

Privacy and Confidentiality Charter
for
ACUTE CARE ENHANCED SURVEILLANCE
“ACES”

Policies and Procedures for the Protection of Health Information

Privacy and Confidentiality of Health Information and ACES

This document covers policies and procedures for the protection of health information used in ACES.

Executive Summary

The Acute Care Enhanced Surveillance (ACES) team comprises a multidisciplinary group of physicians, researchers, systems analysts, engineers, software developers, and the local Medical Officer of Health, working collaboratively to design, develop and maintain a real-time integrated public health system for syndromic surveillance. The project is endorsed and funded by the Ontario Ministry of Health and Long-Term Care and will be conducted and supported under the authority of Kingston, Frontenac and Lennox and Addington Public Health (“KFL&A”).

The mandate of the ACES team is:

- to work with federal, provincial and local health authorities to design, develop, pilot and maintain a Syndromic Surveillance system that will accept raw data stripped of identifiers from a number of disparate sources such as: hospital emergency departments, admissions to acute care settings, and (potentially) over-the-counter pharmaceutical sales, 911/EMS, Tele-Health and other sources yet to be identified. This data will be classified and stored in a queryable database for subsequent analysis and decision support.

Respecting personal privacy, safeguarding confidential information and ensuring security of data are critical to this mandate. The ACES team has taken the following steps to ensure that the operation of ACES is informed by an active privacy policy:

- Ensure that security practices within ACES are current and consistent with any applicable federal or provincial privacy legislation.
- Monitor, and where appropriate adapt to, developments in privacy legislation, privacy-enhancing technologies and public opinion respecting privacy.
- Ensure transparency and promote awareness of ACES privacy principles, policies and procedures.
- Enhance ACES data protection tools and activities.
- Enforce controlled access to and responsible use of any health information under ACES' control.
- Encourage responsible external agencies to verify ACES' compliance with any applicable privacy legislation, including Ontario's *Personal Health Information Protection Act, 2004* (“PHIPA”).

A core component of ACES' Privacy Program is its statement of privacy policies and procedures. These policies and procedures provide the framework for ACES' operations and inform those who wish to know of ACES' privacy practices.

ACES regularly reviews its principles and policies to ensure that they are in alignment with PHIPA and any other applicable privacy legislation and that they conform to any best practices related to protection of health information, bearing in mind the particular context in which ACES operates (i.e. public health surveillance) and the nature of the information used in ACES (i.e. data that is stripped of key identifiers but is protected in accordance with the principles of PHIPA applicable to personal health information in order to protect against any situation where a collection of the data may meet the definition of personal health information).

ACES's Privacy Program

The ACES Privacy Program includes:

An active Privacy, Confidentiality and Security team comprised of the Clinical and Technical Directors of ACES who represent all areas of the organization such as standards, information systems, databases, research and analysis. As well, a KFL&A Privacy Officer is appointed to monitor emerging trends in privacy standards and determine the applicability of those standards to ACES' current practices. The Privacy Officer is accountable to the Board of Health and Medical Officer of Health of KFL&A. Key Activities of the Privacy Program include:

- Policy analysis and application:
 - Monitoring privacy and data protection legislation.
 - Conducting and updating privacy impact assessments of ACES.
 - Frequent, unannounced security audits of applications and databases.
 - Compliance with the following principles underlying PHIPA, in the context of ACES's use of health information:
 - Accountability
 - (Note: Consent deemed inapplicable in context of ACES)
 - Identifying Purpose
 - Limiting Collection
 - Limiting Use, Disclosure, Retention
 - Accuracy
 - Security Safeguards
 - Openness
 - Individual Access
 - Complaint Process
 - Challenging Compliance.
- Fostering a culture of respect for privacy protection principles at ACES:
 - Supporting development activities to ensure that privacy and data protection issues are identified and addressed.
 - Working with Federal, Provincial, and local Health Authorities to enhance ACES data protection practices and tools.
 - Conducting staff training and communicating with staff on privacy and confidentiality policies and procedures.
 - Enforcing confidentiality protocols for staff and imposing disciplinary action if breaches occur, as outlined in Procedure 1.2.
 - Using encryption wherever practicable.

- Using pseudonymity code data where practicable (currently unnecessary as data is stripped of identifiers).
- Conducting privacy impact assessments.

Principles and Policies for the Protection of Health Information

Principle I: Accountability for Health Information

ACES is responsible for health information under its control and has developed a policy to ensure compliance to this principle.

