., 2019).

Below is an overview of each of the dimensions of the RE-AIM framework:

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The video below of Dr. Russ Glasgow provides an overview of the history and the next steps of the RE-AIM framework:

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Examples of the use of the RE-AIM framework can be found throughout the literature and with even a quick Google search! One recent paper describes the summative use of RE-AIM to evaluate a collaborative care intervention to treat primary care patients with comorbid obesity and depression (Lewis et al., 2021). This project incorporated qualitative interviews at various time points of the project with core stakeholders, which were then compared back to the dimensions of the RE-AIM framework to identify the programs' translational potential for public health impact in future implementations. Using RE-AIM, the project leads identified the importance of more flexible scheduling and the need for more diverse and broad recruitment in the clinical setting (Reach), a need to tailor the program components (Effectiveness), the importance of focusing on creating buy-in across the clinical settings to enhance uptake (Adoption), the need to map workflow and align communications (Implementation), and the need to address concerns about cost-effectiveness (Maintenance). The authors anticipated that by addressing these areas for improvements, the program would achieve its intended health outcomes for patients.

Practical, Robust Implementation and Sustainability Model (PRISM)

PRISM is yet another model that helps to support thinking related to moving research to practice. This framework allows for the understanding of the impact of internal (organizational characteristics) and external (influences on the implementation of a change with consideration of these aspects at various times throughout the implementation. As outlined by McCreight et al. (2019), this framework has a multi-level lens that combines the Diffusion of Innovation, the Model for Improvement, and the RE-AIM framework. The extension of this theory is that it emphasizes fit within the **context** and understanding of strategy and outcomes and their importance to implementation and sustainability. McCreight et al. (2019) have provided an excellent overview of this model and a figure that describes the interacting layers of the intervention, recipients of the change, and the internal environment – all with a lens on how this interacts to support the achievement of outcomes with the RE-AIM framework.

Model for Improvement

Check out the video below from the Institute for Healthcare Improvement (IHI) about quality improvement in health care:

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The Model for Improvement is a quality improvement model developed in 1996 by Associates in Process Improvement following the work of Joseph Juran, W.E. Demming, and Philip Crosby (Courtland et al., 2009). The model is a method that can be implemented effectively across organizations regardless of size and is centered on producing results that are measurable and specific (Courtland et al., 2009). The Model for Improvement includes three core questions and a change cycle that are used together with measurement tools and processes to enact change (IHI, 2022a). The focus of this model is formative and is to be used iteratively to effect change during implementation.

The model for improvement asks the following questions, which provide direction and focus for the improvement effort (IHI, 2022a; Boland, 2020):

1. What do we want to accomplish?

2. How do we know that a change is an improvement?
3. What change can we make that will result in improvement?

The first question, “What do we want to accomplish?”, is addressed by creating an aim statement. This is a statement that outlines the expected outcomes of the change effort. It should be time specific, measurable, and define the population or system that will be impacted (IHI, 2022a; Boland, 2020).

The second question, “How do we know that a change is an improvement?”, is addressed by defining the measures to be used for the change effort. Outcome, process, and balancing measures are commonly used to quantify change in the Model for Improvement. Outcome measures reflect the expected outcome(s) and should reflect how the system impacts users (e.g., patients, staff, stakeholders, community members) (IHI, 2022a; Boland, 2020). Process measures reflect the actions being taken to bring about change. They should address the functioning of various parts of the system being changed – if they are performing as planned and if changes are occurring according to schedule (IHI, 2022a; Boland, 2020). Finally, balancing measures reflect the potential impact of the change effort on other parts of the system. They should address potential problems being caused in other parts of the system as a result of the change effort (e.g., inefficiencies, increased workload or strain, patient outcomes, etc.) (IHI, 2022a; Boland, 2020). Data from each of these measures should be plotted over time on a **run chart**, thereby allowing the team to visualize the pattern of change (IHI, 2017).

The third question, “What change can we make that will result in improvement?”, is addressed by implementing small-scale change concepts. Change concepts are general approaches to change that are specific, actionable, and testable. Commonly used change concepts in a healthcare setting include improving workflow, managing time, changing the work environment, error proofing, and eliminating waste (IHI, 2022a; Boland, 2020). Change ideas can be identified through current research, best practices, or expertise within the team.

CASE STUDY: Tracking Improvements in Hospital Acquired Infection Rates Over Time

Photo by JC Gellidon on Unsplash

A team of quality improvement specialists at a local hospital is tasked with reducing the rates of hospital-acquired infection and determined that the best way to do this would be to examine and influencing handwashing behaviors. After forming a team, defining the expected outcomes of the change effort (increased observed hand washing and decreased infection), and developing a plan for change, the team implemented two small-scale changes. First, posters were created to encourage frequent hand washing and placed in high-traffic areas within the target hospital unit (Change 1). Initially, this change resulted in improvement in hand washing and infection rates decreasing over time, but as the team continued to measure infection rates, a plateau was observed. Following this, a second change was implemented, whereby the team used a targeted communications with unit champions through staff huddles and shift change overs (Change 2). The effects of this change on infection rates were tracked over time. Each plot point on the **run chart** represents data related to the change effort at a specific point in time. Annotations are used to indicate when change efforts were initiated as well as to make note of any external factors that may have affected the change.

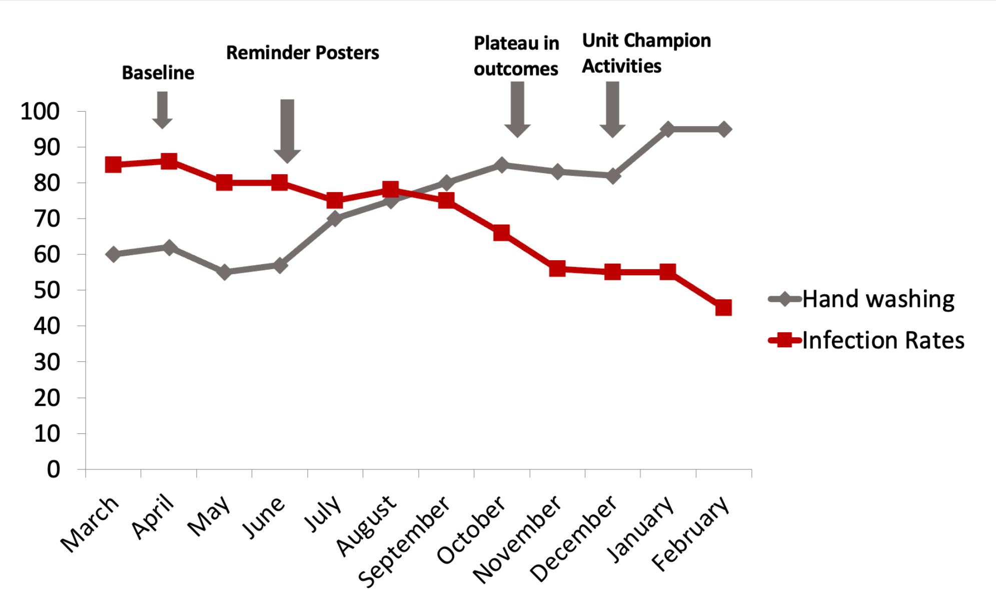

Figure 3.1 *Run Chart. Source: Dr. Madelyn P. Law*

Deeper Dive

- For more information about run charts, check out this website: [A-guide-to-creating-and-interpreting-run-and-control-charts.pdf (england.nhs.uk)]

The Model for Improvement Change Cycle is a six-phase iterative process. The "Getting Started" phase involves a team being brought together, identifying areas for improvement, and defining how success will be measured and sustained throughout the process. "Defining the Problem" is the phase in which current processes and underlying problems are clarified. Tools such as the **fishbone diagram** can be used to identify specific areas for improvement and identify target outcomes. "Understanding Your System" is the phase in which data related to the improvement effort is collected and analyzed. This stage allows for a better understanding of how the system is performing and may further highlight opportunities for improvement. “Designing and Testing Solutions” is an action phase in which change efforts are enacted on a small-scale using **Plan Do Study Act (PDSA) cycles**. “Implementing and Sustaining Changes”, as the name suggests, is concerned with the long-term uptake and maintenance of a change effort. This phase occurs when the change effort is integrated into daily practice or workflows. Finally, “Spreading Change” involves expanding the change effort between systems, departments, or organizations.

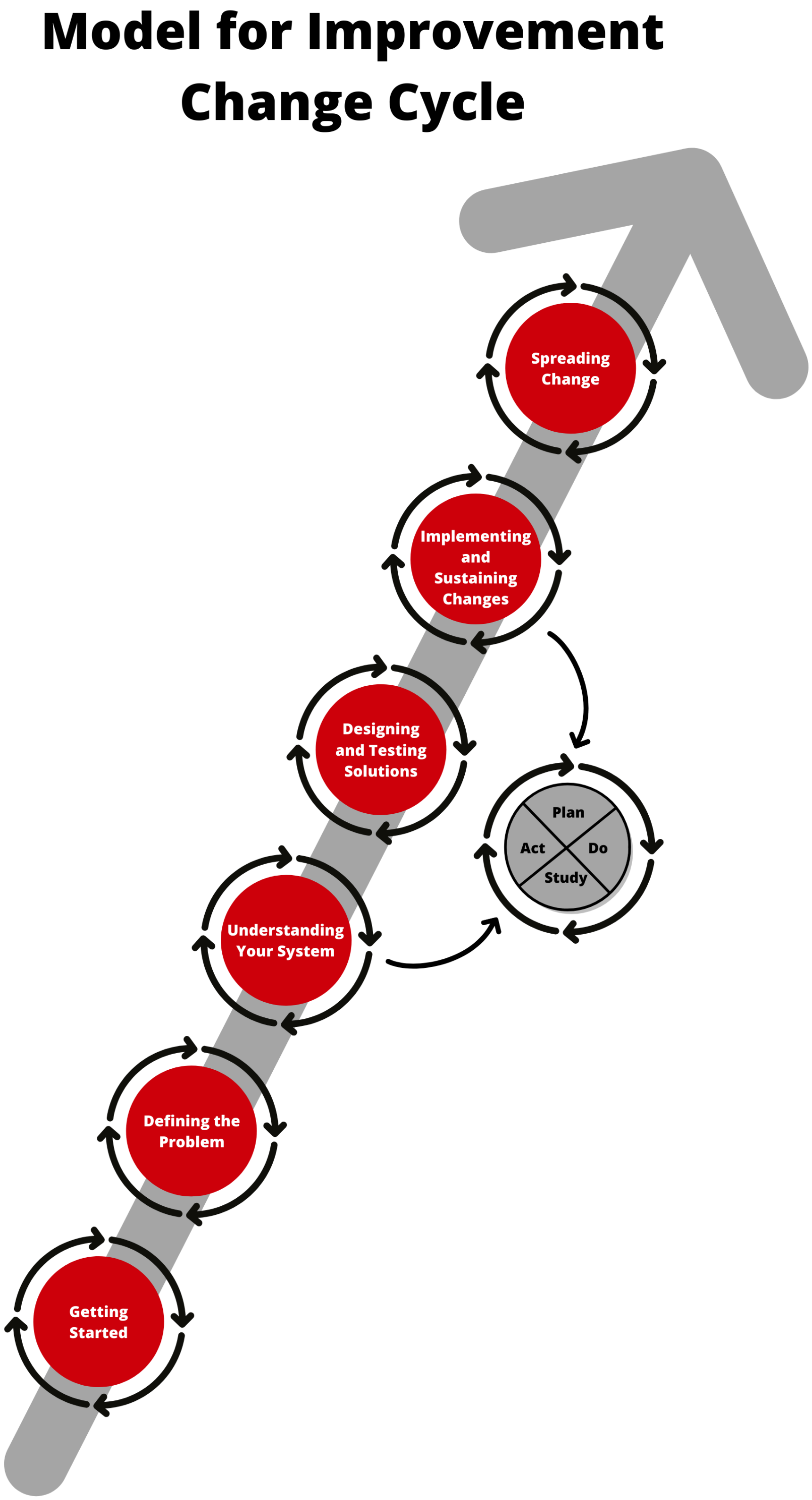

Figure 3.2 *The Model for Improvement Change Cycle. Source: Caitlin Muhl*

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The Model for Improvement Change Cycle relies on **PDSA cycles** to inform changes in real-time to ensure that the aims of the work are being achieved. This continuous cycle of focusing on the **PDSA** work ensures that the change is optimized after improvements are made before looking to spread the change more broadly.

The **PDSA cycle** is a four-stage rapid cycle used to test a change effort. In the Plan phase, the team should clearly outline the objective of the test (using an aim statement is beneficial), make predictions about the outcome, create a plan to test the change, and determine the data that will be collected (IHI, 2022b). In the Do phase, the team will carry out the test on a small scale – this is important as it is unwise to implement a large-scale change without understanding how it will impact the system (remember the balancing measures!). Documenting observations about the process and beginning to analyze data are key components of the Do phase. In the Study phase, the team will complete **data analysis**, compare their expected outcomes with the observed outcomes, and outline what was learned from their attempt(s) to implement the change (IHI, 2022b). Finally, in the Act phase, the team will modify the change based on what was learned. A single change effort often goes through numerous **PDSA cycles** to refine the change being made before applying it on a larger scale.

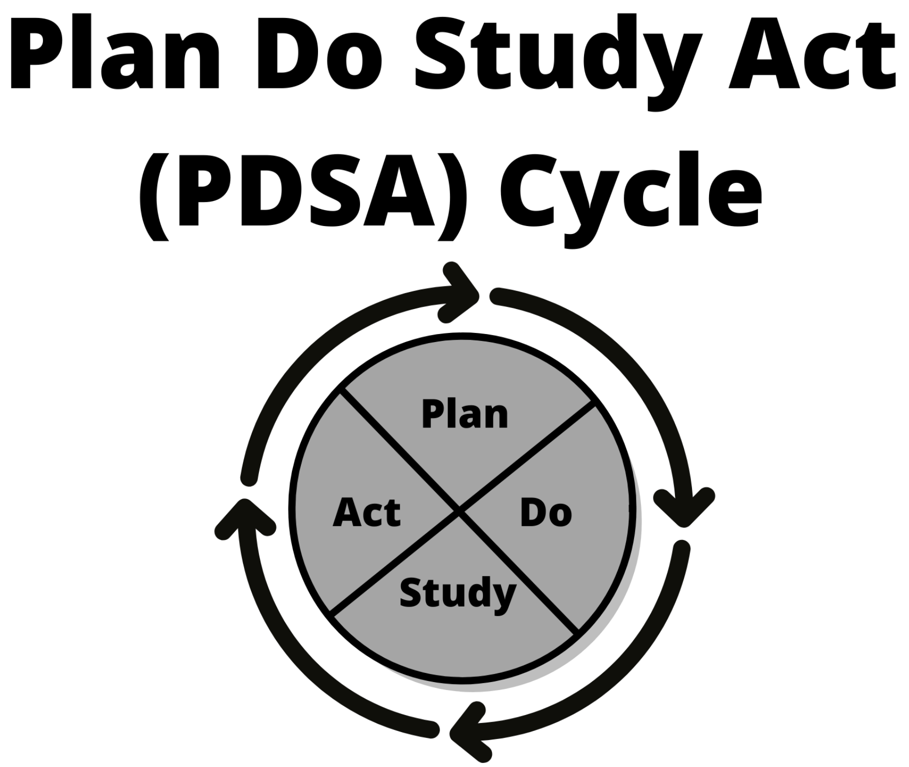

Figure 3.3 *The Plan Do Study Act (PDSA) Cycle. Source: Caitlin Muhl*

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Define, Measure, Analyze, Improve, Control (DMAIC)

DMAIC is a process improvement methodology that was developed out of the **Six Sigma** approach to quality improvement. **Six Sigma** is a statistical approach to process improvement that is focused on finding the root cause of the variation in a process when the variation is outside what would be considered normal. The name **Six Sigma** gives you a hint as to what is considered “atypical variation”: anything more than three standard deviations from the mean. If you’re thinking “this sounds technical”, you would be correct! **Six Sigma**, and for our purposes here, DMAIC, are highly structured and rigorous improvement processes that require both statistical knowledge and accessible, timely, and reliable data. Each letter in the acronym outlines a step in the five-phase improvement process and is associated with specific tools to facilitate improvement. Consult Table 3.1 to learn about the steps and improvement tools that are central to the DMAIC methodology (American Society for Quality, 2022b).

Table 3.1 DMAIC Phases, Definitions, and Tools

Phase	**Definition**	**Tools**
Define	Define the problem, opportunity for improvement, improvement effort, and specific goals of the project.	• Project charter
Measure	Measure the current process and identify measures necessary for the improvement effort.	• Process map • Pareto chart
Analyze	Determine the root causes of non-optimal performance or defects in the process.	Activities • Root cause analysis • Failure mode and effects analysis
Improve	Eliminate or minimize the root causes identified in previous steps and introduce adjustments to improve the process.	Activity • Kaizen event
Control	Manage the newly improved process to sustain performance.	• Mistake proofing

Improving patient flow and efficient access to care is a challenge faced by many Canadian healthcare organizations. While the solutions are immensely complex in nature, especially for patients needing an inpatient bed, for patients who never get admitted to hospital, perhaps there are opportunities to take a systematic approach to making their emergency department visits more efficient. One of the contributors to a longer emergency department visit is the time a patient may spend waiting for a diagnostic test such as a **computerized tomography (CT) scan**. This can help determine the plan of care.

If we use DMAIC as our guide, to define the opportunity, we might say our goal is to reduce the turnaround time for a **CT scan** for non-admitted emergency department patients. We may create a project charter identifying key stakeholders, including physicians, nurses, managers, medical imaging technologists, patients, and families. In this charter, we could also take the time to define some of the nuances to our focus by specifying a type of CT scan (e.g., non-head CT scans only), how frequently we will measure (e.g., weekly), what the specific outcome measure will be (e.g., time from CT scan ordered to CT scan taken), what type of measure we will use (e.g., 90th percentile), and whether we need to divide our measure based on known differences in the **context** that will knowingly cause atypical variation (e.g., day shift, evening shift, night shift due to different staffing models).

When our interdisciplinary team that is outlined in our project charter has defined some of these specifics, we are ready to go ahead and measure our indicator, plotting it on a control chart that gives us a visual representation of our variation and helps to identify a realistic goal to work toward. By using a control chart, we are also setting up the process of monitoring both improvements and the control process as we work towards our goal.

In the analyze phase, we have multiple options for tools to support us in identifying the contributors to our variation. Using a root cause analysis would help us to uncover if there is a delay in turnaround time because requisitions are not always fully completed before sending them to the medical imagining team. In this case, the requisition gets sent back to the ordering healthcare professional to be revised and then sent back to medical imaging. As you might have guessed, in a busy emergency department, someone might not always be readily available to make changes to their paperwork, which can lead to notable delays.

In the improvement phase, the interdisciplinary team has the task of determining what actions could be taken to ameliorate some or all the “defects” in the process that were identified in the analyze phase. In this case, we might look to adjust the requisition form to make it easier to complete the necessary components, or in the case of electronic forms, we could institute mandatory fields that would prevent the requisition from being sent until the fields are complete.

The final phase is to control, which is the monitoring phase. Once our improvement(s) have been implemented and identified as effective in achieving our outcome (i.e., reducing turnaround times), we would then monitor our outcome indicator regularly to ensure the change is sustained. Some variation is expected but our control chart will signal to us when the variation is no longer in an expected range. This can indicate that our intervention or change is no longer working or may be a symptom of a new contextual factor that has influenced the process.

Realist Evaluation

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Within the **context** of **implementation science**, we can consider applying process evaluation methods, **formative evaluation** methods, or **summative evaluation** methods. There is however another perspective that researchers and evaluators can consider, and it has relevance in the **context** of healthcare: the **realist evaluation**, which can be applied both in the **contexts** of the formative and **summative evaluations**.

Pawson and Tilley (2004) describe the realist evaluation as an approach that considers what works for whom, in what circumstances, in what respects, and how? In essence, the realist evaluation approach contributes to our understanding of the contextual factors impacting the success of an intervention. Salter and Kothari (2014) specifically note that the realist evaluation is best described as a “logic of inquiry” rather than a method or evaluation technique. In healthcare, when we so often focus on removing all confounding variables, including the participant variability from the equation when testing evaluations, the realist evaluation adds to the literature on **implementation science** by urging us to acknowledge, embrace, and measure the disruption of an intervention. This can make it challenging for some to embrace or a breath of fresh air in terms of approaches to understanding complex interventions. We'll use an example of implementing a **medication reconciliation** process in an acute care organization to depict approaches to a realist evaluation.

The starting point of the realist evaluation approach is the theoretical foundation on which the program or intervention being evaluated has been based. This is a common starting point among many types of formal program evaluations and the distinctive feature of the realist evaluation method at this phase is the act of refining program hypotheses using interviews with practitioners about successes and failures of the program or intervention to begin uncovering more contextual hypotheses about what works, for whom, and when (Pawson & Tilley, 2004). Taking a realist evaluation approach to the implementation of a **medication reconciliation** process, we would use our intuition to assume that the theory behind the program is that by systematizing the way in which home medications are documented in hospital, we reduce the potential for adverse drug events. We would also interview stakeholders from Safer Healthcare Now! or Accreditation Canada to understand the theoretical bases for the program.

Once you have an understanding of the theory driving your program or practice change, it is important to understand all the activities contributing to your intervention and how they link together. When you detail the activities and links, you will start to be able to conceptualize your evaluation questions based on the hypotheses of how the program works in its ideal state. In our example, the activities associated with the intervention of **medication reconciliation** are numerous, however, we include a couple of them here: developing the standardized home medication documentation form (Best Possible Medication History), educating staff on the roles of the interprofessional team in the process and aligning practice changes with external partners, such as home and community care who will support the final transition phase home. The activities all connect through key linkages such as documentation, education, communication, practice change, and finally, outcomes.

The realist evaluation then moves to a data collection phase, where the multiple hypotheses uncovered and the plethora of evaluation questions linked to your activities begin to be tested. Quantitative and qualitative measures are both used. When data has been collected, the researcher or evaluator must then systematically test the initial group of hypotheses, testing various combinations of hypotheses in order to help find patterns that determine successes and failures. This can be an in-depth process when there are multiple activities and evaluation questions to answer regarding the effectiveness of your intervention. In our example, let's take one specific activity in the intervention and break it down: If we ask, "is the completion of the best possible medication history on admission to hospital being accurately completed"? To answer just this question, we have several secondary questions linked to it, including: Were more than two sources of information used to determine the medication list?; Was the patient consulted to verify medications (as possible)?; Were dose, strength, and frequency documented for all medications on the list?; Was the list documented accurately (e.g., no missing medications, no duplicate medications, current medications only)? This data might be collected via an audit and tells us a great deal about whether we need to modify the approaches to implementing this aspect of the intervention.

The final stage of the realist evaluation is cyclical as the analysis is interpreted and the hypotheses about mechanisms of program or intervention functioning are assessed and revised. The cyclical nature allows continued revision of hypotheses to understand the complex interplay of factors including **context**, individuals, and processes, all of which are seen to influence the intended outcome (Pawson & Tilley, 2004).

As you can see, the realist evaluation requires many considerations, however, the complex nature of healthcare interventions may warrant approaches like this which offer opportunities to appreciate and adjust for the complex environment and how it interacts with our complex interventions rather than simply trying to control for the inherent messiness!

Summary

You are the practitioner or the researcher and now you are wondering…which of these frameworks and approaches should I consider!? The answer is – it depends! If you are looking to evaluate an existing program or service that you did not create but are tasked with understanding if it is effective – then you can apply a CFIR lens, the RE-AIM framework, or conduct a realist evaluation. If you would like to implement a new change based on new evidence or make an improvement to an existing service or program, then perhaps starting with an analysis of the

context with the CFIR followed by the implementation strategies and tools set out by the Model for Improvement would be ideal next steps. The point here is that the framework you choose will depend on your situation, question, and requirements for actions. We hope this has provided you with a set of frameworks that resonate with you and a toolkit of information that will enable you to make sure that data can be realized in practice and not simply sit on a shelf for another 17 years.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Deeper Dive

- For more about CFIR: https://cfirguide.org/
- For more about Six Sigma: https://asq.org/quality-resources/six-sigma
- For more about the RE-AIM framework: https://www.nccmt.ca/knowledge-repositories/search/70
- The following website provides practical and user-friendly information about RE-AIM and PRISM. There is a guide for step-by-step use: https://re-aim.org/
- For more about the Model for Improvement: How-to-Design-Implement-a-QI-Project.pdf (pedsanesthesia.org)

Section 3: Factors Influencing Change Efforts

DR. MADELYN P. LAW; DR. ELAINA ORLANDO; AND LIDIA MATEUS

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Section Overview

This section will highlight several core concepts at the **micro**, **meso**, and **macro-level** that influence change efforts. Moving from the previous section focused on frameworks supporting implementation, this section helps to understand the dynamics between individuals and their organizational environment and how that influences the ability to use data to foster change in the health sector.

Section Objectives

By the end of this section, you will be able to:

- **Define and understand micro, meso, and macro-level factors that influence change;**
- **Critically reflect on examples of micro, meso, and macro-level factors in relation to the concepts; and**
- **Synthesize the information across these levels to explain why change succeeds or fails.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Introduction

Without question, there are numerous **change management** models and theories available. The video below is from Kotter's 8 Step Change Management Model. We present this model here to start out the section as a broad framework of steps that gives consideration to **micro**, **meso**, and **macro levels**. Kotter's model is one of the most widely used, likely because it is easy to understand, makes intuitive sense, and has demonstrated great utility in organizations.

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In terms of thinking about this model in relation to supporting individuals' and organizations' use of data to drive their decisions, this can be seen in many of the steps. For example, using data to create a sense of urgency for the change is essential. Highlighting what is wrong with the current system, using data and evidence, will help individuals identify what needs to be modified and feel confident in the impeding change. Having a clear vision for a change that has an evidence-informed goal with measurable outcomes will allow for a clear vision of change. Using data to demonstrate short-term wins will help to reinforce behaviors and the desired change. The use of data in this approach is twofold: you may want to see new evidence-informed practices become integrated within an organization and Kotter's model provides **change management** steps to achieve this. We can use data throughout the process of change to help individuals buy-in to the change and succeed in making this part of the way they work in the future.

