

Standards of Practice for Survey & Evaluation Services

DATA INTEGRATION, MEASUREMENT & REPORTING
ALBERTA HEALTH SERVICES

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Introduction

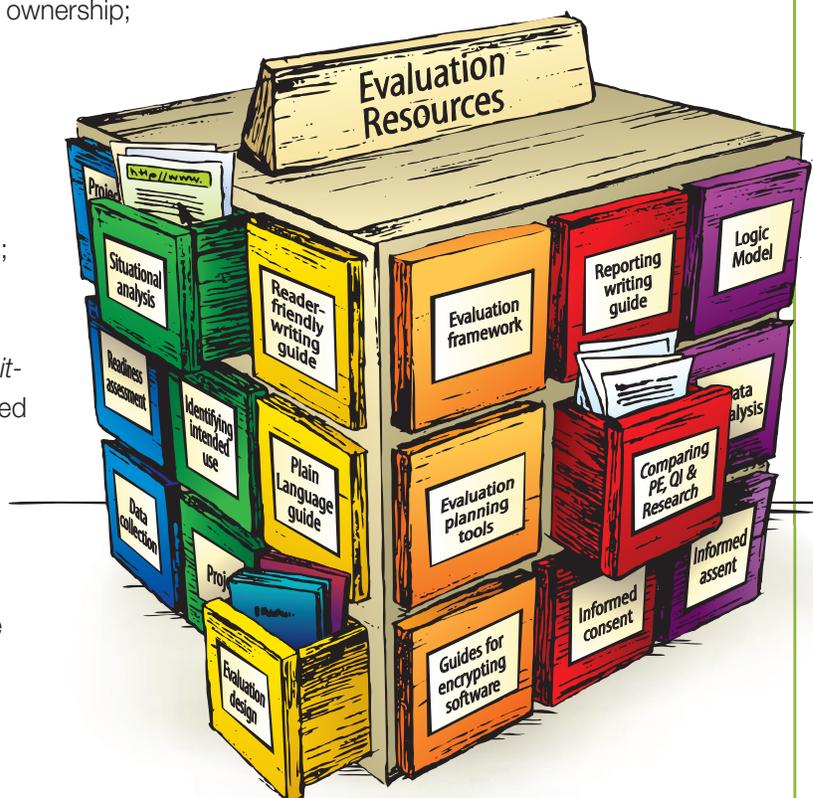
The *AHS Standards of Practice for Survey & Evaluation Services* is a useful guide for planning, conducting and reporting evaluations. The development of explicit standards of practice helps to establish consistent and reliable professional practice in all activities related to evaluation within Survey & Evaluation Services, Data Integration, Measurement & Reporting of Alberta Health Services (AHS). These standards help to ensure the:

- Protection of participants and their health-related information
- Professional integrity and conduct within Survey & Evaluation Services, AHS

These standards of practice are a compilation of new and existing policies and resources that have been selected to meet the needs of the newly established Alberta Health Services. Whenever possible, we draw guidance from governing bodies, whose purpose is to help inform and improve practice, such as Alberta Innovates – Health Solutions, Canadian Evaluation Society, Research Ethics Boards of Alberta, and Treasury Board of Canada. Distinguished mentors and scholars in the field of evaluation, such as Michael Quinn Patton, John Owen, and Evert Vedung, also help to guide this practice.

The *AHS Standards of Practice for Survey & Evaluation Services* address many areas relative to professional practice, including principles of practice; ethical conduct for projects; guidelines for informed consent, recall and the use of incentives; protection and safe handling of evaluation data; intellectual ownership; and archiving protocols. In addition, this document is supplemented by a separate resource, the *AHS Companion Guide to the Standards of Practice for Survey & Evaluation Services* which contains practical tools; templates that can be customized and adapted to the needs of the specific projects; step-by-step guides; and *do-it-yourself* information sheets—all designed to help increase consistency and improve understanding of evaluation processes.

While the primary purpose of developing these standards of practice



is to guide the professional practice of Survey & Evaluation Services and other practitioners within the evaluation community who are searching to inform their own practice are welcome to use this information. The development of this resource is ongoing and will evolve over time as we identify additional needs. Therefore, we welcome and encourage feedback from everyone who uses it.

Please forward your comments and ideas to: surveyandevaluation@albertahealthservices.ca

The *AHS Standards of Practice for Survey & Evaluation Services* is based on guidelines that provide foundation and structure for appropriate evaluation conduct. Table 1 summarizes the guidelines and indicates the page they are further explained within the document.

TABLE 1. Summary of guidelines

PAGE	GUIDELINES
5	Bias and conflict of interest Survey & Evaluation Services provides an internal model for evaluation within AHS. For that reason, service is limited to health-related programs and projects that are governed by portfolios other than Data Integration, Measurement & Reporting.
5	Problem solving for evaluation planning and reporting Survey & Evaluation Services provides peer support to evaluators for problem solving and addressing issues while providing best strategies for inappropriate requests that may violate the standards of practice. The evaluation team is responsible for requesting an ad hoc review committee within the organization to determine appropriate solutions. This process will occur without undue delay.
11	Selectivity of evaluation projects based on application of results Priority of service from Survey & Evaluation Services will be reserved for stakeholders who are determined most likely to use the evaluation results to improve the delivery of the healthcare service. Survey & Evaluation Services retains the right to decline a request for service based on the perceived need and use for evaluation results. As required, an ad hoc review committee from within the organization will provide peer support when requests for service are declined.
20	Screening for ethical oversight in project design and protocol Survey & Evaluation Services recommends screening all evaluation project designs for ethical oversight using the ARECCI process. This process will help to establish primary purpose of the project; identify the level of risk; and facilitate the appropriate follow-up strategies required to minimize or mitigate risk to participants.
20	Evaluator competency for ethical oversight in project design and protocol Survey & Evaluation Services employees are expected to obtain proficiencies in project ethics and the use of ARECCI tools through available training and practice. All employees involved in designing evaluation projects are required to have the minimum requirement of ARECCI Project Ethics Course Level 1.
29	Determining consent for evaluation projects Whenever there is a concern about participant consent, the person involved in the development of the evaluation plan will initiate a consultation process with an ad hoc committee to determine the most appropriate protocol. The ad hoc committee will consist of the Director of Survey & Evaluation Services, Evaluation Lead, and business partner involved in the project. This review process must be documented and archived with project records. Archived records must include persons involved, protocol, decision rationale, decision and date.

TABLE 1. Summary of guidelines...continued

PAGE	GUIDELINES
31	Determining timelines for participant recall The upper limit for follow-up for individuals who have received healthcare services is up to 6 weeks. In some cases, it may be okay for follow-up to occur up to 6 months providing questions are general in nature. Follow-up after 6 months is not recommended.
32	Offering financial inducements for participation A decision to offer financial inducements is made with careful consideration in keeping with the best interests of the participants and in collaboration with business partners and stakeholders of the evaluation project. Costs of financial inducements are over and above the cost of the evaluation.
35	Protecting personal health information Survey & Evaluation Services works within the guidelines of legislative governance and ethical conduct. Practices ensure all safeguards for protecting personal health information used in evaluative data.
39	Protecting evaluation data while inside of the AHS sites A number of protocols serve to safeguard evaluative data within secure AHS sites (current project data and archived records).
41	Protecting evaluation data while outside of AHS sites A number of protocols serve to safeguard evaluative data reports while in transit or outside of secure AHS sites.
44	Copyright notice for reports internal to Alberta Health Services Reports prepared by Survey & Evaluation Services that are internal to Alberta Health Service should include a copyright notice, regardless of size. Copyright notice should also appear on all evaluation resources developed in-house (such as survey tools, teaching resources and so on). The template illustrates the recommended standard. Location of the notice in the report is up to the discretion of the author. However, in large reports, this notice should appear after "Acknowledgements."

Principles of Practice

An internal model for evaluation

Alberta Health Services (AHS) views evaluation as central to organizational effectiveness and an integral part of the culture within AHS. Survey & Evaluation Services offers a fully integrated internal model of evaluation within AHS. In addition, services are also provided to external health-related business partners, such as the Primary Care Networks. Both approaches to service make an important contribution to the delivery of healthcare services by improving their quality through an increased understanding of operations and by helping operations to be accountable to their stakeholders and the citizens of Alberta.

In situations where the evaluator and the service provider are funded by the organization responsible for the service, the evaluation process may be considered a type of institutional self-study. If the evaluators are individuals who have a long-term, ongoing position within the organization, they are considered internal. External evaluators are typically evaluative researchers from an academic setting, independent consultants, or individuals from consulting firms under contract to the organization to execute evaluations and produce results (Patton, 2008; Vedung, 2005).

The literature defines an internal model for evaluation and recognizes the merits of such a model including:

- Engaging an evaluator who is in tune with the agency; one who knows the subtle nuances of the operation and can often be sensitive to organizational relationships and norms.
- Through increased understanding of the organization, the internal evaluator can often see additional ways in which evaluation can make a difference and avoid mistakes due lack of knowledge.
- The knowledge and insight gained by the evaluator during the process is not lost to the organization after the evaluation is completed. However, this type of loss often occurs with an external evaluator.
- Building strong credibility between the evaluation and stakeholders over time can foster increased commitment and use of evaluation findings.
- Since the system often absorbs certain overhead costs for internal evaluators, overall costs related to evaluation can be reduced.

An internal model of evaluation works best when the environment offers two critical components. First, the business partners are genuinely committed to learning about themselves and want information—both positive and negative—that will help to inform and improve their practice. Second, the evaluator is accepted as a critical friend who is fearless in *speaking the truth*. While acknowledged as intrinsic to the nature of the work, speaking the truth to power can be a risky and painful business (for both internal and external evaluators).

The evaluator also needs to be able to provide advice and, when appropriate, guide the business partner in determining the best strategies to implement changes that result from the evaluation process (Patton, 2008; Owen, 2007).

However, an internal model for evaluation may be suspect if the evaluator is not able to maintain an acceptable level of objectivity towards the evaluation subject due to organizational policies, value systems, internal politics and power hierarchies. Undo pressure can be placed on internal evaluators to present only positive results or manipulate the evaluation process that distorts findings or corrupts the inquiry (Patton, 2008; Vedung, 2005). The Canadian Evaluation Society's Guidelines for Ethical Conduct provides a solid approach to practice for both internal and external evaluation models within Survey & Evaluation Services (see Ethics section in this document). The standard of practice that addresses conflict of interest excludes service to any AHS program or project that falls under the same governing portfolio of Data Integration, Measurement & Reporting (DIMR).

Guideline

Bias and conflict of interest

Survey & Evaluation Services provides an internal model for evaluation within AHS. For that reason, service is limited to health-related programs and projects that are governed by portfolios other than Data Integration, Measurement & Reporting.