Policies	Related Procedures
<p>Policy 1.1 Accountability for ACES compliance with the principles rests with the Project Leader of ACES, even though other individuals within ACES are responsible for the day-to-day management and security of health information collected by and used in ACES.</p> <p>Policy 1.2 Although ACES uses health information from which identifiers have been stripped, ACES acknowledges evolving privacy principles applicable to collections of data elements. ACES maintains responsibility for all health information collected as if it were in every instance personal health information and as such, with the exception of requiring consent, ACES has put into place procedures to give effect to the PHIPA principles of:</p> <ul style="list-style-type: none"> • Accountability • Identifying Purpose • Limiting Collection • Limiting, Use Disclosure, Retention • Accuracy • Security Safeguards • Openness 	<p>Procedure 1.1</p> <ol style="list-style-type: none"> a) The Privacy, Confidentiality and Security team and other external sources will prepare a draft privacy delegation chart¹ and recommend its approval to the Project Leader of ACES. b) The Project Leader: <ul style="list-style-type: none"> • Reviews the delegation chart; • Modifies the delegation chart as s/he deems appropriate; and • Approves the privacy delegation chart for release c) The Privacy, Confidentiality and Security team: <ul style="list-style-type: none"> • Reviews the delegation chart as required and • follow steps a) to b) above to prepare and issue a revised chart. <p>Procedure 1.2 To maintain practices consistent with PHIPA principles, ACES has prepared Policies and Procedures to enforce the principles delineated in Policy 1.2, as follows:</p> <ul style="list-style-type: none"> • See Principle 1 and Related procedures. • See Principle 2 and Related procedures. • See Principle 3 and Related procedures. • See Principle 4 and Related procedures. • See Principle 5 and Related procedures. • See Principle 6 and Related procedures. • See Principle 7 and Related procedures. • See Principle 8 and Related procedures.

¹ See Attachment A

Policies	Related Procedures
<ul style="list-style-type: none">• Individual Access• Complaint Process• Challenging Compliance	<ul style="list-style-type: none">• See Principle 9 and Related procedures.• See Principle 10 and Related procedures.• See Principle 11 and Related procedures.

Principle II: Identifying Purposes for Collection of Health Information

ACES identifies the purposes for which it collects health information prior to the time information is collected.

Policies	Related Procedures
<p>Policy 2.1 Identifying the purpose for which it collects health information prior to the time of collection allows ACES to determine the information it needs to fulfill these purposes and to limit collection for those specific purposes.</p>	<p>Procedure 2.1</p> <ol style="list-style-type: none"> a. The program manager drafts a statement that identifies the purpose of the data collection. b. The program manager seeks input on the draft statement from the privacy officer and, as appropriate, from related advisory groups and key stakeholders. c. If required, the program manager revises the draft purposes statement based on the input received. d. Prior to the collection of health information, the program manager communicates with the data providers to: <ul style="list-style-type: none"> • Provide the statement of purposes for the data holding in order to facilitate their understanding of and support for the purposes
<p>Policy 2.2 ACES and its research partners collect purposive health information identified in consultation with stakeholders and approved by the Queens Research Ethics Board (QREB).</p>	<p>Procedure 2.2</p> <ol style="list-style-type: none"> a. Data collected for research purposes will be dictated by the limits imposed by the QREB, MOHLTC, and local Public Health facility. b. Data collected for public health syndromic surveillance purposes will be dictated by the project scope and the purposes outlined in data share agreements.

Principle III: Consent for the Collection, Use or Disclosure of Health Information

ACES acknowledges the principle that “the knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate.” ACES consults with Ministries of Health and data providers about the implementation of this principle. As ACES obtains health information from data providers (who are themselves covered by legislation) and not directly from individuals, ACES recognizes that data providers must determine what actions are necessary to ensure their own compliance with any consent requirements in their jurisdiction.