Micro-Level Change

Micro-level factors are those that are at the individual level. Change at an individual level equates and rolls up to a larger **meso level** change seen in an organization. Organizations use numerous tactics to influence, persuade, and accept change but, to do so it is important to understand what types of factors may impede or support the individual behaviors that one is trying to achieve. This is particularly important to consider when thinking about how we get individuals to use data to drive decision-making. What are those individual factors that play a role in why an individual may choose to use data?

Educational Background


Photo by Janko Ferlič on Unsplash

Using data in decision-making is not an inherent skill nor is it something that is taught explicitly in all educational programs. As educators and academics, we do ask students to use research and evidence in authoring their papers and other types of assignments. However, if students have not had the chance to engage in cases or experiential opportunities that allow for critically reviewing and using data to analyze a problem and provide recommendations and future steps – then this skill has not been realized before entering a profession. In the health field, this skill is vitally important. Having an educational program that promotes the use of data and is also explicit in identifying and discussing the topics (such as those in this book!) will in turn support individual skills, knowledge, and attitudes towards the importance of using data to drive decisions.

Psychological Safety

You may be wondering how **psychological safety** relates to the frameworks, tools, and measurements of **implementation science**. At the individual level, **psychological safety** is extremely important in creating a working environment that fosters the development and adoption of innovation, which are key to the central purpose of **implementation science** (Edmondson et al., 2016; Wang et al., 2018). A variety of factors impact **psychological safety** within and across organizations including leadership styles, **organizational culture**, social support, recognition, and psychological demands on employees, among others. While it is outside the scope of this chapter to discuss each of these many factors, the section that follows will give you an understanding of how to develop **psychological safety** within a team and how this impacts performance.

Psychological safety can be defined as being able to communicate concerns, express questions, provide ideas, or admit mistakes without fear of negative consequences such as punishment, humiliation, or damage to career or status (Javed et al.,2017). It is recognized as being critical to helping people learn new behaviours and enact change in complex and high-stakes **contexts** (e.g., modifying workflow processes, implementation of best practices, adopting change in emergency departments, etc.) (Javed et al.,2017). Creating a psychologically safe work environment begins with those in leadership positions (Javed et al.,2017). One strategy is to create opportunities for dialogue and reduce barriers that exist by providing formal and informal opportunities for feedback, allowing staff to provide anonymous feedback, and having open meetings for employees across organizational levels (Grailey et al., 2021). Another is for leaders to model openness and fallibility to their team members by being transparent about errors and near-misses (Grailey et al., 2021). Leaders can also develop policies and share human resources information that promotes civility and accountability among employees (Grailey et al., 2021). Even actions as simple as using supportive language, learning the names of team members, and recognizing accomplishments during meetings can improve **psychological safety** within an organization (Grailey et al., 2021).

Organizations with elevated levels of **psychological safety** are positively correlated with knowledge sharing, creative performance, technical performance-extending to patient outcomes in healthcare settings, and continuous quality improvement efforts among employees (Javed et al.2017; Grailey et al, 2021). Leaders can shape employees' perceptions of the **organizational culture** and **context** in a way that directly impacts their **psychological safety**. When leaders use their influence to create an open, inclusive, and communicative environment, they directly facilitate employee innovative work behaviour and learning. Creating psychologically safe environments is key to encouraging employees to partake in **implementation science** and related improvement activities.

Grief Cycle and Individual Response to Change

The Kubler-Ross Grief Cycle has been used to help understand resistance to change and the stages that individuals must go through before there is acceptance of a new change. When asked to change, there is an associated loss to an individual and they must, therefore, grieve that loss. Individuals will go through the stages of grief at different rates. Some will move quickly, others may take some time to process and move forward, and others yet might never be able to let go of the existing practice that is being changed. In the Kubler-Ross Grief Cycle, there are five stages that an individual progresses through that are outlined in the figure below:

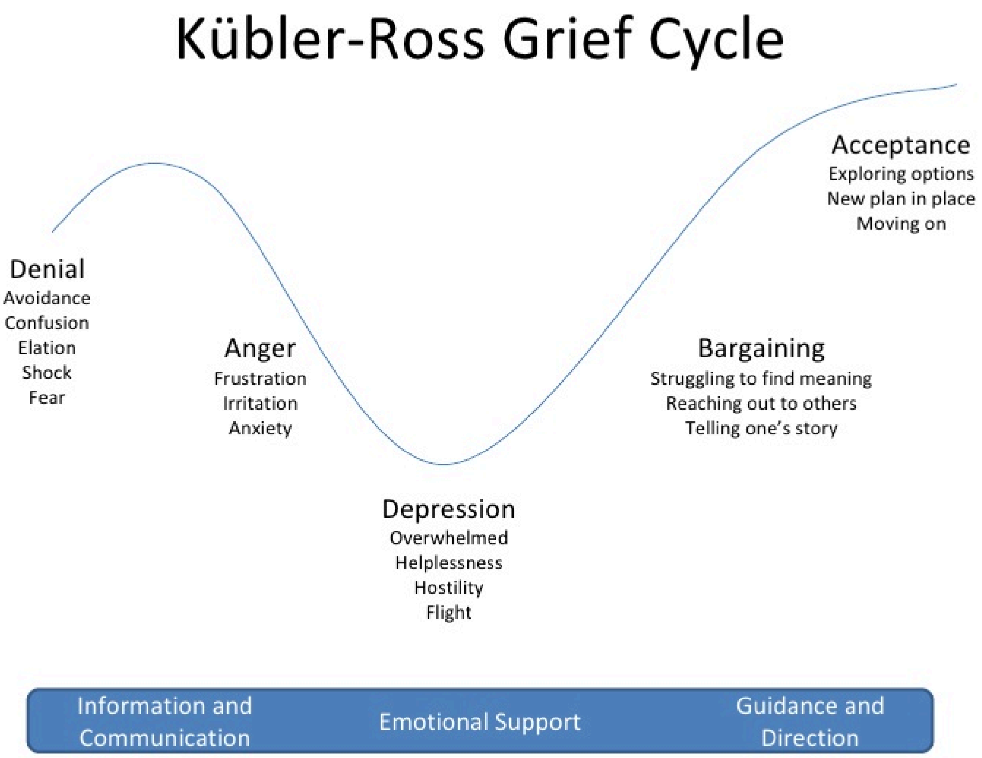

Figure 3.4
The Kubler-Ross Grief Cycle. Source: Illustration by U3173699 on Wikimedia Commons is licensed under CC BY-SA

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Meso Level

Meso-level factors are those that are at an institutional level. For example, thinking about an organization-wide change to a new electronic medical record system given that the evidence demonstrates that the new system will enhance efficiencies and reduce medical errors. All individuals in an organization will collectively have to move to a new system – but there are numerous organizational-level factors that will impact the success of this type of change including readiness, **organizational culture**, teamwork, leadership, and diffusion of innovation.

Organizational Readiness for Change

Above we discussed the concept of individual readiness – which in turn, dictates the **organizational readiness for change**. Weiner (2009) define **organizational readiness for change** as "a shared psychological state in which organizational members feel committed to implementing an organizational change and confident in their collective abilities to do so." (p. 6). In this definition, there are two key factors that are of importance: "committed" and "confident". As outlined by Weiner (2009), to be confident in moving forward with the change, individuals must feel like the organization has the supports in place for them to be successful. More recently, Shea et al. (2014) describe **organizational readiness** as "'the extent to which organizational members are psychologically and behaviorally prepared to implement organizational change". Implementing organizational changes is a complex and multi-layered process and any large-scale change requires "collective action by many people, each of whom contributes something to the implementation effort." (Weiner, 2009, p. 2). When people feel committed and confident in a change, their readiness to change is high and they are more likely to engage in change efforts.

The following figure from Weiner (2009) provides an overview of the theory of **organizational readiness for change**. The figure outlines possible contextual factors, including **organizational culture**, policies and procedures, past experience, organizational resources, and organizational structure, and how these flow to the concept of change valence (i.e., how much individuals value the change) and informational assessments (i.e., task demands, resource perceptions, and situational factors). Together, these aspects form the change commitment and change efficacy, which corresponds to **organizational readiness for change**. This leads to change-related effort, including initiation, persistence, and cooperative behaviour, which ultimately leads to implementation effectiveness.

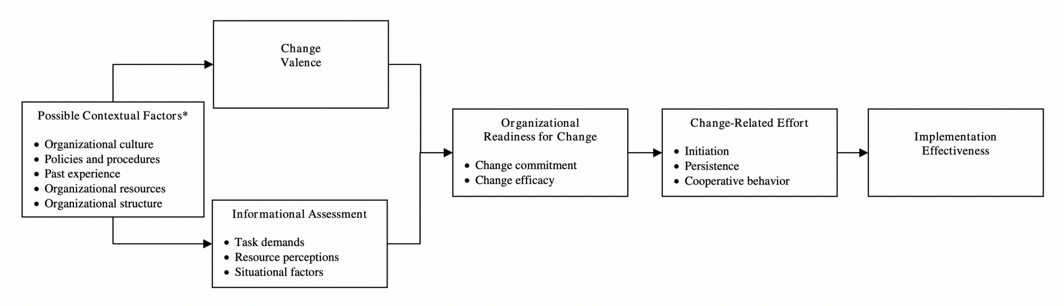

Figure 3.5 *Determinants and Outcomes of Organizational Readiness for Change. Source: Illustration by [Weiner (2009)](#) is licensed under [CC BY](#)*

Thinking through this concept in relation to using data to drive change is interesting and multi-faceted. An organization that values and uses data to drive decisions would want to make sure they leverage the data messaging through core communications for a pending organizational change. Using statistics and new research to communicate the urgency of change to organizational members would in turn help to develop change valence and encourage commitment and confidence in the change.

One example of this is the COVID-19 pandemic response in public health units in terms of holding pop-up vaccine clinics. Fears circulated about no one showing up and clinics not being in the right place that was accessible to all. The change in the model of delivery from static clinics to drop-in pop-ups was a major operational shift requiring workflow changes and major organizational reconfigurations. Public health units were able to leverage existing vaccine rate data, together with numerous social determinants of health and mobility data, to make the case for specific locations which would help to support location decisions. This resulted in being able to gather commitment from staff and confidence in the fact that the effort to shift to this mode of delivery was the right one to serve those populations most at risk with low vaccine rates.

Organizational Supports

Aligned with this notion of an **organizational culture** that values the use of data in driving decisions, it is also essential that there are organizational supports and resources that will enable this to be realized in practice. Having a division that is dedicated to proactively reviewing data and providing this information in real-time to those decision-makers helps to encourage and support the use of data in decision-making. This must also be backed up with the proper training and methods (e.g., dashboards, reporting schedules, relationships) that would enable the use of data. For example, in a public health unit, a dedicated team of epidemiologists, program evaluation specialists, and quality improvement facilitators who are part of a program delivery team would have the role of creating excellent data collection tools, reporting, and **knowledge mobilization** methods that would support the entire project team in the success of their work. An organization that invests in supports for **evidence-based decision-making** will in turn, support a culture of evidence-informed decision-making.

Teamwork

Photo by Dylan Gillis on Unsplash

A **team** is a group of individuals with interdependent tasks and a shared responsibility of outcomes (Cohen & Bailey, 1997). A strong team shares a common goal, possesses its own set of norms, and can be open and trusting with each other. Strong teams are vital in healthcare as they can positively impact patient outcomes (Baggs et al., 1999), lead to higher quality and safer care, and improve work satisfaction for staff (Rosenstein & O'Daniel, 2008). There are four key team processes: communication and collaboration, leadership, decision making, and conflict. It is important to recognize that the **context** in which a team works can have direct impacts on its performance, cohesion, and effectiveness. This can contribute positively or negatively toward effective team dynamics. When there is a positive dynamic and cohesive team, this can be an immense competitive advantage for an organization (Lencioni, 2002).

There are five stages of team development as identified and researched in 1965 by Bruce Tuckman, which continue to hold true today. The five stages of team development remains one of the most used frameworks for understanding how teams function. Stage 1 is called "Forming". This stage is characterized by relationships being established among team members, wherein communication is guarded, and individuals are on their best behaviour. In Stage 2, "Storming", the team has developed a level of comfort with each other that enables the free expression of one's personal views and agendas. This can generate stress among the team and conflict may arise. Stage 3, "Norming", sees the team transition to a more cooperative form of working together. The energy of individuals tends to be focused on team goals and productivity as well as effectively resolving conflicts. By Stage 4, the team begins "Performing" and starts to see the output of a strong team. There is a high level of cooperation, shared leadership, and facilitation among the group and a collective celebration of progress. The final stage in the model, Stage 5, is "Adjourning" or the cease-function(ing) of the team. The end of the team may be a result of changing organizational structures or when a project has been completed. This stage is characterized by team members experiencing different feelings including anxiety, sadness, and satisfaction.

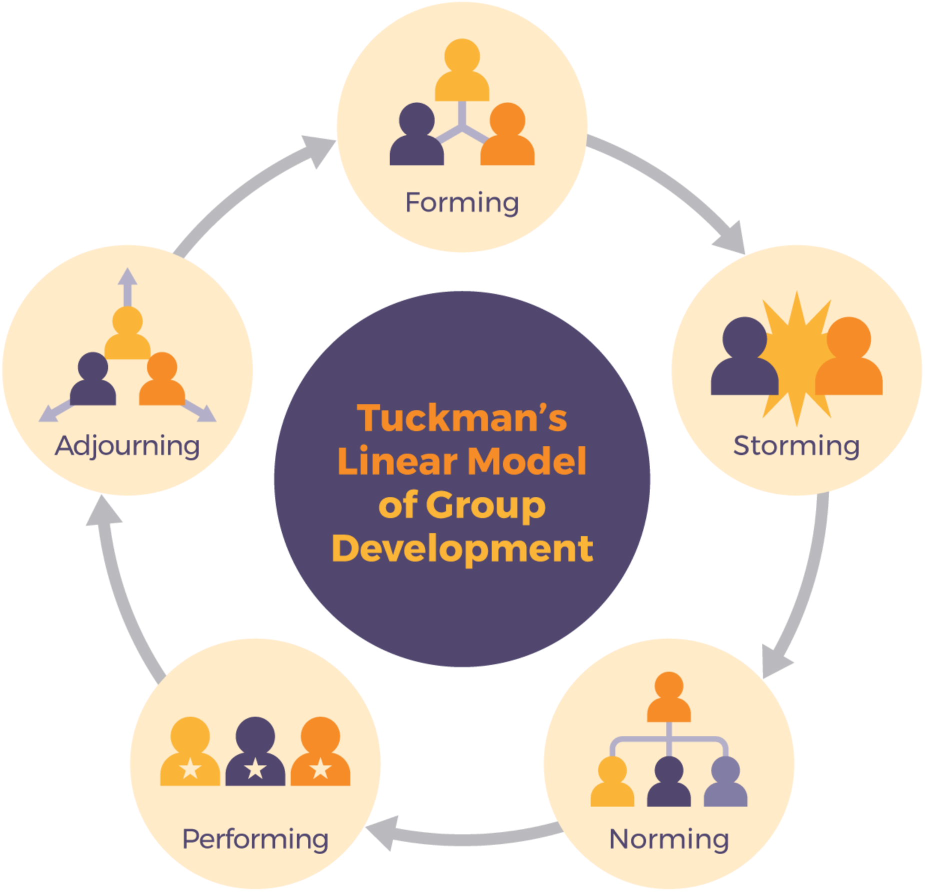

Figure 3.6 *Tuckman's Linear Model of Group Development. Source: Illustration by eCampusOntario (2018) is licensed under CC BY-SA*

In 2002, Patrick Lencioni published the model, “Five Dysfunctions of a Team” to assist organizations and leaders with understanding where they can intervene to create more highly effective teams (Lencioni, 2002). The model is intentionally structured in a pyramidal way to show that elements of team functioning, much like the team themselves, are interdependent and need to be built step-by-step on a strong base.

In his model, the foundational dysfunction of the team is an absence of trust (Lencioni, 2002). Lencioni (2002) describes the concept of vulnerability as having a definitive role in the absence or presence of trust among team members. Where trust does not exist or has difficulty flourishing, we often find team members who fear being vulnerable. Lencioni (2002) suggests that it is the leader of the team who must go first to demonstrate vulnerability and show the rest of the team members that it is acceptable to do this. According to this model, when team members demonstrate vulnerability, they can help foster trust among each other and overcome the team dysfunction of absence of trust.

The second step in the pyramid of dysfunction is the fear of conflict (Lencioni, 2002). This reflects the “Forming” stage of team development wherein members attempt to preserve the artificial harmony among the group and suppress productive conflict. According to Lencioni (2002), this is a result of the absence of trust. The ability to successfully deal with conflict is key to the progress of teams through their development. In fact, conflict can be quite beneficial to a team if they have established ways of dealing with it and have a solid foundation of trust to manage through difficult times.

Third in Lencioni’s model is lack of commitment (Lencioni, 2002). Lencioni (2002) indicates that without healthy and productive conflict among the team, there is lack of clarity regarding the plans, actions, and focus of the team. When the goals are unclear to team members, they are reluctant to consistently take action to benefit the team and are reluctant to make decisions.

The inability to commit to a clear team direction and take actions can generate an avoidance of accountability among the team (Lencioni, 2002). There can be reluctance to hold each other accountable or ask for help to perform tasks because the goal is unclear and there is a fear of conflict.

The final dysfunction is inattention to results stemming from the pursuit of individual goals above the team’s collective success (Lencioni, 2002). The act of putting personal needs, successes, and development above the team goals is a result of failing to hold one another accountable for actions and performance.

Figure 3.7 *Lencioni's Five Dysfunctions of a Team. Source: Caitlin Muhl*

Organizational Culture

Edgar Schein (2010) is one of the most notable scholars in **organizational culture**, which is defined as: “a pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration, which has worked well enough to be considered valid and therefore, to be taught to new members as the correct way to perceive, think and feel in relation to those problems.” (p.18)

There are three fundamental levels of **organizational culture**: observable artifacts, values, and basic underlying assumptions, which can be seen in the figure below. At level one, artifacts are the visible, tangible, and/or audible results of behaviour, such as the physical layout of the organization, statements, meetings, and personal protective equipment (Guldenmund, 2000). These artifacts could be statements in strategic plans that use words like “evidence informed decision” or “use of data to drive innovation”. Values are the next level of the **organizational culture**, which refers to the reason why certain observed phenomena happen the way they do. Values are the conscious, affective desires and wants (Schein, 1990; Ott, 1989). Examples of an individual who has a value focus on data would be the school public health nurse calling the epidemiologist to ask for the latest data on her school’s vaccine rates and for any current research on interventions on how to enhance vaccine uptake in a targeted age group. Behaving in a way that aligns with the stated value demonstrates an alignment of the culture. The third level of **organizational culture** is the basic underlying assumptions, defined as perceptions, thought processes, feelings, and behaviours (Schein, 1990). Basic assumptions are unconscious, relatively unspecific, and permeate the whole organization. An example would be observing a Vice President of a hospital discussing data trends for inpatient fall rates and working with directors to determine how they can use this data to drive improvements in their unit. If you asked this Vice President, “what prompted that discussion?”, they would most likely say – “because that is just the way we do things around here.” This denotes the fact that they do not consciously think about the reason they use data to drive their decision – it has just become an ingrained behaviour.

Having a culture that values the use of data in their decision-making is, arguably, the most important factor in driving change and improvement in health care. If individuals do not value the use of data to inform their behaviours, or the organization does not explicitly state and reinforce the use of data, then why would individuals use evidence to inform their decisions?

Leadership

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Over centuries, leadership thought has developed from studying military and political leaders who have inspired others to follow them toward a deeper understanding of the contextual influences on leadership and back again. In the 1940s and 1950s leadership research was focused on the identification of traits that seemed to be characteristic of successful leaders. This transitioned to a behavioural approach to leadership research that examined the impact of leadership styles on work-group performance and satisfaction. Because of the lack of success of trait and behavioural models in predicting leadership success, contingency models evolved that proposed that the type of leadership needed should depend on the situation or circumstances. In the early 80s Charismatic leadership, which focuses on inspiring others, was discussed as the complex evolving from the relationship between the leader, the followers, the **context** and the ideas. Transformational leadership became the model for leadership behaviour for almost all organizations in the last quarter of the 20th century as they sought to transform organizations in contrast to maintaining the status quo as described in the term transactional leadership.

Distributed Leadership

Although distributed leadership is not a new concept insofar that it was first described by Gibb in 1954, it has become increasingly important as it pertains to facilitating organizational change. Gibb (1954) describes **distributed leadership** as leadership that is collective in nature and extends beyond a singular individual within an organization. The importance of this style of leadership, which is not solely top-down in nature, has been reinforced in a number of studies where the notion of collective, distributed, or concentric leadership is seen as important to facilitating successful organizational change within healthcare (Battilana et al., 2010; Buchanan et al., 2007; de Búrca, 2008; Denis, et al. 2001; Lukas et al., 2007; Roberts & Coghlan, 2011).

Individuals in formal leadership roles can encourage distributed leadership through appropriate structures (Roberts & Coghlan, 2011) and processes (Buchanan et al., 2007), while being cognizant that **organizational cultures** can act as a barrier to distributed leadership (Roberts & Coghlan, 2011). It has been suggested that for distributed leadership to be successful, approaches to support distributed leadership must be aligned with the goals of the senior organizational leadership (Battilana et al., 2010). The effectiveness of distributed leadership may also be impacted by the composition of the leadership team (Denis et al., 1996).

This changing view of leadership away from individualistic models and the heightened focus on distributed leadership has the potential to greatly impact how we approach and implement change within healthcare. There are multiple existing structural and professional hierarchies that exist in most healthcare organizations and the ability to generate distributed leadership wherein individuals throughout the organization play leading roles in driving successful change may be imperative to achieving the desired outcomes. Distributed leadership doesn’t spontaneously arise however and requires strong, formalized, leadership to actively encourage its existence for it to develop.

The Diffusion of Innovation Theory

The Diffusion of Innovation Theory was developed in 1962 by Everett M. Rogers in the field of communications. This theory describes the pattern by which groups of people are likely to adopt an innovation over time (Robertson, 1962). In this theory, the population is divided into five groups: innovators, early adopters, early majority, late majority, and laggards. Innovators, who comprise 2.5% of the population, are the first to adopt the change. This is followed by the early adopters, who comprise 13.5% of the population, the early majority, who comprise 34% of the population, the late majority, who also comprise 34% of the population, and finally, the laggards, who comprise 16% of the population (Bhattacharya & Singh, 2019). As the innovation curve progresses from left to right, the people who fall into each category are slower to adopt change, ending with the laggards who are either very late to adopt or resist change altogether.

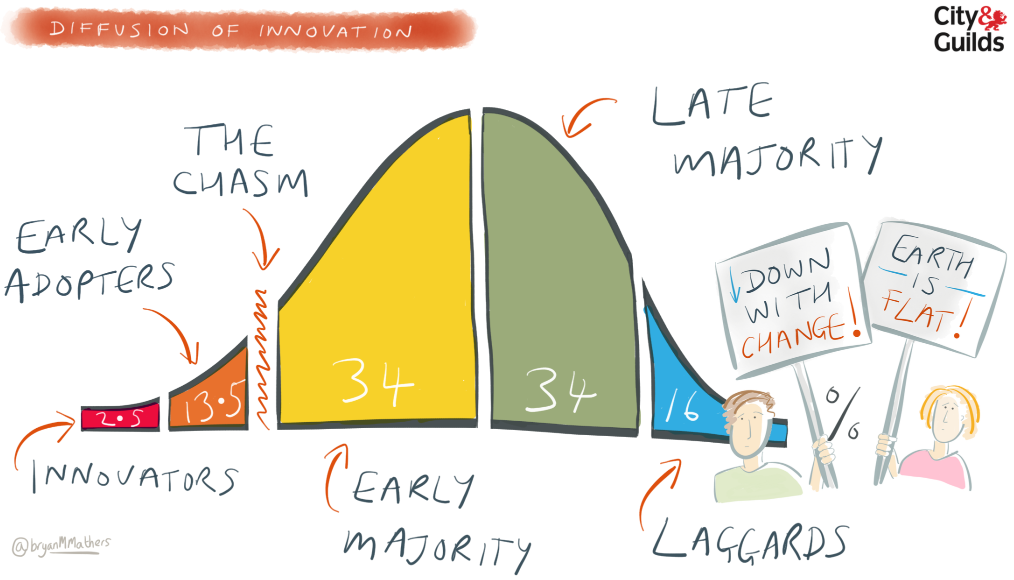

Figure 3.8 *The Diffusion of Innovation. Source: Illustration by [Bryan Mathers](#) on [Flickr](#) is licensed under [CC BY-ND](#)*

There are five key factors that can be used to leverage the adoption of a change. First is competitive advantage: people must perceive the change as being better than the previous course of action. Second is compatibility: the change must be compatible with the needs, values, and/or culture of the target population. Complexity also plays a role and innovation should be user friendly and easy to understand. Next. there is testability: the ability of the target population to test innovation before committing to the change. The final factor to leverage is observability: the ability of the innovation to result in measurable change. The Diffusion of Innovation Theory is a useful framework that allows us to understand how innovation may be adopted within organizations. It also provides us with methods for effective ways to introduce and implement innovation that may enhance the likelihood of successful uptake.

