A Guide to Data Privacy for Non-Profit Organizations in New Brunswick

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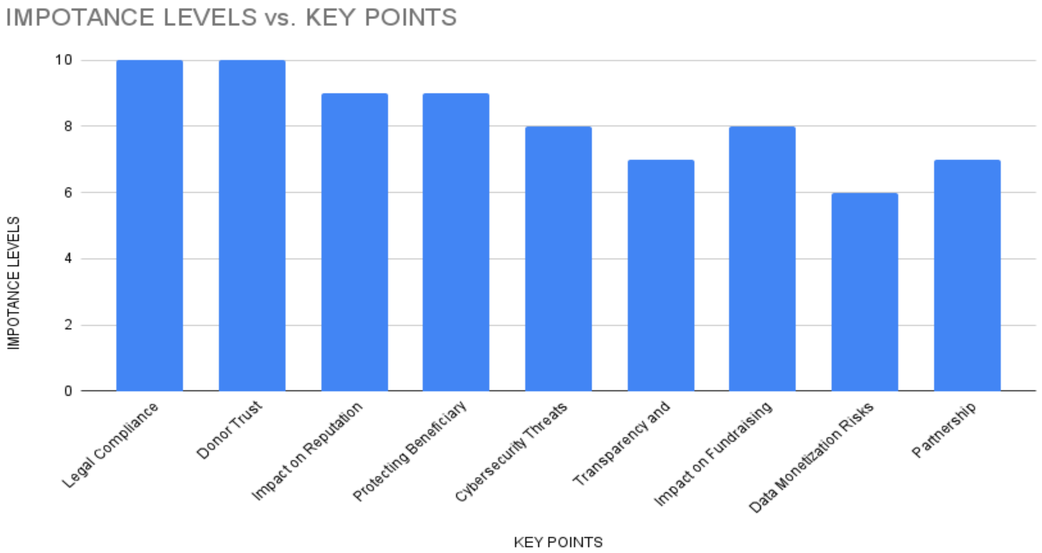
Introduction

The Importance of Data Privacy for Non-Profits



In an increasingly digital world, non-profit organizations hold vast amounts of sensitive data. Some of which are processed, stored, transmitted and shared in a poorly secured environment. A 2016 study found that 63 percent of nonprofit organizations (NPOs) had suffered at least one breach in the previous year.

Due to the COVID-19 pandemic, more people are working from home and relying on the Internet than before. In fact, according to Smallbiztrends, 66% of employees are now working from home. This is true even for nonprofits, who've historically been reluctant to embrace new technology.

However, as more and more organizations move online without taking the proper data security and privacy precautions, the chance of hacks increases exponentially for example the data breach at People Inc. This could be you!

Data privacy holds immense significance for non-profit organizations for compelling reasons which are listed below:

- **Protecting Vulnerable Populations:** Many non-profits serve vulnerable populations, such as children, refugees, or individuals with health challenges. Ensuring their data is protected is not only a legal obligation but a moral imperative.

- **Demonstrating Ethical Leadership:** Adhering to strong data privacy practices demonstrates an organization's commitment to ethical leadership and responsible stewardship of resources, including data in the community.
- **Maintaining Trust and Credibility:** Non-profits rely heavily on public trust and credibility. When individuals, donors, and partners believe their data is handled responsibly, they are more likely to engage with and support the organization.
- **Protecting Sensitive Information:** Non-profits often deal with highly sensitive information, such as medical records, financial details, and personal histories. Ensuring the privacy of this data is crucial for safeguarding individuals' rights and well-being.
- **Compliance with Legal Obligations:** Many regions have strict regulations governing the collection, storage, and use of personal data. Non-profits must comply with these laws e.g., PIPEDA in Canada, GDPR in Europe, HIPAA in the U.S., to avoid legal penalties and reputational damage. In New Brunswick, the office of the OMBUD is responsible for privacy related matters.
- **Preventing Data Breaches and Cyber Threats:** Non-profits, like any other organization, are vulnerable to cyber threats. A data breach not only compromises individuals' privacy but also exposes the organization to financial losses and reputational harm.
- **Facilitating Effective Operations:** Proper data privacy practices streamline operations. When data is organized, secure, and accessible only to authorized personnel, non-profits can operate more efficiently and effectively in achieving their mission.
- **Enhancing Stakeholder Confidence:** Stakeholders, including donors, volunteers, and beneficiaries, want assurance that their information is protected. Demonstrating a commitment to data privacy builds confidence and encourages continued engagement.
- **Enabling Responsible Data Sharing:** Non-profits often collaborate with other organizations, governments, and stakeholders. Adhering to data privacy principles allows for responsible sharing of information, which can lead to more effective partnerships.
- **Mitigating Reputational Risks:** Any incident involving mishandling of data, whether intentional or accidental, can lead to significant reputational damage. This, in turn, can affect fundraising efforts, volunteer recruitment, and partnerships.

- **Fostering Innovation and Growth:** A strong data privacy framework can foster a culture of trust within an organization. When employees and stakeholders feel confident in data handling practices, they are more likely to embrace innovation and contribute to organizational growth.
- **Adapting to Changing Regulations:** Data privacy laws and regulations are constantly evolving. By proactively addressing privacy concerns, non-profits position themselves to adapt to new legal requirements, ensuring continued compliance.

Scope and Purpose of this document

This document explores the critical aspects of data privacy that non-profit organizations must be aware of. Covering topics from legal frameworks and compliance to best practices in data handling, this guide aims to equip non-profits with the knowledge necessary to safeguard the trust of their stakeholders, be it donors, clients, volunteers etc

The objective of this document is to provide the Non-Profit Organizations in New Brunswick an overview of Data Privacy as it relates to them: what it is, how it applies to them and what they need to understand.

Understanding Data Privacy

Definition and Components of Data Privacy

Data privacy is a concern for everyone, not just big businesses. Non-profits working to further certain causes are no exception. When dealing with the personal information of your donors or recipients of your services, you need to be cognizant of legal concerns related to protecting sensitive information. Effective cybersecurity will keep important information safe so you can keep fulfilling your mission because what you don't know puts your mission at risk!

The terms Data Privacy and Data Security are sometimes confused and mistakenly believed that keeping personal and sensitive data secure from hackers means that they are automatically compliant with data privacy regulations. This is not the case. Data security protects data from compromise by external attackers and malicious insiders whereas Data Privacy governs how the data is collected, shared and used.

Data privacy is focused on the use and governance of personal data—things like putting policies in place to ensure that clients' personal information is being collected, shared and used in appropriate ways. Security focuses more on protecting data from malicious attacks and the exploitation of stolen data for profit. While security is necessary for protecting data, it's not sufficient for addressing privacy.

