# PHP 5
Privacy and Confidentiality for Public Health Practitioners

# EXCERPTS

This document contains excerpts from PHP 5 and is not intended for use.

Privacy and Confidentiality for Public Health Practitioners is offered as part of the Skills Online series of continuing education modules hosted by the Public Health Agency of Canada.

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# Lesson 1
Fundamental Principles and Concepts: Their Definitions and Foundations

## Introduction

In the mid-1980s, the Red Cross found itself facing a dilemma. Newly-available HIV tests had identified a number of HIV-positive blood donors - testing to which the donors had not given consent. Should the donors be notified, and should they be reported to the province in the interests of public health? Or does the donors' right to privacy trump all?

Privacy seems an intuitive concept, a value we all share. Dilemmas, however, force us to be precise: what does privacy and personal information really mean, particularly in the sensitive context of public health?

This lesson provides an introduction to the fundamental principles and concepts of laws and codes that govern contemporary public health practice in Canada. The examples and case law provided will allow you to explore how these concepts are applied in real life situations, and will illustrate some of the practical distinctions between privacy, confidentiality, and security. Finally, we will find that our best guide to navigate these laws and codes may be a model code providing us with ten principles.

Your objectives for this first Lesson are to:
- Define concepts of privacy, confidentiality, and security.
- Identify concepts of "personal information" and "personal health information" for individuals.
- Give examples of challenges to privacy posed by data linkages using the practical distinctions between aggregate, non-identifiable, and anonymous data.
- Explain how the three sources of laws that protect privacy rights and impose obligations to maintain confidentiality and protect security of information are used for ruling in case studies or from professional practice.
- Contrast codes of ethics and codes of conduct developed by professional associations that may include principles related to privacy protection, confidentiality duties, and security measures between various health organizations.
- Use the Model Code for the Protection of Personal Information by the Canadian Standards Association (CSA) to determine how well an organization is implementing the ten key fair information principles.
- Propose a plan for how an organization might better implement privacy principles.

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# Lesson 1 Summary

*Propose a plan for how an organization might better implement privacy principles. (Synthesis)*

Privacy and respect for personal information may be a value that we all intuitively share, but it is a value requiring a complex legal framework and codes of conduct to protect it. Personal information is recorded information about an identifiable individual, but we've seen that even with the best of intentions, protected information can be compromised if it can be re-identified. Health professionals are entrusted with some of the most sensitive and private details of our lives, a trust that demands a conscientious and methodical response.

We have studied three sources of laws regulating privacy and how those laws are applied in real cases. Beyond the letter of the law, we draw upon professional codes of ethics and codes of conduct. Ultimately, our best guide - and the most critical thing to remember - to navigate these laws and codes may be the 10 principles of the CSA Model Code.

ACTION: DISCUSSION

> Select an organization and share its privacy principles. Generate a plan for how this organization might implement one missing or improve one existing privacy principle covered in this lesson. Post your answer to the discussion forum. This posting should be about 3-4 paragraphs long.

> Instructions: Introduce the organization selected, and provide a brief overview of its privacy principles. Compare these principles to the 10 key fair information principles from the Model Code for the Protection of Personal Information by the Canadian Standards Association (CSA). Generate a reasonable plan for how this organization might implement one missing or improve one existing privacy principle based upon what you have learned in this module.

> Excellence: Includes all of the above, but may also consider more than one missing or inadequate privacy principle. Also includes references to all sources cited in the posting. Posting demonstrates evidence of cumulative understanding of lessons in the module, such as the inclusion of other privacy principles outside the CSA model code, challenges to privacy by data linkages, and other issues of privacy, confidentiality, and security not considered in the privacy principles provided by the organization being examined. May present more than one plan. Plan presented is novel, while feasible to implement.

> Download the Activity Guide and Rubrics (PDF) for a full set of instructions and evaluation criteria.

DISCUSSION CHECKLIST

> Discussion postings in Lesson 1 are required for:
> - Section 4: Legal Foundations
> - Section 5: Codes of Ethics and Codes of Conduct
> - Lesson 1 Summary

# Lesson 2
Legislation Related to Public Health and Protection of Personal Health Information

## Introduction

In Lesson 1, we looked at the complex nature of privacy in the public health field and began to consider the equally-complex legal and ethical frameworks developed to protect personal health information. During this second Lesson, we will unfold some of these legal complexities, sorting through the various layers of law under which public health staff must operate every day. We will return to ethical considerations in Lesson 3.