The video below provides a quick overview of the Diffusion of Innovation Theory:

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Deeper Dive

- Read this article about a road map for diffusion of innovation in health care: https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.1155?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed

Macro Level

Macro-level factors are defined by Smith et al., (2019) as those that are “structural, legal, regulatory or economic conditions that are often beyond the influence of a specific individual or an organization itself”. These **macro-level** factors include government regulations, **accreditation** standards, state of the workforce at any given time, and any associated health policies. All these factors will have an influence on the change activities that must occur in an organization. Of interest here is how these **macro-level** factors, by design, require organizations to collect, report, and act upon data to enhance health services. Ultimately, some organizations would be doing this regardless, given their culture of evidence-informed decision-making. However, these **macro-level** factors do make this somewhat of a requirement that helps to motivate some who may otherwise not help to reinforce specific changes and actions for those organizations.

Governmental Regulations

Regulations, legal acts, and associated policies that are passed or enacted at a provincial level or national level, as is the case in Ontario, will in turn impact an organization’s requirement for change. Often, organizations will be tasked with understanding these requirements within their own **context** and then creating their own strategies and changes to align with them. An example of an Act that supported changes to enhance health system quality was the Excellent Care for All

Act. The Excellent Care for All Act required that all organizations establish quality committees, create, and implement quality improvement plans, link executive compensation to achievement of quality targets, ensure that staff and patient satisfaction surveys were done, develop a declaration of values through public consultation and establish a patient relations process. Hospitals, and subsequently other health organizations, such as long-term care and community health centres, were required to enact these activities. How this was done varied but all had requirements for reporting to the government. What many of these activities then required was the collection of data, reporting, and then acting on areas that required improvements. In a way, these activities helped to drive the culture of using evidence to inform decision making to enhance quality to another level for organizations.

Accreditation Standards

Accreditation is defined as “the action or process of officially recognizing someone as having a particular status or being qualified to perform a particular activity.” Logically, we would want to make sure that our health care organizations are accredited. Depending on the health sector, there are accreditation bodies that are either mandatory or voluntary. For example, hospitals must go through an accreditation process every five years, whereas public health units may elect to move through an accreditation cycle but, this has not been mandated by the provincial government bodies. Accreditation in the health sector is focused on ensuring that high-quality services and programs are delivered to our communities. For example, Accreditation Canada (n.d.) “inspires people to make positive change that improves the quality of health and social services in Canada and around the world.” Through this accreditation process, organizations work through achieving a set of standards and modifying their practices to ensure they meet these standards. The standards are informed by the best available evidence and the current health system **context** that are created in collaboration with providers, patients, and policy makers. This ongoing process helps organizations identify areas of weakness and make necessary changes. Surveyors attend the site to review the changes, ask questions, and engage in discussions about areas for improvements that they see as outsiders of the organization. The process supports high-quality services and continuous improvement based on evidence in reports, observations, and qualitative information during onsite visits.

Summary

As the chapter notes, making change is easier said then done. Factors at the **micro**, **meso**, and **macro-level** will all influence the success of a change. New knowledge on processes and practices that is gleaned through research is not enough to influence behavior or process change to a new state. Understanding factors that impact how individuals use new information and what motivates individuals to incorporate new evidence in to their decision making is an essential part of change in our health system.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=233#h5p-23

Deeper Dive

Check out these resources for more information on the topics that were covered in this section:

- https://rnao.ca/news/now-available-leading-change-toolkit

- https://www.ahrq.gov/evidencenow/tools/keydrivers/index.html
- https://mentalhealthcommission.ca/national-standard/

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CHAPTER 4: KNOWLEDGE TRANSLATION AND EXCHANGE TO SUPPORT DECISION MAKING

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Chapter Objectives

By the end of this chapter, you will be able to:

- **Understand what KTE/KMb refers to and the other associated terms within this field;**
- **Understand the general theories, frameworks, and models that underpin KTE/KMb;**
- **Conceptualize relevant strategies for your KTE/KMb;**
- **Understand plain language writing and its relevance to KTE/KMb;**

- **Have a broad understanding of several key considerations for KTE/KMb, including evaluation, budget, and staffing requirements; and**
- **Understand how equity, diversity, and inclusion should be considered and incorporated within your KTE/KMb.**

Section 1: Introduction and History of Knowledge Translation/Mobilization

DR. KAREN A. PATTE; JAYNE MORRISH; AND MEGAN MAGIER

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Section Overview

In this section, you will be introduced to the what, who, and why of **KTE/KMb**. You will learn about the concept and goals, who is involved, why **KTE/KMb** is important, and how it has evolved over time.

Section Objectives

By the end of this section, you will be able to:

- **Define KTE/KMb and identify the key characteristics;**
- **Identify who is involved in KTE/KMb;**
- **Describe the goals and importance of KTE/KMb; and**
- **Outline the history of KTE/KMb and how the field has evolved.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=60#h5p-2

The Many Terms for KTE/KMb

Knowledge Translation and Exchange (KTE) and **Knowledge Mobilization (KMb)** are umbrella terms that refer to the many activities that contribute to the relational, iterative, and context-sensitive process of moving of knowledge to action, including the synthesis, dissemination, exchange, and application of knowledge. Numerous terms are often used interchangeably to refer to the concept as a whole or to specific components of the process, such as **knowledge dissemination**, **knowledge translation**, knowledge transfer, **knowledge exchange**, and research utilization.

Over 100 different terms were used to describe KMb in health literature in 2006 alone (McKibbon et al., 2010). The varied terminology and definitions partly reflect the emergence of the field from varied roots and the evolution of practices over time, with the choice of term sometimes dependent on the discipline. Research utilization was long used in nursing, while KMb is generally used in social sciences and humanities fields, and **Knowledge Translation** (**KT** or **KTE**) are common in health research. In this chapter, we will use the umbrella terms **KTE/KMb**.

The Social Sciences and Humanities Research Council (2019) uses the term KMb and specifies co-creation or co-production of knowledge in the definition:

> "An umbrella term encompassing a wide range of activities related to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and **knowledge users**." (para. 4)

KT or **KTE** are commonplace terms today in health and medical fields. First coined in 2007 by Graham et al., **KT** gained prominence when adopted by the Canadian Institutes of Health Research (CIHR), Canada's national funding agency for health research. CIHR (2012) defines **KT** as:

> "A dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system." (p. 1)

Similarly, adapting CIHR's definition, the World Health Organization (2005) defines **KT** as:

> "The synthesis, exchange, and application of knowledge by relevant **stakeholders** to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health." (p. 2)

These definitions share a multifaceted conceptualization of **KTE/KMb**, including activities spanning the synthesis of knowledge to its application. **KT** has evolved to **KTE** over time, in order to recognize the importance of exchange within the process and emphasize that rather than a unidirectional process, effective **KTE/KMb** involves a bi-directional flow of information, rather than a unidirectional process (Graham et al., 2006). **Knowledge exchange** is a collaboration involving regular sharing of information, ideas, and experience between those who generate knowledge and those who might put the knowledge to use (Reardon et al., 2006).

Knowledge dissemination is considered to be an active "make it happen" process to communicate knowledge by targeting, tailoring, and packaging the message for a particular target audience. Traditionally, dissemination was primarily used to refer to sharing research with academic audiences through peer-reviewed research journals and scholarly conferences, but it is now understood to include any activity that enables the use of knowledge by making it accessible, understandable, and useful to individuals, groups, and organizations. **Knowledge dissemination** differs from the **diffusion of knowledge** – a passive and unplanned "just let it happen" process, in which the potential user of knowledge needs to seek it out – which was more often used in early **KTE/KMb** approaches.


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Overlap between **KTE/KMb** and related fields has also caused confusion. **Translational research** is the transition from basic laboratory research (e.g., animal and basic research to identify disease mechanisms), to applications to human health and clinical settings (e.g., human clinical and efficacy studies), and finally, to evidence-based practice guidelines (e.g., effectiveness, dissemination, and implementation research) (Zoellner et al., 2015). As outlined in **Chapter 3: Implementing Change – Easier Said Than Done**, **implementation science** is "the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care" (Eccles & Mittman, 2006, p. 1). As opposed to the practice of implementing evidence, the objective of **implementation science** is to discover the processes, barriers, facilitators, and strategies to improve implementation, and to develop, test, and refine implementation theories and methods (National Academies of Sciences, Engineering, and Medicine, 2016).

Regardless of the term used, **KTE/KMb** is a proactive process to ensure the right information is available to the right people, at the right time, and in the right format. Definitions emphasize that the goal goes beyond simply sharing or transferring knowledge, to its implementation and impact on health care and systems. To do so effectively, relationship building and collaboration are critical. Next we discuss who is involved in this process.

Who is Involved?

When planning and evaluating **KTE/KMb** strategies, it is important to ask *a priori*, which audiences are involved, when, how, and in what **context**? Similar to the many terms for the process of **KTE/KMb** or its components, several labels are applied to the different parties concerned, and these too have continued to evolve with the move to more inclusive conceptualizations of knowledge and the "co-production" of knowledge. There are three key groups to consider in **KTE/KMb**: **knowledge creators**, users, and **stakeholders**. **KTE/KMb** may also employ **knowledge brokers.**

Knowledge creators or producers are individuals who create new knowledge. Most commonly, **knowledge creators** are researchers.

Knowledge users or end users are the potential audience of created knowledge. **Knowledge users** may be people who will receive the care or practice that is based on the knowledge (e.g., patients, the general public) or have the capacity to implement the knowledge (e.g., health decision-makers, practitioners, policy makers). However, **knowledge users** also hold important knowledge and can actively participate in the process of creating knowledge. Rather than just a reactive audience to already created knowledge, engaging **knowledge users** throughout the research process helps to ensure the knowledge created is relevant and useful, and therefore, more likely to be applied to practice. Researchers can also be the primary **end users** of knowledge. Not all research has direct implications for practice, or is ready for external **KTE/KMb**, but it should be mobilized to other researchers to advance future research in the field, either theoretically, methodologically, or empirically.

Recognizing that **knowledge user** and creator groups are not mutually exclusive, there has been a move towards terminology such as next users and knowledge holders. Similarly, the terms **content experts** and **context experts** have emerged from community engagement literature (Attygalle, 2017). **Content experts** are individuals with "formal power who have knowledge, tools, and resources to address the issue" (p. 3) – often professionals, service providers, and leaders, whereas **context experts** have lived experience of the situation or issue at hand, which may include children, youth, and patients (Attygalle, 2017).

There is a continuum of engagement of groups around **KTE/KMb**, from **end users** who play a more passive role at the end of a research project, to partners at the most engaged end of the continuum. Research partners agree to participate throughout the research process, as they have specific knowledge to contribute to the creation of knowledge and its dissemination and uptake.

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The term **stakeholders** typically refers to individuals, organizations, or communities in which next users and researchers are situated and that may be indirectly affected by research (Jull et al., 2019). That is, **stakeholders** may have a direct interest in the knowledge and its use – the process and outcomes of a project – but are not anticipated to directly influence or use the knowledge (Boaz et al., 2018; Jull et al., 2019). Effective **KTE/KMb** needs to consider the **context** in which the knowledge is to be applied, which includes the local opinion leaders, given the many political, social, organizational, and environmental influences on change. Tugwell et al. (2006) characterized candidate **stakeholders** central to the implementation of health science knowledge as the "6Ps", including patients, public (community), press, physicians, policy, and the private sector. Larkin et al. (2007) later proposed "8Ps", adding public health and third-party payers as important parties for successful **KTE/KMb**.

Knowledge brokers are the middle people or intermediaries who facilitate interactions between **knowledge creators** and next users – or researchers and decision makers. A **knowledge broker** works to understand the culture, goals, and needs of **knowledge users**, and identifies, synthesizes, interprets, and translates research evidence into **context** appropriate recommendations for them (Dobbins et al., 2009).

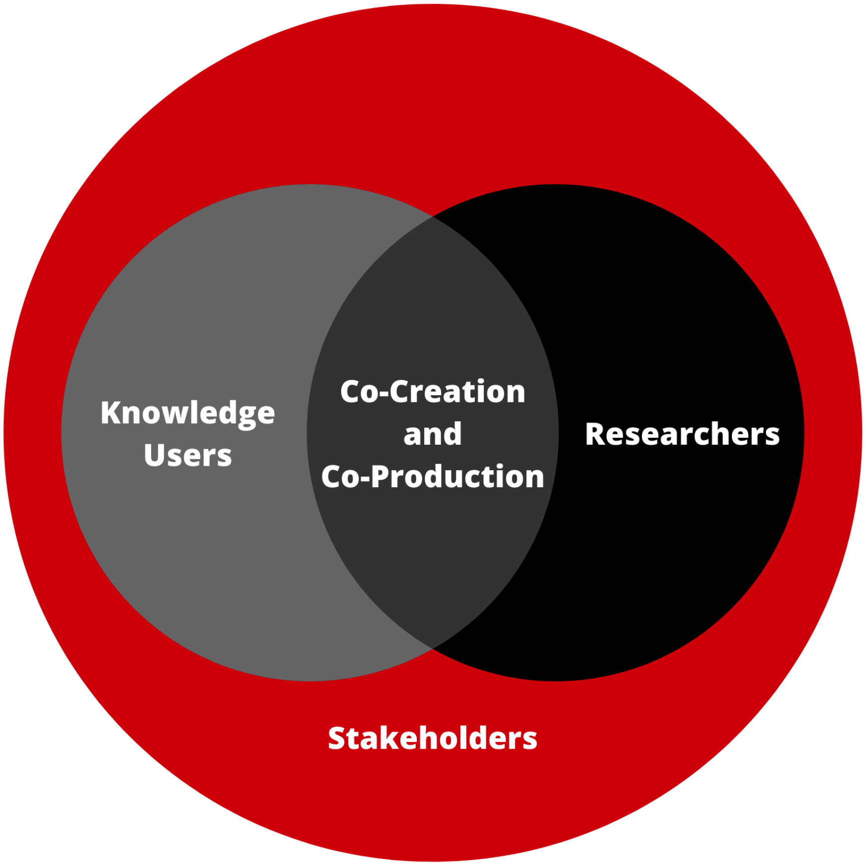

Figure 4.1
Knowledge Users, Researchers, and Stakeholders. Source: Caitlin Muhl

Why Do We Mobilize?

When evidence is mobilized to other researchers, **KTE/KMb** may serve to inform and advance research agendas, theory, and/or methods. Funding agencies now require clear and detailed **KTE/KMb** plans to ensure timely research uptake, to demonstrate impact, and to justify expenditures. Beyond academic audiences, mobilizing evidence can draw awareness to issues, prompt changes in perspectives or behaviour, and inform policies, processes, and practice. In the case of health, this impact may be defined as informing health care and policy, and ultimately, improving health outcomes.

Attempts have been made to categorize the purposes or types of knowledge use, including instrumental or knowledge-driven use, political or symbolic use, tactical use, and conceptual use (Davies et al., 2015). In a review of **KTE/KMb** models, Ward (2017) developed 5 outcomes of mobilizing knowledge:

1. To develop local solutions to practice-based problems;
2. To develop new policies, programs, and/or recommendations;
3. To adopt or implement clearly defined practices and policies;
4. To change practices and behaviours; and
5. To produce useful research or scientific knowledge.

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Health research is often conducted under the assumption that it will advance knowledge and eventually translate into improved policies, practices, resources, or programs, and in turn, health. However, despite a strong emphasis on evidence-based practice – in which practitioners make practice decisions based on the integration of research evidence with clinical expertise and the patient's unique values and circumstances in health care fields (Straus et al., 2005) – the transfer of research evidence to practice continues to be "slow and haphazard" (Graham et al., 2006). As outlined in **[Chapter 3: Implementing Change – Easier Said Than Done](#)**, it is estimated to take approximately 17 years for evidence to be fully adopted in practice (Morris et al., 2011). The failure or lag in evidence uptake means many patients are denied the best possible care (Graham et al., 2006) and the persistent use of outdated approaches represents missed opportunity, potential harm, and wasted human and financial resources (Powell et al., 2017).

Recognition of this "knowledge to action" or "know-do" gap has led to a growing emphasis on **KTE/KMb**. In a bulletin of the World Health Organization, Pablos-Mendez et al. (2005) stated:

> Research, we believe, has to be a component of a strategic process rather than an end in itself. Ill-health and premature deaths from preventable causes persist… in spite of available cost-effective interventions in part because there is a gap between what is known and what gets done in practice, i.e., the 'know-do' gap. This gap between available evidence and its application in policy and practice is not new, but strategic approaches to address it are urgently needed. To bridge the know-do gap, knowledge must be leveraged

> effectively to achieve better health. The generation and sharing of knowledge are necessary steps in its effective application. (para. 1)

Knowledge must be heard and understood by people in a position to bring about change, but the process of **KTE/KMb** must also consider the complex systems and **contexts** in which decisions are made, with political, organizational, economic, and social influences.

The sheer amount and rapid production of evidence now further complicates implementation and necessitates effective KMb. The challenges and importance of **KTE/KMb** have become even more apparent in the **context** of the COVID-19 pandemic, which has been referred to by some as a crisis of misinformation following a larger trend of "truth decay" (Kavanagh & Rich, 2018). The World Health Organization has warned about an "infodemic", defined as "an overabundance of information – some accurate and some not – that makes it hard for people to find trustworthy sources and reliable guidance when they need it".

Deeper Dive

To take a deeper dive on what **KTE/KMb** is and how it functions within the research process, use these resources:

- Lavis, J., Robertson, D., Woodside, J., McLeod, C., & Abelson, J. (2003a). How can research organizations more effectively transfer research knowledge to decision makers? *Millbank Quarterly, 81*(2), 221-248
- Lavis, J. (2003, March 13). *How Can Research Organizations More Effectively Transfer Research Knowledge to Decision Makers?* [Presentation]. World Health Organization, Geneva, Switzerland. https://pdfs.semanticscholar.org/50c5/429ce338c7a9f2e69d080f1cfdaf96ab74b4.pdf
- Reardon, R., Lavis, J., & Gibson, J. (2006). *From research to practice: A knowledge transfer planning guide*. Retrieved from Institute for Work & Health website: http://www.iwh.on.ca/from-research-to-practice.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. *(2006).* Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions, 26*(1), 13-24.
- A Guide to Researcher and Knowledge-User Collaboration in Health Research – https://cihr-irsc.gc.ca/e/44954.html
- Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches – https://cihr-irsc.gc.ca/e/45321.html

- The University of British Columbia. IKT Guiding Principles. https://ikt.ok.ubc.ca
- Boland, L., Kothari, A., McCutcheon, C. *et al.* (2020). Building an integrated knowledge translation (IKT) evidence base: colloquium proceedings and research direction. *Health Res Policy Sys, 18,* 8. https://doi.org/10.1186/s12961-019-0521-3
- Bowen, S., & Graham, I. D. (2013). Integrated knowledge translation. *Knowledge translation in health care: Moving from evidence to practice*, *2*, 14-21.

History of KTE/KMb

From Passive Diffusion to "Science Push" Strategies in the Era of Evidence-Based Medicine

As we can see from the above sections, there is clearly a need for equitable and authentic **KTE/KMb**. You might wonder how this field emerged in the first place. Looking to history, we can see that after the second World War, in "the golden era of modern research", the publication of research in scholarly journals and reports was considered sufficient and followed by passive diffusion (Landry et al., 2006). The movement of knowledge-to-action was approached as linear, fixed, and transferable (i.e., one directional and one-size fits all, irrespective of **context** and next users), with change occurring at the end of the research process.

The 1980s saw the birth of **evidence-based medicine**, which served as the basis for other evidence-based movements. Researchers and medical professionals aimed to improve clinical decision-making by promoting the use of the latest scientific knowledge, as opposed to practice based on the status quo, individual habits, or pharmaceutical marketing efforts. Gordon Guyatt, a professor of medicine and clinical epidemiology from McMaster University in Hamilton, Ontario, Canada, first coined the term **"evidence-based medicine"** in 1990 (Guyatt, 1991). Sackett et al.'s (1996) definition of **evidence-based medicine** is one of the most frequently cited: "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (p. 71).

The failure to effectively disseminate evidence was believed to account for the "know-do gap", and as such, active "push" dissemination approaches emerged to ensure evidence made it into **knowledge users**' hands. **KTE/KMb** strategies remained primarily unidirectional, from researchers to practitioners, and included the preparation and dissemination of systematic reviews, practice guidelines, and research reports, along with educational workshops to assist with interpretation (Landry et al., 2006). In the 1990s, a global network of researchers and health professionals established the Cochrane Collaboration, producing systematic reviews and databases on specific medical issues with the goal to inform health care decisions.

The legacy is that academic researchers are primarily trained and rewarded for scholarly books, peer-reviewed journal articles, and conference presentations, for which the intended audience is typically other scholars. While this system involving rigorous peer-review has important strengths in ensuring the research disseminated is of high standard, it has also contributed to the division between academic researchers and practitioners (Gaetz, 2014). In what has been called a "trickle down" view of the knowledge chain, the researcher's role was seen as creating and testing knowledge, with dissemination and implementation largely handled by someone else (Van de Ven & Johnson, 2006). While potentially sufficient for basic science, this model has limitations for more applied health research that has direct implications for health policy and practice. For example, many barriers in access exist for non-academic audiences, including the use of technical language, required knowledge to interpret research, and paywalls and copyright restrictions. Also, the one-way flow of information impedes implementation, as the research may not be readily applicable to practice, whether failing to account for the 'real-world' **context** and many barriers to change, or not fitting the next users' priorities.

The Emergence of the KTE/KMb Field

Despite initial success of **evidence-based medicine**, the knowledge-to-action gap persisted into the 1990s and today (Graham et al., 2006). An extensive evidence base had developed but it was not being implemented into new or improved health policies, products, services or outcomes (Landry et al., 2006). Further, the knowledge-to-action problem was now conceived as more complex and beginning upstream, in which research was not meeting the needs of **knowledge users**. That is, the failure to bridge the knowledge-to-action gap is argued to not be a *knowledge transfer* problem but a *failure of knowledge production* (Bowen & Graham, 2013; Van de Ven & Johnson, 2006). The research was not addressing questions seen as relevant or of interest to **end users**, thwarting its use and application (Gaetz, 2014).

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In addition to the research-to-practice gap, a practice-to-research gap exists in the mobilization of evidence gained from practice to inform more relevant research. Knowledge is often conceived exclusively as research evidence (Van de Ven & Johnson, 2006). However, beyond promoting the relevance and likelihood of uptake, practice-based knowledge also advances research, providing valuable lessons to promote innovative theories and models to be tested in a discipline (Smith & Wilkins, 2018; Van de Ven & Johnson, 2006).

The former Canadian Health Services Research Foundation (CHSRF) was established in 1996 "to support evidence-informed decision-making, management and delivery of health services through funding research, capacity building and knowledge transfer," which promoted awareness of the concept of "linkage and exchange" among policy/decision-makers into the early 2000s (Nguyen et al., 2020, p. 2). The CHSRF had set the scene for the CIHR's initial mandate (Graham et al., 2006) to advance both the creation of new knowledge and the translation of this knowledge from research into "real-world applications". Meanwhile, the CHSRF drafted new strategic priorities by 2009 to focus on the identification, spread, and scale of proven healthcare innovations, in response to the ongoing failure to transfer and apply research findings by scaling up approaches that have already been shown to work, and instead funding new research in what they referred to as "a country of perpetual pilot projects."

Over the past two decades, there has been a rapid growth in the **KTE/KMb** literature, including a plethora of definitions, models, and frameworks (Powell et al., 2017). The growth of **KTE/KMb** has expanded and changed the traditional roles of researchers, moving from an 'independent' and detached scientist to becoming an 'interdependent', other-focused collaborator and communicator (Gaetz, 2014).

Several shifts are said to have occurred from the era of **evidence-based medicine** to the **KTE/KMb** movement. First, the complexity of **KTE/KMb** as a relational and iterative process was recognized, as opposed to a linear, rational, and one-size fits all event. Second, with increased recognition that evidence is often bound to **context** and not universal, context-sensitive knowledge grew to be preferred over context-stripped evidence (Reimer-Kirkham et al., 2009). Third, researchers in universities and **knowledge users** in public or private sector institutions became less siloed with university and community or clinical partnerships. Lastly, there is a move toward more inclusive views of knowledge, with the growing recognition of the diverse ways of generating knowledge beyond formal research. According to Reimer-Kirkham et al. (2009):

> From a postcolonial feminist perspective, these concerns extend to name narrow interpretations of evidence that marginalize certain types of knowledge. By relying primarily on knowledge generated through randomized controlled trials that typically do not involve non-English speaking patients, do not account for the social **context** of people's lives, and historically have not included representation from women, incomplete non-representative knowledge is applied. (p. 160)

KTE/KMb Timeline

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=60#h5p-3

The Current Context of KTE/KMb

Recent literature increasingly recognizes **KTE/KMb** as "relational and political", with knowledge "value-laden"; change is complicated by the scope, scale, and number of actors involved, and a range of political, **contextual**, personal, interpersonal, and organizational influences (Bate et al., 2012; Powell et al., 2017). Acontextual **KTE/KMb** and reductionists' views of health and illness are critiqued as not considering the "messiness of everyday" practice, the "complicated power relations shaping any exchange" and the social conditions that determine health (Gaetz, 2014; Powell et al., 2017). To impact change, research evidence needs to be integrated with "informal" knowledge, such as the experiences of health professionals, patients, and carers (Bowen & Graham, 2013; Powell et al., 2017). Thus, effective **KTE/KMb** must also be "relational and contextually sensitive" (Powell et al., 2017). Further, it must take into account inequities in access to information, the ability to evaluate its quality, and the capacity to apply evidence. **KMb/KTE** often favours audiences already "information privileged" and fails harder to reach audiences. As explained by Gaetz (2014):

> Effective approaches to KMb must not only reimagine how research content is produced and distributed but also address barriers that users face in accessing and utilizing research knowledge, including lack of time, resources, skills, organizational support, and perception that research is not valuable, timely, or relevant. (para. 12)

Newer models of **KTE/KMb** emphasize the value of going further than simple engagement of next users to developing true and authentic partnerships at an early stage and collaborating throughout the research process (Smith & Wilkins, 2018). Community-engaged collaborative research has long been used in social sciences, unlike the medical sciences where practical applications have historically been developed based on researcher-created evidence (Gaetz, 2014). While less relevant for basic sciences, for health care, policy, and practice research, partnership approaches are said to enhance the relevance, uptake, and impact of research (Oborn et al., 2013; Skipper & Pepler, 2021).