Evaluators are accountable to providing sound methodology, analysis and reporting. That does not imply, however, that they are responsible to make all decisions in isolation. In order for evaluation to remain an objective and value-free social science, Survey & Evaluation Services provides peer support for the process of quality assurance at the department level to ensure the integrity of the evaluation process and data reports when issues arise. Whenever there is a request or demand placed upon the evaluator by a business partner to participate in an activity that may violate Survey & Evaluation Services' principles of practice, formal direction from the organization needs to be provided before proceeding.

Guideline

Problem solving for evaluation planning and reporting

Survey & Evaluation Services provides peer support to evaluators for problem solving and addressing issues while providing best strategies for inappropriate requests that may violate the standards of practice. The evaluation team is responsible for requesting an ad hoc review committee within the organization to determine appropriate solutions. This process will occur without undue delay.

In the interest of being forthright and transparent in the approach to service, the following statement addressing the issue of bias and conflict of interest is to be embedded in all full evaluation reports:

FIGURE 1. Template for internal evaluation reports**EVALUATION PRINCIPLES**

Survey & Evaluation Services is an internal resource for Alberta Health Services (AHS) and is responsible for providing evaluations across the province. As a result, this relationship may put into question the service's ability to be objective, especially in relation to the stakeholders of [PROJECT NAME] and [GOVERNING FACILITY OR PROJECT TEAM]. An internal model of evaluation is defined in the literature (Patton, Owens). While internal practitioners may have a better understanding of the general environment than external evaluators, a risk to objectivity is a concern unless clearly defined standards of practice and principles are understood. The Survey & Evaluation Services business standards of practice ensure objectivity, as well as comply with the code of ethics as described by the Canadian Evaluation Society.

Survey & Evaluation Services does not report to any of the operational Vice Presidents of AHS who are responsible for the [GOVERNING FACILITY OR PROJECT TEAM]. For that reason, the evaluator can maintain an objective distance from those with more invested interest. Survey & Evaluation Services has an ethical commitment to report on what the data presents and will not entertain any requests to exclude or adjust findings unless there is evidence that this is a valid request. This does not mean that the [PROJECT NAME] will not have input into the final report; they are critical in the final interpretation of results by providing understanding and context through their intimate knowledge of the program environment.

The importance of applying what is learned through the evaluation cannot be overestimated. We are committed to producing meaningful evaluation findings for all stakeholders. This will include follow-up with clinical teams and other decision-makers to ensure that they understand the findings as related to their program, and support the use of evaluation results to improve practice.

Improving the application of evaluation results

A prevailing issue with evaluation is that, for a number of reasons, results are not often used as a useful management tool after the final report is delivered to the commissioners of the evaluation project. Underutilization of results is a constant and familiar lament of both evaluators and within academic literature (Vedung, 2005; Patton, 2008; Owen, 2007). Underutilization is a serious concern considering the cost and burden of evaluation on people and the healthcare system, the lost opportunity to learn from experience and improve service, and the lack of careful stewardship of resources. To help improve this situation, Survey & Evaluation Services takes an approach to the evaluation design and execution so that, from beginning to end, everything that is done affects the application of evaluation results into practice.

As guided by Michael Quinn Patton, an internationally recognized scholar in organizational development and evaluation, a **utilization-focused approach to evaluation** begins with the premise that evaluations should be judged by their utility and actual use. This type of approach attempts to reduce the non-use of evaluation results by creating a climate and culture in which the

people who are involved are willing to examine basic assumptions and are engaged in the evaluation process. A major focus remains on what real people in the real world need from evaluation and what it takes for them to use the results. This approach to evaluation planning is highly personal and situational. The work requires developing a strong working relationship with the intended users (business partners) and their engagement at every stage of the evaluation, including:

- Selecting the most appropriate type of evaluation for their needs and situation
- Determining what success looks like within the context of the project or program and articulating key success factors as related to their local environment and situation
- Helping to determine the most appropriate method to work with participants involved in the project or program to help reduce the burden of evaluation and ensure the application of ethical considerations
- Sharing in the responsibility of collecting project metrics and other types of data needed to establish outcome results
- Helping to provide a critical understanding of data reports and context of the local environment during the analysis phase of the evaluation

The Treasury Board of Canada (TBC) also validates involving business partners in the evaluation process, which is considered a best practice in producing useful evaluations that are relevant, timely and defensible (TBC, 2010; Patton, 2008). The role of business partners in the planning process is to help decide what will be measured during the evaluation; they are also responsible for finding consensus amongst their group about what will be studied. The business partners are ultimately accountable to their stakeholders to provide feedback based on the most meaningful data that will help inform and improve their practice. The evaluator, on the other hand, helps to facilitate the decision-making process of what will populate the evaluation framework. The evaluator is also accountable for ensuring the integrity of the evaluation process through a design that uses sound methodology, analysis and reporting.

Program evaluation is all about understanding an activity within the context of its environment. The business partners are engaged to provide understanding and context of what the data is illustrating. Their input is critical in the final interpretation of results by providing their intimate knowledge of the program environment. The evaluator has an ethical commitment to report on what the data presents in a balanced manner (including both positive and negative outcomes). Requests to exclude or adjust findings will not be entertained unless there is valid reason to do so. The evaluator maintains the right to decide what will appear in the final report.

Business partners who are more actively involved in their evaluation can benefit in a number of ways. Involved partners develop a stronger understanding of how evaluation can be a more beneficial and less punitive and judgemental process. Partners realize that evaluation is more about learning what is working well and identifying areas of their practice that need to be strengthened. Having their input into planning helps to ensure more meaningful and useful results. Being involved provides experience and helps them build their own internal capacity to do and use evaluation.

Table 2 outlines how business partners are involved. A series of checklists to help guide evaluation planning in the utilization-focused method is available in the *AHS Companion Guide to Standards of Practice for Survey & Evaluation Services*.

TABLE 2. Eight-step process for conducting an evaluation

STEP	DESCRIPTION	INVOLVEMENT
Initiation	The evaluation team and individual business partners or groups consult to determine the context of needs of individuals and their operations for evaluation. An evaluability assessment may also be completed.	Evaluation team and business partners
Negotiation & Formulation	<p>The evaluation team leads a process where business partner(s) are actively engaged in determining the structure and design of the evaluation plan, including key success factors, evaluation questions, strategies, methods, indicators, and timelines. Core documents and existing resources, such as databases, related to the project or program are declared. The development of a logic model is optional.</p> <p>The evaluation team creates an evaluation framework based on the consultation process and best practice standards. Negotiation and forming the framework may require a series of reviews with business partners to refine the document.</p>	Evaluation team and business partners
Reviewing knowledge	The evaluation plan is informed and evidence-based. A review of existing knowledge on evaluating the area of focus is conducted (may include a review of existing literature and trialed methods by other evaluators). Background information on the area of focus accessed at this point may also help provide context and narrative for the final report.	Evaluation team (Business partners may also provide relevant information)
Finalizing the evaluation design	<p>The evaluation team determines the most appropriate methods for gathering data in consultation with business partner(s).</p> <p>The business partners provide approval of the final evaluation design.</p>	Evaluation team and business partners Business partners
Data collection	Data management and analysis process is determined. Business partners may already be involved in collecting data that will support the evaluation process. The degree to which the business partners are involved in collecting new evaluation data is based on feasibility and appropriate practice.	Evaluation team and possibly business partners
Data analyses and reporting	The evaluation team are involved in analyzing the data and reporting. The business partners are engaged to review data reports and provide explanation and context around the results.	Evaluation team and business partners
Applying results into practice	The evaluation team supports the business partners to ensure that results are understood so that this new knowledge can be applied to improve practice.	Evaluation team and business partners
Reflective practice (metaevaluation)	A successful evaluation is one that is useful, practical, ethical and accurate. Was the evaluation well done? Did it meet professional standards and principles? Did the evaluation provide the business partners with the right types of information to inform their practice?	Evaluation team and business partners

Although the literature describes many different types of approaches to evaluation, the information in Table 3 is adopted from Patton (2008).

TABLE 3. Types of evaluation approaches

PURPOSE	DESCRIPTION
Rendering judgement	<ul style="list-style-type: none"> • A summative evaluation that aims at determining the overall merit, worth or value of the service. • Asks questions such as: What is the overall effectiveness? Are the intended needs met? What is the worth to the larger community or society? Should the service be continued, ended or expanded?
Facilitating improvements	<ul style="list-style-type: none"> • A formative evaluation or quality improvement approach that focuses on making things better. • Gathers a variety of data about strengths and weaknesses with the expectation that both will be found and each can be used to inform an ongoing cycle of reflection and innovation. • Also asks questions such as: To what extent are anticipated outcomes being met? Who is making good progress? Who is not, and why not?
Generating knowledge	<ul style="list-style-type: none"> • While all listed types of evaluation can be considered, knowledge-generating, this type is unique because the approach specifically looks across findings from different programs to identify general patterns of effectiveness. • It may look to formulate generalizations about processes and interventions that make a difference and synthesize findings from different studies. • Asks questions such as: What are the lessons of successful programs?
Accountability	<ul style="list-style-type: none"> • This function involves oversight and compliance, and is closely related to judgement, in its purpose. There is debate whether accountability is evaluative or more managerial. • Performance measurement is a common approach used, but may need to be comprehensive in its approach to be reliable. • Asks questions such as: Are goals and targets being met? Are indicators showing improvement? Are staff qualified? Are participants eligible?
Monitoring	<ul style="list-style-type: none"> • This function is used as a guide for managers by providing information they need to know if a program is functioning, as intended. The findings are also used for reporting to external stakeholders. • Uses performance indicators like accountability functions, but is distinctive from accountability and evaluation. Monitoring is more often linked with evaluation (M & E).
Development	<ul style="list-style-type: none"> • A rigorous inquiry about the development of a new innovation where the path and the destination are evolving and key variables are always changing. The intent of the evaluation is to capture system dynamics, interdependencies and emergent interconnections.

The use and misuse of evaluation results

Understanding how the evaluation results will be used can help to inform the organization of the timing and of the design of the evaluation plan to enhance the usefulness of the final results. The use of results not only has the potential to improve the delivery of healthcare services, but also has an impact on the overall cultural value placed on evaluation as an important operational process within Alberta Health Services.

Appropriate use

The use and misuse of evaluation results is discussed at length in the literature (Patton, 2008; Vedung, 2005). Comprehending the motivation for evaluation ahead of time helps to support the careful decision-making and stewardship of healthcare resources. Table 4 lists application types and the underlying motivations. Stakeholders who intend on applying their evaluation results according to the *process* and *instrumental* application types are ideal and desirable candidates to become engaged in evaluation. The *interactive* and *conceptual* application types are familiar in the healthcare landscape and speak to common reality. While not ideal, stakeholders who use these application types are viewed as having an honourable intention and may have the potential to become more sophisticated in their use of the evaluation results through increased understanding and coaching.

