Review and assessment of the termination of evidence-based programs in pharmaceutical and related health services: Ministry of Health Response to Ombudsperson's Recommendation 34

Outline

i. Introduction
    - Health Research at the Ministry of Health
    - Ombudsperson's Report

ii. Approach to review and assessment of program gaps

iii. Intangible impacts

iv. Evidence-informed pharmaceutical policy
    - Overview
    - Affected programs
    - Remaining gaps

v. Evidence-informed population and public health surveillance
    - Overview
    - Affected programs
    - Remaining gap

vi. Evidence-informed programs and decision-making in health services
    - Overview
    - Affected programs
    - Remaining gaps

vii. High quality data analytics
    - Overview
    - Affected programs
    - Remaining gaps

viii. Conclusion

I. Introduction

Health Research at the Ministry of Health

As the overall steward of the health system in British Columbia (BC), the Ministry of Health (the Ministry) is primarily responsible for supporting improved health and wellness, high-quality patient care and a sustainable, affordable, publicly-funded health care system.

Ministry policies, planning and decision-making are ideally informed by strong evidence derived from high-quality analyses, from program evaluation, from the ever-growing body of international health research literature and from direct commissioning of new research when it is necessary. This approach requires the Ministry to have the capacity and processes in place to integrate research into policies, planning and decision making and to build constructive relationships with the research community. The Ministry also has a role in supporting the conditions for researchers to produce high quality, relevant research and in clearly and consistently focusing on internal analytics and external research investments that directly inform or support the Ministry in carrying out its stewardship responsibilities.

Ombudsperson's Report

The BC Ombudsperson was asked by the Select Standing Committee on Finance and Government Services to investigate issues arising from the 2012 Ministry employee termination matter.

The BC Ombudsperson's report: *Misfire: The 2012 Ministry of Health Employment Terminations and Related Matters* addresses the investigations and decision-making (hereafter referred to as the investigation) that resulted in actions that had significant consequences.

The Ministry accepted the Ombudsperson's Report and its 41 recommendations to government.

This document details a response to Recommendations 34:

R 34- By September 30, 2017, the Ministry of Health review and assess the extent to which the termination of evidence-based programs during the internal investigation may have created gaps that now remain in providing evidence-informed, safe, effective and affordable drug therapy and related health care services to British Columbians.

II. Approach to review and assessment of program gaps

In considering its response to the Ombudsperson's report, the Ministry engaged in several activities to inform the content of a gap analysis.

Ministry of Health staff read and discussed the report and, informed by the Ombudsperson's findings, reviewed internal documentation on the programs known to be affected by the investigation. Ministry staff also reviewed the formal evidence-based programs and programs of research in pharmaceutical services, health services and population and public health to determine if there were any additional direct or indirect effects on other evidence-based programs.

In June 2017, the Ministry held a dialogue and invited the academic researchers directly affected by the investigation as well as others who had worked with Ministry programs to build evidence in policy and planning. This dialogue featured researchers with expertise in such areas as health care priority setting, patient-reported outcomes, children's health policy, access to medicines, applied public health research- contraceptive access, drug assessment and evaluation, the aging population, healthcare costs and economics, obesity prevention and physical activity, public health services and systems, substance use prevention and education, chronic disease modeling, rural health care services and HIV/AIDS and addictions. The purpose of the event was to provide an update on changes that had occurred in the Ministry's approach to research and analytics in the last several years and to seek advice on how the Ministry's relationship with the research community could be improved.

In early September, the Ministry invited researchers and contractors known to be directly affected by the investigation to provide comments and feedback on the results of the Ministry's internal analysis. In total, eighteen individuals participated in in-person meetings or telephone conversations. These responses were taken into account regarding the details presented in this report.

What follows in this report is a summary of the findings from the above process as well as insights gained from the additional time, consideration and further review by Ministry staff.

III. Intangible impacts

This paper focuses on documenting the effects of the investigation on evidence-informed pharmaceutical and related health care services. It details the specific effects (direct and indirect) of the investigation on the features of evidence-informed programs and details the gaps that may currently remain.