Policies	Related Procedures
<p>Policy 3.1 ACES acknowledges the principle of knowledge and consent for the collection, use and disclosure of personal health information with partner organizations.</p> <p>All clinical data collected for the express purpose of providing health care or for assisting in the provision of health services by a healthcare provider is assumed by ACES to have been collected with such consent as is required from the individual.</p> <p>ACES acknowledges that data collected from a patient for research purposes must receive prior approval of the appropriate Research Ethics Board and, if deemed appropriate by that Board, explicit consent from the patient may be required.</p> <p>Policy 3.2 ACES works with partner organizations to implement knowledge and if appropriate, consent processes for data holdings.</p>	<p>Procedure 3.1 The Project Leader communicates with the data providers to indicate that ACES:</p> <ul style="list-style-type: none"> • Supports the principle that “the knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate”; and • Recognizes that data providers must determine what actions are necessary to comply with legislation in their jurisdiction. <p>The Project Leader communicates with Ministries of Health to indicate that ACES:</p> <ul style="list-style-type: none"> • Supports the principle that “the knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate”; and • Recognizes that data providers must determine what actions are necessary to comply with legislation in their jurisdiction. <p>Procedure 3.2</p> <ol style="list-style-type: none"> a. The Project Leader consults with advisory groups and partner organizations on the application of the principle of notification and consent for the collection, use and disclosure of personal health information. b. The Project Leader will collaborate with partner organizations, as appropriate, to support their use of notification, consent, or both.

Policies	Related Procedures
<p>Policy 3.3 ACES confirms with partner organizations that data collected for ACES will be stripped of identifiers but may nevertheless, under the evolving principles of PHIPA, qualify in certain circumstances as personal health information under PHIPA. Accordingly, all health information collected will be treated in accordance with PHIPA principles applicable to personal health information.</p>	<p>Procedure 3.3 Data share agreements are prepared to reflect the principles and protections of PHIPA applicable to personal health information. The sharing of personal health information under the data share agreements is authorized under PHIPA without consent.</p>

Principle IV Limiting Collection of Health Information

ACES limits the collection of health information to that which is necessary for its identified purposes. Data collected by clinicians as part of their clinical management responsibilities will vary by clinical service based on the established clinical practice for that service. Data collected by researchers will be determined by the research objectives but limited to the data set approved by the Queen’s Research Ethics Board. Data collected by partner organizations (i.e. hospitals) participating in ACES for public health syndromic surveillance will be in accordance with the terms of a data share agreement entered by the parties and guided by the principles of PHIPA.

Policies	Related Procedures
<p>Policy 4.1 Both the amount and the type of health information collected are limited to what is necessary to fulfill the purposes identified for a data holding.</p>	<p>Procedure 4.1 For each new data holding that contains health information:</p> <ol style="list-style-type: none"> a. The Project Leader consults with advisory groups, the privacy officer, and other appropriate stakeholders to define the health information necessary for the identified purposes of the new data holding. b. Following consultation, the Project Leader prepares one or more data sets (e.g., minimum, comprehensive, etc.), which lists the data elements, with definitions or explanations and documents the need for each identifying data element in relation to the identified purposes of the data holding. c. Once there is broad agreement among key stakeholders on the proposed data sets, the Project Leader approves the data sets and provides a copy to advisory groups, the privacy officer and other key stakeholders as appropriate. d. The privacy officer maintains an inventory of the approved data sets for all data holdings that contain health information. e. For ACES’ public health syndromic surveillance system, participants agree on the data elements collected and used in accordance with the terms of the data share agreement.

Policies	Related Procedures
<p>Policy 4.2 ACES promotes health information collection practices that are transparent, justifiable in accordance with the purposes and principles underlying ACES and lawful, and conveys to participants in ACES the purposes for which information is being collected.</p>	<p>Procedure 4.2 The Project Leader communicates with the data providers to indicate that ACES:</p> <ul style="list-style-type: none"> • Supports health information collection practices that accurately convey to participants the purpose for which information is being collected; • Recognizes that the data providers must determine what actions are necessary to comply with legislation in their jurisdiction

Principle V: Limiting Use, Disclosure and Retention of Health Information

ACES does not use or disclose health information for purposes other than those for which it is collected, except as required by law. Health information is retained only for as long as is necessary for the fulfillment of those purposes, and in accordance with the terms agreed upon by the participants in ACES pursuant to the data share agreements entered by the participants.

Policies	Related Procedures
<p>Policy 5.1 ACES uses health information for analyses and reporting, consistent with the identified purposes of the data holdings, ACES’ mandate and core functions, and the data share agreements that govern the use of the information.</p>	<p>Procedure 5.1 The Project Leader:</p> <ol style="list-style-type: none"> a. Reviews the uses of health information in the data holding and, if required, consults with appropriate advisory groups and key stakeholders. b. When the proposed use is consistent with the identified purpose of the data holding and in accordance with the terms of data share agreements between participants in ACES, the Project Leader may authorize that use of the health information. c. The program manager monitors all uses of health information in the data holding to ensure they have been authorized. d. When a new use is requested, the Project Leader reviews that use under steps a. to c. above. e. Any use must be in accordance with the terms of a data share agreement pursuant to which the information was collected.
<p>Policy 5.2 If ACES uses health information for a new purpose, it does so only in accordance with the terms of any applicable data share agreements and PHIPA.</p>	<p>Procedure 5.2 The Project Leader:</p> <ol style="list-style-type: none"> a. Reviews each proposed new purpose for health information and consults with advisory groups, key stakeholders and the privacy officer, as appropriate, to determine if the proposed new purpose falls within the approved purposes statement for the data holding and the terms of applicable data share agreements. b. If the new use is not covered by the approved purposes statement and any applicable data share agreements, the Project Leader will not add the new purpose without the agreement of parties to the relevant data share agreements.

