PolicyWise
BUILD BETTER DATA

Data Lifecycle Resources

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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),

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[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:

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[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

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

Considerations & Lenses

Considerations & Lenses

The considerations and lenses are activities that must be considered in each phase of the data lifecycle. For example, the "considerations" are principles such as context, complexity, and nuance that may be useful to reflect on while engaging in each phase of the data lifecycle. The "lenses" refer to the process of aligning approaches to collecting, preparing, and using data on specific communities (e.g., visible minority, LGBTQ2S+) that are being served by the organization.

Considerations

As you review and implement the resources from Build Better Data within your organization, there are several things to take into consideration:

Context: The context in which you do your work - who your clients are, what services you provide, what subsector you represent, what your overall organizational goals are, what resources you have to put to data collection - should inform what data you collect, why you collect it, and how you collect it. Asking and answering the question "why this data?" will help you determine which parts of the toolkit will work best for your organization.

Nuance: Entries included in the toolkit have potential values that range from more to less concrete. For example, a question about income could be as straightforward as "What was your income last month?" where the desired response is a number. A much more nuanced question might ask "Which social class group do you identify with?", which indirectly speaks to income, but incorporates the many aspects that make up social status. Going back to why you are asking for this data will help you determine the level of detail you are looking for in your responses.

Complexity: Entries included in the toolkit have potential values that range in complexity. For example, age is rather less complex, although even that is not as straightforward as it may seem at first glance. (For example, do you ask "How old are you?" or do you ask "What is your date of birth"). Others are much more complex. For example, questions around Sex and Gender reflect both individual and social constructs and speak to issue of self-identification and self-determination. Going back to why you are asking for this data will help you determine which questions you need to ask.

Overlap: Entries included in the toolkit are often found, in practice, clustered together. For example, an entry like Ethnicity is often used as a collective label for aspects of Citizenship Status, Race, or Immigration Status. It can often also be found combined with questions around Language or Country of Origin. Going back to why you are asking for this data will help you determine which specific aspects of these larger categories are the most relevant to address in your data collection.

Lenses

The Build Better Data resource is designed to help with the "how" of data collection. Before this step is the exercise of determining "why" you are collecting the data. You may wish to approach your data collection work through the lens of a particular framework or set of guiding principles, which will shape how you think about your data collection and the ways in which you apply the Toolkit. The following list, while not exhaustive, includes some common frameworks you may want to consider.

GBA+ (Gender-Based Analysis Plus)

"GBA+ is an analytical process used to assess how diverse groups of women, men, and gender diverse people may experience policies, programs and initiatives"[5]. GBA+ encourages us to look at the ways in which identity factors such as gender intersect and impact how individuals experience the world around them. You can apply GBA+ to your data collection by considering if you and your organization believe that the issues you work on are gender neutral, and whether organizational assumptions prevent asking certain questions and hearing certain responses, or limit the range of possibilities that are considered.

Resources:

- Status of Women Canada. (2020, October 28). *What is GBA+.*Government of Canada. https://cfc-swc.gc.ca/gba-acs/index-en.html
- Guide to Gender-based Analysis (GBA+) and Inclusive Open Government Partnership. (n.d.). *Guide to gender-based analysis plus (GBA+) and inclusive open government*. https://www.opengovpartnership.org/wp-content/uploads/2019/05/Guide-GBAandInclusive-Open-Government.pdf
- Canadian Human Rights Commission Gender Integration Framework Canadian Human Rights Commission. (n.d.). *CHRC's gender integration framework (GIF).* https://www.chrc-ccdp.gc.ca/sites/default/files/gender_integration_framework.pdf

Sustainable Development Goals (SDGs)

The United Nations "Sustainable Development Goals are the blueprint to achieve a better and more sustainable future for all. They address global challenges we face, including poverty, climate change, environmental degradation, peace and justice"[6]. Reflecting on the SDGs and how your organization's work contributes to creating a better world can help you determine what kind of data you can collect to best position your organization to achieve its mission. In the context of many community organizations, SDGs numbers 3 (Good health and well-being), 5 (Gender equality), 10 (Reduced inequalities), and 11 (Sustainable cities and communities) may be of particular interest.

Resources:

- United Nations. (n.d.). *Take action for the sustainable development goals*. Retrieved February 8, 2021, https://www.un.org/sustainabledevelopment/sustainable-development-goals/

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[5] Status of Women Canada. (2020, October 28). What is GBA+. *Government of Canada*. https://cfc-swc.gc.ca/gba-acs/index-en.html

[6] United Nations. (n.d.). *Take action for the sustainable development goals.* Retrieved February 8, 2021, https://www.un.org/sustainabledevelopment/sustainable-development-goals/

- Sustainable Development Solutions Network. (12, June 2015*). Indicators and a monitoring framework for the sustainable development goals*. https://sustainabledevelopment.un.org/content/documents/2013150612-FINAL-SDSN-Indicator-Report1.pdf
- Thurston, A. (2020). *A matter of trust: Building integrity into data, statistics and records to support the sustainable development goals*. University of London Press. https://humanities-digital-library.org/index.php/hdl/catalog/view/amot/188/372-1

Trauma-Informed Approach (TIP)

A Trauma-Informed Approach is one that is "based on the knowledge and understanding of trauma and its far-reaching implications"[7]. This approach recognizes the wide ranging and long lasting impact that traumatic events can have on individuals, families, and communities, and acknowledges that many organizations, even though they are aimed at service provision, can induce trauma. Following key principles of a trauma-informed approach - including safety, trustworthiness, peer support, collaboration, empowerment, and considering cultural, historical, and gender issues - will help you think through what data should be collected and, more importantly, how to do so in a respectful and appropriate way.