Data privacy for non-profit organizations refers to the protection of sensitive information that the organization collects, processes, stores, and shares about individuals, including donors, volunteers, beneficiaries, and employees. It involves safeguarding this data from unauthorized access, use, disclosure, or alteration, ensuring that individuals' rights and privacy expectations are respected.

The components of data privacy for non-profits include:

- **Consent and Transparency:** Non-profits must inform individuals about the purposes for which their data is collected and obtain their explicit consent. Transparent communication ensures that individuals understand how their information will be used.
- **Data Collection and Minimization:** Non-profits should only collect data that is necessary for achieving specific purposes. Unnecessary data should not be collected, reducing the potential risks associated with data handling.
- **Data Security and Protection:** This involves implementing technical and organizational measures to safeguard data from unauthorized access, breaches, and cyber threats. It includes encryption, access controls, firewalls, and secure storage.
- **Data Accuracy and Quality:** Non-profits are responsible for maintaining accurate and up-to-date data. Regularly reviewing and correcting inaccuracies ensures that decisions based on this data are reliable and fair.
- **Purpose Limitation:** Data should only be used for the purposes for which it was collected. Using data for other, unrelated purposes without proper consent can infringe on individuals' privacy rights.
- **Data Retention and Disposal:** Non-profits should establish clear policies on how long data will be retained and when it will be securely disposed of. This helps prevent the unnecessary storage of data and reduces the risk of data breaches.

- **Access and Portability:** Individuals have the right to access their own data and, in some cases, request it to be transferred to another entity. Non-profits must have procedures in place to facilitate these requests.
- **Data Sharing and Third-Party Relationships:** When sharing data with third parties, non-profits should have agreements in place to ensure that these parties also uphold data privacy standards. This includes vendors, partners, and service providers.
- **Training and Awareness:** Employees and volunteers should receive training on data privacy policies and procedures. This ensures that everyone involved in data handling understands their responsibilities and knows how to protect sensitive information.
- **Incident Response and Reporting:** Non-profits should have a plan in place for responding to data breaches or incidents. This includes notifying affected parties and relevant authorities in accordance with legal requirements.
- **Compliance with Legal and Regulatory Frameworks:** Non-profits must adhere to applicable data privacy laws and regulations, which can vary by region. This includes understanding and complying with laws like the GDPR, HIPAA, or other regional data protection laws.
- **Accountability and Governance:** Designating a Data Protection Officer (DPO) and establishing clear governance structures for data privacy helps ensure that the organization's practices align with its policies.

Ethical Considerations in Handling Data

Ethical considerations in handling data are paramount in ensuring that individuals' rights and privacy are respected. This is especially crucial for non-profit organizations, which often deal with sensitive information. The following are key ethical considerations:

1. **Informed Consent:** Obtaining informed consent from individuals before collecting their data is a fundamental ethical principle. This means individuals should be aware of what data is being collected, how it will be used, and have the option to consent or decline.
2. **Purpose Limitation:** Data should only be used for the purposes for which it was collected and communicated to the individuals. Using data for unrelated purposes without proper consent is ethically unacceptable.

3. **Data Minimization:** Non-profits should collect only the data that is strictly necessary for the stated purposes. Collecting excessive or irrelevant data infringes on individuals' privacy rights.
4. **Accuracy and Transparency:** Non-profits have an ethical obligation to maintain accurate and up-to-date data. Transparency in data handling practices helps build trust with stakeholders.
5. **Security and Protection:** Ethical responsibility includes implementing robust security measures to protect data from unauthorized access, breaches, and cyber threats. Failure to do so can result in harm to individuals and reputational damage.
6. **Data Sharing and Third Parties:** Ethical handling of data includes ensuring that any third parties or partners with whom data is shared adhere to the same high standards of data privacy.
7. **Respect for Privacy Preferences:** Individuals may have specific privacy preferences or opt-out requests. Non-profits should respect and honor these requests in an ethical manner.
8. **Data Retention and Disposal:** Ethical considerations dictate that non-profits should establish clear policies for how long data will be retained and how it will be securely disposed of when no longer needed.
9. **Fairness and Non-Discrimination:** Data should be used in a manner that is fair and free from discriminatory practices. Biases or discriminatory practices based on data can result in harm and are ethically unacceptable.
10. **Accountability and Transparency in Data Handling Practices:** Ethical non-profits take responsibility for their data handling practices. This includes designating a Data Protection Officer (DPO), establishing governance structures, and conducting regular audits.
11. **Empowering Data Subjects:** Ethical considerations include empowering individuals to exercise their data privacy rights. This includes providing mechanisms for individuals to access, correct, or delete their data.
12. **Ethical Use of Analytics and AI:** When utilizing advanced technologies like analytics and AI, non-profits must ensure that these tools are used ethically and do not infringe on individuals' rights or perpetuate biases.
13. **Crisis Management and Incident Response:** Ethical organizations have plans in place for responding to data breaches or incidents, which includes notifying affected parties promptly and providing them with the necessary support.

14. **Continual Monitoring and Improvement:** Ethical non-profits continually assess and improve their data handling practices to stay aligned with evolving ethical standards and legal requirements.

By incorporating these ethical considerations into your data handling practices, you demonstrate your commitment to respecting individuals' rights, upholding their ethical obligations, and building trust with your stakeholders.

Legal Frameworks

In New Brunswick, Canada, non-profit organizations handling personal data are encouraged to adhere to various legal frameworks applicable to them to ensure data privacy and compliance. Here are the key legal frameworks that apply to non-profits in New Brunswick:

Personal Information Protection and Electronic Documents Act (PIPEDA):

- PIPEDA is a federal privacy law that applies to private-sector organizations conducting commercial activities. While it primarily applies to commercial entities, non-profits may be subject to PIPEDA if they engage in commercial activities, such as selling goods or services.

New Brunswick's Right to Information and Protection of Privacy Act (RTIPPA):

- RTIPPA is a provincial legislation that applies specifically to public bodies in New Brunswick, including government agencies and institutions. It governs access to information held by these entities and sets out rules for the protection of personal information.

Personal Health Information Privacy and Access Act (PHIPAA):

- PHIPAA is specific to health information and applies to health care providers and organizations in New Brunswick. It governs the collection, use, and disclosure of personal health information.

Electronic Transactions Act:

- This provincial act provides a legal framework for electronic transactions and e-commerce in New Brunswick. It includes provisions related to electronic signatures and the protection of electronic records.