Beyond the identification of specific gaps in evidence programs, however, the Ministry would also like to acknowledge there were other kinds of gaps and impacts that occurred as a result of the data investigation. Many of these are less tangible and not easily quantified. The Ministry had conversations with some of the employees who were terminated and with impacted contractors, which served to highlight and further illuminate these impacts. We are grateful to those individuals who were willing to meet with Ministry staff and speak with us about these.

Quality research and analytical work is enhanced by interconnectedness between researchers, as well as between program/policy people wrestling with problems and academic researchers who are advancing methods and knowledge. These networks tend to occur both intentionally as well as serendipitously. Being part of a collegial network of people who share ideas, technical knowledge and lessons learned and who promote introductions and new relationships with other capable people is satisfying. It reinforces a commitment to produce high quality, meaningful, impactful work. Fundamentally, these networks are nourished by individuals' credibility and their willingness to share and build their expertise.

The investigation impacted directly many of these networks within the Ministry and with the external research community. It affected others indirectly and had a ripple effect across the Ministry culture. The investigation put a chill on the sharing of ideas, on participation in external research projects and on the trusting relationships that had provided resiliency to sustain productive networks. It slowed the momentum of internal efforts to strengthen the Ministry's analytic capacity across all program areas and to harness long standing connections between Ministry staff and the research community.

The opportunity costs of the investigation will never be fully known. Over the course of a very short time, the Ministry abruptly lost a considerable amount of institutional knowledge and expertise. The Ministry and BC researchers lost access to the linkable self-reported survey data from British Columbians in the Canadian Community Health Survey. We know that BC's scientific and technical leadership in chronic disease surveillance, for example, diminished. We know that in certain cases, researchers working in areas of importance to British Columbians and the health care system were not able to proceed. Anecdotally, we were advised of a student researcher whose career trajectory was shifted away from research involving

Ministry of Health data and a clinician who gave up on research out of frustration after losing data access. We heard from several sources that analysts inside the Ministry and researchers outside have modified their projects in order to minimize the amount of data they use, thereby diminishing the analytical power. Ministry staff lost access to external analytical expertise and a tool providing readily accessible aggregate data. And we heard that the chill spread to other Ministries in government.

Most notably, a life full of future potential was lost. In addition to the loss to his family, friends, coworkers and community, we will never fully know the academic contributions to health research that Roderick MacIsaac might have made and how the health system may have benefited from his research.

We don't know what other research collaborations might have yielded, what technical advancements in analytical, surveillance and information technology might have emerged, what the results of ongoing studies would have revealed, whether BC researchers would have received larger shares of the federal research funding and ultimately if some parts of the health care system would be working better if these networks had not been broken nor the work of its members disrupted. We do know these impacts had ramifications for the pharmaceutical, public health, health services and data interests of the health system and the Ministry of Health.

Against these effects, the work of the Ministry of Health had to continue. Over the years since the investigation, the Ministry has clarified and communicated its strategic priorities and core functions and restructured some Ministry divisions to better align with these. Two changes, particularly relevant to this analysis were the 2015 consolidation of research oversight in the Partnerships and Innovation Division and the consolidation of analytic resources in the Health Sector Information, Analysis and Reporting Division. These changes were made partly in response to issues that emerged during the aftermath of the investigation but also more importantly to ensure maximum alignment and impact of Ministry investment in external health research and to strengthen data management practices and analytic capacity within the Ministry. Further information about these changes is provided throughout this report.

In addition to the organizational changes, there have been retirements and new hiring, there have been shifts in the needs of the health system such that policy changes have been required and new evidence needs have continually emerged. Because of these factors, attribution of the effects of the investigation on evidence-informed programs is not precise. However, where possible in this document, available information has been used to document and to be as specific as possible about these effects and the gaps that may still remain.

IV. Evidence-informed pharmaceutical policy

Overview

The Ministry's PharmaCare program has a long history of evidence-informed programs and decision-making and is recognized nationally and internationally for its leadership in public policies, strategy, and expertise in pharmaceuticals. With the establishment of the Therapeutics Initiative (TI) in 1994, BC was one of the first jurisdictions to consider independent research focussing on the efficacy and safety of new drugs before including them on the provincial PharmaCare formulary. Advice from the TI informed formulary decision-making, leading to lower rates of prescribing in BC of some drugs that were subsequently shown to have significant safety concerns or that were withdrawn from the market (e.g., rofecoxib, rosiglitazone).