Resources:

- SAMHA's Trauma and Justice Strategic Initiative. (2014, July). *SAMHA's concept of trauma and guidance for a trauma-informed approach*. Substance Abuse and Mental Health Services Administration. https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf
- Klinic Community Health Centre. (2013). *Trauma-informed: The Trauma Toolkit*. https://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed_Toolkit.pdf
- BC Provincial Mental Health and Substance Use Planning Council. (2013, May). *Trauma-informed practice guide*. https://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf

Anti-Racism

"Racism is a structural system that assigns value and grants opportunities and privileges based on race"[8]. An anti-racist approach or framework acknowledges racism and actively works to address and prevent racism and create a more inclusive and equitable society. Taking an anti-racist approach can help your organization critically examine what data you are collecting, and why, to ensure that it is not contributing to continued systemic racism.

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[7] SAMHA's Trauma and Justice Strategic Initiative. (2014, July). *SAMHA's concept of trauma and guidance for a trauma-informed approach.* Substance Abuse and Mental Health Services Administration. https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf

[8] National Collaborating Centre for Determinants of Health. (n.d.). *Let's talk racism and health equity.* https://nccdh.ca/images/uploads/comments/Lets_Talk_Racism_and_health_equity_EN_web.pdf

Resources:

- National Collaborating Centre for Determinants of Health. (n.d.). *Let's talk racism and health equity*. https://nccdh.ca/images/uploads/comments/Lets_Talk_Racism_and_health_equity_EN_web.pdf
- Canadian Institute for Health Information. (2020). *Proposed standards for race-based and Indigenous identity data collection and health reporting in Canada*. https://www.cihi.ca/sites/default/files/document/proposed-standard-for-race-based-data-en.pdf
- Government of Ontario. (n.d.). *Data standards for the identification and monitoring of systemic racism*. https://files.ontario.ca/solgen_data-standards-en.pdf

OCAP® (Ownership, Control, Access, Possession)

"The First Nations principles of OCAP® are a set of standards that establish how First Nations data should be collected, protected, used, or shared"[9]. The principles confirm that a community or group owns information collectively, that First Nations have the right to control over all aspects of data collection that impacts them, that First Nations must have access to data about them, and that they should have possession of, or physical control over, that data. OCAP® encourages us to approach work with First Nations with respect and to carry it out with integrity, and can help you identify what data you collect, how you collect it, and how you work with First Nations' individuals, communities, and organizations to ensure its appropriate stewardship and use.

Resources:

- First Nations Information Governance Centre. (n.d.). *The First Nations Principles of OCAP®*. https://fnigc.ca/ocap-training/
- First Nations Information Governance Centre. (n.d.). *Understanding the First Nations Principles of OCAP®*. https://fnigc.ca/wp-content/uploads/2020/09/2be8f15f2eff14b1f122b6a26023836a_fnigc_ocap_brochure_en_final_0.pdf
- First Nations Information Governance Centre. (2014, May 23). *Ownership, Control, Access and Possession (OCAP): The Path to First Nations information governance*. https://achh.ca/wp-content/uploads/2018/07/OCAP_FNIGC.pdf

CARE Principles for Indigenous Data Governance

The CARE principles - Collective Benefit, Authority to Control, Responsibility, Ethics - "are people and purpose-oriented, reflecting the crucial role of data in advancing Indigenous innovation and self-determination. The principles complement the existing FAIR principles (http://www.go-fair.org/) encouraging open and other data movements to consider both people and purpose in their advocacy and

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[9] First Nations Information Governance Centre. (n.d.). *The First Nations Principles of OCAP®*. https://fnigc.ca/ocap-training/

pursuits" [10]. The CARE principles encourage us to acknowledge that Indigenous individuals have the right to derive benefit from data collected and the authority to control how and by whom that data is used, that those working with that data are responsible and accountable to those individuals, and that Indigenous peoples' rights and well-being should drive the data collection. These principles will help you determine what data to collect, how to collect it, and how to use it in respectful and appropriate ways.

Resources:

- Research Data Alliance International Indigenous Data Sovereignty Interest Group. (2019, September). *CARE principles for Indigenous data governance*. The Global Indigenous Data Alliance. https://static1.squarespace.com/static/5d3799de845604000199cd24/t/5da9f4479ecab221ce848fb2/1571419335157/CARE+Principles_One+Pagers+FINAL_Oct_17_2019.pdf/CARE+Principles_One+Pagers+FINAL_Oct_17_2019.pdp
- OCLC Research. (2020, August 11). *Operationalizing the CARE principles for Indigenous data governance*. https://www.oclc.org/research/events/2020/081120-operationalizing-care-principles-for-indigenous-data-governance.html
- United Nations. (2008, March). *United Nations Declaration on the Rights of Indigenous Peoples*. https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf

Disability Rights

Although disability rights are enshrined in the Canadian Charter of Rights and Freedoms, individuals with disabilities face continue to face discrimination and encounter barriers that prevent them from the same opportunities afforded to others. Disability rights and disability justice movements "recognize the intersecting legacies of white supremacy, colonial capitalism, gendered oppression and ableism in understanding how people's bodies and minds are labelled 'deviant', 'unproductive', 'disposable', and/or 'invalid'"[11].This framework encourages us to think about how our organizations and our work can contribute to breaking down systemic barriers that hinder or harm individuals with disabilities. It can help you think about the data you are collecting, how you are collecting it, and how it can contribute to a more just and equitable society.