Privacy Impact Assessments (PIAs):

- While not a legal framework in itself, PIAs are a mandatory process for government institutions and health care organizations in New Brunswick. They are used to assess the privacy risks associated with new or significantly modified programs or activities that involve the collection, use, or disclosure of personal information.

Charitable Status and Federal Income Tax Act:

- Non-profits seeking charitable status under the federal Income Tax Act must adhere to certain guidelines for handling donor information. This includes maintaining the confidentiality of donor records and using donor information only for legitimate fundraising purposes.

Sectoral Privacy Laws:

- Some industries in New Brunswick, such as health care and social services, have specific legislation and regulations that pertain to the privacy of personal information within those sectors. Non-profits operating in these industries must comply with the relevant sector-specific privacy laws.

As a non-profit organization in New Brunswick, it is important that you are aware of, and comply with these legal frameworks to ensure the protection of individuals' privacy rights if it applies to your services. Regular consultation with legal counsel and staying informed about any updates or amendments to privacy legislation is crucial for maintaining compliance.

Types of Data Held by Non-Profits

Personal Identifiable Information (PII)

Non-profit organizations handle various types of data, with Personal Identifiable Information (PII) being one of the most critical categories. PII refers to any information that can be used to identify an individual. This data is sensitive and requires special safeguards. Here are some common types of PII held by non-profits:

- **Names:** Full names, including first names, middle names, and surnames, are common forms of PII.
- **Contact Information:** This includes addresses, phone numbers, and email addresses, which are essential for communication and outreach efforts.
- **Social Security Numbers:** In some cases, non-profits may need to collect social security numbers for specific purposes, such as tax reporting or beneficiary verification.
- **Government IDs:** This can include passport numbers, driver's license numbers, or other government-issued identification numbers.

- **Date of Birth:** Birthdates are crucial for verifying age, eligibility for programs, and ensuring legal compliance.
- **Financial Information:** Non-profits may collect financial data, such as bank account numbers, for donation processing or direct deposit purposes.
- **Health Information:** For non-profits involved in healthcare or social services, medical records or health-related data may be collected. This is particularly governed by specific regulations like HIPAA.
- **Donation History:** Information about past donations, including amounts, dates, and purposes, helps non-profits in donor stewardship and fundraising efforts.
- **Volunteer Records:** Data on volunteers, including contact information, skills, and hours worked, is essential for coordinating volunteer efforts.
- **Employment History:** Non-profits may collect information about employees, such as resumes, references, and work history.
- **Membership Information:** For organizations with membership structures, data on members, including their names, contact information, and membership status, is typically collected.
- **Demographic Information:** This includes details about race, ethnicity, gender, and other characteristics, which may be collected for statistical or program evaluation purposes.
- **Photographs or Videos:** Visual representations of individuals, such as photos or videos, are considered PII.
- **Online Account Information:** For non-profits with online platforms, login credentials and account information are PII.

Does your non-profit organization collect any of the above listed PII’s, it's crucial to handle PII with the utmost care. This includes implementing robust security measures, obtaining proper consent, and adhering to relevant privacy laws and regulations. Additionally, it is recommended that non-profits should regularly review their data handling practices to ensure compliance with changing standards and evolving best practices in data privacy.

Sensitive Data for Non-Profits:

Sensitive data refers to information that, if exposed, could lead to potential harm or a breach of privacy for individuals. Some non-profit organizations handle sensitive data in various forms, depending on the nature of their operations. Safeguarding this information is crucial. Examples of sensitive data held by non-profits may include:

- **Health Records:** Information related to the physical or mental health of individuals, including diagnoses, treatment plans, medication history, and medical test results. This is particularly relevant for non-profits in the healthcare sector.
- **Financial Information:** Details about an individual's financial status, including bank account numbers, credit card information, income, and tax records. Non-profits often handle financial data when processing donations and managing grants.
- **Sensitive Personal Identifiable Information (PII):** This includes data that can be used to identify individuals, such as social insurance numbers.
- **Client and Beneficiary Records:** Information about the individuals or families receiving services from the non-profit, including their personal circumstances, needs, and progress.
- **Donor and Volunteer Information:** While this data is essential for maintaining relationships and acknowledging contributions, it can also be considered sensitive. Donors may have preferences about how their information is used and shared.
- **Legal Records:** Information related to legal proceedings, court records, case details, and any criminal history if relevant to the non-profit's activities.
- **Social Services Data:** Information about vulnerable populations, such as refugees, survivors of domestic violence, or individuals seeking assistance with housing and basic needs.
- **Ethnicity, Race, and Demographic Information:** Collecting demographic data may be essential for programs aimed at specific communities, but handling this information requires care to avoid potential bias or discrimination.

It's imperative for you to establish data privacy policies and security measures to protect sensitive information. If applicable, measures like encryption, access controls, secure storage practices, and regular training for staff and volunteers on handling sensitive data responsibly may be put in pplace. Additionally, compliance with relevant data protection regulations should be a priority for organizations handling sensitive data.

Donor and volunteer information

This type of data pertains to individuals who support the organization through donations of funds, goods, or services, as well as those who dedicate their time and skills as volunteers. Managing this information effectively allows non-profits to maintain relationships, acknowledge contributions, and engage their supporters in meaningful ways. Here are some key aspects of donor and volunteer information:

- **Contact Details:** This includes names, addresses, phone numbers, and email addresses of donors and volunteers. It allows for communication and updates about the organization's activities and initiatives.
- **Giving History:** This involves tracking the history of donations made by individuals. It includes details such as donation amounts, frequency of donations, and specific campaigns or projects the donations were directed towards.
- **Preferred Communication Methods:** Knowing how donors and volunteers prefer to be contacted (e.g., email, phone, mail) helps tailor communication to their preferences, enhancing engagement.
- **Areas of Interest or Causes Supported:** Understanding the specific interests or causes that donors and volunteers are passionate about enables the organization to provide opportunities that align with their values.
- **Recognition Preferences:** Some donors and volunteers may have preferences regarding how they are recognized for their contributions. This could include acknowledgment in publications, plaques, or events.
- **Volunteer Skills and Availability:** For volunteers, it's important to know their skills, expertise, and availability. This helps in matching them with appropriate projects and tasks.
- **Feedback and Surveys:** Gathering feedback from donors and volunteers about their experiences with the organization can provide valuable insights for improvement.
- **Privacy Preferences:** Respecting individuals' privacy preferences, such as opting out of certain communications or remaining anonymous, is crucial for building trust.
- **Relationships with Other Supporters:** Understanding any connections between donors and volunteers (e.g., family members or colleagues) can help identify potential collaborative opportunities.