PharmaNet was launched in 1995, and captures drug claim data dispensed through community pharmacies for all BC patients; this is a considerable strength compared to other jurisdictions that do not have a complete administrative set of pharmaceutical claims for all patients.

From the early 1990s, the TI was one of the only groups available to inform BC PharmaCare formulary listing decisions. In 2003, the Common Drug Review process was established at the Canadian Agency for Drugs and Technology in Health Care (CADTH) to provide standardized advice and recommendations to public drug plans to inform listing decisions for new brand name drugs. All Canadian publicly-funded drug plans (with the exception of Quebec) participate in the Common Drug Review. CADTH also now provides a number of other relevant services, including the pan-Canadian Oncology Drug Review, therapeutic reviews of categories or classes of drugs (e.g., drugs for diabetes) and optimal drug use initiatives.

In 2006, the Ministry's PharmaCare staff were expanded and reorganized as the Pharmaceutical Services Division (PSD). Capacity was added to better position the Ministry to optimally manage pharmaceuticals and community pharmacy services. The reorganization had the following structures to:

i. Develop the best policies supported by evaluation and research (Policy, Outcomes, Evaluation and Research Branch,—now renamed PharmaCare Information Policy & Evaluation—PIPE);
ii. Select the best drugs for provincial public coverage (Drug Intelligence Branch, now renamed Drug Intelligence & Optimization—DIO);

iii. Support the most appropriate drug prescribing (Drug Use Optimization Branch, now merged with DIO);
iv. Negotiate the best value for drug prices and have the best prescription drug tracking system *PharmaNet* (Business Management Supplier Relations and Systems Branch—BMSRS).
v. Collaborate with Canadian jurisdictions on a national pharmaceuticals strategy (National Pharmaceuticals Strategy Branch, which was closed due to a change in priorities and the revival of the priorities has shifted the work to DIO).

In 2010, the pan-Canadian Pharmaceutical Alliance (pCPA) was established to negotiate lower prices for brand name and generic drugs for publicly-funded drug programs. In addition, various P/T and F/P/T working groups have been formed to collaborate on various other national pharmaceutical issues to improve the affordability, accessibility and appropriate use of pharmaceuticals in Canada.

The Ministry's external research investments and contractual arrangements have changed over time to reflect these changes in the landscape of research for public drug plan policy and increased internal research and analytic capacity.

Affected Programs

There have been many evidence-based pharmaceutical programs undertaken by PSD. Several of them can be considered to have been affected by the investigation, to different degrees, and those listed below are simply some examples of programs that were affected.

One example is the Alzheimer's Drug Therapy Initiative (ADTI), a "coverage with evidence" development project. The ADTI was a series of research studies launched in 2007 to examine and confirm the real-world effectiveness, safety, and cost-effectiveness of a class of Alzheimer's drugs, the cholinesterase inhibitors. The research was intended to address gaps in clinical evidence and to make an informed listing decision. Temporary coverage of the cholinesterase inhibitor drugs was provided for British Columbian patients while the research was ongoing. The ADTI research studies were interrupted by the investigation.

Another example, Education for Quality Improvement in Patient Care (EQIP), was a quality prescribing program. The EQIP program provided family physicians with personalized computer-generated prescribing portraits and educational messaging. A component of the

program was to evaluate the impact of the portraits on physicians' prescribing practices. EQIP was not renewed. The EQIP program's educational materials and messages were also used in the prototype learning sessions of Doctors of BC Practice Support Program (PSP) initiative called Optimal Prescribing Update and Support (OPUS). OPUS' aim was to improve prescribing of selected medications by providing assistance to physicians to develop action plans to prompt reviews of a patient's use of selected medications. Prototype sessions were held November 2011 and March 2012. A formal launch of OPUS did not occur.

The Medication Management Program (MMP), a pharmacy services program, was a collaboration between PSD and the BC Pharmacy Association. It was established in 2009, initially as a pilot project, and was intended to support specific changes to dispensing practices and pharmacists' reviews of patient medications in order to evaluate specific impacts of patient prescription adaptation (renewing a prescription, changing the dosage, or making a drug substitution) and the costs to pharmacies of providing patient consultations related to prescription adaptation. Some evaluations were planned, pending data access, which was interrupted [1].