Inappropriate use

Evaluation also has its limitations, risks and problems. Sometimes it is necessary for the evaluator (and the organization) to decide when it is not appropriate, or in their best interest, to become involved or continue in an evaluation process. Circumstances, such as lack of valid questions, lack of clear direction, stakeholders who cannot come to agreement, and lack of sufficient funds, are acceptable reasons for withdrawing (Fraser Health, 2009). The evaluator may also encounter situations when stakeholders present with less than honourable reasons for seeking evaluation. Hidden agendas can undermine the primary intent and purpose. These types of motivators are also described in Table 4 under the *mechanical*, *legitimization* and *avoidance* application types. It is important for evaluators to unveil deeper purposes whenever possible and contemplate the implications before committing to these types of projects.

For example:

- When the demand for evaluation within the healthcare system continually exceeds the ability to meet that demand, does Survey & Evaluation Services want to allocate resources where it will be little or no chance of impacting the improvement of the healthcare services?
- Retrospectively-planned evaluations pose many limitations to providing results that are useful and meaningful. These types of evaluations are more resource-dependent and often fail to meet the expectations and needs of the stakeholders. Not only is the reputation of the evaluator at stake, but compressed schedules often restrict the delivery of results in a timely way, even if there is potential for application of results and learning in the end.
- Due to the unscrupulous motivations of evaluations done for the purpose of *avoidance*, the evaluation process may be put at higher risk of being challenged to work outside of the established

standards of practice. Once committed to the project, the evaluator and the organization may be put in a vulnerable position with considerably evaluated levels of risk. To ensure the delivery of sound ethical practice, the evaluator and organization must determine what type of demands will be tolerated, endured and nurtured.

It is important that evaluations that are deemed to add value to stakeholders and the greater healthcare system take priority over those that have less than honourable intentions.

Guideline

Selectivity of evaluation projects based on application of results

Priority of service from Survey & Evaluation Services will be reserved for stakeholders who are determined most likely to use the evaluation results to improve the delivery of the healthcare service. Survey & Evaluation Services retains the right to decline a request for service based on the perceived need and use for evaluation results. As required, an ad hoc review committee from within the organization will provide peer support when requests for service are declined.

Evert Verdung (2005) and Micheal Quinn Patton (2008) both address the use and misuse of evaluation results. Table 4 provides some common examples.

TABLE 4. Using evaluation results

APPLICATION TYPES	DESCRIPTION
Process	Changes occur with the business partners by virtue of their involvement with the evaluation process. Activities such as clarifying goals, understanding logical relationships between inputs and outcomes, identifying evaluation priorities, and participating in decisions about design, measurement and interpretation of results provide opportunity for growth that can impact change. Those changes may be cognitive and behavioural, and can impact the program or organization.
Instrumental	Evaluative knowledge is used directly for decision-making. Recommendations are generated and applied to practice.
Interactive	Decision-makers taste, swallow and digest different kinds of information. Evaluation results become only one of many sources of knowledge that contribute to making final decisions. Other sources include knowledge generated from research, conventional wisdom, common sense, and first-hand experiences. Legal issues, democratic values, associated costs and political consequences also carry significant weight.
Conceptual	A conceptual approach contributes to scrutiny of the project, deeper understanding of merits and limitations. Evaluation results may influence how people think about a program or policy through better understanding. However, while this enlightenment may change their concept of the topic, these insights do not necessarily become instrumental and transformed into action.

TABLE 4. *Using evaluation results...continued*

APPLICATION TYPES	DESCRIPTION
Mechanical	Motivation for the evaluation is compliance with funding requirements rather than general interest in being more effective. The evaluation is required and so it is done. There is no intention to apply results. Often with this type of ritual use, evaluations are commissioned at the 11 th hour of the granting period and must be planned retrospectively.
Legitimization	The primary purpose of the evaluation is to legitimize decisions that are already made by unscrupulous decision-makers. They want to use the evaluation to justify current views or policies.
Avoidance	The evaluation is commissioned as a tactical strategy to gain time and avoid responsibility. The primary motivation may be to cover-up or whitewash faulty results; avoid public debate or criticism; or provide a false impression of commitment to the outside world. The importance of initiating the evaluation is not for the eventual findings, but the fact that the evaluation has been arranged and is underway.

Building evaluation capacity

Growing capacity

Today there is a growing field of interest within North American learning institutions to offer more in-depth formal training programs specific to evaluation. However, in the past, many practicing evaluators have had to capitalize on the intermittent training opportunities for evaluation to supplement their skill and knowledge of research methodology to increase rigour and ensure defensible evaluation results. Over time, they have developed and cultured their skills in evaluation through hands-on experience. With the ever-growing need for assessment and accountability in health-related services, Survey & Evaluation Services maintains a strong commitment to growing the organization's capacity for evaluation. An important part of the service component is through nurturing skills of interested individuals before and after completion of undergraduate and graduate studies by maintaining a strong teaching focus and apprenticing skills through practical application and hands-on experience.

Reducing anxiety and fear of evaluation

Increasing active involvement of business partners provides them with the opportunity to be part of the evaluation, instead of being passive and feeling subjected to the process. Being a part of the decision-making can provide teachable moments that help to increase understanding, and hopefully, reduce the anxiety and fear of evaluation. Patton (2008) talks about the counterproductive impact of pre-evaluation stress syndrome. He states that people often view evaluation as punitive; the resulting stress creates dysfunction and puts everyone into survivor mode. This emotional response can

result in evaluation recipients who will attack the final report without regard for how well it has been produced (2008). An important approach to service is through a leadership role that helps business partners and their staff understand how evaluation can help to inform their practice and build internal capacity within their own professional sphere of influence.

Building a culture of evaluation

In addition, Survey & Evaluation Services promotes the culture of evaluation by being an active member of the network of people involved in health-related evaluation, both within and outside of Alberta Health Services. The evaluation process is often inclusive of partners and mentors that cross corporate boundaries. Good working relationships once established seldom terminate at the end of the project. Ongoing relationships are important for sustaining support and building an enduring capacity for evaluation.

Survey & Evaluation Services takes an active role in facilitating and sustaining the **Alberta Evaluation Network**. The Network serves as a virtual meeting place to connect people who are involved in health-related program evaluations within Alberta by:

- Providing a forum for sharing ideas, exchanging information, networking and learning
- Increasing opportunities to collaborate, resulting in reduced burdens and increased efficiencies within the healthcare system

Standards of Practice for Survey & Evaluation Services

Survey & Evaluation Services adopts the Canadian Evaluation Society's standards of practice for program evaluation. The following criteria are used with permission from the Canadian Evaluation Society (2011). This information is also available at www.evaluationcanada.ca/site.cgi?s=6&ss=10&_lang=EN.

Utility Standards

The utility standards are intended to ensure that an evaluation will serve the information needs of intended users.

Stakeholder Identification

Persons involved in or affected by the evaluation should be identified, so that their needs can be addressed.

Evaluator Credibility

Persons conducting the evaluation should be both trustworthy and competent to perform the evaluation, so that the evaluation findings achieve maximum credibility and acceptance.

Information Scope and Selection

Information collected should be broadly selected to address pertinent questions about the program and be responsive to the needs and interests of clients and other specified stakeholders.

Values Identification

The perspectives, procedures and rationale used to interpret the findings should be carefully described, so that the bases for value judgements are clear.

Report Clarity

Evaluation reports should clearly describe the program being evaluated, including its context and the purposes, procedures and findings of the evaluation, so that essential information is provided and easily understood.

Report Timeliness and Dissemination

Significant interim findings and evaluation reports should be disseminated to intended users, so that they can be used in a timely fashion.

Evaluation Impact

Evaluations should be planned, conducted and reported in ways that encourage follow-through by stakeholders, so that the likelihood that the evaluation will be used is increased.

Feasibility Standards

The feasibility standards are intended to ensure that an evaluation will be realistic, prudent, diplomatic and frugal.

Practical Procedures

The evaluation procedures should be practical to keep disruption to a minimum while needed information is obtained.

Political Viability

The evaluation should be planned and conducted with anticipation of the different positions of various interest groups, so that their cooperation may be obtained, and so that possible attempts by any of these groups to curtail evaluation operations or to bias or misapply the results can be averted or counteracted.

Cost Effectiveness

The evaluation should be efficient and produce information of sufficient value, so that the resources expended can be justified.

Propriety Standards

The propriety standards are intended to ensure that an evaluation will be conducted legally, ethically, and with due regard for the welfare of those involved in the evaluation, as well as those affected by its results.

Service Orientation

Evaluations should be designed to assist organizations to address and effectively serve the needs of the full range of targeted participants.

Formal Agreements

Obligations of the formal parties to an evaluation (what is to be done, how, by whom, when) should be agreed to in writing, so that these parties are obligated to adhere to all conditions of the agreement or formally to renegotiate it.

Rights of Human Subjects

Evaluations should be designed and conducted to respect and protect the rights and welfare of human subjects.

Human Interactions

Evaluators should respect human dignity and worth in their interactions with other persons associated with an evaluation, so that participants are not threatened or harmed.

Complete and Fair Assessment

The evaluation should be complete and fair in its examination and recording of strengths and weaknesses of the program being evaluated, so that strengths can be built upon and problem areas addressed.

Disclosure of Findings

The formal parties to an evaluation should ensure that the full set of evaluation findings along with pertinent limitations are made accessible to the persons affected by the evaluation and any others with expressed legal rights to receive the results.

Conflict of Interest

Conflict of interest should be dealt with openly and honestly, so that it does not compromise the evaluation processes and results.

Fiscal Responsibility

The evaluator's allocation and expenditure of resources should reflect sound accountability procedures and otherwise be prudent and ethically responsible, so that expenditures are accounted for and appropriate.

Accuracy Standards

The accuracy standards are intended to ensure that an evaluation will reveal and convey technically adequate information about the features that determine worth or merit of the program being evaluated.

Program Documentation	The program being evaluated should be described and documented clearly and accurately, so that the program is clearly identified.
Context Analysis	The context in which the program exists should be examined in enough detail, so that its likely influences on the program can be identified.
Described Purposes and Procedures	The purposes and procedures of the evaluation should be monitored and described in enough detail, so that they can be identified and assessed.
Defensible Information Sources	The sources of information used in a program evaluation should be described in enough detail, so that the adequacy of the information can be assessed.
Valid Information	The information-gathering procedures should be chosen or developed and then implemented so that they will assure that the interpretation arrived at is valid for the intended use.
Reliable Information	The information-gathering procedures should be chosen or developed and then implemented so that they will assure that the information obtained is sufficiently reliable for the intended use.
Systematic Information	The information collected, processed and reported in an evaluation should be systematically reviewed, and any errors found should be corrected.
Analysis of Quantitative Information	Quantitative information in an evaluation should be appropriately and systematically analyzed so that evaluation questions are effectively answered.
Analysis of Qualitative Information	Qualitative information in an evaluation should be appropriately and systematically analyzed so that evaluation questions are effectively answered.
Justified Conclusions	The conclusions reached in an evaluation should be explicitly justified, so that stakeholders can assess them.
Impartial Reporting	Reporting procedures should guard against distortion caused by personal feelings and biases of any party to the evaluation, so that evaluation reports fairly reflect the evaluation findings.
Metaevaluation	The evaluation itself should be formatively and summatively evaluated against these and other pertinent standards, so that its conduct is appropriately guided and, on completion, stakeholders can closely examine its strengths and weaknesses.