Resources:

- Berne, P., Levins Morales A., Langstaff D., and Invalid S. (2018). *Ten principles of disability justice*. WSQ: Women's Studies Quarterly, *46*, pp.227-230. https://muse.jhu.edu/article/690824/pdf
- Project LETS. (n.d.). *History of disability justice*. https://projectlets.org/disability-justice
- Disability Justice Network of Ontario. https://www.djno.ca

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[10] Research Data Alliance International Indigenous Data Sovereignty Interest Group. (2019, September). *CARE principles for Indigenous data governance*. The Global Indigenous Data Alliance. https://static1.squarespace.com/static/5d3799de845604000199cd24/t/5da9f4479ecab221ce848fb2/1571419335157/CARE+Principles_One+Pagers+FINAL_Oct_17_2019.pdf/CARE+Principles_One+Pagers+FINAL_Oct_17_2019.pdp

[11] Project LETS. (n.d.). *History of disability justice*. https://projectlets.org/disability-justice

- United Nations. (n.d.). *Convention on the Rights of Persons with Disabilities (CRPD)*. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Design Thinking

"Design thinking is a human-centered approach to innovation - anchored in understanding customer's needs, rapid prototyping, and generating creative ideas - that will transform the way you develop products, services, processes, and organizations"[12]. Design thinking focuses on the human aspect of the work we do, centering activities in relationships with our users and clients. It reminds us that the processes of defining the what and how of data collection and use are iterative and should be revisited and examined on a regular basis. In a data context, design thinking can help you think about why you are collecting data, and how you can collect and use it in appropriate ways.

Resources:

- IDEOu. (n.d.). *Design thinking.* https://www.ideou.com/pages/design-thinking
- IDEOu. (n.d.). *Design thinking resources.* https://www.ideou.com/pages/design-thinking
- Mitroff Silvers, D. (2013*).* Design thinking: A powerful tool for your nonprofit. *Connect*. https://www.nten.org/article/design-thinking-a-powerful-tool-for-your-nonprofit-0/
- Brown, T. & Wyatt, J. (2010). Design thinking for social innovation. *Stanford Social Innovation Review.* https://ssir.org/articles/entry/design_thinking_for_social_innovation#
- Woods, R. (2019). A design thinking mindset for data science. *Towards Data Science.* https://towardsdatascience.com/a-design-thinking-mindset-for-data-science-f94f1e27f90

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[12] IDEOu. (n.d.). *Design thinking.* https://www.ideou.com/pages/design-thinking

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.

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[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

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=tEeuoPlsNyl
- 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]
Communication
Collect Minimal Data
Accuracy
Interoperability
Good Governance

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[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:

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[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.

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[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

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[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/*

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[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

Build

Build

In the build phase, a key goal is to decide on how data are going be collected and organized (e.g., what methods will be used, how to categorize each variable).

Common Identifiers

A **common identifier** is a client ID that is used to denote your client across programs. Setting up a common identifier has many potential implications.

1. It can increase your understanding of your clients, allowing you to share data from other programs.
2. It supports integrated service delivery across your organization, as common identifiers link clients across programs. This can facilitate cross-program communication.
3. It supports research and evaluation to improve programs, which is more impactful on the client level.

Potential solutions for creating common identifiers are: setting up a common intake process and using methods to connect the same client in your database using identifiers (deduplication). Both benefit from coordination across your organization to standardize intake identifiers collected, as this makes it easier to associate a client to their previous service use.

Linkage to Other Datasets

It is possible to link your data to related service use from other organizations (e.g., healthcare use and employment income [via T1 tax data]) using the client identifiers that you collect (e.g., names and date of birth). This can increase the impact of your data by allowing you to tell stories about how your services relate to outcomes outside your organization (e.g., do you programs decrease hospitalization or increase ability of clients to work).

A few key considerations to facilitate this process are:

1) Gold standard identifiers (e.g., a personal health number [PHN] or Alberta Student Numbers) can make it very easy to link to related data (e.g., a PHN for healthcare data). However, collection of these identifiers may not be justified for your intake processes;
2) key linkage identifiers are: 1) first name, 2) middle name, 3) last name, and date of birth;
3) useful linkage identifiers are: 1) gender, 2) postal code, 4) other unique identifiers;
4) It is important to standardize your processes for collecting identifiers. For example, making sure dates of births are in the same order/format and names are collected the same way (i.e., legal names) can increase your ability to link.

Data Collection Modalities

In this section, we will outline the pros and cons of collecting data in the following modalities:

Paper-based[33]

Digital

Paper based data collection. With digital data collection becoming easier to use and more accessible some may question whether there is a need for paper based collection. The truth is, many organizations still opt to collect certain data on paper. In fact, in the event of power or equipment failure it is important to always have an option for filling out information on paper. Here are some of paper's overall advantages.