Managing donor and volunteer information with care and respect is essential for maintaining strong relationships and fostering a sense of community within the non-profit organization.

Data Collection and Consent Best Practices

Data collection and obtaining consent are crucial steps in ensuring that non-profits handle personal information responsibly and ethically.

Best Practices for Obtaining Consent

Here are best practices for obtaining consent:

- **Clear and Specific Purpose:** Clearly communicate the purpose for which data is being collected. Specify how it will be used, who will have access to it, and for how long it will be retained. Data should only be used for the consented purpose; any new processing requires new and specific consent.
- **Explicit Consent:** Seek explicit and informed consent from individuals before collecting their data. This means they must understand what data is being collected and for what purpose, and they must willingly agree to it.
- **Opt-In Mechanisms:** Use opt-in mechanisms rather than opt-out. This means individuals actively choose to provide their data, rather than having to take steps to prevent it.
- **Granular Consent:** Provide options for individuals to consent to different types of data processing. For example, allow them to consent to receiving newsletters but not to receiving promotional emails.
- **No Pre-Ticked Boxes:** Do not pre-select options for individuals. Allow them to make active choices regarding their data.
- **Simple Language:** Use clear and simple language to explain the purpose of data collection and how it will be used. Avoid legal jargon or complex terms.
- **Easy Withdrawal of Consent:** Inform individuals that they have the right to withdraw their consent at any time, and provide clear instructions on how to do so.
- **Age Verification for Children:** Implement age verification measures to ensure that individuals providing consent are of legal age. This is particularly important when dealing with children's data.

Children's Data and Parental Consent

- **Age Verification:** Implement mechanisms to verify the age of individuals providing consent. This helps ensure that children under the legal age are not providing their own consent.
- **Parental Consent:** When dealing with children's data, especially for online services, obtain verifiable parental consent before collecting any information from a child.
- **Clear Information for Parents:** Provide parents with clear and accessible information about the data being collected from their child, the purpose, and how it will be used.
- **Parental Access and Control:** Allow parents to access and control the information collected from their child. They should be able to review, edit, or delete it if needed.
- **Ongoing Communication with Parents:** Maintain open communication with parents about data handling practices. Inform them of any changes in policies or practices related to children's data.

Transparent Data Collection Policies

- **Clear Privacy Policy:** Have a clear and accessible privacy policy that outlines how data is collected, used, and protected. Make it easily available on your website or at the point of data collection.
- **Provide Notice:** Notify individuals about data collection at the time it occurs. This can be through pop-up notices, forms, or other means.
- **Regular Updates:** Keep individuals informed about any changes in data collection practices. Update your privacy policy as needed and notify individuals of the changes.
- **Educate Stakeholders:** Provide education and information about data privacy to stakeholders, including employees, volunteers, donors, and beneficiaries. This promotes transparency and builds trust.

By following these best practices, non-profit organizations can ensure that data collection is conducted responsibly, with respect for individuals' privacy rights, especially when dealing with children's data. Transparent policies and clear consent mechanisms are essential in building trust with stakeholders. Click here for more on Privacy and Consent.

Data Storage and Security

Ensuring the security of stored data is a critical responsibility for non-profit organizations. Here are best practices for secure data storage:

Secure Data Storage Practices:

- **Physical Security:** Ensure that physical storage facilities are secure, limiting access to authorized personnel only. This includes locked rooms, cabinets, and secure storage containers.
- **Access Logs and Monitoring:** Implement systems to monitor and log access to physical storage locations. This allows for the tracking of who accessed the data and when.
- **Regular Audits:** Conduct regular audits of physical storage areas to ensure compliance with security protocols and to identify and address any vulnerabilities.
- **Data Segmentation:** Segregate different types of data based on sensitivity. For instance, highly sensitive information should be stored separately from less sensitive data.

Encryption and Access Controls:

- **Data Encryption:** Data is encrypted and decrypted via the use of encryption keys. Key Management is the process of putting certain standards in place to ensure the security of cryptographic keys in an organization. Keys provide compliance with certain standards and regulations to ensure your organization is using best practices when protecting cryptographic keys. Well protected keys are only accessible by users who need them. This forms the basis of data security. Click here for more info
- **User Authentication:** Utilize strong authentication methods, like multi-factor authentication, to ensure that only authorized users can access sensitive data.
- **Role-Based Access Control (RBAC):** Implement RBAC to restrict access based on job roles and responsibilities. This ensures that individuals only have access to the data necessary for their duties.
- **Regular Password Changes:** Enforce policies that require users to change their passwords regularly, and encourage the use of strong, complex passwords.

For more information on data security for non profits click here

Cloud-Based Solutions and Security Considerations:

According to research, a whooping 66% of employees now work from home, non-profits inclusive. This means that you as we speak you are probably working on cloud (e.g Gmail Suite, Microsoft Teams etc) to access some of your services or collaborate. The following are best practises to follow:

- **Vendor Due Diligence:** When using cloud-based storage solutions, conduct thorough due diligence on the chosen vendor. Ensure they have robust security measures in place and comply with relevant data privacy regulations.
- **Data Encryption in the Cloud:** Utilize encryption tools provided by the cloud service provider to ensure that data stored in the cloud remains secure.
- **Data Backups and Redundancy:** Regularly back up data stored in the cloud to prevent data loss in case of system failures or security incidents. Consider using redundant storage options for added security.
- **Data Ownership and Control:** Clarify in contracts with cloud service providers who owns the data, and establish mechanisms for data retrieval and portability.
- **Compliance with Data Privacy Laws:** Ensure that the cloud service provider complies with relevant data privacy laws, and that there are mechanisms in place to address any potential compliance issues.
- **Regular Security Updates:** Keep all cloud-based solutions up-to-date with the latest security patches and updates to protect against known vulnerabilities.

By following these best practices, your organization can enhance the security of your stored data, protect sensitive information and ensure compliance with data privacy regulations. Click here for more information

Data Handling Procedures

Effective data handling procedures are crucial for non-profit organizations to ensure that personal information is managed responsibly and in compliance with privacy regulations. Here are best practices for data handling:

Data Minimization and Purpose Limitation:

- **Collect Only Necessary Information:** Gather only the data that is directly relevant and necessary for the stated purpose. Avoid collecting excessive or irrelevant information.

- **Clearly Define Purposes:** Clearly communicate the purpose for which data is being collected at the time of collection. This helps individuals understand why their information is being requested.
- **Regular Data Audits:** Conduct regular audits to identify and eliminate any unnecessary or outdated data. This ensures that only relevant information is retained.