Guidelines for ethical conduct of evaluators

Survey & Evaluation Services adopts the Canadian Evaluation Society's guidelines for ethical conduct. The following criteria is used with permission from the Canadian Evaluation Society (2011). This information is also available at http://evaluationcanada.ca/site.cgi?s=5&ss=4&_lang=en.

Competence

Evaluators are to be competent in their provision of service.

- Evaluators should apply systematic methods of inquiry appropriate to the evaluation.
- Evaluators should possess or provide content knowledge appropriate for the evaluation.
- Evaluators should continuously strive to improve their methodological and practice skills.

Integrity

Evaluators are to act with integrity in their relationship with all stakeholders.

- Evaluators should accurately represent their level of skills and knowledge.
- Evaluators should declare any conflict of interest to clients before embarking on an evaluation project and at any point where such conflict occurs. This includes conflict of interest on the part of either evaluator or stakeholder.
- Evaluators should be sensitive to the cultural and social environment of all stakeholders and conduct themselves in a manner appropriate to this environment.
- Evaluators should confer with the client on contractual decisions such as confidentiality; privacy; communication; and ownership of findings and reports.

Accountability

Evaluators are to be accountable for their performance and their product.

- Evaluators should be responsible for the provision of information to clients to facilitate their decision-making concerning the selection of appropriate evaluation strategies and methodologies. Such information should include the limitations of selected methodology.
- Evaluators should be responsible for the clear, accurate, and fair, written and/or oral presentation of study findings and limitations, and recommendations.
- Evaluators should be responsible in their fiscal decision-making so that expenditures are accounted for and clients receive good value for their dollars.
- Evaluators should be responsible for the completion of the evaluation within a reasonable amount of time as agreed with the clients. Such agreements should acknowledge unprecedented delays resulting from factors beyond the evaluator's control.

Ethical considerations for evaluation projects

Health-related research, evaluation and quality improvement all generate new knowledge that contributes to informing policy, decision-making and managing quality health service. Any type of project work involving people and their health information inherently will involve some level of risk to participants. The majority of evaluation and quality improvement projects, by design, are generally low risk to participants, evaluators and the organization; however, some projects do present the potential of being higher risk.

Research has a long-established formal process that helps to safeguard against ethical oversight. In Canada, any research involving human subjects is governed by three national research granting bodies and their Tri-Council Policy Statement*. The Tri-Council's goal is to promote the highest ethical standards for research. So, all research funding from these sources must receive approval from their governing Research Ethics Boards (REB). Currently in Alberta, there are several REBs that are designated under legislation based on the TCPS to provide review for ethical oversight to research proposals and their protocols**. Practitioners of health-related evaluation and quality improvement projects, on the other hand, have been without a supporting structure to help ensure that ethical considerations have been integrated into the project design and methods.

Beginning in 2003, a number of representatives from the REBs and former Regional Health Authorities, now *Alberta Health Services*, were brought together to address the issues of project ethics and create a supporting infrastructure for healthcare practitioners to deal with ethical oversight for non-research projects. ARECCI's *Protecting People While Increasing Knowledge Recommendations* and the *ARECCI Ethics Decision-Support Tools for Projects* were developed by the participating representatives who became the Alberta Research Ethics Community Consensus Initiative (ARECCI) Network. This achievement was possible through the leadership and support of Alberta Innovates - Health Solutions and funding through the Alberta Heritage Foundation for Medical Research Endowment Fund.

* Three main research granting bodies includes Canadian Institute on Health Research (CIHR); Natural Science and Engineering Research Council of Canada (NSERC) and Social Science and Humanities Research Council of Canada (SSHRC).

** Research Ethics Boards in Alberta include:

- Health Research Ethics Board (HREB) serving Edmonton and studies originating from the University of Alberta in the faculties of Medicine, Nursing, Pharmacy, Physical Education, Rehabilitation Medicine and the School of Public Health.
- Community Research Ethics Board (CREBA) serving rural and urban Alberta communities that do not have a duly constituted health research ethics board and process.
- Alberta Cancer Research Ethics Committee (ACREC) serving Alberta Health Services throughout the province of Alberta providing scientific and ethical review for cancer researchers.
- The Conjoint Faculties Research Ethics Board (CFREB) serving the University of Calgary in the faculties of Kinesiology, Medicine, Nursing and health professionals within the healthcare setting in Calgary and surrounding area.
- Red Deer College Human Research Ethics Board serving the employees or students at Red Deer College.
- University of Lethbridge Human Subject Research Committee.
- College of Physicians and Surgeons Research Ethics Review Committee serving physicians involved in human research that is ineligible to be reviewed by other Alberta REBs.

ARECCI offers two automated decision-support tools to assist with the integration of appropriate ethics considerations into project plans to protect participants and their health information. These tools provide a screening process to safeguard against ethical oversights and to help reduce risk to participants.

- **ARECCI Ethics Guidelines for Quality Improvement and Evaluation Projects** provides a framework for project planning that identifies and integrates appropriate ethics considerations. This web-based tool is available at www.ahfmr.ab.ca/arecci/guidelines.
- **ARECCI Ethics Screening Tool** is a four-step process that helps to identify the project as research or non-research; the level of risk that exists within the plan; and the recommendations for additional steps for mitigating or reducing risk. This web-based tool is available at www.ahfmr.ab.ca/arecci/screening.

Project ethics recognizes the same ethical principles as research that involves humans¹. Table 5 outlines the ethical principles of practice.

TABLE 5. Ethical principles of practice

EVALUATION PRINCIPLE	DESCRIPTION
Respect for human dignity	This is an overarching tenet that aspires to protect the participant in respect to different domains of a person's life, including physical, psychological and cultural integrity.
Respect for informed consent	This tenet is based on the presumption that participants have the capacity and right to make free and informed consent. Respecting participants' rights involves dialogue, rights, duties, and requirements for free and informed consent. It also includes the right to refuse or withdrawn participation.
Respect for vulnerable persons	This tenet includes respect for participants who are considered vulnerable because they may not have the capacity to make decisions for themselves.
Respect for privacy and confidentiality	Privacy and confidentiality are considered fundamental to human dignity. This tenet ensures that steps are taken to respect personal information and protect the participant from mental or psychological distress due to misuse of information gathered.
Respect for justice, fairness & equity, inclusiveness	Projects designs should be fair and equitable to all. No segment of the population should be unfairly burdened with the harms of a study, while other groups reap the benefits of the advancement of knowledge.
Balance of harms and benefits	The potential identified harms, or risks, should be balanced against the perceived benefits of a study. When risk exists in a project plan, the level of risk should not exceed the organization's tolerance for risk. This tenet strives to minimize harm while maximizing benefits to participants.
Maximizing benefits	Project work is intended to produce new knowledge and benefits for participants, other individuals and the organization, and for society.

¹ For additional information on ethical principles and project ethics, see ARECCI Reference (2011).

Alberta Innovates - Health Solutions provides training to advance the knowledge and understanding of ethical oversight for front-line practitioners through ARECCI workshops and discussion forums. They continue to work toward addressing the gap in supporting infrastructure for project ethics.

Survey & Evaluation Services adopts the ARECCI process as a standard of practice. The use of ARECCI information is used with permission from Alberta Innovates - Health Solutions.

Guideline

Screening for ethical oversight in project design and protocol

Survey & Evaluation Services recommends screening all evaluation project designs for ethical oversight using the ARECCI process. This process will help to establish primary purpose of the project; identify the level of risk; and facilitate the appropriate follow-up strategies required to minimize or mitigate risk to participants.

Guideline

Evaluator competency for ethical oversight in project design and protocol

Survey & Evaluation Services employees are expected to obtain proficiencies in project ethics and the use of ARECCI tools through available training and practice. All employees involved in designing evaluation projects are required to have the minimum requirement of ARECCI Project Ethics Course Level 1.

Guidelines for Informed Consent

Introduction

Unlike research studies, evaluation projects may not always collect a signed consent when working directly with participants. Considering the context of the evaluation project will help to determine whether consent is collected, the type of consent needed and the process to collect consent. Regardless of whether consent is collected or not, it is important that participants are properly informed about the purpose of the evaluation project and what their involvement requires. A standard of practice for Survey & Evaluation Services is that potential participants are provided with enough information so that they can make a sound decision about participating. Consent is free and informed when three basic requirements are met:

- Adequate information is provided in a form and manner that is easy to understand
- The participant understands that involvement is voluntary
- The participant has the opportunity to evaluate the relative weight of any risks and benefits that may concern them

Providing adequate information

Typically, the process of obtaining informed consent requires providing the participant, or their legal authority (such as parent, welfare guardian or representative with enduring power of attorney), with a minimum standard of information, including:

- The purpose and nature of the study
- What participation will require
- How information will be gathered from them
- Expected duration of participation
- Any risks that may be involved
- Any probable benefits
- Their understanding that participation is voluntary and that they have the right to withdraw their contribution to the study at any time during the project
- How confidentiality and anonymity will be assured, and any limits to this assurance
- Who will have access to the study data
- How the information will be used
- Who to speak to about any concerns (including name and contact information of the evaluator)

Any printed resources, including the consent document, should include written language that is comprehensible and design elements that are appropriate to the targeted user group. Regardless of what group is involved, the resource must be easy to read and understand. Improving readability

involves the application of plain language, principles for layout and design, and appropriate reading level. Survey & Evaluation Services recommends that reading level for adult consent forms not exceed an 8th grade reading level according to the Flesch-Kincaid Readability Test (CREBA, 2010; Morse, 1995; Crosby, DiClemente, Salazar, 2006).

Signed assent forms are only used with younger children who can read—generally speaking, that would apply to children who are over the age of seven. The reading level should be geared to the cognitive level of the children involved. For example, a 6th grade reading level might be used for assent forms designed for older children (CREBA, 2010; Health Canada, 2010), while a 2nd or 3rd grade level may be used for younger children (Seattle Children’s Hospital Research Foundation, 2010). The use of a larger font size, pictures or graphics for younger children is also recommended (University of Kentucky, 2010).

Vision impairment is another issue affecting readability that involves a large number of the population. Strategies include the selective use of font type, size, formatting and colour as well as colour of paper. Low literacy is prevalent in Canadian society: collecting informed consent must include sensitivity to this issue and strategies to anticipate and address the special needs of the participants. The *AHS Companion Guide to the Standards of Practice for Survey & Evaluation Services* offers provides tips for improving readability through the application of plain language rules and elements of design, and ways to test the document or tool under development.

Voluntary participation

It is important that participants are free of manipulation, coercion, excessive inducement, or any other undue influence to be involved in a study. This goes for consumers of healthcare services as well as staff providing health services. Refusal may be articulated verbally or behaviourally, such as throwing out a survey or hanging up on a phone interview. For all projects within Survey & Evaluation Services, participation in evaluation is strictly voluntary. Informed consent is not static—it can be withdrawn at any time. The following statements should be articulated to participants:

- Participation in the evaluation is strictly voluntary.
- Participants have the right to refuse or withdraw at any time without question.
- Refusing to participate will never result in penalty or retribution such as a loss of healthcare services to themselves or their family (or lost of employment, if the participant is an AHS staff member).