Pros:

- ✓ It's accessible to everyone. In our modern digital society it is easy to just assume everyone has access to a computer. Not everyone has access to a computer or even feels comfortable working with one. Having a paper option allows clients without computer skills to still register with an organization in their own way.
  Also staff may have limited computer skills but work very well with clients face to face. A paper form facilitates a more personable interview.
- ✓ Security is easier with paper. Ensuring privacy is as simple as having a locked cabinet with a key.
- ✓ Computers don't work 100% of the time. The power can go down, the internet can go off, and computers break. Whatever the reason having a paper option will ensure that clients can start receiving services.

Cons:

- x Unless there are offsite copies of forms natural disasters will pose a risk to your information.
- x Paper data collection takes longer and is more expensive than electronic data collection. Paper data collection also often does not eliminate the need for transferring your data to electronic media. That process is time consuming. It is standard practice to have a second person check paper responses as well as electronic entries to ensure they are correct.
- x Until the data is entered electronically its use can be restricted. Analysis is easier with an electronic tool. If a client is being referred, information will often need to be transferred electronically. This is especially true if the organization being referred to sees a high volume of clients.

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

Digital data collection. As previously stated, collecting data digitally is usually easier and more accessible than paper. It can range from entering data directly on a spreadsheet to using a commercial data collection application. Consider what your needs are first and then make an appropriate choice.

Pros:

- ✓ Electronic data is the easiest and most efficient way of analyzing and sharing data. Consider transferring all of your data to electronic media.
- ✓ Most computers have a spreadsheet application that can be used for data collection. While they are not the best solution they are convenient and can be a starting point for further electronic data collection and analysis.
- ✓ When you are ready you may want to consider moving to a commercial data collection application. Many commercial data collection applications are designed specifically for collecting client demographic information. This includes enforcing validation rules, proper field formatting, and including mandatory fields. Checks such as these save a lot of time on quality assurance later on. Consider if one of these applications would be a solution for your organization.
- ✓ Depending on what you decide to use there are a variety of data security solutions. Make sure you have proper security practices and IT staff to guide you.
- ✓ Some commercial applications have built-in reporting functionality. For many organizations this is often adequate for reporting to funders.

Cons:

- x Electronic data collection is more convenient but also fraught with more risks. Power failures, equipment failures, and computer hackers are some of the many potential hazards. Make sure you have adequate security policies and IT support to protect your clients and your organization.
- x Depending on your data collection solution, costs can get very high. If your budget is limited you may be restricted to inexpensive software (like Excel). For more intensive applications with many features, including security and backup, consider getting a license for a commercial application. These applications can get expensive but may be worth it. Make sure you can match your budget to your needs.
- x Electronic data collection is less personal than using paper. Design data collection protocols that keep the focus on the client during intake and referral processes.

Digital Data Hardware Options

Just as paper is one medium for collecting data, there are a few technologies for collecting data digitally. These allow more portability. Consider how services are provided at your organization and what hardware solutions might work for data collection (see table below).

Modality	Pros	Cons
Desktop Computer	• Desktops are everywhere. • Spreadsheets are available on most computers if a commercial data collection application is not available. • As a desktop computer comes with a keyboard and mouse data entry can be easy and efficient. • Unlike iPads, tablets, and laptops you don't have to worry about batteries running out. • Often attached to very fast direct internet connections. • Adds additional security for your data if your organization is behind a firewall.	• Not portable. Moving the computer can be cumbersome. • Will not work if the power goes out or the network is down. • Can be less personal if the client is talking to staff with a monitor in front of them.
iPad, Tablet, or Laptop	• Less intrusive • Tools can be designed for touchscreens making processes easier for those less experienced with computers. • IPads and tablets often don't use a keyboard making them less cumbersome and easier to use than laptops or desktops. • Some custom applications can even allow data collection without an internet connection. This enables data collection in remote areas. • Intake and client interaction is easier, (e.g., client can fill out form in a waiting area).	• Batteries can run out. Make sure a power cord is handy. • Many applications still won't work without an internet connection. Have a backup solution in case (e.g. spreadsheet, Word document, paper form). • Less secure and can be easily stolen.
iPhone	• Some applications allow transmitting a link by QR code or email. This allows forms to be pushed out to clients wherever they may be. • More accessibility for clients who only have a phone. • Touchscreen interactivity is easier for those less experienced with computers. • Less overhead for organizations since they don't need to invest in more hardware such as desktops, iPads, etc.	• Many forms may not render well on a phone. Perform adequate testing before considering this as an option. • Can be a potential security risk if the client is not filling forms out discretely.

Collect

Collect

In the collect phase, the processes of data collection and training must be established and carried out (e.g., how to ensure consistency and relatedness in collection methods).

Relational Aspects of Data Collection

Collecting qualitative and quantitative data often involves building relationships and trust with the individuals being interviewed or surveyed. There are certain characteristics about collecting data and the methods used when it comes to the relational aspects of collecting data.