Retention and Disposal Policies:

- **Establish Clear Retention Periods:** Define specific timeframes for how long different types of data will be retained. This should be based on legal requirements, operational needs, and the purpose for which the data was collected.
- **Secure Data Disposal:** Implement secure disposal methods, such as shredding physical documents or using secure data erasure software for digital data. Ensure that disposal practices comply with applicable privacy laws.
- **Document Disposal Procedures:** Document and communicate clear procedures for data disposal to all staff members and volunteers involved in handling data.
- **Regularly Review and Update Policies:** Periodically review and update retention and disposal policies to ensure they align with current legal requirements and organizational needs.

Data Portability and Access Requests:

- **Establish Data Portability Procedures:** Define processes for individuals to request their data in a portable format. This may include providing data in a structured, commonly used, and machine-readable format.
- **Timely Response to Access Requests:** Respond to access requests promptly, typically within a legally mandated timeframe. Provide the requested information along with an explanation of how the data is used.
- **Identity Verification:** Implement measures to verify the identity of individuals making access requests to prevent unauthorized disclosures.
- **Maintain Records of Access Requests:** Keep a record of all access requests and the actions taken in response. This helps demonstrate compliance with privacy regulations.

- **Educate Staff and Volunteers:** Ensure that staff and volunteers are aware of the procedures for handling data access requests and understand the importance of timely and accurate responses.

Following these data handling procedures, you can effectively manage personal information, respect individuals' privacy rights, and maintain compliance with data privacy regulations. Additionally, clear and well-documented procedures help build trust with stakeholders and demonstrate a commitment to responsible data management. Click here for more information on data management procedures for non profits.

Compliance and Legal Obligations

Ensuring compliance with relevant data privacy regulations is a critical aspect of responsible data management for non-profit organizations. Here are the key compliance considerations for non-profits:

HIPAA Compliance for Health-Related Non-Profits:

- **Understanding Applicability:** If your non-profit deals with protected health information (PHI), compliance with the Health Insurance Portability and Accountability Act (HIPAA) is crucial. This applies to healthcare providers, health plans, and healthcare clearinghouses.
- **Privacy Policies and Procedures:** Develop and implement comprehensive policies and procedures for the handling of PHI, including access controls, training, and incident response.
- **Business Associate Agreements (BAAs):** If your non-profit works with third-party vendors who handle PHI, ensure that you have signed BAAs in place. These agreements outline their responsibilities for protecting PHI.
- **Physical and Technical Safeguards:** Implement physical and technical safeguards to protect electronic PHI. This includes access controls, encryption, and secure storage.
- **Training and Awareness:** Train staff and volunteers on HIPAA compliance and regularly update them on any changes or new requirements.

Click here for more information.

New Brunswick Right to Information and Protection of Privacy Act (RTIPPA):

- **Understanding Applicability:** The RTIPPA is a provincial law specific to New Brunswick that governs access to information held by public bodies, including government agencies and institutions. It also outlines rules for the protection of personal information. For detailed information refer to https://laws.gnb.ca/en/pdf/cs/R-10.6.pdf
- **Access to Information:** Public bodies in New Brunswick are obligated to provide individuals with access to their own personal information held by the organization, subject to certain exceptions.
- **Privacy Protections:** The Act sets out principles for the collection, use, disclosure, and retention of personal information by public bodies. It emphasizes the need to protect individuals' privacy rights.
- **Duty to Assist:** Public bodies are required to assist individuals in exercising their right to access information and ensure that they understand how their personal information is being handled.
- **Exceptions and Exemptions:** The Act outlines specific circumstances where access to information may be denied, such as when it would compromise law enforcement, legal proceedings, or national security.
- **Compliance and Accountability:** Public bodies are accountable for complying with the Act and are subject to oversight by the Office of the Ombudsman and Access to Information and Privacy Commissioner.
- **Recordkeeping and Transparency:** Public bodies must keep records of their decisions and actions related to access to information and privacy, promoting transparency and accountability.
- **Training and Awareness:** Ensure that staff members and volunteers are aware of the Act's provisions and their responsibilities under it.

If you are a Non-profit organizations operating in New Brunswick, familiarize yourself with the RTIPPA and take steps to ensure compliance with its requirements, especially if you are considered a public body under the Act. This includes understanding individuals' rights to access their personal information and implementing appropriate privacy protections.

GDPR Compliance for Non-Profits:

- **Understanding Applicability:** Determine whether your non-profit falls within the scope of the General Data Protection Regulation (GDPR). It applies to the processing of personal data by any organizations (including Canadian organizations) that are established in the EU, regardless of where data processing occurs.

- **Data Subject Rights:** Familiarize yourself with and respect the rights of data subjects, including the right to access, rectify, and erase their personal data. Establish procedures for handling data subject requests.
- **Data Protection Officer (DPO):** Appoint a Data Protection Officer if required by GDPR. This person is responsible for overseeing data protection activities within the organization.
- **Consent and Transparency:** Ensure that you obtain clear and explicit consent from individuals before processing their data. Be transparent about how their data will be used and provide accessible privacy notices.
- **Data Breach Notification:** Establish procedures for detecting, reporting, and investigating data breaches. GDPR mandates the notification of certain breaches to supervisory authorities and affected individuals.
- **International Data Transfers:** If your non-profit transfers data outside of the European Economic Area, ensure that you have appropriate safeguards in place to protect the data.

Other Regional Regulations:

- **PIPEDA Compliance (Personal Information Protection and Electronic Documents Act):** As a non-profit operating in Canada, PIPEDA applies to you. Comply with its requirements for the collection, use, and disclosure of personal information. For further information see:https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/
- **CCPA Compliance (California Consumer Privacy Act):** If your non-profit collects and processes personal information of California residents, ensure compliance with CCPA. This includes providing opt-out options and honoring consumer rights. For detailed information see this link
- **Other Regional Laws:** Depending on your location and operations, be aware of and comply with any other regional or national data protection laws that apply to your non-profit.

By understanding and adhering to these compliance considerations, your organizations can effectively protect personal data, uphold individuals' privacy rights, and maintain trust with stakeholders. Regularly review and update compliance measures to adapt to changes in regulations and organizational operations.