This Lesson discusses various statutes relevant in the public health context that impose obligations or duties in regard to collection, use and disclosure of personal information. The following types of laws will be described in general, with attention to any key commonalities or differences across Canada:

- public health acts
- personal information protection laws
- vital statistics and statistics acts
- disease registry acts
- other reporting acts with a public health focus
- emergency acts

Your objectives for this second Lesson are to:
- Highlight the similarities and differences between the powers and responsibilities of key public health officials as legislated by various Canadian provincial and territorial Acts.
- Determine the key impacts of the public or private sector act that primarily regulates the collection, use, and disclosure of public health information in various health organizations.
- Identify general features of the Personal Information Protection (PIP) Laws relevant in the public health context by matching terms and concepts.
- Identify which federal and provincial laws authorize the collection of statistical information about the Canadian population and what the key functions of these laws are.
- Assess the moral and ethical implications of having personal patient information registered in specific disease, demographic data, and outcome data repositories.
- Determine when and how to comply with legal reporting duties imposed on public health practitioners by using a case study example.
- Describe and assess the data handling and information sharing protocols during a public health emergency in various jurisdictions.
- Prepare a Privacy Impact Assessment from a case study that can be used to identify potential privacy risks in specific health programs or organizations.
- Appraise the main privacy implications and findings resulting from the use of a Privacy Impact Assessment (PIA) in identifying potential privacy risks in specific health programs or organizations.

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# PHP 5
Privacy and Confidentiality for Public Health Practitioners

# Core Competencies for Public Health

1.0 (Public Health Sciences),
2.0 (Assessment and Analysis),
3.0 (Policy and Program Planning, Implementation and Evaluation)
6.0 (Communication), and
7.0 (Leadership)

Competencies to be addressed in PHP5 Privacy and Confidentiality for Public Health Practitioners module, as listed in the original draft document.

3.0 Policy and Program Planning, Implementation and Evaluation
3.3 Develop a plan to implement a course of action taking into account relevant evidence, legislation, emergency planning procedures, regulations and policies.
4.0 Partnerships, Collaboration and Advocacy
4.3 Mediate between differing interests in the pursuit of health and well-being, and facilitate the allocation of resources.
7.0 Leadership
7.3 Utilize public health ethics to manage self, others, information and resources.
7.5 Contribute to maintaining organizational performance standards.

## Identified Competencies

### 1.0 Public Health Sciences

This category includes key knowledge and critical thinking skills related to the public health sciences: behavioural and social sciences, biostatistics, epidemiology, environmental public health, demography, workplace health, and the prevention of chronic diseases, infectious diseases, psychosocial problems and injuries. Competency in this category requires the ability to apply knowledge in practice.

1.5 Demonstrate the ability to pursue lifelong learning opportunities in the field of public health.

### 2.0 Assessment and Analysis

This category describes the Core Competencies needed to collect, assess, analyze and apply information (including data, facts, concepts and theories). These competencies are required to make evidence-based decisions, prepare budgets and reports, conduct investigations and make recommendations for policy and program development.

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# Lesson 1
Fundamental Principles and Concepts: Their Definitions and Foundations

## Section 1    What is Privacy?

*Define concepts of privacy, confidentiality, and security. (Knowledge)*

ACTION: JOURNAL
> Write a journal entry describing the forms of confidential information held by your organization (or an organization with which you are familiar). Which confidential information is essential to the operation of this organization?

## Section 2    What is Private Personal Information?

*Identify concepts of "personal information" and "personal health information" for individuals. (Comprehension)*

ACTION: JOURNAL
> Write a journal entry comparing your entry for the previous section with the lists of personal information and personal health information given in this section. Did you miss any? Which information might be collected incidentally by the organization, without a specific plan or even being aware of it?

## Section 3    Re-Identification: How the Private Can Be Made Public

*Give examples of challenges to privacy posed by data linkages using the practical distinctions between aggregate, non-identifiable, and anonymous data. (Comprehension)*

ACTION: JOURNAL
> Write a journal entry identifying one example challenge to privacy posed by data linkage for each category of aggregate, non-identifiable, or anonymous data. Explain why you believe each example belongs to the category you have selected.

## Section 4    Legal Foundations

*Explain how the three sources of laws that protect privacy rights and impose obligations to maintain confidentiality and protect security of information are used for ruling in case studies or from professional practice. (Comprehension)*

ACTION: DISCUSSION

> Read the four case studies presented above. Select one or present a case from your own experience or research. Explain the ruling and your own judgement of it in the discussion forum. Your posting should be about 2 paragraphs long.