Determining the potential risks and benefits

All evaluation plans include some level of risk. The ARECCI process helps disclose possible risks so that the evaluators can mitigate or reduce the level of risk to participants. As with research, evaluation is guided by the ethical principle of non-maleficence. As much as possible, planning should reduce the amount of risk to participants. Existing levels of risk must be weighed against the possible benefit of improving healthcare service. Participants must be informed if their participation exposes them to any potential risk. In addition, they need to know about the altruistic nature of their

contribution to the evaluation process; although the evaluation results may not help them personally, it may help to improve future service for others.

Determining when consent is required in evaluation

The evaluator must always consider the context and situation of the project and the special needs of project participants when making decisions about the most appropriate approach of consent. While standards for consent do exist, professional judgement is also required. As well, the evaluator must understand the level of risk involved and the tolerance for risk by the organization and business partner. The ARECCI process helps identify the level of risk and provides several questions that you can reflect upon in the decision-making process.

- Are you or other team members in a position of power or authority over the people who need to be a part of the project? If yes, how will you ensure that they do not feel coerced into participating?
- Do you or other team members have a conflict of interest with any aspect of this project (e.g., potential for financial gain)?
- Is the approach to informed consent appropriate for the project and its participants?
- Are you using any undue influence or pressure (whether obvious or implied) when asking participants to be part of the project?
- How will you let people know that they can withdraw from the project at any time?
- Will people likely consent to their information being used, or information about them being used, to carry out your project?
- Consider the implications for consent should there be potential for some comments to identify an individual in the case where you are using a small sample. This possibility should be explained to the participant.
- If you get informed consent, but are choosing not to obtain consent, why did you make that choice? Will anyone be angry, frustrated, or hurt if they find out about your project afterwards and realize they weren't informed of their participation or asked for their consent?

(Alberta Research Ethics Community Consensus Initiative, 2011)

Verbal Consent

The participant agrees to participate verbally. If the participant is considered a vulnerable person (such as someone under care), this exchange should be documented somewhere such as in the patient's chart.

Written Consent

The participant confirms consent by signing a written document.

Implied Consent

Consent is implied by virtue of the fact that the participant engages in the evaluation process.

Assent

Where vulnerable individuals are unable to provide consent (because they are children, or adults with physically or mental incapacity to making sound decisions), assent or affirmative agreement to participate is obtained. No individual should be forced to participate, even if their legal authority consents to their participation on their behalf.

Document verbal assent when there is a patient record. Written assent is also preferred, when possible.

Obtaining consent from vulnerable populations

Some potential evaluation participants are not in a position to provide informed consent because their current situation in life makes them vulnerable individuals. For example, children and some younger adolescents are considered vulnerable because they lack the intellectual capacity and judgement to make their own decisions. While the ability of children to make their own decisions based on age is often a debatable topic, the need for parental consent for older adolescents is based upon the presenting situation. Additionally, adults who are mentally incapacitated due to brain injury or dementia-related conditions may be incapable of making sound decisions and are not deemed competent to consent. In such cases, a qualified person of authority must provide consent. Those persons in authority must also be given the opportunity to observe the study as it progresses so that they can judge at any time if the consent to participate should be withdrawn.

Evaluation involving children

The Province of Alberta has no established definition for *age of majority* for children. Often, in the case of informed consent, individuals 15 years of age or older are considered old enough to provide informed consent for themselves. In certain situations when the topic of investigation is of a sensitive nature, some younger adolescents (ages 13–14) may be allowed to provide their own consent. The decision to collect consent must be determined case-by-case when planning evaluation projects with young adolescents. Sound arguments must consider level of risk (in relation to the type of information involved) and must be reasonable, feasible and practical. Decisions should always default to the best interest of the participants involved and can be made in collaboration with business partners and stakeholders connected to the evaluation project.

A standard of practice for Survey & Evaluation Services is to obtain written consent from a parent or person with legal authority for involvement of children who are 12 years of age and younger. When working with school populations, the standard for consent will align with internal policies of the school involved. Many school administrations within Alberta obtain parental or legal guardian consent for all children up to the age of 18 years. In addition to parental consent, verbal assent should also be obtained from the child participant who can read. Verbal assent should be obtained from children who cannot read (CREBA, 2010).

Where vulnerable individuals are unable to provide consent (because they are minors and lack the intellectual capacity and judgement to make decisions, or adults who are physically or mentally incapable of making decisions), assent or affirmative agreement to participate is obtained. No individual should be forced to participate, even if their legal guardian consents to their participation. Verbal assent should be documented in patient records and obtaining written assent is also preferred, if possible.

Evaluation involving people with cognitive disabilities

Cognitive disabilities can affect people of all ages, so the ability to provide consent for disabled individuals must be related to their ability to make informed decisions. Professional discretion is

always required when determining whether the person is *cognitively intact* (informed and capable of consenting) to participate in an evaluation. The preferred method for determining the capacity to make informed decisions is through assessment using the Mini-Mental State Examination (MMSE). A qualified professional (such as case manager, nurse, or mental health worker) is required to administer an MMSE. A score of 23 or greater (out of 30) is considered sufficient for the participant to provide his or her own informed consent.

If the MMSE is not available, the evaluator can test comprehension by providing the participant with all necessary information about the study and then have the participant paraphrase the information back to the evaluator. Out of respect and in a respectful manner, every effort should be made to help the individual to understand the purpose of the project and allow that person to indicate how they feel about participating. People with cognitive disabilities may have values and decision-making skills that have served them in their lives and may continue to exist at some level, even if they can no longer express themselves coherently (Slaughter, Cole, Jennings, & Reimer, 2007).

People with cognitive disabilities may have a person who has legal authority for the welfare of the participant. As with children, participation is always voluntary, so verbal and/or written assent should also be obtained from the participant and respected, even when a person with legal authority has provided written consent.

Determining when to waiver consent

While informed consent is important for ethical conduct within the evaluation process, occasionally there may be reasons to waive written or verbal consent because it is unreasonable, impractical or not feasible for the participant to actually sign a consent form (Province of Alberta, 2003). For example:

- When conducting interviews or focus groups with people about **sensitive issues** where confidentiality is of utmost importance. Examples of sensitive issues may include political or religious beliefs and controversial activities such as illegal drug use or involvement in the sex trade, sexual orientation or sexual activities of minors. If persons in authority, such as political or religious community leaders, law enforcement, the community or parents, were to find out that the individual was involved, then that person may be at increased risk of being put in conflict with the legal system, socially stigmatized or punished. When the only record of participation would be a signed consent, it is not reasonable, practical or feasible to expect the individual to provide consent.
- When conducting interviews or focus groups with **AHS staff about workplace issues or lifestyle behaviours**. When confidentiality is of the utmost importance and the threat of disclosure may increase the risk of loss of economic loss, prestige or self-esteem, expecting the individual to sign a consent is not reasonable, feasible or practical.
- **Retroactive review of pre-existing patient charts** involving of a large population base. It would not be feasible to contact everyone in the collection of charts for review because the scope of review is extensive, contact information would be out of date, some would be lost to follow-up and others may be deceased. Information taken from the charts would be limited to the purpose of the study and not include any identifiable information.

- **Chart review for deeper dives** to verify the quality of a program database used for the evaluation project. An evaluation framework serves as a guide to investigation, but there is always the potential for the unexpected to emerge. Concerns about data integrity of a secondary database or new evaluation questions may surface during the analysis phase of the project. Either may be a catalyst for the need for further investigation. Since the Alberta Evidence Act identifies evaluation as a quality assurance-related activity, AHS is afforded special privileges to access personal health information for the purpose of continual healthcare service improvement (2010). This special privilege is a defining difference that separates evaluation and quality improvement from research. In research, the need to alter the protocol set in an ethics review would require an additional amendment to the ethics approval process. Accessing patient charts are always done with the permission of the business partner. As custodian of that information, they may limit access to select patient files, as they see fit.
- Consent is also waived when observing human behaviour, such as methods use in **ethnography and field studies**. If the person being observed knew that someone was watching what they were doing, there is a strong likelihood that awareness would alter their behaviour and skew the results of the investigation. Consent is waived because the data collection process does not involve direct engagement, nor does it extract and record personal information.

Process for obtaining a waiver of consent

The evaluator is responsible for calling an ad hoc review committee to support decision-making that includes the following people:

- Director of Survey & Evaluation Services
- Lead for the evaluation project
- Business partners commissioning the evaluation project
- Sponsor of project

Rationale to waive written and verbal consent or assent must be accompanied by sound arguments supporting the waiver including:

- Assessment of level of risk based on the type of information being collected
- Benefits to acquiring additional information (balanced by any potential risks)

TABLE 6. Guidelines for obtaining participant consent

Evaluation Activity	Standard of Practice	Rationale & Guidelines
Recruitment of participants	<p>Recruitment for participants for face-to-face or telephone interviews and surveys or focus groups may be done through the assistance of an intermediate health service provider for potential participants who are, or have been, patients in care.</p> <p>An intermediate healthcare service provider may be a physician, nurse practitioner, case manager, registered nurse, rehabilitation practitioner, service manager, and so on.</p>	<p>Obtaining written consent from persons in care can be threatening to the patient/client. When there is a trusting care relationship with someone already inside the circle of confidentiality, it is appropriate for that person to approach the patient/client first. Often, an intermediate service provider can support the project by obtaining verbal consent.</p> <p>This procedure is appropriate as long as a notation is made in the patient chart by the person obtaining verbal consent.</p>
	<p>Another less employed, but optional method for recruitment is through the use of an introductory letter. The letter provides the adequate information (see section under Guidelines for Informed Consent) and selection process as well as provides the potential participant with the option to have their name removed from the call list ahead of time. The letter is prepared by the evaluator, but sent under the cover of someone responsible for the delivery of service (manager or executive).</p>	<p>Consent is implied if the potential participant does not ask to have their name removed from the list.</p>
Telephone surveys	<p>An oral introductory statement containing adequate information (see section under Guidelines for Informed Consent) always precedes the work of telephone surveys or interviews.</p> <p>Following the introduction, the participant is asked if they would like to proceed.</p>	<p>Verbal consent or assent.</p>
Paper surveys	<p>The introduction on the top of the survey provides adequate information. No written or verbal consent is required.</p>	<p>Consent is implied by virtue of participation.</p>
Web-based surveys	<p>The introduction on the top of the survey provides adequate information. The first statement reads: <i>I have read and understand the purpose of this survey.</i></p> <p>First question reads: <i>Would you like to continue? YES NO</i> (a <i>NO</i> answer ends the survey)</p>	<p>Written consent.</p> <p>If the participant answers <i>NO</i>, the survey is designed to automatically prevent them from completing the survey.</p>

TABLE 6. Guidelines for obtaining participant consent...continued

Evaluation Activity	Standard of Practice	Rationale & Guidelines
Intercept surveys and interviews (interviews location)	Participant is asked if it is okay to proceed after adequate information is provided.	Verbal consent.
Ethnography & field studies (observation only)	No written or verbal consent or assent is required.	Observation is not direct engagement or extraction of personal information. Awareness by the subject of being observed would alter that behaviour.
Focus groups & interviews	Signed consent for participating adults. Signed consent by legal authority of children under 15 years of age, including verbal assent by child participant. Written assent by child participants between 12–15 years who are more cognitively developed when parental consent is waived (due to the nature of the study). Signed consent by legal authority for persons with cognitive disabilities including verbal assent by the participant.	Participation in focus groups and private interviews is often completed with a third party who has helped in recruitment. Obtaining signed consent ensures due diligence and participant consent at all stages.
	Waived consent.	Depending on the level of risk, consent may be waived in special situations such as when confidentiality is of the utmost importance because disclosure may include information that may put the participant at risk of punishment from persons in authority (legal system, political or religious communities, community, or family). Waiving consent must supported by sound arguments and permission from an internal review process.
Chart audit (as a planned evaluation strategy or for unscheduled deeper dives to explore negative outcomes)	Waived consent.	Obtaining consent is not reasonable, practical or feasible. Evaluation is provided with special access to personal information as a strategic process to improve healthcare service. Waiving consent must supported by sound arguments and permission from an internal review process.