Quantitative vs. qualitative. Data types in a Western context are often categorized as quantitative (i.e., information that is counted or compared on a numerical scale) and qualitative (i.e., information gathered through descriptive questions). Relationship-building is possible across all types of data collection, and with all types of data collection it must be an intentional aspect of the process. Data collection methods can be categorized across dimensions such as: quantitative and qualitative, and formal (i.e., requires structure and standardization) and formal (i.e., requires less structure, flexible). The choice to collect data must always match the intent (as stated in the “Plan” section), and also consider the ability to foster trust and rapport with the client.

Formal vs. informal. Formal methods could be structured interviews or focus groups, closed-ended questions, counts, and the use of administrative data. Informal methods could be open-ended questions, motivational or semi-structured interviews. The benefits of formal methods are that questions are consistent across clients, meaning everyone is asked the same question. The benefits of informal choices of data collection are that the conversation and responses evolve and address topics that may arise during conversation.

What helps clients to experience data collection as relational?

According to studies in healthcare and community settings,[34,35,36] there are ways to ensure that relationships are at the heart of the collection of data. The following is a compilation of these strategies:

- Availability and accessibility of the service provider
- Helping the client to feel emotionally and physically safe
- Helping the client to feel at home and valued as an individual

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[34] Dinç, L., & Gastmans, C. (2013). Trust in nurse–patient relationships: A literature review. *Nursing Ethics, 20*(5), 501–516. https://doi.org/10.1177/0969733012468463

[35] Hall, K. Gibbie, T., & Lubman, D. (2012). Motivational interviewing techniques: Facilitating behaviour change in the general practice setting. *Australian Family Physician 41*(9), 1-8.

[36] Kelley, A., Piccione, C., Fisher, A., Matt, K., Andreini, M., & Bingham, D. (2019). Survey Development: Community Involvement in the Design and Implementation Process. *Journal of public health management and practice : JPHMP*, *25,* S77–S83. https://doi.org/10.1097/PHH.0000000000001016

- Being adequately informed
- Getting to know the person first before offering services
- Harm reduction strategies
- Honouring client autonomy
- Honouring unique language, culture, and history of clients in the intake design process
- Keeping number of questions to as short as possible

Easy Data Wins; Big Impact

The Build Better Data resources offer strategies to increase the impact of your data. Below, we highlight **three quick wins** to enhance your data and improve the impact of your data analysis.

Win #1

Clearly mark missing data. Indicating where data is missing or unknown with standard, easy to identify values (i.e., mark entries as 'missing') and differentiating between different forms of missing data (i.e., not answered vs not applicable vs not asked) makes it easier to work with data and supports robust analyses.

Below are common examples of missing data entry issues and solutions:

- **Assigning a default value to missing data.** In this example, the default date (typically the intake date) may lead to a case of mistaken client identity.

	Date of Birth
Client answer	Not answered
Problematic entry	1/11/2021
Improved entry	999

[37]

- **Assigning an incorrect value to unknown or not applicable missing values.** In this example, the client was not asked the question but a response of 'no' rather than not asked was recorded. This would lead to incorrect analysis of this data.

	Health need expressed
Client answer	Not asked
Problematic entry	No
Improved entry	888

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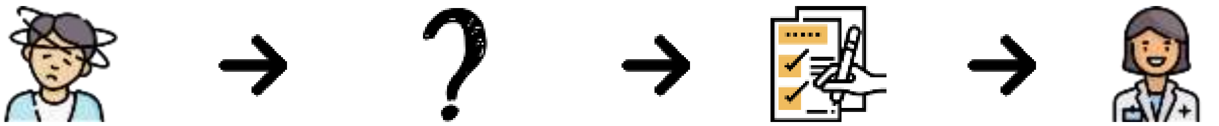
[37] Icons in this section made by Freepik from www.flaticon.com.

Collect



- **Assigning all entries missing when only part of data is missing.** In this example, the year of birth is valuable information that can be used to calculate age. If it is not recorded, it is a missed opportunity to analyze partial data.

	Month Birth	Day Birth	Year Birth
Client answer	Not answered	Not answered	1975
Problematic entry	Not answered	Not answered	Not answered
Improved entry	999	999	1975

Win #2

Collect name and date of birth: Collecting your clients' full legal name and date of birth helps you to track their journey through services, both internal and external to your organization. Other demographic information (e.g., gender, postal code.) is also helpful to collect.

Below is an illustration of the power of using demographic data to link identities. **Linking a person based on full name and date**. In this example, the same person can be connected to different programs and services over time.