The Canadian Network for Observational Drug Effect Studies (CNODES) is one of the arms of the Drug Safety and Effectiveness Network (DSEN). CNODES, funded by the Canadian Institute for Health Research, is intended to examine drug safety and effectiveness through collaborative, population-based approaches. Data access in BC has not been as streamlined as other jurisdictions, which has hampered BC-based researchers' effective participation in CNODES.

While the actual delivery of the Provincial Academic Detailing (PAD) was not directly affected, the evaluation of the PAD program was affected in that some planned evaluations of selected topics and the contribution of BC research towards a national evaluation project called Professional Academic Detailing Partnership Team (ADEPT) were not continued.

[1] In May 2017, the Therapeutics Institute published the results of a 2013-14 evaluation of the Medication Management Program and a systematic review of the services provided through the program (Therapeutics Letter, *Does Medication Review Improve Health?* http://www.ti.ubc.ca/wordpress/wp-content/uploads/2017/05/104.pdf.

Remaining Gaps

The Ministry identified the following four broad gap areas in the Ministry's capacity to support evidence-informed programs and decision-making in pharmaceuticals.

1. Quality prescribing (optimal drug use) support for health professionals

Several programs and projects used to support quality prescribing and optimal drug use were interrupted or stopped. For example, the EQIP program that provided physicians with personalized prescribing portraits and educational messaging to support optimal use, was not continued.

2. Systematic approach to utilization and therapeutic reviews to inform decision-making

There is no current program for systematic drug utilization reviews or systematic monitoring for select targeted drugs and drug classes. Drug utilization reviews would supplement the Ministry's existing analytical work, and may be used to support evidence-informed decisions and to ensure a contemporary and cost-effective PharmaCare program. Utilization reviews can also support other synergistic initiatives or programs (e.g., prescriber feedback, academic detailing etc.) and may also lead to further evidence reviews or additional research to improve the optimal use of drugs and the PharmaCare program.

3. Optimal utilization of the expertise of researchers to inform PharmaCare policies, programs and drug listing decisions

There is evidence-informed PharmaCare policies, programs and drug listing decisions, but these could be further enhanced through more independent research. Research that could include evaluation of specific Ministry programs and policies (e.g., after new programs are launched like PharmaCare's Medication Review Services or existing programs like PAD) and may also be used to support drug listing decisions (e.g., coverage with evidence development research like the ADTI). Support for researchers may include those located in BC (e.g., TI) or those through national collaboration (e.g., DSEN) and the support provided should also include facilitating timely data access. As well, the Ministry of Health has been working towards optimized capacity for providing advanced analytics in house.

4. Sufficient internal capacity focused on the integration of evaluation and research outputs

There is insufficient internal capacity within PSD to bridge the interaction and relationships with external researchers and also to integrate evaluation and research outputs and transform them into evidence-informed policy and decision-making.

V. Evidence-informed public health surveillance

Overview

Public health surveillance is the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice. Such surveillance can:

- serve as an early warning system for impending public health emergencies;
- document the impact of an intervention, or track progress towards specified goals; and
- monitor and clarify the epidemiology of health problems, to allow priorities to be set and to inform public health policy and strategies.

The Ministry has a Population Health Surveillance and Epidemiology (PHSE) Team, whose mandate to the Office of the Provincial Health Officers is to support non-communicable disease epidemiology and population health surveillance. PHSE have also provided support when needed to the Ministry, Population and Public Health (PPH), regional medical health officers (MHOs) and their epidemiology/surveillance staff, and other Ministries of government when support was required (e.g., MCFD, RCY, etc.).

The Provincial Health Officer is the senior public health official for BC, and is responsible for monitoring the health of the population of British Columbia and advising, in an independent manner, the ministers and public officials on public health issues and on the need for public health related legislation, policies and practices. Since 1993, the Provincial Health Officer has been required by the *Public Health Act* to report annually to British Columbians on their health status and on the need for policies and programs that will improve their health. The public can access these reports: http://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications.

