PolicyWise
BUILD BETTER DATA

Data Lifecycle Resources:

Plan

February 2021

PolicyWise for Children & Families

EDMONTON COMMUNITY FOUNDATION
Alberta
COMMON APPROACH TO IMPACT MEASUREMENT
SSHRC CRSH

Introduction & Starting Point

The Data Lifecycle is a tool to proactively plan an organization's data journey. It provides a bird's eye view of how data can evolve from inception to reporting and beyond. The intent of the Data Lifecycle is to build a foundational tool for non-profit organizations to use when collecting data to inform service delivery and organizational planning. Good data collection can look different depending on each service organization and their client base and can be reflected upon throughout the Data Lifecycle. It is important to understand how to collect data and then use the data consistently in decisions being made for your organization.[1]

For non-profit organizations, the data lifecycle can be used as a way to inform the planning and implementation of services. The development of outcome measurements is important for the success of the organization and for the progression of clients.[2] Building appropriate processes in advance can also streamline the generation of reports and funding applications when that time comes. The clients are the primary drivers in guiding and generating desired outcomes.[1] It is important to recognize that non-profits are often responsive to community needs and are leaders for underrepresented or marginalized groups.[2]

Data lifecycles provide a structure to organize and think about the activities involved in managing and using data within a project or organization. The data lifecycle resources are organized into the following sections. Each of these topics can be explored in more detail within each section of the Data Lifecycle.

- Considerations & Lenses
- Plan
- Build
- Collect
- Prepare
- Analyze
- Inform

The Data Lifecycle addresses some of the main concerns around data collection, starting with the questions of why and how data is being collected. These sections explore how non-profit organizations can collect data in a manner that is sensitive to the realities of their clients and authentic to their mission. Furthermore, the Data Lifecycle discusses the importance of communication (both internal and external),

[1] Nonprofit hub & Everyaction. (n.d.). *The state of data in the non-profit sector.* https://nonprofithub.org/datareport/

[2] Benjamin, L.M. & Campbell, D.C. (2015). *Nonprofit performance: Accounting for the agency of clients*. DOI: 10.1177/0899764014551987

minimizing data collection, accuracy, interoperability, and good governance. These aspects are engaged in greater detail in the various sections. For instance, Plan explores best practices of data collection and Collect describes how organizations can increase the impact of their data. The Data Lifecycle serves as an organized guide to the most important facets of data collection, providing a roadmap for non-profit organizations as they work with clients.

> *Where to start in your data journey? We encourage starting with two key questions:*

1. Why are you collecting data?

Data may seem disconnected from the overall mission of an organization. Most staff are dedicated to helping clients first and foremost. Collecting data may seem like additional work. Collecting and using data well can contribute greatly to an organization's mission. Effective data collection and use can help improve programming to be more efficient and impactful.[3]

Data fits within an organization by:

- Building trust
- Demonstrating how organizations achieve their missions
- Creating buy-in from staff
- Providing essential information for funders

For more information, go to the following sections of the Data Lifecycle:

Considerations & Lenses 

Plan 

Inform 

2. How are you collecting data?

To support the needs of clients and provide effective services, data needs to be collected. Data is about people's journeys and stories However, in the rush to get the needed information it is possible to compromise relationships with clients. By thoughtfully considering how you are engaging with your clients, you can foster a more positive relationship.

When collecting data from clients, consider:

[3] Fruchterman, J. (2016). *Using data for action and impact*. Stanford Social Innovation Review. https://ssir.org/articles/entry/using_data_for_action_and_for_impact

- Ways to build trust including engaging in conversation as an accessible way to collect data. For example, questions and response choices reflect their individual circumstances.
- The way in which questions are asked, which depends on the sensitivity of the information that could be provided (e.g., asking about immigration status, emergency contacts vs. services required, postal code) and in demonstrating transparency and authenticity. For example, clients need to know how the information they give will be used to benefit them.

For more information, go to the following sections of the Data Lifecycle:

Build

Collect

Analyze

[4]

Disclaimer – the information provided in the Data Lifecycle could evolve. If you have ideas or feedback please email info@policywise.com

[4] Icons made by Freepik from www.flaticon.com.