More recently, the **integrated knowledge translation (iKT)** approach was developed in medical and health fields, in recognition of the values of collaborative research and with more similarities than differences to existing models, such as Engaged Scholarship, Co-Production or Co-Creation, and Participatory Action Research (Nguyen et al., 2020). **iKT** is defined by ongoing and authentic partnerships where researchers and **knowledge users** are equal partners in a mutually beneficial research project. The collaboration occurs from start to end, including priority setting and identifying problems, refining research questions, deciding on design and methods, collecting data, analysis and interpretation of results, and dissemination of findings.

Photo by Gabriella Clare Marino on Unsplash

Lavis and colleagues (2003a) make note of the *knowledge exchange model*, which posits that **KTE/KMb** requires mutually beneficial relationships to be built, developed and maintained across a project between **knowledge creators** and **knowledge users**. They explain that "over long periods of time, two-way 'exchange' processes that give equal importance to what researchers can learn from decision makers and what decision makers can learn from researchers can produce cultural shifts" (p. 227).

Likewise, Bowen and Graham (2013) describe the broad history behind **KTE/KMb** and, discussing the strengths and limitations of various approaches to **KTE/KMb** work, note that "there is increasing evidence that simply disseminating knowledge to potential users of that knowledge after the research has been completed is likely to be of limited effectiveness even if multiple and creative methods are used" (p. 5). The authors further state that "this evolution, from transfer to engagement, in **KT** theory and practice is occurring alongside, and in response to, other challenges to traditional research approaches, and reflects increasing societal expectations that knowledge must not only be scientifically valid, but also socially robust" (p. 5).

Goodman and colleagues (2017) comment that from a public health and community engaged research perspective "engaging community members in the research process is often the missing link to improving the quality and outcomes of health promotion activities, disease prevention initiatives, and research studies" (p.18).

Applying various collaborative models, knowledge is co-created *with* and not *on* or *for* individuals, groups, or organizations. These approaches necessitate positive and trusting relationships, based on principles of respect, co-learning, openness, support, reciprocity, and shared decision making (Bradbury-Huang et al., 2010; Nguyen et al., 2020; Skipper & Pepler, 2021). Both researchers and **knowledge users** are considered experts bringing complementary skills and knowledge to the team. Ideally, some of the typical barriers between researchers and users are broken down, and they learn from each other. Researchers bring research methodological skills and content expertise, while next users bring expertise related to the research topic and **context** and are well-positioned to move results into practice. Ultimately, their diverse perspectives can foster a more complex understanding of issues, the challenges and opportunities for change, and innovative solutions. However, despite recognition of the values of collaboration, the difficulties initiating and sustaining such work (e.g., in terms of issues and politics around sharing power, resources, and credit) prevent widespread engagement (Lozano et al., 2012; Plamondon & Pemberton, 2019). You will learn more about **knowledge exchange** in terms of selecting **KTE/KMb** strategies in [Section 3: Knowledge Translation/ Mobilization Strategies]().

Deeper Dive

Community engagement and equitable **knowledge exchange** are complex and involve long-term relationship building and collaboration (Goodman et al., 2017). Understanding the principles and complexities of community engagement with the **KTE/KMb** context goes beyond this chapter, but to take a deeper dive, use these resources:

- Attygalle, L. (2020). Understanding Community-Led Approaches to Community Change. Tamarack Institute. Retrieved from https://www.tamarackcommunity.ca/library/paper-understanding-community-led-approaches-community-change-lisa-attygalle
- Cazaly, Lynn (n.d). Levels of Participation [Video]. Vimeo. Retrieved from https://vimeo.com/93902630
- Chin, S. (2019). Best Practices for Community Engagement (Doctoral dissertation, University of British Columbia). Retrieved from https://open.library.ubc.ca/soa/cIRcle/collections/graduateresearch/66428/items/1.0386712
- Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement (2011). Principles of Community Engagement (2nd ed.). Retrieved from https://www.atsdr.cdc.gov/communityengagement/
- Gonzalez, R. (2020). Spectrum of Community Engagement to Ownership. Facilitating Power. Retrieved from https://www.facilitatingpower.com/spectrum_of_community_engagement_to_ownership
- Neufeld, S. D., Chapman, J., Crier, N., Marsh, S., McLeod, J., & Deane, L. A. (2019). Research 101: A process for developing local guidelines for ethical research in heavily researched communities. Harm reduction journal, 16(1), 1-11. Retrieved from https://harmreductionjournal.biomedcentral.com/articles/10.1186/s12954-019-0315-5
- University of South Florida, Office of Community Engagement and Partnerships. (n.d.). Community-engaged Scholarship Toolkit. Retrieved from https://www.usf.edu/engagement/faculty/community-engaged-scholarship-toolkit.aspx

Summary

KTE/KMb is a multidimensional concept encompassing the many activities that aim to close the knowledge-to-action gap. It is a proactive and iterative process comprising all steps between the creation of new knowledge and its application and impact, including knowledge synthesis, dissemination, exchange, implementation, and sometimes, co-production. To be effective, **KTE/KMb** must be tailored with an understanding of the audience and **context** in which the knowledge is to be applied. For this reason, building relationships and ongoing collaboration are central to the process.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

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Section 2: Introduction to Theories and Models of Knowledge Translation/ Mobilization

DR. KAREN A. PATTE; JAYNE MORRISH; AND MEGAN MAGIER

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Section Objectives

By the end of this section, you will be able to:

- **Understand key KTE/KMb theories, frameworks, and models; and**
- **Explain elements common across many theories, models, and frameworks and how they can be applied to KTE/KMb planning.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Background

KTE/KMb theories, models, and frameworks can assist in designing and implementing more effective plans. Theories convey how change and **KTE/KMb** occurs, models guide the process, and frameworks explain the factors believed to influence an outcome. However, the proliferation of **KTE/KMb** literature has created confusion around which to select (Esmail et al., 2020; Strifler et al., 2018). A 2018 scoping review identified 159 unique **KTE/KMb** theories, models, or frameworks, and the majority (87%) were used in five or fewer studies, with 60% used only once (Strifler et al., 2018). Models were most commonly used to inform **KTE/KMb** planning/design, implementation, and evaluation activities, and least commonly to inform dissemination and sustainability/scalability activities. Given the countless theories, models, and frameworks, this chapter will cover the most frequently cited examples to guide **KTE/KMb** design and understand the mechanisms and components involved in the process of moving knowledge to action.

KTE/KMb Theories, Models, and Frameworks

Diffusion of Innovation Theory (Everett Rogers, 1962)

Everett Rogers (1962) was a Professor in Communication Studies who theorized how new ideas or behaviours gain momentum and spread through a social system over time. As outlined in **Chapter 3: Implementing Change – Easier Said Than Done**, Rogers established the Diffusion of Innovation Theory, which outlines five segments of the population that adopt new ideas or behaviours at different times:

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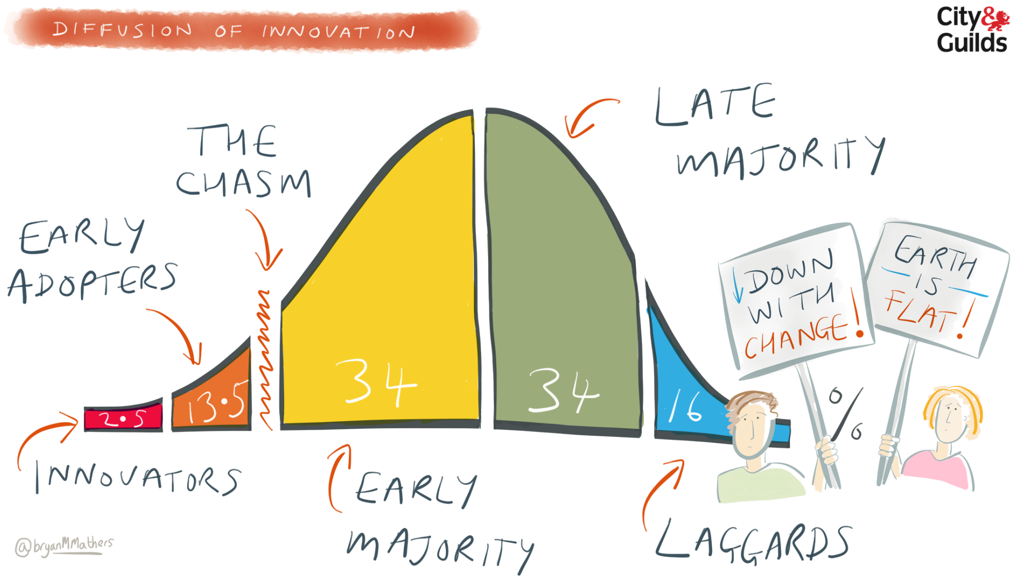

Figure 4.2 *The Diffusion of Innovation. Source: Illustration by [Bryan Mathers](#) on [Flickr](#) is licensed under [CC BY-ND](#)*

Rogers (1962) proposed that adoption occurs in five stages:

1. **Awareness:** An individual becomes aware of the idea, behaviour, or product;
2. **Persuasion**: An individual develops a favourable or unfavourable attitude toward the idea, behaviour, or product, and are compelled to seek out information;
3. **Decision**: An individual decides to adopt or reject it, weighing the pros and cons;
4. **Implementation**: An individual tries it but is still deciding whether to continue; and
5. **Continuation**: An individual evaluates the results and comes to a final decision about whether to continue with the idea, behaviour, or product.

The Diffusion of Innovation Theory was not developed explicitly to apply to new health behaviours or innovations, although it has been applied in multiple fields, including public health. Several limitations of the theory have been noted, including that it does not foster a collaborative partnership or participatory approach to adoption of health programs, it works better with the adoption of new behaviours rather than the cessation or prevention, and it does not account for individual's resources or social support for adoption.

Deeper Dive

To take a deeper dive, try this resource:

- Green, L. W., Ottoson, J. M., García, C., & Hiatt, R. A. (2009). Diffusion theory and knowledge dissemination, utilization, and integration in public health. *Annual Review of Public Health*, *30*, 151–174. https://doi.org/10.1146/annurev.publhealth.031308.100049

Lavis et al. (2003b) “Push, Pull, Exchange, Integrated KT” Model

Developed for health care decision making, but widely applicable, Lavis and colleagues (2003b) described four general categories of **KTE/KMb** strategies:

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Lavis and colleagues (2003a) have also presented a **KTE/KMb** framework that highlights 5 questions for research teams to consider when working to mobilize knowledge:

1. What should be transferred to decision makers (the message)?
2. To whom should research knowledge be transferred (the target audience)?
3. By whom should research knowledge be transferred (the messenger)?
4. How should research knowledge be transferred (the knowledge-transfer processes and supporting communications infrastructure)?
5. With what effect should research knowledge be transferred (evaluation)?

Knowledge-to-Action (KTA) Cycle (Graham et al., 2006)

One of the most highly cited frameworks for guiding **KTE/KMb** is the Knowledge-to-Action (KTA) cycle. The framework was originally developed by Dr. Graham and colleagues in 2006, and later adapted by the Canadian Institutes of Health Research (CIHR) and other organizations globally.

The KTA cycle consists of two larger components:

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The KTA cycle takes a **systems perspective**, which Graham et al. (2006) describe as “situating knowledge procedures and users in a system of knowledge that is responsive, adaptive, and unpredictable”. Phases are connected by bidirectional arrows to emphasize that the KTA process is iterative and dynamic; one can start at any phase, and the steps do not necessarily occur in sequence. The action cycle components can also inform knowledge creation.

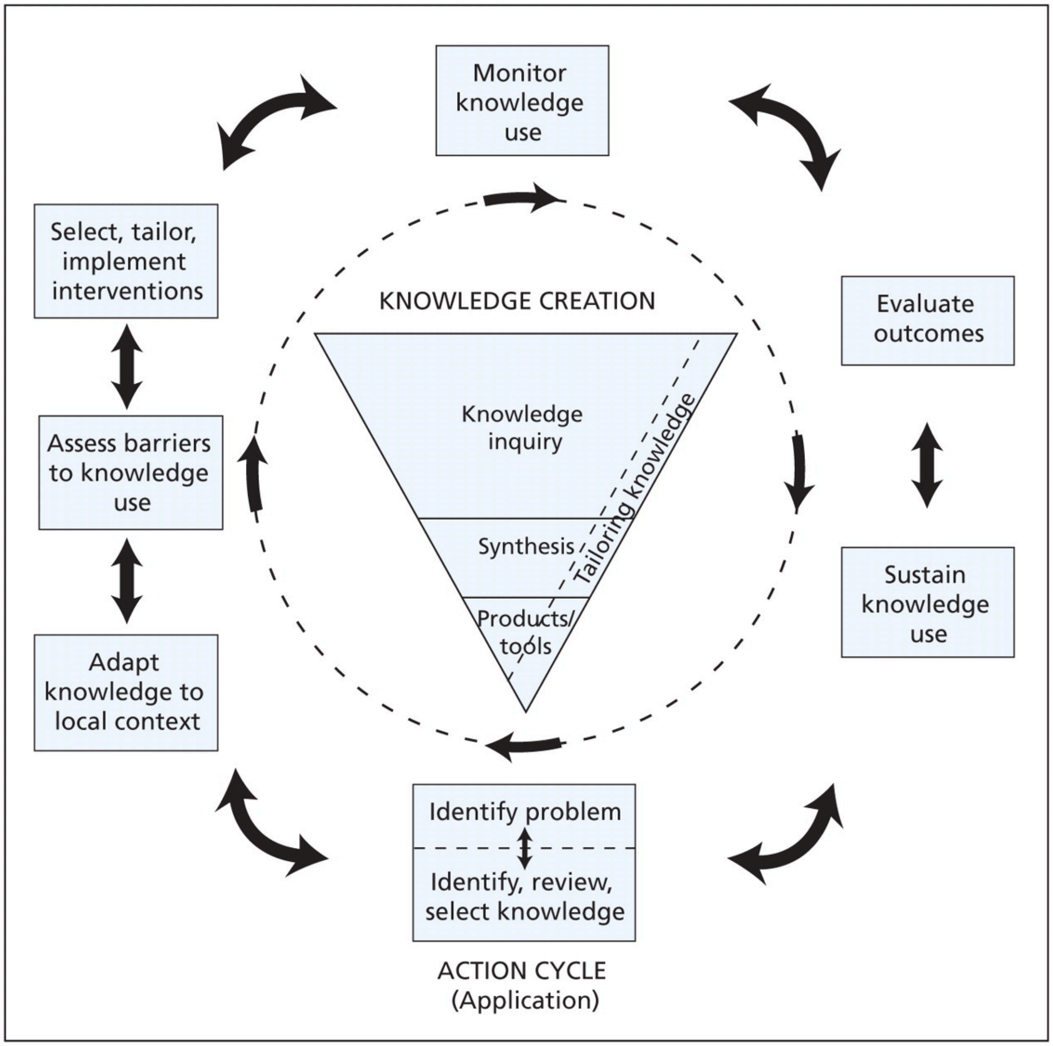

Figure 4.3 *The Knowledge-to-Action Cycle. Source: Illustration reproduced with permission from Straus et al. (2009)*

Co-Produced Pathway to Impact (Phipps et al., 2016)

More recently, the Co-Produced Pathway to Impact was developed by Phipps and colleagues (2016) to address the difficulty of using existing complex **KTE/KMb** models to monitor the impact of large collaborative research networks involving multiple partners and research institutions. To illustrate, the team applied the framework to Promoting Relationships and Eliminating Violence Network (PREVNet), a pan-Canadian community-university network that mobilizes knowledge on bullying prevention and the promotion of healthy relationships among children and youth.

The framework draws on a **logic model** and incorporates the iterative aspects of prior circular and cyclical **KTE/KMb** models to show sustained engagement between researchers and partners. The central overlapping space is where co-production occurs throughout the process with illustrated benefits for both researchers and partners at each stage. Engagement is maintained from research development to impact, as well as to inform new research questions and knowledge. The **logic model** allows for metrics at each of the 4 stages for evaluation:

1. **Dissemination** moves research into practice and policy settings where it can progress towards impact (e.g., press releases, clear language summaries, social media, meetings);
2. **Uptake** occurs when an organization looks to determine whether the research knowledge is useful for informing decisions. Activities may include staff meeting presentations, internal evaluation, and comparisons to literature and existing practices;
3. **Implementation** is when the knowledge is used to inform decisions, such as improved policies and practices; and
4. **Impact** refers to the effect that the research-informed policies or practices have on **end users** as measured by the partner (e.g., improved health).

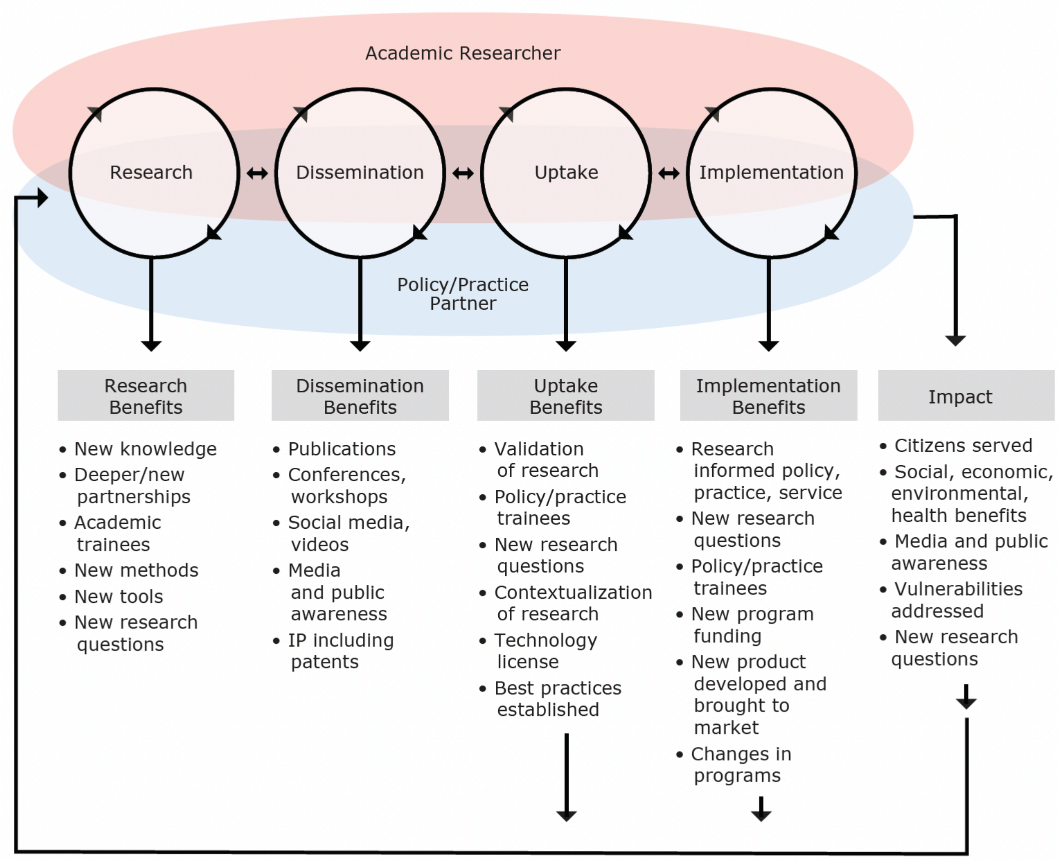

Figure 4.4 *The Co-Produced Pathway to Impact. Source: Illustration reproduced with permission from [Phipps et al. (2016)]*

Ward (2017): "I Want to Help [WHO] to Mobilize [WHAT] by [HOW] in Order to [WHY]"

To help guide knowledge mobilizers and increase clarity and understanding amongst the diverse and fragmented literature, Dr. Vicky Ward (2017) created a simple framework for thinking about **KTE/KMb** based on a review of 47 **KTE/KMb** models. The framework consists of four questions, with common potential responses based on the literature:

1. **Why mobilize knowledge?**
    - To develop local solutions to practice-based problems
    - To develop new policies, programs and/or recommendations
    - To adopt/implement clearly defined practices and policies
    - To change practices and behaviours
    - To produce useful research/scientific knowledge

2. **Whose knowledge?**
    - Professional knowledge producers (e.g., researchers, academics, evaluators)
    - Frontline practitioners and service providers (e.g., health and social care professionals, teachers)
    - Members of the public and people in receipt of services (e.g., community groups, charities, service user groups)
    - Decision makers responsible for commissioning services and/or designing policies and strategies (e.g., policy makers, commissioning managers)
    - Product and program developers responsible for designing, producing, and/or implementing products, services, or programs (e.g., service providers, operational managers)

3. **What type of knowledge?**
    - Scientific/factual knowledge (i.e., research findings, quality and performance data, population data and statistics, and evaluation data)
    - Technical knowledge (i.e., practical skills, experiences, and expertise)
    - Practical knowledge (i.e., professional judgements, values, beliefs, and intuition)

4. **How is knowledge mobilized?**
    - Making connections (e.g., establishing networks, brokering relationships between users and producers)
    - Disseminating and synthesizing knowledge (e.g., online databases, communication strategies, evidence synthesis services)
    - Facilitating interactive learning and co-production (e.g., participatory research, action learning)

Health Equity and KTE/KMb Models

Davison et al. (2015) conducted a scoping review to identify **KTE/KMb** models and evaluate their usefulness for promoting health equity. They identified a total of 48 unique models or frameworks published between 1997 and 2015. Each model was assigned a rating based on 6 characteristics identified as important for supporting health equity:

1. A specific focus, mention or consideration of **equity**, equality, justice, disadvantaged or vulnerable groups;
2. An inclusive conceptualization of knowledge (beyond scientific research) that ensures that different types of knowledge and/or ways of knowing might be considered in the evidence base;
3. Community members are represented and/or community participation is an explicit part;
4. Interactions are supported across disciplines or sectors;
5. Specifically refers to the social, physical, political, and/or economic **context** of knowledge generation and use; and
6. Has an applied, proactive, or problem-solving focus.

None of the included 48 models scored perfect on all six characteristics. Low scoring models were most often lacking attention to a multisectoral approach. However, there were some promising approaches identified that could be enhanced to further support **equity**.

The highest scoring model was the *Knowledge Brokering Frameworks* by Oldham and McLean (1997), which proposed 3 frameworks for thinking about Knowledge Brokering:

1. The Knowledge System Framework relates most closely to private sector knowledge managers, in which **knowledge brokers** facilitate how knowledge is created, diffused, and used by various institutions and their interactions;
2. The Transactional Framework views **knowledge brokers** as linkage agents, focused on the interface between "creators" of knowledge and organizations that are "users" of knowledge in the **context** of specific "transactions" (i.e., relevant to specific decisions or projects); and
3. The Social Change Framework focuses on building capacity and potentially leading to positive social outcomes, where **knowledge brokers** enhance access to knowledge by providing training, such as when the users of knowledge are members of the general public.

From an **equity** perspective, strengths of this model were that it supported an inclusive conceptualization of knowledge, prioritized engagement of a variety of **stakeholders**, had a strong emphasis on contextual factors as important health and health equity determinants, and discussed how the use of a social change framework could help address power differentials.

The second highest scoring model was the *KTE with Northern Aboriginal Communities* by Jardine and Furgal (2010). Noted strengths of this model included the establishment of partnerships and trust with and among community members, an inclusive conceptualization of knowledge, the undertaking of capacity development activities, meaningful and prolonged engagement of communities in all research stages, and a sensitivity to contextual factors. In two participatory action research projects, Jardine and Furgal (2010) reconfirmed the importance of spending time developing relationships and trust among all research partners through regular face-to-face, interpersonal contact in order to instill confidence in the researchers and projects, and address the suspicions fostered by previous inappropriately conducted research in the north. They identified five components as fundamental to the **KTE/KMb** in their study:

1. Establishing partnerships and trust with the communities;
2. Using trained community field workers/researchers for all stages of the research;
3. Holding regular workshops for all members of the research team, which enabled a true two-way exchange of knowledge and mutual learning environment;
4. Making a commitment to return the research results to the participants and communities first, for verification and validation; and
5. Translating the research results for government decision-makers so that they might be used to inform policy and practice.

Please go to **Chapter 2: Data for Equity?** for more information about this topic.

Summary

The examples presented in this section represent a select sample of the numerous **KTE/KMb** models, theories, and frameworks in what has been referred to as a "**KT** swamp". Common across many models and frameworks is the understanding of the **KTE/KMb** process as a collaborative one that involves multiple, dynamic, and iterative steps. They emphasize the importance of tailoring and targeting messaging to audiences, adapting knowledge and strategies to the **context**, and engaging and establishing partnerships with next users. Many models also highlight the importance of evaluation, which is covered in **Section 4: Other Key Considerations**. Next, we will discuss specific strategies for disseminating and exchanging knowledge.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=63#h5p-5

Section 3: Knowledge Translation/Mobilization Strategies

DR. KAREN A. PATTE; JAYNE MORRISH; AND MEGAN MAGIER

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Section Overview

In this section, you will learn about **KTE/KMb** strategies, which are the "how" or the "doing" part of **KTE/KMb**. How will you mobilize/translate your research/findings? How will you engage with people to mobilize/translate the knowledge that you have? This section provides a high-level overview of what **KTE/KMb** strategies are and includes resources to support you in actually carrying out **KTE/KMb**.

Section Objectives

By the end of this section, you will be able to:

- **Explain key KTE/KMb strategies;**
- **Understand the importance of knowledge exchange in the KTE/KMb strategy process;**
- **Access relevant resources to support your own development of KTE/KMb strategies;**
- **Understand the importance of and how to use plain language communication; and**
- **Understand some of the relevant equity, diversity, and inclusion considerations when developing KTE/KMb strategies.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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CASE STUDY: Engaging With Youth to Create Meaningful KMb Materials of Mental Health Research

How can all of the abovementioned lessons about **KTE/KMb** come together to form meaningful and accurate engagement around research knowledge? How can a researcher or a team be sure that they are selecting **KTE/KMb** strategies that are relevant, accessible and equitable for their audiences – with **context** being considered? This case study explores how one national research project has intentionally engaged with their audience and **context experts** to ensure that their **KTE/KMb** is centred around how, why and what their **knowledge users** want to see around research findings.