Provincial Health Officer's Annual and Special Reports represent a comprehensive view of the health status and well-being of British Columbians. To do so, they rely on the scope and expertise of the Provincial Health Officer, as well as on expert data analysis, interpretation and preparation by PHSE team and on the research contributions of experts and provincial agencies across BC.

The PHSE had contracted Blue Thorn Research and Analysis to enhance the team's capabilities in Provincial Health Officer Reports, and also in projects of provincial and national importance.

Affected Programs

Blue Thorn's contract suspension severely restricted the capabilities of PHSE and its ability to fulfill its obligations for a period of 16 months (not including the time to re-establish a contract team, full data access, software capabilities and email access). Transitory records and project histories were lost and this was followed by many months of attempting to restart and finish projects.

BC has participated in national chronic disease surveillance since 2000. PHSE works with the Public Health Agency of Canada under a memorandum of agreement, and a new 3 year agreement was delayed as there was some uncertainty whether the work could be completed without Blue Thorn contracted resources. BC had been a technical and epidemiological leader in the development of national surveillance. This incident damaged BC's national surveillance leadership role and reputation, due to unavailable contract resources and inability to fulfill commitments.

BC's provincial chronic disease surveillance was also impacted due to lost expert technical, epidemiological, and surveillance experience from PHAC and other jurisdictions. In particular, the Canadian Chronic Disease Surveillance System, National Population Health Study of Neurological Conditions (NPHSNC) and Provincial Chronic Disease Surveillance programs were affected, and BC's role as a leader and trusted scientific partner was diminished. BC lost some Public Health Agency of Canada funds for the Canadian Chronic Disease Surveillance System (CCDSS) as some deliverables were not completed. These funds were not recovered. BC's inability to complete some NPHSNC project requirements delayed the national project, as well as delaying further development and expansion of national surveillance to neurological diseases. Finally, the risk factor and drug usage portions of the NPHSNC were not completed, so those effects for British Columbia's population remain unknown.

PHSE surveillance programs also had a provincial focus. For example, the Health Care Costs by BMI category and Risk Factor project was designed to describe health care utilization and costs for different categories of body mass index and for chronic diseases, to inform MoH policy and service planning. PHSE was never able to complete the third phase of this project, as its access to the required data, the self-reported Canadian Community Health Survey, has not been restored. PHSE also had project delays for surveillance relating to: unintentional injuries, opiate addiction, substance use, flu and falls.

Remaining Gaps

The Ministry identified the following gap in the Ministry's capacity to support evidence-informed public health surveillance programs, health public policy and decision-making:

1. **Access to the Canadian Community Health Survey**

   The linkage of British Columbians' self-reported Canadian Community Health Survey (CCHS) data to the MoH administrative data creates a valuable and irreplaceable information source for understanding the health and well-being of British Columbians and for designing policy and programs in health. Some CCHS data are publicly available, but access to the CCHS files that are required for this linkage have not yet been restored for use by the PHSE, other Ministry staff or by researchers.

VI. Evidence Informed Health Services

Overview

The Ministry is a large organization with many parts. Corporately, solid effort has been made to engage and support the research community. Over the years, some Ministry program areas have developed and maintained strong relationships with the research community and have even engaged in research and evaluation of policy and programs. The design, methodology and/ or implementation of such Ministry evaluations have been strengthened by the contributions of academic researchers. Researchers have contributed this expertise to Ministry staff through both informal and formal mechanisms.

Up until 2012 there were some relationships with researchers who were provided direct access to Ministry data for specific projects identified by the Ministry. These included research involving health data and other social determinants data. Some of these agreements were ended as a result of the investigation and some have not been reinstated,

although researchers have continued to have access to Ministry data though Population Data BC (discussed in more detail below).

In several areas of the Ministry and health sector, formal processes of evidence development to inform decision making and policy exist. Some of these processes were well established and continued through the investigation and others have been newly developed since, in response to emerging policy needs. Processes of evidence development may emerge to meet new policy and decision making needs in the Ministry of Health, Health Authorities and other parts of the health sector. In other program areas, the approach to evidence development may be more ad hoc and formal processes have not yet developed.

Finally, the Ministry has made a commitment not only to support the capacity to use evidence to inform health services delivery in several areas, but also to invest in infrastructure that supports high quality, relevant health research in the province.