Plan

Plan

In the plan phase, it is important to address what data are going be collected (e.g., what type, how much, from whom) and for what purposes (e.g., how will these data serve the project or organization's purpose).

Why Collect Data?

Data is but one part of PolicyWise' iterative data-to-wisdom cycle[13,14,15]. Data are distinct pieces of information. Data may be expressed quantitatively such as in numbers, or qualitatively such as in words or experiences. When data has been transformed into a useable and organized form to describe a situation or condition, this meaningfully organized data is information. When information has been derived from a range of sources that have been subjected to testing and is found to be credible, this information becomes evidence. Sources of information can be, but are not limited to, research, experience, evaluation, information from the local context and environment, economics, and politics. Knowledge is derived from the practical use of evidence. Knowledge involves personal experience to interpret and apply the evidence. Finally, the ability to successfully apply knowledge to make strategic decisions is wisdom. That is, the soundness of an action or decision with regard to the application of experience, knowledge, and good judgment.

Data can inform the work of nonprofits at several levels: the program level, the organization level, and at the collaborative level. Nonprofits use and benefit from data in many ways[16]. Organizations may collect data at the program level to report back to funders, to manage service delivery, to evaluate the effectiveness of the program, and to better understand the needs of their clients, and in turn improve, and expand programming. At the organization level, data may be used to make a case for funding and for decisions about services and resources. Data are also helpful for strategic considerations for an organization and with regard to opportunities around collaboration and to influence policy makers and funders.

What agencies really want to know and the methods used to answer the "why?" are often not in alignment. "The Why?" looks different depending on who is asking – frontline staff, managers, EDs, and funders all have different information needs[17]. Content of data collection is often driven by funder-information needs first and therefore data is usually "good enough" for reporting back to funders.

---

[13] CHEO, KMb Toolkit http://www.kmbtoolkit.ca/what-is-kmb

[14] Bellinger, G., Castor, D., & Mills, A. (2004). Data, Information Knowledge, and Wisdom. Retrieved from the internet on March 5, 2018 from www.systems-thinking.org/dikw/dikw.htm.

[15] Ackoff, R. L. (1989). From data to wisdom. Journal of Applied Systems Analysis, 15: 3-9.

[16] Zhang, Y. & Barbosa, P. G. (2018). *SAGE Not-for-profit data capacity & needs assessment survey*: Results report. Edmonton, AB: PolicyWise for Children & Families.

[17] Data Orchard. (2019, September). Data maturity framework for the not-for-profit sector. https://www.dataorchard.org.uk/what-is-data-maturity

Plan

It's important to invest time in seeking out your "Why?" with data. In general we have found that organizations have many uses for data and the value of data is generally felt – but it's sometimes difficult to articulate. Spending time to really dig into the why of the data you're collecting is time well spent.

Resources:

- Though in the context of business more than nonprofits – may be useful to explore Simon Sinek's "Start with Why?" https://www.youtube.com/watch?v=IPYeCltXpxw
  And have a listen to his take on defining the why (and how!) for "impact organizations" https://www.youtube.com/watch?v=tEeuoPlsNyI
- Try the 5 whys technique to uncover the root causes of why you're collecting data see https://www.mindtools.com/pages/article/newTMC_5W.htm
- Have a look at some learnings from the work of the C5 in Edmonton exploring their why for collecting data: https://policywise.com/resource/c5-collaborative-data-linkage-project/

Data Types

Data can generally be categorized as quantitative or qualitative. Quantitative data is data that can be counted or compared on a numerical scale, and generally answers "what?" and "how many?" type questions. For example, "Is your employment status full-time or part-time?" or "How old are you?" would result in data that would be considered more quantitative in nature. Other types of data are descriptive, and capture qualities or characteristics. For example, "What is your gender identity?" or "What social class group do you identify with?" would result in data that would be considered more qualitative in nature. Reflecting on why you are collecting data will help you determine which types of data are most relevant and useful.

Data Collection Best Practices

In this section, we will outline six principles of good data collection practices:

Planning[18] 

Accuracy 

Communication 

Interoperability 

Collect Minimal Data 

Good Governance 

[18] Icons made by Becris from www.flaticon.com

Planning. Start with the end in mind.