The COMPASS study is a national initiative headquartered at the University of Waterloo. Since its inception in 2012, COMPASS researchers have been collecting health information from about 65,000 Grade 9 to 12 students attending more than 130 secondary schools in Ontario, Alberta, Quebec, and British Columbia. The Canadian Institutes of Health Research (CIHR) and Health Canada are funding the research. One component of the COMPASS study is the mental health section, which explores youth mental health and the impact of school programs and resources, and relationships with various behaviours such as physical activity, substance use, sleeping, eating behaviours, bullying/aggression, peer and familial relationships, and screen time.

The team overseeing the mental health section of the COMPASS study continually focuses on ensuring that they are providing their data and results to other researchers as well as broader **knowledge user** groups such as schools, public health, community organizations, and policy makers. However, the team realized that there was a gap in their **KTE/KMb** work in that they were not always reaching youth themselves. Looking to the above outlined lessons on the importance of equitable exchange with **knowledge users**, the team formed the COMPASS Youth Knowledge Mobilization Leaders committee, composed of youth from the age groups that participate in COMPASS. This committee meets regularly (either bi-weekly or monthly) to learn more about COMPASS study findings and strategize ways of sharing results that are engaging and relevant for youth. The committee is entirely youth-led, in that the youth members set the agenda, select research findings that they feel are most relevant for youth, and develop the **KTE/KMb** tools to share the information in ways likely to be engaging for youth. At the current point in time, the committee is mainly focused on sharing results via social media, having selected Instagram as the platform where youth would want to learn about research, but this may expand in the future.

What is so impactful about COMPASS' youth-led **KTE/KMb** work is that youth are not only at the table informing **KTE/KMb** for their peers, but they also have an active and respected voice in the decision making and creation for **KTE/KMb** plans/materials for the project. As mentioned earlier within this chapter (and will be outlined more later in this section), **KTE/KMb** work should be based on how and why individuals want to and can access information. The most equitable way to accomplish that is via authentically engaging with **context experts** around **KTE/KMb** planning. In the case of the COMPASS Youth Knowledge Mobilization Leaders committee, the youth-members are looked to for their knowledge of the type of information that youth would want to know about from the research findings, as well as the ways in which youth would want to have that information presented to them, and how the team can best engage with broader groups of youth. Moreover, the entire process is underpinned by full respect of the youth's time and expertise, with all members being paid for their time contributed to the project, being offered time to practice leadership skills, and being provided tangible professional experiences to lend to their own resumes.

As the team moves forward they will continue to lead youth-focused **KTE/KMb**, as well as translate all posts so that the work is bi-lingual and reaches Francophone youth. The broader COMPASS team is also focusing on training researchers on equitable youth engagement principles and practices to inform future COMPASS **KTE/KMb** work. To learn more about the COMPASS Youth Knowledge Mobilization Leaders committee, please see this Brock News article.

Below are some samples of the COMPASS Youth Knowledge Mobilization Leaders Instagram posts (check out the English and French Instagram accounts).

the_compass_study

31 posts **202** followers **266** following

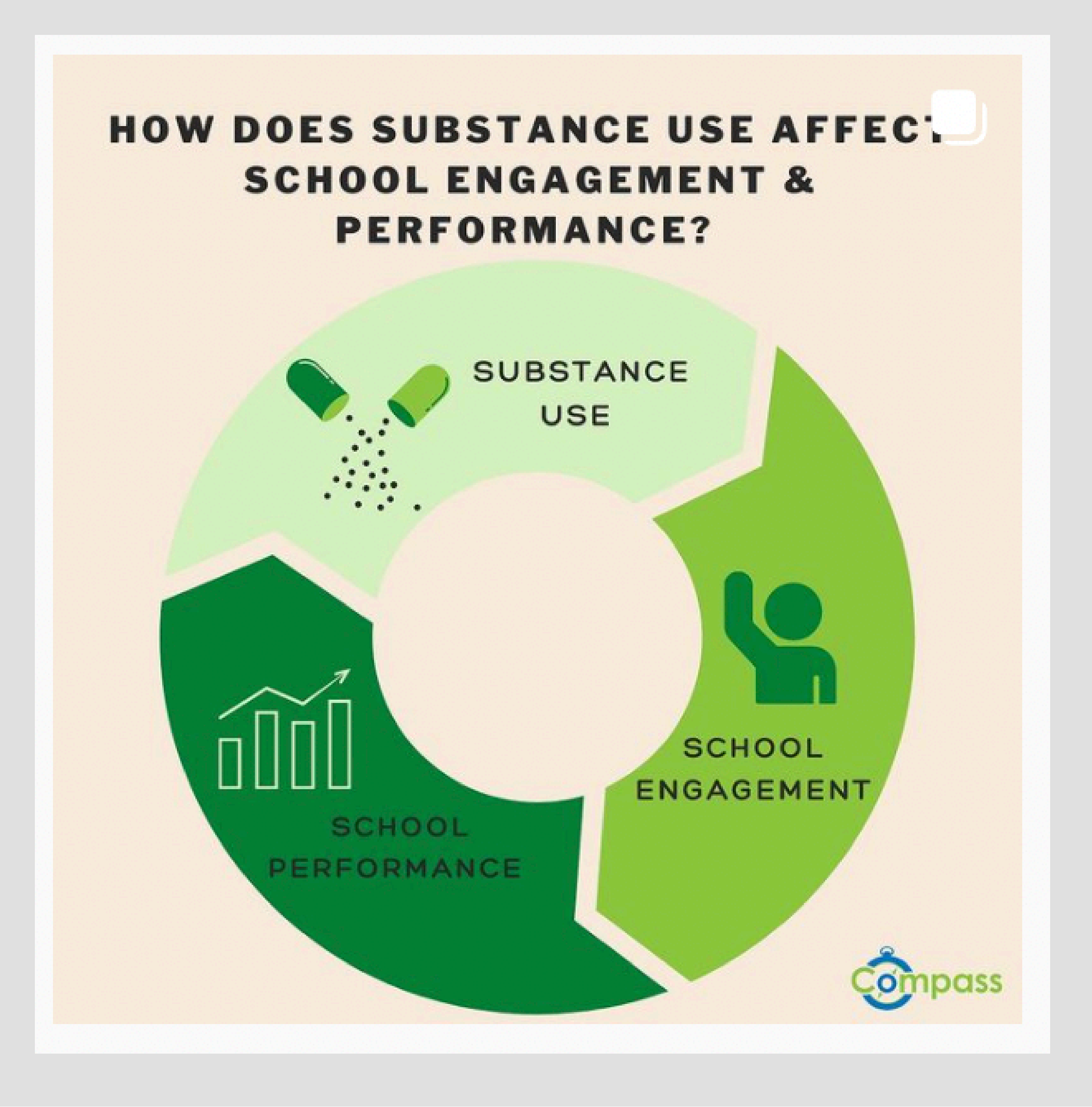
The COMPASS Study

Educational Research Center

The COMPASS study (started 2012/13) follows Canadian high school students to better understand how to effectively improve their health.

uwaterloo.ca/compass-system/compass-system-projects/youth-engagement


BULLYING
What is the MOST COMMON Form of Bullying?
1
Compass


HOW DOES SUBSTANCE USE AFFECT SCHOOL ENGAGEMENT & PERFORMANCE?
SUBSTANCE USE
SCHOOL ENGAGEMENT
SCHOOL PERFORMANCE
Compass


what is
income inequality ?
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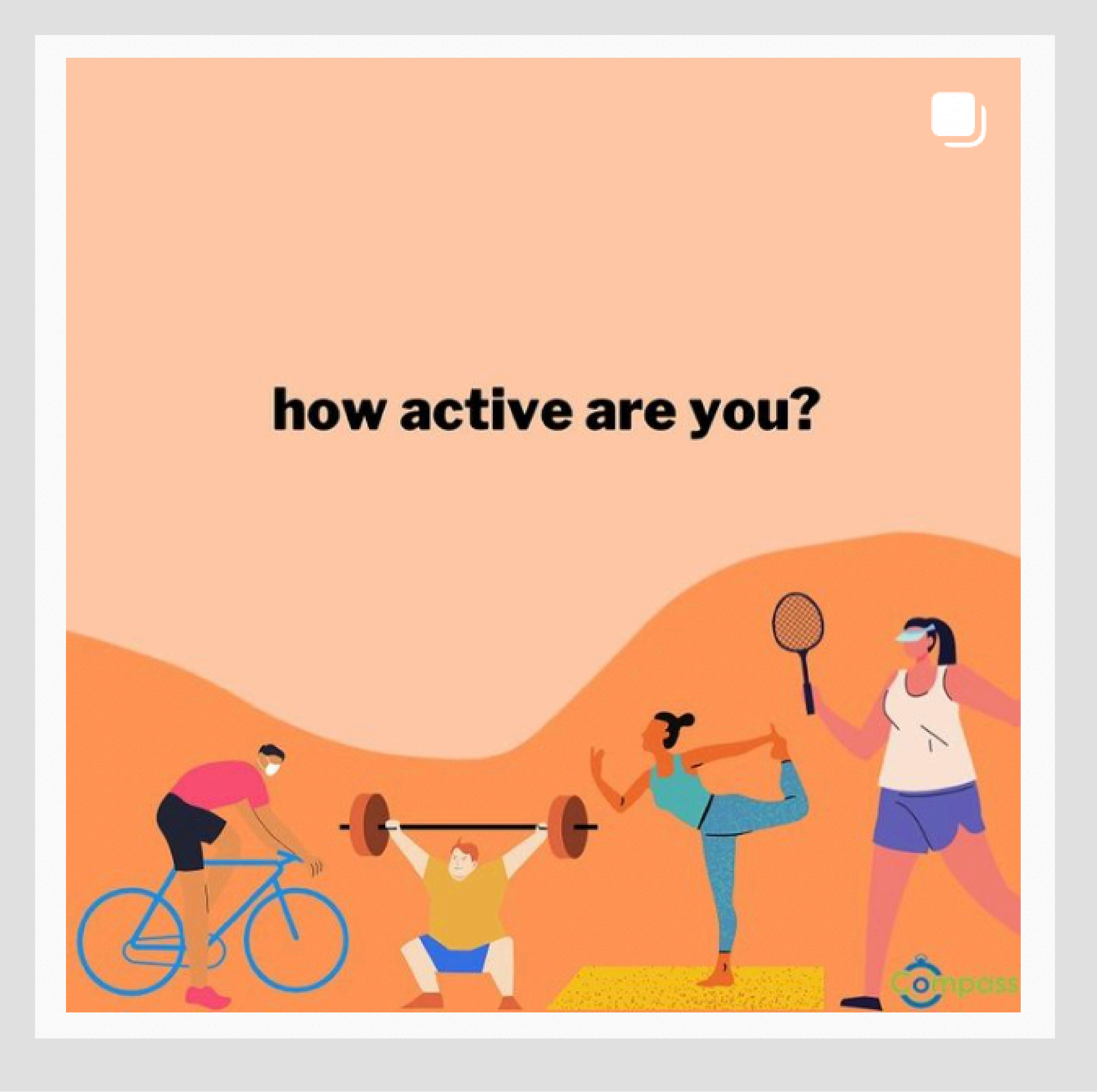
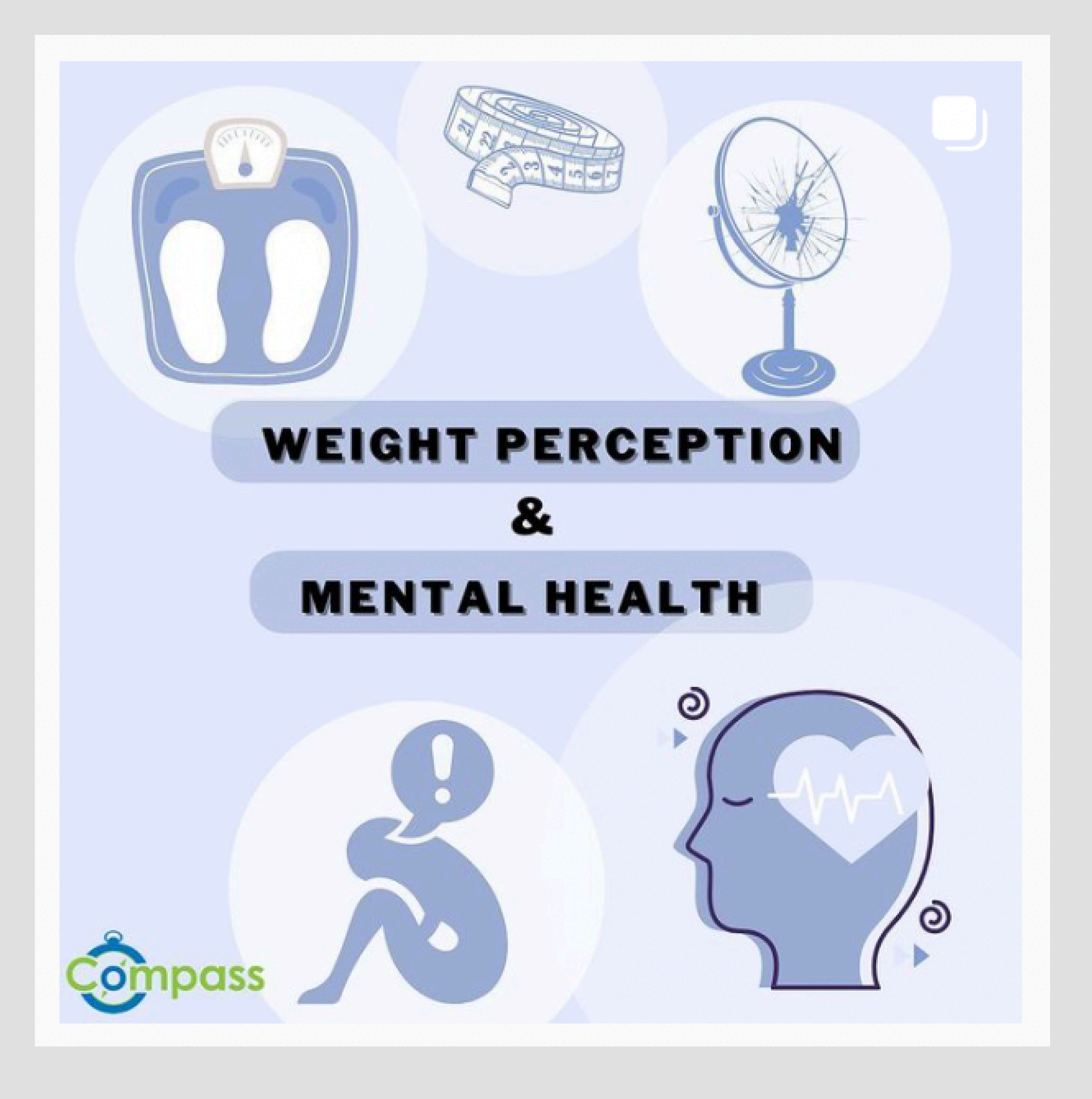

how active are you?
Compass


WEIGHT PERCEPTION
&
MENTAL HEALTH
Compass

Planning KTE/KMb Strategies

From the previous sections, it is clear that there is a need for **KTE/KMb** and that this work should be based on how and why **knowledge users** engage with knowledge, as well as recognizing the value in the different types of knowledge that **knowledge users** may bring to the **KTE/KMb** process (e.g., **context** and **content experts**). The question that arises now is how can individuals/teams effectively mobilize/translate their research/findings? The "how" of **KTE/KMb** is accomplished through what are commonly called **KTE/KMb** strategies.

Next, we will review different examples of and resources for **KTE/KMb** strategies. Please note that this is not an exhaustive list. Some research from the healthcare field has indicated that "so called "multifaceted" or complex interventions are more effective than "single" or simple interventions" (Kitson & Harvey, 2016, p. 295) in facilitating knowledge into policy and practice. That is, a single **KTE/KMb** strategy alone may not be enough to produce a meaningful and long-lasting impact.

Keep in mind when reviewing this section that **KTE/KMb** strategies should always be carefully selected based on the knowledge at hand, what is relevant to your **knowledge users**, and how your **knowledge users** actually access information. As noted above, **KTE/KMb** strategies should ideally involve some level of authentic exchange and engagement; consider what knowledge and information they have to contribute to the process. You should never select a **KTE/KMb** strategy because it is easy or popular; you need to mobilize/translate *with* and *for* your **knowledge users**. As we have learned, **KTE/KMb** is not a one-size fits all or unidirectional process; it is a collaborative process that should be unique to each team/project.

Examples and Resources

Research Summaries/Plain Language Summaries

Photo by Rawpixel on iStock

Gudi et al. (2021) define a **plain language summary** as a "synopsis of research findings written in an easily understandable way, so that even a lay audience would grasp the content" (p.1). As stated by Phipps and colleagues (2013) "research summaries come in many forms, including press releases, policy briefs, clinical practice guidelines, research fact sheets, knowledge briefs, and structured abstracts" (p. 3), and are documents that summarize research findings and potential implications in clear and concise ways, using plain language and clear examples (e.g., are written for non-academic audiences). There is some research indicating that research summaries may be effective tools for **KTE/KMb** work (Bredbenner & Simon, 2019), but the research is limited. Also, it is important to note that most academics/researchers do not have training in writing for non-academic audiences.

Deeper Dive

Please see this article by Gudi et al. (2021) on the role of plain language summaries in **KTE/KMb**:

- Gudi, S. K., Tiwari, K. K., & Panjwani, K. (2021). Plain-language summaries: An essential component to promote knowledge translation. *International Journal of Clinical Practice, 75*(6), e14140. Retrieved from https://onlinelibrary.wiley.com/doi/pdf/10.1111/ijcp.14140?casa_token=bigNzGsOilwAAAAA:SyhvqqAOt77bveLN63_3Uq4Cb2flOfwbwNz5B-TgsG8cx4x9bmOgIqU8q8gBPI_H_PDDEgJA7KKybosE

Please also see this article by Phipps and colleagues (2013) on the development of clear language research summaries for more information and background on this type of **KTE/KMb** work:

- Phipps, D., Jensen, K., Johnny, M., & Myers, G. (2013). A field note describing the development and dissemination of clear language research summaries for university-based knowledge mobilization. *Scholarly and Research Communication, 4*(1). Retrieved from https://src-online.ca/index.php/src/article/view/44

Infographics

Short for “information graphics”, **infographics** simply refers to visual/graphical depictions of information. Infographics generally exist on the age-old concept that “a picture is worth a thousand words”, and that humans have used images to display information/tell stories from even early cave paintings (Lankow, et al., 2012; Smiciklas, 2012). The process of creating infographics has been broadly referred to as **data visualization** (Smiciklas, 2012). Research has shown that infographics can generally help to explain and present complex information to external/broader groups (Smiciklas, 2012). In general, infographics' purpose is to "capture users' attention, help them better understand the information presented, increase their ability to retain and recall the message, and encourage them to act in accordance with the information" (Mc Sween-Cadieux, et al., 2021, p. 2). There have been numerous empirical studies of the use of infographics in the **KTE/KMb** field, and while no broader scoping review has been conducted, Mc Sween-Cadieux and colleagues (2021) state that that type of review is currently being undertaken and should be available in the future. In a study by Provvidenza and colleagues (2019) of the role of infographics in **KTE/KMb** around concussion education, students, teachers, and health care professionals reported that the infographics provided new knowledge and they intended to use them to educate others, but also that developing infographics collaboratively to appeal to different audiences and to share lived experiences of individuals with concussions would further enhance the impact.

There are numerous software options available to help support the creation of infographics, one excellent resource to start with is *Information is Beautiful.*

Deeper Dive

To take a deeper dive into infographics, below are some additional resources with further information on infographics:

- Lankow, J., Ritchie, J., & Crooks, R. (2012). *Infographics: The power of visual storytelling*. John Wiley & Sons.
- Mc Sween-Cadieux, E., Chabot, C., Fillol, A., Saha, T., & Dagenais, C. (2021). Use of infographics as a health-related knowledge translation tool: protocol for a scoping review. *BMJ open*, *11*(6), e046117.
- Provvidenza, C. F., Hartman, L. R., Carmichael, J., & Reed, N. (2019). Does a picture speak louder than words? The role of infographics as a concussion education strategy. *Journal of Visual Communication in Medicine*, *42*(3), 102-113.
- Smiciklas, M. (2012). *The power of infographics: Using pictures to communicate and connect with your audiences*. Que Publishing.

Graphical Abstracts

According to Elsevier (n.d.):

> Journals are increasingly requesting the submission of a “graphical” or “visual abstract” alongside the body of the article. This is a single, concise, pictorial and visual summary of the main findings of the article. It could either be the concluding figure from the article or better still a figure that is specially designed for the purpose, which captures the content of the article for readers at a single glance. (para. 1)

Research has shown that **graphical abstracts** may be effective at mobilizing/translating healthcare-focused research, particularly when disseminated via social media (Ibrahim et al., 2017; Chapman et al., 2019).

Deeper Dive

Please see this resource by Elsevier (n.d.) to take a deeper dive on graphical abstracts, how to create them, and examples:

- https://www.elsevier.com/authors/tools-and-resources/visual-abstract
- https://www.elsevier.com/connect/authors-update/vga

Social Media


Photo by gorodenkoff on iStock

Social media is a very broad type of **KTE/KMb** strategy, as there are numerous platforms and ways in which those platforms can be used. As noted by Phipps (2011), "social media can theoretically support a co-creation **KMb** method where researchers and their decision-maker partners go beyond exchanging knowledge to co-create knowledge" (p. 7), as it may allow for broader networking, engagement, and sharing across **context** and **content experts**. Reibling (2015) has outlined numerous recommendations for the effective use of social media in **KTE/KMb** work, including integrating social media throughout the research process, questions to consider for social media (e.g., "do I need an online presence" (p. 11)), considering your social identity, and considering your audience.

Deeper Dive

Please see this presentation by Reibling (2015) to take a deeper dive on the role of social media in **KTE/KMb**:

- Reibling, S. (2015). *Effective Use of Social Media For Knowledge Mobilization* [Presentation]. Knowledge Mobilization Institute Summer School 2015. https://www.slideshare.net/sreibling/reibling-effective-use-of-social-media-for-knowledge-mobilization

Here are some examples of **KTE/KMb** based social media accounts:

- https://twitter.com/kmbyork
- https://twitter.com/vlward
- https://twitter.com/mobilemobilizer
- https://twitter.com/implementsci
- https://twitter.com/kmbeing
- https://twitter.com/MelanieBarwick
- https://twitter.com/CIHR_IRSC

Arts-Based KTE/KMb

According to Kukkonen and Cooper (2019):

> **Arts-based knowledge translation (ABKT)** is a process that uses diverse art genres (e.g., visual arts, performing arts, creative writing, multimedia including video and photography) to communicate research with the goal of catalyzing dialogue, awareness, engagement, and advocacy to provide a foundation for social change on important societal issues. (p. 293)

In general, the 2021 UNESCO document *Imagining the Future of Knowledge Mobilization: Perspectives from UNESCO Chairs*, outlines several ABKT projects from across the globe, including using artwork to discuss the issue of poverty among homeless/street-involved women (p.72) and participatory videos for storytelling and action in Brazil (p. 74). Kukkonen and Cooper (2019) outline a four-stage planning framework for ABKT work of "(1) setting goals of ABKT by target audiences; (2) choosing art form, medium, dissemination strategies, and methods for collecting impact data; (3) building partnerships for co-production; and (4) assessing impact" (p. 293).

Deeper Dive

To take a deeper dive into AKBT, below are some additional resources with further information:

- Hewitt, T. (2021). *Imagining the Future of Knowledge Mobilization: Perspectives from UNESCO Chairs*. Canadian Commission for UNESCO. Retrieved from https://en.ccunesco.ca/-/media/Files/Unesco/Resources/2021/01/ImaginingFutureOfKnowledgeMobilization.pdf
- Kukkonen, T., & Cooper, A. (2019). An arts-based knowledge translation (ABKT) planning framework for researchers. *Evidence & Policy: A Journal of Research, Debate and Practice*, *15*(2), 293-311.

Policy Papers

As noted by Scotten (2011), “a policy paper is a research piece focusing on a specific policy issue that provides clear recommendations for policy makers” (slide 3). The general purpose of **policy papers** is to share knowledge/research on a specific policy issue in an easily accessible and understandable format, in order to inform a policy maker’s decisions around said issue (Scotten, 2011). Policy papers are typically written in plain language (which you will learn more about below) and are short documents which may be accompanied by **plain language summaries** of related research (Political Science Guide, 2017).

Deeper Dive

To take a deeper dive, below are some additional resources with further information on policy papers:

- Glover, D. J. (2002). What makes a good” policy paper”?: ten examples. *EEPSEA special paper/ IDRC. Regional Office for Southeast and East Asia, Economy and Environment Program for Southeast Asi* https://idl-bnc-idrc.dspacedirect.org/bitstream/handle/10625/27168/118102.pdf
- Herman, L. (2013). *Tips for Writing Policy Papers*. Stanford Law School. https://www-cdn.law.stanford.edu/wp-content/uploads/2015/04/White-Papers-Guidelines.pdf
- Political Science Guide. (2017, July 12). *Policy Paper | A Political Science Guid* A Political Science Guide | For students, researchers and others interested in doing the work of political science. https://politicalscienceguide.com/home/policy-paper/
- Scotten, A. (2011). *Writing Effective Policy Papers. Translating Academic Knowledge into Policy Solutions* [PowerPoint slides]. University of Arizona. https://cmes.arizona.edu/sites/cmes.arizona.edu/files/Effective%20Policy%20Paper%20Writing.pdf

Academic KTE/KMb

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Two general academic-oriented forms of **KTE/KMb** work include peer-reviewed journal publications and scholarly conference presentations. For both of these **KTE/KMb** strategies it is important to consider how to disseminate information more broadly in conjunction with academic **KTE/KMb** (e.g., a **graphical abstract** along with a journal publication).