Programs of Evidence

The Ministry commissions and engages in several evidence-based programs to inform policies and health services as outlined in Figure 1. These programs existed before, during and after the investigation. For example:

- The BC Health Technology Review is a joint ministry and health authority process used to make evidence-informed decisions on which health technologies (devices, diagnostics and clinical procedures) should be publicly provided in the province. The provincial Health Technology Assessment Committee began with the signing of the MOU with all health authorities in late 2011 and the first technology was assessed in 2013. The new model with expanded budget and bolstered academic research capacity came into play in 2015-16, following recommendations from a program evaluation in 2014.

- The BC health sector's clinical prevention review process, the Lifetime Prevention Schedule (LPS), was established in 2009. The LPS annually assesses behavioral interventions and preventive medications provided by a health-care provider that are considered to be evidence based, cost effective and to have a population health impact. The LPS committee membership, contracted resources, and public reporting was not delayed or otherwise altered due to the investigations. The LPS continues to provide evidence-based advice to clinicians and the public regarding preventive care.

- The Guidelines and Protocols Advisory Committee (GPAC), established in 1993, is an advisory committee to the Medical Services Commission and has representatives from both the Doctors of BC and the Ministry of Health. It supports effective utilization of clinical services and high quality, appropriate patient care through the development, publication and promotion of evidence-based clinical practice guidelines and protocols. Over 100 guidelines and protocols are available. GPAC continues to assist practitioners and patients make decisions about appropriate health care for clinical circumstances ranging from depression to perinatal care. This process of evidence development may have experienced delays in the development of its reviews, analyses and/ or evaluations as a result of the loss of appropriate and timely access to data (this effect on the Ministry's analytics and IMIT areas is discussed in further detail in VII. Ministry Capacity for High Quality Data Analytics). For example, publication of the BC Guideline on cognitive impairment was delayed as a result of the delays in the ADTI project, but has been published and updated since that time.

Figure 1. Examples of Formal Evidence Development Processes in BC's Health System

Researcher Engagement and Internal Capacity Development

In addition to the Ministry's evidence-based programs which involve academic and clinical experts, the Ministry is involved in work internally and with external stakeholders to derive benefit from existing and commissioned research. This includes the direct commissioning of research from organizations and from individual researchers as well as collaborations with the Michael Smith Foundation for Health Research, the province's health research funding agency. Some examples include the Science Policy Fellows program, which embedded researchers in the Ministry to conduct a research project of policy interest and the CIHR/ MSFHR Best Brains Exchange, where researchers and health system decision makers could collaborate to solve a health system problem of interest.

The Ministry actively supports a number of programs and initiatives to build internal research literacy and to strengthen and sustain relationships between the Ministry, decision makers, clinicians, patients and researchers working in areas relevant to planning, policy and health care service delivery. The longest running examples of these are: (1) the services of the Health and Social Services Library located at the Ministry and staffed by health librarians and (2) the monthly Ministry's Research Round series, begun in the mid-1990's, which promotes engagement between local and international researchers and Ministry program staff.

Provincial Research Infrastructure Initiatives

BC has approximately 2500 health researchers and over 100 health research centres, units and centres of excellence. Approximately 85 per cent of health research done in the province is conducted in hospitals and other health authority facilities and is done so with federal, philanthropic, provincial and private sector funding. Given this rich environment of activity, one could hope that the many of the problems of medicine, health care and population health are being addressed. The reality is that there is excellent research taking place, however, existing incentives and organizational structures often work against collaboration and there remains a gap between the vast investment of funding and talent and measurable collective impact in the health care system.

It has become increasingly apparent over the past five or so years, that the Ministry has an opportunity and a responsibility to engage in and support provincial initiatives in partnership with the Michael Smith Foundation for Health Research, Genome BC, universities, health authorities and other organizations. These initiatives are important mechanisms for reducing the gap between research and action, creating greater alignment between research investments and health sector priorities, and streamlining research processes for greater efficiency and impact.