> Instructions:    Summarize the case clearly and concisely. Identify the privacy right in question, the source of authority, and relevant legal rule. Explain how the ruling is applied to privacy rights and imposes obligations to maintain confidentiality and protect security of information. Determine if you agree with the ruling and explain your rationale.

Excellence:  Includes all of the above. Gives examples or further information on the ruling and of how the privacy right in question affects an individual's privacy. Offers clear rationale for justification of personal judgment regarding ruling in the case. Provides references to source of authority and relevant rule information.

| Criterion | Needs Revision | Satisfactory | Excellent |
|---|---|---|---|
| **Content** | | | |
| *Describes case context clearly and concisely* | Case context is missing or very unclear to readers | Presents context of case, but could be written more clearly or concisely | Presents context of case clearly and concisely (e.g., in 4-6 sentences) |
| *Identify privacy right in question* | Unable to identify privacy right in question | Identifies privacy right in question | Identifies privacy right in question, and provides an example of how this affects an individual's privacy |
| *Identifies correct source of authority* | Unable to identify correct source of authority | Identifies correct source of authority | Identifies correct source of authority, with reference |
| *Identifies relevant legal rule* | Unable to identify relevant legal rule | Identifies relevant rule | Identifies relevant rule, with reference |
| *Provides personal judgment of ruling* | Does not provide personal judgment of ruling | Provides personal judgment of ruling | Provides personal judgment of ruling clearly and concisely; may provide examples to support position |
| **Logic/Critical Thinking** | | | |
| *Explains how the ruling is applied to privacy rights* | Explanation of how the ruling is applied to privacy rights is missing or very unclear | Explanation of how the ruling is applied to privacy rights is clear, although more detail could be provided | Explanation of how the ruling is applied to privacy rights is very clear; examples or further information for support is provided |
| *Explains how the ruling is applied to confidentiality and security of information* | Explanation is missing or very unclear | Explanation is clear, although further detail could be provided | Explanation is very clear; examples or further information for support is provided |
| *Justifies personal judgment of the ruling* | Does not justify personal judgment of ruling | Justifies personal judgment of ruling, although rationale may be weak or confusing | Justifies personal judgment of ruling; provides clear rationale for judgment |
| **Posting Criteria** | | | |
| *Posting is made in a timely manner* | Posting is missing or added long after expected posting date | Posting is on time | Posting is on time or early |
| *Responds to peer postings appropriately* | Does not respond to peer postings or responds in a defensive or otherwise negative manner | Responds respectfully and thoughtfully to others' postings; postings may be somewhat tardy | Responds respectfully and thoughtfully to other's postings; offers additional resources or points of view; encourages discussions; posts in a timely manner |

| Overall Evaluation | | | |
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# STA 2
Survey Methods in Public Health

# EXCERPTS

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# Lesson 1
Defining Your Survey

## Introduction

This lesson provides an overview of what is meant by 'survey' for this module. In this lesson, we will:
- Introduce the concept of a population-representative descriptive (aka "observational") study
- Distinguish this design from other research designs

By the end of this lesson you will be able to:

- Distinguish a descriptive, population-representative survey from other observational research designs.

- Develop survey proposals that appraise various issues to consider (from the planning to dissemination stages) when working with data that describe people.
    - Apply the principles of defining the problem, state or condition to be described.
    - Define a population to be studied.
    - Assess the mode (or modes) of sampling, recruitment, and data collection used in the development of a survey proposal.
    - Outline how stakeholders and users of survey information may be included in the development of a survey plan.
    - Assess additional related survey needs that might be addressed in the development of a survey proposal.
    - Map out a plan for presentation of survey results in the form of sample results tables.

Note: This module often uses less statistical language than many books, but also includes more 'advanced' considerations, along with practical tips and tricks. These were gleaned from experience working with real staff in public health settings and the challenges that they face.

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# Lesson 1 Summary

*Develop survey proposals that appraises various issues to consider (from the planning to dissemination stages) when working with data that describe people. (Evaluation)*

A survey - or to be precise, a *descriptive, population-representative probability sampling survey* - is a systematic collection of data, pertaining to a defined condition in a defined population. It is this descriptive nature which separates it from analytical, hypothesis-testing studies. In this first Lesson, we have considered the preliminary steps through which a survey can be planned.

A survey plan begins by carefully defining, or *operationalizing*, the population and condition to be studied. The target population can be considered in terms of "person, place, and time", including the unit of analysis, exclusion criteria, potential subpopulations, and time period. Following the principle of starting where we want to end up, we draft a sample results table, displaying projected results in enough detail to show clearly what we want to communicate at the end of the survey, complete with sub-headings and questions for analysis.