Policies	Related Procedures
<p>Policy 5.3 ACES allows only authorized staff to access and use specific data holdings of health information on a need-to-know basis, that is, when required to perform their duties.</p> <p>Policy 5.4 Given the mandate and role of ACES, it does not use personal health information to make decisions about an individual’s entitlement to health services and benefits.</p> <p>Policy 5.5 ACES retains health information, that is stripped of identifiers, in electronic format in accordance with the terms of the data sharing agreements pursuant to which it is collected and used.</p>	<p>Procedure 5.3 Employee access is controlled through the Project Leader for each data holding. Access is monitored and action is taken to address any unauthorized attempts by employees to access data holdings.</p> <p>“Employees” includes students and contractors.</p> <p>The employee’s manager and the employee discuss: The need to access a specific data holding(s). Why access is required for the employee’s job responsibilities; and Whether the requirement is on-going or short-term</p> <p>Procedure 5.4 No related procedure necessary.</p> <p>Procedure 5.5 The Project Leader regularly monitors retention practices with reference to any limitations agreed upon in data share agreements.</p>

Principle VI: Accuracy of Health Information

ACES depends upon partner organizations participating in ACES to provide accurate, complete and current (at the time of disclosure to ACES) health information.

Policies	Related Procedures
<p>Policy 6.1 Health information collected for use in ACES is presumed to be accurate, complete and current at the time of collection from partner organizations. Participants in ACES are advised that information provided to ACES must meet these qualities in order to fulfill the syndromic surveillance purposes of ACES.</p> <p>Policy 6.2 ACES uses education programs, data quality programs, data coding standards and data edits to foster the collection and use of quality health information for its purposes. Data providers are responsible for ensuring the health information they provide to ACES is accurate, complete and up-to-date for the purposes specified and agreed upon in data share agreements.</p>	<p>Procedure 6.1, 6.2</p> <p>a. The ACES Project Leader implements practices and processes to foster the collection of quality data, which may include:</p> <ul style="list-style-type: none">• The development and communication of data coding standards;• The training of data provider staff in the use of data coding standards;• The use of data edits to identify data errors and omissions; and• The use of other measures, such as an ACES data quality program, to enhance the quality of health information in the data holding. <p>b. The Project Leader ensures that health information is only updated in accordance with the purposes of the data holding.</p>

Principle VII: Safeguards for Health Information

ACES protects health information with security safeguards appropriate to the sensitivity of the information.

Policies	Related Procedures
<p>Policy 7.1 The security safeguards protect health information against loss or theft, as well as unauthorized access, disclosure, copying, use or modification. ACES protects health information that it holds or transmits regardless of the format in which it is held.</p> <p>Policy 7.2 The nature of the safeguards depends on the sensitivity of the information that has been collected, the amount, distribution and format of the information and the method of storage. A higher level of protection safeguards more sensitive information.</p> <p>Policy 7.3 Care is used in the disposal or destruction of health information to prevent unauthorized parties from gaining access to the information.</p>	<p>Procedure 7.1 , 7.2 and 7.3</p> <p>a. The Director, Information Systems, or designate(s) is responsible for protecting health information in electronic formats against loss or theft, as well as unauthorized access, disclosure, copying, use or modification, by:</p> <ul style="list-style-type: none"> • Developing, implementing and monitoring procedures and processes to support the secure collection, use, storage, disclosure and destruction of health information; • Implementing privacy and security enhancing technologies to counter threats to health information; • Maintaining data recovery plans; • Responding to security incidents and breaches and taking corrective action to prevent similar breaches in future; • Maintaining detailed inventories of system hardware, software and data; • Maintaining up-to-date system control and audit logs; and • Regularly reviewing and testing the effectiveness of the safeguards. <p>b. The Project Leader is responsible for protecting health information in non-electronic formats against loss or theft, as well as unauthorized access, disclosure, copying, use or modification by:</p> <ul style="list-style-type: none"> • Implementing and monitoring program procedures and processes to safeguard health information from such risks, in keeping with the policies; • Designating staff who have responsibilities under the program procedures; and • Regularly reviewing and testing the effectiveness of the safeguards. • Providing for the secure disposal and destruction of non-electronic records containing health information. <p>[Note: ACES currently does not use non-electronic or paper records, but in the event of such use, the procedure above would apply.]</p>