Examples of this work include two related projects:

Ministry staff members have actively contributed to the development of the Strategy for Patient Oriented Research (SPOR) BC SUPPORT Unit. The SUPPORT Unit is a multi-partner initiative co-funded by the Canadian Institutes of Health Research. It represents a major provincial resource with $80 million in financial and in-kind support over 5 years. The SUPPORT Unit has two main roles: providing services to researchers, patients, health care providers and health system decision makers; and facilitating initiatives identified as provincial priorities. It is part of a nascent provincial Academic Health Science Network that is promoting new relationships between clinicians, researchers, patients, administrators and policy makers to accelerate the translation and application of research into clinical practice throughout the province and to shifting academic and practice education to better align with patient and health system needs.

The health data platform, partly funded through the SUPPORT Unit, will be a shared common data environment that enables multiple uses of health data by multiple types of data users built on leading privacy and security practices. Goals for this initiative will include:

- Improved timeliness, efficiency and greater breadth in researcher data access;
- BC being positioned for excellence in data-driven evidence for health and health research sectors; and,
- Increased security and functionality in data capture, storage and retrieval for health research, including real world clinical trials and randomized controlled trials (RCTs).

Taken together, these components along with other efforts underway have the potential to transform the research landscape. They were not directly adversely affected by the investigation.

Affected Programs

In 2010, the Ministry, working with the Michael Smith Foundation for Health Research and the health authorities, collaborated on the Monitoring, Evaluation and Learning System (MELS) initiative, a project to develop capacity to undertake provincial evaluations of major health care initiatives. MELS featured a provincial network of 15 evaluators embedded in the 5 regional health authorities, external expert advisory groups and initial work on a secure data collection and reporting system. Michael Smith Foundation for Health Research made a significant investment in funding and staffing to support the initiative.

The true potential value of MELS spanned beyond its three components. It was considered to be a foundational first step in the creation of a learning health system in BC and was in many ways, a forerunner for the Academic Health Sciences Network described above. The goal of gathering and linking together a wide range of health-related administrative and qualitative data, MELS was intended to provide the BC healthcare community with access to a robust infrastructure capable of supporting continuous learning, improvement and decision-making at multiple levels of the health system. With the cancellation of the Resonate contract, efforts to establish the data collection and reporting system were halted. The program depended on an underpinning data system and therefore, funding for the entire initiative was eventually discontinued.

Additionally, some evaluations for other program areas of the Ministry were affected. For example, a lack of timely and appropriate data access delayed the Ministry's analysis of the use of the prostate serum antigen test (through linkage of registry and lab data) to understand appropriate use of the PSA test, provincially.

Remaining Gaps

The Ministry identified the following broad gap area in the Ministry's capacity to support evidence-informed programs and decision-making in health services:

1. **Systematic Evaluations**
   The development of provincial monitoring and evaluation infrastructure was not realized. Without this infrastructure, the Ministry lacks the ability to efficiently undertake rapid cycle evaluation of initiatives and policy. The MELS infrastructure would also have more readily allowed for engagement and participation of the research community, which would have lent strengthened methodological quality and context.

VII. Ministry Capacity for High Quality Data Analytics

Overview

For many years BC has enjoyed a reputation of having some of the best health data holdings in Canada (e.g., population level data on dispensed drugs) and excellent disease registries (e.g., cardiac, trauma, cancer, perinatal). More recently, significant effort has been underway to coordinate and make available high quality patient-reported data, an area where the province has demonstrated national leadership.

While BC has been a pioneer in some areas, the province had fallen behind in providing timely data access for researchers and in continuing to enable secure linkage to additional important data sources in the health sector. Before the investigations, the Ministry was trying to address long standing issues in appropriate and timely access to data (for example, the Office of the Information and Privacy Commissioner (OIPC) hosted a Roundtable Discussion on Access to Data for Health Research on June 25, 2012 and the Ministry's *Timely Data Access Report* was developed in July 2012). These efforts cooled with the investigations and momentum was lost.

Post-investigation, the Ministry recognized that the first priority needed to be enhancing data security and privacy protection and to develop clear, consistent, and streamlined processes for managing data within Healthideas, the Ministry's data warehouse. This work was implemented in earnest at substantive effort and expense over a two year period. At the same time, the services of PopData BC continued for the research community. Subsequently, the Ministry and PopData BC have continued to try and accelerate the approval and processing of requests; the SPOR vision for improved research access to data is being addressed, in part, through work actively underway to develop the provincial health data platform and tools such as a cohort browser tool for researchers, and to make additional data sets available to the research community through PopData BC.