Having defined precisely what we hope to obtain, we can now determine how we will obtain it: our survey *mode*, or the means (such as face-to-face interviews or online questionnaires) by which we will take a sample of the population and collect our data. Sampling will be the focus of the next Lesson, while data collection will be covered in Lesson 3.

Finally, we have considered the role of others in defining our survey plan. Our goal in public health is seldom pure knowledge; our survey has value when it can guide policy and decision-making. It is therefore never too early to involve various stakeholders and users of our survey, or to weigh the practical benefits and consequences of combining our survey efforts with those of others.

To sum up Lesson 1, then, you should at this point have a clear concept of a survey and how to define with precision the information a given survey can obtain. The next Lesson will become more technical, outlining specific survey designs and moving into essential statistical concerns. While we will try to keep the mathematics to a minimum, we cannot of course ignore the numbers and factors driving the analysis. As we proceed, be sure never to lose sight of the essential concepts of Lesson 1: that a survey gives us insight into real conditions affecting real people, insight guiding us in making informed decisions to improve lives through public health.

ACTION: DISCUSSION
1. Determine a survey need for your workplace (or potential workplace); define the population to be surveyed and what is to be measured and reported, using the example table you drafted in your journal as a guide; determine any sub-groups; explain how you would involve survey users early in the process; choose a survey mode and explain your choice. Post your answers to the discussion forum. Your posting should be 3-4 paragraphs long.
2. Review and comment on 2 peer-postings, considering the criteria used in developing your own survey plan. Your responses should be about 6-10 sentences long.

Download the Activity Guide and Rubrics (PDF) for a full set of instructions and evaluation criteria.

| Criterion | Needs Revision | Satisfactory | Excellent |
|---|---|---|---|
| **Content** | | | |
| *Identifies a survey need in the workplace or potential workplace* | Is not able to clearly identify a survey need; may be confused as to what a survey is | Identifies a survey need, but the parameters may be too broad, or the need may require further clarification | Clearly identifies a practical survey need |
| *Defines target population* | Definition of target | Definition of target | Definition of target |

| | | | |
|---|---|---|---|
| *to be surveyed, any sub-groups, and what is to be measured and reported* | population, any sub-groups, and/or what is to be measured and reported is missing, incomplete, confusing, or otherwise hard to understand | population, any sub-groups, and/or what is to be measured and reported is present, but some aspects of the definition could be written more clearly or concisely | population, any subgroups, and what is to be measured and reported is clearly and concisely presented |
| *Explains how survey users might be involved early in the survey process* | Does not offer ideas or suggestions for how survey users might be involved early in the survey process | Offers 1 suggestion for how survey users might be involved early in the survey process | Offers more than 1 suggestion for how survey users might be involved early in the survey process; |
| *Identify and explain a survey mode for proposed survey* | Unable to identify and/or explain a survey mode for proposed survey, or presents vague or confusing explanation | Identifies and explains a survey mode for proposed survey, but explanation may be weak or otherwise indicate unclear understanding of how the selected mode can be used for the identified survey | Identifies and explains a survey mode for proposed survey clearly and concisely, demonstrating clear understanding of how the two are related |
| **Logic/Critical Thinking** | | | |
| *Critically evaluates various issues to consider (from the planning to dissemination stages) when working with data that describe people* | Little to no evidence of critical evaluation of more than half of the issues to consider (from the planning to dissemination stages) when working with data that describe people | Critically evaluates various issues to consider (from the planning to dissemination stages) when working with data that describe people, although appraisal may be weak, vague, or inaccurate in some respects | Critically and accurately evaluates various issues to consider (from the planning to dissemination stages) when working with data that describe people |
| **Posting Criteria** | | | |
| *Posting is made in a timely manner* | Posting is missing or added long after expected posting date | Posting is on time | Posting is on time or early |
| *Responds to peer postings appropriately* | Does not respond to peer postings or responds in a defensive or otherwise negative manner | Responds respectfully and thoughtfully to others' postings; postings may be somewhat tardy | Responds respectfully and thoughtfully to other's postings; offers additional resources or points of view; encourages discussions; posts in a timely manner |
| **Overall Evaluation** | | | |

# Lesson 2
Determining Your Survey Sample

## Introduction

This lesson will:
- Introduce and define the simple random sample (SRS) design
- Introduce the advantages of this design
- Show means of random selection

You were expecting to read about questionnaire design before analysis, weren't you? In this case, either of the following sayings is appropriate:
- "Fail to plan; plan to fail" and,
- "If you don't know where you are going, you will probably end up someplace else."