Training and Awareness

Ensuring that your employees, volunteers, and stakeholders are well-informed about data privacy practices is essential for maintaining a culture of responsible data handling. Here are best practices for training and awareness:

Employee and Volunteer Training Programs:

- **Customized Training Modules:** Develop training modules tailored to the roles and responsibilities of employees and volunteers. Address specific data privacy concerns relevant to their tasks.
- **Regular Training Sessions:** Conduct regular training sessions, especially for new hires or those handling sensitive data. Ensure that all staff members and volunteers receive training as part of their onboarding process.
- **Interactive Workshops:** If time permits, incorporate interactive elements like case studies, simulations, and quizzes to engage participants and reinforce key concepts.
- **Role-Based Training:** Provide training that is specific to the roles and functions of employees and volunteers. For example, fundraising staff may receive different training than program coordinators.
- **Clear Communication:** Emphasize the importance of data privacy and the organization's commitment to protecting sensitive information.
- **Legal Requirements:** Ensure that training covers relevant legal requirements

Awareness Campaigns for Stakeholders:

- **Clear Communication Channels:** Establish effective communication channels to disseminate information about data privacy policies and practices to stakeholders. This can include newsletters, emails, and social media.

- **Privacy Notices:** Provide clear and accessible privacy notices to stakeholders, explaining how their data is collected, used, and protected.
- **Highlighting Rights:** Educate stakeholders about their rights regarding their personal information, including the right to access, rectify, and delete data.
- **Engagement and Feedback:** Encourage stakeholders to provide feedback and engage in discussions about data privacy. This helps build trust and demonstrates a commitment to transparency.

Continuous Learning and Updates:

- **Regular Seminar:** Take part in regular seminar courses and updates on data privacy practices to reinforce knowledge and address any evolving threats or compliance requirements.
- **Stay Informed About Regulatory Changes:** Keep staff and volunteers informed about any changes in data privacy regulations that may impact the organization's practices.
- **Internal Communication Channels:** Establish internal communication channels, such as a dedicated email address or forum, where staff and volunteers can ask questions or seek clarification about data privacy matters.
- **Reporting Concerns:** Create a culture where employees and volunteers feel comfortable reporting any concerns or potential breaches related to data privacy.

By implementing these training and awareness practices, non-profit organizations can instill a strong culture of data privacy awareness, ensuring that all stakeholders are equipped to handle sensitive information responsibly and in compliance with legal requirements.

Incident Response and Reporting

Having a well-defined incident response plan is crucial for non-profit organizations to effectively manage data breaches or incidents. Here are best practices for incident response and reporting:

Developing an Incident Response Plan:

- **Cross-Functional Team:** Form a cross-functional incident response team that will include relevant employees and assign specific roles and responsibilities to each team member.

- **Identify and Classify Incidents:** Define what may constitute an incident and classify incidents based on severity levels. This helps prioritize response efforts.
- **Response Procedures:** Establish clear procedures for identifying, containing, eradicating, recovering from, and documenting incidents. Include step-by-step instructions for each phase.
- **Communication Protocols:** Define communication protocols for notifying internal stakeholders, regulatory bodies, affected parties, and the public, as appropriate.
- **Testing and Simulation:** Regularly test and simulate incident scenarios to ensure that the response plan is effective and that team members understand their roles.

Reporting Obligations for Data Breaches:

- **Legal Requirements and Regulatory Notifications:** In New Brunswick, public bodies under the Right to Information and Protection of Privacy Act may use this form:https://ombudnb-aip-aivp.ca/wp-content/uploads/2020/01/Privacy-Breach-Reporting-Form-RTIPPA-ENG-Jan-2020.pdf to report a privacy breach to the OMBUD NB office. Send the form by fax: 506.453.5963, email: aip-aivp@gnb.ca or regular mail: 230-65 Regent Street, Fredericton, NB E3B 7H8
- **Documentation:** Keep detailed records of the breach, including the date and time of discovery, nature of the breach, and actions taken in response.
- **Internal Reporting:** Ensure that all incidents, regardless of severity, are reported internally. This helps maintain transparency and allows for a thorough investigation.

Communication with Affected Parties:

- **Timely Notification:** Notify affected parties promptly after confirming a data breach. Transparency is crucial for maintaining trust.
- **Clear and Informative Communication:** Provide clear information about the nature of the breach, the types of data affected, potential risks, and the steps being taken to address the situation.
- **Contact Methods:** Use reliable and secure communication channels to inform affected parties, such as email, phone, or postal mail.
- **Provide Guidance:** Offer affected parties guidance on steps they can take to protect themselves, such as changing passwords or monitoring their accounts for suspicious activity.

- **Regulatory Requirements:** Ensure that your communication with affected parties complies with any legal or regulatory requirements for breach notifications.

Non-profit organizations may follow these best practices for incident response and reporting, by doing so, they can effectively manage data breaches or incidents, minimize potential harm, and demonstrate a commitment to responsible data handling.

Third-Party Relationships and Data Sharing

Is your organization partnering, collaborating and sharing data with third parties? Effectively managing these relationships and data sharing is crucial to ensure that sensitive information is handled responsibly. Here are best practices for third-party relationships and data sharing:

Evaluating Third-Party Service Providers:

- **Security Measures and Due Diligence Process:** Ensure that third-party providers have robust security measures in place to protect any data they handle on your behalf. This includes encryption, access controls, and regular security audits. Conduct thorough due diligence when selecting third-party service providers. Assess their data handling practices, security measures, and compliance with privacy regulations.
- **Privacy Policies:** Review their privacy policies to ensure they align with your organization's data privacy standards and compliance requirements.
- **Contractual Obligations:** Include specific data protection clauses in contracts with third-party providers, outlining their responsibilities for protecting the data they handle.
- **Regular Monitoring and Audits:** Periodically review and monitor the data handling practices of third-party providers to ensure ongoing compliance with data privacy standards.

Data Processing Agreements:

- **Formal Agreements:** Establish formal data processing agreements (DPAs) with third-party service providers. These agreements should clearly outline the roles and responsibilities of each party regarding data protection.

- **Data Handling Instructions:** Specify in the DPA how the third-party provider is allowed to process the data, including limitations on use and strict adherence to your organization's data privacy policies.
- **Security Standards:** Require that the third-party provider maintains adequate security measures to protect the data they handle, and stipulate reporting mechanisms for any breaches.
- **Subcontractor Management:** If the third-party provider engages subcontractors, ensure that they also adhere to data privacy standards and are covered by the DPA.

Sharing Data Responsibly for Collaborative Initiatives:

- **Define Purpose:** Clearly articulate the purpose and scope of data sharing in collaborative initiatives. Ensure that all parties involved understand and agree to the intended use of the data.
- **Minimize Data:** Share only the minimum amount of data necessary to achieve the collaborative goals. Avoid sharing excess or unnecessary information.
- **Consent and Transparency:** Obtain informed consent from individuals when sharing their data, and communicate transparently about how the data will be used in the collaborative effort.
- **Data Ownership and Control:** Clarify in agreements who owns the shared data and establish mechanisms for data retrieval and portability.
- **Compliance with Regulations:** Ensure that all parties involved in the collaborative initiative comply with relevant data privacy regulations and establish procedures for addressing any potential compliance issues.