The Community Research Ethics Board of Alberta (CREBA) provides a guide for practitioners who need to obtain informed consent. The *AHS Companion Guide to the Standards of Practice for Survey & Evaluation Services* provides CREBA's standard templates for collecting informed consent and assent, including an information letter provided to participants.

Guideline

Determining consent for evaluation projects

Whenever there is a concern about participant consent, the person involved in the development of the evaluation plan will initiate a consultation process with an ad hoc committee to determine the most appropriate protocol. The ad hoc committee will consist of the Director of Survey & Evaluation Services, Evaluation Lead, and business partner involved in the project. This review process must be documented and archived with project records. Archived records must include persons involved, protocol, decision rationale, decision and date.

When consent is not necessary

Often evaluation makes use of patient information collected as part of the program operations that helps to populate operational system-based databases. Information may include program volumes, types of services provided, frequency of those events and so on. Information may also track the impact of service on individuals, such as health outcomes, and record change over time. The Alberta Evidence Act helps to define quality assurance-related activities, of which evaluation is related. This Act allows AHS employees special privileges to access personal information for assessing the quality and effectiveness of health services for evaluation and quality improvement. This one distinction sets evaluation apart from researchers external to the health system.

Another important consideration to make is that employing secondary data sources to satisfy evaluation questions can help maximum limited resources as well as reduce the burden of evaluation on patients, staff and the greater health system.

Determining Timelines for Participant Recall

The evaluation process often involves examining the impact of a service or intervention on the human experience. This is especially true for evaluation frameworks that include a qualitative approach to collecting information from people through survey, focus groups or interviews. In a healthcare setting, people who might be involved commonly include:

- Healthcare consumers: patients from acute care settings, clients who live in the community, and residents of long-term care facilities
- Service providers who work on the front lines
- Management teams and other stakeholders

Collecting reliable information requires that participants have the ability to recall their experience with accurately. The decision-making process must consider the context around the evaluation situation. As with informed consent, context weighs in significantly. Critical thinking and professional judgement are essential elements of the decision-making process.

The art of evaluation planning is complex. Unlike research, evaluation is not conducted in a controlled environment and there can be many circumstances that can interfere with executing a perfect plan. Some experts discuss the fact that no survey tool or test is perfectly reliable (Litwin, 2003; Patton, 2008). Errors may occur at different times of the evaluation process, including issues when respondents are engaged and the types of questions asked. Sequencing the time for follow-up after an intervention or service with individuals involved is important. These timelines also have impact on whether you can ask questions that require detailed feedback or questions that are more general in nature. Asking questions that the individual can easily recall because the topic is recent and memorable can help to increase your confidence in the trustworthiness of the feedback received from respondents (Dillman, Smyth, & Christian, 2009).

According to Dillman et al. (2009), there are three basic problems with recall:

1. Memory tends to decay or fade with the passing of time and the longer the lapse of time, the less reliable a respondent's feedback will be about their experience.
2. Individual episodes of everyday events (regular occurrences or mundane tasks) are usually not remembered very precisely.
3. Respondents do not usually remember information by precise month and year.

TABLE 7. Questions to ask when determining recall

Questions to ask yourself	Practical Examples
What seems to be a reasonable timeline for follow-up?	One study required adolescent respondents to share how much and how often they used tobacco/marijuana. Recall was set for 7 days—this was considered a reasonable follow-up to avoid the <i>decay of memory</i> . The study team also felt that the timeframe was reasonable because adolescents think of their life in terms of weeks and not months or years (Crosby et al., 2006).
What level of detail does the study require?	<p>Fine details of the respondent’s experience (such as details about something they have done and relative frequency, personal interactions with others and conversations) may be difficult or impossible to answer if too much time has lapsed.</p> <p>Questions about factual or demographic information can usually be collected accurately regardless of time.</p> <p>If asking broader, general questions, then a lapse of time may be appropriate (2–6 months).</p>
Are the respondents frequent users of healthcare services?	<p>A shorter timeline for follow-up for individuals who are frequent users of healthcare services is preferred, especially if you expect the respondent to separate their healthcare experience from the program being evaluated and other segments of the broader organization and surrounding community that they might have received (Patton, 2008).</p> <p>Six weeks would be considered the upper limit for this type of follow-up.</p>
Have the respondents been critically or chronically ill?	<p>Individuals who have experienced a critical illness or considerable trauma should not be subjected with the burden of recall involving a lapse of time.</p> <p>Medication usage can also have an impact on the ability to recall with accuracy or think clearly.</p> <p>While six weeks for follow-up would be considered the upper limit, less time such as 4 weeks or less might be considered more reasonable for respondents who fit this description.</p>
Does age matter?	<p>Age does matter and its impact should be considered.</p> <p>The aging process often has a negative impact on short- and long-term memory. However, one study tested the validity, reliability and degree of error of patient recollection of their postoperative health status following total hip arthroplasty in patients over 55 years. They reported that patients could recall with accuracy at 6 weeks. (Marsh, Bryant, & MacDonald, 2009).</p> <p>Medication usage commonly increases in older age cohorts.</p> <p>While cognitive ability does not always discriminate by age, neither does maturity. Younger children may also not have the aptitude to recall with accuracy.</p>
When would it not be appropriate to follow up soon after service delivery?	<p>Sometimes it is important for a lapse of time to occur between the intervention or service and follow-up. This is particularly true when the intervention attempts to help someone adopt and sustain a change in behaviour. It might also involve a period of time for convalescence or rehabilitation so the respondent will have time to realize the benefits or reflect upon the impact of the intervention has had upon his or her life.</p> <p>Depending on the nature of the intervention, follow-up may occur up to 6 months afterwards.</p>

Guideline

Determining timelines for participant recall

The upper limit for follow-up for individuals who have received healthcare services is up to 6 weeks. In some cases, it may be okay for follow-up to occur up to 6 months providing questions are general in nature. Follow-up after 6 months is not recommended.

Offering Financial Inducements for Participation

Offering financial inducement to participants is common in evaluation and is often done to enhance recruitment. While this may be viewed as a necessary and acceptable practice for some, others believe that inducements are ethically wrong and maybe even coercive, especially for participants who are considered vulnerable. According to Grady (2005), there is limited evidence that inducements are necessary or effective for recruitment. Several other influences besides financial inducements may motivate participants including curiosity, altruism, sensation seeking and a desire for attention.

The Research Ethics Boards of Alberta will allow this practice in circumstances where the financial inducement helps to offset and compensate the cost for the participant.

Guideline

Offering financial inducements for participation

A decision to offer financial inducements is made with careful consideration in keeping with the best interests of the participants and in collaboration with business partners and stakeholders of the evaluation project. Costs of financial inducements are over and above the cost of the evaluation.

When considering the use of inducements, it is important that the evaluator appreciate the controversial nature of the practice and take a thoughtful and careful approach to planning. The decision-making to offer inducements to participants must consider both advantages and disadvantages (as shown in Table 8). This process must be complete in collaboration and agreement with the business partners to ensure that the supporting organization or operation does not prohibit or discourage the use of financial inducements.

Inducements involving children

Since children do not provide their own consent to participate, there is concern that if incentives are lucrative enough, that payments might sway parental decision-making. To avoid children being used as commodities, Grady (2005) recommends to not use money as an incentive for child participation. The American Academy of Paediatrics suggests providing the child with a gift. Reimbursing parents for their time and inconvenience is fine.

TABLE 8. Types of financial incentives

Model of Inducement ²	Potential Advantages	Potential Disadvantages	Notes & practical examples
<p>Market (Incentive)</p> <p><i>Payment is a straightforward incentive. The amount given is determined by the current economic market—whatever it will take to recruit participants.</i></p>	<ul style="list-style-type: none"> • More rapid and improved recruitment • Overcomes inertia, lack of interest and financial barriers • May overcome barriers unique to certain population subgroups (due to lack of awareness or distrust) and improve racial, ethnic, gender and social diversity in the sample 	<ul style="list-style-type: none"> • Undue inducement may compromise informed consent and reduce interest in understanding the related risks • May compromise the voluntary nature of participation • Money may influence participants to misrepresent themselves • May attract those from lower socioeconomic status, causing disproportionate burden of evaluation on this population • Lack of trust may be exacerbated by the offer of financial inducements 	<p>Modest amounts of inducement might minimize the impact on participants to be unduly influenced, impair their judgement or conceal information.</p> <p>For example:</p> <p>Participants are offered an opportunity to enter a contest for a prize for completing a survey. To protect anonymity, the context ballot must be provided under a separate cover from the survey. Any concern about cheating should be tempered with the guiding belief that people are inherently good.</p>
<p>Wage-payment (Compensation)</p> <p><i>Participants with essential jobs receive a standardized wage for time and effort.</i></p>	<ul style="list-style-type: none"> • Recognizes contributions of participants • May help to recruit those who believe they should be fairly compensated for their time and effort 	<ul style="list-style-type: none"> • May have little impact on recruitment • May under compensate some and preferentially attract others • Inequitable pay schedules for compensation implies that one individual's time and contribution is more important than another's 	<p>Offers a standardized hourly wage and additions for added inconveniences.</p> <p>For example:</p> <p>Participants who hold high positions (community leaders, professionals, government officials) may be provided with a full meal and cash honorarium to cover travelling expenses and parking.</p> <p>Physicians may be provided with a cash honorarium to cover their time and travelling expenses.</p>

² This table is primarily based on Grady (2005). Some practical examples provided originate from AHS practice.