Think about the following:

- Who will be your participants?
- Are you trying to answer a specific question?
- Consider consent – see principles above.
- What is your timeline?
- What data is already available?
    - Within your organization.
    - Outside your organization.
- Build a project plan.
    - The data lifecycle is one planning tool.

Communication. Data collection requires working with several different groups of people. This includes not just clients, but also funders and the staff that will be implementing your collection practices. Clear communication with all these groups of people is vital for effective data collection and will ensure that every member of your organization is on the same page.[19] Furthermore, communicating with clients and funders will help foster a relationship.

Some tips to consider are as follows:

- Have clear governance documents. See the 'Good Governance' section below for more details.
    - Train staff in best practices.
    - Staff must sign appropriate documents and agreements.
    - Client consent process.
- Document your data.
    - Collection protocols.
        - Standardize your methods of obtaining data.
        - Train your staff.
    - Codebooks/Data dictionaries.
        - Make sure the data users understand what your data means.
- Engage with your staff to have regular meetings about data.
- Ensure that clients understand how their data is going to be used and if results need to be communicated back to them.
- Make sure your reports convey the importance of the data you collect. Use results to get buy-in from staff and stakeholders.
- Connect your data collection activities back to your organization's mission. This isn't merely about collecting data for administrative purposes. It's about:

[19] Hajric, E. (2020, February 26). *Improve your nonprofit's internal communication and collaboration*. Nonprofit Pro. https://www.nonprofitpro.com/article/improve-your-nonprofits-internal-communication-and-collaboration/

- Demonstrating how your agency fulfills its mission.
- How that mission has a positive impact on people and the community.
- Ensuring your organization can thrive into the future.

Collect Minimal Data[20]**.** Organizations need to limit the collection of data to the minimum required for their purposes.[21] Minimizing data collection will prevent a build-up of information for your organization to store, and it will also reduce the time that clients will have to spend providing what may be sensitive information.

Consider the following:

- Define your objectives. Will the data be used for:
  - Providing services?
  - Evaluating outcomes?
  - Referrals?
  - Reporting?
- Demographics are essential to informing the above objectives.[22]
  - Since the datapedia is about demographics it can benefit each of those activities.
- Consider client relations
  - Always collect enough to identify unique individuals.
  - Ideally clients should only have to tell their story once.
- The Golden Rule
  - Personal information must be collected solely for specific purposes and that only the personal information required to fulfill these purposes be collected.[23]

Accuracy. It's important to follow current best practices to collect accurate data, for example, having standard practices around collecting demographic data – resources to explore are in the Build Better Data: Datapedia. Also, make sure that your analysts and data collectors have the appropriate level of training in data quality.

---

[20] Pittman, A. (2018, May 21). *What type of data should my nonprofit or foundation collect?* TechSoup. https://philanthropynewsdigest.org/columns/techsoup-pnd/what-type-of-data-should-my-nonprofit-or-foundation-collect

[21] Information and Privacy Commissioner of Ontario. (2015, April). *Best practices for protecting individual privacy in conducting survey research*. https://www.ipc.on.ca/wp-content/uploads/2015/04/best-practices-for-protecting-individual-privacy-in-conducting-survey-research.pdf

[22] PEAK Grantmaking. (n.d.). *Insight, impact, and equity: Collecting demographic data*. https://www.peakgrantmaking.org/wp-content/uploads/2019/01/EP-Docs-PG-Demographic_Data_Report.pdf

[23] Ahmad, Imran and Gagné, Eloïse, (n.d.). *Data privacy and the law: Understand your nonprofit's legal obligations*. TechSoup Canada. https://www.techsoupcanada.ca/en/community/blog/data-privacy-and-the-law-understand-your-nonprofits-legal-obligations

Interoperability. Interoperability refers to standards for data elements that are understood and used across agencies and sectors. Interoperability is a way of standardizing data so that data items, such as education or citizenship, are following a recognized standard. This allows collaboration with other agencies. It also limits the number of times a client may need to tell their story. One of the greatest barriers to use of data in the social sector is interoperability.[24] A key feature of the Datapedia is interoperability.