By implementing these best practices, your organization can establish responsible data sharing practices and manage third-party relationships in a manner that upholds individuals' privacy rights and complies with legal and regulatory requirements.

Privacy by Design

Privacy by Design is a proactive approach to data protection that involves embedding privacy considerations into the design and development of your programs, systems, and processes from the very beginning. This sample toolkit is a great tool to implement privacy. Here are best practices for implementing Privacy by Design:

Integrating Data Privacy from Program Inception:

- **Early Involvement of Privacy Experts:** Involve privacy experts or officers from the outset of any program that involves the collection or processing of personal data. This ensures that privacy considerations are integrated into the planning stages.
- **Privacy as a Core Requirement:** Make data privacy a core requirement of any program or system. Clearly define privacy objectives and ensure that they are prioritized alongside other project/program goals.
- **Collaboration between Team:** Foster collaboration between different teams or departments in your organization, practise carrying everyone along when it comes to Privacy policies
- **Documentation and Records:** Maintain detailed records of the privacy measures implemented throughout the project, including design decisions, risk assessments, and compliance with relevant regulations.

Conducting Privacy Impact Assessments (PIAs):

- **Confirm if you need a PIA:** This is necessary for most government public bodies and may apply to their partners. Information here may serve as guidance on how to conduct Privacy Impact Assessments for all new programs, especially those involving the processing of personal data. This helps identify and mitigate privacy risks early in the project lifecycle.
- **Risk Assessment:** Assess the potential impact on individuals' privacy rights and identify any risks associated with data collection, processing, storage, and sharing.
- **Mitigation Strategies:** Develop and implement strategies to mitigate identified risks. This may involve adjusting project/program plans, implementing additional security measures, or modifying data handling processes.
- **Ongoing Monitoring and Updates:** Regularly review and update PIAs as the project progresses to account for any changes in data handling practices or emerging privacy risks.

Fostering a Culture of Privacy Awareness:

- **Staff Training and Awareness Programs:** Provide ongoing training and awareness programs for all staff members, volunteers, and stakeholders involved in data handling in your organization. Ensure they understand the importance of privacy and their role in protecting personal data.
- **Clear Communication of Privacy Policies:** Clearly communicate the organization's privacy policies and procedures to all stakeholders. Make these policies easily understandable and accessible and provide opportunities for individuals to ask questions or seek clarification.
- **Leadership Support:** Ensure that organizational leadership actively supports and promotes a culture of privacy awareness. This sets a clear tone that privacy is a priority for the entire organization.
- **Recognition and Rewards for Privacy Compliance:** Acknowledge and reward individuals and teams who demonstrate exemplary compliance with privacy policies and procedures.

By implementing Privacy by Design principles, you can proactively protect individuals' privacy rights and ensure compliance with data protection regulations. This approach helps build trust and demonstrates a commitment to responsible data handling.

Accountability and Governance

Establishing a robust framework for accountability and governance is essential for non-profit organizations to effectively manage data privacy. Here are best practices for accountability and governance:

If Possible, Designate a Data Protection Officer (DPO):

- **Role and Responsibilities:** Appoint a Data Protection Officer (DPO) responsible for overseeing data protection activities in your organization. The DPO should does not necessarily need to have expertise in data privacy but this individual may read up and attend trainings to be knowledgeable in this space.
- **Compliance Oversight:** The DPO should ensure that the organization complies with relevant data protection laws and regulations. They serve as a point of contact for individuals regarding privacy matters.
- **Educating and Advising:** Provide ongoing training and advice to staff members and volunteers on data protection best practices, in accordance with the DPO's advise.

- **Reporting and Communication:** The DPO should report directly to the highest level of management. They should also communicate regularly with staff and stakeholders regarding privacy matters.

Establishing Privacy Policies and Procedures:

- **Create Privacy Policy:** Develop a privacy policy that outlines how personal data is collected, used, stored, and protected in your organization. This policy should also provide information on individuals' rights regarding their data.
- **Procedure Documentation:** Document specific procedures for data handling, including data collection, consent processes, data storage, and breach response. Make these procedures simple to digest and accessible.
- **Compliance with Laws:** If applicable, ensure that privacy policies and procedures are aligned with applicable data protection laws and regulations: RTIPPA
- **Regular Review and Updating:** Regularly review and update privacy policies and procedures to ensure they remain current and in compliance with applicable evolving legal requirements.

Regular Audits and Compliance Checks:

- **Internal Audits:** Conduct regular internal audits to assess compliance with data protection policies and procedures that you have established in your organization.. Identify any areas where improvements or corrective actions are needed.
- **External Audits or Assessments:** Consider engaging third-party to conduct periodic external audits or assessments of the organization's data protection practices. This provides an independent evaluation of compliance. A useful resource in this regard may be CivicTech Fredericton
- **Compliance Checks with Legal Requirements:** Continuously monitor changes in data protection laws and regulations to ensure ongoing compliance. Adjust policies and procedures as needed to address new requirements.
- **Recordkeeping of Audits:** Maintain records of audit findings, corrective actions taken, and any changes made to policies and procedures as a result of the audit.

Implementing these accountability and governance best practices will demonstrate a strong commitment to data privacy, effectively manage personal information. It also helps ensure compliance with legal and regulatory requirements, reducing the risk of data breaches and related liabilities.

Transparency and Communication

Establishing transparency and effective communication regarding data privacy practices with your clients is crucial to uphold their commitment to responsible data handling. Here are best practices for transparency and communication:

Privacy Notices and Disclosures:

- **Clear and Accessible Privacy Notices:** Provide clear and easily accessible privacy notices that inform individuals about how their personal data is collected, used, stored, and protected. Ensure that these notices are prominently displayed on your website and at the point of data collection. Here is a sample privacy notice.
- **Transparent Data Use:** Clearly state the purpose for which data is being collected and the lawful basis for processing it. Explain any third parties with whom data may be shared and the individual's rights regarding their data.
- **Plain Language:** Use plain, non-technical language in privacy notices to ensure that individuals can easily understand the information provided.
- **Notification of Changes:** Clearly communicate any changes to your privacy practices or policies. Notify individuals of these changes in a timely and transparent manner.