TABLE 8. *Types of financial incentives...continued*

Model of Inducement ²	Potential Advantages	Potential Disadvantages	Notes & practical examples
<p>Appreciation (Reward) <i>Reward is provided as a token of appreciation.</i></p>	<ul style="list-style-type: none"> Expresses gratitude for contribution of participants to the common good Avoids undue inducement 	<ul style="list-style-type: none"> Likely to have little impact on recruitment 	<p>For example: An intercept survey may offer a small token of appreciation (such as a pen, food product, or retail coupon).</p>
<p>Reimbursement <i>Participants are reimbursed for expenses incurred, such as transportation, meals, lodging, child care, respite care, and parking.</i></p>	<ul style="list-style-type: none"> Participation is revenue neutral—there is little or no financial sacrifice for the participant May enable some to participate who otherwise could not afford to do so or unwilling to make a financial sacrifice There is little risk of undue inducement 	<ul style="list-style-type: none"> May have little impact on recruitment 	<p>For example: Cash honorarium that covers the anticipated cost of participating in a focus group or interview. The cost is averaged out. Each participant gets the same amount. Participants may also be provided with light refreshments.</p>

² This table is primarily based on Grady (2005). Some practical examples provided originate from AHS practice.

Protecting Personal & Health Information

Survey & Evaluation Services is committed to ensuring standards and safeguards for maintaining privacy, integrity and availability of information collected and stored for the purpose of evaluation conducted within Alberta Health Services. The Province of Alberta's legislative Acts, the corresponding Alberta Health Services internal policies, govern the work of Survey & Evaluation Services.

Guideline

Protecting personal health information

Survey & Evaluation Services works within the guidelines of legislative governance and ethical conduct. Practices ensure all safeguards for protecting personal health information used in evaluative data.

Province of Alberta Legislations

- The Health Information Act (HIA)
- Freedom of Information and Protection of Privacy (FOIP)
- Alberta Evidence Act (AEA)
- Privacy Impact Assessment (PIA)

Alberta Health Services Information and Technology Management Policies

Policy IM-01 Governs physical access controls and security of AHS sites as well as protection of information processing, storage and IT resources.

Policy IM-03 Governs the conditions by which information can be transmitted by facsimile and electronic mail in compliance with FOIP and HIA.

Policy IM-04 Governs the collection, use, access and disclosure of personal information and health information under the control or custody of AHS in compliance with FOIP and HIA.

Policy IM-05 Governs the requirement for collection, use, access and disclosure of personal information and health information under the control or custody of AHS and compliance with FOIP (such as access to information for patients, researchers).

Policy IM-06 Governs acceptable and secure use of information technology resources, including access to the Internet, intranet, email and other AHS IT resources.

TABLE 9. AHS classifies information at different levels of sensitivity³

Category	Description
Restricted	Information where the unauthorized disclosure could cause serious risk or harm to any individual, AHS, third-party, or to the integrity, image, service delivery, or sustainability of AHS.
Confidential	Information where the unauthorized disclosure could cause moderate risk or harm to any individual, AHS, third-party or to the privacy of individuals, compromise the organization's ability to respond to disaster, or threaten the secure containment of vital records.
Protected	Information where the unauthorized disclosure could cause low risk or harm to any individual, AHS, or third-party. Protected information is available to AHS employees and persons acting on behalf of AHS who are authorized to view protected information.
Public	Information which can be distributed to any person inside or outside of AHS and which is generally considered to be in the public domain.

Data collected for the purpose of evaluation has the potential to fall into any of the categories listed in Table 9. As AHS employees and members of the Survey & Evaluation Services team, each individual is:

- Provided corporate access to AHS information
- Bonded by a confidentiality agreement
- Expected to maintain the protocols established to protect personal information used for the purpose of evaluation
- Personally responsible to:
 - Ensure safety and security of personal information within and outside of the office setting
 - Report all, or suspected, breaches of information, confidentiality, security or privacy to the AHS Information and Privacy Officer

The following information provides a *brief overview* of the legislations and polices in relation to the work of Survey & Evaluation Services under DIMR. The legislation overview is followed by *Applying the law into practice*, which provides practical examples of how the law informs and drives our practice. Each team member is encouraged to become well informed about the laws and safeguards that govern practice.

Health Information Act (HIA)

Alberta's Health Information Act was passed in 1999, proclaimed in 2001 and revised in 2010. The purpose was to establish rules that govern how to safely collect, use, disclose and protect health information. HIA enables individuals to access their health information records. The Act also makes the people who hold those records (referred to as *custodians*) accountable for decisions or actions they take in respect to the management of personal health information. People who are bound by

³ Protection and Privacy of Health and Personal Information Policy IM-05 (September 2010).

HIA include:

- **Custodians:** Organization or regulated health professionals in publicly funded health system
- **Affiliates:** Employees, agents, contractors and volunteers of custodians
- **Responsible Affiliate:** Anyone identified by the custodian who has responsibility for administering HIA (such as a FOIP coordinator)
- **Information and Privacy Commissioner:** This position monitors compliance with the Act, investigates complaints and acts as an independent arbiter
- **All DIMR employees**

HIA protects the following types of information that has been collected by custodians:

- Diagnostics, treatments and care reports
- Registration (PHN, ULI, demographics, birthdates, billing information)
- Health providers (professional registration numbers, credentials, competencies, disciplinary action, evaluation reports and anything else that is in personal health provider files)

Freedom of Information and Protection of Privacy (FOIP)

The Freedom of Information and Protection of Privacy Act was first passed in 1995, and was lastly amended in October 2009. This Act applies to all public bodies including ministries, Crown Agencies and Crown Corporations, municipalities, hospitals, schools, universities and colleges. The principles of FOIP are similar to the HIA by ensuring that the individuals have the right to access personal records held by public bodies. FOIP also protects individual privacy of patients and AHS staff by governing the collection, use and disclosure of personal information. It differs from HIA because it deals with general records and personal information, and not just health-related records (FOIP, 2010).

Alberta Evidence Act (AEA)

The Alberta Evidence Act (AEA) is important to Survey & Evaluation Services because it helps to define quality assurance-related activities to which evaluation is related. Section 9 of the Act relates to operations that involve “systematic and planned activities that study, assess or evaluate the provision of health services for the purpose of continual improvement”. The significance of this statement is that it provides Survey & Evaluation Services, as appointed by AHS, with special privileges to access personal and health information (AEA, 2010). Of course, along with those special privileges comes the added responsibility of protecting and safeguarding the information entrusted to the evaluators.

Privacy Impact Assessment (PIA)

A privacy impact assessment is an exercise in due diligence to analyze the potential impact of collecting, using or disclosing individually identifiable health information. The PIA process helps the applying organization to identify and address potential privacy risks that may occur within the

operation and explore ways to protect privacy and mitigate or eliminate any impacts for major projects. While not a mandatory process under FOIP, PIAs are required by HIA before a custodian can implement proposed administrative practices or information systems related to collecting using or disclosing individually identifying health information. The applying organization must ensure privacy protection and address relevant considerations before a PIA is granted (OIPC, 2010).

PIAs are directly linked to the FOIP Act. FOIP provides authority to the Office of Information and Privacy Commissioner of Alberta to be involved in determining the impacts and implications of freedom of information and protection of privacy.

Routine evaluations do not normally require a PIA because evaluation is viewed as a systematic and planned activity to contribute to the improvement of healthcare services, and thus, granted special privileges to access personal healthcare information. Occasionally, the PIA process has been brought into evaluation practice when the project plan requires:

- Matching data from two or more different sources without the consent of the individuals
- Implementing a new software system to develop a new large-scale database
- Collecting new health-related information that has never been collected before
- Involving multiple custodians from different organizational bodies, such as AHS, Primary Care Networks and Alberta Health and Wellness

Direct any questions regarding the need for a PIA to consultative services, available from the AHS Privacy Commission team, at privacy@albertahealthservices.ca or the Privacy Intake Line 1-877-476-9874.

Applying the law into practice

Applying the guidelines from the legislative acts and AHS policies help to inform the use of the standards of practice and are reflected in daily work in a number of ways.

Protecting and respecting evaluation participants

Evaluation participants include healthcare patients, clients and service providers. When working directly with evaluation participants (e.g., conducting interviews or doing surveys), it is important to treat the participant in a respectful manner. Client comfort is your responsibility. Ways to increase client comfort are:

- If the client is not alone, ensure that he or she is comfortable talking in the presence of a third party
- Identify yourself and obtain permission from the participant (see Informed consent)
- State your purpose and authority to collect information (see Informed consent)

Protecting evaluation data while working within a secured AHS office setting⁴

Alberta Health Services provides consistent physical, administrative and technical access controls to safeguard the security of information in any AHS office setting. These safeguards include site security

⁴ Items pulled from all AHS policy sources are based on new drafts (dated September 8, 2010) and may be subject to change depending on final revisions.

as well as security of electronic records for internal networks and shared-file drives. Additionally, all AHS employees are bound by a signed confidentiality agreement prior to commencing duties on behalf of AHS. Every day, Survey & Evaluation Services team members should keep in mind the activities listed in Table 10 to help prevent unauthorized access, damage, theft and interference of health and personal information.

Guideline

Protecting evaluation data while inside of AHS sites

A number of protocols serve to safeguard evaluative data within secure AHS sites (current project data and archived records).

TABLE 10. Protecting evaluation data while working within a secured AHS office setting

Activity	Safeguarding evaluation data
Restricted access	<ul style="list-style-type: none"> AHS employees are provided with a unique AHS email account and restricted access to file storage that is password protected. Authorized users are responsible to take necessary precautions to protect their passwords to prevent misuse. Sharing passwords and user IDs is prohibited. If suspected that the assigned credentials and user identification has been lost or compromised, the user must notify AHS IT Help Desk for assistance and direction without delay. Access lists for shared drives (such as G-Drive in Edmonton Zone) must be updated as service agreements expire.
Accessing information for evaluation	<ul style="list-style-type: none"> Access to information required for evaluation purposes should be limited to minimal information necessary to perform duties and responsibilities. This rule is applied to electronic information as well as when executing other evaluation activities such as chart audits.
Reporting breach of security	<ul style="list-style-type: none"> Survey & Evaluation Services and DIMR staff acting on behalf of AHS must: <ul style="list-style-type: none"> Report any suspected breach of security, including misplaced evaluation data containing personal and health information. Cooperate with investigations into breaches of confidentiality, requests for information and other activities undertaken by the AHS chief privacy officer.
Reducing the risk of unintended exposure	<ul style="list-style-type: none"> Survey & Evaluation Services team members are expected to respect and abide by physical access control measures implemented at their office site (such as wearing identification badges at all times, safeguarding access cards or keys, and immediately reporting lost cards or keys). Unauthorized site visitors are not allowed to wander through AHS secure office sites. All AHS staff are responsible for ensuring security by approaching visitors without identifications and offering to redirect them. Personal and sensitive information should not be exposed or left unattended in workspaces (such as desktops or printing stations) providing unauthorized access by others. Information must be kept in secure locations such as locked office and filing cabinet when the authorized person is not around.