Benefits of interoperability include:

- Linkage across datasets:
    - Within organizations.
    - Across organizations.
- Ability to make comparisons between datasets and supports analysis across different datasets between organizations.
- Consistent and comparable data would also allow analysis and research at a sector or population level to inform impact and service coordination.
- Efficient data collection across multiple organizations can be a tool to streamline service delivery.

Good Governance[25,26] . Organizations should familiarize themselves with their requirements under various acts governing information. This includes Privacy Information Protection Act (PIPA), Health Information Act (HIA), and FOIP (Freedom of Information and Protection of Privacy Act (FOIP). Data governance is a complex topic, not fully covered here. Critically, considering what data you are collecting and how you are collecting it must be informed by your governance.

Disclaimer – the information provided in this section should not be construed as legal advice. If you have advice or feedback you would like to share, please email info@policywise.com

[24] *Increasing Interoperability of Social Good Data (Round 11*). (n.d.). https://gcgh.grandchallenges.org/challenge/increasing-interoperability-social-good-data-round-11

[25] Manhas, K.P. (n.d.). *Law & governance of secondary data use: Obligations of not-for-profit organizations in Alberta*. PolicyWise for Children & Families. https://policywise.com/wp-content/uploads/2017/08/LAW-GOVERNANCE-OF-SECONDARY-DATA-USE.pdf

[26] Service Alberta and the Office of the Information and Privacy Commissioner. (2008, November). *A guide for businesses and organizations on the Personal Information Protection Act*. https://www.oipc.ab.ca/media/383666/guide_for_businesses_on_pipa_nov2008.pdf

A few things to consider:

- Consent
    - Make sure your client understands
        - What data you are collecting.
        - Why the data is being collected.
        - How the data will be used.
        - The client provides consent for the stated purposes.
    - There are many resources about consent on the web.
        - Office of the Privacy Commissioner of Canada: Consent[27]
- Agency level policies including privacy policies, breach response protocols, disclosure policies, etc.
    - Office of the Privacy Commissioner of Canada: Privacy Policy and Transparency[28]
    - Office of the Information and Privacy Commissioner: How to report a privacy breach in Alberta[29]
    - Designate certain qualified staff as privacy officers. Have a chain of command when privacy incidents occur.
- Make sure your data infrastructure (databases, servers) matches your required level of security.[30]
    - Perform a risk assessment of your organization's data. There are a number of templates that can guide you through this. These are just 2 examples:
        - https://docs.google.com/spreadsheets/d/1L1FP-ePpPLcrkYKKQkuLdFHV6xj9Y-k6z4jaBQKxgKE/edit#gid=0
        - https://digitalimpact.io/tools/digital-data-inventory/
    - National Institute of Standards and Technology (NIST) has some tools to guide in the creation of cybersecurity frameworks.[31,32]

PolicyWise has developed a framework to support **ethical decision-making for information sharing**. This tool leads service providers step-by-step through foundational values and essential practice considerations. This framework was originally developed for the information sharing in the homeless-service sector, but may have broad applicability to the wider adult social serving sector. It can be viewed here: *https://policywise.com/resource/ethical-decision-making-framework-for-information-sharing/*

---

[27] Office of the Privacy Commissioner of Canada. (2018, May). *Guidelines for obtaining meaningful consent*. https://www.priv.gc.ca/en/privacy-topics/collecting-personal-information/consent/gl_omc_201805/

[28] Office of the Privacy Commissioner of Canada. (2018, November). *Ten tips for a better online privacy policy and improved privacy practice transparency*. https://www.priv.gc.ca/en/privacy-topics/collecting-personal-information/02_05_d_56_tips2/

[29] Office of the Information and Privacy Commissioner of Alberta. (n.d.). *How to report a privacy breach*. https://www.oipc.ab.ca/action-items/how-to-report-a-privacy-breach.aspx

[30] National Council of Nonprofits. (n.d.). *Cybersecurity for nonprofits*. (n.d.) https://www.councilofnonprofits.org/tools-resources/cybersecurity-nonprofits

[31] National Institute of Standards and Technology. (2017, January 10). *NIST releases update to cybersecurity framework*. https://www.nist.gov/news-events/news/2017/01/nist-releases-update-cybersecurity-framework

[32] National Institute of Standards and Technology. (n.d.). *Cybersecurity framework.* https://www.nist.gov/cyberframework