Within all of the abovementioned strategies, having a dedicated facilitator role to support the knowledge-to-action process may be critical for **KTE/KMb** initiatives in a clinical setting (Kitson & Harvey, 2016). You will learn more about the importance of having staffing support for **KTE/KMb** in **Section 4: Other Key Considerations**.

Deeper Dive

There are numerous resources that can help to support **KTE/KMb** planning and the selection of strategies. We have included a non-exhaustive list of some of these resources below:

- Barwick, M. (2008). *Knowledge Translation Planning Template*. ON: The Hospital for Sick Children. Retrieved from https://www.sickkids.ca/en/learning/continuing-professional-development/knowledge-translation-training/knowledge-translation-planning-template-form/
- Briggs, G., Briggs, A., Whitmore, E., Maki, A., Ackerley, C., Maisonneuve, A., & Yordy, C. (n.d.). *Questing Your Way to a Knowledge Mobilization Strategy.* Retrieved from https://carleton.ca/communityfirst/wp-content/uploads/KMB-Questing-Your-Way-to-a-KMb-Strategy-Jun-29-2015.pdf
- Canadian Institutes of Health Research. (2012). *Guide to knowledge translation planning at CIHR: integrated and end-of-grant approaches*. Canadian Institutes of Health Research. Retrieved from https://cihr-irsc.gc.ca/e/45321.html
- Levin, B. (2008, May). Thinking about knowledge mobilization. In *an invitational symposium sponsored by the Canadian Council on Learning and the Social Sciences and Humanities Research Council of Canada* (pp. 15-18).
- Ontario Centre of Excellence for Child and Youth Mental Health. (n.d.). *Knowledge*

Mobilization Toolkit. Ottawa, Ontario. Retrieved from http://www.kmbtoolkit.ca

- Reardon, R., Lavis, J., & Gibson, J. (2006). *From research to practice: A knowledge transfer planning guide*. Retrieved from http://www.iwh.on.ca/from-research-to-practice
- Social Sciences and Humanities Research Council. (2019). *Guidelines for Effective Knowledge Mobilization*. Retrieved from https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge_mobilisation-mobilisation_des_connaissances-eng.aspx
- *How to build Your Knowledge Translation and Transfer (KTT) Plan*. (n.d.). Retrieved December 8, 2021, from http://www.omafra.gov.on.ca/english/research/ktt/kttplan/buildkttplan.htm
- Knowledge Translation Tools. (n.d.). *Melanie Barwick Consulting*. Retrieved December 8, 2021, from http://melaniebarwick.com/knowledge-translation-tools/
- Lavis, J. (2003, March 13). *How Can Research Organizations More Effectively Transfer Research Knowledge to Decision Makers?* [Presentation]. World Health Organization, Geneva, Switzerland. Available from: https://pdfs.semanticscholar.org/50c5/429ce338c7a9f2e69d080f1cfdaf96ab74b4.pdf
- Lavis, J., Robertson, D., Woodside, J., McLeod, C., & Abelson, J. (2003a). How can research organizations more effectively transfer research knowledge to decision makers? *Millbank Quarterly, 81*(2), 221-248. https://www.ncbi.nlm.nih.gov/pmc/articles/pmc2690219/
- Lavis, J., Ross, S., McLeod, C., & Gildner, A. (2003b). Measuring the impact of health research: Assessment and accountability in the health sector. Journal of Health Services Research Policy, 8(3), 165-70. https://www.researchgate.net/profile/John-Lavis/publication/10655602_Measuring_the_Impact_of_Health_Research/links/54a6da0e0cf256bf8bb6a772/Measuring-the-Impact-of-Health-Research.pdf
- Phipps, D. (2011). A report detailing the development of a university-based knowledge mobilization unit that enhances research outreach and engagement. *Scholarly and Research Communication, 2*(2).

Plain Language Communication

A key aspect of most **KTE/KMb** strategies is being able to communicate in accessible terminology, or what is often referred to as **plain language communication**. As outlined by Wicklund and Ramos (2009), “plain language is communication that an audience can understand the first time they read or hear it. It is clear and concise, and uses short sentences and simple words. It keeps to the facts and is easy to read and understand. Plain language is simple and direct but not simplistic or patronizing” (p.178).

Watch the video below on **plain language communication**:

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=65#oembed-1

Plain language communication has become increasingly important in several areas of today's society. For example, the United States has implemented the Plain Writing Act of 2010, which "requires federal agencies to write clear Government communication that the public can understand and use" (Quality AfHRa, 2016, para. 1). See more here.

In the healthcare field, work has demonstrated that communicating effectively/plainly may be critically important due to the varying (and sometimes limited) health literacy levels of patients/caregivers (Wicklund & Ramos, 2009). Moreover, some research has attempted to establish the "need for **plain language communication** as a core competency in medical education to enable providers to better meet the needs of an increasingly globalized health system" (Warde et al., 2018, p. 52). In the **KTE/KMb** field, **plain language communication** has become a cornerstone to most work, such as in research summaries/**plain language summaries**, which were previously outlined in this section. As noted in their work on **plain language summaries**, Gudi et al. (2021) state that "often, scientific papers are authored in a complex manner using technical terminology, especially jargons, which, indeed, makes it challenging, in fact, troublesome to understand for those outside of that field. On this account, to make the science more visible and accessible, various kinds of summaries such as **plain language summaries**, video abstracts, **graphical abstracts** and podcasts have come into action" (p. 1).

One activity that you can try to test your own **plain language communication** skills is using the online Simple Writer tool by Randall Munroe by going here. This online tool identifies if you have used a word that is not among the 10,000 most common words in the English language. While it is not a perfect tool for ensuring that you are communicating in accessible/equitable terms, it may be helpful for demonstrating the terms that you are using which may be too complex for a general audience.

Deeper Dive

To take a deeper dive into plain language communication, here are some additional resources that may help to support further learning:

- *Health Literacy Consulting—Helen Osborne*. (n.d.). Health Literacy Consulting. Retrieved October 22, 2021, from https://healthliteracy.com/
- Heath, C., & Heath, D. (2007). *Made to stick: Why some ideas survive and others die*. Random House LLC.
- *Plainlanguage.gov.* (n.d.). Retrieved October 22, 2021, from https://www.plainlanguage.gov/
- CBC Radio. (2021, April 13). *Say what? More jargon in a paper means fewer scientists will read it, study finds*. CBC Radio. https://www.cbc.ca/radio/asithappens/as-it-happens-tuesday-edition-1.5985611/say-what-more-jargon-in-a-paper-means-fewer-scientists-will-read-it-study-finds-1.5985613
- Centres for Disease Control. (2010). *Simply put; a guide for creating easy-to-understand materials*. (n.d.). Retrieved October 22, 2021, from https://stacks.cdc.gov/view/cdc/11938
- Goldstein, C. M., Murray, E. J., Beard, J., Schnoes, A. M., & Wang, M. L. (2020). Science communication in the Age of Misinformation. *Annals of Behavioral Medicine, 54*(12), 985-990.
- Plain Language at AHRQ. (2021, March). Agency for Healthcare Research and Quality, Rockville, MD. Retrieved Oct 22, 2021, from https://www.ahrq.gov/policy/electronic/plain-writing/index.html
- Wicklund, K., & Ramos, K. (2009). Plain language: effective communication in the health care setting. *Journal of Hospital Librarianship*, 9(2), 177-185.

Equity, Diversity, and Inclusion (EDI)

A very important aspect of developing **KTE/KMb** strategies is Equity, Diversity, and Inclusion (EDI). EDI refers to the following points (Please note that the below definitions come directly from the University of British Columbia Equity and Inclusion Office's Equity and Inclusion Glossary of Terms (n.d.) which is available here):

> **Equity** refers to achieving parity in policy, process, and outcomes for historically and/or currently underrepresented and/or marginalized people and groups while accounting for **diversity**. It considers power, access, opportunities, treatment, impacts, and outcomes, in three main areas:

- **Representational equity**: the proportional participation at all levels of an

    institution;
    - **Resource equity**: the distribution of resources in order to close equity gaps; and
    - **Equity-mindedness**: the demonstration of an awareness of, and willingness to, address **equity** issues.

> **Diversity** is a concept meant to convey the existence of difference. Differences in the lived experiences and perspectives of people that may include race, ethnicity, colour, ancestry, place of origin, political belief, religion, marital status, family status, physical disability, mental disability, sex, gender identity or expression, sexual orientation, age, class, and/or socio-economic situations.
>
> **Inclusion** is an active, intentional, and continuous process to address inequities in power and privilege, and build a respectful and diverse community that ensures welcoming spaces and opportunities to flourish for all.

Within the development of **KTE/KMb** strategies it is critically important to ensure that you have considered all aspects of EDI, such as: who do your selected images/examples/materials represent (and importantly who may not feel represented by them), have you authentically engaged relevant **context experts** in the selection and creation of your **KTE/KMb** strategies (within this you should also consider how to respectfully compensate individuals for this work and cite them within your materials), are your **KTE/KMb** materials accessible, how will you incorporate land acknowledgements into your work, etc.?

Please go to Chapter 2: Data for Equity? for more information about this topic.

Deeper Dive

To take a deeper dive into some resources that may help to support EDI considerations within your work on planning **KTE/KMb** strategies, use these:

- *Accessibility for Ontarians with Disabilities Act*, 2005, S.). 2005, c. 11 (2014, July 24). Ontario.Ca. https://www.ontario.ca/laws/statute/05a11
- A guide to Indigenous land acknowledgment. (2019, October 22). *Native Governance Center*. https://nativegov.org/a-guide-to-indigenous-land-acknowledgment/

- *Accessibility for Ontarians with Disabilities Act (AODA)*. (n.d.). Accessibility for Ontarians with Disabilities Act (AODA). Retrieved October 22, 2021, from https://www.aoda.ca/
- *Collaborating for Equity and Justice Toolkit*. (n.d.). Retrieved October 22, 2021, from https://myctb.org/wst/CEJ/Pages/home.aspx
- Girratana, M. (2021). Land Acknowledgement Practices: Functions, Efficacy, Controversy, and Union College. *The Charles Proteus Steinmetz Symposium*. https://digitalworks.union.edu/steinmetzsymposium/steinmetz_2021/oralpresentations/275
- Government of Canada. Best Practices in Equity, Diversity and Inclusion in Research. (2021, June 22). Retrieved October 22, 2021, from https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/edi-eng.aspx
- *Guide to Acknowledging First Peoples & Traditional Territory | CAUT*. (n.d.). Retrieved October 22, 2021, from https://www.caut.ca/content/guide-acknowledging-first-peoples-traditional-territory
- *Hayden King and others question the effectiveness of land acknowledgements*. (2019, January 29). The Eyeopener. Retrieved October 22, 2021, from https://theeyeopener.com/2019/01/hayden-king-and-others-question-the-effectiveness-of-land-acknowledgemenets/
- Web Accessibility Initiative (WAI). *Home*. Web Accessibility Initiative (WAI). Retrieved October 22, 2021, from https://www.w3.org/WAI/
- *Territory Acknowledgement*. (n.d.). Native-Land.Ca. Retrieved October 22, 2021, from https://native-land.ca/resources/territory-acknowledgement/
- Thomson, G. (2019, August 26). AODA Requirements for Educational Institutions. *Accessibility for Ontarians with Disabilities Act (AODA)*. https://www.aoda.ca/aoda-requirements-for-educational-institutions/
- U.S. Department of Arts and Culture. (2017, October 3). *#HonorNativeLand*. Retrieved October 22, 2021, from https://www.youtube.com/watch?v=ETOhNzBsiKA

Summary

KTE/KMb strategies are where all of your work comes together in the form of materials or initiatives that aim to spread your knowledge out to broader groups as well as engage with those groups. As outlined in this section, there are numerous **KTE/KMb** strategies that can be implemented, but these strategies are not one-size fits all approaches and need to be selected based on several factors (e.g., type of research, feedback from **context experts**, EDI considerations, budget, etc.). Additionally, individuals/groups should try to base their **KTE/KMb** strategies off of some form of equitable **knowledge exchange** with relevant groups/experts. Finally, this section touched on the importance of **plain language communication** when developing **KTE/KMb** strategies.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=65#h5p-10

Section 4: Other Key Considerations

DR. KAREN A. PATTE; JAYNE MORRISH; AND MEGAN MAGIER

Photo by [Glenn Carstens-Peters](#) on [Unsplash](#)

Section Objectives

By the end of this section, you will be able to understand several broad key considerations for KTE/KMb work, including:

- Evaluation;
- Budget/staffing considerations; and
- Careers in KTE/KMb.

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=67#h5p-12

Evaluation

Photo by Christin Hume on Unsplash

How do you know if your **KTE/KMb** work is going well? Are your **KTE/KMb** strategies having the intended impact, or any impact at all? How are your partners, **knowledge users** and collaborators feeling within the **KTE/KMb** process?

These are important questions to consider around **KTE/KMb** and one way to begin to answer them is through examining your **KTE/KMb** work and impact via evaluation. A broad understanding of evaluation comes from Mark et al. (2000), stating that evaluation is the rigorous collection of valuable, reliable, and useful information about a program or project for the purposes of one or more of the following: programs and organizational improvement, oversight and compliance, assessment of worth, and knowledge development. According to Patton (2008) – one of the leaders in the field of utilization-focused evaluation, evaluation involves “the systematic collection of information about the activities, characteristics, and outcomes of programs, for use by people to reduce uncertainties, improve effectiveness, and make decisions” (p. 39). Beyond these definitions, evaluation refers to the systematic process of ensuring that your work had the impact that it intended to have, looking for any unexpected impacts, and understanding why (or why not) your project had the outcomes/impacts that it did. As noted by Mark et al. (1999), evaluation can be thought of as "assisted sensemaking" (p. 179) which may help you understand where things are going well and where you may need to make some changes within your **KTE/KMb** work.

But how do you incorporate evaluation within your **KTE/KMb** work? There are numerous evaluation frameworks for **KTE/KMb**, and a full discussion of evaluation goes beyond the scope of this chapter, but below is a non-exhaustive list of some evaluation resources relevant for **KTE/KMb**. An excellent resource to start developing a general understanding of evaluation with the **KTE/KMb** process is by reviewing the *Evaluating KMb* section of the Ontario Centre of Excellence for Child and Youth Mental Health's online *KMb Toolkit*, which is available here. When reviewing the below resources, it is important to remember that the level, scope, and type of evaluation work needed for **KTE/KMb** is specific to each project, and not all **KTE/KMb** will have large evaluation components.

Deeper Dive

- Barwick, M.A. (2008, 2013, 2019). *Knowledge Translation Planning Template*. Ontario: The Hospital for Sick Children. https://www.sickkids.ca/en/learning/continuing-professional-development/knowledge-translation-training/knowledge-translation-planning-template-form/
- Bowen, S., and P.J. Martens. 2006. A model for collaborative evaluation of university-community partnerships. *J Epidemiol Community Health*. *60*(10):902–7.
- Bowen, S., Martens, P., & Need to Know Team. (2005). Demystifying knowledge translation: learning from the community. *Journal of Health Services Research & Policy, 10*(4), 203-211.
- Davison, C. M. (2009). Knowledge translation: Implications for evaluation. *New directions for evaluation*, 2009 (124), 75-87.
- Innoweave. (n.d.). *Developmental Evaluation self-assessment tool*. https://innoweave.ca/streams/developmental-evaluation/
- Levin, B. (2008, May). Thinking about knowledge mobilization. In an *invitational symposium sponsored by the Canadian Council on Learning and the Social Sciences and Humanities Research Council of Canada* (pp. 15-18).
- National Collaborating Centre for Methods and Tools. (n.d.). *Registry of Methods and Tools for Evidence-Informed Decision Making*. https://www.nccmt.ca/knowledge-repositories/registry
- Ontario Agri-Food Innovation Alliance. (n.d.). *KTT Plan Checklist*. https://www.uoguelph.ca/alliance/system/files/KTT%20Plan%20Evaluation%20Tips_2019.pdf
- Ontario Centre of Excellence for Child and Youth Mental Health. (2013). *Program Evaluation*

Toolkit. Ottawa, Ontario. https://www.cymh.ca/Modules/ResourceHub/?id=6d1cdf70-8a99-4432-aba6-e19862da6857

- Pencheon, D. (2008). *The Good Indicators Guide: Understanding how to use and choose indicators*. The NHS Institute for Innovation and Improvement. https://webarchive.nationalarchives.gov.uk/20170106081109/http://www.apho.org.uk/resource/item.aspx?RID=44584
- Phipps, D., Cummins, J., Pepler, D. J., Craig, W., & Cardinal, S. (2016). The co-produced pathway to impact describes knowledge mobilization processes. *Journal of Community Engagement and Scholarship, 9*(1), 5.
- Phipps, D.J., Johnny, M. and Poetz, A. (forthcoming) Demonstrating impact – considerations for collecting and communicating the evidence of impact. In *The Impactful Academic*. Ed. Wade Kelley. Emerald Publishing, Bingley, UK.
- Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies, and measures*. Austin, TX: Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research. https://ktdrr.org/ktlibrary/articles_pubs/ktmodels/index.html
- Tamarack Institute. (n.d.). *Evaluating Community Impact*. https://www.tamarackcommunity.ca/evaluatingcommunityimpact
- University of Calgary Knowledge Exchange team. (n.d.). *Knowledge Engagement Impact Assessment Toolkit*. https://research.ucalgary.ca/engage-research/knowledge-engagement/ke-toolkit
- Worton, S., Loomis, C., Pancer, S., Nelson, G., & Peters, R. D. (2017). Evidence to impact: A community knowledge mobilisation evaluation framework. *Gateways: International Journal of Community Research and Engagement, 10*, 121-142. https://epress.lib.uts.edu.au/journals/index.php/ijcre/article/view/5202/6046#

Resources – Budget and Staffing Considerations

Another important consideration within **KTE/KMb** work is the resources needed to fully carry out **KTE/KMb** plans. Two key resources are budget/funding and staffing.

Budget

Budget/funding generally refers to the cash and/or in-kind support to cover all of the expenses related to a project. Budget considerations are very specific to an individual project and may include various items such as:

- Salary/support for staff (see point below for more resources/information on staffing);
- Compensation for involvement of community partners/**stakeholders** (e.g., compensation or honoraria for time involved in **KTE/KMb**);
- Meeting costs (e.g., rental space, food, travel, facilitation etc.);
- Costs for developing and disseminating **KTE/KMb** projects/resources (e.g., creation, design, distribution, online hosting, event planning, etc.); and
- Conference and publication costs, including open-access fees.

Photo by Josh Appel on Unsplash

KTE/KMb should be planned and budgeted for within any relevant grant/funding application, and there are often **KTE/KMb** specific funding opportunities available from external funding agencies and within university and other institutional Research Office internal funding portfolios. Two examples of **KTE/KMb** specific funding include SSHRC's Connection Grants and the Ontario Ministry of Agriculture, Food and Rural Affairs (OMAFRA) KTT Mobilization Initiatives. Additionally, it is important to consider potential in-kind support from the institution where the research is based and partner/**stakeholders** around supporting **KTE/KMb** work (e.g., Marketing and communications support from your home institution's centralized marketing and communications team, or design support for **KTE/KMb** materials from a designer at a partner/**stakeholder** organization, etc.).

When planning a **KTE/KMb** budget, consider any rules and restrictions that may be in place by the funding source for a project. Working with your institution's research support team (e.g., Office of Research Services) may be helpful when determining the policies in place around allowable/relevant **KTE/KMb** costs and budget.

Staffing

Within the budget, salary and support for staff needs to be considered. Staffing for **KTE/KMb** work requires hiring the appropriate number of people with the appropriate skill sets to support a given project. The number and type of staff needed will differ from project to project, and will often fluctuate depending on the stage of **KTE/KMb** that a given project is in. For example, if a team is focusing on end-of-grant **KTE/KMb**, then they may not need **KTE/KMb** staffing until much later in a project, whereas a team focusing on integrated **KTE/KMb** would need **KTE/KMb** staffing support throughout. There are various roles within the broader **KTE/KMb** and communications sphere, and it is important to work to ensure that you have the correct type of staff/roles assigned within your own **KTE/KMb** work (Barwick et al., 2014). Funding for staff may come from external and/or internal resources, but once again, it is important to work with your own institution to understand the policies in place around funding for staff.

Careers in KTE/KMb

The expansion of **KTE/KMb** has led to new roles in the field. Consider how the **KTE/KMb** field may fit with your career planning.

Barwick and colleagues (2014) describe the following four general grouping of roles that are often mentioned within discussions of **KTE/KMb** and communications:

An interactive H5P element has been excluded from this version of the text. You can view it online here: *https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=67#h5p-13*

Beyond the above groupings, there are two typical avenues for careers that directly involve **KTE/KMb**:

1. The first avenue is *academic careers*, whereby you would be employed by an

academic institution (e.g., a university or college) and would either focus on **KTE/KMb** within your broad area of research, or would research **KTE/KMb** as a concept (e.g., [Vicky Ward](#)). An example of this would be the Research Based Knowledge Translation Practitioner described above. To progress in this area, it is generally recommended that academics work to build their capacity for **KTE/KMb** through training and continuing education, and have a direct focus on **KTE/KMb** within their research/projects.

2. The second avenue is *non-academic careers*, whereby you would be supporting **KTE/KMb** at an institution or organization. For example, an Institutional Knowledge Translation Practitioner as described above (e.g., a staff member tasked with guiding and informing **KTE/KMb** practices at an organization). Non-academic careers that include **KTE/KMb** are becoming increasingly available across sectors such as education, government/policy, social services, public health, and health care. To progress in this area, it is generally recommended that individuals work to build their capacity for **KTE/KMb** through training and continuing education, and connect with others in the field.

Deeper Dive

To take a deeper dive into **KTE/KMb** training and continuing education, as well as careers, try these:

- Knowledge Translation Canada: https://ktcanada.org
- The Canadian Knowledge Transfer and Exchange Community of Practice (KTECOP): https://www.ktecop.ca

Summary

This section outlined three broad key considerations for **KTE/KMb** work, specifically evaluation, the resources required to carry out **KTE/KMb** plans, and **KTE/KMb** roles for career planning. Evaluation generally refers to the rigorous tracking of the impact (expected and unexpected) of your **KTE/KMb** work. Several resources to support evaluation were listed within this section. The two resources described in this section were budget considerations (e.g., the funding needed) and staffing (e.g., the human capacity and skill sets needed). In terms of **KTE/KMb** roles, there are various avenues that one can explore to integrate this area into their careers.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=67#h5p-12

Deeper Dive

In addition to the resources cited throughout this chapter, these resources may support further learning around the entire **KTE/KMb** process across disciplines:

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CHAPTER 5: USING HEALTH ECONOMIC EVIDENCE TO INFORM DECISIONS ABOUT RESOURCE ALLOCATION

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Chapter Objectives

By the end of this chapter, you will be able to:

- **Demonstrate a broad, comprehensive understanding of data-driven evidence to inform resource allocation decisions in healthcare;**

- **Critically analyze a case study and synthesize information pertinent to setting priorities in long-term care (LTC) homes during the COVID-19 pandemic;**
- **Gain an understanding of the theoretical underpinnings of health economic evidence;**
- **Identify health economic measures (i.e., costs and outcomes) relevant to resource allocation decisions in healthcare; and**
- **Describe the perspective of economic evaluation and levels of stakeholder engagement in the decision-making process.**

Section 1: Introduction to Data-Driven Decisions and the Economics of Healthcare

DR. ASIF KHOWAJA AND KRISTIN MECHELSE

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Section Overview

In this section, you will be introduced to key terminologies pertinent to health economics and the role of data-driven decision-making for resource allocation in the **context** of long-term care (LTC) homes in Canada. This chapter uses long-term care throughout to illustrate the concepts of health economics that can also be applied to other health sectors as well.

Section Objectives

By the end of this section, you will be able to:

- **Briefly describe data-driven decision-making in healthcare;**
- **Gain an understanding of health economics data to inform resource allocation decisions;**
- **Critically appraise the information provided in a case study of COVID-19 in LTC homes in Ontario, Canada; and**
- **Identify issues pertinent to resource allocation decisions during the COVID-19 pandemic in LTC.**

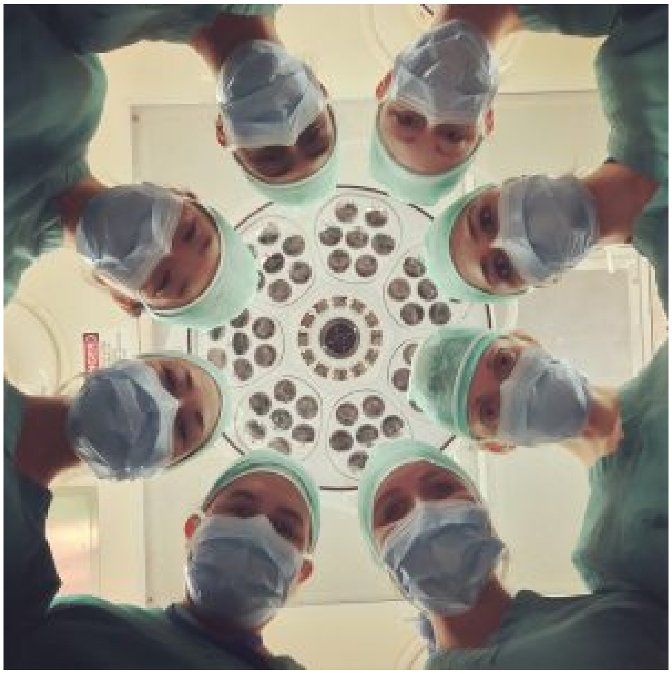
Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=77#h5p-26

Application of Data-Driven Evidence in Healthcare

Data-driven decisions refer to the use of scientific metrics, facts, and information to guide decision and policy-making to align with the overarching organizational goals and objectives (Provost & Fawcett, 2013). Real-time data pertinent to costs and health outcomes also plays a pivotal role in informing healthcare resource allocation decisions and guiding policies for maximizing the reach and quality of services in clinical and public health domains. To simplify, data-driven evidence not only addresses service delivery gaps but provides all the necessary information to increase healthcare efficiency.