While it is clear from researcher feedback, there is still considerable room for improvement, processing times for researcher data requests have improved significantly over the past 5 years and the results of the SPOR work will begin to becoming increasingly visible over the next two years. Additionally, the Ministry is taking steps to improve the work environment, including addressing the fear-based behaviour in staff regarding data that is attributed to the investigation. These efforts are described in the Ministry's response to Recommendation 33.

In June 2016, the Deputy Minister announced the Consolidated Analytics Target Operating Model, bringing all data and analytics work in the Ministry under the HSIAR Division with the aim of creating a single source of truth and using data as a strategic asset that informs evidence based decisions to improve health outcomes. Under the new model, HSIAR is focusing efforts on the highest priorities and work in a standardized way across business lines to collect, link and manage data sets, monitor health sector performance, lead cross-sector analysis, provide advice, and develop comprehensive insights and information. Divisions will be enabled with high quality, timely, accurate and consistent information and analysis that support health system performance management, the delivery of core business and strategic priorities.

Affected Programs

Information Management/ Technology infrastructure requires maintenance, development and updating to remain secure, current and supportive of analysis. The investigation resulted in the cancellation of the Resonate contract; this had a short term operational impact on Healthideas as it halted a contracted resource which provided after-hours support to ensure data loads occurred smoothly and that staff had access to the data warehouse during business hours.

Furthermore, the investigation resulted in a 'culture of fear,' where analysts and IT staff no longer wanted to work with, handle or transfer data due to fear of losing their jobs. This had an impact on professional development and on the Ministry's capacity to build expertise. However, one positive impact of the investigation was the investment in enhanced secure protections in Healthideas and development of clear and consistent processes for managing data within the Ministry.

Remaining Gaps

The Ministry identified the following three broad gap areas in the Ministry's capacity to support high quality data analytics:

1. **Optimized development and maintenance of Healthideas, the Ministry data warehouse, to support secondary data access**

   The Ministry's physical environment and security practices are more secure as a result of the investigations; however, much work is still required to optimize data use such as the creation and implementation of analysis-ready data sets, support for products that enable responsible use and interpretation of the data, and enablement of wider access to the data asset in a way that recognizes different technical and data literacies.

2. **Ready access for Ministry staff to aggregate statistics**

   Before and since the investigation, the Ministry has invested in powerful business intelligence tools (i.e., advanced SAS and Microstrategy) that can provide analysis-ready data sets and enable visual display and interpretation of data. These have not yet replaced the services provided by Quantum Analyzer in terms of creating a reliable source of aggregate statistics.

3. **Appropriate and timely data access for Ministry internal staff, health authorities and researchers**

   There remains a gap in the in how the Ministry balances the protection of privacy with timely access to data. The Ministry's approach for protecting privacy in health data is not clearly articulated, leading to discrepancies in interpretation and a data access management system that strongly weights approvals at the front end with limited or no back end audit, even with users who have long track records of working appropriately with Ministry data and would provide enormous value to the health system.

VIII. Conclusion

The Ministry needs and values the work of the research community and the expertise and the rigour that scientific methods bring to our understanding of the health care system, health services, patients and the population.

A number of programs within the Ministry and the research community have a history of strong and positive relationships, but the investigations and their aftermath led to far reaching and harmful consequences and are now also a part of that history. In response to the Ombudsperson's recommendation, the formal opportunity/requirement to review gaps has illuminated areas of impact that had not previously been fully acknowledged.

In analyzing the gaps, it is clear that two axioms co-existed: at the same time that people, programs and initiatives were dramatically and negatively impacted, other significant initiatives and collaborations with researchers were beginning and other strong Ministry evidence development processes continued. One did not cancel out the other.

The Ministry looks forward to presenting a plan for strengthened capacity in developing, accessing and applying evidence across its program areas. This plan will also articulate the Ministry's plan to improve research access to data. The Ministry intends these efforts to strengthen the quality and sustainability of BC's health care system and the health of British Columbians.