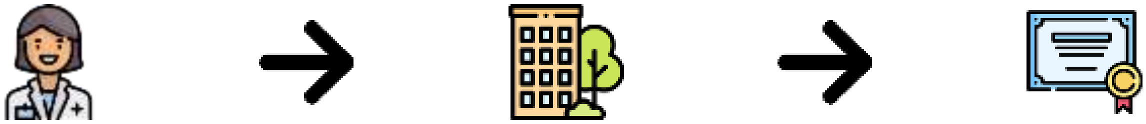
Person

Jacob Albert Reynolds
9/7/1975

Jacob Albert Reynolds
9/7/1975

Jacob Albert Reynolds
9/7/1975

Service use journey



1/5/2015
Hospitalized for complications due to experiencing homelessness

4/21/2015
Received housing support

5/14/2019
Graduated from university

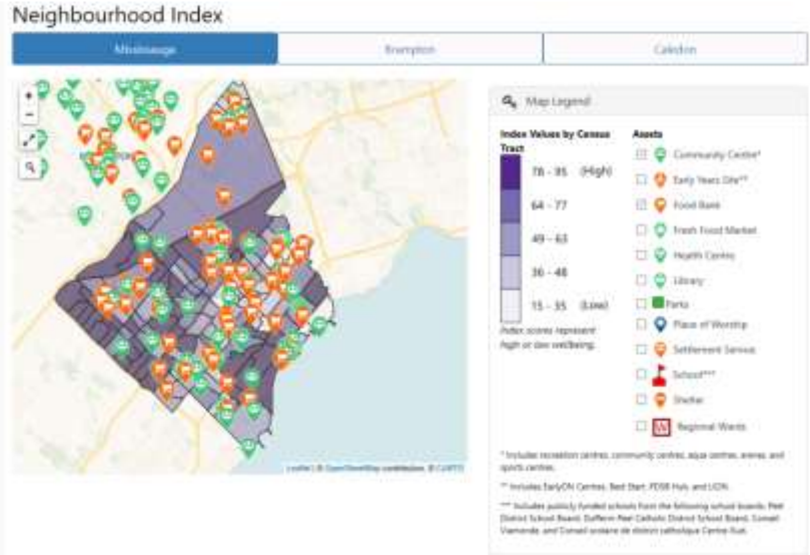
Win #3

Collect client postal codes with other demographic data. When possible, collect the full, 6 digit postal code rather than just the first 3 digits. Postal codes can be used to examine geography, health, and socio-economic variables.

Examples of questions that geographic analyses can answer:

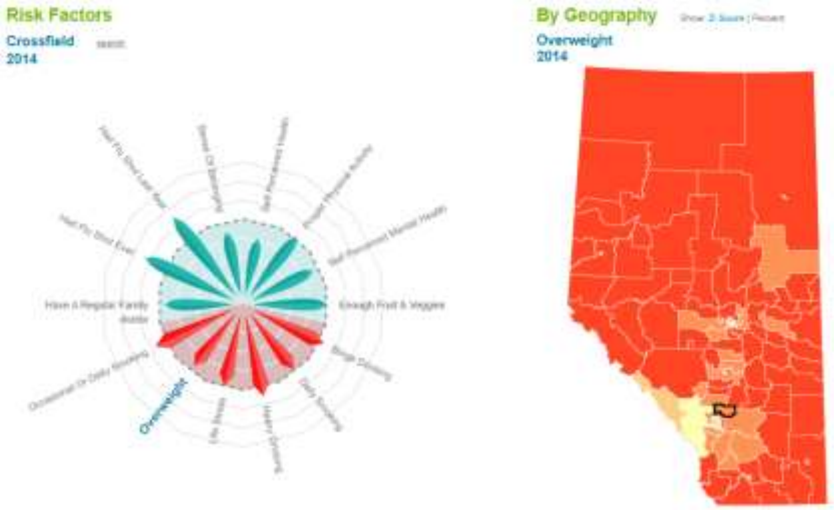
- **Where do people live?**
  This can help for strategic initiatives to expand services or target different client groups.

- **What other services are accessible nearby?** This can help identify local supports.



Source: Neighborhood Information Tool, https://www.peelregion.ca/planning-maps/nit/

- **How 'healthy' are peoples' neighborhoods?** This can help examine client vulnerabilities to other risks.



Source: AEPHIN Public health risk factors: http://aephin.alberta.ca/risk/

Prepare

Prepare

In the prepare phase, it is important to become familiar with the data collected (e.g., document observations, nuances, and quality of the data) and ensure the data is amenable for further analysis and reporting.

Document your Data

1. **Keep documentation in one place.** Place all of the preceding documentation in a single place which is accessible by all staff. Organize all of these documents accordingly.
    - Data collection staff.
        - Data collection protocols.
        - Consent processes.
        - Process flows for clients based on their needs.
    - Clients who are providing data.
        - Consent processes.
        - Program information.
    - Staff who will analyze data for evaluation and reporting.
        - Data dictionaries. A data dictionary is a technical document describing what each value or response means.
        - Cleaning and validation protocols.
        - Analysis plans, KPIs, strategic documents, funders' applications, etc. that can help guide in the analysis of your data.
    - Data consumers inside and outside your organization (e.g., board members, directors, the general public, funders, partnering organizations, etc.).
        - Include all of aforementioned documentation. They may never need to know all of the details of your data collection program. No less, having them at your disposal will show accountability and will allow you to answer questions as they arise.

2. **Building your data documentation.** First off let's adopt the term 'data documentation'. Intake forms, data collection protocols, and referral forms are some examples of things that can be included in your documentation.

3. **Curating our data documentation.** As workers in the non-profit sector we can simply use the term 'data documentation', which are documents that describe the data and allow us to understand it.

4. **What does your data mean?** Very often data files are just large quantities of numbers arranged by rows and columns. What does it all mean? It is understandable why people may disengage from trying to understand their data. Especially if there is no accompanying documentation. For every data set you collect it is important to have all of the documents associated with it collated in a single place. Remember data is a tool to tell stories. Without enough documentation to explain your data those stories lose impact and context.

Principles of Data Documentation

Every organization should invest time and energy into building their data documentation resources. Just as the data life cycle is a tool for building your data collection program, a data documentation system is a way of documenting that program.