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When formulating policies, health system planners, administrators, and care providers often utilize data pertinent to the costs of interventions and programs, patients' health outcomes, and quality of life. But one may ask, is it enough to simply know how much a given health technology program costs (in dollars) when making such decisions, or perhaps, do we need to know much more to make an informed decision? More importantly, health system stakeholders look for information that could affect costs and outcomes in healthcare. For example, when discussing the total cost of a given health technology over a long period of time, it is essential to consider other implementation factors such as additional training of healthcare providers, frequent patient follow-ups, and potential disruptions due to technology malfunctioning.

Externalities, such as environmental pollution, increase in productivity due to better health outcomes, and influence of social media on choices can also be factored into data-driven decisions. One example of externalities is the consequence of air pollution on society caused by a hospital's waste disposal process for plastic syringes, single-use gowns, surgical instruments, and sterile supplies. Therefore, externalities could play an important role in addressing why and how we allocate resources in healthcare. Thus, a comprehensive understanding of quantitative (i.e., frequency, proportion, mean, etc.) as well as qualitative data (voices, stories, perspectives, etc.) pertinent to externalities is the foundation of data-driven decision-making in healthcare.

Economics of Healthcare

Health economics is a branch of economics in which fundamental principles such as supply and demand, efficiency, program effectiveness, value-based services, and human behaviour in the provision and consumption of healthcare are studied (Parkin, 2017). More broadly, health economists evaluate healthcare interventions' design and implementation aspects to estimate a full spectrum of costs and outcomes. Health economic data (such as information about the frequency and extent of resource use) are primarily obtained from participants recruited in the healthcare settings or intervention groups, institutional financial reports, and consultation with implementing partners, funders, and community members directly and indirectly affected by the decision. Most importantly, we want to ensure that enough medical supplies are on hand (especially during a crisis), enough medical professionals are available to provide necessary care and services, appropriate medical technology is available to address emergencies, and an advanced supply is available for further necessities. The COVID-19 pandemic, however, has changed the landscape of decision-making in healthcare to become one in which decisions need to be made in the moment and are not necessarily based on previous experiences due to rapidly changing situations.

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Although this was not the first pandemic faced by humanity, organizations were ill-prepared for the novel coronavirus and therefore entered a vicious cycle of decision-making rooted in trial-and-error. To no surprise, health system planners and administrators were faced with issues related to resource scarcity and were compelled to make difficult choices such as disinvesting or redirecting resources in almost every health sector. Reflecting on situations emerging from the COVID-19 pandemic, we wonder if anything could have been done differently to balance the budget in healthcare or to reassess interventions and programs which drive higher costs but yield lower values? Of course, traditional economic principles of allocative efficiency can help organizations choose whether to procure a new piece of equipment such as a Magnetic Resonance Imaging (MRI) machine or to hire another staff member such as a clinical psychologist for providing mental health services at the hospital. However, this pandemic is challenging organizations to think outside the box and apply a broader health economics framework (via multi-criteria decision-making) to study short and long-term costs and the impacts of choosing wisely in healthcare. While living through the COVID-19 pandemic, we also realized that certain situations require decisions to be made on the spot (most of the time there was premature or no available evidence) suggesting wider implications for the healthcare system and society at large.

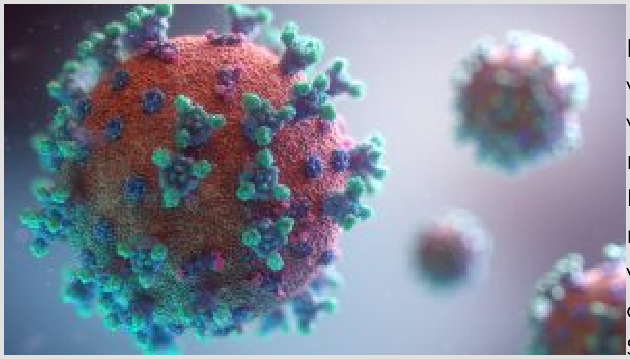
In this section, a case study is presented to highlight decisions made in the **context** of LTC homes during the COVID-19 pandemic, focusing specifically on LTC homes in Ontario, Canada. LTC homes are facilities where adults (mostly older adults) require and receive 24-hour nursing and personal care services which are typically not provided in a retirement home or supportive housing environment (Ministry of Health and Long-Term Care, 2022). The LTC system exists to support the advanced care needs of the elderly population and serve as residents' homes, where the elderly are able to live in a safe, secure, and comforting environment (Ministry of Health and Long-Term Care, 2020). For the purposes of this case study, information and examples provided are based on real-life experiences throughout the current COVID-19 pandemic in the LTC homes operated by the Regional Municipality of Niagara (Niagara Region), although many LTC homes may have had similar experiences or challenges.

CASE STUDY: The Chronicles of COVID-19 in LTC Homes

The COVID-19 pandemic was declared by the World Health Organization (WHO) on March 11th, 2020 (Detsky & Bogoch, 2020). This pandemic caused many challenges for those living in, working in, and visiting LTC homes, as this environment was hit incredibly hard with illness and death from COVID-19 due to rapid spreading of the virus, especially among residents with pre-existing health conditions. In an attempt to keep LTC residents safe, Ministry of LTC directives and public health regulations in Ontario were implemented and continuously updated as the pandemic progressed and as more information was released about the novel coronavirus.

Due to the pandemic, many restrictions were introduced into the LTC environment (e.g., social distancing, cohorting, increased infection-prevention and control practices, etc.), with one of the most significant measures being the temporary ceasing of all in-person visits for approximately three months from March to June of 2020 as well as additional periods of visitor restrictions where only those identified as Essential Caregivers were permitted. These restrictions led to some residents exhibiting increased rates of responsive behaviours and adverse mental health outcomes such as depression, anxiety, agitation, cognitive decline, and decreased social activity alongside the risk of social isolation.

Responsive behaviours represent meaningful responses to an environment and may reveal underlying concerns such as pain, loneliness, or not wishing to receive personal care and can be defined as the verbal or physical actions that can cause disruption or challenges to other people living in the environment (Song et al., 2019). Other examples of responsive behaviours include but are not limited to physical responses such as hitting, spitting, and resisting care, and verbal responses such as yelling, swearing, and crying.



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To address these mental health concerns and keep residents and families connected during the visitor restrictions that were put in place, virtual visits were implemented across all eight of the not-for-profit LTC homes operated by the Niagara Region (located in Ontario, Canada) as well as many other LTC homes across the country. Virtual visits consisted of technology-driven communication methods such as Facetime and Skype (or a variety of other social media applications), telephone calls, and emails as well as other activities such as handwritten letters and window visits where loved ones could see and communicate with residents from the safety of outdoors. Additionally, recreation staffing was increased in these LTC homes to help keep residents connected and engaged in activities of interest to support their mental health and well-being during this challenging time. Staff from other departments across the organization were also temporarily redeployed into the Niagara Region LTC homes to assist with these virtual visits, recreation programming opportunities, screening of staff and visitors, and additional high touch point cleaning.

Despite substantial financial investments in LTC, many LTC homes experienced devastating levels of loss of life of residents due to COVID-19. This brought to the forefront the need for increased care measures and additional expenditure capabilities granted by provincial and local governmental authorities such as the Ministry of LTC in Ontario and the Regional Municipality of Niagara (Niagara Region). In addition to financial support, emergency pandemic supplies were necessary, which meant keeping a larger supply of Personal Protective Equipment (PPE) on hand. PPE supplies included surgical masks, N95 masks, goggles, face shields, gowns, and gloves, as well as an increased supply of wipes and disinfectants. LTC homes were encouraged (whenever possible) to keep additional PPE supplies on hand because supply chains were detrimentally affected.

It is important to note that access to appropriate medical supplies was limited due to restrictions brought on by COVID-19 and the sheer volume of required supplies needed everywhere in the healthcare sector. Having additional supplies on hand helped to decrease staff anxiety levels, allow corrective measures to be followed throughout the pandemic, and prepare for further cases. However, in addition to supply concerns, we must also consider the human factor when we think of the challenges caused by COVID-19. One can imagine how difficult it must have been for LTC residents when they had to be isolated (for up to 14 days at a time) due to either experiencing possible symptoms of COVID-19, testing positive for COVID-19, being exposed to someone who contracted COVID-19, returning from hospital requiring a mandatory isolation period, or just because of the changing directives put in place to keep them safe. Imagine how emotionally and physically exhausting it must have been for the staff working in these LTC facilities, as well as for the family members and residents that were temporarily separated. Also consider the financial costs associated with the supplies and human resources necessary to support the Ministry of LTC and public health directives, especially in situations when there were cases of COVID-19 present in the LTC home.

Emerging Problems and Mitigation Strategies

Throughout the COVID-19 pandemic, healthcare costs have been rising dramatically, particularly in LTC. This is mainly because of increased demand for staffing (including nursing and recreation staff as well as staffing from other departments), supplies, and technological needs associated with medical care and social connections (Estabrooks et al. 2020). In order to conceptualize this problem, it is crucial to understand that prior to the COVID-19 pandemic, most decisions were budget-driven; however, during the pandemic, some decisions were made by prioritizing safety over budget. For example, although not included in the allocated annual budget, the number of staffing hours in each department was temporarily increased in the LTC homes operated by the Niagara Region during different waves of the pandemic (including support from redeployed staff) to ensure appropriate levels of care could be provided if/when staffing challenges were present. The Niagara Region was fortunate to be able to utilize these additional human resources to ensure residents' needs were met and share the financial burden across the organization in combination with the additional funds provided by the Ministry of LTC.

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LTC homes everywhere were challenged with staffing shortages due to a variety of reasons such as ministry directives, which required staff to only work in one care environment for a period of time, lengthy periods of isolation and outbreaks as well as the implementation of a mandatory COVID-19 vaccination policy which saw some staff choosing layoffs or termination rather than becoming vaccinated. Due to these requirements and outcomes, many LTC homes were trying to hire additional staff from all disciplines as were other healthcare sectors such as hospitals which presented additional human resource challenges across the entire healthcare system. In addition to staffing challenges, a large number of pandemic supplies were needed and purchased causing increased demand for supplies across the entire healthcare sector. Fortunately, the Niagara Region had pandemic supplies in place as part of an organized pandemic plan that was put into place after SARS which immensely helped with the supply challenges experienced.

On a positive note, there is emerging evidence that shows increasing staffing and programming opportunities can positively impact or improve residents' well-being and mental health outcomes (Bethell et al. 2021). A recent study conducted at Upper Canada Lodge in Niagara-on-the-Lake, Ontario, Canada (which is one of eight LTC homes operated by the Niagara Region) indicated that the increased level of recreation staff improved the mental health outcomes of residents by decreasing responsive behaviours and improving overall wellness. It was observed that as residents connected more with staff and their family members amidst the pandemic restrictions, these closer relationships and communications led to residents exhibiting positive behaviours, healthy relationships, and efforts towards their personal growth. It was determined that these interventions helped to minimize anxiety and worry about loved ones, and therefore residents experienced decreased rates of depression. Residents with little to no levels of depression were also positively affected by the increased recreation staffing and activities provided.

The findings from this project highlight substantial financial implications for LTC homes and the wider health system in the Niagara Region, and elsewhere. It is important to note that budget decisions for staffing (in all departments including programs and support services) and supplies is allocated by the Ministry of LTC, therefore, in order to appropriately address all tangible needs of LTC homes throughout the pandemic and beyond, further conversations, advocacy, and planning are required because of supply chains and the increased need and demand for resources across the country. Assuming that allocation of resources was made pre-pandemic, how could we possibly prepare for a tragedy like the COVID-19 pandemic without going over the financial resources that were allocated? Would this even be possible?

The reality is that the entire world was experiencing this pandemic, thereby demanding supplies and resources (driving up supply and demand), struggling to retain and hire staff, and requiring additional funding to maintain operations was a much larger challenge than anyone could have imagined (O'Sullivan et al. 2021). In addition, robust data on costs relative to improved health outcomes is required to demonstrate the economic impact and cost-effectiveness of health interventions such as the increased recreation staffing, particularly in a situation such as a pandemic. Demonstrating documented decreases in responsive behaviours, improved depression rating scales and decreased falls across the organization while recreation staffing levels were increased would help direct best practice decisions in the future. Further preparing for contingencies and reinforcing the importance of designating appropriate resources to create better health and well-being outcomes will be increasingly important. Demonstrating cost-effectiveness can highlight how certain health interventions prove futile as new interventions emerge. For example, the expansion of recreation staffing during the pandemic highlighted the positive outcomes experienced during this difficult time by keeping residents engaged and connected so why would we not want to find ways to increase recreation staffing on a permanent basis so our residents can always have these additional opportunities? In the subsequent sections of this chapter, we will shed light on key theoretical as well as translational aspects of health economics and how this relates to data-driven decisions in the **context** of LTC.

Summary

Data-driven decisions in healthcare encompass a wide array of information processing, analyses, and interpretations that seek to lower costs and maximize health gains for patients, care providers, and health system administrators/planners. However, the COVID-19 pandemic challenged the decision-making dynamics associated with resource scarcity and information gaps. Thus, preventing the morbidity, mortality, and adverse mental and physical health outcomes brought on by COVID-19 were mitigated alongside the rising healthcare costs to allow for safer and more optimal outcomes for residents in LTC homes. The road to recovery from the COVID-19 pandemic will continue to rely heavily on emerging data, further preparing for contingencies alongside designating necessary resources and demonstrating the cost-effectiveness of current and new healthcare interventions.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=77#h5p-26

Section 2: Introduction to Health Economics Principles and Theories Pertinent to Decision-Making in Long-Term Care

DR. ASIF KHOWAJA AND KRISTIN MECHELSE

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Section Overview

In this section, you will be introduced to health economics principles and theories to better understand the decision-making **context** in LTC homes.

Section Objectives

By the end of this section, you will be able to:

- **Gain an understanding of the key elements associated with welfare economics;**
- **Recognize macro and micro-economic aspects; and**
- **Identify and define types of healthcare financing perspectives.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

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Theoretical Foundations: Economics of Healthcare

Welfare economics refers to resource and finance allocation to maximize social welfare of community members in the society at large (Sen et al., 2020). In healthcare, welfare economics relates to the allocative efficiency – the ability to choose between two or more alternatives based on the evidence of cost relative to health gain (Paulden et al., 2014). For example, the number of lives saved from a health education program to prevent motor vehicle accidents costs $10,000 per life saved. If another maternal and newborn health promotion program is less expensive and saves more lives (i.e., $5000 per life saved), this may be considered a better investment option based on the principle of allocative efficiency. In contrast, technical efficiency refers to maximizing the reach and scale-up of health interventions while lowering costs (Akazili et al., 2008). For example, the decision-makers would explore various strategies to increase the vaccine coverage from 70% to 95% in a given population while controlling (or preventing) additional program expenses. It is imperative to understand the fundamentals of welfare economics and how these factors affect the healthcare decision-making process.


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Firstly, welfare economics is interwoven with utility, which aims to study the perceived value of healthcare services or interventions. In the free market, individuals can maximize their utility by virtue of purchasing goods or consuming services based on their affordability. However, unlike commercial economics, in which buyers and sellers make informed choices, patients or general members of the public often lack sufficient knowledge about medical conditions and illness and the nature of treatment modalities, including the provision of health services, drugs, and technologies (Major, 2019). For example, an elderly person diagnosed with dementia may not be in a position to decide the best course of treatment or efficacy of other alternatives. In this case, patients and their family members (who are often a substitute decision maker) often rely on the knowledge and expertise of healthcare providers to recommend the best possible treatment.

Secondly, welfare economics is rooted in the laws of supply and demand of goods and services. According to this theory, buyers will demand fewer goods and services at a higher price. In contrast, almost all healthcare services are considered essential, and patients want to get the highest possible standard of care. In situations when drugs, supplies, and technologies are not covered by public health (universal) and/or health insurance (selected services), patients and their family members are expected to pay out-of-pocket for these services (Markit, 2017). In the worst-case scenario (in the absence of universal healthcare or health insurance), people may be denied essential health services if they cannot afford to pay for these services.

This often leads to issues related to access, availability, and affordability depending on what is (or is not) covered and who is (or is not) eligible to receive these services.

The Role of Macro and Micro-Economics in Healthcare

Macroeconomics is a branch of economics concerned with large-scale or general economic factors, such as interest rates and national productivity (Eichenbaum et al., 2021). For example, macroeconomics is used to determine that as the world's population increasingly ages and the elderly population becomes exceedingly larger, there is a need for more LTC facilities on a national level.

In comparison, microeconomics is a branch of economics used to study the behaviour of individuals and interactions between buyers and sellers regarding choices made for consumption and/or allocation of scarce resources (Moore and Coddington, 2018). For example, in LTC, the decision to hire more recreation staff and invest in social technologies is often based on price, quantity, and quality of care.

The differentiation between macro-economics versus micro-economics, however, is important because the latter puts a significantly larger financial stress (opportunity cost) for institutions at the grassroots level. For example, the pandemic required LTC homes to make additional budgetary allocations to mitigate potential risks and to improve health outcomes among residents such as increasing staffing levels and ongoing purchasing of much higher amounts of PPE. But how can you put a dollar figure on such important improvements that positively affect the quality of life for residents living in LTC? The reality is that increased staffing and PPE was a necessity that had to be implemented, whether the funds to cover these additional costs were available or not. Finding ways to maintain or possibly increase the staffing levels that were implemented during the COVID-19 pandemic due to the improvements that were experienced would be an important consideration for future discussions.

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Financial Perspectives

At the micro-level, financial spending could be better understood using four perspectives in the context of Canadian healthcare system. Therefore, the economic perspective is one of the important considerations when calculating the costs and outcomes of healthcare interventions. There are four major perspectives of health economic evidence relating to the healthcare **context** in Canada: (1) Public payer perspective; (2) Patient/family perspective; (3) Third-party payer (insurance provider) perspective; and (4) Societal perspective (Glied, 2008).

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Summary

Allocating resources based on **equity** or fairness are deeply rooted in welfare economics. For example, deciding who (different types of patients with varying levels of disease severity) gets what (the type and amount of funding) and when (now or later) depends on factors associated with the supply and demand, utility, and efficiency principles. At the **macro-level**, budget and policies are geared to maximize the public good at a societal level. However, financial decisions and policies at the **micro-level** primarily affect how individuals receive care in acute and/or chronic health facilities. The public payer perspective is often preferred in universal healthcare in which the single public-payer pays a vast majority of costs. However, in settings where a big chunk of health service delivery happens in the private sector, the patient-payer perspective is needed. Overall, it is important to understand how decision-making affects everyone using fundamental health economics principles and theories covered in the section above.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=347#h5p-27

Section 3: Overview of Health Economics Data Including Costs and Outcome Measures

DR. ASIF KHOWAJA AND KRISTIN MECHELSE

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Section Overview

In this section, you will be introduced to costs and outcome measures reported in health economics literature supporting decisions of resource allocation. The terminologies are described with examples in the **context** of LTC homes in Canada.

Section Objectives

By the end of this section, you will be able to:

- **Describe the commonly reported financial and opportunity costs of programs in healthcare; and**
- **Describe the commonly used outcome measures in health economics modeling.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=354#h5p-28

Health Economics Data

Health economics data refer to costs and outcome measures which are commonly reported in the literature surrounding decision-making in healthcare. A comprehensive understanding of costs and outcomes data are important to inform policy decisions for allocating resources in healthcare (Fuchs, 2000). Table 5.1 presents various types of cost data and relevant examples in the **context** of LTC homes in Canada.

Table 5.1 Cost Data with Descriptions and Examples in the Context of Canadian LTC Homes

Cost Data	Description	Example in the Context of Canadian LTC Homes
Direct Medical Costs	The direct medical costs refer to patient care such as diagnostic, in-patient hospitalization, procedures and/or interventions, and ambulatory visits for acute, chronic or follow-up care. In Canada, there is a universal healthcare system and the direct medical costs are almost entirely (except drugs and certain cosmetic procedures) paid by a public payer (O'Brien et al. 2001).	Programs and services associated with the LTC home, such as nursing, physiotherapy and recreation services, are examples of direct medical costs.
Indirect Medical Costs	The indirect costs refer to a wide range of other costs (albeit not directly related to patient care) that are important in providing and utilizing healthcare services. For example, overhead costs associated with human resources, volunteer services, hydro, heating, laundry, information technology, maintenance, etc. Additionally, vulnerable patients (e.g., children, older adults, and people with chronic conditions) may require assistance from a family member or friend to accompany them to and from the hospital. Therefore, if somebody in the family is taking time off from work to accompany a patient to and from the hospital, these are also considered indirect medical costs (Merkesdal et al., 2001).	Everyday expenses such as heating, electricity, office supplies, entertainment programs, food costs, and iPads (technological devices used for resident communications, programming opportunities, and online medical appointments) are examples of indirect medical costs.

Incremental Cost	The incremental cost represents the additional cost incurred due to providing one service over another. The incremental cost looks at the differential between a new program and an old or existing program cost. For example, a recent study reported incremental frailty costs of $10,845 for persons with and without dementia in residents aged 50 years or older in Ontario (Mondor et al., 2019).	A new Wound Care Application was purchased and introduced in the Niagara Region LTC homes. This application allows registered staff to photograph, measure and track worsening or improvement of wounds and share this information with other members of the interdisciplinary healthcare team. Prior to introducing this application, wounds were manually measured, could not be shared and allowed room for human error. Utilizing the new approach and moving on from the older one represents an example of a relatively higher incremental cost.
Marginal Costs	The marginal cost is the cost of producing one more unit of a good or service (Jackson et al. 2011). For example, inviting one additional participant to join in a lifestyle modification program or treating one additional patient with a new drug or health technology.	During the COVID-19 pandemic, the Niagara Region LTC homes provided additional recreation staff (work hours) to engage residents in day-to-day activities and to improve mental health outcomes. The marginal increase in recreation hours was deemed necessary to keep residents and family members connected and engaged as the pandemic continued. For example, a part-time staff member that was typically scheduled to work 16 hours per week was offered to work up to 40 hours per week (in this case an additional 24 hours = approximately $600 per week). Each home may have different staffing capabilities based on many variables but this is an example of a marginal cost.

Intangible Costs	The intangible costs represent expenses associated with the pain, anxiety, or distress of receiving treatment or participating in the healthcare program. Traditionally, intangible costs are not explicitly captured in the economic evaluation of public health interventions (Inter-Parliamentary Union, 2008).	Emotional costs such as pain or anxiety suffered by residents from not being able to see their family members during the pandemic-imposed visitor restrictions are an example of an intangible cost that is immeasurable and cannot be itemized.
Fixed Costs	This refers to fixed capital and overhead costs, like furniture, fixtures, or buildings which do not depend on the level of activity and are usually incurred by the facility regardless of people or patients attending the program (Roberts et al., 1999).	Upfront capital costs for purchasing diagnostic or technological devices in LTC homes are examples of fixed costs.
Variable Costs	The variable costs refer to expenses depending on the amount of activity and/or frequency of services (Roberts et al., 1999). For example, patients hospitalized due to severe respiratory problems may need more frequent testing as opposed to non-severe patients with the same medical diagnosis. The variable costs are also affected by the change in demand and supply of services.	The Niagara Region contracted personal protective equipment (PPE) supplies where costs increased from $0.03 to up to $1.25 per surgical mask during the pandemic due to overwhelming demand and limited supply (an increase of almost 42x the contracted price). This is an example of variable costs.

Commonly Reported Outcome Measures

In order to evaluate the cost-effectiveness of healthcare interventions (i.e., bang for the buck), it is critical to use appropriate outcome measures when evaluating healthcare programs. Researchers often model a wide range of clinical and non-clinical outcome measures in the economic evaluation of healthcare interventions. Table 5.2 presents commonly used outcome measures for decisions on resource allocation and relevant examples in the **context** of LTC homes in Canada.

Table 5.2 Outcomes Measures with Descriptions and Examples in the Context of Canadian LTC Homes

Outcome Measures	Description	Example in the Context of Canadian LTC Homes
Health-Related Quality of Life	The health-related quality of life represents a generic measure of well-being which is measured as quality-adjusted life years (QALY). The QALY ranges from 0 (representing death) and 1 (representing one year of perfect health). Thus, measuring QALY takes into account the quality and quantity of life years lived (Vergel & Sculpher, 2008).	In a previously conducted quality improvement study in long-term care homes, reducing the inappropriate use of antipsychotic medications was found to have higher QALYs (mean score of 0.859) compared to residents in the control group (Khowaja et al., 2021).
Quality of Care	Quality of care represents generic measures and/or disease-specific indicators related to the effectiveness, efficiency, safety, **equity**, and time-to-diagnosis or provision of treatment (Van Servellen et al., 2006). The continuity or quality of care measures could be used either as primary or secondary outcome measures depending on the research question under investigation.	Health economics studies conducted in LTC homes report quality of care variables such as the number of falls or injuries prevented (Patterson et al., 2011; Hewitt et al., 2019), length of hospital stay avoided (Stern et al., 2011), cognitive improvement (Twigg et al., 2019), reduction in the disease incidence (Makai et al., 2010), and infection prevention (Cohen et al., 2016).

Summary

The economic analysis of healthcare interventions requires a thorough understanding of all the necessary costs and outcome measures of the healthcare program. The program development often presents fixed costs which are usually paid up front. However, the variable costs (operating costs) of healthcare programs can vary over a long period of time, and this is a crucial consideration for health promotion or disease prevention programs that yield an impact in the long term. It is not uncommon that clinicians would prefer to see the cost relative to health gains (i.e., clinical improvement) in patients treated with a new program compared to standard care. In addition, quality of life or health-related quality measures generally provide a generic measure that combines health and quality of life, which are more comparable outcome measures between different health programs. The decision to include clinical or other non-clinical outcome measures depend on the nature of the healthcare intervention and the time frame to assess the relevant outcomes.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=354#h5p-28

Section 4: Stakeholder Engagement in Resource Allocation Decision-Making

DR. ASIF KHOWAJA AND KRISTIN MECHELSE

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Section Overview

In this section, you will be introduced to the stakeholder engagement and how decisions affect patients, care providers, and policy makers at different levels in healthcare.