TABLE 10. *Protecting evaluation data while working within a secured AHS office setting...continued*

Activity	Safeguarding evaluation data
Recycling paper	<ul style="list-style-type: none"> • Sensitive information must be recycled into a secured container with a locked top. • Recycling sensitive information should be completed at the end of every workday. • Staff who use recycling boxes in their office space are responsible for recycling their own paper to secure containers. Security is breached when janitorial staff mistakenly collect recycled paper from evaluation offices. If this occurs, the incidence must be reported immediately to housekeeping and the paper must be retrieved from the trash.
Storing evaluation data in electronic files	<ul style="list-style-type: none"> • The AHS Information Technology system provides consistent physical, administrative and technical access controls to safeguard the security of information in any AHS office setting. • Storing electronic data files is considered safe because of the implemented levels of security required to access the AHS protected network drives (e.g., limited access and password protection).
Archiving final evaluation data and reports	<ul style="list-style-type: none"> • At the completion of evaluation projects that have a definitive beginning and end, files should be purged of unnecessary paper and information. Any information involving personal and health information must be disposed appropriately (see Recycling paper). • All vital data used in evaluation reports are archived in secure storage for 5 years. Archived information must be able to demonstrate a clear paper trail upon which data results are based. • Project information should be bundled and sealed. • The package should be labelled with the name of the project, the date it was completed and date that the contents can be destroyed.
Archiving and coding manuals	<ul style="list-style-type: none"> • Evaluation data reports containing personal identifiers should not be archived unless the identifiers are separated from the rest of the data report. This rule applies to both paper and electronic files. • Coding manuals containing personal identifiers are stored in a separate location from project files and archived data. Personal identifiers may include information such as: <ul style="list-style-type: none"> - Project code and corresponding personal name - Assigned healthcare code (such as personal healthcare number [PHN], Unique Lifetime Identifier [ULI], homecare number) - Contact information (at home, workplace, etc.) • The rule for coding does not apply to electronic data files used for ongoing evaluation reports (see Digital audio files and recording).
Digital audio files and recordings	<p>Digital audio files, such as recordings of interviews and group discussions, must be clearly labelled, dated and transferred to the secure Alberta Health Services (AHS) electronic file network system as soon as possible. The original digital files on the audio recorders should be scrubbed from the recorder as soon as the file has been safely transferred. Recorders that contain files are not to be returned to storage. At the completion of the evaluation project, the digital files should be either:</p> <ul style="list-style-type: none"> • Archived in G drive/evaluation resources/Archives for Digital Files • Destroyed at the end of the evaluation project after transcription

TABLE 10. Protecting evaluation data while working within a secured AHS office setting...continued

Activity	Safeguarding evaluation data
Conducting business over the phone	<ul style="list-style-type: none"> • Due diligence and caution are important steps when sharing any information by phone. Ensure that you are speaking to the correct person. • Use your instincts, especially if the person has asked for more information than you are comfortable providing. When unsure, seek advice and direction first.
Dissemination of evaluation results	<ul style="list-style-type: none"> • Completed evaluation reports are delivered only to persons identified in the dissemination plan by the commissioner(s) of the evaluation project. • Evaluation databases, results and final reports cannot be share with any external party without explicit permission from both the commissioner of the evaluation project and the Director of Survey & Evaluation Services.

Protecting evaluation data while outside of the secured AHS office setting

Table 11 shows the activities and considerations needed to protect the evaluation data while in transport between Survey & Evaluation Services offices and business partners, another AHS workplace or off-site location. Due diligence is important because breaches of confidentiality or failure to secure information during transport can be considered grounds for disciplinary action, up to and including dismissal.

Guideline

Protecting evaluation data while outside of AHS sites

A number of protocols serve to safeguard evaluative data reports while in transit or outside of secure AHS sites.

TABLE 11. Protecting evaluation data while outside of the secured AHS office setting

Activity	Safeguarding evaluation data
Reducing the risk of unintended exposure	<ul style="list-style-type: none"> • When transporting evaluation data out of a secure AHS site, it is your personal responsibility to safeguard all information under your direct control at all times. • Evaluation data should not be removed from an AHS secured site unless this is absolutely necessary to perform job-related duties. • When transporting data, only take the minimum amount of data required to perform the task at hand. • Information must be secured in a closed non-transparent container (such as brief case or opaque container) during transport. • The container must be labelled “confidential” and the responsible person must attach his or her AHS contact information to the container.

TABLE 11. Protecting evaluation data while outside of the secured AHS office setting...continued

Activity	Safeguarding evaluation data
Using mobile computing and storage devices⁵	<ul style="list-style-type: none"> • You are responsible for the security and protection of IT resources in your possession. To minimize the risk of theft of laptops and flash drives, you must: <ul style="list-style-type: none"> - Use locking mechanisms for laptops whenever possible - Ensure that devices are in your possession at all times - Not use automatic log-in procedures (password saving) - Store the device in a secure location when not in use (out of sight) • Information must be transported on mobile computing devices and mobile storage devices that meet standards set by AHS IT Security and Compliance because the device can be encrypted. This ensures confidentiality and integrity of stored data. • All flash drives and laptops used to carry evaluation data must be encrypted and password protected. • Carry only the minimal amount of necessary and required information on mobile computing and storage devices.
Transporting data and equipment by vehicle	<ul style="list-style-type: none"> • When travelling in a privately-owned or rental vehicle, the authorized person shall secure all information in the vehicle's trunk (or equivalent) during transport. • Information should never be visible at any point during transport or left unattended in a vehicle.
Working off-site	<p>While off-duty (end of shift or scheduled break), the authorized person must ensure that the information is secure by:</p> <ul style="list-style-type: none"> • Keeping it in their possession at all times • Depositing it in a secure AHS facility • Storing it in a protected place within their private residence
Transporting data by email with internal business partners (with an AHS email account)	<p>Electronic transport of data files containing personal identifiers by email with internal business partners (who have an AHS email account) must be transported under limited conditions. The following protocols help to ensure the safety and security of the information:</p> <ul style="list-style-type: none"> • Encrypting data files and using password protection⁶ • Passwords must be sent to the receiver through a separate email message • Extremely sensitive information is only sent by email in emergency situations <p>The <i>AHS Companion Guide to the Standards of Practice for Survey & Evaluation Services</i> provides step-by-step instructions to password protect for different software applications, including Excel 2003 & 2007, Access 2003 & 2007, and WinZip. Please note that SPSS files cannot be encrypted.</p>

⁵ *Mobile Computing Devices* include Portable Digital Assistants (PDAs), palm pilots, pocket PCs, Blackberries, text pagers, smart phones, and laptops. *Mobile Storage Devices* include flash drives, digital voice recorders, external hard drives, memory cards, CDs, and DVDs.

⁶ **IM-06** states that personal and health information via external email shall only occur through AHS-approved encrypted email systems. **IM-06** states that transmission via file transfer process shall only be through secure AHS implemented file transfer process.

TABLE 11. *Protecting evaluation data while outside of the secured AHS office setting...continued*

Activity	Safeguarding evaluation data
Transporting data by email with external business partners (without an AHS email account)	<p>Electronic transport of data files by email with external business partners (who do not have an AHS email account) shall be protected as per the external business partner's organization policy. Examples of past protocols used between AHS and external partners to ensure safety and security of data files include:</p> <ul style="list-style-type: none"> • Using encryption software (such as WinZip) and password-protected information. Both parties must have access to the same software. For example, all data from Primary Care Networks served by Survey & Evaluation Services uses WinZip to protect their information during transmission. <ul style="list-style-type: none"> - Passwords must be sent to the receiver through a separate email message • The email should include a disclaimer statement (see IM-03 #3.4). • Email address should be visually checked prior to sending for possible errors. • If the external partner does not have an organizational policy in place, the sender should provide Survey & Evaluation Services with the data backed up on a CD. <ul style="list-style-type: none"> - When possible, password protection for the data on the CD is preferred • Transporting the CD should be done by an authorized person, registered mail or private courier service.
Courier	<ul style="list-style-type: none"> • When evaluative data is transported by courier, the package must be registered, requiring a signature at its destination. • AHS internal courier service is not be used for evaluation data containing sensitive information.
Posted mail	<p>When evaluative data is transported by mail, the package must have:</p> <ul style="list-style-type: none"> • A return address • Be sent by registered mail (requiring signature) • Posted as confidential on both sides of the envelope
Facsimile	<ul style="list-style-type: none"> • If other viable options for transmitting evaluative data are available, avoid faxing. • Extremely sensitive information shall not be sent by fax. • When faxing is necessary: <ul style="list-style-type: none"> - Ensure that the fax cover sheet includes all the contact information of the recipient of the fax - An AHS confidentiality statement and disclaimer (see IM-03 #2.4) - The cover sheet must not include confidential or personal identifying information - As a sender, one must follow up with the recipient to ensure the information was received or, as a receiver, one must confirm receipt - If a fax is not successful in reaching the destination, report the situation immediately to the Information and Privacy office as an Information Security Incident - Promptly remove fax copies from the fax machine

Copyright Protocol for Evaluation Reports & Resources

Introduction

Copyrights are established in order to credit the creator of a tangible medium of expression; they are only placed on original work and ensure that the original creator receives proper acknowledgement for any reproductions of their work. Survey & Evaluation Services uses copyrights to ensure that all work is credited back to Alberta Health Services and its members and is not reproduced illegally.

Reports that are external to AHS

At any given time, Survey & Evaluation Services may be under contract with different business partners who are external to AHS. The nature of those contracts may be ongoing, such as those with several Primary Care Networks, or time-limited, such as research projects with partners from university settings. External business partners are the owners of all reports and resources that are produced as a result of the contracted work. Serving copyright notice is up to the discretion of the business partner.

Reports that are internal to AHS

Guideline

Copyright notice for reports internal to Alberta Health Services

Reports prepared by Survey & Evaluation Services that are internal to Alberta Health Service should include a copyright notice, regardless of size. Copyright notice should also appear on all evaluation resources developed in-house (such as survey tools, teaching resources and so on). The following template illustrates the recommended standard. Location of the notice in the report is up to the discretion of the author. However, in large reports, this notice should appear after “Acknowledgements.”

FIGURE 2. Copyright template for large reports

This work is owned and copyrighted by Alberta Health Services (AHS). It may be reproduced in whole or part for internal AHS use. For any use external to AHS, this work may be produced, reproduced and published in its entirety only, and in any form including electronic form solely for educational and non-commercial purposes without requiring consent or permission of AHS and the author. Any such reproduction must include the following citation:

[Name of author] [YYYY]. [Full title of the report]
Copyright © [YYYY], Alberta Health Services.

The [Full title of the report] has been prepared on behalf of the [Program or project funding agency] for:

[Name of Business Partner]
[Title of Business Partner], [Location]
[Contact information]

The report was prepared by:

[Author]
[Title of author]
Survey & Evaluation Services
Data Integration, Measurement & Reporting
Alberta Health Services, Edmonton
[Contact information of author]

FIGURE 3. Copyright template for small reports and documents

Copyright © [YYYY], Alberta Health Services

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