When building your documentation it is helpful to think of metadata. This is a term most often referred to in research or industry. It literally means 'data about the data'. There are many advanced and technical tools for creating and using metadata which are beyond the need of most non-profits. However, adopting a few basic metadata principles will greatly help in building their documentation resources.

1. Think of all the use cases of your data then collate all corresponding documents. Refer to the data life cycle to understand what documentation is needed at each step. Before we get lost in collating of all your documents, consider not only staff and clients, but your audiences as well. Who will be exposed to your organization's data? What would you need to tell them about your data collection program? How do you remain accountable to staff, clients, or people outside of your organization? While many of these groups may never look at your documentation you need to have answers for them as questions arise. This isn't just about the data itself but **contextualizing** the data. It's also about clear **communication**. If someone asks questions about your data you need to be able to answer them.

2. Consider the following groups of people, their questions, and how your documentation will inform them:

Group of People	What questions may arise?	What documentation will help answer the question or guide the process?
Data collection staff	• How do I intake a client? • How is the consent process executed with a client? • What programs do they need to refer clients to?	• Data collection protocols. • Consent processes. • Process flows, eligibility criteria for programs and clients based on their needs.
Clients	• How is their data being used? • What programs do they need?	• Consent forms. • Program information.
Staff who will analyze data for evaluation and reporting.	• What does a certain data element mean? • What checks have been done on the master data set? • What metrics are needed on the upcoming report?	• A data dictionary, which is a technical document describing what each value or response means. • Cleaning and validation protocols. • Analysis plans, KPIs, strategic documents, funders' applications, etc. that can help guide in the analysis of the data.
Data consumers inside and outside your organization. E.g. Board members, directors, the general public, funders,	• Were low referrals to organization X this year due to funding? • Does this agency follow OCAP principles when	• See any of the above documentation. • These groups may never need to know all of the details of your data collection program. No less, your accountability will depend on how prudent your

Group of People	What questions may arise?	What documentation will help answer the question or guide the process?
partnering organizations, etc.	reporting? How is that covered in consent? • Why is this number so low in the report? How was this data cleaned or collected? • How are referrals to a partnering organization handled?	organization is in documenting all aspects of data. • Having these documents at your disposal will increase accountability and allow you to answer questions as they arise.

3. Have a system of maintaining your documentation. Once you have gathered all of the relevant data documentation place your documentation on a network drive. Assign distinct folders depending on the function or stage of the data life cycle. Work with your staff and consider what structure is relevant for your organization. While you may want some discretion on whom to share documents with it is also good to have some transparency. This will help facilitate their understanding of processes.

Also many of your documents will be subject to revisions. Make sure you keep versions up to date but also make sure you keep past versions of documents. This is important for institutional memory or in case staff want to verify past results and processes.

The following folder structure is a suggestion. Maintain a folder structure that reflects the flow of processes in your organization. Consider which groups in your organization will access documents.

Process	Name of Top Folder*	Name(s) of Sub Folder(s)*	Type(s) of Information in Sub Folder(s)*
Data Collection	Data Collection	Intake Process	• Consent • Intake/registration forms
		Programs	• Program A • Program B
Data Analysis	Data Analysis	Data Cleaning Processes	• Intake form data • Program A data • Program B data
		Data Analysis Processes	• Funder report program A • Funder report program B • Analysis of intake program A • Data quality assessment program A
Reporting	Reporting	Funder Program A Report	• Reports from current and previous years
		Funder Program B Report	• Reports from current and previous years

**Note:* None of these folders will ever contain actual data. It is recommended that data itself are only accessible to authorized staff in a restricted folder. There are a variety of ways of managing and maintaining the security of your data. Make sure that your organization has a plan for maintaining data security and strictly adheres to it.

4. Assign a staff member to maintain data documentation. There are many people who may work with data at your organization. However, not everyone will understand the entire process. Having a single staff member to maintaining documentation will help communicate processes and ensure that institutional memory is captured. It will also help answer any potential questions or issues when they arise.

Analyze

Analyze

In the analyze phase, it is important to answer the goals that were originally set out by the organization or project.

1. **Setup your data**, much of your final analysis is determined by previous steps
    - **Plan ahead**: what you can show from your data is determined by what data you collect. Consider planning for the analysis you'd like in the earliest stages of your project.
    - **Read**: use literature to create analyses that are based on previous literature, as you can have more confidence in findings that are theory driven and replicated.
    - **Clean**: remove clear artifacts in your data before you use it. Data cleaning is often a major step in data analysis.
        - Clean data tells a more reliable story
        - Data cleaning is a major step in most data analysis
            - How you clean data is determined by assumptions in your analysis
            - Preventing errors in data collection is best
            - Cleaning clear mistakes after is possible (i.e., not possible answers)
    - **Combine**: Consider grouping data to improve your story
        - Less information is easier to follow
        - Group those that logically fit together (children under 18; and adults 18+)
        - Consider how 'identifiable' people are if they aren't grouped together. It is easier to identify a person from 5 clients grouped together than 20.