Section Objectives

By the end of this section, you will be able to:

- **Describe the role of stakeholders;**
- **Gain an understanding of levels of decision-making in healthcare; and**
- **Critically appraise the role of resident-centered care approaches in terms of resource allocation.**

Test Your Knowledge

Complete the following activity to assess how much you already know about the content that will be covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=75#h5p-29

Engaging Stakeholders in Resource Allocation Decisions

Resource allocation decision-making occurs at multiple levels and requires stakeholders from both health and non-health settings. There are three important levels of decision-making: **micro**, **meso**, and **macro levels** (Guindo, et al., 2012).

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Traditionally, decisions in LTC are made from a **macro-level** perspective where processes and policies have been directed from higher authorities (e.g., Ministry of LTC) and are expected to be followed by those on the ground (Kapiriri et al., 2007). Resource allocation in this environment can pertain to healthcare resources and human resources. In contrast, the LTC home management or administrative staff, which are at the **meso-level**, are responsible for developing need-driven criteria to make resource allocation decisions. One problem that has been brought to the forefront during the COVID-19 pandemic is that residents in LTC and/or their family/substitute decision-makers should have been more involved in some of the decision-making processes (**micro-level**), such as requirements for visiting (whenever possible; understanding that many decisions were made based on safety and were time-sensitive in nature), as these stakeholders were most affected by illness and death as well as the pandemic restrictions that were put into place. Meso-level decision-making in LTC during the pandemic was mainly utilized while interpreting and implementing the directives from the Ministry of LTC as homes were directed what to do, not necessarily how to do it.


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Focusing on the most affected stakeholder (i.e., the resident) is referred to as resident-centred care and should drive decision-making in LTC. (Scott et al., 2001). The Ontario Association of Residents' Councils (OARC) recently took this resident-centred care approach to seek input into vaccination requirements for visitors entering LTC homes (Fleming, 2018). The OARC promotes the vision that every long-term care resident in Ontario shapes the place they call home. This is achieved through ongoing communication, meaningful engagement, and collaboration between residents, their Residents' Councils, and their LTC teams (OARC, 2022).

Knowing that mandatory vaccination policies have now been implemented for all staff working in LTC in Ontario, the OARC posed questions via an online survey as to whether residents wished for all visitors to be fully vaccinated to be granted access into LTC homes. Involving residents in this discussion and decision-making process considered the intangible costs experienced in LTC and included these very important stakeholders in the dialogue. Results from the survey were not released but the directive released from the Ministry of LTC a few weeks after the survey was launched stated that all visitors coming into LTC homes required full vaccination (i.e., a minimum of 2 doses of an approved COVID-19 vaccine) to be granted entry. Seeking residents' input was a novel process implemented by the OARC as it provided residents with an opportunity to be heard and included in decisions that directly affect them while also highlighting the importance of keeping the lines of communication open from the top down.

All stakeholders and decision-makers need to understand the working environment of LTC – LTC settings are home to a variety of residents (18 years of age and older but mostly elderly residents) where they live, eat, socialize, and receive immediate care 24-hours a day. This needs to be considered and respected at all times, as residents in LTC homes are valued members of the community with voices that deserve to be heard and consulted. LTC homes are required to have Residents' Councils where residents have the opportunity to bring forward any questions or concerns that they may have, to be informed of changes that are taking place in the home (including discussions about costs associated with LTC), and to be involved in the decision-making process. Moving forward, all LTC homes should prioritize seeking input from these stakeholders for all decision-making processes. Whether decisions are sought regarding food items on the menu, how often to have Residents' Council meetings, what safety measures need to be put in place, or where Ministry funding should be directed, residents' opinions and insight should be included without exception. The motto used in the Niagara Region LTC homes is "nothing about me, without me" which is a great example of resident-centred care and supports the vision of the OARC.

Summary

Resource allocation is a process that requires thorough consideration of various levels of the stakeholders in both healthcare and non-healthcare settings. It is imperative to understand that each level has its own perspective of the decision-making process and its function. For example, during the COVID-19 pandemic, special consideration was given to the residents of the LTC homes by involving them in the discussions at a higher level. Previously, LTC homes were required to have Residents' Councils and hold regular meetings; however, this was even more necessary during the pandemic so that information regarding restrictions and regulations could be communicated to those who wished to participate and have a greater understanding of the changes as they occurred. This allowed them to partake in meetings related to decisions made about their livelihoods, which empowered them and their sense of control, thus contributing to more satisfied stakeholders. Therefore, moving forward, it is imperative to create pathways to integrate all stakeholders in the decision-making process, specifically the ones directly affected by the policies in place.

Test Your Knowledge

Complete the following activity to assess how much you learned about the content that was covered in this section.

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://ecampusontario.pressbooks.pub/drivingchangeinthehealthsectoranintegratedapproach/?p=75#h5p-29

Chapter Summary

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It is imperative that resource allocation decisions are based on health economic evidence and that contingencies are planned for in the future. It is inevitable that we will face another worldwide tragedy like the COVID-19 pandemic, but we will hopefully not make the same mistakes and can learn from this experience moving forward. As learned in this chapter, LTC homes in Canada (and across the world) have suffered on numerous fronts throughout this pandemic – the outbreaks, deaths, supply, and staffing shortages have highlighted the need for drastic changes in LTC. If this pandemic has taught us anything, it is that we need to look more closely at existing processes, direct more appropriate funding to help fix the neglected healthcare system, and provide the necessary human resources to support LTC homes to prevent this from happening again.

The Ministry of LTC has recently made funding commitments for the next 3 years to assist with increasing the number of direct hours of care; infection, prevention and control measures (IPAC) as well as additional support to programs and services. The Niagara Region LTC homes are currently in the process of creating many new frontline positions with this necessary funding (e.g., Personal Support Workers, Registered Nurses, Registered Practical Nurses, recreation staff). Ultimately, we need to do everything possible to provide the support and quality of care that the residents in these facilities deserve and this additional funding will be a positive step in the right direction.

In addition, the dedicated and compassionate staff that work in healthcare deserve recognition and appreciation for all they have done and will continue to do to provide the best level of care and support possible for residents in LTC during an incredibly challenging time. These staff have been called healthcare heroes, but most would say they work in this environment because they want to help others and give back, not to receive recognition or praise. The best outcome of this pandemic would be that additional staffing and safer working conditions are made top priorities. If the Canadian and/or provincial government continues to increase the financial support provided to LTC homes as promised, this could help turn a tragedy into a world of new possibilities. Together, we need to find new and creative ways to use the health economic evidence learned in this chapter to inform decisions about resource allocation and set out to truly make a difference in the lives of those who need and deserve the best care and quality of life possible.

Overall, health economics evidence could play a pivotal role in informing stakeholders at all levels of the costs and relative health gains (or losses) of interventions in healthcare. Undoubtedly, our healthcare needs are rising as we live through the COVID-19 pandemic, however, other similar pandemics will continue to impose a significant challenge of ever-rising healthcare needs in Canada and globally. Consequently, healthcare costs continue to surpass the historical expenditure trends, and future pandemics will make funding choices even more difficult. Thus, there are substantial implications for data-driven decisions based on comprehensive costs and health outcomes in healthcare.

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Jayne Morrish is the Knowledge Mobilization Officer at Brock University's Office of Research Services, where she supports Brock's Lifespan Development Research Institute. In her role, Jayne leads knowledge mobilization, partnership work, capacity building and community engagement initiatives – focusing on building support and connections around the research of Lifespan Institute members and their students. Jayne has completed a SSHRC funded Master's Degree in Lifespan Development from Brock University, a Bachelors of Health from York University, the Knowledge Translation Professional Certificate from the University of Toronto, the Mobilize YU Certificate from York University, and the Leadership Niagara Certificate.

Kristin Mechelse, BRLS

NIAGARA REGION

Kristin Mechelse is the Long-Term Care Program Manager at Upper Canada Lodge (Niagara Region) and holds a Bachelor of Recreation and Leisure Studies from Brock University as well as a Diploma in Recreation and Leisure Studies from Niagara College, and has worked in long-term care for 26 years. In her current role, Mrs. Mechelse is passionate about implementing new ways to improve residents' quality of life and makes resource allocation decisions through evidence-based research and best practices in all dimensions of care relating to recreation programming. She is also the Health & Safety Management Co-Lead in her home, is a Certified Joint Health and Safety Committee Member through the Ministry of Labour (Long-Term Health Care Sector Specific) and supports the belief that by working together and sharing responsibility for health and safety, workers, supervisors and employers can reduce the number of injuries, illnesses and fatalities in our workplace.

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Noah James is in the Bachelor of Science (Honours) in Medical Sciences program at Brock University. He plans to continue his education in a Master of Science program. Noah is interested in improving the healthcare system by using evidence and data. He is also interested in connecting health information across the continuum of care to enhance patient experience and continuity of care.

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Lidia Mateus is a graduate student at Brock University. She works in the field of health sciences with an emphasis on virtual care and the use of quality improvement in clinical practice. Lidia's work has been presented at a number of conferences including the Canadian Association of Emergency Physicians Conference and the Canadian Association for Health Services and Policy Research Conference.

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Dr. Kelly A. Pilato is a Research Associate in the Department of Health Sciences at Brock University. Kelly's research is focused on evidence-based policy development and implementation as a framework for enhancing health at a population level. Her work is applied in nature and contributes to scientific knowledge related to policies with real-world impacts that support the health and wellness of a given population within the context of their lives and social determinants of health. She has experience in both quantitative and qualitative research methods, scoping reviews, systematic, and rapid reviews.

Glossary

Accreditation

The action or process of officially recognizing someone as having a particular status or being qualified to perform a particular activity.

Arts-Based Knowledge Translation (ABKT)

A process that uses diverse art genres (e.g., visual arts, performing arts, creative writing, multimedia including video and photography) to communicate research with the goal of catalyzing dialogue, awareness, engagement, and advocacy to provide a foundation for social change on important societal issues (Kukkonen and Cooper, 2019, p. 293).

Change Management

The process, tools, and techniques used to manage change, including planning, validating and implementing change, and verifying effectiveness of change (American Society for Quality, 2022a).

The practice and process of supporting people through change, with the goal of ensuring that the change is successful in the long-term (World Health Organization, 2019, p. 3). Change management helps people to change their behaviors, attitudes, and/or work processes to achieve a desired business objective or outcome.

Collection of Personal Health Information

The gathering, acquiring, receiving, or obtaining of personal health information by any means from any source (Information and Privacy Commissioner of Ontario, 2015a).

Computerized Tomography Scan

This scan combines a series of X-ray images taken from different angles around your body and uses computer processing to create cross-sectional images (slices) of the bones, blood vessels and soft tissues inside your body (Mayo Clinic, n.d.). CT scan images provide more-detailed information than plain X-rays do.

Confidentiality of Personal Information

The obligation of a health care provider (or other person) to protect the secrecy of personal information.

Content Experts

Individuals with formal power who have knowledge, tools, and resources to address the issue (Attygalle, 2017, p. 3).

Context

The interrelated conditions in which something exists or occurs (Merriam-Webster, 2022).

Context Experts

Individuals with lived experience of the situation or issue at hand (Attygalle, 2017).

Data

Facts and statistics in their raw form, collected for reference, analysis, or decision making.

Data Analysis

The knowledge and skills required to ask and answer a range of questions by analyzing data including developing an analytical plan, selecting and using appropriate statistical techniques and tools, and interpreting, evaluating, and comparing results with other findings (Statistics Canada, 2020).

Data Architecture

A set of rules, models, policies, or standards that govern which data is collected, and how it is acquired, stored, arranged, secured, accessed, and used (Olavsrud, 2022).

Data Assets

A named collection of related data elements that is formally managed as a single unit. They may be a collection of facts represented as text, numbers, graphics, images, sound, video and is the raw material from which information can be derived - and decisions can be made.

Data Awareness

The knowledge required to know what data is and what are different types of data (Statistics Canada, 2020). This includes understanding the use of data concepts and definitions.

Data Cleansing

The knowledge and skills to determine if data is 'clean' and if not, using the best methods and tools to take necessary actions to resolve any problems (Statistics Canada, 2020).

Data Discovery

The knowledge and skills to search, identify, locate, and access data from a range of sources related to the needs of an organization (Statistics Canada, 2020).

Data Ethics

The knowledge that allows a person to acquire, use, interpret and share data in an ethical manner including recognizing legal and ethical issues (e.g., biases, privacy) (Statistics Canada, 2020).

Data Exploration

The knowledge and skills required to use a range of methods and tools to explore patterns and relationships in the data (Statistics Canada, 2020). The methods include summary statistics, frequency tables, outlier detection, and visualization to explore patterns and relationships in the data.

Data Gathering

The knowledge and skills to gather data in simple and more complex forms to support the gatherer's or organization's needs (Statistics Canada, 2020). This could involve the planning, development, and execution of surveys, or gathering data from other sources such as administrative data, satellite, or social media data.

Data Governance

A discipline which provides the necessary policies, processes, standards, roles, and responsibilities needed to ensure that data is managed as an asset (Fircan, 2021b).

Data Interpretation

The knowledge and skills required to read and understand tables, charts, and graphs and identify points of interest (Statistics Canada, 2020). Interpretation of data also involves synthesizing information from related sources.

Data Lifecycle

The sequence of events that data goes through from its initial creation or capture to its eventual archiving or destruction at the end of its usefulness.

Data Literacy

The ability to understand and communicate data as information (Jackson & Carruthers, 2019).

Data Management

The business function of planning for, controlling, and delivering data (Fircan, 2021b).

Data Management and Organization

The knowledge and skills required to navigate internal and external systems to locate, access, organize, protect, and store data related to the organization's needs (Statistics Canada, 2020).

Data Modelling

The knowledge and skills required to apply advanced statistical and analytic techniques and tools (e.g., regression, machine learning, data mining) to perform data exploration and build accurate, valid and efficient modelling solutions that can be used to find relationships between data and make predictions about data (Statistics Canada, 2020).

Data Privacy and Security Management

The planning, implementation, and control activities to ensure that data services provided comply with all regulatory and legislative requirements that an organization is subject to.

Data Quality

The knowledge and skills to assess data sources to ensure they meet the needs of the gatherer or organization (Statistics Canada, 2020). This includes both identifying errors and taking action to address the issues with the data.

Data stewardship

Data Tools

The knowledge and skills required to use appropriate software, tools, and processes to gather, organize, analyze, visualize and manage data (Statistics Canada, 2020).

Data Visualization

The knowledge and skills required to create meaningful tables, charts and graphics to visually present data (Statistics Canada, 2020). This also includes evaluating the effectiveness of the visual representation (i.e., using the right chart) while ensuring accuracy to avoid misrepresentation.

Diffusion of Knowledge

A passive and unplanned “just let it happen” process, in which the potential user of knowledge needs to seek it out.

Disclosure of Personal Health Information

The fact that, as a general rule, consent is required to disclose an individual's personal health information, unless PHIPA allows the disclosure without consent and it means to make the personal health information available or to release it to another custodian or person (Information and Privacy Commissioner of Ontario, 2015a).

Distributed Leadership

Leadership that is collective in nature and extends beyond a singular individual within an organization (Gibb, 1954).

Diversity

A concept meant to convey the existence of difference (The University of British Columbia, n.d.).

Equity

Achieving parity in policy, process, and outcomes for historically and/or currently underrepresented and/or marginalized people and groups while accounting for diversity (The University of British Columbia, n.d.).

Equity-Mindedness

The demonstration of an awareness of, and willingness to, address equity issues (The University of British Columbia, n.d.).

Evaluating Decisions Based on Data

The knowledge and skills required to evaluate a range of data sources and evidence in order to make decisions and take actions (Statistics Canada, 2020). This can include monitoring and evaluating the effectiveness of policies and programs.

Evidence-Based Decision-Making

The knowledge and skills required to use data to help in the decision-making and policy-making process (Statistics Canada, 2020). This includes thinking critically when working with data, formulating appropriate business questions, identifying appropriate datasets, deciding on measurement priorities, prioritizing information garnered from data, converting data into actionable information, and weighing the merit and impact of possible solutions and decisions.

Evidence-Based Medicine

The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Sackett et al., 1996, p. 71).

Fishbone Diagram

A tool for analyzing process dispersion (American Society for Quality, 2022a). It is also referred to as the “Ishikawa diagram" and "cause and effect diagram". The diagram illustrates the main causes and subcauses leading to an effect (symptom).

Formative Evaluation

A rigorous assessment process designed to identify potential and actual influences on the progress and effectiveness of implementation efforts (Stetler et al., 2006).

Formative Framework

A framework that allows for formative evaluation to occur throughout a change effort in a rapid way.

Graphical Abstract

A single, concise, pictorial, and visual summary of the main findings of an article (Elsevier, n.d.).

Health Information Custodian

A person or organization listed in PHIPA that, as a result of his, her or its power or duties or work set out in PHIPA, has custody or control of personal health information (Information and Privacy Commissioner of Ontario, 2015a, p. 7).

Implementation Science

The scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care (Eccles & Mittman, 2006).

Improvement Science

An applied science that emphasizes innovation, rapid-cycle testing in the field, and spread in order to generate learning about what changes, in which contexts, produce improvements (Institute for Healthcare Improvement, 2022c).

Inclusion

An active, intentional, and continuous process to address inequities in power and privilege, and build a respectful and diverse community that ensures welcoming spaces and opportunities to flourish for all (The University of British Columbia, n.d.).

Indigenous Data Governance

The governance or stewardship of data itself, and the processes that are needed in order to implement Indigenous control over Indigenous data (Carrol, Rodriguez-Lonebear, & Martinez, 2019).

Indigenous Data Sovereignty

The right of Indigenous Peoples to own, control, and use Indigenous data (Rainie et al., 2019).

Indigenous Identity

First Nations, Inuit, and Métis (Constitution Acts, 1867).

Indigenous Peoples' Data

(1) Information and knowledge about the environment, lands, skies, resources, and non-humans with which they have relations; (2) information about

Indigenous persons such as administrative, census, health, social, commercial, and corporate; and (3) information and knowledge about Indigenous Peoples as collectives, including traditional and cultural information, oral histories, ancestral and clan knowledge, cultural sites, and stories, belongings (Carroll et al., 2020, p. 3).

Infographic

Visual/graphical depiction of information.

Information

Data that is processed, interpreted, organized, structured, and presented to make it meaningful.

Integrated Knowledge Translation

Ongoing and authentic partnerships where researchers and knowledge users are equal partners in a mutually beneficial research project.

Knowledge Brokers

The middle people or intermediaries who facilitate interactions between knowledge creators and next users - or researchers and decision makers.

Knowledge Creators or Producers

Individuals who create new knowledge. Most commonly, knowledge creators are researchers.

Knowledge Dissemination

An active “make it happen” process to communicate knowledge by targeting, tailoring, and packaging the message for a particular target audience.

Knowledge Exchange

A collaboration involving regular sharing of information, ideas, and experience between those who generate knowledge and those who might put the knowledge to use (Reardon et al., 2006).

Knowledge Translation

A dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system (Canadian Institutes of Health Research, 2012, p. 1).

The synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health (World Health Organization, 2005, p. 2).

Knowledge Translation and Exchange (KTE) and Knowledge Mobilization (KMb)

Refers to the many activities that contribute to the relational, iterative, and context-sensitive process of moving of knowledge to action, including the synthesis, dissemination, exchange, and application of knowledge.

Knowledge Users or End Users

The potential audience of created knowledge.

Logic Model

Logic models are a common tool used in program and intervention planning, implementation, and evaluation to visually depict processes, or chains of events, including activities and expected outcomes.

Macro-Level

Factors that are structural, legal, regulatory or economic conditions that are often beyond the influence of a specific individual or an organization itself (Smith et al., 2019).

Medication Reconciliation

A formal process in which healthcare providers work together with patients, families, and care providers to ensure accurate and comprehensive medication information is communicated consistently across transitions of care (Institute for Safe Medication Practices Canada, n.d.). It requires a systematic and comprehensive review of all the medications a patient is taking to ensure that medications being added, changed, or discontinued are carefully evaluated. It is a component of medication management and will inform and enable prescribers to make the most appropriate prescribing decisions for the patient.

Meso-Level

Factors that are at an institutional level.

Metadata

This is data about data, including the definitions and descriptions about the data, and makes finding and working with data easier.

Metadata Creation and Use

The knowledge and skills required to extract and create meaningful documentation that will enable the correct usage and interpretation of the data (Statistics Canada, 2020). This includes the documentation of metadata which is the underlying definitions and descriptions about the data.

Micro-Level

Factors that are at the individual level.

Organizational Culture

A pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration, which has worked well enough to be considered valid and therefore, to be taught to new members as the correct way to perceive, think and feel in relation to those problems (Schein, 2010).

Organizational Readiness for Change

A shared psychological state in which organizational members feel committed to implementing an organizational change and confident in their collective abilities to do so (Weiner, 2009).

PDSA Cycle

A four-step process for quality improvement (American Society for Quality, 2022a). In the first step (Plan), a way to effect improvement is developed. In the second step (Do), the plan is carried out. In the third step (Study), a study takes place between what was predicted and what was observed in the previous step. In the last step (Act), action should be taken to correct or improve the process.

Personal Health Information

Identifiable health information collected on an individual by an organization on behalf of a health information custodian (either orally, documented on paper, or electronically).

Personal Information

Data about an "identifiable individual" (Government of Canada Office of the Privacy Commissioner, 2018). It is information that on its own, or combined with other pieces of data, can identify you as an individual such as demographic information (e.g., age, sex, financial information, race, ethnicity, social insurance number, etc.).

Plain Language Communication

Communication that an audience can understand the first time they read or hear it (Wicklund & Ramos, 2009, p.178). It is clear and concise, and uses short sentences and simple words. It keeps to the facts and is easy to read and understand. Plain language is simple and direct but not simplistic or patronizing plain language communication.

Plain Language Summary

Synopsis of research findings written in an easily understandable way, so that even a lay audience would grasp the content (Gudi et al., 2021).

Policy Paper

A research piece focusing on a specific policy issue that provides clear recommendations for policy makers (Scotten, 2011).

Population Health Management

Processes within health organizations that use data on the people they serve to:
1. Measure health status, unmet health and social needs, and healthcare experiences and outcomes;
2. Group patients or community members according to health and social and demographic characteristics, healthcare use, or likelihood of needing healthcare in the future;
3. Proactively design and advocate for services and policies that promote health, prevent disease, reduce inequities, and improve healthcare outcomes; and
4. Implement changes and evaluate whether they are leading to improved health or healthcare outcomes in a population (Primary Health Care Performance Initiative, 2018; Social Care Institute for Excellence, 2018; Waddell, Reid, et al., 2019).

Privacy Breach

When personal health information is collected, used, or disclosed without authorization (Information and Privacy Commissioner of Ontario, 2018).

Privacy Impact Assessment

A risk management tool used to identify the actual or potential effects that a proposed or existing information system, technology, program, process, or other activity may have on an individual's privacy.

Privacy of Personal Information

The right of an individual to control the collection, use, disclosure, and retention of their personal information.

Psychological Safety

Being able to communicate concerns, express questions, provide ideas, or admit mistakes without fear of negative consequences such as punishment, humiliation, or damage to career or status (Javed et al., 2017).

Realist Evaluation

An approach that considers what works for whom, in what circumstances, in what respects, and how (Pawson & Tilley, 2004).

Representational Equity

The proportional participation at all levels of an institution (The University of British Columbia, n.d.).

Resource Equity

The distribution of resources in order to close equity gaps (The University of British Columbia, n.d.).

Resuscitation

Administration of emergency measures to sustain or restore life (Davis, 2021).

Run Chart

Graphs of data over time and one of the most important tools for assessing the effectiveness of change (Institute for Healthcare Improvement, 2017).

Security of Personal Information

The tools and techniques we use to protect the confidentiality, integrity, and availability of personal information.

Six Sigma

This is a method that provides organizations tools to improve the capability of their business processes (American Society for Quality, 2022b). This increase in performance and decrease in process variation helps lead to defect reduction and improvement in profits, employee morale, and quality of products or services.

Stakeholders

Individuals, organizations, or communities in which next users and researchers are situated and that may be indirectly affected by research (Jull et al., 2019).

Storytelling

The knowledge and skills required to describe key points of interest in statistical information (i.e., data that has been analyzed) (Statistics Canada, 2020). This includes identifying the desired outcome of the presentation, identifying the audience's needs and level of familiarity with the subject, establishing the context, and selecting effective visualizations.

Summative Evaluation

Process of evaluating a program's or intervention's impact or efficacy through careful examination of program design and management (Frey, 2018).

Summative Framework

A framework that allows for evaluation at the end of an implementation.

Systems Perspective

Situating knowledge procedures and users in a system of knowledge that is responsive, adaptive, and unpredictable (Graham et al., 2006).

Team

A group of individuals with interdependent tasks and a shared responsibility of outcomes (Cohen & Bailey, 1997).

Translational Research

The transition from basic laboratory research (e.g., animal and basic research to identify disease mechanisms), to applications to human health and clinical settings (e.g., human clinical and efficacy studies), and finally, to evidence-based practice guidelines (e.g., effectiveness, dissemination, and implementation research) (Zoellner et al., 2015).

Use of Personal Health Information

Handling or dealing with personal health information (Information and Privacy Commissioner of Ontario, 2015a).

Feedback Form

As a reflection of our commitment to continuous quality improvement, we would appreciate it if you could take some time to complete the following feedback form. Using your feedback, we will strive to improve the book and incorporate ideas for changes to enhance the learning experience with our book.

Please click here to connect to the feedback form.