The latter leads to the following advice - start with the desired product and work backward. In reality, survey planning is an iterative process, where one has to keep adjusting everything from the objectives to the dissemination strategy until the overall plan is feasible and acceptable. With experience (with surveys generally, the subject matter, and population involved) one can work on all aspects of planning simultaneously.

In this lesson, we will cover:
- Considerations for sample size requirements
- Privacy and confidentiality
- Techniques for calculating sample size requirements for relatively simple survey designs

By the end of this lesson, you will be able to:
- Justify if a simple random sample (SRS) is appropriate for a particular survey by testing the definition of SRS and its related frame and sampling methodology.
- Assess the value of using a frameless sampling design for a particular survey.
- Assess the value of using a complex sampling design for a particular survey.
- Analyze the consequences of sharing data that fails to meet various standards of precision.
- Modify definitions of survey populations and reporting conditions to reduce the risk of data suppression.
- Identify practical calculations of sample sizes for a non-cluster survey design.
- Justify a priori response rates in a survey with a specific study population.
- Outline how proposed survey findings might be generalized for use with a broader population.
- Justify an appropriate survey sampling design and size for various surveys, including considerations of precision, inflation, confidentiality, and data suppression.

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# STA 2
Surveys for Public Health Module

# Core Competencies for Public Health

1.0 (Public Health Sciences),
2.0 (Assessment and Analysis),
3.0 (Policy and Program Planning, Implementation and Evaluation)
6.0 (Communication), and
7.0 (Leadership)

## 1.0 Public Health Sciences

This category includes key knowledge and critical thinking skills related to the public health sciences: behavioural and social sciences, biostatistics, epidemiology, environmental public health, demography, workplace health, and the prevention of chronic diseases, infectious diseases, psychosocial problems and injuries. Competency in this category requires the ability to apply knowledge in practice.

1.1 Demonstrate knowledge about the following concepts: the health status of populations, inequities in health, the determinants of health and illness, strategies for health promotion, disease and injury prevention and health protection, as well as the factors that influence the delivery and use of health services.

1.3 Apply the public health sciences to practice.

1.4 Use evidence and research to inform health policies and programs.

1.5 Demonstrate the ability to pursue lifelong learning opportunities in the field of public health.

## 2.0 Assessment and Analysis

This category describes the Core Competencies needed to collect, assess, analyze and apply information (including data, facts, concepts and theories). These competencies are required to make evidence-based decisions, prepare budgets and reports, conduct investigations and make recommendations for policy and program development.

2.1 Recognize that a health concern or issue exists.

2.2 Identify relevant and appropriate sources of information, including community assets and resources.

2.3 Collect, store, retrieve and use accurate and appropriate information on public health issues.

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# Lesson 1
Defining Your Survey


## Section 1     What is Meant by a Survey?

*Distinguish a descriptive, population-representative survey from other observational research designs. (Analysis)*

ACTION: JOURNAL
> Write a journal entry describing a survey need in your organization. Does it meet the definition of a descriptive, population-representative survey given above (as opposed to an analytical study)? You will be returning to this question for the discussion activity at the end of this Lesson, and you will continue exploring and refining this survey in your journal entries and discussion activities through the rest of the course.


## Section 2     Defining the Population to be Surveyed: Think Person, Place, and Time

*Define a population to be studied. (Application)*

ACTION: JOURNAL
> Write an entry describing the target population for the survey you proposed in the first section of this Lesson. Be sure to note exclusion criteria, the unit of analysis, any potential sub-populations, and the time period.


## Section 3     Defining What is To Be Measured and Reported

*Apply the principles of defining the problem, state, or condition to be described. (Application)*

ACTION: JOURNAL
> Reflect on your previous entries and take a moment now to refine the description of your survey. Write an entry defining all key terms required to make your survey results precise. Describe any potential unintended exclusions. What might cause the practical population sampled to be different from your target population sample? What solutions can you suggest to reduce this effect?


## Section 4     Mapping Out the Basic Definitions and Elements: Making Up the Plan for a Survey

*Map out a plan for presentation of survey results in the form of sample results tables. (Synthesis)*

ACTION: JOURNAL
> Prepare at least one example table and figures to show your projected results, with enough detail really to show what you want to communicate at the end of your survey and to make it comparable to similar surveys in your field. Include detailed titles. Include all headings and subheadings. Write supplementary material for the tables.

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