2. **Analyze your data,** some simple descriptions of types of analysis are:
    - **Descriptive**: provides a snapshot of your client's characteristics and/or service use patterns (e.g., client age, gender, referral patterns, service use, etc.)
    - **Relational**: looks at the relationship between variables. This can be correlational, factor analysis, modelling, etc. Variables measured before an intervention can be used to 'predict' later outcomes, but should rule out alternative explanations
    - **Experimental**: understands if an intervention 'caused' a change in outcome. Strongest evidence includes random assignment to intervention and control group to compare without intervention, and rules out alternative explanations.
    - **Administrative**: links secondary data to your data to add to the story. Data can often be linked with things such as name and date of birth, and postal code. For example, health, education, geographic, and tax data can be linked to your data, with varying difficulty.
    - **Qualitative**: interviews, focus groups, observational data, etc. collected to provide a narrative understanding of clients, and is systematically analyzed

3. **Your journey is just beginning**
    - **Visualize it**: carefully consider simple, but not misleading, ways to represent your data visually to increase its impact.
    - **Improve**: use your findings to improve service delivery.
    - **Start with analysis**: consider starting your data life cycle with a simple round of analysis with existing data. This is easy, cheap, and can help show parties the potential impact of data before major change. In addition, it may help you think about what data you want.

- **Don't force it**: Data often do not meet all of your questions. That's OK! Don't force a false story on the data. Data use is iterative; just collect what you need next time. It is natural that your ability to use data will increase over iterations of analysis.
- **Plan, plan, plan!** Remember, the more you plan for data collection and analysis upfront, the more you'll answer your questions!

Resources

- Data Orchard (September, 2019). *Data maturity framework for the not-for-profit sector*. https://static1.squarespace.com/static/5d514d1775e9c90001345670/t/5d9f402df0b6312eb6c55f69/1570717742668/Data+Orchard+Data+Maturity+Framework+NFP+Sector+2019.pdf
- Cotgreave, A. (n.d.). *6 best practices for creating effective dashboards.* http://www.umsl.edu/~sauterv/DSS/whitepaper_6bestpracticesforcreatingeffectivedashboards_engfinal.pdf

Inform

Inform

In the inform phase, it is important to demonstrate how an organizations' use of data addresses the original goal for collecting the data. Using data to inform means understanding and sharing the story the data can tell. Effective storytelling requires an understanding of the issue, audience, questions of interest, and the different types of data that can be used to help answer those questions.

Satisfying reporting obligations to funders is typically the primary goal of data collection. Funders often require specific data from a set time. For example, organizations may collect data on the populations accessing services (demographics), service delivery (process data), service use and the effects of service use (outcome data), and whether these services are ultimately influencing larger social issues (impact data). Reporting on some or all of these data points may be based on the fiscal year, funding cycle, or specific program timelines.

There are additional goals that can be considered to maximize data (i.e., demographics, process, outcome, and impact data) collection efforts. Data can also be used to inform:

- client-centered practices;
- design, content, processes, and evaluation of social serving work;
- priorities and directions of organizations; and,
- challenges and potential solutions for the broader social issues at play.

Creating a plan for collecting and analyzing data to address multiple goals can help to maximize the organizational resources already dedicated towards reporting obligations and contribute to robust, evidence-informed internal and external processes. These can include:

1. **Supporting clients to meet additional needs** – demographic and outcome data may be important to share with other social serving organizations to support clients to meet additional needs. Data sharing may be an important client-centered tool to support efficient and effective navigation of complex systems of services; however, there are important legal and ethical obligations to consider. If data doesn't need to be connected to a specific individual, it should be anonymized to protect privacy. If data does need to be connected to a specific individual to ensure safety and appropriate referrals, consent from that client should be obtained wherever possible and reasonable.

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/*

2. **Internal decision-making** – rather than going with your 'gut' or using anecdotal data that can be subject to unconscious bias, internal decisions, such as strategic priorities, organizational or programming changes, and funding allocations, can be grounded in your data. The type of data you could use would be contingent on the question or decision you are facing.

3. **Program improvement** – by bringing together demographic, process, and outcome data, gaps in accessibility, service delivery, and outcome attainment can be identified. You can also consider collecting targeted data to understand more specific information about how, where, and why these gaps exist. With this data you are well equipped to make a plan to improve your programming to address existing gaps.
4. **Program development** – if an existing program cannot be improved to address identified gaps in accessibility, service delivery, and outcome attainment or if your organization is considering new directions, new programs may need to be created. Your existing data can be used to create a compelling story to pursue funding for this new initiative, or you could explore data related to client satisfaction, preferences, and needs to help inform the design, content, and delivery of a new program or service.
5. **Strategic planning** – examining trends in your data over time can help you to understand internal changes as well as broader social shifts. Using this information in your strategic planning can help your organization to make predictions in order to be responsive to change over time. For example, shifts in population demographics, service use, available funding or services, are all important data trends that can inform organizational decision-making, improvement, and future development.
6. **Advocacy** – your data tells a story that is unique to your organization. Depending on your organization's strategic priorities and desired impact, it may be important to leverage your story to take a position on an important topic. Advocacy can take many forms. You can share your story and your data in support of a cause, to argue against a course of action, or to request something like additional funding or supports from other organizations or decision-makers. Your story can help shape government policies or contribute to a larger social conversation that is already underway. Remember, anytime your internal data will be made public, make sure that it is made anonymous so that no one individual can be connected back to your organization or the data you are sharing.

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