Building Trust with your Clients/Stakeholders:

- **Open and Honest Communication:** Foster a culture of open and honest communication regarding data privacy. Address any concerns or questions from your clients/stakeholders in a transparent manner.
- **Demonstrate Commitment to Privacy:** Actively demonstrate your organization's commitment to protecting personal information by implementing robust privacy measures and regularly communicating your privacy efforts.

- **Engage with Stakeholders:** Actively engage with clients /stakeholders through various channels, such as newsletters, social media, and events, to provide updates on privacy practices and initiatives.
- **Showcase Privacy Efforts:** Highlight your organization's privacy efforts on your website and in communications materials to showcase your dedication to responsible data handling.

Handling Privacy Concerns and Inquiries:

- **Establish Clear Communication Channels:** Provide multiple channels (such as dedicated email addresses or contact forms on websites) for individuals to submit privacy concerns or inquiries. Ensure that these channels are monitored regularly.
- **Timely Response:** Respond promptly to privacy concerns and inquiries. Acknowledge receipt of the concern and provide a timeline for when the individual can expect a resolution.
- **Investigate and Address Concerns:** Thoroughly investigate privacy concerns and take appropriate action to address them. If a breach has occurred, follow your incident response plan (find Sample here) and notify affected parties as required by law.
- **Provide Updates:** Keep individuals informed about the progress of the investigation and any actions taken to address their concerns. This demonstrates transparency and accountability.

Oyet to pen communication helps address privacy concerns promptly, reducing the potential impact on individuals and the organization.

Future Trends and Emerging Technologies

The landscape of data handling for non-profit organizations is continually evolving, influenced by advancements in technology and shifts in societal expectations. Here are some future trends and emerging technologies that are likely to impact non-profit data handling:

Artificial Intelligence (AI) and Machine Learning in Non-Profit Data Handling:

- **Data Analysis and Insights:** AI and machine learning can be used to analyze large volumes of data, providing non-profits with valuable insights into donor behavior, program effectiveness, and areas for improvement.

- **Predictive Analytics:** By utilizing AI algorithms, non-profits can predict donor behavior and identify potential supporters. This can inform targeted fundraising efforts and improve resource allocation.
- **Personalization of Communication:** AI-powered tools can help customize communication with donors and beneficiaries, ensuring that messages are relevant and engaging.
- **Automated Data Management:** AI-driven automation can streamline data entry, validation, and processing, reducing the potential for human error and improving data accuracy.

Blockchain for Enhanced Data Security:

- **Immutable Data Records:** Blockchain technology can create a tamper-proof ledger of transactions and data records. This ensures the integrity and authenticity of information, which is particularly important for financial and donor data.
- **Enhanced Trust and Transparency:** The decentralized nature of blockchain builds trust with clients/stakeholders by providing a transparent and unchangeable record of data transactions.
- **Secure Donor Transactions:** Blockchain can facilitate secure and transparent donation processes, ensuring that funds reach their intended recipients without intermediaries.
- **Smart Contracts for Accountability:** Smart contracts can automate certain processes, such as disbursing funds when specific conditions are met, ensuring greater accountability and transparency in non-profit operations.

Ethical Considerations in Emerging Technologies:

- **Algorithmic Bias and Fairness:** Non-profits must be vigilant in addressing biases that may be present in AI algorithms, ensuring that data-driven decisions are fair and unbiased.
- **Data Privacy in Emerging Tech:** As non-profits adopt new technologies, they must remain vigilant in protecting the privacy of individuals' data, particularly in the context of AI and blockchain.
- **Transparency and Accountability:** Non-profits should be transparent about their use of emerging technologies, clearly communicating how they are employed to achieve their mission and the measures in place to ensure ethical use.

- **Continuous Learning and Adaptation:** Keeping abreast of evolving ethical standards and best practices in the use of emerging technologies is crucial for non-profits to maintain their commitment to responsible data handling.

Staying informed about these emerging technologies and their ethical implications, your organizations can leverage these advancements to enhance your data handling practices, while also ensuring that you are aligned with their mission and values. This forward-thinking approach allows non-profits to harness the power of technology for positive social impact.

Conclusion

In an era defined by the rapid evolution of technology and the increasing digitization of operations, data privacy has become a paramount concern even for non-profit organizations. The imperative to safeguard sensitive information for non-profits is mostly a moral and ethical responsibility than legal.

The Imperative of Data Privacy for Non-Profits:

Data privacy is not a mere compliance requirement; it is a fundamental pillar that underpins the trust and credibility of non-profit organizations. Upholding the privacy of personal information is an assurance to donors, beneficiaries, and stakeholders that their trust is well-placed. It fosters a sense of security, encouraging individuals to engage with the organization confidently.

Moreover, respecting data privacy is a demonstration of respect for individuals' autonomy and dignity. It ensures that their personal information is handled with care, and their rights are upheld. This commitment to privacy aligns with the ethical foundations of non-profit work, emphasizing respect for individuals and communities.

Empowering Non-Profits for a Secure Digital Future:

As non-profits navigate the complexities of the digital landscape, they must equip themselves with the knowledge, tools, and practices necessary to protect data effectively. This involves training, the implementation of policies, and the adoption of secure technologies.

Empowerment also means being forward-looking. Understanding and harnessing emerging technologies such as AI, blockchain, and other innovations can revolutionize how non-profits operate. These technologies not only offer efficiency gains but also enable heightened levels of security and transparency in data handling.
In this dynamic digital environment, non-profit organizations must remain adaptable and proactive. Staying informed about best practices, and emerging technologies ensures that they are well-prepared to navigate the challenges and opportunities that lie ahead.

In conclusion, data privacy is not merely a regulatory box to tick; it is a commitment that non-profit organizations make to the individuals and communities they serve. By prioritizing data privacy, non-profits are fostering trust, respecting individuals' rights, and upholding their ethical responsibilities. In doing so, they are poised to thrive in a secure digital future, continuing to make a positive impact on the world.

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Appendices

Appendix A: Privacy Policy Checklist

Click for a sample privacy checklist

Appendix B: Sample Privacy Policy

Click here for non-profits subject to PIPA

Appendix C: Incident Response Plan Template

Sample Incident Response Plan from CyberSecure Canada.

Appendix E: Privacy Impact Assessment (PIA) Checklist

Private Sector Privacy Impact Assessment (PIA) Template for Organizations

Privacy Impact Assessment (PIA) Questionnaire

Appendix F: Data Retention Policy Guidelines

PIPEDA Personal Information Retention and Disposal: Principles and Best Practices

Privacy and Data Protection Guidelines - Retention and Disposal of Personal Information