Policies	Related Procedures
<p>Policy 7.4 ACES makes its employees aware of the importance of maintaining the confidentiality of health information, including when it has been de-identified, through a privacy training program and mechanisms for communicating information about ACES policies and procedures.</p> <p>Policy 7.5 ACES prepares privacy impact assessments for its data holdings.</p>	<p>Procedure 7.4</p> <p>a) The Project Leader ensures that:</p> <ul style="list-style-type: none"> • Each ACES staff member receives a copy of the ACES Privacy and Confidentiality of Health Information Charter • Each ACES staff member is required to sign a confidentiality pledge. • ACES employees are prohibited from exercising their administrative access privileges to clinical databases under their interim care for any purpose other than to fulfill their employment obligations to ACES. • Physical access to servers containing ACES data will be restricted to authorized personnel in accordance with KFL&A's and ACES's security policies and procedures. The room in which servers containing ACES data are located will be locked whenever the room is unattended by unauthorized personnel. <p>Procedure 7.5</p> <p>a. The Project Leader maintains a template for privacy impact assessments.</p> <p>b. The Project Leader, or designate, completes a draft privacy impact assessment for the data holding, in consultation with program staff, and others as appropriate.</p>

Principle VIII: Openness about the Management of Health Information:

ACES makes information available about its policies and practices relating to the management of health information to any interested party.

Policies	Related Procedures
<p>Policy 8.1 ACES is open about its policies and practices with respect to the management of health information. Individuals are able to acquire information about ACES' policies and practices without unreasonable effort. This information is made available in a format that is generally understandable.</p>	<p>Procedure 8.1 Following consultation with federal, provincial and local public health authorities, ACES determines the most appropriate means to make information available to persons inquiring about ACES' management of health information. Such means may include:</p> <ul style="list-style-type: none">• ACES web site; and• Brochures, booklets and/or copies of privacy related documents.

Principle IX: Individual Access to and Amendment of Own Health Information

Since all health information disclosed to ACES by partner organizations is stripped of identifiers before being disclosed, ACES does not have access to identifiable personal health information and therefore, ACES is not able to provide an individual with access to that individual’s health information that may be contained within the data sets in ACES. However, ACES recognizes that partner organizations who disclose health information to ACES pursuant to data share agreements will have to make their own determinations respecting access in accordance with their legal obligations and applicable privacy legislation and internal policies.

Policies	Related Procedures
<p>Policy 9.1 In accordance with the terms of the data sharing agreements for ACES, if KFLA as host of ACES receives an inquiry from an individual who wishes to know whether ACES has access to health information derived from that individual’s personal health information collected by a partner organization, ACES Project Lead will refer the individual to the appropriate partner organization as being the original health information custodian who collected information from the individual.</p>	<p>Procedure 9.1 An individual may make an inquiry to the Project Lead: Dr. Kieran Moore KFL&A Health Unit 221 Portsmouth Avenue Kingston, Ontario Fax (613) 549-7896</p>

Principle X: Complaints about ACES, Computer Solutions, Handling of Health Information

An individual or agency is able to address a challenge concerning ACES' compliance with privacy principles to the Project Lead of Syndromic Surveillance, who is accountable for ACES' compliance with privacy principles.

Policies	Related Procedures
Policy 10.1 Where persons wish to challenge the compliance of ACES with privacy principles, such as those enshrined in PHIPA, the Project Lead will provide a response.	Procedure 10.1 The Project Lead will address as appropriate any concerns raised by persons who challenge ACES' compliance with applicable privacy laws and/or principles.

Principle XI: Challenging Compliance

Policies	Related Procedures
<p>Policy 11.1 The Project Leader will ensure that appropriate safeguards are in place to ensure the privacy and confidentiality of health information at ACES.</p>	<p>Procedure 11.1 The Project Leader will regularly update the PIA and this Charter with a view to ensuring ongoing compliance with applicable principles of privacy and confidentiality.</p> <p>Experts at the local health unit, hospital and provincial level will be encouraged to evaluate ACES' compliance with PHIPA and any other applicable privacy legislation.</p>

ACES PRIVACY DELEGATION