Benefits and Drawbacks of Collecting, Using, and Re-Using Data

	Benefits	Drawbacks
Collecting Data (e.g., gathering information through surveys, interviews, and focus groups)	• Data can be used to help clients achieve their goals • Data can be used to make strategic decisions and respond to emerging issues • Data can be used to advocate for continued funding	• Unnecessary data that is collected can increase risk to the clients or organization • Harm inflicted on clients due to the ways in which data is collected (e.g., re-traumatizing clients)
Protecting Data (e.g., access control, security, encryption, governance, consent)	• Safeguards the data that is collected by the organization • Abides by the agreements/promises made to clients in consent • Establishes trust	• Privacy can be breached if data are not protected properly – could lead to legal and monetary consequences enforced by privacy laws • Noncompliance of staff in protecting data • Losing trust from community to safeguard personal information
Use and Reuse of Data (e.g., sharing data with others, re-use in repository)	• Connect data to other organizations or researchers • Contribute to larger social issues • Inform clients of the impact of their data	• Unapproved re-use of data may lead to concern from clients • Quality improvement vs. research • Not planning to re-use from the beginning

Static vs. Dynamic Data

After you determine which demographics are most important for your organization to track, one thing to keep in mind is whether or not those demographics are expected to change. This can make a difference in decisions of when and how to track them.

Static, or “Tombstone” demographics generally do not change throughout the person’s life. These are things like the person’s date of birth, gender identity and ethnicity.

Other demographics such as marital status, or level of education may change. Some of these “dynamic” demographics, such as employment, income or housing situation may even be a target of change for your organization, or different programs. It’s important to keep this in mind when making decisions around how and when to collect this information.

Collection of Static Demographics

We recommend that these demographics are collected at intake; since they are more unlikely to change, they can serve as a basis for a participant’s “profile” or basic identifying information in the database.

- Date of Birth
- Gender Identity
- Ethnicity

Collection of Dynamic Demographics

These demographics describe the life situation that the participant has in the moment that it is collected. These may be collected at intake but may need to be updated at a later date, depending on organizational need. If a dynamic demographic is a target of change for an organization or a program, such as housing status or employment status, it may be desired to understand the progress from the start to a later date, or the outcome for participants in that regard. If this is the intent, it is important to "time-stamp" when the information is collected initially and at follow up. The follow up(s) may be triggered by a change in the situation, a specific period of time (e.g. 3 months) or exit from the program. Ensure that you are collecting the initial and follow up information in separate forms so that they are not overwritten, and the results can be exported for comparison.

Some demographics may only be collected when triggered by a specific case plan or program participation; for example, some organizations may choose to only ask participants about employment status if they take part in a program that helps with employment. The strength in this approach is less burden of data collection on participants and staff. Other organizations may choose to track employment throughout organization as a whole; the strength in this approach is a greater sample size to understand employment status throughout the organization, and the ability to compare across different programs.

Examples:

- Marital Status
- Address/Postal Code
- Employment
- Housing Status
- Income
- Language proficiency

Acknowledgements

Primary Contributors

Robert Jagodzinski, Sharon Farnel, Saira John, Carley Piatt, Lauren Albrecht, Matthew Russell, Maria Savidov, Shannen Shott, Rebecca Taylor, Naomi Parker, Cathie Scott, and Xinjie Cui

Project Funders

This project was made possible by generous support from the Government of Alberta Community Initiatives Program grant, a Connection grant from the Government of Canada's Social Sciences and Humanities Research Council, funding from the Edmonton Community Foundation, and the Common Approach to Impact Measurement, as well contributions from an anonymous donor.

Acknowledgements

It is with thanks that we acknowledge the individuals who have contributed their wisdom, experience, and perspectives to this project. PolicyWise would like to thank the participating agencies that shared their intake and registration forms with us, as well as the many advisors who guided us along the way from agencies across Alberta and Canada.

Suggested Citation

Jagodzinski, R., Farnel, S., John, S., Piatt, C., Albrecht, L., Russell, M., Savidov, M., Shott, S., Taylor, R., Parker, N., Scott, C., Lau, J., & Cui, X. (2021). Build better data: Data lifecycle resources. Edmonton, AB: PolicyWise for Children & Families.